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## Ongoing Information and Support Needs of Parents of Children with Epilepsy

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A thesis submitted in partial fulfillment of the requirements for the Master of Health Information Science degree in Health Information Science

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## Abstract

The purpose of this research is to gain insight into the ongoing information and support needs of parents of children with epilepsy. Using descriptive content analysis of text found in twenty client case files, communication logs, and email correspondence, parents requested information and support provided by a community epilepsy agency to mitigate changes in treatment protocols, challenging child behavior, rushed healthcare provider communication, lack of access to mental health services and barriers encountered in the school system. Parents requested system navigation and school advocacy from community epilepsy agency staff intermediaries to develop rescue medication protocols and to mediate parent-school disputes. Parents requested peer mentors to reduce feelings of uncertainty, worry and social isolation. The findings from this research indicate families would benefit from coordinated care between the clinic and the community to reduce social isolation and to cope with the unpredictability, fear and lifestyle challenges inherent in childhood epilepsy.

## Keywords

Parents, Children with Epilepsy, Information, Support Needs, Community Epilepsy Agency, Family-Centered, Coordinated Care

## Lay Summary

This research is a descriptive content analysis of text found in the client case files of twenty families who requested information and support from a community epilepsy agency over a 36-month period. The overall aim of this research is to provide a composite picture of engagement with a community epilepsy agency from the perspective of a parent supporting a child with epilepsy and to identify both the content and context of parent requests for ongoing information and support. Within the field of health information science, the research will examine the types of information and support that are requested by parents and the psychosocial context that leads to these requests providing insights into the information needs that may not be met through patient education and the psychosocial support needs that may not be met in the clinic. Through the analysis of the text found in the twenty client case files, communication logs, and email correspondence, parents requested information and support provided by a community epilepsy agency to mitigate changes in treatment protocols, challenging child behavior, rushed healthcare provider communication, lack of access to mental health services and barriers encountered in the school system. Parents requested system navigation and school advocacy from community epilepsy agency staff intermediaries to develop rescue medication protocols and to mediate parent-school disputes. Parents requested peer mentors to reduce feelings of uncertainty, worry and social isolation. The findings from this research indicate families would benefit from coordinated care between the clinic and the community to reduce social isolation and to cope with the unpredictability, fear and lifestyle challenges inherent in childhood epilepsy.

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# Chapter 1

## Introduction

Epilepsy [Appendix A] is a brain disease characterized by a predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of the condition (Fisher et al., 2017). Epilepsy affects over 15,000 children in Ontario under the age of 18 (Ng et al, 2015). Parents supporting a child with epilepsy need to cope with the complex demands of this chronic disease which include clinic visits, diagnostic tests and treatments. They also need to deal with lifestyle management including stigma, social isolation, discrimination, seizures at school and the cognitive and behavioural challenges that are prevalent comorbidities.

This research is a descriptive content analysis of text found in the client case files of twenty families who requested information and support from a community epilepsy agency over a 36-month period. The overall aim of this research is to provide a composite picture of engagement with a community epilepsy agency from the perspective of a parent supporting a child with epilepsy and to identify both the content and context of parent requests. Within the field of health information science, the research will examine the types of information and support that are requested by parents and the psychosocial context that leads to these requests providing insights into the information needs that may not be met through patient education and the psychosocial support needs that may not be met in the clinic.

### 1.1 Epilepsy Southwestern Ontario (ESWO)

The twenty families in this research requested information and support services provided by Epilepsy Southwestern Ontario (ESWO) over a 36-month period. ESWO is a registered not for profit, community epilepsy agency located in London, Ontario. The mandate of ESWO is to enhance the lives of people who are affected by epilepsy and seizure disorders through the provision of information and support services. The programs offered by ESWO include individual and family education and seizure first aid training. ESWO staff provide care coordination including referrals and assistance in

accessing government and mental health programs and school and healthcare system navigation for children and their parents. ESWO offers a ‘Student Support Program’ which includes teacher training, classroom presentations, development of learning and behavioural plans, and support in creating and implementing seizure safety protocols to administer rescue medication at school. ESWO offers a parent peer mentor program, parent on-line and in-person support groups, and skill development programs for children with epilepsy including *Game ON* recreation program, *Wacky Wednesday Summer Camp* and *Youth Empowerment Program*. ESWO develops evidence informed brochures, video’s, newsletters and curricula, and facilitates workshops and presentations in the school, workplace and community to improve general knowledge and understanding of epilepsy and to dispel misconceptions that perpetuate stigma.

## 1.2 Health Information and Support Needs

Health information is recommended to reduce the fear that parents feel when their child has a seizure and to increase general knowledge, well-being, quality of life, coping, seizure control, self-efficacy, and self-esteem in children with epilepsy (May & Pfafflin, 2002; Couldridge, Kendall & March, 2001). In several pediatric epilepsy studies, parents describe a need for more information about their child’s diagnosis wanting anticipatory guidance about treatment options, clinical manifestations, prognosis and help with discerning when a seizure is a medical emergency (Jones et al., 2019; McNelis, Buelow, Myers & Johnson, 2007; Aytch, Hammond, White, 2001). A criticism of many parents is that the healthcare appointment focuses solely on medication management and the number of seizures leaving no time to talk about emotions, managing problems at school and with the child’s behaviour (Kilinc, Campbell, Guy & Van Wersch, 2020; Lewis, Noyes, Mackereth, 2010; McNelis et al., 2007). Primary care and specialists acknowledge that clinic-based epilepsy education is a low priority (Noble et al., 2016; Ostbye et al., 2005) and a systematic review of unmet healthcare needs in epilepsy indicated rushed consultation time with healthcare providers was the most commonly cited reason followed by insufficient physician knowledge and lack of care coordination (Mahendran, Speechley, Widjaja, 2017; Wiebe et al., 2014).

Multiple qualitative studies identify that parents supporting children with epilepsy require system navigation and support programs to cope with the emotional burden associated with this stigmatized condition (Jones et al., 2019; Pieters, Iwaki, Vickrey, Mathern & Baca, 2016; McNelis et al., 2007). Parent-identified facilitators to improved emotional well-being include champions or advocates, connecting with other parents and coordinated care that extends beyond the clinical setting (Jones et al., 2019; Pieters et al., 2016; McNelis et al., 2007).

### 1.3 Clinic to Community<sup>®</sup> Program

A Cochrane review of health information, care delivery and self-management strategies in pediatric epilepsy criticized the quality of existing programs stating none fully address the health and social care needs of families (Bradley, Lindsay & Fleeman, 2016). Self-management [Appendix A] of epilepsy refers to a wide range of health behaviours and activities that a person can learn and adapt to control their seizures and improve their well-being (Bradley et al., 2016). The desire to provide parents with proactive health information and ongoing support was the impetus for Epilepsy Southwestern Ontario and the Pediatric Neurology Department at Children's Hospital of Western Ontario to co-develop the Clinic to Community<sup>®</sup> (C2C) healthcare linkage program. The co-development of the C2C program was a recognition of the time constraints in the clinic, the ongoing information and support needs of the families, and the belief in the value of family-centered coordinated care [Appendix A].

The C2C curriculum was developed to address the full spectrum of biomedical and psychosocial information and support needs [Appendix B]. Using a stair step approach to walk through information the program begins with an individualized education session attended by the parents and other family members. This session typically takes an hour and covers the use of a seizure log and the content listed in the patient education checklist of the *Provincial Guidelines for the Management of Epilepsy in Adults and Children* [Appendix C]. The session is delivered face-to-face which helps to establish trust, identify gaps in parent understanding, assess individualized informational needs and parent health literacy. To ensure that families access the program, a referral mechanism is used to bring together all sectors of this formal help system [Appendix D]. After

receiving the basic education, a family is provided with a link to the C2C website and contact information for Epilepsy Southwestern Ontario and are encouraged to engage this community epilepsy agency if they require additional information or support.

The twenty consenting parents in this research all received the Clinic to Community<sup>®</sup> education session. They were included in this research because they requested post-education health information and post-education support services offered through Epilepsy Southwestern Ontario.

## 1.4 Researcher Reflexivity

I have worked for ESWO (formerly Epilepsy Support Centre) for the past 19 years. Working in the community I have a unique vantage point in that I have provided information and support to hundreds of individuals and families living with epilepsy. I have seen the fear after the first seizure and the misconceptions that newly diagnosed people share. I have witnessed the erosion of hope when seizures persist and when treatments fail. As a direct service provider I have helped individuals and families seeking information and support during a crisis, after the loss of a job, a driver's license or an embarrassing seizure at school. I believe that the healthcare system needs to be proactive and provide every newly diagnosed person with information and support before they are in crisis and at-risk.

In my role as the Executive Director (2001 - 2014), I witnessed dozens of seizures and have spoken to individuals and their families about the impact of living with stigma and disabling co-morbidities. I have vivid recollections of the first encounters with families who were deeply grieving the death of a loved one to a seizure-related injury, a drowning, suicide or SUDEP [Appendix A]. Many were burdened by the reality that they learned more about epilepsy after their tragic loss and this increased their anger and feelings of self-blame. Despite strong research evidence that the impact of epilepsy goes far beyond the medical management of the seizure, we still see health policy and healthcare providers ignoring the non-seizure needs of families living with epilepsy.

In the community setting we prioritize ‘solutions’ and develop and deliver interventions based on the identified needs of the families we serve. For many reasons; lack of skills, time, human resources, funding, expertise and priority, these programs are rarely formally evaluated and in this current economy that means these programs may not receive future funding. Accessing operational funds to sustain programs to support children with epilepsy to succeed in school and in the community has become challenging with local hospitals and universities competing for scarce donor dollars. In 2014, I made a personal decision to move away from the day-to-day management of ESWO to focus on long term organizational sustainability through program development and program evaluation.

Changing my perspective from community advocate to researcher has been a challenge. I have been reminded throughout the research process that I have to differentiate between my experience-based knowledge and the knowledge that is found in the research data.

## 1.5 Organization of the Thesis

This chapter provided an introduction to the health information and support needs of parents of children with epilepsy and a description of Epilepsy Southwestern Ontario. It also included an overview of the Clinic to Community<sup>®</sup> education program that each of the twenty families in the research received. The first chapter ended with my researcher reflexivity. In Chapter 2, a literature review will give insight into the potential future trajectory when seizures begin in childhood, the consequences and comorbidities of epilepsy, and the health information needs of parents. Chapter 3 is the methods section with details of this descriptive content analysis and the coding process. Chapter 4 identifies the findings using quotes from text found in the communication logs and parent emails and the themes that were identified through the coding process. Chapter 5 is a discussion of the findings, implications, limitations and future research. A glossary of common terms used in this thesis can be found in Appendix A.

## Chapter 2: Literature Review

Epilepsy is the most common chronic neurological condition of childhood with the highest incidence in the first decade of life when children begin a critical part of their social, emotional and educational development (Shinnar & Pellock, 2002). Epilepsy is a spectrum disorder with varying degrees of seizure frequency, type and severity. Some children have good seizure control, while an estimated 30% have drug refractory epilepsy [Appendix A], which means they experience seizures that do not respond to treatment with two or more appropriate trials of anti-seizure medications (Kwan & Brodie, 2000). While the prognosis for seizure control is favorable, with 66% to 80% of children becoming seizure free in the long term (Beghi, Giussani & Sander, 2015), it has long been recognized that the impact of epilepsy extends far beyond the seizures (Sillanpaa et al., 2016; Rodenburg, Meijer, Dekovic & Aldenkamp, 2005).

### 2.1 Adult Trajectory

The potential trajectory for children with epilepsy can be demonstrated through adult data. Five longitudinal studies in Canada, USA, Japan, Finland, and the Netherlands identified higher rates of incomplete education, poverty, social isolation, inadvertent pregnancy, and psychiatric disorders in adults with child onset epilepsy compared to the general population (Camfield & Camfield, 2014). In the US study, adults with epilepsy had poorer social outcomes, were less likely to be married, more likely to have lower levels of education, employment and income (Kobau et al., 2008).

The majority of adults living with epilepsy, including those diagnosed as children, are not well informed about their condition (Johnson et al., 2012; Coker, Bhargava, Fitzgerald, Doherty, 2011; May & Pfafflin, 2002) and when they do not understand their disease and effective ways of managing it they are far more likely to experience adverse health outcomes (Cole & Gaspar, 2015; May & Pfafflin, 2002) including more frequent, clinically unnecessary and costly emergency visits to the hospital (Noble, Goldstein, Seed, Glucksman & Ridsdale, 2012).

## 2.2 Co-morbidities

Co-morbidity [Appendix A] is the co-occurrence of two conditions with a greater frequency than found in the general population. Co-morbid conditions are common in pediatric epilepsy and their presence has important implications for diagnosis, treatment, medical costs and quality of life. The incidence rates of anxiety and depression are higher than in the general population, occurring in approximately one-third of children with epilepsy (Reilly, Agnew & Neville, 2011). Attention Deficit Hyperactivity Disorder (ADHD) is significantly more common in children with epilepsy than in the general population with approximately 30 – 40% meeting criteria, with higher rates in children with drug refractory epilepsy (Besag et al., 2016; Reilly et al., 2014). Even when the seizures are controlled parents report ongoing struggles related to learning problems, social difficulties, attention problems, organizational problems, irritability, anxiety, and depressive symptoms in their child with epilepsy (Jones et al., 2019; Baca, Vickrey, Caplan, Vassar & Berg, 2011). Compared to other individuals their age, a greater number of students with epilepsy will experience mild, moderate or significant weaknesses in their intellectual reasoning abilities (Prasad, Burneo & Corbett, 2014). Seventy percent of children with epilepsy report issues with memory in their daily lives and over 50% display weakness in some aspect of memory when formally assessed (Reilly et al., 2014; Smith, Elliott & Lach, 2006). Parents identify that despite the presence of behavioural needs, the possible association between epilepsy and neurobehavioral challenges was often not considered or discussed in their medical appointments and parents only became aware of the association when concerns were expressed by teachers at school (Jones et al., 2019; Lewis et al., 2010; McNelis et al., 2007).

These comorbidities often go untreated and unrecognized leaving children with epilepsy and their parents with significant unmet mental health needs (Mahendran et al., 2017; Reilly et al., 2014; Baker, 2006). An Ontario study looked at the health-resource utilization (HRU) of children with epilepsy and found that increasing number of comorbidities increased HRU with each additional comorbidity increasing the risk of neurology visits by 1.65 times, emergency department visits by 2.55 times, and

hospitalizations by 3.17 times (Puka, Smith, Moineddin, Snead & Widjaja, 2016. P. 153). This study indicated that 89% of emergency department visits in children with epilepsy were for non-epilepsy related conditions presumably related to a lack of access to psychologists as families are more likely to report unmet mental health needs (Puka et al., 2016).

### 2.3 Health Related Quality of Life (HRQOL)

HRQOL [Appendix A] is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. In pediatric epilepsy studies, poorer HRQOL correlates to the embarrassment and stigma associated with having a seizure, the periods of intense emotional distress related to the unpredictability of the next seizure, and with the loss of control over one's body (Elliott, Lach & Smith, 2005). Even children with a single seizure have a reduction in HRQOL compared to those without a history of epilepsy (Modi et al., 2009). Children with epilepsy have fears about how to handle seizures in social situations and worry about telling others or being teased or bullied because they have epilepsy (Benson, Lambert, Gallagher, Shahwan & Austin, 2015; Elliott et al., 2005).

Several studies have looked at the HRQOL in children with new onset epilepsy and have identified that seizure type, frequency, and epilepsy severity did not have a significant impact on a child's HRQOL (Reilly et al, 2015; Wu, Follansbee-Junger, Rausch, & Modi, 2014; Ferro et al., 2013; Speechley et al., 2012). These studies did find that potentially modifiable factors including parent and family stress, parental fears, co-morbid learning disabilities, ADHD and perceived stigma were identified as negatively impacting child HRQOL above and beyond seizure control (Wu et al., 2014; Ferro et al., 2013; Speechley et al., 2012). Multiple studies suggest that the co-morbidities of childhood epilepsy place a greater negative impact on HRQOL and life outcomes than do epilepsy-specific factors (Prasad et al., 2014; Kanner, 2014; Speechley et al., 2012; Baca et al., 2011). Canadian researchers have been studying the HRQOL trajectories of 374 children with epilepsy over time and have identified that problems associated with child behaviour and cognition are the strongest predictors of poor HRQOL and less favorable long term



outcomes (Ferro et al., 2013). Engaging families early in the care of their child with epilepsy could improve HRQOL (Wu et al., 2014; Ferro et al., 2013; Modi et al., 2009).

