ABSTRACT

Title of Dissertation:	COMPUTER-MEDIATED HEALTH COMMUNICATION AND LENNOX-GASTAUT SYNDROME: UNDERSTANDING SOCIAL SUPPORT AND INFORMATION SHARING IN A CLOSED, RARE-DISEASE FACEBOOK SUPPORT GROUP
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Computer-mediated health communication (CMHC) has increasingly played a role in connecting individuals across the globe to health information and online support groups. For individuals living with a rare disease, and their caregivers, CMHC can serve as a critical tool for social support and information seeking, while addressing feelings of isolation due to the low prevalence of living with a rare disease. Over the past two decades, there has been an increase in scholarship surrounding CMHC and social support. However, scholarship within the context of CMHC in rare diseases has only increased within the past few years and lacks an explicit connection to important theoretical constructs in both communication and public health. Thus, this dissertation aims to explore the intersection of CMHC, interpersonal communication, and social support among caregivers who use Facebook groups as a CMHC tool for Lennox-

Gastaut Syndrome, a rare, catastrophic epilepsy syndrome. Long-standing communication theories, including social penetration theory and communication privacy management, guide the theoretical framework for this dissertation while theoretical constructs from public health, including social support and health literacy are addressed.

COMPUTER-MEDIATED HEALTH COMMUNICATION AND LENNOX-GASTAUT SYNDROME: UNDERSTANDING SOCIAL SUPPORT AND INFORMATION SHARING IN A CLOSED, RARE-DISEASE FACEBOOK SUPPORT GROUP

by

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Dedication

I dedicate this dissertation to my brother Michael, who was my inspiration behind the LGS Foundation, and to my friends in the rare epilepsy community.

Acknowledgements

First, I would like to acknowledge my committee chair, Dr. Lindsey B. Anderson, who supported me—and believed in me—as I worked to complete this dissertation. Dr. Anderson, you provided me with incredible guidance, feedback, and critiques along the way. I couldn't have done this without you—thank you for everything. I would also like to acknowledge my dissertation committee members, Dr. Andrew Wolvin, Dr. Kang Namkoong, Dr. Catherine Knight Steele, and Dr. Sharon Desmond. Your perspectives and suggestions have been invaluable over the years. Thank you for serving on my committee and for making me a better scholar.

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Lastly, to my parents and siblings: thank you for always supporting my career ambitions and being by my side as I paved the path for the LGS Foundation. I acknowledge and appreciate everything you have all done for me.

Table of Contents

Chapter 1: Introduction

When I was seven years old, I witnessed the first of what would be more than 40,000 lifetime seizures that my younger brother would experience over 30 years. Michael, my younger brother, who was three years old at the time, fell to the floor, convulsing from a tonic-clonic seizure. I had never seen a seizure before; I thought he was having a heart attack and that he would die. He was later diagnosed with a rare pediatric form of epilepsy called Lennox-Gastaut Syndrome (LGS). It wasn't until 16 years later that I would understand how communication, social support, and this very personal experience would shape my academic interests, my professional career, and ultimately lead me to this dissertation project.

A disease in the United States is considered 'rare' when it affects less than 200,000 individuals (CDC, 2016). There are more than 7,000 rare diseases documented in the world; nearly one out of 10 people in the U.S. lives with a rare condition. Rare diseases, as a whole, represent a large medical challenge (Global Genes, 2018) and are a serious public health issue.

Living with a rare condition may feel isolating for the individual diagnosed with the disease and their family, particularly if the family has never interacted with anyone else with the same diagnosis. However, online support groups (OSGs), a form of computer-mediated health communication (CMHC), may help rare disease patients and caregivers feel less isolated by connecting them to a community that understands the characteristics and challenges of a disease.

Many rare diseases, like Lennox Gastaut Syndrome (LGS), are considered "catastrophic" due to poor prognoses, high burdens of care, high mortality, and increased healthcare utilization. Catastrophic rare diseases not only affect the individual living with the disease, but often the entire family. Pediatric, catastrophic rare diseases have an extremely negative psychological effect on parents and siblings of the child (Mebert, 2012). One such disease that this applied dissertation will highlight is Lennox Gastaut Syndrome (LGS), a severe childhood-onset form of epilepsy that is catastrophic, life-long, and severely debilitating.

Key Definitions and Background

Adding to the need to study rare diseases, specifically Lennox-Gastaut Syndrome, is the evolution of new technologies over the past twenty years which has created a proliferation of new ways in which individuals communicate about health issues, seek social support, and address feelings of isolation within a rare disease context. New technologies, specifically Facebook groups, as an extension of online support groups and computer-mediated health communication, are briefly introduced in this section and later described in more detail in the literature review. Additionally, two communication theories - social penetration theory and communication privacy management, which guide this dissertation, are also briefly discussed in this section.

Social support

Social support is 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 life experience” (Albrecht & Adelman, 1987, p. 19). It refers to the emotional, informational, or instrumental resources provided by one’s social networks that help her or him to cope with stressful events (Cohen, 2004). More recent research (Goldsmith & Albrecht, 2011; Shaw & Grant, 2002) concludes that social support and interpersonal relationships have a substantial impact on our physical health and our psychological well-being.

Computer-mediated health communication

One way that individuals communicate about health topics, obtain social support, and learn about health issues is through the use of computer-mediated communication (CMC) and health-related online support groups (OSGs). Computer-mediated communication in health contexts is known as computer-mediated health communication (CMHC), a growing area of research within the health communication discipline. CMHC is defined as the "use of computers to exchange health-related information" (Yang, 2015) and may also be referred to as interactive health communication (Lustria et al., 2007). While both terms describe the use of communication technology to transmit health-related information or to receive guidance and support (Robinson, Patrick, Eng, & Gustafason, 1998), for this dissertation, CMHC will be the term commonly used when referring to online support groups, specifically Facebook Groups.

Facebook Groups as CMHC

According to the Pew Research Center, as of 2018, 89% of Americans use the internet and 80% of those users use the internet for health information. In terms of social media use, 68% of Americans use Facebook (Pew Research Center, 2018) and Facebook remains the most popular social media site in the world with over 2.8 billion active users globally (Facebook, 2021). One of the most popular features that Facebook offers is its group function, where users may join private, secret, or public groups based on shared interests or commonalities. Many Facebook groups have been established to connect individuals who share similar health concerns or diagnoses. As such, these Facebook groups can be considered a form of CMHC as an extension of OSGs. These groups are virtual spaces where individuals who share common health experiences can find support through the exchange of messages (Chuang & Yang, 2010). Interaction through online support groups provides needed information, peer support to users, and encourages increased health communication (Hu, Bell, Kravitz, & Orrange, 2012). Online support groups may be of particular interest to users who are facing a rare disease, where face-to-face support may not be possible due to barriers of distance, time, and finances. OSGs for rare disease patients and caregivers allows users to connect and establish supportive relationships, and some research (Wright, 2016) has shown that OSGs in rare diseases can increase social support and reduce feelings of isolation.

Social Penetration Theory

Social Penetration Theory is an interpersonal communication theory developed in 1973 by Altman and Taylor that describes relational development and self-disclosure. SPT suggests that in order for individuals to form strong relationships, they go through gradual stages to get to know one another. This process is sometimes described as an “onion,” in which layers are peeled away as relationships becomes more intimate. SPT has increasingly been studied in online environments to better understand how much information individuals disclose, particularly when the audience is not always known online (Berstein, Bakshy, Burke & Karrer, 2013). Given the scope of this dissertation, which addresses social support and information sharing in CMHC environments, SPT is an appropriate theory to apply when seeking to understand the relational developments and self-disclosures of CMHC users for Lennox-Gastaut Syndrome.

Communication Privacy Management

The second interpersonal communication theory that is explored in this dissertation is communication privacy management (CPM). First developed by Sandra Petronio in 1991 (which was originally called Communication Boundary Management), CPM seeks to explain why people withhold or share private information about themselves and how they make decisions to reveal or conceal private information (Petronio, 2002). The theory suggests that the ways in which people handle or share private information are dependent upon the interaction of their boundary structures and rule-based management systems (Pecchioni & Keeley, 2011; Petronio, 2010). CPM complements SPT in some ways (e.g. helps to understand how, why, and to which degree individuals share information about themselves) but while SPT focuses mostly on self-disclosure and openness, Petronio developed CPM to understand how privacy plays a role in communication.

Lennox-Gastaut Syndrome

Lastly, Lennox-Gastaut Syndrome (LGS), the disorder that this dissertation focuses on within the CMHC environment of Facebook groups, is briefly defined here. LGS is a rare and catastrophic form of epilepsy that begins in childhood, usually with a peak onset of 3-5 years old (Camfield, 2011). The syndrome is characterized by frequent seizures of multiple types, a slow-spike-wave reading on the electroencephalogram (EEG), and moderate to severe cognitive impairment. Most individuals diagnosed with LGS as children will never become seizure-free and will continue to face a plethora of co-morbidities throughout their lifetime. Due to the catastrophic nature of the disorder and the intellectual disability that accompanies the diagnosis, many individuals with LGS are unable to use CMHC independently; therefore, this dissertation focuses on caregiver communication of those living with the disorder instead of individuals living with the diagnosis themselves.

Rationale

Given the increasingly important role that computer-mediated communication, specifically online support groups, plays in health communication, an important topic in health communication research is how this technology is used to communicate about health issues (Yang, 2015). As technology has evolved over the past few decades, individuals are increasingly using OSGs in new ways in order to seek health information and social support. Those with rare diseases, in particular, may benefit from OSGs for social support due to its convenience and ability to transcend barriers in meeting others face-to-face for support. However, there is a dearth of literature that studies the impact of OSGs and social support in rare disease communities. With that said, the purpose of this applied dissertation project is to understand how caregivers in the rare disease population of Lennox-Gastaut Syndrome use a closed Facebook support group page that is managed by the LGS Foundation, the leading organization in the world dedicated to improving the lives of individuals living with Lennox-Gastaut Syndrome.

Implications of this Study

This study has the potential to fill various gaps in the current literature surrounding CMHC and rare diseases, practically and theoretically. For example, social penetration and communication privacy management, the two key theoretical constructs that guide this dissertation, have yet to be studied in a rare disease, OSG context. Qualitative research surrounding caregiver perspectives in Lennox-Gastaut Syndrome are lacking, especially in the areas of CMHC and Facebook groups. In fact, this is the first study of its kind that addresses LGS caregivers and their communicative behaviors in a Facebook group.

This research will add to the bodies of scholarship in multiple disciplines including rare diseases, epilepsy, public health, and health communication. While some studies of a qualitative nature have been conducted in LGS, they have largely looked at quality of life issues – not communication needs and social support. Thus, this project aims to address these unmet areas while adding to a critical body of scholarship that has been historically lacking.

Organization of Dissertation

The following chapter further defines the literature that guides this study's research questions and methodology. Literature is reviewed in interpersonal communication, CMHC, social support, health literacy, and two communication theories – social penetration theory and communication privacy management. I will also contextualize the topic of rare diseases generally—and LGS specifically—in the literature review section before detailing my proposed methodology.

The third chapter discusses the methodology employed in this project to collect and analyze the data. Rationale is provided for the choice of qualitative methods and concludes with information on reflexivity given the applied nature of this dissertation project. The fourth chapter provides the results of the data collected through qualitative interviews. Finally, the fifth chapter is reserved for a discussion on how LGS caregivers use CMHC to address informational needs, social support needs, and health literacy alongside the theoretical frameworks of social penetration theory and communication privacy management. This dissertation concludes with thoughts for future research across various disciplines and limitations of this study.

Additionally, self-reflective vignettes as a form of autoethnography are woven into each chapter to provide additional perspective and method. These vignettes are provided for context – as well as personal narrative—in the context of Lennox-Gastaut Syndrome, social support, and online support groups.

Chapter 2: Literature Review

Vignette: Explaining LGS

LGS is an uncommon disorder that lacks public awareness, so I often found it difficult explaining the disorder to others. When our family went out in public, (such as a grocery store) it wasn't unusual for people to stare. My brother Michael wore a helmet when he was younger due to atonic (drop) seizures which would cause a sudden, often violent, fall to the ground. It was not unusual for him to have bruises and cuts on his face, along with the occasional broken bone from a seizure. Communicating about LGS to others was not an easy task, particularly when some people didn't understand why he couldn't "just take medicine" to improve his seizure outcomes. Unbeknownst to them, Michael was, at any given time, on at least three different anti-epileptic medications, but continued to have dozens of seizures per week due to the refractory nature of LGS.

This chapter begins with reviewing the relevant literature in health communication, computer-mediated communication, and computer-mediated health communication, including online support groups and Facebook Groups. It then defines and describes Lennox-Gastaut Syndrome and the context of the disorder within other rare diseases. Finally, theoretical frameworks are reviewed including social support, health literacy, communication privacy management, and social penetration theory.

Health Communication

Various definitions of health communication have been posited over the past few decades. Jackson and Duffy (1998) define health communication as the "study of the interactions among various participants in the health care process, the dissemination of health-related messages and messaging by individuals, groups, and/or mass media to other individuals, organizations, and/or the general public, and the interpretation of these messages" (Jackson & Duffy, 1998, p. 31). Cline (2003) describes health communication as an area of theory, research, and practice that focuses on the relationships between health and communication, as well as health beliefs and behavior (Cline, 2003). The Centers for Disease Control defines health communication as the study and practice of communication to inform and influence individuals and communities to make decisions that enhance health (CDC, 2020). Schiavo (2014) defines health communication as a "multifaceted and multidisciplinary field of research, theory, and practice concerned with reaching different populations and groups to exchange health-related information, ideas, and methods in order to influence, engage, empower, and support individuals, communities, health care professionals, patients, policymakers, organizations, special groups and the public, so that they will champion, introduce, adopt, or sustain a health or social behavior, practice, or policy that will ultimately improve individual, community, and public health outcomes" (Schiavo, 2014, p. 9).

The likely reason each definition differs slightly is because health communication scholarship has experienced a growth and evolution that still continues today (Schiavo, 2014). Health communication is a multi-disciplinary field that links together public health with communication and has been influenced theoretically by other fields such as the behavioral and social sciences and medicine. Theoretical constructs are imperative in health communication, as they are used to guide practice and scholarship and can help researchers, scholars, and practitioners understand how individuals seek health information and how health messages influence an individual’s health behavior. Understanding health communication is vital to understanding the processes of forming and developing supportive relationships (Virtanen & Isotalus, 2011), particularly when health messages are being shared and exchanged that produce health-related outcomes (Burleson et al. 1994).

Within the field of health communication, there are various sub-areas of the discipline, including, but not limited to: health behavior, health promotion, health literacy, health education, computer-mediated health communication, and interpersonal contexts of health communication. Researchers across disciplines study health communication in various settings, including patient-provider communication, communication technology, campaigns and interventions, and communication inequalities (National Communication Association, n.d.). Thus, while health communication is a diverse, broad field of research and scholarship, I will focus on the intersection of interpersonal communication and health communication through computer-mediated environments for this applied dissertation research project.

Interpersonal Health Communication

Interpersonal communication also has varied definitions (Bochner, 1989; Knapp & Daly, 2010; Miller & Steinberg, 1975;). Wood (1999) has defined interpersonal communication as a “selective, systemic, unique and ongoing process of reciprocal interaction between individuals who build personal knowledge of one another as they create meaning” (Wood, 1999, p. 24). Knapp and Daly (2010) define interpersonal communication as a “process whereby one individual stimulates meanings in the mind of another through verbal and/or nonverbal means” (p. xxi).

Burleson (2010a, p. 151) suggests that interpersonal communication is a “complex social process in which people who have established a communicative relationship exchange messages in an effort to generate shared meanings and accomplish social goals”. While all three definitions are slightly different, most scholars agree that in an interpersonal communication setting, there are at least two communicators whose actions embody each other’s perspectives (Bochner, 1989). However, Knapp and Daly (2011) argue that in order to differentiate interpersonal communication from group communication, the number of people involved can only be two, although the dyadic interactions may be extensions of larger social networks or groups.

Interpersonal health communication (IHC) lies at the intersection of interpersonal communication and health communication (Obregon & Waisbord, 2012). Interpersonal communication is pervasive in healthcare settings, healthcare decision-making, and health-related information seeking. Scholars in the interpersonal health communication field seek to understand how meanings are produced between individuals when discussing health content, whether it’s between patients and providers, caregivers and patients, or in family settings. IHC is also shaped by health beliefs, health behaviors, attitudes, and health literacy. Research has shown that interpersonal communication processes in healthcare settings are essential to better adherence to treatment regimens, improved clinical outcomes, more accurate patient reporting, and enhanced prevention of diseases (Arora, 2003).

A characteristic of interpersonal communication that some researchers debate is whether the interaction needs to take place face-to-face in order to be truly considered interpersonal (Knapp & Daly, 2011). However, while interpersonal communication is often researched in face-to-face settings, it is being increasingly studied through social media (DeVito, 2017). Scholarship that explores interpersonal communication by telephone, computer and other technologies has become an increasingly important part of the literature in interpersonal communication as it reflects modern communication mediums/preferences.

Recently, more research has emerged that examines computer-mediated environments and how they relate to interpersonal health communication (Favotto, Michaelson & Davison, 2017). The widespread availability of technology for communicating has increasingly played a role in the way interpersonal transactions are manifested. Interactive video, virtual reality, text messaging, and social media lend to an increasingly interpersonal world that is much different from previous definitions of interpersonal communication (Knapp & Daly, 2011). As such, some interpersonal communication scholars have increasingly focused on computer-mediated environments to understand how technology influences interpersonal relationships.

Computer-Mediated Communication

Computer-mediated communication (CMC), as the name suggests, describes the use of computers to exchange information between individuals. CMC can be synchronous, meaning the interaction takes place in real time (e.g. a live webinar or video conference), or asynchronous, where there may be time constraints on responses between the sender and receiver (e.g. online support groups or text messaging). CMC is now widely recognized as a form of interpersonal communication, and some scholars (Fox, Warber & Makstaller, 2013; Walther, 1992) have argued that CMC has become integral in the initiation and maintenance of interpersonal relationships and can substitute or complement face-to-face relationships.

Although CMC may complement traditional communication methods, Jarvenpaa and Lang (2005) argue that some forms of CMC may have adverse effects, particularly the absence of nonverbal cues. Examples of such cues include facial expressions, eye movements, and body language. Wright and Bell (2003) have noted other potential negative aspects of CMC, including delayed feedback in an asynchronous environment, credibility issues of users, and short-term participation.

However, there are many notable advantages of using CMC. First, CMC eliminates the dependence on time and physical location. Second, compared to face-to-face communication, CMC allows users to reach a vast number of receivers simultaneously, such as in an online support group setting or through social media. Third, CMC may help reduce isolation and allow users to feel more connected with others who share similar interests, experiences, or concerns. These points are especially relevant given the limitations members of the rare disease community face in terms of accessing health information and forming relationships with other caregivers.

Over the past decade, the literature on CMC and interpersonal communication has steadily increased (Favotto, 2017). Scholars from other disciplines, including sociology, education, and business have also studied the effects of CMC on their respective disciplines (see Bob & Sooknanan, 2014; Katz, Rice & Aspen, 2001; Meskill, 2008) and have largely reported positive outcomes. For example, Bob and

Sooknanan (2014) investigated how CMC impacted productivity within an electricity company and reported that 73% of the respondents agreed that CMC enhanced their interpersonal communication, productivity and efficiency in the workplace. Meskill (2008) studied how CMC was used in a Russian language course within the United States and discovered that it increased their academic literacy and interpersonal transactions when using the Russian language. While these examples are not rooted in health communication, they are provided for context to better understand the benefits of using CMC for interpersonal communication across disciplines.

The literature within the communication and public health disciplines that links CMC to health outcomes, particularly in relation to increased social support among users, has also increased over the past decade. For example, Rains, et. al (2016) studied reduced social cues associated with CMC on social support and found that reduced cues encouraged greater message elaboration on supportive interactions (Rains, et. al, 2016). Eden and Heimen (2011) studied the relationships between the use of CMC by students with learning disabilities to understand how they perceived social support and found that those with learning disabilities used CMC for support more than those students without learning disabilities (Eden & Heimen, 2011). Thus, applying scholarship within interpersonal communication in health contexts can provide future research opportunities that extend into computer-mediated environments (Cline, 2003). Further, linking CMC scholarship with interpersonal communication and health communication provides new opportunities for research in the communication field.

Computer-Mediated Health Communication

The application of CMC specifically to interpersonal health communication has been referred to as computer-mediated health communication (CMHC) or “interactive health communication” (Lustria et al., 2007). CMHC is a growing area of scholarship within the communication discipline and is defined as the use of computers to exchange health-related information (Yang, 2015). CMHC research that explores interpersonal contexts in computer-mediated environments has increased since the 1990’s and has altered existing definitions and applications of both interpersonal communication and health communication.

Online Support Groups. One of the most commonly used computer-mediated tools is online support groups (OSGs). These are virtual spaces where individuals who share common health experiences can find support through the exchange of messages (Chuang, 2010). Interaction through online support groups provides needed information, peer support to users, and encourages increased health communication (Hu, Bell, Kravitz, & Orrange, 2012).

Wright (2016) argues that participation in online support groups is influenced by perceptions of the convenience and flexibility with these groups. CMHC transcends time and physical location, allows users to exchange messages that are specific to their health needs, and helps individuals feel less isolated about their health condition (Wright, 2016). In health contexts, OSGs offer a way for patients and caregivers living with a similar illness to exchange specialized health-related support (Gage-Bouchard, LaValley, Mollica & Beaupin, 2017). Facebook is the largest platform to host online support groups and is used to connect members of their platform to share advice, support, and sources of information with others who identify with their experiences (Wen, McTavish, Kreps, Wise, & Gustafson, 2011). In addition to patients, providers and caregivers also use digital communication channels to gather health information and to interpersonally communicate about important health issues. A number of factors have been shown to motivate individuals to seek CMHC (Turner, 2001; Wright, 2003). A few of these factors include stigma about a disease or illness, control over content, or those living with a rare disease who may have limited access to face-to-face support (Wright, 2016).

For individuals living with a rare disease, or caregivers of someone facing a rare disease, CMHC may be attractive since face-to-face interpersonal relationships may not be possible. OSGs allow those living with a rare condition, as well as caregivers and family members, to exchange messages about their health concerns and reciprocate support. OSGs can also help people reduce their sense of isolation (Holbrey & Colson, 2013). Online support groups have risen in ubiquity over the past decade and have become an important tool for reaching others who face a similar health challenge. Examples of health-related OSGs include Inspire, a rare disease forum with 2 million members (Inspire, 2021) and Patients Like Me, a patient network founded in 2004 that has 830,000 members (Patients Like Me, n.d.). The website AllFacebook.com, which tracks Google's indexing trends, reported that as of February 2010, Google indexed 620 million groups. In 2020, Facebook reported “tens of millions of active Facebook groups” with 1.8 billion Facebook Group users (Facebook, 2020). While Facebook does not have published data on how many of those groups are rare disease groups, it is fair to assume that millions of rare disease patients are using Facebook groups to connect with others.

Facebook. Facebook can be considered a CMHC medium in situations of health-information seeking or for disease support. Facebook is also considered a form of new media, which are defined as “the mass communications that rely on digital technologies such as social media, online games and applications, multimedia, productivity applications, cloud computing, interoperable systems, and mobile devices. New media are part of mass media.” (Rohlinger, 2019, p. 1). Facebook, as an extension of CMHC, relies on digital technologies in order for users to exchange health information. This is often done in Facebook groups. Therefore, it is important to also address group communication in the context of CMHC and Facebook groups to better understand how and what health information is shared among group members and whether this impacts social support and health literacy.

Group communication refers to messages, either verbal or non-verbal, exchanged in the context of a specific group. Understanding group communication in the context of CMHC and Facebook groups may help researchers better understand how and what health information is shared among its members. For example, a Facebook group user may publish a question on the group, asking questions or “venting” to those who share similar experiences. This action has the potential for thousands of other users to view and react to the post, which emulates group communication behavior (Namkoong, Nah, Record & Van Stee, 2016). However, once a dialogue is produced by comments, specifically those between the individual that published the post and one or more users with directed response, the communication turns more interpersonal. In large OSG settings such as Facebook groups, interpersonal relationships can still become intimate, perhaps leading to increased social support while addressing feelings of social isolation.

Lennox-Gastaut Syndrome

Lennox-Gastaut Syndrome (LGS) is a rare disease that is characterized by refractory epilepsy, intellectual disability (moderate to severe) and an abnormal slow-spike wave pattern on an electroencephalogram (EEG). The prevalence of LGS within the United States is estimated to be between 38,00- 49,000 with an incidence of 1:50,000 live births (Trevathan, Murphy & Yeargin-Allsopp, 1997). LGS is considered a “catastrophic epileptic encephalopathy,” meaning that the severe nature of the epilepsy causes progressive cerebral dysfunction over time. Many individuals living with LGS also experience a plethora of co-morbidities associated with the condition including, but not limited to, aggression, psychosis, gait and balance issues, and sleep disturbances. In addition, 26% of those diagnosed with LGS use a gastrotomy tube (G-tube), 72% use a wheelchair, and 59% are non-verbal (LGS Foundation, 2018).

Despite more than 25 FDA approved anti-epileptic drugs available along with a poly-therapy approach to treatment, many individuals living with LGS will continue to have hundreds of seizures per month, or even per day in the most extreme cases. The burden of care is astounding and the yearly costs of caring for an individual with LGS are between $25,000- $40,000 (Pina-Garza, 2017). Consequently, caregiver stress is high, as is the burden of care and healthcare utilization.

A 2009 study by Gallop reported that the health-related quality of life (HRQoL) among LGS caregivers was not surprisingly low. Health-related quality of life is defined as the value assigned to the impact and duration of life by the impairments, perceptions, social opportunities, and functional states that are influenced by a disease or injury (Patrick & Erikson, 1993). LGS caregivers face an overwhelming challenge to care for their loved ones. Gallop (2009) further reported that LGS caregivers are impacted physically by the demands of caregiving, including reduced sleep, constant stress, and chronic fatigue. Anecdotally, many caregivers report receiving physical injuries as a result of attempting to prevent their child from falling during a seizure. In addition to the physical impact on a caregiver, there are financial impacts, social impacts, and psychological impacts. Psychological considerations include poor emotional adjustment, anxiety, depression, feelings of isolation, and a low perceived level of support. Thus, it is not surprising that LGS caregivers seek support from other individuals who face similar challenges in order to increase their psychological well-being and to reduce isolation. Given the barriers to meet face-to-face due to distance and financial restraints, many rare disease caregivers turn to online support groups to communicate with others.

The most common way for LGS caregivers to communicate online is through the LGS Foundation's Facebook Group page. The LGS Foundation is the leading non-profit organization in the world dedicated to this patient population. Their mission is to improve the lives of individuals living with LGS, and their families, through research, family support programs, and education. The LGS Foundation's Facebook group serves as online support for 5,800 members across 90 countries. It is the most popular CMHC channel in the LGS community.

Rare Diseases and CMHC

CMHC for rare diseases is unique, as many users may not be able to receive social support without computer technologies or social media. This contrasts larger, more prevalent diseases where social support may be attained from in-person support groups, from meeting others through hospital networks or during routine clinical visits who share the same diagnosis, or for parents/caregivers of children (e.g. children with autism) in special needs classrooms, community programs, the Special Olympics, or day habilitation programs. In comparison to highly prevalent diseases such as adult-onset diabetes (typically type two), which affects nearly one out of ten adults in the United States (CDC, 2019), rare disease patients and their caregivers may struggle to connect with others with the same diagnosis, particularly those who are considered “ultra-rare,” a disease that affects fewer than 20 patients per million.

Using adult-onset diabetes to contextualize LGS against a prevalent disease, a simple search for “type two diabetes” in Facebook groups in 2020 generated more than 100 results for groups across the world; most were established as support groups and platforms for information sharing, but others existed for recipe sharing, weight management, physician-only exchanges, and reversal tips. This searched yielded approximately ten times more results than a search for “Lennox-Gastaut Syndrome Support Group”, which generated only 11 groups. Compared to the LGS Foundation Facebook group, a majority of the diabetes groups were found to be far less active when calculating user numbers vs. the number of posts per month. Out of 100 groups, the largest group (n=38,469) focused on recipe-sharing with an average of 140 posts per month (this translates to .003 posts per month per member). The second most popular group (n=35,614) was established for type two diabetes support and received

605 posts per month (.016 posts per user per month). The third most popular group (n=31,488) was established for reversing type two diabetes and received an average of 3,222 posts per month (.10 posts per user per month). In comparison, the LGS Foundation Facebook group has 5,800 members with an average of 468 posts per month, which translates to .08 member posts per month.

However, the posts per month per member equation may not be a reliable indication of how truly active a Facebook group is. Reactions and comments should be taken into account as well. Surprisingly, there is a dearth of research on “engagement” in Facebook support groups in the CMHC body of literature. Engagement can consist of emoji responses (a small digital image used to express an emotion) such as a thumbs up for a like, a heart which symbolizes love, a sad/tearful face which symbolizes sadness, a laughing face which symbolizes humor, a shocked face which symbolizes surprise, and an angry/red face which symbolizes anger. In 2020, Facebook added a “caring” emoji which symbolizes a caring embrace. This was announced by Facebook to represent a “virtual hug” and was launched during the COVID-19 pandemic. Reactions as a form of engagement presents another opportunity for future research in CMHC and can help researchers understand how truly active a CMHC Facebook group is, particularly in terms of social support.

There is also the strong likelihood that lurkers (an internet user that is passively observing rather than actively engaging and revealing information about him/herself) are digesting the information in CMHC environments but choose to be a silent consumer of information. In fact, online forum participation often follows the 90-9-1 rule where 90% of participants are lurkers rather than contributors of content

(Wilkerson, 2016). The “90-9-1 Rule” was first described by Nielson (2006) and described the pattern of engagement behavior by users. They found that only one percent of users were “heavy” users, nine percent were inactive users, and the remaining 90 percent typically lurked. Thus, lurkers should not be discounted, as they may still be actively engaged despite their lack of visible exchange in a CMHC environment.

Vignette: The LGS Foundation

Fourteen years ago, I founded the LGS Foundation, the first non-profit organization established in the United States dedicated to Lennox-Gastaut Syndrome. For years prior to the inception of the LGS Foundation, I had an interest in using computer-mediated communication platforms to connect with other LGS caregivers from across the United States. At the time, there was no central organization that existed for the disorder and the leading epilepsy organization in the United States lacked comprehensive information about the syndrome on their website. Therefore, I decided to fill a much-needed gap by launching www.lgsfoundation.org and vfdscreating a message board / forum for families to connect; soon after, LGS Foundation, a 501(c)3 non-profit organization was born.

Theoretical Frameworks

In this section of the literature review, I will detail the specific theoretical frameworks from the health and interpersonal communication bodies of scholarship that I will draw upon to inform this research. Specifically, I will explain how elements from social support intersect with the theoretical tenets of social penetration theory and communication privacy management. I will conclude by discussing health literacy as these online forums may be a space to provide health information and aid in caregiver/patient understanding.

Social Support

Social support refers to the emotional, informational, or instrumental resources provided by one’s social networks that help her or him to cope with stressful events (Cohen, 2004). Social support is a multidisciplinary area that seeks to understand why people who are involved in relationships have better mental and physical health than those who are not involved in relationships (Goldsmith, 2008). Early social support researchers (Cobb, 1976; Kaplan, Cassel & Gore, 1977) linked social support to health outcomes and demonstrated that social relationships can moderate or “buffer” potentially deleterious health effects of psychosocial stress (House, Umberson & Landis, 1988). More recent research (Goldsmith & Albrecht, 2011; Shaw & Grant, 2002) concludes that social support and interpersonal relationships have a substantial impact on our physical health and our psychological well-being.

Although most of the early research in social support was related to face-to-face interactions, more recent studies have shown that benefits of social support extend to online channels (Wright & Bell, 2003). Mo and Caulson (2010) found that those who are active users of CMC for social support reported higher satisfaction with health information in the online support group and more satisfaction with other members in the group. Other researchers (Van Uden-Kraan, Drossaert, Taal, Seydel, & Van de Laar, 2008) found that active participants reported greater psychological well-being than lurkers within an online support group. This research supports what Altman and Taylor (1973) argued when developing the Social Penetration theory, an interpersonal communication theory. Social Penetration Theory (SPT) supports the idea that in an online environment, lurkers may become more active over time as interpersonal relationships build. SPT will help guide this dissertation and research questions, particularly when understanding how users change their relational behavior over time in the LGS Foundation Facebook group.

Health Literacy

Health literacy is the second framework used in this dissertation. Health literacy is the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (HHS, 2010). Health literacy is dependent on a number of factors including knowledge of health topics, communication skills, culture, and education. Low health literacy is associated with poorer health outcomes and higher healthcare utilization costs (HHS, 2010). Only 12 percent of adults in the United States have proficient health literacy and approximately 77 million people have difficulty with common health tasks, such as understanding and following directions on a prescription drug label (NCES, 2003).