Families of children with epilepsy fare worse than other families on quality of parent-child relationships, parenting confidence, family functioning and stress, and parental psychopathology (Rodenburg, et al., 2005). Parents have poorer HRQOL, and recent systematic reviews report that up to 50% of mothers of children with epilepsy are at risk for clinical depression and 58% for anxiety (Jones & Reilly, 2016; Asato, Caplan, Hermann, 2014; Lv et al., 2009; Ferro & Speechley, 2009). Caring for a child with epilepsy may result in clinical loss of sleep and social isolation of the parent, and limit the parent's ability to pursue their own interests outside of caregiving (Smith et al., 2014; Wirrell, Wood, Hamiwka & Sherman, 2008). Stress is heightened in parents when the child with epilepsy has co-morbid anxiety, depression, ADHD or intellectual disability (Jones et al., 2019; Ferro & Speechley, 2009, Lv et al., 2009; Wirrell et al., 2008; McNelis et al., 2007). Parents report stress related to worry about the future, communication with healthcare providers, changes in family relationships, interactions with the school, and support within the community (Smith et al., 2014).

## 2.4 Stigma in Epilepsy

Stigma [Appendix A] is defined as an attribute, behaviour or reputation which is socially discrediting in a particular way; causing an individual to be mentally classified by others as undesirable, rejected, stereotyped (Goffman, 2009). Epilepsy is unique amongst chronic conditions in its unpredictability and high stigma in the community. Social stigma is common in epilepsy and can lead to the child with epilepsy having low self-esteem and a reduction in motivation to engage with school learning and activities (Elliott et al., 2005). Children who do not socialize or interact with their peers are at risk for poor outcomes as adults (Camfield & Camfield, 2014; Bekesi et al., 2011).

*Epilepsy: A public health imperative* (WHO, 2019) and the Institute of Medicine (IOM) Report: *Epilepsy across the Spectrum: Promoting Health and Understanding* (2012) identify the importance and priority of eliminating stigma which leads to social isolation, delays in seeking treatment and care, reduced educational attainment, unemployment,

poverty and poor mental health in people with epilepsy across the lifespan (WHO, 2019; IOM, 2012).

## 2.5 Health Information and Support Needs

This chapter began with the literature related to the adult trajectory for children with epilepsy with evidence that comorbidities and stigma have a greater negative impact on the health related quality of life of children with epilepsy and their parents. Several researchers have identified that when epilepsy knowledge is improved and coordinated care is provided, there is a reduction in stigma, morbidity and mortality, and improved HRQOL in families living with epilepsy (Lewis et al., 2010; Couldridge et al., 2001; Buelow & Johnson, 2000).

This research aims to understand the ongoing information and support needs of parents of children with epilepsy because the provision of health information is a critical first step in family-centered care and leads to improvements in knowledge of epilepsy, coping, seizure frequency, medication tolerability, and improved child psychosocial functioning (Bradley et al., 2016; Walker et al., 2009; May & Pfafflin, 2002). Children with epilepsy rely on their parents for guidance about their disease and when parents lack information they can impose unnecessary restrictions on daily life (May & Pfafflin, 2005) and develop negative attitudes and reduced expectations for their child (Frank-Briggs & Alticor, 2011). Emotions such as anger, fear, frustration, and depression are commonly experienced by people with chronic diseases (like epilepsy) and managing these emotions is deemed part of the work required to manage the condition (Lorig & Holman 2003).

### 2.5.1 Health Information Seeking

When receiving health information, parents have identified the importance of not being overloaded with too much information especially in the beginning and during a time of crisis, preferring ongoing, tailored information and personalized support on a need to know basis (Jones et al., 2019; Buchanan, Jardine, Ruthven, 2019; McNelis et al., 2007). Parents identify that individualized information and advice, appropriate support and

counseling related to how to adapt to the problems they face on a daily basis is a priority (Kilinc et al., 2020; Mahendran, et al., 2017; May & Pfafflin, 2005; Elwyn et al., 2003).

There is evidence that parents may not ask questions in healthcare appointments because they do not know how or what to ask, or they may feel stigmatized, anxious and threatened by the information they receive (Buchanan et al., 2019; Pieters et al., 2016; Couldridge et al., 2001). There is evidence that information is sought based on situational and contextual variables and that information seekers value help that is easily accessible and is provided in a caring, compassionate, relational and supportive manner (Buchanan et al., 2019; Harris et al., 2001; Harris & Wathen, 2007; Wathen & Harris, 2006).

A Canadian pediatric epilepsy team surveyed parents asking them to rank the quality of health information available to them and where they obtain their information. Clinic-recommended internet sites were ranked highest (100%) but despite the high ranking, 83% (70/84) of parents did not access the recommended sites and were more likely to consult friends and other families living with seizures, lay organizations, or their own choice of websites (Lu, Wirrell & Blackman, 2005, p.908). Accessing information close to home from informal sources including family and friends that are perceived as non-threatening, caring and supportive is a common health seeking strategy (Buchanan et al., 2019; Harris et al., 2001; Harris & Wathen, 2007).

Parents often seek information on the internet after a diagnosis and qualitative studies identify that search results often come up with irrelevant and inappropriate information or frightening, worst-case scenarios causing increased stress, worry and confusion (Jones et al, 2019; Buchanan et al., 2019; Pieters et al., 2016; Lewis et al., 2010; Harris & Wathen, 2007).

### 2.5.2 Parent Support Needs

Parents supporting children with epilepsy have identified the need for informal social support: connecting with other families with a shared experience, parent support groups, online communities, peer mentors and internet forums (Jones et al., 2019; Pieters et al.,

2016; Wagner et al., 2015; Wirrell et al., 2008; Shore et al., 1998). Informal social support networks have an added benefit in that incidental information is shared and acquired through casual conversation allowing parents to learn strategies and pathways to care (Buchanan et al., 2019; Harris & Wathen, 2007; Harris et al., 2001).

Studies have identified the benefit of having care coordinators (also called champions, liaisons, intermediaries or advocates) who can steer parents to the right information in pediatric epilepsy care and also help with school system navigation (Jones et al., 2019; Hafeez, Miller, Patel & Grinspan, 2017; Pieters et al., 2016; Smith et al., 2014; McNelis et al., 2007; Shore et al., 1998). Care coordinators are perceived as more accessible and supportive to a parent because they are able to take the time to provide validation and to develop strong relationships with the families, improve communication between the family and healthcare team, coordinate services, and act as liaisons for the family within the school and community settings (Hafeez et al., 2017; Pieters et al., 2016). In the health information seeking literature, ‘personalized’ information that is communicated in an empathic manner and readily accessible is often sought prior to engagement with more formal institutional service provision (Harris et al., 2001; Harris & Wathen, 2007; Wathen & Harris, 2006).

Parents of children with epilepsy have identified a need for support to cope with caregiving responsibilities, burnout and exhaustion arising from a number of concerns, including worry that their child may be harmed during a seizure, lack of sleep because of constant vigilance, and anxiety related to the uncertain timing of the next seizure (Harden, Black, Chin, 2016).

An identified parent need is counselling, informational and emotional support beyond the time of the initial diagnosis to manage the child’s behavioural challenges which are prevalent in childhood epilepsy (Jones et al., 2019; Smith et al., 2014; Wirrell et al., 2008; Couldridge et al., 2001).

## Chapter 3: Methods

This thesis is a descriptive content analysis of text found in the client case files of 20 consenting families. The thesis will identify the ongoing information and support needs of parents of children with epilepsy who engaged with Epilepsy Southwestern Ontario (ESWO) over a 36 month time period.

### 3.1 Content Analysis

Content analysis [Appendix A] is a “research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use” (Krippendorff, 2004, p. 18). It is rooted in the naturalistic paradigm allowing researchers to develop and extend knowledge of the human experience of health and illness (Graneheim, Lindgren, Lundman, 2017; White & Marsh, 2006; Hsieh & Shannon, 2005). This flexible and pragmatic method is used by qualitative researchers because the analysis goes beyond counting words to examining language for the purpose of classifying large amounts of text into an efficient number of categories that represent similar meanings, patterns or themes (Hsieh & Shannon, 2005). The notion of inference is especially important in content analysis (White & Marsh, 2006), which is why data analysis begins with the reading of all of the text repeatedly to achieve immersion and to obtain a sense of the whole allowing new insights to emerge (Hsieh & Shannon, 2005).

The method is often used in information science (White & Marsh, 2006) to identify the person’s perspective on the topic. For example, researchers have used this method to understand the emotional needs of expectant fathers through analysis of posts on the Internet (Pilkington & Rominov, 2017); and to understand the informational needs of cancer patients through analysis of semi-structured interviews (Heidari & Mardani-Hamooleh, 2016). In a study seeking to understand the information seeking behaviours of urban young adults, researchers used content analysis of written activity logs (Agosto & Hughes-Hassell, 2005).

The trustworthiness of the findings using content analysis depend on the availability of rich, appropriate and well-saturated data (Elo et al, 2014). For this research, I had access to three years of retrospective, chronological text for each of the consenting families which made this method appropriate to gain insight into the month to month and year to year changes that can happen in epilepsy with seizures that are both acute and episodic, and a disease that is chronic. Other qualitative methods (focus groups, interviews, surveys) capture the parent perspective at a single time point which did not seem sufficient to document the changing and evolving needs as the child ages and when there is variability in the child's seizure activity. The goal of content analysis is to provide knowledge and understanding of the phenomenon, in this case, the ongoing information and support needs of parents of children with epilepsy. Having access to parent's actual requests for engagement at different time points, I was able to draw conclusions and interpret meaning from the text about the communicator, the message of the text, and the situation or context surrounding its creation (White & Marsh, 2006).

### 3.2 Families in the Research

For this thesis, I used a convenience sample, selecting, from a total sampling pool of 36 cases, the 20 ESWO client case files that would provide the best knowledge concerning the research topic. This was determined by narrowing the inclusion criteria to children between the ages of 2 and 10 years whose parents had greater than 5 post-education requests for information or community epilepsy agency support over a 36-month period and where there was sufficient text data to understand the content and context of this engagement. For the purpose of this research a client case file represents a 'family' defined as the parent/child dyad with documentation of the parent's perspective. The parent in this research is primarily a matriarch as the majority of email correspondence was written by mothers and one custodial grandmother. While some communication logs indicated that the father was present at the time of the education session and attended school team meetings, follow up requests for information and support were primarily sent from the mother's email addresses. A chart with the characteristics of children in the research can be found in Appendix E.

Data collection for the Clinic to Community<sup>®</sup> (C2C) evaluation was funded by the Ontario Brain Institute (OBI) and approved by Western ethics (HSREB #105783) under the study title *From 'Clinic to Community': a feasibility study of a healthcare linkage program*. The full study aim was to assess the feasibility of implementing the program into clinical practice and to understand the benefits, gaps and challenges of offering the C2C healthcare linkage program in the clinic and in the community. The research ethics board protocol included written parental consent allowing ESWO to document the information requests and use of community programs which is the data set for this research.

### 3.3 Unit of Analysis – Client Case File

Every time you visit your family doctor they document the appointment in your medical file. They use your medical file to keep track of your health, prescription refills, specialist referrals, clinical case notes, blood work, etc. In the community, ESWO uses the same approach but instead of documenting the medical information they open a 'client case file' to keep track of all requests for information, all use of community agency programs, and all referrals. The information in the ESWO client case files is stored in an electronic database (SUMAC) used by many not-for-profit organizations to manage client data. Data can be entered into the SUMAC database using descriptive text. It is the responsibility of the ESWO staff member (Executive Director, Client Services Coordinator, C2C educator, receptionist) who interacts with the family to input a case note in the client case file every time they interact with the family.

All attendance at ESWO programs including children's programs and parent support groups is entered into the client's case file. Requests for school, healthcare and community-based advocacy and system navigation are documented in the client case file. In many cases, there is also a paper file for a client. A paper file is used to keep photocopies of emails, minutes from school and healthcare team meetings, seizure safety protocols, copies of psychological assessments, program registration forms, and any other relevant information related to the client. Following Graneheim and Lundman (2004) I have chosen the 'client case file' as the unit of analysis for this research. Within the

‘client case file’ there are several sub-files including the 1) new client intake form, 2) communication log and 3) email communication between parents and ESWO staff.

Together these three sub-files will be used to answer the research question: ‘What are the ongoing information and support needs of parents of children with epilepsy?’

### 3.3.1. New Client Form

At the time of the C2C education session, the C2C educator filled out a new client intake form for each family in the research and collected baseline demographic and seizure related information on the child with epilepsy. Child characteristics that were collected include the child’s name, gender, date of birth, approximate month/year of first seizure and seizure type. The date of the education session and a list of known comorbidities was also documented on the New Client Form [Appendix F].

### 3.3.2. Communication Log

In the client case file there is a ‘communication log’. The purpose of this log is to provide ESWO staff with a chronological summary of all communication with and on behalf of the client. The communication log includes the date of the interaction and identifies ‘how’ the person engaged with ESWO, either by email, phone, and in-person or through attendance at an ESWO program. A description of the purpose of the engagement and the context is included in the communication log. The initials of the staff person who input the data are identified for accountability and follow up when necessary. Table 3.1 provides an example of the descriptive text that is found in a ‘communication log’. The information in this ‘communication log’ provides context for the families’ requests for information and support services. For example, reading this log, the ESWO staff can identify the gender and age of the client and the date of the C2C education session. They can identify that the social worker in the pediatric neurology department at Children’s Hospital of Western Ontario made the referral requesting help to reduce parent anxiety. The child has a brain abnormality and is not responding to medication, causing the parent to ask about medical marijuana and the neurologist to recommend surgery as a treatment option. The parent is anxious about surgery and was



matched with a peer mentor. The child did undergo surgery and there was a reduction in seizures but not full remission. The parent re-engaged with ESWO seeking advice on audio-video equipment to track and quantify nocturnal seizures. The parent re-engaged with ESWO asking for help in developing a school safety protocol. The parent asked about programs to support the child’s gross motor skill development and subsequently enrolled the child in the *Game ON* physical literacy program offered by ESWO for children with epilepsy. *Game ON* staff identified the child had some physical coordination issues. In November the parent requested classroom education for the child’s classmates.

**Table 3.1 Sample Communication Log**

| <b>Date</b>    | <b>Engagement Type</b> | <b>Communication Log</b>  | <b>Staff</b> |
|----------------|------------------------|---|--------------|
| March 3, 20XX  | C2C Given              | Referral was made by the SW, Ped. Neuro at CHWO: Mom has anxiety around medication and the diagnosis. XX was born X, XXXX. First seizure was at X months old. Child has a condition called ‘cerebral dysplasia’. Seizures are not well controlled by medication.  | RS           |
| March 8, 20XX  | Phone Call             | XX called wanting to learn more about alternative therapies including medical marijuana.  | RS           |
| April 18, 20XX | Email                  | Anxious and mixed emotions about surgery. Matched with parent XX as peer mentor for surgery.  | JM           |
| Dec 19, 20XX   | Phone Call             | XX had brain surgery with an 80% reduction in seizures<br><br>XX still taking daily medication and parent concerned with tracking and quantifying seizures overnight.<br><br>Seizures are non-convulsive and difficult to detect.<br><br>Given a referral to XXX for assessment and lending of audio-video equipment prior to deciding if X wants to do a custom install. | JM           |
| Dec 20, 20XX   | Email                  | Emailed a package of information about seizure tracking devices   | JM           |
| Sept 11, 20XX  | In-person              | Starting school. Met at ESWO office to develop school seizure safety protocol.  | JM           |

|               |                        |   |    |
|---------------|------------------------|---|----|
| Sept 25, 20XX | Programming            | Teacher in-service (types of seizures, seizure first aid, safety protocol)  | RS |
| Oct 15, 20XX  | Phone Call             | Mom has concerns about motor skills and lack of physical activity. Wanted to know about Game ON and whether XX would benefit from the program.                                    | JM |
| Oct 20, 20XX  | Programming            | Attended 'Game ON' program. Difficulty with balance and kicking ball in gym. Was reluctant to participate at first but joined the group at snack time and for the parachute game. | TV |
| Nov 13, 20XX  | Classroom Presentation | Classroom presentation at XX Public School  | RS |

In this research there were 367 discrete entries in the communication logs of the 20 client case files supported by 142 emails.

### 3.3.3. Email

For this research, email exchanges provided important information because they are written by the parent, dated and show the sender/receiver/sender messaging in one document. I used the email correspondence in this research to help understand the context based on the parent's descriptions of their situation and needs. The following text was transcribed from an email, sent by a parent who was providing background information to an Epilepsy Southwestern Ontario staff member who was going to attend a school team meeting in support of her child with epilepsy: "He is just finishing up a grade 1 reading level and will be going into grade 3 in September. I will bring with me on ... a copy of the Woodcock Johnson III testing and his report card from February. X has issues with focusing and attention which is part of the epilepsy." Examples of email correspondence can be found in Appendix G.