Lee, Arozullah and Cho (2004) reported that positive resources and support in one's social networks might buffer and alleviate the adverse health consequences of low health literacy. However, there is a dearth of literature on how social support through CMHC may enhance or buffer health literacy. Willis (2013) researched the role of online health communities and health literacy in arthritis and noted that "continued research is needed to further examine the role of online communities in increasing health literacy regarding chronic disease." Therefore, further research into

CMHC, social support, and health literacy using the above theoretical frameworks is a worthwhile area to explore.

Through online support groups and computer-mediated communication, caregivers of individuals with Lennox-Gastaut Syndrome may become more empowered to increase or change their dialogue with their providers based on conversations that take place among their peers. The health literacy of patients and caregivers has increasingly been recognized as an important factor affecting patient-physician communication, specifically regarding treatments for their loved one (NIH, 2020). OSGs offer a platform for caregivers to learn from one another and question what may be a “status-quo” relationship with their physician. Thus, health literacy may improve among LGS caregivers from new information they access through computer-mediated environments about disease-specific areas they were not previously familiar with. This may include, but is not limited to, new treatment options, devices that are available or becoming available to help seizure control (e.g. vagus nerve stimulator, deep brain stimulation), technology that helps detect and alert seizures (e.g. smart watches, cell phone apps, bed sensors that detect seizures), alternative and complementary therapies that are used, genetics, and clinical trial opportunities. Caregivers must process the information they find in computer-mediated environments and be able to decipher opinions and anecdotes from factual information. Thus, the provider extrinsically plays a role in helping to reconcile this information during office visits.

It is not unusual for a provider to receive questions from a patient or caregiver they read online (Erdem & Harrison-Walker, 2006). Research has shown that health-information seeking patients from the internet can improve the relationship between patients and physicians if the patient discusses the information they gathered online with their provider (Tan & Goonawardene, 2017). A provider must listen to concerns and answer the questions being asked without judgement. Researchers have found that providers who are skilled at listening in a clinical environment produce more trust and satisfaction among patients than those who are poor listeners (Berman & Chutka, 2016). Listening is an equally important component of communication for patients as well. In a clinical setting, patients must be able to process complex health information and follow through on suggestions from their physicians. Research has shown that the greater listening skills of patients and stronger provider-patient communication a patient has, the more compliant the patient will be for a health recommendation (Lu & Zhang, 2019). Further, questions asked by a patient plays an important role in patient engagement and health literacy and helps to aid in shared decision making (Mazor, et. al., 2015). Health literacy, which is the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions (HRSA, 2019) is also an extension of listening. There has been a recent emergence of research in health literacy-listening, specifically in cancer research, and its relationship between question-asking from patients (Mazor, et. al., 2012). Thus, patients who ask questions and have high health literacy-listening skills have a higher rate of compliance and more positive relationships with their providers overall.

While health literacy research has mainly focused on “readability of written documents” (Rubin, 2012), oral communication plays a factor in how individuals make decisions about their health. Listening literacy as an extension of interpersonal communication and health literacy is an emerging area of scholarship but it is nevertheless critical in decision making and improving health outcomes.

Social Penetration Theory

Social penetration theory (SPT) proposes that as relationships grow, communication transitions from shallow transactions to more intimate ones (Altman & Taylor, 1973). SPT is based on four basic assumptions. First, relationships develop over time from superficial layers to more intimate ones. Second, interpersonal relationships develop in a systematic and predictable manner. Third, relational development may move backward, resulting in de-penetration and dissolution. Fourth, self-disclosure is imperative in facilitating relationship development. Self-disclosure means disclosing and sharing personal information to others. It enables individuals to know each other, form relationships, and plays a crucial role in determining how far a relationship can go.

SPT can be applied to OSGs for individuals who are seeking a community for a health issue that affects them in order to become more informed, to connect with others who are facing similar health challenges, or who wish to feel less isolated based on their diagnosis. In an OSG environment for a rare disease, SPT may help predict which members stay engaged over time based on the degree in which they engage and participate in the group. At baseline, members may begin as “lurkers” in OSGs in order to digest conversations and read interactions between other members to understand lived experiences of a disease. Alternatively, they may join and immediately become active posting questions and interacting with other members in the group. The theory has also been applied in CMC contexts such as online dating and virtual teams (Carpenter & Greene, 2015) but there has been little research in interpersonal health communication contexts.

As noted, the key element to SPT is self-disclosure (Taylor & Altman, 1973). SPT predicts that those who disclose information about themselves are more likely to develop stronger relationships over time. Application of SPT in the LGS Foundation's online support group page may help to understand how, and to which degree, individuals' relationships grow over time in CMHC environments, particularly in terms of social support. Applying SPT to CMHC environments may also help researchers to understand if/how SPT facilitates health literacy about an individual's health issue.

While self-disclosure is an important process in establishing relationships in CMC environments, users may pick and choose what they are willing to share, particularly when it is related to health information about someone that they care about. Information sharing is a key component to developing relationships, but "over-sharing" may have negative consequences as well. Therefore, Communication Privacy Management (CPM) may help to understand which information caregivers are willing to share about their loved ones in an OSG, and how remaining private about issues that affect their child may influence the amount of social support they provide or receive.

Vignette: Manifestations of Relationships

I have observed many friendships develop on the LGS Foundation's support group page over the past decade. Some families get to know one another through shared experiences about their loved ones via posts and comments, and over time,

> *their relationships become more intimate. It's incredible to observe the process that these friendships undergo and what happens when they are able to meet face-to-face for the first time after spending years interacting online.*

Communication Privacy Management

Communication Privacy Management (CPM) is the second communication theory that will guide this dissertation and research questions. CPM seeks to explain why people withhold or share private information about themselves (or their children) and how they make decisions to reveal or conceal private information (Petronio, 2002). The theory seeks to explain ways that people handle or share private information are dependent upon the interaction of their boundary structures and rule-based management systems (Pecchioni & Keeley, 2011; Petronio, 2010). CPM complements SPT in some ways (e.g. helps to understand how, why, and to which degree individuals share information about themselves) but while SPT focuses mostly on self-disclosure and openness, Petronio developed CPM to understand how privacy plays a role in communication. Petronio uses a boundary structure to explain how individuals navigate their privacy and disclose private information based on what their expectations are from others who are making meaning of their private information. In other words, individuals develop their own privacy boundaries with other people based on what they perceive to be the benefits of sharing vs. the risks.

CPM is based on the concept that individuals own their own information and have the right to control the information that they share. In a closed Facebook support group page, where the information is not available to the general public, members may feel safer about the information that they share rather than posting to an “open” group or a public online forum. Therefore, if their information is shared in any way without their consent, CPM would suggest that members would feel violated, whether it was intentional or unintentional. Thus, there are expectations and a rule-based system that members follow, either consciously or unconsciously, that helps to protect them from information being shared without permission, especially if the Facebook group is closed or private.

Rainie and Duggen argue (2016) that if a privacy violation (e.g. copying and pasting a post a member shared inside of the group outside of the group) occurs, that users may experience boundary turbulence and distrust in the group. Therefore, the violated user may discontinue use in the group, or lessen the amount of activity that they share. In turn, if privacy is violated, then social support may be impacted. While the theory was originally developed in 1991 for interpersonal privacy negotiations (and was first named Communication Management Theory), it has been applied to other areas in communication such as OSGs, blogs, and health information disclosures (Petronio, 2010). However, CPM and social support in rare diseases is not a well-studied area. Thus, this study would contribute to the understanding of how self-disclosure of LGS caregivers and need for privacy of caregivers manifests in the OSG setting.

Vignette: Privacy Violations

Although I find that there is a high level of trust within the LGS Foundation Facebook Group, there have been instances of privacy breaches. One such example occurred six years ago, when a “troll” was admitted into the group and used photos of members’ children. He then proceeded to share those images publicly on his personal page. Another example, more recently, occurred when a person, who was admitted to the group after being authorized by administrators,

created a "fake" profile and pretended to have a child with LGS.
Weeks later, after dozens of posts, she spread a lie that her child died.

Summary and Research Questions

While the broad literature on social support and health is robust, some scholars argue that new research should be conducted to help explain why individuals seek social support through computer mediated channels (Reblin & Uchino, 2008; Wright, 2003). Thus, interpersonal communication theories such as SPT and CPM will guide this research to help understand the rationale as to why individuals seek CMHC as a tool for social support and whether the amount and type of information they share affects the amount of social support they receive. Further, health literacy, as an important health communication concept, may intrinsically be tied to social support in CMHC for LGS caregivers, but it is unknown to which degree.

Based on the preceding argument, I have developed four research questions that I will address in in this study:

RQ1: How, if at all, do LGS caregivers receive or provide social support through CMHC environments?

RQ2: How do caregivers determine which / how much information to share?

RQ3: How do users manage their privacy in OSGs?

RQ4: How is a user's health literacy affected by using an OSG for information-seeking?

Chapter 3: Methods

The theoretical framework and research questions discussed in the previous chapter establish the rationale for the methods used in this dissertation. This study seeks to understand how LGS caregivers use computer-mediated health communication, specifically Facebook groups, as an online support group to address social support and health-information needs. Information was co-produced by the participants and the researcher using qualitative methodology. This chapter addresses reasons why qualitative methods—interviews and personal narratives—were used, followed by information on the interview and the participants, recruitment procedures, interview procedures, personal narratives, data analysis, and coding techniques. I close this chapter with discussing quality in qualitative research, which addresses both validity and reliability. This chapter also addresses my reflexivity and positionality as a qualitative researcher with personal experience in LGS as well as limitations of the methods used.

A Qualitative Approach

Qualitative methodology is an appropriate research method for this study given the need for the caregiver voice, the deeper emotions surrounding CMHC and social support, and the ability to understand how caregivers make meaning of CMHC based on the theoretical frameworks discussed earlier. Qualitative methods also helped to understand the way in which relationships and interactions emerge and change, and how participants evidenced their feelings for each other (Tracy, 2013). Creswell (2005) defined qualitative study as: a type of educational research in which the researcher relies on the view of participants, asks broad, general questions, collects data consisting largely of words (or texts) from participants, describes and analyzes these words for themes, and conducts the inquiry in a subjective, biased manner (p. 39). Denzin and Lincoln (2005) state that, "qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them" (p. 3). Two forms of qualitative methods were employed in this dissertation: mediated interviews and autoethnography, specifically personal narrative. This was chosen as a second form of qualitative methodology because, as Miles, Huberman, and Saldana (2018) note, "words and images, especially organized into vignettes, stories, and evocative visual representations, have a concrete, vivid and meaningful flavor that often proves far more persuasive to a reader than pages of summary statistics" (Miles, Huberman, & Saldana, 2018, p. 4).

Interviews: Data Collection

Semi-structured, in-depth interviews are a commonly used format for interviewing in qualitative research (DiCicco & Crabtree, 2006). This method for data collection "allows the researcher to collect open-ended data, to explore participant thoughts, feelings and beliefs about a particular topic and to delve deeply into personal and sometimes sensitive issues" (DeJonckheere & Vaughn, 2019, p. 1). Semi-structured interviews offer flexibility through its format and allows the emergence of new topics and findings during the conversation, but at the same time requires thorough preparation before the interview meeting begins and careful listening throughout the conversation (Gillham, 2005). Semi-structured interviews were employed because it allowed me to ask open-ended questions based on an interview guide (see Appendix C) in different ways depending on the participants and their responses.

In-depth interviews were used to help better explore and understand the personal perspectives of participants. In-depth interviews also facilitated *thick description* (see Geertz, 1973), a term used in qualitative research that “does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another” (Denzin, 1989, p. 83). Thus, in order to understand the complex social and emotional components of LGS caregiving, in-depth interviews were the most appropriate technique to employ.

Interview: Recruitment Procedures

I am fortunate to have access to thousands of LGS caregivers from across the world, the vast majority who I have met through CMHC and have established relationships with over the past 13 years. After I obtained IRB approval, I announced the opportunity to participate in my research on Facebook. Through a Facebook post on my personal Facebook page (see appendix B), I was able to recruit 25 participants for an interview with the anticipation to recruit an additional five LGS caregivers for member checks after the interviews were complete. I chose to limit my recruitment post to my personal Facebook page because I felt that reaching out to my personal network on Facebook (e.g. Facebook friends) was more intimate than posting to the larger Facebook group. 25 participants was the original goal for recruitment, as this number seemed appropriate in order to reach saturation.

Recruitment started after I received approval from the Institutional Review Board. To begin, I shared the Facebook post on my timeline. Within only a few minutes, I had a received nearly a dozen responses from LGS friends and acquaintances who indicated that they were interested in participating. The high response rate was greatly encouraging, as this was a good indication that recruitment of the remaining participants would likely not be an arduous process. After I received those initial responses, I sent either an email or a private Facebook message to them with a custom-made link to Calendly, a website that assists in scheduling events like these easily. Once an agreed upon time was confirmed, a link to a consent form was sent to the participants through DocuSign. Within a few days of the Facebook recruitment post, I had scheduled all of the 25 interviews.

Interview: Participants

I conducted interviews with 23 LGS caregivers plus completed five member checks, all of whom were mothers to an individual with the disorder and identified themselves as women (see Table 1 for a summary of participant information). This demographic makes sense given the disproportionate amount of caregiving work with which women are tasked (see Oh & Lee, 2009; Vadivelan, Sekar, Sruthi, & Gopichandran, 2010). Caregivers varied in age, geographic location, socioeconomic status, educational attainment, and degrees of severity in respect to their child's diagnosis. The interviewees represent a variety of geographic regions in the United States (U.S.).

Interviews were scheduled during the month of September 2020. Initially 25 female participants were recruited but only 23 interviews were completed over the course of one month. While the goal for interviews was originally 25, two canceled with short notice due to childcare issues and were not rescheduled. Eligibility criteria included the following: (1) participant must be a caregiver of an individual with Lennox-Gastaut Syndrome; (2) be over the age of 18; (3) be active in the LGS Foundation Facebook group (at least two reactions or posts per week) and (4) live in the United States. A draft of the recruitment script is included in the appendices.

There were many considerations to selecting participants in order to ensure that a diverse set of voices were heard. I wanted to ensure that the caregivers recruited represented an array of ages (of their children), geographic locations, and degrees of severity in terms of their child’s phenotype. Although not ideal, the respondents did not represent a wide range of ethnicities or race, and all respondents were mothers. This disproportion can be explained by the predominance of women serving as primary caregivers of disabled children (see Oh & Lee, 2009; Vadivelan, Sekar, Sruthi, & Gopichandran, 2010) and perhaps a lack of diversity of participants in rare epilepsy studies (see Hessdorfer et al., 2020).

In order to assure that I received diversity in age (of child), severity of phenotype, and geographic location, I used a combination of convenience and snowball sampling. Convenience sampling was chosen as one method due to the convenience of the potential participants’ accessibility to me as the founder and former executive director of the LGS Foundation and as a friend to some of the members in the group. Snowball sampling was also employed so that I had the opportunity to reach and potentially recruit others within the group who I did not have a personal relationship with, or who were recommended by other participants.

Data saturation was reached around interview 18, but I continued to conduct an additional five telephone interviews that had already been scheduled. I suspected at that point I had reached saturation because responses from participants were becoming repetitive and my notes indicated many of the same possible themes. The additional five interviews, therefore, also helped to confirm that no new themes would emerge. Fusch and Ness (2015) argue that while there is no “one-size-fits-all” method to reaching data saturation, qualitative researchers agree that saturation is reached once there is no new data, no new themes, and the ability to replicate the study (Fusch & Ness, 2015; Guest, et al., 2006). An additional five member checks were conducted through email which confirmed my findings after I reached data saturation. Member checks, also known as participant or respondent validation, is a way to ensure the credibility of the results. Lincoln and Guba (1985) refer to member checks as the most crucial technique for establishing credibility (p. 314). Data gathered during the qualitative research process—from interviews in this case—was returned to additional participants to check for accuracy and to explore whether the data and emerging themes resonated with their experiences (Birt, Scott, Cavers, et al., 2016). Member checks were performed rather than member reflections (Tracy, 2018) because the intention was to validate the data. Conversely, member reflections, which allows researchers to gather additional insight that informs continued data collection, was not necessary at this point because data saturation had been reached and there were no plans for continued data collection. Participant information is summarized in tables 1 and table 2.

Table 1

Interview Participant Summary

Pseudonym	Gender	Geographic Location	Age of Child (Years)	Length of Interview (Minutes)	Number of Transcribed Pages (Double Spaced)
Abby	F	Northeast USA	20's	18	13
Lilly	F	Northeast USA	Teenage	18	14
Victoria	F	Northeast USA	Teenage	20	18
Josephine	F	Northeast USA	Teenage	20	17
Kallie	F	Southeast USA	20's	20	18
JoJo	F	Northeast USA	Teenage	22	20
Lisa	F	North-Central USA	20's	22	19
Dee	F	Southeast USA	30's	23	20
Samantha	F	Northeast USA	Teenage	23	14[1]
Katie	F	Southwest USA	30's	24	22
Debbie	F	Northeast USA	20's	25	22
Stephanie	F	North-Central USA	20's	25	22
Francis	F	North-Central USA	20's	25	18[2]
Laren	F	Southeast USA	Teenage	28	25
Abigail	F	Southwest USA	Teenage	31	28
Brenda	F	Southeast USA	Under 10	33	31
Deloris	F	Southwest USA	Teenage	33	31

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[1] Handwritten notes were taken

[2] Handwritten notes were taken

Theresa	F	North-Central USA	Teenage	36	34
Emily	F	Northwest USA	40’s	38	33
Dora	F	North-Central USA	20’s	36	32
Kierra	F	Northwest USA	Teenage	41	37
Korin	F	Northeast USA	30’s	44	39
Dorris	F	Southwest USA	20’s	51	46

Table 2
Member Check Participant Summary

Pseudonym	**Gender**	**Geographic Location**	**Age of Child (Years)**	**Number of Pages of Email Correspondence (Double Spaced)**
Colleen	F	Northwest USA	20’s	2
Veronica	F	North-Central USA	20’s	1
Heather	F	Northeast USA	Teenage	2
Kat	F	Northeast USA	30’s	1
Florence	F	Northeast USA	20’s	1

The length of the interviews ranged from 18 minutes to 58 minutes with an average of 30 minutes. The interviews resulted in over 500 double-spaced pages of transcribed audio. Two of the participants did not wish to be recorded, so 32 pages of hand-written notes were taken to capture their thoughts in the place of an audio recording.

It is important to note that all of the participants were personal contacts of mine. While the degree of the relationships among the participants varied from very close friends to acquaintances I had only met once, all of the participants knew me personally as a sibling to someone with LGS and professionally from my tenure at the LGS Foundation as executive director. Therefore, I occupied a unique role as both friend and researcher to many of the participants. While some researchers (see, for example, Huisman, 2008) explain potential dilemmas that may surface in having a dual role of researcher and friend (e.g., lack of reciprocity or emotional harm to participants), Ellis, Adams, and Bochner (2010) argue that many scholars are able to successfully wear multiple hats and are able to understand participants' stories differently when they know them more intimately (Ellis, 2010). Therefore, it was important to follow a "relational ethics of care" (Ellis, 2007), which refers to the way in which the researcher interacts with his or her participants while focusing on the story at hand, not the "universal, abstract, and theoretical" (Bochner, 1994). In relational ethics of care, the researcher acknowledges that they are part of the conversation and are able to successfully navigate their own issues while exploring the responses of others (Fahie, 2014).

Interview: Procedures

All interviews were conducted over the phone with the exception of one, which was conducted via Zoom. This was because the respondent did not have strong cellular service living in a mountainous region in the pacific northwest. The interview protocol consisted of 35 questions with prompts that were mapped out under the research questions (see Appendix C). The questions were purposeful and intended to not only answer the research questions posed, but also, to more deeply understand the lived experiences of caregivers with LGS. The participants were asked to recall often painful memories of their LGS journey, from the first seizure their child experienced to present day medical circumstances. Weaved into the interview protocol were questions that built rapport (if not already established) and prompts for me to insert myself as a researcher-participant. The researcher-participant role is discussed later, in the reflexivity section.

As mentioned, the interview protocol was developed with the research questions mapped out. For example, the first research question, which seeks to understand how LGS caregivers receive/provide social support through OSGs, included questions for participants. Sample questions include: *Do you feel supported when you post specific questions about your loved one?; How supportive do you feel in helping other families?; Tell me a little bit about how you felt before joining the group in terms of social support.* Interview questions associated with the second research question related to privacy and LGS. Sample questions here included: *Do you feel as though your privacy in this group is safe?; Do you ever worry about others sharing stories contained inside the group outside of it?;* Questions related to how caregivers determine which/how much information to share included: *What type of information do you find most useful in the group?; What types of questions do you find most useful answers that you specifically post?; How much information do you feel like you share about your experience living with LGS?;* For the fourth research question, which was related to why caregivers use online support groups for LGS, this question was asked: *What were your initial reasons for joining the LGS Foundation Facebook page?* And finally, for the fifth research question, which sought to explore the topics that users most often discussed in the group, included questions such as: *What type of information do you find most useful in the group?; What types of questions do you find most useful answers that you specifically post?; Which areas related to LGS do you feel as though you have gained the most knowledge in?; Which areas related to LGS do you feel as though you still are looking for answers in?*

Prior to beginning the interview, I reminded the participants about their right to privacy and confidentiality as well as their right to decline being audio-recorded. Since health information was discussed, I also ensured participants that their privacy would be protected, including assigning pseudonyms for them and their child and scrubbing the data to remove any identifying markers. Finally, I explained that if at any time, they felt uncomfortable answering a question, they were free to skip the question.

Rapport building, while important in qualitative research, was not necessarily a goal of mine since I already knew many of my participants fairly well. Some scholars (see DiCicco-Bloom and Crabtree, 2006) would argue that rapport building is essential for trust, but I felt as though I was acquainted well-enough with most of my participants that trust had already been established. Plus, I preferred to use the time scheduled for the interview conservatively, focusing on the interview questions rather than spending an ample amount of time on opening / rapport building questions. However, there were a few participants whom I only met once or twice in person and had not spoken to in a few years, so in order to re-acquaint ourselves, I began the interview with simple “catch-up” questions, mostly related to our loved ones with LGS. Catch-up questions served a different purpose than rapport building by allowing me to re-familiarize myself quickly with their child and the state of their LGS diagnosis.

Each interview (with the exception of two) were audio-recorded and automatically transcribed using the software app Otter.ai. I also took hand-written notes throughout the interview--noting powerful quotations, capturing responses that helped address my research questions, and memoing about possible emerging themes in real time. I saved each audio recording along with the transcribed text to a secure, password protected drive that required two-step authentication. Hand-written notes were stored in my home office in my personal filing cabinet.

Data saturation was reached after interview 18. However, because I had scheduled another seven interviews, I continued to conduct the interviews with some emerging themes in mind that helped guide the conversations. Five additional interviews were completed (two canceled and were not rescheduled). Data analysis began next, which is discussed in a later section, followed by member checks with five participants.

Mediated Interviews

Mediated interviews were chosen as my first method of data collection for various reasons. Mediated interviews are interviews that do not occur face-to-face, but rather via technological media such as a telephone, a computer, or other hand-held device (Tracy, 2013). Due to social distancing protocol during the COVID-19 pandemic as well as the geographical limitations to reach participants in person, telephone interviews were chosen as the medium for the interviews. Further, mediated interviews were noted to be more flexible for LGS caregivers who are already limited in free time due to the constant constraint of caring for their child. Lastly, mediated interviews were the preferred method for interviewing because of the potential for participants to better control their self-presentation and therefore, be more sociable and relaxed than in person (Tracy, 2013).

Personal Narrative

Personal narratives, as a form of autoethnography, accounts for vignettes throughout this dissertation. Personal narratives incorporate stories about the author throughout evocative narratives that focus on various aspects of the author's life (Berry & Patti, 2015; Ellis, Adams & Bochner, 2010). Ellis (2004) explains that personal narratives propose to "understand a self or some aspect of a life as it intersects with a cultural context, connect to other participants as co-researchers, and invite readers to enter the author's world and to sue what they learn to reflect on, understand, and cope with their own lives" (Ellis, 2004, p. 46). This dissertation uses vignettes as a personal narrative for these reasons, in addition to the aforementioned data collection through qualitative interviews.

Autoethnography, overall, is an approach to research that seeks to describe and systematically analyze personal experiences in order to understand others' experiences (Ellis, 2004; Holman & Jones, 2005). Autoethnographers recognize the ways that personal experience influences the research process. In my case, I'm a researcher studying social support and information sharing in LGS because of personal experience as a family member and as the founder of the LGS Foundation. Therefore, reflexivity is discussed in the next section.

As a method, autoethnography combines characteristics of autobiography and ethnography (Ellis, 2011). Autoethnography strives to connect the researcher's life experience with their research methodology that would be overlooked in traditional ethnographic methods (Robert, 2010). A key component of autoethnography is self-examination, which offers an important context for qualitative research (Tracy, 2013). Autoethnography also embraces a researcher's subjectivity and recognizes how intimately involved a researcher may be in their scientific process.

Ellis, Adams, and Jones (2015) published a list of goals for assessing what they consider a "good" autoethnography. These components include: descriptive writing, perspective of the researcher, practical goals, and theoretical bases. Further, they agree that autoethnography: makes contributions to knowledge, values the personal and experiential, demonstrates the power, craft, and responsibilities of stories and storytelling, and takes a relationally approach to research practice and presentation (Ellis, Adams, & Jones, 2015).

Researcher Reflexivity

I was led to this applied dissertation project due to my personal experiences as a sibling of a man living with Lennox-Gastaut Syndrome, as founder and former executive director of the LGS Foundation, and as a scholar of communication studies. Thus, these are significant reasons for me to address reflexivity. Reflexivity in qualitative research is an awareness of the researcher's role in the practice of research and understanding how it influences ways in which she or he can affect the research process and outcomes (Alvesson, Hardy & Harley, 2008). I certainly recognized that I might approach this research with biases from decades of experience as a LGS sibling and with experiences that differ from those of my participants. In fact, only a few of the caregivers that I interviewed had as many years of lived LGS experience that I did. However, I recognized and appreciated that the breadth and depth of the caregiving from mothers I interviewed was significantly different than mine, and my perspective as a sibling differed greatly from theirs.

I was inspired by social support in CMHC environments for this project because I personally experienced a lack of support before the LGS Foundation was started. I attribute this to two factors. First, I was a sibling, so I understood that my social support needs were different as a child and teenager than those of mothers who have children with LGS are. Second, the internet was still young when I was a youth and is vastly different today than it was in the 1990's and early 2000's. Therefore, social support needs may differ based on the age of the child due to advances of the internet, CMHC, and online support groups. I recognized these factors when developing my interview questions as part of the reflexive process.

I was drawn to the theories of social penetration theory and communication privacy management for this project not only because they are two interpersonal communication theories that address information sharing and privacy concerns, but also because they have not been applied in CMHC environments in rare diseases. Anecdotally, as noted in some of my reflexive vignettes, the tenets of these theories "made sense" to me in the context of the LGS Foundation Facebook group, but as a scholar of communication, I wanted to ensure that my reflexivity did not affect the way in which these theories were addressed.

I was also acutely aware of my role as the founder and executive director when this project was conceived. I was concerned that there might be a power dynamic between myself and my participants (since I held a leadership position with the organization for 13 years), and I was concerned that some participants might feel intimidated or obligated to participate out of gratitude for receiving benefits from the LGS Foundation in the past (e.g. a travel scholarship to a past conference or financial assistance). However, these concerns dissipated when I stepped down from my position as the director in 2020 and no longer served in a leadership capacity for the organization. Finally, my reflexivity as an educated, middle class female was also taken into consideration. I knew that while some of my experiences would be remarkably similar to those I was interviewing, I was also aware that my socio-economic position may differ greatly from some of the participants I spoke with.

Data Analysis

The intent of data analysis is to make sense out of the findings; it involves segmenting and taking apart the data (like peeling back the layers of an onion) and then putting it back together (Creswell, 2014). Essentially, it involves making sense of large amounts of data by reducing the volume, followed by identifying patterns and themes, and making meaning from the data (Patton, 2002).

Miles and Huberman (1994) offer three steps to data analysis: data reduction, data display, and conclusion drawing. Data reduction refers to the process of selecting, focusing, simplifying, abstracting and transforming the data (Miles & Huberman, 1994, p.10). Data display is an organized visual display of information that allows the researcher to draw conclusions based on what was previously selected.

Displays may include graphs, charts and matrices and are all designed to assemble information so that researchers can draw conclusions or move onto the next step. Conclusion drawing is the third step where the researcher notes patterns, causal flows and regularities. Miles and Huberman note that at this stage, conclusions are starting to be drawn; they may be vague at first but then become increasingly explicit and grounded, as Glauser and Strauss (1967) first described in grounded theory.

Data from the interviews was analyzed independently using traditional deductive inquiry (Miles & Huberman, 1994). Deductive analysis had been chosen as my means of analysis in order to prove or support existing theories and the research questions posited above. Since my dissertation was guided by the concepts of health literacy and social support as well as the theories of social penetration and communication privacy management, I followed Miles and Huberman's (1994) approach to data analysis that focused more on selective coding rather than open, or axial coding used in grounded theory (Denzin & Lincoln, 2003; Glaser & Strauss, 1967). Miles and Huberman's approach focuses on analyzing the data using conceptual frameworks and research questions to guide the process. They argue that this approach is the best defense against data overload. Since my research was guided by a theoretical framework and research questions, deductive coding was most helpful in reducing such data overload. During the analysis, I began to stratify the information into patterns and themes to see how those themes were implicated against the theoretical frameworks (e.g. Saldana's streamlined codes-to-theory model for qualitative inquiry; see figure 1). According to Miles and Huberman, noting patterns, themes, seeing plausibility, and clustering helps the analysis see what goes with what.

Coding Techniques

Data reduction takes place through the process of coding (Miles and Huberman, 1994). Codes are labels that assign meaning to the information gathered during a study. Codes are usually attached to “chunks” of data of various sizes and can be descriptive, evocative, straightforward, or complex (Miles, Huberman and Saldana, 2013). Saldana (2012) defines a code as a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data. Charmaz (2001) describes codes as a “critical link” between data collection and their explanation of meaning (Chamaz, 2001; Saldana, 2013).

I manually coded the transcripts using a line-by-line coding technique to find emerging themes (Corbin & Strauss, 2008) in Microsoft Word. I relied heavily on markers (within Word) and the comments function to separate different codes into categories. I then handwrote these codes onto paper spreadsheets, using the margins to make additional notes which I would later revisit. This technique turned out to be a bit of “organized chaos,” but in the end, I found it to be the most appropriate way to visualize the concepts. Plus, this coding style is similar to how I’ve analyzed data in past coursework at University of Maryland. In retrospect, however, I might have used an excel document instead given the much larger amount of data that I needed to analyze.

Saldana suggests that coding should take place in two cycles: a first cycle and second cycle (Saldana, 2013). The first cycle should be done through an elemental methodological approach which serves as a foundation for the codes. Miles, Huberman and Saldana (2013) suggest there are three elemental methods to the first cycle of coding: descriptive, in vivo, and process coding. I began with descriptive coding in order to sort codes broadly. Descriptive codes assign labels to data based on short phrases or words, which lead to an inventory of topics for indexing and categorizing (Miles, Huberman & Saldana, 2013). An example of descriptive coding from one excerpt from a participant is as follows:

I had thought for so many years [it] was *depression* and *isolation* and really feeling… that we were *misfits*, that we were the only family like that, and that we did not fit in this world.	1. DEPRESSED 2. ISOLATED 3. MISFITS

The second cycle of coding should follow an affective method of coding, which aims to explore the subjective experiences we encounter and co-constructed feelings we create with our participants. For the second cycle, I revisited the data to look for emotional codes. Other forms of affective coding that Miles, Huberman and Saldana (2013) discuss are value-based coding and evaluation coding. Emotional coding was the most appropriate choice of affective coding given the ubiquity of emotional responses from participants based on their lived experiences. An example of emotion coding follows:

It's my biggest *fear* you know, and so there are times that I don't even put a *heart* or anything [emoji] on there. I don't know... I usually, if someone just announced their kids died, then I will put a *crying* thing on there. But, when they continue to post, I don't know what to do.	1. FEAR 2. LOVE 3. SADNESS

During the first round of coding, a handwritten codebook was developed. The codebook was used to capture initial ideas that emerged through the process of coding. The second round of emotion coding allowed me to finesse these codes further and sort the codes into various bins. For example, coded passages such as "misfit", "we don't belong", and "no one else gets it" were placed into the "feelings of isolation" category while passages such as "share my story" and "I'm an open book" fell into an "openness" category.

After the two cycles of coding and the division of codes into categories, I continued to follow Saldana's (2013) streamlined codes-to-theory model for qualitative inquiry (see figure 1). Since I was using theoretical frameworks to guide my dissertation research, I found this model particularly helpful in the development process from codes to categories to themes to theory, and eventually used this model to apply concepts of social support and health literacy as well as the theories of social penetration and communication privacy management.