Based on the criterion identified for defining a text, the communication log and the email texts are ideal to answer the research question because they have cohesion, intentionality, acceptability and informativity (White & Marsh, 2006). Both the communication log and the email texts are cohesive because the text creates a message. They are intentional since the writer of the text, either the parent of the child with epilepsy or the ESWO staff

member intended for the text to convey ‘new information’ related to the client’s current situation and needs. The recipients of the text are staff at ESWO who understand the meaning and relevance of the text and use this text to keep informed about the client. The text is also dated which builds on the content and context of the broader case file and can be used as a timeline and ongoing conversation to describe the situation and the information or support request of the client and their family.

### 3.4 Coding & Analysis

The success and credibility of content analysis relies on the selection of text and the coding process (Graneheim et al., 2017; White & Marsh, 2006; Hsieh & Shannon, 2005). After selecting the text, I read through the data several times, scrutinized it closely, seeking to identify the big picture concepts and patterns. I chose not to use *a priori* codes since I could not find any publications related to the parent’s perspective of the post-education information and community support needs provided by a community epilepsy agency. The advantage of this approach to content analysis is gaining direct information from the text without imposing preconceived categories or theoretical perspectives (Hsieh et al., 2005, p. 1280). My research question guided my initial approach to data analysis and my coding categories were derived directly from the data. A category is defined as a collection of similar data sorted into the same place, and this arrangement enables the researcher to identify and describe the characteristics of the category (Morse & Richards, 2002, p.727). Using manifest content I identified 9 topics that covered the presenting issues found in the communication logs of the client case files. The topics became the main categories for dividing the text into the following content areas: seizures, medication and treatments, lifestyle, safety, psychosocial, school, children’s programs, system navigation and parent support. These main topics were mainly descriptive and were used in the preliminary stage of the analysis as a way to chunk my data into smaller units. I was able to assign all 367 discrete entries found in the communication logs into one of the 9 main topic categories.

My next step was to develop sub-categories to further refine the topics into sub-topics. For example, under the main topic ‘medication and treatments’, I identified 7 sub-topic categories: side effects, sudden cessation, drug benefit programs, drug shortages, trial

and error, diet therapies and surgery. During the timeline of this research there were national generic drug shortages causing some families in the research to engage with ESWO asking for help in finding stock of their child's anti-seizure medication. I coded these requests under 'drug shortages'. Under drug benefit programs there were requests for help in filling out government forms to request compassionate use when a drug was not listed on a drug benefit plan or when a family could not afford to purchase their child's medication. I added the category 'trial and error' for any entry where a communication log entry or email described the child was starting a new medication. I coded an entry under 'side effects' where a parent contacted the agency with concerns about a specific medication causing an adverse reaction.

I used a 'code' which is a term used to describe the word or short phrase that captures the main meaning of one small dimension of the data (Aurini, Heath, Howells, 2016). A code represents an individual segment of data and is used to label, separate, compile and organize the data. A code is used to further breakdown the category into smaller chunks of data for analysis. I began with 'first cycle' codes which again are more broad and descriptive and capture the central characteristics embedded in the data (Aurini et al., 2016) but as I went back through the data I assigned second and third cycle codes to further refine the data. Developing codes was an iterative process. For each category, I was able to define the codes that I selected. Table 3.2 is an example from the main category 'school' with sub-category codes and their definitions.

**Table 3.2 School Category Codes and Definitions**

| <b>Sub-Category Code</b> | <b>Definition of what is included in this Code</b>   |
|--------------------------|--|
| Rescue Meds              | Development and/or implementation of Emergency Plan of Care. School team training to administer rescue medications (benzodiazepines, Ativan (lorazepam), and midazolam). |
| Teacher Knowledge        | Teacher's practical understanding of epilepsy. Facts, information, and skills to support a child with epilepsy.  |
| Teacher Attitude         | A way of thinking or feeling about someone or something, typically one that is reflected in a person's behaviour.  |
| System Barriers          | System barriers that prevent children from attending school or from reaching minimum education standards. School board policies.   |
| Behaviour                | ADHD, hyperactivity, impulsivity, agitation, aggression, rage, oppositional defiance identified by teachers at school.   |
| Safety                   | The condition of being protected from danger, risk, or injury. Developing seizure safety protocols.  |
| Family                   | Parent or child response after a seizure. School refusal, home schooling, Parent choosing to withdraw their child.   |

|                    |   |
|--------------------|---|
| Teacher In-service | A meeting to provide teachers with professional knowledge, skills, and competence in supporting a child with epilepsy.  |
| Team Meeting       | An IEP, IPRC, or school team meeting to identify the student's specific learning expectations and how the school will address these expectations through appropriate accommodations, program modifications. School board psychological services and academic testing. |
| Cognition          | Child's ability to learn and retain new knowledge, reading, critical thinking, processing language, learning challenges, learning disabilities, Intellectual Disability.  |

It was evident from the communication logs and emails that parents engaged with ESWO because they had a problem that needed to be solved, were upset, frustrated, lonely, stressed or concerned. I used the query tool in SUMAC and identified the entries using the root words - concern, frustration, upset, worry, stress and help. I tagged affective words in the data and used memos to help identify emerging themes related to understanding the context and factors specific to parents' information needs. This is a partial list of the words that I tagged that were used by parents to describe their experience supporting a child with epilepsy: tired, frustrated, stressed, nervous, difficult, helpless, worried, anxious, afraid, terrifying, scary, defenseless, devastating, horrendous, panicked, traumatic, shocked, paranoid, nightmare and emotional. Additional words and phrases can be found in Appendix H.

All of the families in the research had received a basic education session that covered the recommended patient education topics listed in the provincial guidelines document so my intent was to go deeper into the data to identify the context that motivated parents to request further engagement. Was it a need for additional information that may have been missed or misunderstood in the Clinic to Community<sup>®</sup> education curricula or were their unmet support needs? By focusing on the uniqueness of the text I was able to tag metaphors like 'Helicopter Mom', 'roller coaster', 'living on the edge', 'basket case' and 'torn up' which stood out when I was coding the communication logs. The words parents used helped me to interpret the meaning of the text from the perspective of the parent and to identify the events or context that preceded the request for ongoing engagement.

I had access to a chronological timeline in both the communication log and in email texts so I looked at the entries before the tagged words to see if I was able to identify the

circumstances or events which preceded a request for information or support. Examples of circumstances that preceded a request were a student report card, change in teacher, a new treatment protocol, medication side effect, and neuropsychological assessment results, a bullying incident at school, a seizure in public and a hospital admission. This allowed new insight to emerge from the data related to the context and the emotional needs of these parents. I wrote memo's related to the events that often preceded the request for ESWO programs including requests for school advocacy, parent support groups, peer mentors or registration of children in skill development programs. I used memos to document new understandings of the data and developed a final coding scheme (Aurini et al., 2016, White et al., 2006) which is shown in Table 3.3.

**Table 3.3 Final Coding Scheme**

| <b>Main Category Topics</b> | <b>Sub-Category Topics</b>  | <b>Need Domains</b>  |
|-----------------------------|---|----------------------|
| Seizure                     | Seizure Types, Syndromes, Investigative Procedures, Prognosis, SUDEP  | Managing Seizures    |
| Medication and Treatments   | Side Effects, Sudden Cessation, Drug Benefit Programs, Trial and Error, Drug Shortages, Surgery, Diet Therapies   | Managing Seizures    |
| Injury Prevention           | Foam Pillows, Helmets, Seizure Dogs, First Aid, Seizure Detection Devices   | Managing Seizures    |
| System Navigation           | Access to mental health services, Healthcare Provider Communication, Neuro and Psychological Tests  | Lifestyle Management |
| Psychosocial                | Stigma, Memory, Depression, Child Social Anxiety, Behaviour, Fear   | Lifestyle Management |
| Lifestyle                   | Exercise, Sleep, Diet, Sports, Extracurricular Activities   | Lifestyle Management |
| Children's Programs         | Participation In Children's Programs – <i>Game ON, Summer Camp, Youth Empowerment Program</i>   | Lifestyle Management |
| School Advocacy             | Classroom Behaviour, Rescue Meds, Safety Protocols, Teacher In-Service, Cognition, Teacher Knowledge, Teacher Attitude, Team Meeting, System Barriers, Family Factors | Support Needs        |
| Parent Support              | Parent Support Groups, Private Facebook Group, Social Isolation, Parent Anxiety, Peer to Peer Mentors, Respite, Parent Stress   | Support Needs        |

In coding the data it is important to condense or shorten the text while still preserving the core meaning (Graneheim et al, 2004). Table 3.4 was added to show coding examples from the research across several categories: the main category are the presenting issues from the text which is mostly the surface content, the meaning unit column are the words and sentences taken verbatim from either the communication log or parent email text.

The condensed meaning unit is the shortening of the meaning unit text. The code is the label that I assigned to the meaning using both the content and context.

**Table 3.4 Examples of Coded Text**

| Main Topic Category       | Meaning unit from text  | Condensed meaning unit                    | Code                               | Need Domain          |
|---------------------------|---|---|------------------------------------|----------------------|
| Medication and Treatments | Concerned about the medications he is on and what it is doing to his body   | long term use of medication               | Medication Side effects            | Managing Seizures    |
| Parent Support            | Mom had a brother that passed away from a head injury and worries that her son will injure his head during a seizure and die. | Fear of injury and death                  | Parent Anxiety                     | Support Needs        |
| Psychosocial              | When she had the seizure in the playground she wouldn't go back to school for 3 days.   | School refusal                            | Social Anxiety                     | Lifestyle Management |
| Medication and Treatments | I'm freaked out cause she's going to probably go for surgery cause she's allergic to any of the other meds                    | Anxious about surgery                     | Investigative Procedures (Surgery) | Managing Seizures    |
| School Advocacy           | School claimed they needed to have an EA with a medical background  | School refusing to administer rescue meds | Rescue Meds                        | Support Needs        |
| System Navigation         | We have waited 5 years to get the hospital psychometric testing done  | Wait lists for testing                    | Neuro/ Psych Testing               | Lifestyle Management |
| School Advocacy           | Requires EA support for safety and participation in school  | EA for safety                             | Safety Protocols                   | Support Needs        |

The nine categories were further collapsed into three need domains. The 'managing seizures' domain included coded text related to the unpredictability of the seizures, trialing medication, treatment side effects, surgery and injury prevention. The 'lifestyle management' domain reflected the parent engagement related to system navigation and day-to-day challenges with managing child behaviors, child social anxiety, stigma, fear and making lifestyle choices including participation in extracurricular children's programs. The third domain 'support needs' included requests for ongoing support related to school advocacy and parent requests for emotional support to aid in coping and to reduce social isolation.

I had to make a decision about whether the analysis should focus on the visible and obvious text or if I should focus on the underlying meaning, the latent content, which involves an analysis of what the text is talking about. Both are interpretative but the interpretations vary in depth and level of abstraction (Graneheim et al., 2006, p. 106). The identification of categories and sub-categories involved surface level interpretation of data but the final identification which led to finding an answer related to the context of parent needs was an inductive process using open coding, creating categories, condensing and abstraction of text data, using affective words, context and inference. After coding the data I looked for 'themes' which are a thread of underlying meaning that can cut across the three domains and an expression of the latent content of the text. Themes are used in the later phase of a content analysis process to tie everything together and in this thesis to elicit meaning related to both the content and context of the post-education information and support requests found in the 20 client case files.



## Chapter 4: Findings

The overall aim of this research is to provide insight into the underlying circumstances related to parent requests for ongoing information and support and to create a composite picture of engagement with Epilepsy Southwestern Ontario (ESWO) from the perspective of the parent supporting a child with epilepsy. In this findings chapter the nine topic categories have been condensed into one of three distinctive domains. Each domain is defined by the circumstances in which the request was necessary: to manage the seizures, to manage the child's non-medical needs and lifestyle, and to acknowledge the parents support needs. The three final need domains: 'managing seizures', 'lifestyle management' and 'support needs' were identified because they capture all of the content of and psychosocial context for the coded text data. Quotes have been used to identify content taken verbatim from a client case file and a family number (F1 – F20) has been used to represent each of the twenty individual families in the research.

### 4.1 Need Domain: Managing Seizures

In this domain the codes from 3 categories: seizure, medication and treatments, and injury prevention have been grouped together because they all relate to the management of the seizure event. In this domain, codes indicated parents engaged with Epilepsy Southwestern Ontario (ESWO) seeking information and advice when they felt 'uncertain' in their ability to manage their child's epilepsy. The underlying circumstances that led to parent requests for post education information or support in this domain were changes in the type or severity of the seizures, medication side effects, changes in the treatment protocol and a need to keep the child safe.

#### 4.1.1. Seizures

It appeared that after receiving the information at the education session some parents required further clarification or support related to seizures: "I didn't know there were different types of seizures and that they could look different" (F13) and "neither of us had a clue that SUDEP was a thing" (F9) and "Is it true that seizures can be triggered by my child being emotionally scared or upset?" (F17). A feeling of uncertainty and worry was

a common thread in this domain: “I don’t know if I’m doing the right thing” (F15) and “I don’t know how often to expect it” (F5).

There were generic questions about seizure triggers: “should I reduce sugar in her diet?”(F19) “Is heat a trigger?” (F7) “Can he go to an amusement park or will that make his brain jump?” (F17) “Can he go on a plane?”(F1) or “is it safe to play hockey?” (F2). Parents were uncertain about the effects of flashing lights: “the day before he had the first seizure he was playing this little video game non-stop, getting frustrated, freaking out so do you think I should cut him off video games?” (F17) or “I’m nervous to take him to a movie theatre because of the darkness and then all the lights flickering” (F17).

The codes in the seizure category suggested that parents have ongoing information needs beyond the time of diagnosis: “we had new questions that we wouldn’t have had during the diagnosis appointment” (F8) and “we needed time to digest” (F6) or “you goggle something and you read the worst possibility” (F9). Parent emails were sent after a child had a ‘new’ type of seizure: “it’s tough when everything seems to be going along just fine and then a seizure happens out of the blue” (F9) and “it’s a lot of worry about how things are going to change in the future now that he had a loss of consciousness seizure” (F2).

#### 4.1.2. Medication and Treatments

In the medication and treatments category, the trial and error of starting a new medication weighed heavily on these parents: “we put him on medication and that was really stressful” (F9) and “when we upped the medication the behaviour got worse” (F7). One parent shared the feelings of many: “so tired of the crap shoot that medications seem to be...so tired and frustrated for him” (F1) When parents engaged with ESWO staff with concerns about medication it was often to seek an opinion about whether they should contact the clinician about the side effect wanting to know if this was ‘normal’ for a child with epilepsy. Parents identified side effects that were ‘worse than the actual seizures’ and ‘horrifying’ and ‘unacceptable’ that caused developmental regression, behaviour challenges and rage. From the entries it appeared that parents also wanted to share that they felt burdened by any use of daily medications. They expressed concerns that medications were harmful to their child and shared that they were worried about the long-

term effects. Emails and phone calls indicated a need for validation and empathy because parents felt conflicted by their decision to place their child on daily medication sharing they felt “uncomfortable because it’s a pretty strong medication for a little 6-year-old to be on every day” (F15) and “I find it’s very hard on him body-wise and mind-wise to be able to take all that medication” (F20).

Many parents commented that they had been told by the child’s neurologist that the odds were good that their child would outgrow the seizures. This did not seem to alleviate parent uncertainty and worry: ‘During the time she’s seizure free you still worry that she could have a seizure at any time and you don’t know if she’s outgrown it” (F6) and “I’d like to have more answers about what’s going on with her instead of just waiting to see if she grows out of it or not” (F19) and “the Intern told me the diagnosis could change at any time” (F17).

If the child becomes drug refractory the message from the neurologist changes from using medication to recommending surgery as a treatment to stop the seizures. Parents require time to process these inconsistent messages as outgrowing seizures implies the condition is going to go away and is not severe and brain surgery implies the condition is ‘pretty big’ and potentially life threatening. Parents can find expert surgery advice at Children’s Hospital of Western Ontario but client case files showed they engaged community epilepsy agency support when they wanted reassurance that surgery was a necessary choice and help weighing the benefits and risks of making a decision that was seen as irreversible. For these parents, the purpose of engagement was to seek help with processing complex information and to receive emotional support to reduce fear. This engagement often led to the request for a peer mentor, who is a parent with lived experience supporting a child through brain surgery. Parents used strong words to describe how they felt in these deliberations: “I’m freaked out cause she’s going to probably go for surgery” (F10) and “going through the surgery was pretty much the worst time in my life” (F1).

### 4.1.3. Injury Prevention

There were post-education information requests in the injury prevention category related to keeping the child safe. Parents asked where they could purchase anti-suffocation foam pillows, alarm systems and audio video monitors for the child's bedroom. Two families requested information about protective helmets, one family asked about the Embrace<sup>®</sup> watch used to detect and notify when there is a seizure, and another about a seizure companion dog.

## 4.2 Need Domain: 'Lifestyle Management'

Parents also require information to manage the non-medical consequences which include fear, societal stigma, challenging behaviours, social anxiety, mental health and the extracurricular needs of the child. In the lifestyle management domain the codes from 4 categories (system navigation, psychosocial, lifestyle and children's program) have been grouped together as requests in these non-medical categories provide insight into the psychosocial consequences of living with an epilepsy diagnosis.