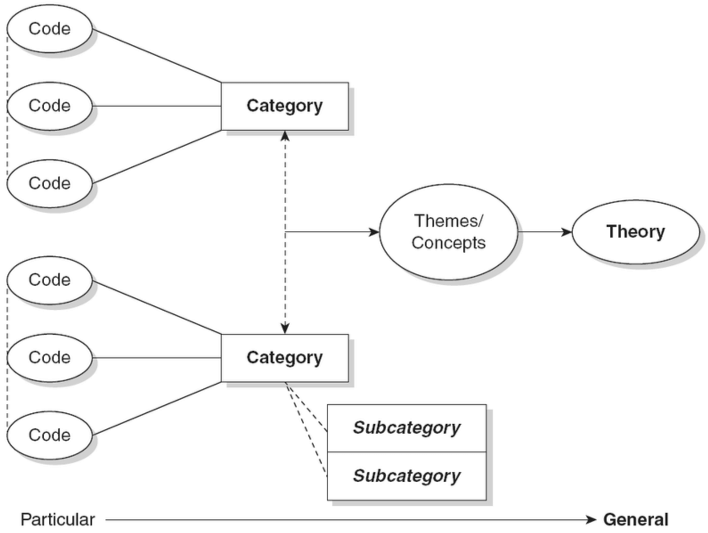

Figure 1

Figure adapted from Saldana (2013)

Limitations

As is the case with all research project, this dissertation had limitations. First, all of the participants were mothers of children with LGS. There were no fathers interviewed. This is likely due to the disparity of caregiving, which more commonly falls on women serving as primary caregivers of disabled children (for example, Oh & Lee, 2009; Vadivelan, Sekar, Sruthi, & Gopichandran, 2010). This can also be explained because I recruited for this study on my personal Facebook page and am friends with more mothers who are LGS caregivers rather than fathers. Future research could seek to explore the father-caregiver role in CMHC environments and rare disease, broadly, if not LGS, specifically.

Second, participants were asked to recall events that happened in the past. Therefore, their recollection of experiences pertaining to lived experiences with LGS or specific situations within the LGS Foundation Facebook group may not be precise and responses may suffer from recall bias. Some participants have decades of experience with Lennox-Gastaut Syndrome, so memories may have been blurred over time. However, I asked participants to recall events as “best as they could” and inserted follow-up probes to help spark memories they may have pushed aside over time.

Lastly, the data collection method for this project was conducted through telephone interviews. Therefore, I may have missed non-verbal cues associated with a response that may have helped me to more appropriately understand their emotions. However, this may be a common limitation with interviewing rare disease patients and caregivers given the difficulty in accessing participants face to face due to distance barriers and lack of in-person access. Further, these interviews took place during the COVID-19 pandemic, which added an additional barrier in accessing participants face-to-face, even if meeting caregivers in person was not an issue (e.g. at a LGS conference or fundraiser).

Validity and Reliability

Multiple perspectives and definitions exist in qualitative scholarship to describe validity in qualitative research. However, there is a general consensus that qualitative researchers need to demonstrate a credible study (Creswell & Miller, 2000 citing Lincoln & Guba, 1985). Lincoln and Guba (1985) use the word *trustworthiness* to describe validity which can be achieved by credibility, transferability, a long time in the field, strong methodological choices, and triangulation (Lincoln & Guba, 1985). More recently, Creswell and Poth (2013) describe validity as the way to assess the credibility of results; they suggest that validation is used to emphasize a process instead of a verification. They also suggest that validity is reached by spending a long time in the field, through rich description, and when there is a close relationship between the researcher and the participants (Creswell and Poth, 2013). Based on these criteria, validity was reached for this study in a number of ways. First, the close relationship between researcher and participants has been described previously in this chapter. Second, while the interview process with participants did not require a long time in the field, I have decades of personal experience with LGS (as a family member and founder of the LGS Foundation) and have developed strong relationships with others who care for people with LGS. Further, my background in the LGS community helped inform my decision to incorporate the autoethnographic method (personal narrative through vignettes) that are used to provide an additional methodology in this dissertation. This not only provides additional description, but also helps to triangulate the findings. Triangulation, for this project is based on a triad of the personal narrative, qualitative interviews, and theoretical constructs.

According to Lincoln and Guba (1985), reliability is equal to *dependability*. Campbell (1996) suggests that reliability in a research study can be achieved when the steps of the research are verified through examination of such items as raw data, data reduction products, and process notes (Golafshani, 2003, citing Campbell, 1996). A question that many qualitative researchers ask when considering reliability is this: is the process of the study consistent and reasonably stable over time and across researchers and methods? (Miles & Huberman, 1994, p. 278). In other words, if another qualitative researcher were to look at the methods used and the data collected, would they draw similar conclusions? However, when it comes to autoethnography, reliability is a bit more elusive. Bochner (2000) argues that self-narratives/ autoethnography should not follow the same standards as other qualitative methods because they are “not so much academic as they are existential, reflecting a desire to grasp or seize the possibilities of meaning, which is what gives life its imaginative and poetic qualities…a poetic social science does not beg the question of how to separate good narrativization from bad…[but] the good ones help the reader or listener to understand and feel the phenomena under scrutiny (Bochner, 2000. p. 270). Therefore, while reliability in this study is met through the qualitative interviews and analysis, some scholars (see, for example, Holt, 2003; Sparkes, 2000) would argue that the autoethnographic approach used in this dissertation should not be judged by the same traditional criteria used to judge other qualitative investigations.

Chapter 4: Findings

This chapter summarizes the research findings, which address the research questions that guide this dissertation. As a reminder, the research questions focused on social support within the CMHC environment of Facebook groups, information sharing and information seeking (specifically health information related to LGS), reasons for participant use of online support groups, and privacy concerns among members of the Facebook group.

Data collected from participants suggested that participants used Facebook groups to provide and receive social support reciprocally from other members and for information-seeking and information-giving about the disorder, associated co-morbid conditions, or other LGS-related concerns. Findings also suggested that privacy was not a major concern for members. Five prevailing themes emerged from the data and are described below. Each theme is introduced with a vignette that presents a personal narrative to further situate my experience as a member of the community and communication researcher.

Facebook Groups as a Medium for LGS caregivers

Vignette: CMHC for LGS Caregivers

After I founded the LGS Foundation in 2007, I turned to social media to find and connect with other LGS families. The first connections I made through social media were through Myspace[3]*, the most popular social networking site at the time which, in 2007, surpassed Facebook in the number of users. I used Myspace to*

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[3] Myspace was the most popular social networking site in the world at the time, briefly surpassing Google as the most visited website in 2006 (Prescott, 2006; Thelwell, 2008). Facebook, on the other hand, was just getting started in the public domain. While it had been created in 2004 for college students, Facebook didn't open access to the general public until 2006 (Cassidy, 2006).

> *connect with other families somewhat easily; a keyword search for "Lennox-Gastaut Syndrome" led to a short results page with Myspace profiles that contained the phrase. I messaged the owners of these pages introducing myself and to the newly formed LGS Foundation. For the first time in nearly 20 years, I finally felt connected to other LGS families.*

Social media can be a lifeline for those living with a rare disease (Stone, 2015), particularly when no advocacy group exists to represent or support their diagnosis. Fortunately, LGS caregivers have multiple social media platforms to tap into, including groups that exist for epilepsy (broadly), groups for comorbid conditions or co-diagnoses, and groups for treatment options specific to LGS (e.g. cannabis for LGS, ketogenic diet groups, and surgical groups). The ubiquity of online support groups provides LGS caregivers the opportunity to join an array of social networking sites to satisfy their needs. For example, LGS caregivers may join disease or health-specific social networking sites such as Patients Like Me or Inspire where they can connect to groups related to other primary or secondary diagnoses (e.g., cerebral palsy, autism, and gene-specific etiologies), or they may turn to more mainstream social networking sites like Twitter and Facebook to connect with others.

Twitter, for example, may fill informational needs about LGS through "tweetchats" by organizations that represent their interests or by following individuals who share common experiences. In fact, twitter has increasingly become a popular platform for physicians to communicate with their followers about research studies and news about diseases and disorders of interest to them, which can be a benefit to LGS caregivers who wish to stay informed from doctors they trust. Instagram accounts by fellow LGS caregivers or advocacy organizations visually connect them to others through photos and videos. Social media researchers Kim and Kim (2020) suggest that photos and videos can be an effective way of showcasing the expertise of organizations and for delivering health information because of their visual format. Facebook groups, on the other hand, offers a unique structure and algorithm that allows for highly interactive information exchange between members. Facebook was noted by participants to be the preferred CMHC medium for LGS caregiver to caregiver communication.

However, before the internet age, and more recently, the advent of Facebook groups, families facing a LGS diagnosis had very few places to turn when seeking connections with other caregivers. Therefore, it's not surprising that caregivers with older children more frequently recalled feelings of isolation prior to the availability of the internet and specifically Facebook, over parents with children diagnosed more recently. Korin[4], whose son is 33 years old, noted, "We got the diagnosis of LGS before the internet really took off, so we had never met another person with LGS. We thought we were the only ones out there." The year of her son's diagnosis was 1989, long before consumer internet was widely available. Another LGS caregiver, Katie, noted how she wished she had gotten the diagnosis [for her daughter] during the age of Facebook. She said,

> Oh, goodness, I constantly say this to other people, that it would be so much better to have gotten the [LGS] diagnosis now that there's the Facebook groups and that sort of thing, because I wouldn't have been quite as scared.

She elaborated on this statement later in the interview. She added,

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[4] All names are pseudonyms.

> Before I found Facebook and the LGS group, I felt completely alone. Then one day I found it and said, “Oh, my God, there are other people out there!” And all of a sudden, I went from feeling completely alone to feeling like there's a group of us. Yay, I'm not completely alone in the world. Just the idea that there are other people out there going through the same thing!

Here, Katie suggests that if she received the diagnosis of LGS today rather than 20 years ago, she may have felt more connected to a group of others who knew what living with LGS was like, due to the connectiveness that the internet – and online support groups – afford. While Katie didn’t use other social networking sites prior to her finding LGS groups on Facebook, she suggested that having the option for online support groups two decades ago would have made a difference in her life.

Other participants described their experiences finding groups outside of Facebook at first, including groups through MySpace and Yahoo! groups, which were social networking sites available to the public before Facebook groups launched in 2010. This is important to note because despite Facebook being the preferred medium for caregiver-to-caregiver communication noted by the participants, it highlights the importance of online support groups in general for LGS. Laren, for example, explained how she found online support almost immediately after her son’s first seizure:

> I consider myself lucky because I found the online support group very quickly. Pretty much the same day that [my son] had his very first head drop. It was the infantile spasms group online and it was on the Yahoo forum... So, from there, I knew many things that I wouldn't have known going into my

> doctor's appointments if I hadn't talked to them first. And so I knew that there was almost always a cause of the infantile spasms, and it was important to find out what that cause was.

Connections address feelings of isolation. The parents of children affected by a rare disease described caring for their child to be highly isolating, with “loneliness, social isolation, and feeling disconnected from society being mentioned as common problems” (Pelenstov, Fielder, & Esterman, 2016, p. 207). While rare disease families report social isolation and exclusion (Currie and Szabo, 2020) some studies (see, for example, Barton, Wingerson, Barzilay, & Tabor, 2018; Titgemeyer & Schaaf, 2020) have indicated that isolation decreases for rare disease patients through Facebook use. The data collection from this study confirmed these findings, as nearly all caregivers interviewed discussed how they felt some degree of isolation before connecting with others through Facebook groups.

For example, Dee, who has an adult son in his 30’s with LGS, recalls feeling depressed and alone due to the LGS diagnosis decades earlier. She said,

> I had thought [before Facebook] that what I had [felt] for so many years was depression and isolation and really feeling like we were misfits, that we were the only family like this and that we did not fit in this world.

Dee expanded on this thought, explaining that she feels the LGS community helps her manage feelings of isolation. She added,

> Yes, you've got families and friends that love you. They support [you]. They say, ‘call me if you need me’. But [compared to my family] the other families

> [on Facebook] really, really understand and it’s nothing compared to your family.

Here, Dee discussed why she felt the LGS community addressed her feelings of isolation, particularly when comparing her relationships with those on Facebook to those of her family in terms of LGS.

“Feeling alone” was a phrase used by nearly every participant during the interviews. The feeling of loneliness transcended geographic location, age of child or disease severity. Debbie, a mom to a 28-year-old, shared the following sentiment when she recounted her experience interacting with the LGS Facebook group:

> In the beginning, we felt alone as far as a diagnosis and constantly explaining to people that this wasn't just a few seizures, or a mild form of epilepsy, so you don't feel understood. But you go into the [LGS Foundation Facebook] group and you don’t need to explain.

Also of note was a caregiver who experienced geographical isolation in addition to the rare disease isolation that others have articulated. Theresa exemplified this reality, when she said,

> I had been in isolation my whole life. I lived in the country. We didn't even have cable. Suddenly I'm living in a big city in [the Midwest USA], in a Ronald McDonald house, and someone there said, ‘Do you want to apply for an Obama phone?’ I was like, ‘What's that?’ and she just gave me a cell phone well as I was messing with it. Another woman was like, ‘you should get on Facebook’. And that's how I even learned what Facebook was.

Theresa’s quotation raises an important issue to note, that is, experiences from other participants with different socioeconomic backgrounds shared similar feelings of loneliness. While participants were not explicitly asked about their socioeconomic status during the interview process, many participants discussed aspects of their financial situations, employment, and education during the interview. Therefore, another important issue to note is that feelings of isolation did not discriminate based on socioeconomic status for participant.

Abigail, a mother who lives in a suburban area outside of a Southern city in the U.S., indicated that despite a strong support system from her family and friends, she also experienced loneliness:

> I was incredibly alone, supported by family and friends that didn't understand. And my dad's a physician, but he just doesn't get it. It's not necessarily that he doesn't get the neurology part of it, it’s that he does not understand the support aspect of raising a child with a long-term disability.

Korin, who lives in the New York City suburbs, echoed this point when she noted that despite living in a major metropolitan area, she had not met other LGS families when her son was young. She recalled:

> We’re lucky and fortunate to have access to the best hospitals [in New York City]. But my son went to every hospital in the city to get opinions and second opinions and, you know, you would think we would have bumped into other LGS families in the waiting rooms or the hospitals, but we never did. And, I mean, we were going to see the doctors who saw the sickest kids!

Connections facilitate shared lived experiences. In addition to Facebook groups serving as a bridge for caregiver to caregiver communication with a subsequent impact on isolation, participants also noted the impact of sharing similar "lived experiences," which made them feel less alone. Lived experiences is a phenomenon that describes the experiences and choices of a given person and the knowledge they produce from those experiences (Given, 2008). Qualitative research using lived experiences of patients to better understand their perspectives is increasing in health research (Al Kalaldeh, 2018). Here, participants talked about shared lived experiences as they recounted the connections built through the LGS Facebook group.

Some participants recalled discussions with friends or family members that were marked by a misunderstanding of LGS due to others 'walking in their shoes.'.Dee provided the following example of exchanging shared lived experiences. "You can ask questions and you get that support with people raising their hand like, "Oh my God, the same things have happened to us!" and so you don't feel so isolated.

Deloris, a mother from Texas recalled a similar sentiment when she said,

> [When] I have so [many] things on my mind, I want to get on Facebook and make sure to tell parents, you know, because they feel the same way. Or they question the same thing. So it's kind of like to the point where I do it like two, maybe two times a week. I'm trying to get better at it [posting].

She then expanded on her feelings about connecting with people who share similar lived experienced later in the interview. Here she said,

> There's relief because [I realized] I wasn't alone, you know, there's times where you get emotional support, or even have people asking questions that you can help answer like eating habits or questioning this medication.

Deloris recalled times when she read information about others' experiences that were exchanged on the LGS Foundation Facebook page that had been helpful to her, even if she was not the one who posted the question. This suggests that even when information about others' experiences with LGS is not explicitly sought out, information contained within the group can still be helpful to others who are browsing posts. She noted,

> There are [posts] about CBD (cannabidiol) so that is pretty useful for me. Another [post] is hormones, you know, hormones change their seizure activity, and things like that, so that one is really, really useful for me. And homeschooling. You know, homeschooling versus actual virtual learning. That's something that we contemplated as well. A lot of parents do want to keep them at home now [due to COVID].

Another example that illustrates this is from Josephine who has a teenage son currently using a dietary therapy for the treatment of LGS. She explained that although she mostly reads others' posts instead of asking specific questions, when she did need to ask a question, the responses from other families who had experience with the ketogenic diet[5] was helpful to her. She explains,

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[5] The ketogenic diet is a special high-fat, low-carbohydrate diet that has been shown to be effective for seizure reduction in approximately one-half of children after 12 months with LGS (Lemmon, et al, 2012).

> I mostly take the information in. But when I really had questions about specific diet stuff, there were a couple of people that really helped out; their ratio was very similar to ours and we would share recipes and things like that.

Laren noted that she looks for information from others related to daily living and creative solutions. She said:

> [I look for] those kind of things like what we're doing to live our daily lives to help out because, you know, a lot of these kids are runners, they're climbers, you know, that kind of information… but personally I love like the DIY (do it yourself) tips and the…fun things that the family thinks of, like, ‘oh my gosh that's such a good idea’.

While the majority of information exchanged was noted by participants to be health related, there were certainly other topics (e.g., DIY tips as Laren mentioned in her interview) that, when shared among members, can be helpful to fellow caregivers when living with the diagnosis of LGS. The LGS Foundation Facebook group was repeatedly noted to serve as a vehicle for its members to identify with various shared lived experiences and to ask questions that reflect those experiences, including treatments, services, resources, daily living, and overall quality of life.

*Connections extended to other forms of communication***.** Although Facebook served as a bridge for caregiver-to-caregiver communication and as an initial connection point between parents, some participants said that once those relationships were established, they morphed into more intimate relationships. A few participants explained the strengthening of these relationships in more detail, whether it was a simple friend request after meeting in the group or the development of a close friendship that extended to other mediums (e.g., the telephone, text messaging, or face-to-face). Some users described their experience meeting fellow caregivers in person at LGS events and conferences after they met families online. One such opportunity that many participants cited was the LGS Foundation international conference, a three-day meeting held within the United States every 18 months (pre-COVID) that brings together more than 300 LGS family members from across the world. Other participants discussed meeting up with fellow LGS caregivers who live locally after finding them on the LGS Foundation Facebook group. Korin gives an example of such a relationship that developed beyond the original Facebook group medium:

> I remember meeting [Jen] on the Facebook group because I noticed she lived [in the same area as me]. It was though one of those posts that pop up every now and then when someone asks where you live. So I reached out to her…We found out that we're practically neighbors, just a few towns from one another...So we became friends on Facebook and then from there realized we had a lot of the same interests—including politics (laughs). So we sort of just kindred spirits I guess.

Korin described the first time she met Jen in person later in the conversation, saying,

> We could only get together once since we became friends like four or five years ago, but that's because we both work full time and have kids with LGS, well, you know how that goes. But we stay in touch and both belong to a few of the same groups outside of the LGS [Foundation] group too.

Other caregivers discussed their experiences meeting fellow LGS caregivers face-to-face for the first time—ultimately extending their online relationships that were formed via Facebook into non-mediated means. Deloris said:

> If it wasn’t for the [LGS] conference itself, that's the only reason that we became great friends [with Kimmy]. Because there's one thing [communicating] online you know, you check on them here and there, but it's totally different when you actually meet them in person because it's like ‘okay, now I see you, like, now I see how you struggle with [LGS] or you know, or how you do with living [with LGS].

Kierra described a similar experience. She said, “there's so many positives that come with meeting someone face to face, by communicating without any words, any language, and see their body language and seeing how they care, how they carry themselves, and what they are carrying with them.”

Despite the positive experiences that participants described in using Facebook groups for LGS information sharing and social support, a few participants, like Kierra touched on the impact of face-to-face interactions that stemmed from the relationships built through Facebook. Dee is another participant who discussed the value of face-to-face meetings. Dee says, while she uses the LGS Foundation Facebook group regularly, she doesn’t consider herself a ‘hands-on computer girl’ and prefers face to face interaction. She notes:

> I'm not really a hands-on computer girl. But I'm hands-on. A LGS family was in distress the other week, so I drove two hours to see them. And this was because they give back to me way more than I could give them. They know

> what I’m talking about because they live it too, and we can talk about things that you’d be too embarrassed to say to someone else. No holds barred. It's all on the table.

This anecdote highlights the importance of relationship building and relationship maintenance among LGS caregivers. Dee, for example, understands the importance of Facebook for these relationships, but illustrates her need for interactions with other families beyond a CMHC platform that transition into more intimate, personal relationships.

While face to face connections were regarded as positive experiences for participants, it’s important to note that many of the face to face connections mentioned above may not have occurred if relationships were not built on social media first.

Facebook Groups as a Site for Information Sharing and Receiving

Vignette: From Myspace to Facebook

It wasn’t until 2009 when I started to move and expand my online LGS connections from Myspace to Facebook. Not long after I began using Facebook as my primary form of social media, Facebook launched the groups feature (2010). Slowly, I began to grow the group with LGS caregivers, and within a few years, the LGS Foundation Facebook page was the largest group on Facebook for Lennox-Gastaut Syndrome and it remains so today. The purpose of forming the group was to facilitate communication and information-sharing between members of the LGS Foundation. Although I created the group for these reasons, I admit that I too, benefited from the flow of information in the group. As a moderator, I found myself lurking for hours per day on some occasions in order to learn from others. I also lurked with purpose to help learn more about the needs of the community and about gaps that the LGS Foundation could fill within the community.

Constant information sharing within the LGS Foundation Facebook group is perhaps one of the main reasons for its success in the rare disease context. However, the degree to which some members of the LGS group share information versus ask for information varied among users. An emerging theme from the interviews conducted suggests that the age of the child (and subsequently the parents) may be associated with the amount of support and information they provide other caregivers in the group.

For example, the participants I spoke with who had older children with LGS noted that they were more likely to respond to posts where they could share their experiences, rather than post a question to hear others' experiences. This seemed to be particularly relevant when discussing how they helped "new" parents in the group. In this context, the term, "new," was typically referred to those who were newly diagnosed or had young children. Emily, whose son is in his 40's, noted this point in her interview.

> We joined the [LGS Foundation] Facebook page and I just really wanted to get involved because I wasn't looking for support and connection from my perspective, but I just was feeling…this desire to help and support other parents with younger kids and other parents that have dually diagnosed kids. I mean, just the whole gamut because we had, you know, at that point four decades of, of experience with this.

Debbie, who has a 21-year-old daughter, also enacted the information-giver role. She explained,

> I guess I feel a calling myself to try to help. Mentor as best I can. Younger people. I did have a particularly influential mentor in my life. Although she had two disabled adult children, and neither one of them had seizures, the wisdom and counsel that she gave me was so helpful.

These quotes suggest that caregivers with older children perhaps feel as though they are information givers while caregivers with newly diagnosed children are information seekers or receivers.

Abigail, who is an ambassador for the LGS Foundation and has a teenage son with LGS, feels empowered to help new families in the group. The LGS Foundation Ambassador program provides an infrastructure for volunteer LGS caregivers (ambassadors) to help and mentor other LGS caregivers. Ambassadors assist other families in their geographical area with resources, information, and support. She says, “I would like to think any time a new family is diagnosed, I'm able to help navigate questions or navigate answers and support.” Abigail’s involvement with the LGS ambassador program and her willingness to help others in the group suggests that she perceives her role within the LGS Foundation Facebook group as a mentor. Theresa, who also has a teenage child, says she sets goals by answering at least two questions posted by other members when she’s visiting the Facebook page. However, she mentioned that she receives reciprocal support from being involved in the group as well.

> I try to answer two questions for new families, to give back. Like, if I just give a comment to share my experience. Like, I can give them some of my experience then I can pay it forward. And then, I try to go through [the page]

> and read about the older people [with LGS] to see like how they're doing, what kind of stuff they're running into, what medical things they're dealing with, you know, to be ahead of it. My daughter, one of her [diagnoses] was encephalitis, and she took a big hit her kidneys and bladder and her bowels, and I see another family that's going through the same thing, so it's neat to see like how they dealt with it now that this person is 25 or 30 years old.

Here, Theresa explains that although she is giving back to the community by providing a few comments at a time, she also receives support from caregivers who have children older than her daughter. Laren, whose son is 15 years old, shared a similar sentiment:

> What I'm finding is that parents who have older children, like in their 30s and 40s, are like, ‘I remember way back when…this happened to us and that's where they feel most supportive, right? It depends on where you are or how old your child is.

JoJo says that she uses the group to help others, specifically those who are newly diagnosed.

> I love being able to support newly diagnosed or other families, like, I think it helps me help [my son] or helps me to feel like I'm being more helpful towards other people with the same thing if I can share some of my experiences.

Changing Uses of Information. Some participants noted that their use (information receiving and information giving) of Facebook groups for information changed over time or depending on their situation. For example, Victoria said:

> At first, [upon joining] I was just digesting the information. I didn't really understand what was going on [with my child]. At some point, I did start asking questions but I don't think it took all that long…I was a heavier user when I had Facebook on my phone…but then I took it off of my phone and started focusing more on [my daughter], and the one drawback is that I'm not on the page as much. Before I used to read everything and was responding all the time. And then I kind of, you know, go on Facebook just on the computer. Yeah, so it's like once a week or once every two weeks or something.

Other participants indicated that their Facebook groups usage changed over time depending on their needs or comfortability within the group. Like Victoria, some participants explained that they joined the group to read and digest information before interacting with others. Abigail expressed this point during her interview when she said:

> I think that [when I first joined] I was sitting back and reading. Just like how many people went through what I went through. And then on the Facebook page people would post something and I would comment, but it took me a little while to get comfortable enough [to post] because I was always like, ‘is this a dumb question? Did I already know this?’ You know, you learn very quickly that nothing is a dumb question.

The quotes above suggest that the way in which participants give and receive information may change over time or depending on the age of their child. Information seeking—and receiving—appears to be more common when users first join, and information-giving appears to be more common when users have been in the group for a longer period of time.

Facebook Groups as a Source of Social Support

Vignette: Providing Social Support

> *I've lived through the LGS diagnosis as a secondary caregiver and sibling for thirty years. My social support needs have changed drastically over three decades; I am much less in need of the social support that many other LGS families crave, especially those who are newly diagnosed. Therefore, instead of seeking support, I offer it, and Facebook is the primary medium in which I've used to provide it to others.*

Social support refers to the emotional, informational, or instrumental resources provided by one's social networks that help her or him to cope with stressful events (Cohen, 2004). Facebook, as the largest form of social media used for interpersonal social networks, has been found to be an important source of social support (Gilmour, Machin, Brownlow & Jeffries, 2020), particularly in rare diseases (Titgemeyer & Schaaf, 2020).

Facebook Groups were viewed by participants to be a significant part of their social support. While information giving and information seeking were important aspects of group membership, social support was also frequently discussed. Social support can be an extension of information giving or can be a stand-alone attribute offered by others. The participants explained that once connections were made through the LGS Foundation Facebook group, they began to see it as a source of social support.

The definition of social support was described to participants before asking related questions. Social support was explained to be a phenomenon in which one's social networks provide emotional or informational resources to help others—fellow LGS caregivers, in this instance—cope with stressful events (e.g. the "LGS journey"). However, many caregivers described feeling socially supported (by others through the Facebook group) during the interview before the respective social support questions were asked.

Surprised by Social Support. Brenda, who is a new member of the LGS Foundation Facebook group, spoke about feeling surprised by the amount of support she received during her interview. She joined the Facebook group with the intention of asking a question about the electroencephalogram (EEG) related to her daughter's new LGS diagnosis, but found that families extended warm welcomes and "virtual hugs" in addition to providing the information she was seeking. She recalled her experience,

> My daughter was recently diagnosed with LGS, but she doesn't have that exact EEG pattern [slow-spike and wave], so I wasn't sure if we would be really, like really accepted into an LGS group…She is developmentally disabled…and has three different seizure types, but the EEG is not quite there. So when I joined, I wanted to see how, you know, important the EEG was. And the responses I got from my post were so heartwarming. I got a lot of "welcome" posts and "hugs" and things like that, but I also got other moms telling me that their kids also don't have the exact EEG pattern, so I felt like I did really belong in the group.

The above quotation suggests that although Brenda was concerned she would not be accepted because her daughter didn’t fit the exact clinical criteria of LGS (the triad for diagnosis includes multiple seizure types, developmental disability and a slow spike-wave EEG pattern), she was still warmly welcomed and socially supported by others.

Another participant shared a similar situation. It wasn’t until she entered the LGS Foundation Facebook group that she finally felt socially supported by others. She explained that at one point, the only support she received related to the LGS diagnosis came from the LGS Foundation Facebook group despite having a close network of family and friends. She said,

> I think at one point the only support I got [came from] the Facebook group. I really did find a lot of [support] through the group…[it was] for me, the best way of getting it and having to feel that this wasn't something that I've had to be alone [with].

Dee also discussed the “love” and social support that she gives and receives from the group. She explained, “Facebook helps you make that connection with people, and you love each other and you love their families and their kids and you care about them and you want the best for them.”

Reciprocating Social Support. Other participants explained that although they avoid responding to emotionally charged posts for various reasons, they “stick around” to make sure other users respond so the participant in the group is not left without support. Emily said:

> I still read posts a little bit before I react and comment specifically because I don't want to minimize somebody else's experience at all…They're in the middle of it [emotions]. I remember those times, but I'm not currently experiencing it. And I don't want to give a Pollyanna [perspective] like, 'Oh sweetie, it'll be okay.' Although I really do believe ultimately it's going to be okay, but if you say that to somebody in the middle of them pouring their heart out about their concerns and worry and exhaustion and sleeplessness and all of that…So I don't post if I feel like they've gotten enough of a response [from others] and support…[For example], there was a post that I read yesterday that I didn't respond to; it was somebody who felt like she was a bad mom. But there were 27 or 28 posts about reassuring her that she wasn't a bad mom.

Kierra explained that her friendships with people in the group are the strongest when it's mutual or reciprocal. For Kierra, she gravitates towards other members who care about her as much as she cares about them. She explained:

> I think I gravitate toward people where there's a mutual showing up or a mutual presence, where it's not one-sided. Like, it's very hard for me to connect to people that always just need me and they're never saying like, 'How are you?' And so, you know, it's social media that has also given us that platform of like, 'Oh my gosh, our kids are so alike,' you know because I still talk to Stephanie, Joanne and Kaitlin probably the most. And it's not necessarily that our kids are alike, other than just the diagnosis, because they are also different. But the level of connection that we've established I think

> that it's a mutual friendship.

Here, Kierra suggests that the social support she gives and receives is dependent on a mutual understanding of friendship between her and other members. Therefore, a one-sided relationship with other participants in the group would not be as beneficial to her.

Social support through knowledge. In addition to feeling more supported and less alone by being involved in the LGS Foundation Facebook group, participants also indicated that they felt understood by other members. This is likely due to shared experiences and commonalities between their children due to the diagnosis. Caregivers noted that they were often required to explain what LGS was to others, including some medical professionals. Brenda says,

> I went into the group and it was like, I didn't have to explain what LGS was. For years, I had to tell everyone what it was but in the Facebook [group], everyone already knew [about] what I was talking about.

JoJo expressed similar feelings during her interview. "I feel way more supported now and I feel like I have a safe place that I can go to ask a question…a mom recently posted, 'is there such thing as PTSD, or do you panic attacks, anxiety?' I looked at the responses I'm like, holy moly, you know? Look at all of these parents that have that same feeling out there but we're not talking about it?"

PTSD, or post-traumatic stress disorder, is a topic that other caregivers have broached in the group before. A 2019 study by Carmassi and colleagues found that approximately 15.7% of parents of children with epilepsy experienced PTSD (based on the DSM-5 scale – diagnostic and statistical manual of mental disorders) and mothers who witnessed generalized seizures (seizures that occur in both halves of the brain) were more likely to experience symptoms of depression (Carmassi et. al, 2019). However, this study was not specific to LGS or catastrophic epilepsies, which may have much higher rates of PTSD due to the severity of the syndrome.

Immediate Responses. A few participants explained circumstances in which posts were made on the Facebook page and responses from other families occurred almost immediately. One of the benefits to Facebook groups is the possibility to share and receive information and support quickly, 24 hours a day, 7 days a week. While Facebook groups are asynchronous in nature, the immediacy of interactions can make the group seem synchronous when it is heavily trafficked. Emily, for example, discussed receiving support from others in the group in the middle of the night when she needed it the most. She said:

> When (my son) fell the other day, we had to go to the emergency room transport by ambulance in the middle of the night, and being there and posting about that [in the Facebook group], people were amazing. You know, I just, I didn't feel alone. And because of this connection that I've made with other people… it was amazing to connect [with others] through social media.