### 4.2.1 System Navigation

Analysis of the text in the system navigation category indicated that long wait lists for mental health services and behavioural supports prompted parents to engage with staff from Epilepsy Southwestern Ontario (ESWO) to resolve a problem. In the system navigation category there was coded text where parents repeatedly requested neuropsychological and psychological services from both the school boards and from the hospital and were placed on long wait lists. There was bittersweet validation when psychological testing came back with confirmatory evidence that the child with epilepsy warranted additional support and accommodations at school. One parent wrote: "school will change its tune once they read the results of the testing" (F3) and another shared "testing proved to be what I've been saying all along that there is something not right. Teachers have said that she can remember something one day and then the next day it's all gone" (F14). Parents asked for help in accessing mental health services, identifying

the names of respected therapists and psychologists, and requested letters of support to leverage applications for provincially funded mental health programs.

Communication logs showed parents were seeking post-education information about community reading programs, programs to develop math skills and access to tutors. There were requests for travel insurance which is often denied when there is a pre-existing medical condition, pro bono legal support to challenge a disability claim, and help with information sourcing with government programs like Employment Insurance, Ontario Disability Support Payments, Child Tax Benefits and respite funding.

Parents identified times where they felt ‘defenseless’, ‘dumbfounded’ and ‘helpless’ and described situations where healthcare providers did not provide guidance about the anticipated trajectory or prognosis for their child causing one parent to question “are these seizures damaging her brain?” (F16). In the sub-category ‘healthcare provider communication’ there were codes related to rushed healthcare provider communication which left parents feeling anxious and isolated: “seeing a neurologist once a year is not good support” (F14) and being at a “very high stress point feeling like we hadn’t been heard by the doctors” (F5) Parents requested support from epilepsy community agency staff to fill this void: “they (doctors) don’t have time to chat about living with this type of thing” (F9) and “we’ve been thrown into the medical system and we’re trying to navigate” (F15). One parent wrote: “I want to trust the medical system but at the same time I wonder whether or not they have her best interests at heart” (F15) feeling that her healthcare provider was not forthcoming with information about her child’s degenerative condition. One of the programs used by parents in this research was engaging an ESWO staff member in the role of intermediary to attend a clinic appointment “to ensure our concerns are listened to and addressed appropriately” (F1).

#### 4.2.2. Psychosocial

Codes from the psychosocial category showed families in the research had requested an ESWO intermediary to challenge decisions that the parent felt were discriminatory. For example, one family requested advocacy when their child was told they could not register

at the local soccer club (F3) and another family requested support challenging a decision made by a dance studio after the child had a seizure on stage during a performance (F14).

Coded text from the psychosocial domain illustrates the range of parent emotions: 'it's a nightmare', 'you get paranoid', 'disturbing to watch', 'living on the edge' and 'scary for us'. Parents identified that they were afraid: "I worry that my child will be injured" (F1, F2, F3, F9, F12, F18, F20) and described their child's seizures as 'traumatizing', 'terrifying' and 'paralyzing'. Text also showed parents feared that the child could die from a seizure: "I get a feeling of impending doom" (F12) "it could be devastating" (F15) and "I worry that I don't lose him" (F17). Many parents shared that despite having the best medical care they still felt incapable of protecting their child: "You can't do anything to fix it. You can't make her come out of it magically" (F10) and "The stress is never going to go away. You can't help but worry" (F12).

Text identified the fear of an unwitnessed, nocturnal seizure: "I worry about him suffocating in bed" (F2) and "He's still not sleeping in his room because I'm scared he's going to suffocate" (F17). One parent said she hadn't slept through the night since her daughter was diagnosed four years earlier: "I would sleep in her bed if it would hold my weight" (F18). In these entries it appeared that parents were seeking validation and emotional support and engaged with community epilepsy agency staff when they felt vulnerable, seeking a caring, listening ear. This fear extended to activities in the community: "He's at the Y so I'm seeing if they can do one-on-one while he's in the pool in case he has one in the pool. I don't want him to drown" (F17).

In this domain, parents worried about their child's challenging behaviours, accessing mental health services and feeling stigmatized. Epilepsy Southwestern Ontario (ESWO) staff were accessible to parents and offered empathy, compassion and guidance when parents felt vulnerable, worried and afraid. Client case files and email correspondence suggested that parents typically engaged with the same ESWO agency staff member which suggested that this relationship was based on trust built over time: "(name of staff) knows her epilepsy and she's the real deal" (F12) or "thank you...this wouldn't have happened without you being involved" (F11). There was text suggesting this care helped

parents to manage: “I feel calmer now that I understand things a little bit more” (F9) and “...explaining things in such a way that it felt less dire in that moment” (F4). Email correspondence suggested the continuity of this relationship allowed staff to provide reinforcement: “I think you nailed it on the head here” (F3) and to provide praise “this is a great report” (F11) and “you’ve done a fantastic job in getting services for your child” (F18).

### 4.2.3 Lifestyle and Children’s Programs

To reduce social isolation and to develop social, emotional and physical literacy skills, many parents enrolled their child in exercise and extracurricular programs offered by Epilepsy Southwestern Ontario. Client case files showed 8 of the families in the research enrolled their children in the Saturday morning recreation program and/or summer camp. The context identified in the communication logs suggested that parents enrol their child when there are issues at school related to externalizing behaviours (F3, F8, F11, F13); lack of friends (F3, F11, F12); teasing and bullying (F3); or when the child is anxious (F2), angry or frustrated (F3, F20). After coding these texts it was evident that parents also choose these programs when they feel apprehensive that their child is not being properly supervised in school and community organized sports and recreation programs.

## 4.3 Need Domain: ‘Support Needs’

The codes from 2 categories: ‘school advocacy’ and ‘parent support’ have been combined under the domain ‘support needs’. Care is a prevalent theme in this domain and is defined as the provision of emotional support to cope with parent fear and social isolation.

### 4.3.1. School Advocacy

The school advocacy category had the greatest number of codes indicating it was a priority need for parents: “school is something that I have a hard time navigating on my own” (F9) and “staying safe at school is top on our list of worries” (F12). Parents are

required to develop rescue medication protocols and learning and behavioural plans every school year and client case files indicated the development of these plans was stressful. Parents expect the school system will keep their child with epilepsy safe, help them to learn basic skills, gain knowledge, develop talents and provide opportunities to meet new friends and grow into healthy productive adults. When these expectations were not met parents in this research requested community support in the form of school advocacy.

Parents worry that their child will be harmed by a seizure at school: “every week I get an incident report from the school – that yellow form from his teacher showing how many times he has fallen on the playground” (F17) or “every day I have my cell phone on me, just worrying non-stop” (F9). In this research, 90% (18/20) of the families requested help in developing a seizure safety protocol or an emergency plan of action to administer rescue medication at school [Appendix I]. The rescue medication used in epilepsy is often a pill that is put in the mouth at the 5-minute mark during a convulsive seizure. Multiple communication log entries show school personnel have told the parent that they will not administer rescue medication at the school but will instead call 911 to dispatch an ambulance. In the communication logs, parents identified that this was not an acceptable response. One parent from a rural community wrote in an email: “if he were to have one and it lasts longer than 5 minutes, it takes 20 minutes to get an ambulance and then another 20 minutes to get to the hospital” (F2). In the coded data from the school advocacy category, ‘rescue meds’ and ‘safety protocols’ were common sub-categories of support requested by parents and ‘system barriers’ was identified as the contributing factor preceding this engagement: “seizure protocol and additional forms were requested by the school board” (F12) and “the superintendent had concerns about rescue medication training” (F11).

Communication logs showed that when parents feel their child with epilepsy is not safe at school they become protective and withdraw their child which leads to discontinuous, fragmented learning. There was one entry related to a child being kept home for a week after he had a seizure at school. He had lost bladder and bowel control (hallmarks of his seizure type) but was not provided with his prescribed rescue medication. His parent requested that ESWO join them at a school team meeting before they would send him



back to school. The communication log shows that the purpose of the meeting was to re-educate the teachers to recognize his type of seizure and review his rescue medication protocol (F1). Client case files had numerous entries related to parent concerns about school safety: “I don’t think the school has enough support” (F11), “I really don’t want to send her to school. Who’s going to monitor her seizures?” (F18) There were also entries in several communication logs from parents requesting information about home schooling, private schools and recommendations of what school board, public or private, was best suited to meet the needs of their child with epilepsy (F3, F11, F18).

Parent requests for school advocacy were also coded under the sub-category ‘cognition’: “school is saying she’s having a more difficult time focusing” (F10) and “concerns about short term memory which seems to be deteriorating” (F2) and “she was a good student until she started the seizures again” (F14) and “he read a book one day and then he couldn’t read it and he went backwards” (F3).

There were multiple requests coded to the sub-categories ‘teacher in-service’, ‘teacher knowledge’ and ‘teacher attitude’: “teacher is new at the school so she told me a lot of stuff she didn’t understand” (F10). There was evidence that lack of teacher knowledge frustrated many parents: “I can’t sit there and baby them (referring to teachers) and try to teach them everything about epilepsy” (F11) and “(teachers) just think that epilepsy looks like this but epilepsy has many different faces” (F20). One parent recognized: “This whole situation is not fair for anyone involved. I can’t expect her teacher to teach 20 kids plus take care of multiple seizures and after seizure support” (F11). Parents requested school advocacy when they felt their child was poorly supported in the classroom: “I worry a lot about him in relation to school and having a seizure at school and everybody being able to manage dealing with that” (F3) and “there is 1 educational assistant (EA) to 3 children in the classroom and epilepsy isn’t considered a physical disability” (F20).

For many parents, school advocacy was requested to mediate an adversarial parent-principal relationship or parent-teacher dispute at the child’s school. Parents didn’t request websites or booklets or written information, they wanted in-person support in the form of an intermediary or advocate. An intermediary was requested by a working parent

who was repeatedly asked to pick up their child from school because the child was having a 'bad day'. This parent was worried they would lose their job if they kept leaving work and asked for help in resolving this situation (F3). An intermediary was requested by parents who were told that their child with epilepsy could not ride the school bus (F12, F14) or play with their classmates outdoors during recess or attend a field trip because the school did not have the staff to appropriately supervise the child (F4, F10, F11).

In one client file there were several entries related to a principal who had made a unilateral decision to modify the child's school day to half days for the duration of 4 weeks. The communication log confirmed this decision was made because the child was aggressive and violent. His parent requested advocacy citing mitigating circumstances since his behaviour is comorbid with his epilepsy and both are consequences of his brain abnormality (F20). There were other entries in the client case files that were coded under the sub-category 'classroom behaviour' as it was not a seizure that prompted a parent to request school support: "teacher called because my child is experiencing challenges with behaviour at school" (F11) and 'teacher says behaviours are getting in the way of learning' (F3). One communication log entry read "first seizure in 20 months" from a family that had requested ongoing school support four times in the prior 12 months to deal with challenging classroom behaviours (F3). There were multiple requests for an ESWO staff member to attend school team meetings to resolve behaviour issues and to develop behavioural plans. One parent summed it up: "it's the behaviour versus the seizure activity that identifies him" (F3). A chart with additional parent requests for school advocacy can be found in Appendix J.

The research covered a period of 36-months and entries showed that school advocacy was an ongoing need: "I had a great relationship and great communication with the old principal. The new one knows nothing about epilepsy" (F14). There were entries in the communication logs indicating 90% (18/20) of the families had requested a yearly classroom presentation for their child's peers. These presentations are a proactive way to teach school aged children about epilepsy and seizure first aid and to prepare children to act compassionately should they witness a seizure at school.

### 4.3.2 Parent Support

Findings from this content analysis indicate parents engage in programs to make a social connection with other parents. For 15 families in this research, parent support was requested and provided through various modes of interaction; individual one-to-one peer matches, support groups, on-line computer-mediated parent groups or within parent education workshops. Entries in the communication logs suggested a stressor; a new type of seizure, eligibility for brain surgery, a negative social encounter, challenging behaviours, a poor report card, a bullying incident or a restriction in an activity at school preceded requests for parent support.

Parents identified a need to reduce their anxiety and social isolation and identified that support groups helped them to cope: “It’s nice to hear and to know you’re not alone” (F4) and “I have a new group of friends that I can actually talk to and be able to relate to” (F5). Most parents requested peer mentors because they felt burdened by the day-to-day reality of managing their child’s condition: “The whole process has been super hard for me to deal with and I am looking for someone that is going through the same thing” (F16). Parents identified the benefits of an on-line group: “I am reluctant in social situations so something like the online group appeals to me because I am a little bit shy” (F9) and another reinforced: “you can connect with people when you have a need in a fairly quick way which has been helpful” (F7). One parent wrote that talking about epilepsy actually increases their anxiety: “We haven’t had to go through that and it’s daunting to think we might be there in a year. We might be there in 5 years.” (F15).

## 4.4 Crosscutting Themes

The chart (Table 4.1) illustrates areas where parent codes showed trends that preceded the requests. In the ‘managing seizures’ domain the requests often related to a feeling of ‘uncertainty’. The factors that preceded requests for ongoing information or support in the ‘lifestyle management’ domain were the day-to-day ‘worries and stresses’ causing parents to request help in accessing resources or extracurricular activities for their child with epilepsy. The ‘support needs’ domain included the two categories ‘school advocacy’ and ‘parent support’ which were grouped together because of the

interconnected requests for supportive care and community epilepsy agency advocacy in the form of an intermediary. Fear and care were two cross-cutting themes found in all three need domains. Parents identified they often needed to manage the emotion related to the seizure event which could result in a negative social outcome or injury. Parents reached out to community epilepsy agency staff and other parents seeking care to cope with seizure and lifestyle management and to find the strength to challenge the adversity and negative attitudes they often encountered in the school system while trying to find the balance between safety and inclusion for their child with epilepsy.

**Table 4.1 Need Domains and Prevalent Themes**

|  |   |   |
|--|---|---|
| 'Managing Seizures' Domain<br><br>'Uncertainty'                          | 'Lifestyle Management' Domain<br><br>'Worry/Stress'   | 'Support Needs'<br><br>'Advocacy'   |
| Next Seizure<br>Medications<br>Surgery<br>Injury Prevention<br>Prognosis | System Navigation<br>Accessing Mental Health Services<br>Extracurricular Activities<br>Child Safety | School Safety Protocols<br>Rescue Medications<br>Academic Achievement<br>Peer Mentors |
| 'Support Needs' Domain - 'Care'  |   |   |
| 'Fear' of Injury or Death  |   |   |

## 4.5 Summary of Findings

Parent requests for ongoing information related to managing the seizures when there was a change in the type of seizure, a medication side effect or when the epilepsy was drug refractory and a new treatment was proposed. Parents requested information to keep their child safe and to prevent an injury at home and in school. They requested support in the form of an intermediary when they felt stigmatized in the community or when they encountered barriers in the school system. The research indicated that even with seizure remission parents requested support from ESWO staff to develop yearly school safety protocols and yearly learning plans. Parents also requested support to help with challenging behaviours at school and with system navigation to access resources.

## Chapter 5: Discussion and Conclusion

There was a high level of uncertainty reflected in client case files when there were changes in the child's seizures or treatment protocols and evidence that managing the day-to-day activities for their child with epilepsy caused parents to feel stress and worry. The unpredictability of the next seizure left parents feeling a loss of control which resulted in the fear that their child could be harmed at a community event, at school or die after an unwitnessed seizure in bed. This uncertainty, worry and fear were the catalyst for parents to seek a network of support and care that was provided by staff and other parents they met through their engagement with Epilepsy Southwestern Ontario (ESWO). Parents requested ongoing information from ESWO when there were changes in their child's seizures but more often sought care and emotional support from a staff person at the agency in the form of an advocate who could help them to access mental healthcare resources and help them to resolve issues they encountered in the school and community.

When a parent encountered a systemic barrier or needed validation, reinforcement or advice they engaged with staff at Epilepsy Southwestern Ontario (ESWO) or with other epilepsy parents who shared a common bond and understanding. Other researchers have identified that health seekers value personalized information that is provided in a caring, empathic manner by individuals who are good listeners, who are able to spend time with the person in need of assistance (Buchanan et al., 2019; Wathen & Harris, 2007; Harris et al., 2001). The caring support that was provided by peer mentors and staff at ESWO was requested by parents in this research to cope when they felt uncertain, worried, stressed or when they felt afraid that their child would be injured or die because of a seizure. Two cross-cutting themes: 'fear' and 'care' were coded across all three domains in this research and are the focus of this discussion chapter.

### 5.1 Theme: Fear

The parents in this research were seeking personalized information and support to cope with the fear that has been recognized by many epilepsy researchers. In a US community-based study of 1096 people living with epilepsy, 'fear' (of a seizure, of embarrassment, injury, death), was the issue most frequently reported (Fisher, 2000). In

a study by Besag and colleagues (2005), parents who took their child to an emergency department after a seizure stated that they thought their child was dying using terms like ‘terrified’ and ‘panicked’ and ‘suffocated’ to describe the experience (Besag, Nomayo & Pool, 2005). The study identified that regardless of the length of the seizure, many parents think that their child is dying or has died in a seizure when their bodies go limp and lips become blue (Besag et al., 2005). A 1998 study showed that 3 months after the onset of seizures, 43% of 167 mothers were worried that their child’s seizures might cause death and in this same study six months later, 40% of these mother’s continued to worry (Shore et al., 1998). Shore and colleagues concluded that although some parents adjust well, others may feel that each seizure is a re-enactment of their child’s apparent death. A 2018 study of parent’s experience of their children suffering febrile seizures suggested ‘not knowing what to do’ made the parent feel powerless and out of control (Westin & Levander, 2018). The authors in these studies made the same recommendation: healthcare providers can help alleviate parent fear by asking questions about how parents feel and by providing access to coordinated care (Westin et al., 2018, Besag et al., 2005, Shore et al., 1998).

In a large, UK database study of people aged 1 – 24 years, individuals with epilepsy had an 18% increase in their risk of fracture, 49% increase in the risk of being burned, and 247% increase in the risk of poisoning by medication compared to healthy controls (Prasad, Kendrick, Sayal, Thomas & West, 2014). A Canadian population-based study identified that injuries from seizures are a serious, persistent problem in childhood onset epilepsy (Camfield & Camfield, 2015). Thus, parents’ fear, as identified in these studies, is entirely rational and based on clear evidence of significant risk of harm.

Across the continuum from initial diagnosis through ongoing treatments and services, persons with epilepsy and their families need to be aware of the disorder’s potential risks, including the risk of dying (IOM, 2012). All parents in this research had access to the internet where they can easily find information about death in epilepsy and SUDEP which is the sudden and unexpected, non-traumatic, and non-drowning death of a person with epilepsy (Donner et al., 2017, p. 8). It is argued that sharing accurate information about SUDEP can optimize epilepsy self-management, reduce anxiety and levels of

distress (Donner et al., 2017) but surveys of North American neurologists found that 4-7% discussed SUDEP all of the time and 67-68.5% discussed it with a few or none of their epilepsy patients (Friedman, Donner, Stephens, Wright & Devinsky, 2014). In a US study, 91% of parent's desired information about SUDEP, but only 20% of the pediatric neurologists provided this information (Gayatri et al, 2010).

Most SUDEP cases have occurred in an unsupervised setting, often at night and in bed. (Donner et al., 2017, p.10). The literature highlights that the clearest way to reduce SUDEP is to improve seizure control and by early administration of rescue medications (Donner et al., 2017, p. 11) but in this research parents encountered significant barriers in getting the school community to follow the healthcare provider rescue medication protocol. When school staff and school boards overrule the healthcare provider recommendations for administration of rescue medications this increases parent anxiety, worry and fear and causes parents to withdraw their children from school and to request an intermediary to help resolve the situation.

## 5.2 Theme: Care

Parents of children with epilepsy face many barriers causing them to seek care. The school system places barriers in the way of student safety, social and academic success. The healthcare provider doesn't always have adequate time to allay parent fears and worries. Waitlists for mental health services are long and never proactive. The child's behavioural challenges place an enormous burden on parents and teachers. The unknown trajectory of a condition that does not have a blood test or biomarker and the unpredictability of when and where the next seizure may happen force the parent to weigh the pro's and con's in making daily decisions related to their child's activities. Rapid advances in the biosciences mean there are many diagnostic tests and treatment options available to parents of children with epilepsy making medical decision making very complicated. Parents are being offered medications, special diets, genetic testing and brain surgery and each of these options has its own risk profile.

The unpredictable nature of seizures with respect to when and where they may happen can contribute to feelings of fear and worry for the parent, teacher or coach. To manage

this fear, an adult may restrict the child's activities and remove the child from social encounters, recreation and school programming, believing they are protecting them from harm (Elliott et al., 2005). This protection may suggest to the child that they are not normal, that the world is a dangerous place, and that they are not capable of doing things on their own. Eventually these restrictions can cause the child to experience discontinuous, fragmented learning, and to feel hopeless, withdrawn, depressed or socially isolated (Elliott et al., 2005). Parental protection of the child is seen as adaptive and well intentioned (Rodenburg et al., 2013) but there is evidence that overprotection leads to learned helplessness, future dependence, perceived disability and unemployment in adults with child onset epilepsy (Wo, Lim, Choo & Tan, 2015).

Communication logs showed that caring for a child with epilepsy can be exhausting, socially isolating and may limit a parent's ability to work outside the home. When children with epilepsy faced setbacks which included harmful medication side effects, teasing and bullying or restrictions at school, it was evident that this caused their parents to feel worried and stressed. Published studies of parenting stress in epilepsy identify the child's functional status and difficult child behaviour correlated strongly with this parental stress (Reilly et al., 2018; Wirrell et al., 2008) and that enhanced social support has been shown to reduce parenting stress (Carlson & Miller, 2017; Rodenburg et al., 2007).

Variability in functioning from day-to-day is typical in children with epilepsy and should be accommodated (Taylor & Besag, 2013). A child with epilepsy can have 'good days' where a teacher will see that the child is available to learning, engages in discussions, appears to make connections, and displays an even temperament. Conversely, a teacher can see a child with epilepsy on a 'bad day' when the student appears to be readily distracted, has forgotten previously learned information, or may be irritable. Teachers with little epilepsy training will assume that a bad day relates to the child's lack of motivation and lack of cooperation. Parents in this research wanted a community epilepsy agency advocate to join them at school team meetings to defend suggestions that their child with epilepsy was lazy or choosing to deliberately misbehave and ignore adult instructions.



An interesting finding in this study, similar to Jones (2019), Pieters (2016) and Shore (1998) was that parents had information needs that they perceived as being out of the realm of the healthcare system including a need to talk with other parents raising children with epilepsy. Over the time period of 36-months, 75% of the parents in this research participated in parent support programs that included peer mentor matches, parent support groups and an on-line private parent site. These interventions provide support based on the sharing of information and experience, mutual counselling and exchange among ‘peers’ (Doull, O’Connor, Welch, Tugwell & Wells, 2005, p. 2). In this research there was strong evidence that parents request support when they encounter a stressor. Dennis (2003) states this is common as parents need to interpret whether the stressor is a harm, threat or challenge. Having social support to help with coping plays a pivotal role in moderating a parent’s response to the stressor, and if the peer reacts calmly, it increases the chances that the stressor will be interpreted more benignly (Dennis, 2003).

Parents in this research requested emotional support seeking expressions of caring, empathy, encouragement and reassurances from Epilepsy Southwestern Ontario staff and veteran parents. These veteran parents shared their learned epilepsy experience which is seen as cathartic, empathetic and genuine. Appraisal support was valued by parents who needed encouragement and reassurance that they can cope and can manage the child’s condition. Informational support was valued by parents assessing different treatment options or needing strategies to manage the child’s behaviour.

### 5.3 Practice Implications

The findings from this research reinforce that parents want information and support to gain seizure freedom not as an end goal but as one important outcome alongside others such as improved emotional, behavioural and school outcomes (Kilinc et al., 2020; Jones et al, 2019; Smith et al., 2014).

The findings of this research align with others who indicate that parent’s may benefit by having an advocate or an intermediary to help with system navigation and school support (Jones et al, 2019; Smith et al., 2014; McNelis et al., 2007).

This research adds to the recommendations made by other researchers that there is a need for comprehensive childhood epilepsy services to include provision for identification and management of child neurobehavioral needs (Jones et al., 2019; Donner et al., 2017, Smith et al, 2014). Parents would benefit from knowing that cognition and behavioral challenges are common in children with epilepsy allowing them to proactively engage support before the child encounters a restriction at school or a human rights violation in the community.

Improved integration of care has been identified as key to improving the quality, safety, and efficiency of health services for persons with chronic diseases. (Fitzsimons, Normand, Varley, & Delanty, 2012, p. 3). Uncoordinated care in epilepsy can lead to fear, inconsistent advice, inappropriate use of health care services (emergency department, hospital), delays in making treatment decisions (special diets, surgery), injury, or the worst case death (SUDEP, drowning).

#### 5.4 Limitations of the Research

The findings in this research are informative but there are limitations. The sample size was small and was not intended to be generalizable to the entire pediatric epilepsy population. Parents who do not have access to community epilepsy agency programs were not included in the analysis nor were there any families who declined community engagement. The parents in this research were mothers so less is known about the nature and extent of father's requests for post-education information and community support. There was no ability to measure the opinions and needs from the perspective of the children and their siblings in this research.

#### 5.5 Future research

Moving forward, empirical research is needed to identify the potential impacts of early connection with community epilepsy agencies on health and social service utilization and their associated costs. Future research should look at the role of community epilepsy agency intermediaries in help parents to navigate the health and education systems. Many researchers have recommended a paradigm shift to family-centered care in

epilepsy. Research is needed to understand how to deliver this family-centered care and the cost benefits of treating the whole person from the time of diagnosis including the neurobehavioral comorbidities in childhood epilepsy. Rigorous trials are needed to measure the impact of the Clinic to Community<sup>®</sup> education and healthcare linkage program on healthcare utilization, epilepsy knowledge, health related quality of life, stigma and social outcomes. Development and evaluation of teacher education materials to improve knowledge of epilepsy and change attitudes related to the administration of rescue medication are also needed.

## 5.6 Recommendation: Family-Centered Care

For families in this research, many of the factors that can reduce health related quality of life including parent stress, parent fears, perceived stigma and academic challenges could potentially be modified through the provision of family-centered care (Kilinc et al, 2020; Jones et al, 2019; Smith et al., 2014; Ferro et al., 2013).

Family-centered care acknowledges that the majority of health decisions are made by the parent within the context of the family and within the community and that parents need health information, skills and tools to manage their child's epilepsy on a day-to-day basis (IOM, 2012). The goal of family-centered care is high quality health outcomes including optimal functional and clinical outcomes for the child and optimal family adaptation.

## 5.7. Conclusion

The findings from this research align with other studies that have identified the family burden of epilepsy goes beyond the management of the seizure and includes the management of fear, stigma, school and the comorbidities. Addressing the physical and mental health care needs of children with epilepsy could minimize the long term negative impact of epilepsy and comorbidities, as more than 50% of children with epilepsy have psychiatric and social problems and higher unemployment rates in adult life (Camfield & Camfield, 2014; Chin et al 2011).

This research provides a composite picture of engagement with a community epilepsy agency from the perspective of a parent supporting a child with epilepsy. The research

focused on the content for information requests and the psychosocial context that led to these requests. A finding from this research is that parents require both healthcare and supportive care. This care can be provided through the Clinic to Community<sup>®</sup> education program which aligns with the Ontario Ministry of Health's quadruple aim which is to move towards an integrated health care delivery model focusing on improvement in patient and caregiver experience; patient and population health outcomes; value and efficiency; and provider experience (Legislative Assembly of Ontario, 2019).

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## Appendices

### Appendix A: Glossary of Terms Used in Thesis

|  |  |
|--|--|
| Co-morbidity                           | The co-occurrence of two conditions with a greater frequency than found in the general population.   |
| Content Analysis                       | A research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use.  |
| Drug refractory                        | Seizures that do not respond to treatment with two or more appropriate trials of anti-seizure medications.   |
| Epilepsy                               | A brain disease characterized by a predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of the condition.          |
| Family-Centered Care                   | An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families.         |
| Health Related Quality of Life (HRQOL) | A multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning.  |
| Self-management                        | Refers to a wide range of health behaviours and activities that a person can learn and adapt to control their seizures and improve their well-being.                                       |
| Stigma                                 | An attribute, behaviour or reputation which is socially discrediting in a particular way; causing an individual to be mentally classified by others as undesirable, rejected, stereotyped. |
| SUDEP                                  | A sudden and unexpected, non-traumatic, and non-drowning death of a person with epilepsy.  |

## Appendix B

### Clinic to Community<sup>®</sup> Curriculum

| Epilepsy Education Check List   | C2C 60 minute slide deck with script   | C2C Strategy Sheet, Booklet or Brochure   |
|---|--|---|
| <b>General epilepsy information</b>   |  |   |
| <input type="checkbox"/> Definition, seizure types, syndromes, potential causes | <p>A diagnosis of epilepsy is given to a person who has 2 unprovoked seizures or 1 seizure with a strong possibility that they will have another, for example, if they have related findings on their EEG and/or a brain abnormality seen on the MRI that is known to cause repetitive seizures.</p> <p>Types of seizures: focal, generalized, absence and tonic clonic</p> <p>It is very normal to want to know ‘why’ someone has seizures. Anything that can harm your brain can cause it to have seizures. Some of the common causes of epilepsy begin at birth but seizures can begin at any age. They may be the result of an infection like meningitis or encephalitis or a lesion in the brain. It may be caused by a stroke or a head injury or accident. Alcohol withdrawal or alcohol abuse can cause seizures. Epilepsy can be genetic or metabolic.</p> <p>Unfortunately, for some people we do not know why they have epilepsy.</p> | <input type="checkbox"/> Types of seizures Strategy Sheet<br><input type="checkbox"/> Lobes of the Brain/Functions Strategy Sheet<br><input type="checkbox"/> Talking about your Epilepsy Strategy Sheet<br><input type="checkbox"/> Glossary of Terms and Definitions  |
| <input type="checkbox"/> Explanations of investigative procedures               | <p>Your child may have had an EEG. The EEG wires were pasted to their head and the technician recorded brain waves on their computer. A specialist then looked at the recording to see if there were any noticeable spikes or waves. Although the EEG is a good tool to help with identifying ‘red flags’ it often does not give the doctor/nurse all of the information that they need. This is because the brain may show a normal EEG when it is not having an actual seizure. For this reason your doctor/nurse may recommend a longer brain recording called a Video EEG. The Video EEG involves continuous monitoring of brain activity over a longer period of time.</p>  | <input type="checkbox"/> EEG and VEEG Strategy Sheet<br><input type="checkbox"/> Scalp EEG Leads in Epilepsy Monitoring Unit<br><input type="checkbox"/> Intracranial Electrode Implantation<br><input type="checkbox"/> Epilepsy Monitoring Unit at LHSC<br><input type="checkbox"/> Epilepsy Program at Children’s Hospital Strategy Sheet<br><input type="checkbox"/> Complimentary Therapies Strategy Sheet |