Emily also discussed how she was alone with her son in the emergency room without her husband, due to COVID restrictions. Normally, her husband would accompany her to the emergency room in situations like this. However, her quotation suggests that despite being alone with her son in the middle of the night, she still had a network of supportive caregivers through the LGS Foundation Facebook group to reach out to and not feel so isolated.

Other participants noted how quickly responses can happen in the group as well. Teresa explained,

> [Facebook groups] is a wonderful place to get a reaction. You can go on there and just give a quick, ‘this is what's going on, this is what’s taking place right now’ and you got 50 responses from 50 parents who have been there. And what I love about it is that you can do that at three o'clock in the morning and somebody will answer either because there's they're up with you or because they live in a different time zone. And so it's not that big of a deal to answer.

Kierra, a moderator in the group, noted that she tries to stay on top of posts that she notices are quickly populating with responses, particularly when they are filled with potentially misleading information. “I’ll just pop in and say, ‘moderator here watching comments’ on posts that have to do with things like CBD (cannabidiol), which isn’t a controversial treatment, more of just different user experiences that could be potentially misleading to others.”

Moderators aren’t able to watch the page 24 hours per day, so if a post is created by a member that is considered misleading or controversial, action may not be taken immediately to take it down or comment with a clarifying statement or disclaimer. Fortunately, Facebook offers a feature for other members to report suspicious or inaccurate posts which will notify a moderator of the content. Moderators may choose to forward notifications like these to their email or through a text message for increased immediacy, but not all moderators choose to do so. Therefore, posts like these may stay on the Facebook page for a few hours, or potentially until the next day.

However, the immediacy of Facebook responses is perhaps one of the advantages of using Facebook groups over other social networking sites such as Patients Like Me. This is likely due to size of the LGS Foundation Facebook group, the functionality of Facebook notifications (e.g., instant notifications that pop up as soon as someone else comments or reacts to your post), and the camaraderie among users.

Information Sharing and Health Literacy

Vignette: Learning about Genetics

Michael is one of the "cryptogenic" cases of Lennox-Gastaut Syndrome. Cryptogenic is a slightly older and outdated medical term that is used to describe cases of disease that have an unknown cause. I use it here because this is how Michael was described for 20 years by physicians. Today, his cause remains unknown but we hypothesize that his LGS has a genetic, de novo explanation.[6] I first learned the science behind epilepsy genetics through the LGS Foundation Facebook group; I noticed that many families in the group mentioned being involved with a project called EPGP, the epilepsy phenome-genome project. This project was a multi-center collaborative study that sequenced the exomes of individuals with LGS and their parents (trios) to help identify genetic causes of LGS and another form of epilepsy called infantile spasms. After learning about this project, my parents made the informed decision to enroll Michael in the project. Even if the study couldn't help us to identify a causative gene, we enrolled with the hope that his DNA (and my parents') could lead to better understanding genetics and LGS.

Health literacy is the "degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (Centers for Disease Control, 2020). It is also the cognitive and social skills which "determine the motivation and ability of individuals to gain access to, understand, and use information in ways which

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[6] De Novo is a "new" genetic mutation that happens in utero; if a genetic defect is de novo, it is not considered familial (AKA passed down from one parent to the child).

promote and maintain good health” (World Health Organization, 2009). Health literacy goes beyond simply being able to understand or interpret basic health information, however. The WHO (2009) states that by improving people’s access to health information, health literacy also leads to empowerment. Further, health literacy addresses the environmental, political, and social factors that determine health (Healthy People 2020). Increased knowledge about a health topic leads to increased health literacy, and benefits individuals by enabling them to make more informed health decisions.

Health literacy was first defined in the public health and medical literature as having the basic reading and writing skills needed to complete essential health tasks, such as understanding consent forms, reading information leaflets, and following medicine labels. This is referred to as ‘functional health literacy.’ Nutbeam (2000), however, took the definition a step further, elaborating that there are three different forms of health literacy: functional, interactive, and critical. Interactive health literacy is also known as ‘communicative’ health literacy and lends itself to more advanced social skills which can be used for better health communication and information sharing. This term is highly applicable to CMHC and Facebook groups, as it can be argued that a person with high communicative health literacy can be associated with increased information exchange and application of knowledge to their child’s care.

After defining health literacy to participants, questions were asked about whether participants used information in the group to improve their own health literacy about their child/loved one’s diagnosis. While the responses were mixed in what participants considered “health information,” most participants noted that they had shared or learned about treatment options for their child at one point. Other examples of health information obtained included new ketogenic diet recipes (for the treatment of LGS), clinical trial information, emerging or existing therapies, alternative therapies, genetic testing, or advice on what to do in an emergency situation. Health-information seeking behavior during crisis situations from fellow caregivers was noted by some participants in the group.

For example, Korin explained that she often reads posts from members asking health-related questions when they are in an emergency situation, such as a hospital visit. She recalled,

> I see it all the time, when a family is in the ER and they need help with something. Not like help in person or anything like that, but they have a question about what to do next, like if the child is in status [epilepticus][7]… the doctors are there of course [with them in the emergency room], but the families want to know from others what their experiences have been if they've been [through] a similar situation.

Teresa recalled that she often sees other families ask health-related questions on the LGS Foundation Facebook group and explained that they might be asking the question on the group page instead of calling the physician because they are anxious to receive responses or don't have the patience to wait for the doctor to call them back. She noted:

> I hate when I see somebody who's like, 'oh my god we had such a terrible night with Little Johnny, he's seizing all night and I checked his temperature

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[7] Status epilepticus is a life threatening, continuous seizure state that often requires medical intervention to bring the seizure to an end.

> and I don't know what it could be. I think about calling the doctor but I don't want to be a pain'… then there's a lot of responses.

*Fellow Caregivers as Sources of Information***.** Caregivers frequently discussed the value of health information received from other caregivers in the group and compared it to the health information (or in some instances, lack thereof) they received in a clinical setting (e.g. from their physician or neurologist). Some participants noted how they learned something health-related on the Facebook group and then brought the information obtained online to their physician to receive additional information. Abigail said,

> I think the amount of knowledge with LGS that is given by parents [and the level of] support you get from Facebook group is different than the level of support you can get from a physician. You'll never get a candid answer from a physician the way you will from another family, because they're facing the same struggle.

Lisa agreed with this statement when she exclaimed, "I love our doctor and I don't have any issues with him, however, I would definitely trust other caregivers for health information, because the doctor doesn't, you know, he's not walking life with [my child] so he doesn't know all the ins and outs of what we're having to deal with every day."

Lilly, on the other hand, claimed that fellow moms in one of the support groups she was involved in helped her be a better advocate for her son, and ultimately, that is what saved his life. She said:

> Our doctor at the time refused genetic testing and refused to refer us to get a surgical evaluation... So, I knew that we were not getting the proper care, which led us to NYU where we got the right care, and the proper diagnosis. The parents in the support group taught me how to advocate, they taught me what to advocate for. And I believe they saved his life. I think he would still be having infantile spasms, if we didn't know that he wasn't getting the right care.

Another LGS mom boasted being an excellent source of information related to the LGS diagnosis compared to a general physician. She noted, “I feel confident that there isn't too much you could ask me about seizures that I wouldn't know. And I would know it better than your pediatrician, unless they're very high level.” This comment implies that some caregivers feel that they have superior knowledge about LGS than a general physician, likely due to lived experiences with the disorder.

Brenda noted that she learned about genetics from the LGS Foundation Facebook group and brought the information she obtained to her neurologist. “I didn’t know anything about genetics before the group. I’ve actually learned a lot in the group, more than I would have if I left it up to my neurologist.”

Kierra, who is a group moderator, explained that the health information shared among users is typically accurate, even if experiences differ from person to person. “What works well for one person might not work well for another person,” she says, “but I do genuinely think that families realize that on the group. I think that probably has to do with them being able to separate opinion from fact. But every now and then I or another member will remind them, ‘hey what works for one person might not work for you’ and vice versa.”

For members, being able to decipher the accuracy of health information shared in the LGS Foundation Facebook group is likely associated with the interactive health literacy of participants. As explained above, health literacy is not just simply being able to read a pamphlet about a disease or disorder—it goes far beyond that, with implications for information processing to extend to health decision making and patient-provider communication. Health literacy is, in fact, regarded as an important component of clear and effective patient-provider communication. This is especially relevant for people (or caregivers) with one or more chronic condition, who have more frequent interactions with healthcare professionals and who are supposed to be active in the management of their disease (National Library of Medicine, n.d.).

Although this dissertation does not claim to make a correlation between health literacy and improved patient-provider communication or better health decision-making, the responses of participants do suggest that Facebook groups serve as a valuable source of health information and informs how they used the information to make different healthcare decisions for their loved ones.

Privacy Concerns

The degree to which users of the Facebook group shared personal information related to their child's diagnosis varied among participants. Some suggested that the group empowered them to discuss details about their child that they felt reluctant to discuss with others who did not understand the disorder. Other participants noted they were more hesitant to share in the group, citing the lesser degree of severity of LGS their child experiences in comparison to others in the group, perhaps feeling as though others had it worse. A few participants claimed they were an ‘open book’ when it came to their child and hoped that by sharing their experiences, it would help other families in the group.

Communication Privacy Management (CPM), one of the theories that guides this dissertation, is relevant to the findings here. CPM is based on the concept that individuals own their own information and have the right to control the information that they share. In a closed Facebook support group page, where the information is not available to the general public, members may feel safer about the information that they share rather than posting to an open group or an open online forum. The level of trust for the Facebook group in general, as well as the privacy barriers of the group (e.g., being a closed group that requires moderator or administrator approval) was discussed by participants.

> JoJo, for example, explained that she isn’t concerned about sharing stories about her son, especially if it is going to help someone else. She said, **“**No, I don't think so [concerned with privacy]. And what's the worst they're [other members] going to do? Say, “Oh, this person in [the Northeast USA] said this?” So, maybe some of that but that doesn't concern me if there's something about my son’s story that helps somebody.
>
> She continued by discussing how she felt the group was secure. “[When I first joined] I wanted to see what kind of secure group [it was and realized it was] like a lockdown group that you had to get permission to come into.”
>
> JoJo’s comments reflect a feeling that other participants described within the

group; that sharing their child’s story in the secure group was not a concern, particularly if her story could help others learn from experiences with LGS. Abigail shared a similar sentiment. She said,

> [Privacy concerns] are not going to stop me from sharing my son’s story. I do think I'm a little more mindful of what I share, though. In the beginning, I used to share things like seizure activity, and while that part is informative, to some degree, I also want to protect my son’s dignity.

JoJo clarified this further, noting that because she is her son’s voice and he is unable to post to Facebook about his experiences on his own, she chooses what to post in order to respect him and his privacy.

Emily said that sharing her son’s story has gone beyond Facebook groups and her experiences have been the impetus behind a novel she wrote about her son’s diagnosis. With a son now in his 40’s, Emily has four decades of experiences to draw from. She suggests that she is willing to share so much about his life without concerns over his privacy because it will hopefully help other families, including those who do not use social media. This sentiment was echoed many times by other LGS caregivers, as discussed above.

In summary, this chapter illustrates the nature of caregiver-to-caregiver communication in LGS through the CMHC medium of Facebook groups. This chapter has also described how LGS caregivers use the LGS Foundation Facebook group to provide and receive social support, share and receive health information, and contribute to the common good of the group through their respective involvement. It highlights how relationships are built and grown over time, how the roles of participants may change over time, and how privacy within the group was of minimal concern to participants. Theoretical and practical implications for all findings are discussed in the next chapter.

Chapter 5: Discussion

This dissertation provided perspectives from LGS caregivers about their use of Facebook groups as an extension of CMHC for social support and information sharing in Lennox-Gastaut Syndrome. The responses detailed in the results section have helped to address the research questions, theories, and concepts that guided this project. Findings illustrate the importance of CMHC for social support in rare diseases, specifically LGS, while demonstrating the ways in which information was shared among members. Data also uncovered the lack of concern over privacy issues and the ways in which users use the LGS Foundation Facebook group depending on their needs. These findings are further discussed below as I draw implications for health communication theory and practice. This chapter concludes with future directions for research in CMHC and rare diseases.

Theoretical Implications

The frameworks of social support, health literacy, social penetration theory, and communication privacy management have guided this dissertation project; several theoretical implications have emerged from the findings. The implications are discussed below, broken down into sub-sections by category.

Social Support

Although there is an established body of scholarship surrounding social support in caregiving and rare diseases, there is a dearth of literature on social support needs in Lennox-Gastaut Syndrome specifically. Given the psycho-social aspects of LGS caregiving (see Gallop, 2009 and LGS Foundation, 2018), contributions to the literature that explores the positive impact of social support in LGS may help scholars across multiple disciplines understand this phenomenon; not only in LGS, but perhaps other rare diseases as well. While some scholars have made contributions to social support and CMHC over the past decade, there is still a significant need to address the understudied *triad* of social support in CMHC and LGS/rare diseases in the literature, which this dissertation project did. The term triad is used here to define the intersection between CMHC, rare diseases (such as LGS) and social support—three interrelated concepts that form a larger phenomenon. The findings indicate that social support is one of the primary reasons a LGS caregiver joins the LGS Foundation Facebook group, if not to seek it and receive it from others, then to provide it. This is an important implication in the context of social support research because it suggests that not all caregivers join a CMHC environment for 'self-help' reasons (e.g., to receive support from others due to feelings of isolation or lack of understanding from their social networks). Instead, some caregivers join CMHC environments to support others. This point was crystallized by the responses from older caregivers, who continually noted that they felt their role as an information/support giver was more appropriate given the length of their child's diagnosis and the knowledge they had obtained from decades of caregiving experience.

Further, the way in which LGS caregivers give or receive support appeared to change over time due to the age of the child and the lived experiences of the caregivers, progressing from information and social support-seeking behavior to information and social-support giving. Thus, these findings add to the bodies of literature in social support and rare diseases, suggesting caregivers do not use CMHC to receive social support exclusively, and the way in which they use CMHC social support may change over time.

Social support was also revealed to be an extension of knowledge being shared between members. Although information-sharing related to health topics is addressed in the health literacy section below, general information about LGS and subsequent lived experiences from caregivers was noted to play a part in ways in which caregivers felt supported. For example, some participants noted that they felt supported by sharing or receiving information about daily living and quality of life, topics that they describe were only understood by fellow caregivers of those with LGS. Falling into these categories was a wide range of sub-topics, including challenges that families face at home and at school with a LGS diagnosis. Other participants mentioned they would use the LGS Foundation Facebook group as a means to support others over asking for support themselves. This was particularly evident in participants who had older children with LGS.

Added to the benefits of information sharing as a form of social support was an appreciation for the timeliness of responses, particularly when a family was experiencing a crisis. For example, some participants noted feeling supported by others in the Facebook group almost immediately after a post was made. Additionally, differences in time zones were discussed as a benefit to some respondents. For example, one participant explained that when she asked a question in the group in the middle of the night in her time zone (eastern standard time), she assumed she was unlikely to receive many responses from those in her region. However, she did receive responses quickly from others who were still awake on the west coast, or those who had just woken up for the day in Europe, which indicates the benefits of the group being international in scope. It is also appropriate to mention the benefit of the notifications feature within Facebook groups. These can be set to alert a user every time a post is made in a group they belong to. Therefore, if a user has these notifications turned on, they will receive an alert in their notifications area, regardless of what time it is. For these reasons, although asynchronous in nature, active Facebook groups may facilitate synchronous-like features.

Health Literacy

Health literacy is the second framework used in this dissertation. Health literacy is the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (HHS, 2010, n.d.). Health literacy is dependent on a number of factors including knowledge of health topics, communication skills, culture, and education. Health literacy has become an increasingly popular area of scholarship within the public health discipline and health communication field. The definition has evolved over the past two decades and has changed from a basic description of literacy skills in healthcare settings to a more robust phenomenon that seeks to describe how individuals make meaning of health information and use that information to be more empowered in their health decisions. Research question four, which aimed to understand how a Facebook user's health literacy was affected by using an OSG for information-seeking, was explored in this project. The data revealed that health information shared in the LGS Foundation Facebook group had an impact on the health literacy of the Facebook user, including, but not limited to: (1)

medications/therapies for LGS, (2) genetic testing and genetic etiologies, (3) understanding various seizure types associated with LGS, (4) recommendations for clinicians or hospitals to help improve care for a loved one, (5) options for surgery, and (6) understanding clinical aspects of LGS (e.g. how to read an EEG, how to communicate with clinical staff better, and transitioning care from pediatric to adulthood).