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|  | <p>The most effective way for your health care provider to make a diagnosis of epilepsy and to understand ‘why’ your child has seizures is by asking a lot of questions about what happens before, during and after the seizure(s). The doctor/nurse is asking these questions because they are trying to identify where the seizure begins in the brain. Does it begin in one part of the brain like a focal seizure? Do the eyes or head move in a certain direction? Taking a personal history is an important way to understand more about how to treat epilepsy.</p>  |  |
| <input type="checkbox"/> Prognosis         | <p>The good news is that epilepsy is a very treatable condition. Many children outgrow their seizures and 70% will get their seizures controlled with one or more medications.</p>   | <input type="checkbox"/> Comorbidities Strategy Sheet  |
| <input type="checkbox"/> Treatment options | <p>If you have had an appropriate trial of 2 medications and they have not stopped the seizures it is important that you talk to your health care provider about other treatment options.</p> <p>If medication is not stopping the seizures it is important that you get a referral to London Health Sciences Centre where they have a team of epilepsy specialists who will work with you and your family. These specialists can offer different treatments including special diets, Vagus Nerve Stimulation (VNS) and surgery.</p>   | <input type="checkbox"/> Surgery Strategy Sheet<br><input type="checkbox"/> Medication Strategy Sheet<br><input type="checkbox"/> Ketogenic Diet Strategy Sheet<br><input type="checkbox"/> Treatment Pathways |
| <input type="checkbox"/> Seizure Diary     | <p>To make seizures more predictable, we ask that you use a seizure log to record what happens before, during and after your child has a seizure.</p> <p>In your seizure log write down what is happening in your child’s day when they have a seizure. Was the child ill? Did they have a fever? Did they miss a meal or forget to take their medication? Were they taking other medications or vitamins? Were they up all night watching TV or at a sleepover? Were they stressed about an exam or excited about an upcoming event? The answers to these questions can provide valuable information to your clinician.</p> | <input type="checkbox"/> Seizure Log provided to every client<br><input type="checkbox"/> Planning for your Health Care Appointment Strategy Sheet   |
| <b>Medications</b>                         |  |  |
| <input type="checkbox"/> Choice of drug    | <p>There are also other treatments available if the first two medications do not stop the seizures.</p>  |  |

|   |   |   |
|---|---|---|
| <input type="checkbox"/> Side effects   |   | <input type="checkbox"/> Medication Strategy Sheet  |
| <input type="checkbox"/> Compliance   | If your doctor/nurse has provided you with a treatment plan to get the seizures under control - it is important that you follow the plan. If your child cannot tolerate the medication – call your healthcare provider (doctor, nurse). If the side effects are not acceptable to you and your child, document them and call your health care team. Do not stop the medication without speaking to your health care team. | <input type="checkbox"/> Medication Strategy Sheet  |
| <input type="checkbox"/> Drug Interactions  |   | <input type="checkbox"/> Medication Strategy Sheet  |
| <input type="checkbox"/> Missed and sudden cessation of medications   | Take medication at the same time – every day.   | <input type="checkbox"/> Medication Strategy Sheet  |
| <input type="checkbox"/> Medication subsidies/drug plans  |   | <input type="checkbox"/> Drug Benefit Programs Strategy Sheet                                   |
| <input type="checkbox"/> Rescue medications   |   |   |
| <b>First Aid</b>  |   |   |
| <input type="checkbox"/> General first aid information  | Seizures can be frightening because they often happen without warning. The good news is that they are rarely medical emergencies. They are also very common. In fact, 1 in 10 people will have a single seizure in their life. Today we will talk about what you should do if your child has a seizure.   | <input type="checkbox"/> First Aid Bookmark<br><input type="checkbox"/> Seizure First Aid Video |
| <input type="checkbox"/> When a seizure is a medical emergency  | We will also talk about when to call 9-1-1.<br>If it is a first-time seizure.<br>If a seizure is over 5 minutes or if it continues to repeat in an “on and off” manner.<br>If it occurs in water.<br>If the person is pregnant.<br>If the person has diabetes - a person with diabetes may experience a seizure as a result of high or low blood sugar levels.<br>If the person is injured during the seizure.            |   |
| <b>Women and Epilepsy Issues</b>  |   |   |
| <input type="checkbox"/> Contraception, preconception, pregnancy and breastfeeding, pregnancy registry, menopause | Included in youth script  | <input type="checkbox"/> Women’s Health Strategy Sheet  |
| <b>Lifestyle</b>  |   |   |
| <input type="checkbox"/> Diet   | Importance of eating well   |   |



|   |   |   |
|---|---|---|
| <input type="checkbox"/> Exercise                 | Play sports and exercise  | <input type="checkbox"/> Physical Activity in Epilepsy Strategy Sheet   |
| <input type="checkbox"/> Sleep                    | Consistent and regular sleep  |   |
| <input type="checkbox"/> Alcohol, substance abuse | <p>Included in youth script:<br/>If you drink alcohol, use <b>moderation</b> and <b>drink slowly!</b></p> <p>Research indicates that persons with epilepsy may have one or two alcoholic drinks without worsening their seizures or causing changes in the blood levels of their seizure medications.</p> <p>Moderate to heavy alcohol use is never recommended for persons with epilepsy. Alcohol and some seizure drugs have similar side effects. Using both at the same time can lead to potentially dangerous problems.</p> <p><b>Avoid binge drinking</b> – Alcohol usually does not trigger seizures while the person is drinking. “Withdrawal” seizures may occur 6 to 72 hours later, after drinking has stopped.</p> <p><b>Be informed</b> - We can provide you with a strategy sheet about alcohol, seizures and safety.</p> |   |
| <input type="checkbox"/> Driving regulations      | <p>In the youth script:<br/>In Ontario, <u>physicians</u> are required under law to report anyone 16 years and older – regardless of whether or not they have a license - if they believe they are not able to safely drive.</p> <p>What you should know is that you may drive with a seizure disorder/epilepsy in Ontario <b>IF</b>:<br/>Medication appears to have prevented your seizures <b>AND</b> you have been seizure-free for 6 months and your medication does not impair your consciousness.</p> <p>This is one of <b>many good reasons</b> to manage your medication and follow the treatment plan that you were given by your health care team.</p> <p>I can provide you with a strategy sheet for <i>Epilepsy and Driving</i> in Ontario. This sheet provides details on how to get a license reinstated in Ontario.</p>  | <input type="checkbox"/> Epilepsy and Driving in Ontario Strategy Sheet |
| <input type="checkbox"/> Employment               | <p>Included in youth script:<br/>Both the Canadian and the Ontario Human Rights Code state that employers must</p>  | <input type="checkbox"/> Epilepsy and Employment Strategy Sheet         |

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|---|--|---|
|   | <p>accommodate people with a disability (epilepsy is recognized as a disability) <b>UNLESS</b> the disability interferes with performing essential duties of the job (for example driving a bus or flying a plane). Many people do not require any accommodation at work, while others may require accommodations to help them avoid triggers, ensure they remain safe if they have a seizure on the job, or help them adapt to seizure or medication side effects. Workplace accommodations for epilepsy are <u>inexpensive, easy to make, and only require creativity and flexibility</u>. If you have any concerns about your employment or if you feel you need help getting your employer to understand or accommodate your epilepsy – we are here to help.</p> <p>We also can provide a strategy sheet called: <i>Epilepsy and Employment</i> which includes a chart with the advantages and disadvantages of telling your employer about your epilepsy diagnosis.</p> | <input type="checkbox"/> Employment Disclosure Chart  |
| <input type="checkbox"/> School                                     | <p>We can meet with your child's teacher to help them to understand epilepsy. We also offer classroom presentations for children of all ages. We have taught over 35,000 children about epilepsy and what to do if their classmate has a seizure.</p>  | <input type="checkbox"/> Student Support Program Strategy Sheet<br><input type="checkbox"/> Learning Challenges Strategy Sheet<br><input type="checkbox"/> Epilepsy and ADHD Strategy Sheet |
| <b>Safety and Risk Factors</b>                                      |  |   |
| <input type="checkbox"/> Injury prevention at home and in community | <p>If the child has seizures during sleep you can purchase a baby monitor or a video monitor to allow them to sleep in their own room and for you to sleep comfortably in yours.</p> <p>Here are some tips for night time safety:<br/> Choose a foam pillow, not a feather pillow.<br/> Do not sleep in a water bed.<br/> Take your medications as prescribed by your doctor/nurse.</p> <p>Here are some tips to keep your child safe in water:<br/> Set water temperature in your house low so that your child will not be burned if they accidentally hit the hot water tap.<br/> Stay in the bathroom when your child is in the bath.<br/> Always supervise a child when they are swimming.</p>   |   |

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|--|--|--|
|  | If your child is a teen, they should take showers and not bathe. To respect their privacy – hang an ‘occupied sign’ on the outside of the bathroom door instead of locking the door.   |  |
| <input type="checkbox"/> Sudden Unexpected Death in Epilepsy (SUDEP) | <p>Research tells us that families will leave the doctor’s office and go to the internet for more information. On the internet you may read about Sudden Unexplained Death in Epilepsy (SUDEP). The rates of SUDEP in children are very low.</p> <p>It is important for you to work with your healthcare provider to find the best way to treat your child’s seizures and identify any seizure triggers. If you find yourself worrying about the risk of SUDEP and how best to balance the need to keep your child safe with the need to encourage your child’s growth and independence, speak to a member of your healthcare team for support.</p> <p>In the youth script:<br/>The strongest risk factor for SUDEP is having frequent generalized tonic-clonic seizures at night. The more frequent the seizures are the higher the risk. The best way to reduce the risk of SUDEP is to have as <b>FEW SEIZURES AS POSSIBLE</b>.</p> | <input type="checkbox"/> SUDEP Aware Brochure(s)   |
| <input type="checkbox"/> Medic Alert Jewellery                       |  | <input type="checkbox"/> Medic Alert Jewellery Brochure  |
| <b>Possible Psychosocial Consequences</b>                            |  |  |
| <input type="checkbox"/> Perceived Stigma                            | Most people do not know very much about epilepsy and seizures, and the first seizure is often so scary. Our role is to provide you with the information you need to feel comfortable parenting a child with the diagnosis. It is also to help your child to live a normal, happy life.   |  |
| <input type="checkbox"/> Memory loss                                 | Epilepsy is a brain disorder, and the brain controls the way we think, act and behave. If you feel that your child is having problems at school with learning, memory, attention or with behaviour (hyperactivity or impulsivity) – please contact us....we are here to help.  | <input type="checkbox"/> Epilepsy and Memory (Children) Strategy Sheet<br><input type="checkbox"/> Epilepsy and Memory (adult) Strategy Sheet<br><input type="checkbox"/> Helping Children with Organization and Planning Strategy Sheet |
| <input type="checkbox"/> Depression                                  | Epilepsy is a brain disorder and the brain controls the way we feel. There is a higher risk of depression in children with this brain condition (22%). If you feel that your child is overly sad or extremely angry – it is important for you to   | <input type="checkbox"/> Epilepsy and Depression Strategy Sheet  |

|  |  |   |
|--|--|---|
|  | <p>discuss this with me or a member of your health care team. It could just be a normal part of their development, or something that we need to further investigate.</p> <p>In the youth script: administer the NDDI-E a 6 item questionnaire that allows for rapid identification of major depression in epilepsy. NDDI-E scores above 15 are considered positive for depression. If a client scores above 15 we should advise them to speak to their health care provider. We can also tell them that we will be sending a note to their health care provider.</p> |   |
| <input type="checkbox"/> Anxiety   | Anxiety is more common as well (35%).  | <input type="checkbox"/> Epilepsy and Anxiety Strategy Sheet  |
| <input type="checkbox"/> Sexual Difficulties*<br>*not covered in C2C program |  |   |
| <input type="checkbox"/> Low self-esteem                                     | Here are some famous people who have epilepsy.<br>(Neil Young, Danny Glover, Lil Wayne, Leonardo Da Vinci, Prince, Thomas Edison, Florence Griffith Joyner, Derek Morris, Clay Aiken, Charles Dickens)   |   |
| <b>Community Supports</b>  |  |   |
| <input type="checkbox"/> Discussion about Community Epilepsy Agency          | You and your family are not alone. Epilepsy affects 95,000 people in Ontario. It is the most common brain condition in childhood. In every school there are other children with epilepsy. It is estimated that 1 in every 100 school aged children has epilepsy. Epilepsy does not need to become a barrier at school or in the community – but if it does – we are here to help.  | <input type="checkbox"/> Epilepsy Southwestern Ontario Agency Brochure  |
| <b>Other Topics Covered in C2C Program</b>                                   | If epilepsy is causing you and your family financial hardship –we can provide a list of available resources and programs. I have a list of drug programs, disability programs and tax benefits that may fit your situation. We can also help you to find and complete many government forms.   | <input type="checkbox"/> Life Insurance and Epilepsy Strategy Sheet<br><input type="checkbox"/> Seizure Response Dogs Strategy Sheet<br><input type="checkbox"/> Financial Support (EI, Sickness Benefits, Ontario Works, ODSP, CPP Disability Benefits, RDSP, tax credits) Strategy Sheet<br><input type="checkbox"/> Psychogenic Non-Epileptic Seizures |

## V. Patient Education and Counseling

### Patient Education

Once a diagnosis of epilepsy is made, patients and their families will have questions concerning this diagnosis and how it will affect their lives. The lack of knowledge increases the level of felt stigma and negative attitudes about the condition (Austin, Carr, & Hermann, 2006). It is the responsibility of the health care provider to ensure that patients and their families are provided with clear, accurate and timely information about their condition and how they can access needed resources as this affects long-term adjustment to the condition (Institute of Medicine [IOM], 2012). Education and counseling needs will vary across the lifespan.

#### Children and adolescents:

- Managing seizures at school, common learning problems, safety, participation in extracurricular activities
- Dealing with fears (e.g.: future, death, mental health conditions, stigma)
- School and vocational planning
- Establishing healthy habits, drugs, and alcohol
- Transition to adulthood (e.g.: independence, driving, sexuality)
- Impact on family dynamics

#### Adults:

- Career and vocational concerns
- Discussions with employers
- Driving regulations and transportation concerns
- Sexual and gender-specific topics, such as reproductive health and family planning, hormonal changes and seizure frequency, effects of seizure medications on pregnancy
- Drug-alcohol interactions
- Impact on relationships and family dynamics
- Independent living

#### Seniors:

- Medication side effects, adverse interactions, and adherence
- Drug-alcohol interactions
- Independent living
- Safety and injury risks

## Epilepsy Education Check List

This checklist can be used by both patients and healthcare professionals to ensure that patients and their families have the information they need. Ideally, this information can be shared in a timely manner. The information checklist may be revisited if new concerns develop (IOM, 2012). Healthcare providers may discuss the topics listed below based on their clinical judgement.

### *General epilepsy information*

- Definition, seizure types, syndromes, potential causes
- Explanation of investigative procedures
- Prognosis
- Treatment options
- Seizure diary

### *Medications*

- Choice of drug
- Side effects
- Compliance
- Drug interactions
- Missed and sudden cessation of medications
- Medication subsidies/drug plans
- Rescue medications

### *First Aid*

- General first aid information
- When a seizure is a medical emergency

### *Women and Epilepsy Issues*

- Contraception
- Preconception
- Pregnancy and breastfeeding
- Pregnancy registry
- Menopause

### *Lifestyle*

- Diet
- Exercise
- Sleep
- Alcohol, substance abuse
- Driving regulations
- Employment
- School

### *Safety and Risk factors*

- Injury prevention at home and in community
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Medic Alert jewellery

### *Possible psychosocial consequences*

- Perceived stigma
- Memory loss
- Depression
- Anxiety
- Sexual difficulties
- Low self-esteem

### *Community Supports*

- Discussion about Community Epilepsy Agency
- Call 1-866-Epilepsy or find list of local agencies at [www.epilepsyontario.org](http://www.epilepsyontario.org)

## Role of Social Worker

Following discussion with the patient/family, referral to a social worker (where one is available) may be appropriate. The social worker can provide counseling and assist the patient/family with navigating community resources.

## Role of Social Worker and Community Epilepsy Agency

Epilepsy is not just a seizure disorder but one that is known to be associated with major psychosocial challenges (Jacoby, Baker, Steen, Potts, & Chadwick, 1996). Caregivers and patients report high satisfaction with having someone on the care team that is more accessible and who has the capacity to advocate on their behalf (Scottish Intercollegiate Guidelines Network [SIGN], 2003).

A Community Epilepsy Agency can:

- Provide epilepsy education and first aid training to family, friends, employers and other relevant groups.
- Provide counseling for anxiety/depression, stress management, problem-solving; self-esteem etc.
- Facilitate connection to peer supports and support groups based on needs identified.
- Advocate for patients and their families at schools, workplaces and other community agencies where they are experiencing stigma and discrimination relating to epilepsy.
- Assist patients with accessing and navigating community resources (apply for disability, respite, Trillium Drug Program etc.).

Where there is no local agency, Epilepsy Ontario can provide this support. Contact information of the Community Epilepsy Agencies in Ontario is listed in Appendix 4.



Coordinated Care for People with Epilepsy

clinictocommunity.ca  
info@clinictocommunity.ca

## Pediatric Neurology Referral Form

Please fill out and return to Epilepsy Southwestern Ontario:

E-mail: info@clinictocommunity.ca

Phone (519-433-4073) Fax (519-433-4079)

Mail (797 York St., Unit 3 London, ON, N6H 4V3)

Referral Date: \_\_\_\_\_ Guardian Name: \_\_\_\_\_

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Postal Code: \_\_\_\_\_ E-mail: \_\_\_\_\_

Phone: \_\_\_\_\_ Seizure Type(s): \_\_\_\_\_

**Reason For Referral** (check all that apply):

- |   |  |
|---|--|
| <input type="checkbox"/> New Diagnosis / Coping Strategies      | <input type="checkbox"/> School/ Workplace Support |
| <input type="checkbox"/> Seizure Education / First Aid Training | <input type="checkbox"/> Children's Programming    |
| <input type="checkbox"/> Parent and Family Support              |  |
| <input type="checkbox"/> Other _____                            |  |

Referral Made By: \_\_\_\_\_ Neurologist: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Consent to Contact (client / guardian signature): \_\_\_\_\_





## Appendix E

**Characteristics of Children in the Research**

| Gender | Age 1 <sup>st</sup> Seizure | Age at C2C Education (years/months) | Comorbidities  | Seizure Types              | School Support | Parent Support |
|--------|-----------------------------|-------------------------------------|--|----------------------------|----------------|----------------|
| Male   | 9 months                    | 3.2                                 | Intellectual Disability (ID)   | Focal                      | Yes            | Yes            |
| Male   | 9.3 years                   | 9.7                                 | Anxiety  | GTC                        | Yes            | Yes            |
| Male   | 4 years                     | 8.2                                 | Learning Challenges (LC), Behaviour  | Focal<br>GTC               | Yes            | Yes            |
| Male   | 7 months                    | 5.3                                 | Anxiety, obsessive compulsive disorder (OCD), oppositional defiance disorder (ODD), aggression | Absence, GTC, Drop Attacks | Yes            | Yes            |
| Male   | 1.1 years                   | 2.8                                 | ID, Behaviour  | GTC                        | Yes            | Yes            |
| Male   | 4 years                     | 5.6                                 | None   | Focal, GTC                 | Yes            | Yes            |
| Female | 5 months                    | 6.4                                 | LC, Behaviour  | GTC                        | Yes            | No             |
| Female | 11 months                   | 3.7                                 | LC, Behaviour  | Absence<br>GTC             | Yes            | Yes            |
| Female | 7.4 years                   | 7.6                                 | None   | Absence<br>GTC             | Yes            | No             |
| Female | 3 months                    | 10.3                                | ID   | GTC                        | Yes            | No             |
| Female | 6 months                    | 2.7                                 | ID   | GTC                        | Yes            | Yes            |
| Female | 2.6 years                   | 3.8                                 | Behavioural  | Absence<br>GTC             | Yes            | Yes            |
| Male   | 2 years                     | 7.3                                 | ID, ADHD, Behavioural  | Absence<br>Focal           | Yes            | Yes            |
| Male   | 5.6 years                   | 7.3                                 | LC   | Absence, GTC               | Yes            | Yes            |
| Female | 1 year                      | 10                                  | None   | Absence, GTC               | No             | No             |
| Female | 1 month                     | 3.8                                 | ID   | Focal                      | Yes            | Yes            |
| Female | 10 months                   | 4.3                                 | ADHD, LC, Behaviour  | Absence, GTC               | Yes            | Yes            |
| Female | 1.1 years                   | 5.3                                 | ID   | GTC                        | No             | Yes            |
| Male   | 1.7 years                   | 6                                   | ID   | Focal, GTC                 | Yes            | Yes            |
| Male   | 5.2 years                   | 5.3                                 | None   | GTC                        | Yes            | No             |

GTC – Generalized Tonic Clonic seizures.

**CLINIC TO COMMUNITY NEW CLIENT FORM**

|   |   |                       |
|---|---|-----------------------|
| <b>Clinic to Community Educator:</b>  | <b>Referral Date:</b>   | <b>Referral Type:</b> |
| <b>Client ID:</b>   | <b>Consent for Further Contact:</b><br><input type="checkbox"/> Yes <input type="checkbox"/> Research Consent<br><input type="checkbox"/> No <input type="checkbox"/> Research Assent<br><input type="checkbox"/> OTF |                       |
| <b>PERSONAL INFORMATION</b>   |   |                       |
| Name of Person with Epilepsy  | DOB Person with Epilepsy<br><i>Day/Month/Year</i>   |                       |
| Home Address (Street, City, Postal Code)  |   |                       |
| Telephone   | Email   |                       |
| Gender<br><input type="checkbox"/> Male <input type="checkbox"/> Female   |   |                       |
| Person with Epilepsy Living Arrangements<br><input type="checkbox"/> Alone <input type="checkbox"/> Spouse/Partner<br><input type="checkbox"/> With Parents <input type="checkbox"/> Other  |   |                       |
| First Language of the Person with Epilepsy<br><input type="checkbox"/> English <input type="checkbox"/> Other (please list)   |   |                       |
| Name of Caregivers- Parents, Grand Parents and Siblings etc<br><input type="checkbox"/> Parent <input type="checkbox"/> Other Family member<br><input type="checkbox"/> Spouse/Partner <input type="checkbox"/> Non Family member |   |                       |

## CLINIC TO COMMUNITY NEW CLIENT FORM

| EPILEPSY INFORMATION  |  |
|---|--|
| Approximate Date of First Seizure<br><i>Month/Year</i>  | <input type="checkbox"/> Unknown   |
| Approximate Date of Epilepsy<br>Diagnosis<br><br>Month/Year:<br>_____<br><br>Diagnosed by:<br>_____   | <input type="checkbox"/> I have not been diagnosed with<br>epilepsy<br><br><input type="checkbox"/> I have had a single seizure  |
| Type of Seizure(s) &/or Classification<br><br><input type="checkbox"/> Absence<br><br><input type="checkbox"/> Focal<br><br><input type="checkbox"/> Partial<br><br><input type="checkbox"/> Generalized Tonic-Clonic | <input type="checkbox"/> To Be Determined<br><br><input type="checkbox"/> Unsure<br><br><input type="checkbox"/> I Do Not Know<br><br><input type="checkbox"/> Other (please list) |
| Date Attended the C2C In-service<br><i>Day/Month/Year</i>   |  |
| Type/Location of In-service?<br><input type="checkbox"/> Individual Session<br>Location:<br>_____   | <input type="checkbox"/> Group Session<br>Location:<br>_____   |
| Instructed on how to use a seizure<br>record?<br><input type="checkbox"/> Yes   | <input type="checkbox"/> No  |

## CLINIC TO COMMUNITY NEW CLIENT FORM

| COMORBIDITIES  |   |
|--|---|
| <input type="checkbox"/> Intellectual<br><br><input type="checkbox"/> Depression<br><br><input type="checkbox"/> ADHD            | <input type="checkbox"/> Learning Challenges<br><br><input type="checkbox"/> Behavioural<br><br><input type="checkbox"/> Other:<br><hr style="width: 100%;"/> |
| REFERRAL TYPE  |   |
| <input type="checkbox"/> Direct Referral<br><input type="checkbox"/> Indirect Referral<br><input type="checkbox"/> Self Referral | Notes: <i>(ie. Internet self referral)</i><br>Name of Specialist:   |
| <input type="checkbox"/> Family Health Team  | Name/ Location:   |
| <input type="checkbox"/> Community Neurologist   | Name:   |
| <input type="checkbox"/> Community Pediatrician  | Name:   |
| <input type="checkbox"/> Community Care Access Centre (CCAC)/ Community Health Centre  | Name/Location:  |
| <input type="checkbox"/> Public Health Unit  | Name/ Location:   |
| <input type="checkbox"/> Emergency Department  | Name/ Location:   |
| <input type="checkbox"/> First Nations   | Name/ Location:   |
| <input type="checkbox"/> Other   | Notes:  |

## CLINIC TO COMMUNITY NEW CLIENT FORM

I would like help with/information about:

|   |  |
|---|--|
| <input type="checkbox"/> Surgery<br><input type="checkbox"/> Mental Health<br><input type="checkbox"/> Epilepsy/Seizure Information<br><input type="checkbox"/> Social Relationships<br><input type="checkbox"/> Memory<br><input type="checkbox"/> Employment<br><input type="checkbox"/> Public Education<br><input type="checkbox"/> Volunteer Opportunities | <input type="checkbox"/> Peer and Support Networks<br><input type="checkbox"/> Referral (Government Forms)<br><input type="checkbox"/> School Advocacy<br><input type="checkbox"/> Transportation<br><input type="checkbox"/> Disclosure/Anxiety around Disorder<br><input type="checkbox"/> Medication<br><input type="checkbox"/> Safety<br><input type="checkbox"/> Other _____ |
|---|--|

|  |   |
|--|---|
| <input type="checkbox"/> C2C Website Login<br>Date Assigned: | Username: education1<br>Password: education |
|--|---|

Comments/Follow up:

|  |  |
|--|--|
| <input type="checkbox"/> C2C In Service Educator Follow up (Email/Phone)<br><input type="checkbox"/> Date of Follow up : _____ |  |
|--|--|



Epilepsy  
Support  
Centre

Epilepsy Support [REDACTED]

from [REDACTED]

2 messages

8 May 2015 at 18:33

Hi [REDACTED]

Hope the two of you had a good weekend!

The school has cancelled the team meeting. The school is willing to have a meeting to listen on how epilepsy affects learning/academics. We really will need to push on why [REDACTED] needs an IEP or he will not get it even though he is struggling with reading/language and printing. He is just finishing up a grade 1 reading level and will be going into grade 3 in September. I will bring with me on Thurs., May 14th a copy of the Woodcock Johnson III testing and his report card from February. Dr. [REDACTED] when we saw him in April thought that [REDACTED] should be on an IEP and asked why he was not especially because of the type of seizures he has is frontal lower lobe and affects learning. Also [REDACTED] has issues with focusing and attention which is part of the epilepsy.

The school is [REDACTED] London

The meeting that works for the school is Wed., June 10th at 10:25 a.m. I need to know if someone can come to the school with me as I need to book the time off work to do this. Also the school needs confirmation that this date and time will work.

I do know someone where their child has A & B's and has an IEP and it is at their school. The parents had no issues getting it.

I hope that we will get somewhere.

Thanks for your help!

Any other thoughts that would help please let me.



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**Your Xerox WorkCentre 7845 Scan**

7 July 2015 at 15:32

[Redacted]

Hi [Redacted]

Sorry for the delay - finally had some time this afternoon to go over [Redacted] proposed IEP.

I have attached it with my questions written on it, to this email.

I would suggest sending an email to the principal to meet and discuss these or any of your questions prior to signing it, because it would all depend on your comfort level. You also have the ability to request a IPRC review, as outlined in this link:

<http://www.peopleforeducation.ca/faq/what-should-i-know-about-an-iprc-meeting/>

Which would make this entire document much more official and accountable for all involved.

Please let me know your thoughts?

Thank You,

[Redacted]



[Redacted]

Epilepsy Support Centre, 690 Hale St., London, ON, N5W 1H4  
Tel: 519.433.4073 x 205 | Fax: 519.433.4079 | Cell: 226.376.5495  
Sarnia: 519.330.0416 | Chatham: 519.365.5131 | Windsor: 519.890.6614

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[Quoted text hidden]

**Your Xerox WorkCentre 7845 Scan.pdf**



---

from [REDACTED] - RE: [REDACTED] Education

---

[REDACTED]  
[REDACTED]  
15 September 2015 at 21:24

Hope all is well!

Tonight's talk at the support meeting was very interesting.

Question for you:

We have had a tutor-Tom for a year for [REDACTED] reading. He told us on the weekend he feels that [REDACTED] has reached a plateau at his reading and what should he be doing now. He asked me to send a note to his teacher whom is the same teacher from last year that you met. [REDACTED] is a year behind his classmates. The tutor is taking a break for the rest of September and for me to contact him in October if we still need him. What do you think? You read his IEP on what he will be getting at school. Do you think he still needs a tutor on top of that? I was surprised at the tutor's comments.

Your input is greatly appreciated.

[REDACTED]



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---

[REDACTED]  
[REDACTED]  
17 September 2015 at 09:54

If [REDACTED] only a year behind in reading, then that is really not the end of the world whatsoever. Especially with how easily kids close gaps at this age.

From a cost perspective, I'd say see how things go without him for a bit and if you can continue to keep [REDACTED] motivated to read on his own without Tom removing his choice by actually physically tutoring him.

All children should read for enjoyment, regardless of ability, because literacy provides the foundation for later





from [REDACTED]

[REDACTED]  
6 November 2015 at 16:35

Hi [REDACTED]

Hope all is well!

Question for you. On [REDACTED] report it says that he has trouble with attention and focusing which I know that it goes with epilepsy. Is there anything that you know that could help the teacher with this?

Much appreciate your help.

[REDACTED]



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[REDACTED]  
11 November 2015 at 16:12

Hi [REDACTED]

I have attached our Epilepsy: Guide For Teachers booklet in PDF. As long as you're able to have a discussion with the teacher and ensure she is aware that this is a common challenge for individuals with epilepsy, and not a behavioural choice, she should be patient and understanding and have the skills to manage accordingly through teacher training and experience.

I have also attached a resource on how people with epilepsy learn, I can't recall off the top of my head if you have it or not yet so I want to make sure you have it.

Thank You,

[REDACTED]



from [REDACTED]

[REDACTED]  
[REDACTED]  
[REDACTED]  
11 November 2015 at 16:37

I was talking to Mrs. [REDACTED] (teacher) about [REDACTED]. He is having problems in the afternoon not wanting to do math, french, etc. or focusing. She feels if he could focus better he could do better in math and she is seeing a behavior of pouting, talking, singing, etc. She is wondering if you could go to the school in the afternoon at some point and observe [REDACTED] and give her some strategies to help her out. Would this be possible for your schedule to allow this? If so she would like a couple of dates that work for you.

Also he is not sleeping well. He does not fall asleep until 11:00 a.m. and will wake up at 2:00 a.m. Is this normal?

I will send the information that you gave me tomorrow to the school.

Thanks for all your help!

[REDACTED]



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Epilepsy  
Support  
Centre

from [REDACTED]

[REDACTED]  
[REDACTED]  
11 February 2016 at 07:34

Just wanted to let you the school complaints before the meeting and hopefully [REDACTED] can come.

They are complaining that he cannot focus, his behavior has become a flight risk, he is immature and no kids like him in the class. [REDACTED] hates school. Also he is whinning. Also if he has bad behavior at school we should be taking things away from him at home. Also if he could focus more he would not have to be on an IEP.

Hope to have the letter soon from neuropsychology.

Thanks for all your help.

[REDACTED]

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[REDACTED]  
[REDACTED]  
11 February 2016 at 12:48

I had the opportunity to speak with Dr. [REDACTED] about the comments on [REDACTED] teacher. She told me once the results are released to the school that they will understand more. She feels that the teacher is not understanding [REDACTED] medical and academic issues and this is showing up in behaviors with struggles. We should have the letter by early next week as it has been mailed to me.

Thank you so much for everything!

[REDACTED]

This email has been sent from a virus-free computer protected by Avast.



[REDACTED] neuropsych assessment report


15 February 2016 at 18:36

hello,

please find a copy of [REDACTED] neuropsych assessment report for your information.

[REDACTED]

This email has been sent from a virus-free computer protected by Avast.  
www.avast.com

 **neuropsych assessment report.docx**  
6321K

17 February 2016 at 10:29

Thanks for sharing this - this is a great report in terms of breaking down for the school exactly where [REDACTED] has been struggling and what needs to be done in order to help him improve.

In terms of the social issues reported, have you given much thought to evening and weekend programs that [REDACTED] might be interested in as well as his attending of Game On? Game On is scientifically validated as a way of improving his physical literacy skills in regards to his balance and movement and confidence in it, and I am wondering if there are other programs he might be interested in checking out that would appeal to someone of his age group and interests? Whether it be a sport, or cooking class, or some sort of social activity. Two great resources I have discovered have been the spectrum, which are low cost City of London recreation programs broken down by age groups:

<http://www.bluetoad.com/publication/?i=289368&p=&pn=>

and Presidents Choice has cooking classes for kids that are broken down by age group and by subject that he might find interesting and have a good opportunity to practice a wide range of useful skills that engage his reasoning and logic abilities, as well as math skills and fine motor skills and building overall confidence when he gets to taste his finished product:

<http://www.pccookingschool.ca/LCLOnline/cookingSchool.jsp?catId=cat180015&type=browse&>



from [REDACTED]

2 messages

5 April 2016 at 22:02

[REDACTED]  
[REDACTED]  
Here are my answers to the school form:

[REDACTED] strengths:

He loves nature ex. being outside, planting, sweeping leaves, watering plants without being asked. He loves to play hockey, skate, swim, biking, riding his scooter. He loves to cook your something like breakfast, but will ask for your order and write it down in his book. He does chores without being asked to do it. He loves his computer and electronic games. He is also very imaginative in play. Plus he loves music.

Short term goals:

His academic goals will be to try to work more independently with given times by setting a goal. Work on a subject for 10 minutes and keep increasing it. I would recommend putting him in a grade 3/4 split if at all possible. Also when doing a seating arrangement put him beside another student who does not have a lot of behavioral issues and does not talk a lot plus likes to do his/her work. He will need a lot of repetition on his work plus make sure that it is broken down in chunks/sections for [REDACTED] to be able to do his work academically. For his focusing issues I can get the school a bottle of salt in a glass and when it is empty that is when he can stop. He will need extra breaks as he gets tired quicker then other kids. If possible to do harder subjects in the morning and easier courses in the afternoon like music, physical education, library class, etc.

Once [REDACTED] receives his computer in the classroom I would give him the job of turning it off and shutting it down everyday. You can also give him some other jobs like hand out assignments, or giving the secretary the class' attendance.

Socially I would have him work in small groups with other students. If possible I would have him speak to [REDACTED] to help him with his social skills or to use the behavioral special team assessment. For recreational he will be given him some choices of doing hockey again, soccer or tennis. He has expressed an interest to play on the school's hockey team. He will also do game on through the epilepsy team. He also wants to do music lessons on playing the piano.

His environmental planning will be having the computer in his classroom so he can work more independently without struggling and learn more. Also the air conditioner will have to move to his new classroom. We will have follow-up assessments with Dr. [REDACTED] who will monitor his EEG, MRI and medication to see how his epilepsy is doing.

As the parents of [REDACTED] we would like to see a couple of times a year on how he is progressing with the use of the programs on the computer. We will enroll him in the keyboarding class at the London Learning Disabilities Association so he is comfortable using the computer.