Indeed, some users explicitly mentioned that they learned health-related information from being a part of the LGS Foundation Facebook group; specific examples from participants included: learning about the genetics (and the importance of genetic testing) surrounding LGS, finding out about a new medication that was enrolling in clinical trials, or learning about medication interactions and side effects. When asked about whether participants took the health information gained through the LGS Foundation Facebook group into a clinical setting (e.g. to their neurologist/epileptologist), many confirmed that they were the ones to bring up topics to their physician rather than the physician bringing it up to them. This point was most often the case in situations when they learned about a clinical trial that was recruiting LGS patients or when exploring information about genetic testing.

Taken together, these findings suggest that health literacy is an important component of the LGS Foundation Facebook group that may extend to areas outside of the group, such as a clinical setting. The findings may have practical implications for future health communication research as well. Some suggestions, based on the findings from the research in this dissertation, include (1) creating factsheets, which may be developed to help users of a health-related Facebook group understand factual information posted in the group from misinformation or disinformation; (2) completing content analyses which might be conducted in disease-specific groups to help users understand the most popular topics/frequently asked questions related to the disease or disorder in order to increase health literacy among users; and (3) developing toolkits that might be created to help aid in patient-provider relationships based on discussions that take place within the Facebook group. Although these are just a few ideas for health communication practitioners to consider for future projects related to health literacy and CMHC in rare diseases, this dissertation project has laid the groundwork and formative research for these potential applications.

Social Penetration Theory

Social penetration theory (SPT) proposes that as relationships grow, communication transitions from shallow transactions to more intimate ones (Altman & Taylor, 1973). Data revealed that through the LGS Foundation Facebook group, connections between caregivers that emerged often turned into friendships outside of the group. From those friendships, some participants mentioned meeting face-to-face with other caregivers at LGS Foundation events (e.g., conference, fundraiser) while others arranged in-person meetings independently. SPT would suggest that the LGS Foundation Facebook group facilitated this relational development over time.

The second assumption in SPT is that relationships that develop over time are done in a way that is systematic and predictive. Although this study did not seek to understand the predictability of relational development, it is worth noting that there was an apparent course of action to the relationship development. For example, many participants explained that they joined the group to fill informational and social support needs (step one), then began to interact with others through posts about lived experiences (step two). Then, users would explain that they become Facebook friends with others in the group based on shared commonalities or interests (step three). Some participants explained that their relationships developed further through other mediums, such as through telephone or eventually meeting face-to-face.

However, SPT also posits that relationship development may not always be linear. In fact, relationship development may move backward, resulting in de-penetration and dissolution. Although interview questions about de-penetration or weakening of relationships was not explicitly discussed in the interview guide, some participants mentioned that their activity within the group would change based on their use of Facebook. For example, one participant noted feeling “disconnected” from the LGS Foundation Facebook group after she removed Facebook from her phone, reducing her Facebook use to a laptop or desktop only.

Finally, self-disclosure, the fourth tenet of SPT, is imperative in facilitating relationship development. This assumption can be validated by the responses of participants, who repeatedly noted that their relationships strengthened with other caregivers in the group based on the extent to which they shared information and socially supported one another.

Although SPT is an older communication theory that has only recently been applied to CMC environments, this research supports the key principles of the theory in its application to CMHC and rare diseases in respect to the LGS Foundation Facebook group. SPT can explain why members stay engaged in the group over time and how their relational development strengthens based on the extent of information shared. Finally, the assumption within SPT that those who disclose information about themselves are more likely to develop strong relationships, is supported by the data which consistently linked heavier usage of the LGS Foundation Facebook group with strong friendships with other caregivers.

Communication Privacy Management

Communication Privacy Management (CPM) complements SPT in some ways (e.g., helps to understand how, why, and to what degree individuals share information about themselves or their loved ones) but differs in its boundaries and privacy frameworks. CPM seeks to explain why people withhold or share private information about themselves and how they make decisions to reveal or conceal private information (Petronio, 2002). Additionally, CPM suggests that the ways in which people handle or share private information are dependent upon the interaction of their boundary structures and rule-based management systems (Pecchioni & Keeley, 2011; Petronio, 2010). The data from this study revealed that while the definition of boundaries differed between respondents, private information about their loved one with LGS was most frequently shared through lived experiences and shared commonalities between users. Some users also indicated that private health information was shared within the group via a post about their child in an effort to solicit opinions or experiences from others.

Although some participants noted that they were an “open book” in terms of sharing their experiences with LGS, other participants were more guarded in order to protect their child’s privacy or “dignity,” as one participant explained it. Lived experiences with LGS were openly shared in the group to help others navigate the diagnosis, to offer support, or to provide information or recommendations that pertained to a specific post.

The concept of boundaries, as described in CPM, was discussed differently among participants depending on the stage or age of their child’s diagnosis, which corresponded to the age of the parents/caregivers. For example, the data suggested that those who are newer to the diagnosis, or those who have younger children, were more likely to share private information about their loved one (or the LGS diagnosis in general) than those who have older children. This can perhaps be explained by the responses provided from caregivers with older children, who often noted that their activity within the group was based on supporting others. Interestingly, when the participants were asked if they felt as though their privacy would be breached, all of the 23 respondents plus five members who served as member checks stated that they had no concerns. This was an important finding in this research, and it suggests the LGS Foundation Facebook group is a “safe place” where caregivers can discuss intimate details about participants’ experiences with LGS without concerns about privacy violations.

Since CPM is based on the concept that individuals own their own information and have the right to control the information that they share, applying this theory to the data suggests that caregivers may be more likely to share private and intimate information based on the comfortability they feel within the group, perhaps as an extension of SPT, information sharing, and social support.

Future Research

The data collected from this study revealed numerous opportunities for future research in rare diseases and CMHC, social support, health literacy, and the application of SPT and CPM. Although this research provided insights into how LGS caregivers use the LGS Foundation Facebook group as a CMHC medium to address social support needs, the data may not be generalizable to all Facebook groups for rare diseases. Camaraderie, trust of the group (and subsequently, the administrators who manage the page), and the group type (e.g. public vs. private) may be factors that influence the success of a CMHC medium for other rare diseases.

As discussed earlier, the participants for this research project only included mothers of children with LGS who identified as women and did not include other family members such as fathers or siblings. Future research that seeks to understand a different caregiver perspective may offer interesting insights to how other family members make meaning of CMHC for their loved one's rare disease.

In terms of health literacy, this study laid a foundation to better understand how health-information sharing about LGS affected a user's health literacy, but the research did not attempt to understand how the information obtained from the group extended into clinical environments or affected patient-provider communication. Therefore, there may be an opportunity for future research that explores how health information gained in a CMHC environment impacts the way in which caregivers navigate situations where health literacy plays a role outside of the group.

Finally, this study has addressed ways in which social penetration theory and communication privacy management can be applied to CMHC in rare diseases, a previously understudied area in the communication discipline. Future research exploring how SPT applied to other rare diseases may complement the findings of this study, particularly in understanding how users go through the stages of relational development. While this study addressed ways in which caregiver relationships develop over time, it tended to focus more on the strengthening of relationships rather than the de-penetration, or weakening, of relationships This is a worthwhile area to explore in future research in order to understand why Facebook group users become less involved with a Facebook group over time or leave it entirely. Reasons for this, for example, might be attributed to conflict with other members, the death of their child, mistrust of the group, or the removal of their Facebook account. Further, while Facebook is the most popular form of social media today (and consequently, the most popular CMHC medium for LGS caregivers), technology and social media will ultimately change over time, presenting new opportunities for other CMHC platforms to emerge in the future. Therefore, opportunities to study CMHC in LGS and rare diseases in different CMHC mediums will likely arise in the future. Lastly, opportunities for research using CPM as a theoretical guide for an open or public Facebook group for a rare disease may reveal additional findings based on the privacy settings of the group.

Summary and Conclusion

This dissertation study explored the CMHC medium of Facebook groups for Lennox-Gastaut syndrome caregivers in the context of rare disease social support, information sharing, and health literacy. Qualitative interviews were used to gather data from 23 mothers of individuals with LGS in addition to autoethnographic vignettes, which provided an additional method. Several important findings were drawn that can add to the literature surrounding CMHC and rare diseases.

First, Facebook groups, as an extension of CMHC, is a popular form of social media that LGS caregivers use to fill informational needs about the disorder. The LGS Foundation Facebook group page, which is the most popular CMHC platform for the disorder, provides a mechanism for caregivers to exchange health-related and non-health related information about the disorder and lived experiences. Second, users of the group often develop relationships over time with other caregivers which help to address feelings of isolation and impacts the way in which they feel socially supported. Finally, users of the group share information about their loved one and their own personal experiences with LGS to help others navigate the diagnosis and to offer support to others with few concerns about their loved one's privacy being affected. This is likely due to the trustworthiness and camaraderie of the group.

In conclusion, this dissertation addressed the ways in which LGS caregivers use the LGS Foundation Facebook group, as a form of CMHC, to understand social support needs, information sharing processes, and the role of health literacy. Social penetration theory and communication privacy management—two communication theories—guided this research to help explain how LGS caregivers navigate, make meaning of, and participate in the LGS Foundation Facebook group. Although LGS represents only one of 7,000 rare diseases that have been documented in the world, this dissertation project has helped to increase knowledge of CMHC in rare diseases, broadly, and in Lennox-Gastaut Syndrome, specifically.

Appendices

Appendix A

E-mail Recruitment Message

Dear (potential participant):

I hope you are doing well. As you may know, I am a PhD candidate at the University of Maryland currently working on my dissertation. The research that I am conducting is focused on computer-mediated social support in Lennox-Gastaut Syndrome, particularly through the LGS Foundation's Facebook page.

I would be thrilled to interview you to get your perspective on how you perceive being supported by using the LGS Facebook group over the past (# of years / months). I would also like to understand how you manage the type of information that you share with others and the types of topics that you find most useful in this group.

The interview should take approximately one hour and can be conducted via the telephone or through Skype or Google Hangouts. If you agree to participate, I will ask you to sign a consent form prior to the interview. This project is (pending) IRB approved by the University of Maryland.

Sample questions I will ask include:

1. How long ago did you join the LGS Facebook group page?
2. What were your initial reasons for joining the LGS Foundation facebook page?
3. When you were first admitted, tell me about how you interacted with others.
   a. Were you immediately engaged (i.e. did you begin to read other posts right away? Did you begin to comment / react right away?)
4. What was your initial reaction to reading other people's stories and questions?
5. How often do you react, post, or comment on the facebook page?
   a. What do you say you do most often out of those three options, and why?
6. What type of information do you find most useful in the group?
7. What types of questions do you find most useful answers that you specifically post?

If you are interested in participating, please let me know and we can schedule a time within the next few weeks to chat.

Thank you so much for your consideration.
Christina SanInocencio

Appendix B

Facebook Post

Hello everyone, as some of you may know, I am working on completing my PhD degree in health communication, studying computer-mediated health communication in rare diseases – LGS specifically.

I would love to interview some of you to understand how you perceive being supported in this group, what types of information you share, and how you learn more about LGS through other members in this group.

If you are interested, please let me know. The interview will take about an hour and will be completed between November and January via the telephone or Skype / Google Hangouts.

I am happy to report anonymous findings back to this group once the project is complete.

This project is IRB approved so I will ask you to sign a consent form prior to the interview.
Many thanks!

Appendix C

Interview Guide: Computer-Mediated Health Communication in Lennox-Gastaut Syndrome: Understanding Social Support & Information Sharing in the LGS Foundation Facebook Group

Research Questions:

RQ1: How, if at all, do LGS caregivers receive or provide social support through CMHC environments?
RQ2: How do caregivers determine which / how much information to share?
RQ3: How do users manage their privacy in OSGs?
RQ4: How is a user's health literacy affected by using an OSG for information-seeking?

Interview Guide:

Introduction / General Questions

1. Describe your child / loved one who has Lennox-Gastaut Syndrome.
    a. How long ago did they receive the diagnosis of Lennox-Gastaut Syndrome?
    b. Were there other potential diagnoses mentioned prior to you receiving the diagnosis?
    c. How long did it take to receive the diagnosis?
    d. After the seizures began, did you begin to see regression?
        i. If so, can you speak about this a little bit?
    e. How did you / your family feel after you received the LGS diagnosis?
2. How long ago did you join the LGS Facebook group page?
3. How long after you received the diagnosis did you find the LGS Facebook group?
4. What were your initial reasons for joining the LGS Foundation Facebook page?
5. What other types of CMC do you use to communicate with other caregivers?
6. What are your goals for being in this group?
7. Do you foresee yourself staying involved / engaged over time?

8. How many minutes or hours per day / week do you find yourself in the group?

RQ1: How, if at all, do LGS caregivers receive or provide social support through CMHC environments?

9. Did you feel supported by others (friends, family, medical professionals) when first diagnosed?

10. When you were first admitted, tell me about how you interacted with others.
    a. Were you immediately engaged (i.e. did you begin to read other posts right away? Did you begin to comment / react right away?)

11. Do you feel supported when you post specific questions about your loved one?
    a. Do you feel embarrassed at times when you post?

12. How supportive do YOU feel in helping other families?
    a. Who do you feel as though you support the most? (i.e. new members, newly diagnosed, other families in general?)
    b. Can you remember a time when you have shared information or personal experience in the group that made you feel like you were helping others?

13. Tell me a little bit about you felt before joining the group in terms of social support.
    a. If you felt isolated, tell me about how you felt after joining.

14. For new members: Since you are a new member, tell me a little bit about how you feel now vs. how you felt prior to joining the group in terms of building relationships with other families.

15. Are there certain individuals in the facebook group that you feel most connected to?
    a. If so why? (i.e similarities in etiology, phenotype, struggles in daily living, age, etc)

16. Have you ever met other caregivers in a face-to-face environment?
    a. If so, where?
        i. What were some advantages to meeting families face-to-face
        ii. Were there any disadvantages?
    b. If not, why?
        i. What are some of the advantages of sharing information through the LGS Foundation facebook group?
        ii. What are some of the disadvantages of sharing iformation through the LGS Foundation facebook group?

17. Would you like to discuss any specific experiences that have happened in the group that have led you to feel more supported?
    a. What about experiences that have led you to feel less supported?
    b. What about more informed about specific topics?

18. Have you turned to facebook more, less, or about the same for social support during COVID-19?

RQ2: How do caregivers determine which / how much information to share?

19. Tell me about the process of seeking information through Facebook.
    a. How did you hear about, or find the LGS Foundation Facebook page?
    b. Are you a member of other LGS groups?
        i. If so, which ones?

20. What type of information do you find most useful in the group?

21. How often do you react, post, or comment on the facebook page?
    a. What do you say you do most often out of those three options, and why?

22. What type of information do you find most useful in the group?

23. What types of questions do you find most useful answers that you specifically post?

24. What was your initial reaction to reading other people's stories and questions?

25. How often do you react, post, or comment on the facebook page?
    a. What do you say you do most often out of those three options, and why?

26. What types of questions do you find most useful answers that you specifically post?
    a. Do you remember an example of a post / discussion that was particularly useful to you?

27. Let's shift gears for a moment and talk about COVID-19. Do you feel as though your information-seeking or information-sharing behavior on the facebook group has changed at all since the pandemic started?
    a. If so, how?

28. Have you learned anything new about LGS and COVID specifically from the facebook group?

    a. If so what?

RQ3: How do users manage their privacy in OSGs?

29. [Define lurker vs. inactive vs. heavy user]. Which category do you most closely relate to?
    a. Tell me a bit about why you feel [title] is most appropriate?

30. How much information do you typically share about your experience living with LGS?
    a. Are there specific aspects of LGS or the effects LGS has on you / your family that you are not willing to share about your loved one?
    b. Have you ever hesitated to share information that you've found or read online from others? (For example, scientific information, anecdotes from others, news stories etc).
    c. If so, do you mind telling me what those are and why?

31. Do you feel as though your privacy in this group is safe?
    a. If yes/no, why?

RQ4: How is a user's health literacy affected by using an OSG for information-seeking?

32. Do you remember a time where you read something on the facebook group that was inaccurate?
    a. If so, did you respond to the post?
    b. Did the post affect your view on the credibility of the group?

33. Do you feel as though you are more informed about the disorder since joining the group?
    a. Which areas related to LGS do you feel as though you have gained the most knowledge in?
    b. Which areas related to LGS do you feel as though you still are looking for answers in.
    c. Do you feel as though your health literacy has increased? (will define health literacy if needed).

34. Let's talk about caregiver to caregiver communication in the group. Do you feel as though caregivers can offer you as much information as physicians can related to LGS?
    a. If so, why?

35. Is there anything else that you'd like to share with me?

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