We would like a meeting with the new teacher to explain to her/him how [REDACTED] epilepsy affects his learning. Also how any colds, dizziness, sleep etc. affects him. Also if the teacher decides she wants to inform the class that [REDACTED] has epilepsy we would prefer him/her to contact us and would like the epilepsy team to come to the class to do a presentation on it which is free to the school through the epilepsy team.

#### Long-Term Goals:

Is to push the electronics for the future. To see what he is good at and prepare him to go that route for high school and beyond. Our hope is also that he would be able to focus for longer periods of time.

Let me know what you think.

Thanks for all your help!

[REDACTED]

Virus-free. [www.avast.com](http://www.avast.com)

7 April 2016 at 14:46

Hi [REDACTED] I think you nailed it on the head here. I think maybe including in the meeting with the new teacher the discussion of the topic of successful behavioural management/discipline strategies used at home for acting out would be something beneficial to offer as well, and am otherwise very impressed.

Thank You,

[REDACTED]



**Epilepsy  
Support  
Centre**

## Appendix H

### Sample Text from Client Case Files

#### Medical Management

- so *tired* of the *crap shoot* that medications seem to be...so *tired* and *frustrated* for him
- we put him on this medication and everything got *worse*
- how *damaging* is the medication that he's taking into his body
- very *high stress point* feeling like we hadn't been heard by the doctors
- side effects are *worse* than the actual seizures
- very *frustrated* that the doctor wasn't hearing what we were saying
- they (doctors) don't have time to chat about living with this type of thing
- his seizures are getting *worse* and he (doctor) kept saying it is not due to the medication
- it wasn't *this bad* before he started the medication
- such *horrendous* side effects

#### Impact on the Parent

- get *nervous* when my child is sick
- we're all a little *nervous* (teacher, parents)
- it can be incredibly *frustrating* and *difficult* to watch your kid go through this
- Times when you feel so *helpless*
- You just want *normalcy*. It shouldn't be too much to ask for.
- Our little guy is only 5 and I *worry* about how things will change as he gets older
- it's a bit of a *roller coaster*
- *anxious* and *mixed emotions* about situation
- *hopes* of getting some *peer support*
- feel *anxious*...talk to another parent
- *fear* of death continues
- feeling of *impending doom*
- quite *upset*..."no one in the class likes him"
- support with another local mom who has same *issues*
- things getting *worse* not better
- *struggle* with it all the time
- *fear* of her future
- *super hard* for me to deal with

- always on the *edge of the seat* waiting for the next seizure to happen
- just talking about it *reminds me* of everything again
- It's *terrifying*
- it's *scary* for any parent to go through with seizures
- The *stress* is never going to go away
- just watching your child going through it and feeling *defenseless*
- *freaked out* cause she's going to probably go for surgery
- *worrying* about him getting hurt he's got *really bad* separation anxiety - when I drop him off he has these huge crying fits and it's *really hard*
- *anxiety* that builds up inside
- even though he has intellectual disability he still can see that people *don't treat him the same way* they do other kids
- She hits herself if she's *frustrated*
- could be *devastating*
- trying to see if there was some way I could predict it and then adjust our life accordingly to try to *keep them at bay*
- she's had 4 *big ones*
- It was so *scary*
- People just basically *panicked*
- it is *scary* watching your child and wondering if she's going to come out of the seizure
- it was very *traumatic*
- *Worry* about school
- Everybody's a *little bit nervous* that he's going to have a seizure at school
- she's pretty *embarrassed*
- I was *devastated* to see it
- pretty *torn up* about it
- you *never know* when it's going to happen
- there's so much *stigma* for these kids
- I think it's going to *impact* driving, dating...not going over night anywhere
- When it happens you are so *shocked*, you try to time it but it seems like an hour, not 5 minutes
- we will *need to fight* at his school meeting
- *very emotional*, lots of concerns about school
- *concerned* about increase in prolonged seizures
- *concerns* about nocturnal seizures
- *concerns* about emergency response at camp
- *afraid* to leave (child's name) with anyone including his Dad
- *concerns* about getting full dose of medication (spitting it out)
- *worried* that he will never get better
- *fear* that he will never lead a normal life



**PREVALENT MEDICAL CONDITION — EPILEPSY**  
**Plan of Care (Sample)**

**STUDENT INFORMATION**

Student Name \_\_\_\_\_ Date Of Birth \_\_\_\_\_

Ontario Ed. # \_\_\_\_\_ Age \_\_\_\_\_

Grade \_\_\_\_\_ Teacher(s) \_\_\_\_\_

Student Photo (optional)

**EMERGENCY CONTACTS (LIST IN PRIORITY)**

| NAME | RELATIONSHIP | DAYTIME PHONE | ALTERNATE PHONE |
|------|--------------|---------------|-----------------|
| 1.   |              |               |                 |
| 2.   |              |               |                 |
| 3.   |              |               |                 |

Has an emergency rescue medication been prescribed?     Yes     No

If yes, attach the rescue medication plan, healthcare providers' orders and authorization from the student's parent(s)/guardian(s) for a trained person to administer the medication.

Note: Rescue medication training for the prescribed rescue medication and route of administration (e.g. buccal or intranasal) must be done in collaboration with a regulated healthcare professional.

**KNOWN SEIZURE TRIGGERS**

CHECK (✓) ALL THOSE THAT APPLY

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Stress  | <input type="checkbox"/> Menstrual Cycle             | <input type="checkbox"/> Inactivity  |
| <input type="checkbox"/> Changes In Diet                               | <input type="checkbox"/> Lack Of Sleep               | <input type="checkbox"/> Electronic Stimulation<br>(TV, Videos, Florescent Lights) |
| <input type="checkbox"/> Illness                                       | <input type="checkbox"/> Improper Medication Balance |  |
| <input type="checkbox"/> Change In Weather                             | <input type="checkbox"/> Other _____                 |  |
| <input type="checkbox"/> Any Other Medical Condition or Allergy? _____ |  |  |

### DAILY/ROUTINE EPILEPSY MANAGEMENT

| DESCRIPTION OF SEIZURE<br>(NON-CONVULSIVE) | ACTION:  |
|--|--|
|  | (e.g. description of dietary therapy, risks to be mitigated, trigger avoidance.) |
| DESCRIPTION OF SEIZURE (CONVULSIVE)        | ACTION:  |
|  |  |

### SEIZURE MANAGEMENT

Note: It is possible for a student to have more than one seizure type.  
Record information for each seizure type.

| SEIZURE TYPE  | ACTIONS TO TAKE DURING SEIZURE |
|---|--------------------------------|
| (e.g. tonic-clonic, absence, simple partial, complex partial, atonic, myoclonic, infantile spasms)<br><br>Type: _____<br><br>Description: _____ |                                |
| Frequency of seizure activity: _____<br><br>_____   |                                |
| Typical seizure duration: _____   |                                |

## BASIC FIRST AID: CARE AND COMFORT

First aid procedure(s): \_\_\_\_\_

Does student need to leave classroom after a seizure?       Yes       No

If yes, describe process for returning student to classroom: \_\_\_\_\_

### BASIC SEIZURE FIRST AID

- Stay calm and track time and duration of seizure
- Keep student safe
- Do not restrain or interfere with student's movements
- Do not put anything in student's mouth
- Stay with student until fully conscious

### FOR TONIC-CLONIC SEIZURE:

- Protect student's head
- Keep airway open/watch breathing
- Turn student on side

## EMERGENCY PROCEDURES

Students with epilepsy will typically experience seizures as a result of their medical condition.

Call 9-1-1 when:

- Convulsive (tonic-clonic) seizure lasts longer than five (5) minutes.
- Student has repeated seizures without regaining consciousness.
- Student is injured or has diabetes.
- Student has a first-time seizure.
- Student has breathing difficulties.
- Student has a seizure in water
- ★ Notify parent(s)/guardian(s) or emergency contact.

## HEALTHCARE PROVIDER INFORMATION (OPTIONAL)

**Healthcare provider may include:** Physician, Nurse Practitioner, Registered Nurse, Pharmacist, Respiratory Therapist, Certified Respiratory Educator, or Certified Asthma Educator.

Healthcare Provider's Name: \_\_\_\_\_

Profession/Role: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Special Instructions/Notes/Prescription Labels:

If medication is prescribed, please include dosage, frequency and method of administration, dates for which the authorization to administer applies, and possible side effects.

\*This information may remain on file if there are no changes to the student's medical condition.

## AUTHORIZATION/PLAN REVIEW

### INDIVIDUALS WITH WHOM THIS PLAN OF CARE IS TO BE SHARED

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

4. \_\_\_\_\_ 5. \_\_\_\_\_ 6. \_\_\_\_\_

Other Individuals To Be Contacted Regarding Plan Of Care:

Before-School Program  Yes  No \_\_\_\_\_

After-School Program  Yes  No \_\_\_\_\_

School Bus Driver/Route # (If Applicable) \_\_\_\_\_

Other: \_\_\_\_\_

**This plan remains in effect for the 20\_\_ — 20\_\_ school year without change and will be reviewed on or before:** \_\_\_\_\_. (It is the parent(s)/guardian(s) responsibility to notify the principal if there is a need to change the plan of care during the school year).

Parent(s)/Guardian(s): \_\_\_\_\_ Date: \_\_\_\_\_  
Signature

Student: \_\_\_\_\_ Date: \_\_\_\_\_  
Signature

Principal: \_\_\_\_\_ Date: \_\_\_\_\_  
Signature

### School Category Chart with Codes

| <b>Sub-Category Code</b> | <b>Definition of what is included in this Code</b>  |
|--------------------------|---|
| Rescue Meds              | Development and/or implementation of Emergency Plan of Care. School team training to administer rescue medications (benzodiazepines, Ativan (lorazepam), and midazolam).  |
| Teacher Knowledge        | Teacher's practical understanding of epilepsy. Facts, information, and skills to support a child with epilepsy.   |
| Teacher Attitude         | A way of thinking or feeling about someone or something, typically one that is reflected in a person's behaviour.   |
| System Barriers          | System barriers that prevent children from attending school or from reaching minimum education standards. School board policies.  |
| Behaviour                | ADHD, hyperactivity, impulsivity, agitation, aggression, rage, oppositional defiance identified by teachers at school.  |
| Safety                   | The condition of being protected from danger, risk, or injury.<br>Developing seizure safety protocols.  |
| Family                   | Parent or child response after a seizure. School refusal, home schooling, Parent choosing to withdraw their child.  |
| Teacher In-service       | A meeting to provide teachers with professional knowledge, skills, and competence in supporting a child with epilepsy.  |
| Team Meeting             | An IEP, IPRC, or school team meeting to identify the student's specific learning expectations and how the school will address these expectations through appropriate accommodations, program modifications. School board psychological services and academic testing. |
| Cognition                | Child's ability to learn and retain new knowledge, reading, critical thinking, processing language, learning challenges, learning disabilities, Intellectual Disability.  |

| <b>Condensed Meaning Unit</b>   | <b>Codes and Memos</b>          |
|---|---------------------------------|
| seizure protocol and additional forms requested by the school board for medication administration | Rescue Meds<br>System Barriers  |
| School requesting additional forms  | Rescue Meds<br>System Barriers  |
| Teacher hesitant about rescue medication administration   | Rescue Meds<br>Teacher Attitude |
| working on finalizing school staff to administer rescue medication                                | Rescue Meds                     |
| Instructed school staff on how to administer medication   | Teacher In-Service              |
| Help school with safety plan  | Safety                          |
| Safety for him at school  | Safety                          |
| I don't think the school has enough support   | Safety                          |
| There's not enough EA's in the school   | Safety                          |
| It's a rough school area  | Safety                          |
| 1 EA to 3 children in the classroom and epilepsy isn't considered a physical disability           | Safety                          |
| School did not allow us to use the original rescue med protocol                                   | Rescue Meds<br>System Barriers  |
| school claimed they needed to have an EA with a medical background                                | Rescue Meds<br>System Barriers  |

|  |                                 |
|--|---------------------------------|
| I really don't want to send her (to school). Who's going to monitor her seizures?  | Safety<br>Worry and Stress      |
| Help school with safety plan and education materials   | Safety<br>Teacher In-service    |
| worry a lot about him having a seizure at school and everybody being able to manage dealing with that                                | Safety<br>Worry and Stress      |
| didn't have the teachers that were there for support   | Safety                          |
| school's concerns about frequent and increasing seizures   | Safety                          |
| the superintendent had concerns about rescue medication training   | Rescue Meds                     |
| concerns from principal about rescue medication training   | Rescue Meds                     |
| concerns from (school board) about rescue medication training at school  | Rescue Meds<br>System Barriers  |
| concerned about a lack of supervision (school)   | Safety                          |
| information on epilepsy to make my daughters teachers more aware   | Teacher Knowledge<br>In-Service |
| called to the school so many times to pick him up because he was 'sick'  | System Factors                  |
| school has deemed (child's name) a flight risk and insisted that dad pick him up and take him home because he was having a 'bad day' | Safety<br>System Factors        |
| teacher has asked for someone to observe class and give suggestions  | Behaviour<br>Teacher Knowledge  |
| School calling ambulance too often   | System Barriers                 |
| Prolonged seizure at school  | Safety                          |
| hospital asked if (child's name) school could get some education   | Teacher<br>In-Service           |
| school will change its tune once they read the results of the testing  | Cognition                       |
| teachers have been nothing but great advocates   | Teacher Attitude                |
| her teacher is a super star  | Teacher Attitude                |
| teacher this year is very good   | Teacher Attitude                |
| His teacher is new at the school so she told me a lot of stuff she didn't understand   | Teacher Knowledge               |
| They thought it was from a bell that was ringing in the school yard.   | Teacher Knowledge               |
| school was pretty good because they have been involved with the centre   | Teacher Attitude                |
| don't think that teachers understand epilepsy with behaviours, how they're linked together   | Behaviour                       |
| issues with school and stress  | Behaviour                       |
| school refusal   | Family Factors                  |
| school psychologist recommended (child's name) have own computer with the suite software of reading and math                         | Cognition                       |
| issues in school, mostly in afternoon  | Behaviour                       |
| unable to concentrate in school  | Cognition                       |
| requires EA support for safety and participation at school   | Safety                          |

|  |                                    |
|--|------------------------------------|
| Very anxious and nervous...was trembling at school   | Family Factor                      |
| Issues in school...partially due to not sleeping well at night   | Behaviour                          |
| hoping to arrange some support for school  | Teacher Knowledge                  |
| came home from school yesterday saying during gym the kids were really loud  | Family Factor                      |
| Teacher emailed me today saying that (child's name) has been doing some work out in the hall because he finds the noise bothersome....should I be concerned? | Teacher Knowledge<br>Family Factor |
| school saying she's having a more difficult time focusing  | Cognition                          |
| It was right in the school yard, all the kids saw it   | Family Factor                      |
| having a lot of issues at school like with memory  | Cognition                          |
| She was a good student until she started the seizures again  | Cognition                          |
| now she went from having just the teachers know to having the entire school know   | Family Factor                      |
| When she had the seizure in the playground she wouldn't go back to school 3 days.  | Family Factor                      |
| got behaviour issues   | Behaviour                          |
| experiencing challenges with behavior at school  | Behaviour                          |
| School team meeting to review behaviour information  | Behaviour                          |
| parent teacher interviews last night and teacher said (child's name) "had behavioural issues"  | Behaviour                          |
| behavioural supports at school   | Behaviour                          |
| behaviours get in the way of his learning  | Behaviour                          |
| behaviours outside are not good  | Behaviour                          |
| he's got the worst behaviour   | Behaviour                          |
| an increase in some aggressive behaviours  | Behaviour                          |
| not sure we can separate it but it's the behaviour versus the seizure activity that identifies him   | Behaviour                          |
| teacher said his behaviours get in the way of his learning   | Behaviour                          |
| concerns with school standardized tests and performance anxiety  | Team Meeting                       |
| concerns with 'D' in French  | Team Meeting                       |
| concerns about child hitting her son in the face   | Safety                             |
| concerned about academics  | Team Meeting                       |

## Curriculum Vitae

### Mary Secco

**Education**                    Master of Health Information Science  
 September 2015 – present  
 (Includes a 30 month compassionate leave of absence)  
 Western University

   Bachelor of Arts (BA)  
 September 1980 – 1984  
 Queen’s University, Kingston, Ontario

### Peer Reviewed Publications

Ali, A., (co-lead) Lim, K.S., (co-lead) **Secco, M.**, (co-lead), D’Souza, C., Guekht, A., Guilhoto, L., Kerr, M., Wang, W., (2019) Epilepsy: a public health imperative. Chapter 5: The social response: misconceptions and stigma in epilepsy. *World Health Organization*, p. 67-78.

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### **Unrefereed Publications**

Tay, J., Franklin, M., **Secco, M.**, & Sibbald, S. L. (2017). Moving Towards an Inclusive Society: Implementing Epilepsy Awareness Education in the Ontario Elementary School Health Curriculum. *Western Public Health Case Book*.