

The School Experiences of Children with Epilepsy

By

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### ABSTRACT

With between 0.3 and 0.6 percent of Canadian children under the age of 18 affected by epilepsy, it is likely educators will work with this population at some point in their career. Epilepsy is consistently linked to academic underachievement and social difficulties; however, little is known about how students with epilepsy experience school, making their unique needs less familiar to school personnel. The purpose of this phenomenological study is to understand the school experiences of children with epilepsy. The specific objectives are to (1) identify children's perceptions and experiences of having epilepsy at school; and (2) gain insights to inform future studies. Participants include six students (ages 7-12 years) with a diagnosis of epilepsy who reside in Victoria, British Columbia, Canada. Data was gathered through open-ended, semi-structured interviews. The children's narratives were transcribed and analyzed to elicit the essential experiences of school children with epilepsy. Four categories were elicited from the children's narratives: (1) The Seizure Experience, (2) The Educational Experience, (3) Social Belonging, and (4) Awareness. Implications for the school and directions for future research are discussed.

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## Dedication

To Dan: the love of my life, my soul mate, my best friend.

You are the reason I wake up smiling each day. Without your unconditional support and gentle words of encouragement, I would still be stuck on my first sentence.

## Chapter 1: Introduction

In a time when inclusive education is the predominant form of service delivery in Canada, understanding how to best support and accommodate children with special needs is a responsibility of all educators. Schools must therefore be informed of, and attentive to, students requiring extra assistance or adaptations.

While education programs strive to increase knowledge of instructional practises and supports for students with special needs, these programs tend to focus on how to alleviate academic difficulties and physical challenges in the classroom. Often overlooked are students in circumstances that may not be viewed as directly associated with school functioning and adjustment. One such population of students are those with chronic illnesses.

Extant literature suggests a correlation between health and academic success (Ross & Van Willigen, 1997; Tara & Potts-Datema, 2005; Thies, 1999). Students with chronic illness experience many daily challenges that can impact their learning and socialization at school (Tara & Potts-Datema, 2005; Thies, 1999). In fact, students with chronic health conditions experience more academic difficulties than those who are healthy (Thies, 1999). As Thies (1999) explains, children whose condition directly affects their central nervous system (brain and spinal cord) often exhibit impairments of visual scanning, spatial abilities, attention, and memory, each of which have strong implications for academic success. In addition to illness-related issues, students with chronic health conditions are frequently absent from school, and often develop social and emotional complications, each of which can have negative implications for academic achievement and school adjustment (Thies, 1999). Due to its strong implications on school success, it is important for current and future educators to understand the school-related challenges of chronic illnesses so as to best support these students.

### *Why Study Children with Epilepsy?*

While researchers have examined the school experiences of children with chronic illnesses such as AIDS (Roberts, 2000), asthma (Austin, Huberty, Huster & Dunn, 1998), cancer (Zebrack & Chesler, 2002), and pectus excavatum (Roberts, Hayashi, Anderson, Martin, & Maxwell, 2003), little is known of how children with epilepsy experience school. Epilepsy is one of the most frequently diagnosed neurological disorders affecting children (Ettinger et al., 1998; Fejerman, 2002; Lagae, 2008). With between 0.3 and 0.6 percent of Canadian children under the age of 18 affected by epilepsy (Epilepsy Canada, 2003), it is likely educators will work with this population at some point in their career. Epilepsy is consistently linked to academic underachievement (e.g., Aldenkamp, Overweg-Plandsoen, & Diepman, 1999) and social difficulties (e.g. Baker, 2002); however, little is known about how students with epilepsy experience school, making their unique needs less familiar to school personnel (Elliot & Shneker, 2008). As such, it is imperative that research examines how children with epilepsy experience school so as to best inform educators of their unique needs. Doing so will help foster resilience and improve quality of life (QOL).

### *Resilience*

Resilience is an individual's attainment of positive developmental outcomes and avoidance of maladaptive outcomes under adverse conditions (Winslow, Sandler, & Wolchik, 2006). Adverse conditions, described as environmental circumstances that impede the accomplishment of age-appropriate developmental tasks (O'Dougherty-Wright & Masten, 2006), can occur throughout individual, family, or community-organizational domains (Winslow et al, 2006). When faced with adversity, children are exposed to risk factors that elevate the likelihood of undesirable outcomes (O'Dougherty-Wright & Masten, 2006). As risk factors accumulate,

negative outcomes are more probable (O'Dougherty-Wright & Masten, 2006). Cumulative protective factors can moderate the impact of adversity on adaptation (O'Dougherty-Wright & Masten, 2006), and offset the detrimental effects of stressors (Elias, Parker, & Rosenblatt, 2006). It is, therefore, essential to examine these processes so as to promote resilience under adverse circumstances (Elias, et al., 2006).

The Ecological-Transactional (E-T) framework of resilience, adapted from Bronfenbrenner's Ecological Theory of Human Development (Stewart, 2007), emphasises the developmental impact of systems beyond the immediate environments, which includes an integration of biological, social, and cultural processes (O'Dougherty-Wright & Masten, 2006). As such, protective factors are both internal (i.e. impulse control and the ability to form positive relationships with others) and external (i.e. family, schools, local community, and the wider society). All contexts work bi-directionally to influence development (O'Dougherty-Wright & Masten, 2006). The E-T framework of resilience, therefore, stresses the importance of positive experiences in multiple contexts (Stewart, 2007). School contexts are among the strongest influences on children's developmental outcomes, as they have regular access to children and adolescents during their formative years (Johnson, Schwartz, Livingston, & Slate, 2000; Taub & Pearrow, 2006). In this way, schools are an optimal site to influence positive adaptation (Johnson et al., 2000; Short & Talley, 1997).

### *The Importance of School Experiences*

Resilience literature has consistently demonstrated that positive school experiences foster resilience in children faced with adversities (Elias, et al., 2006; Gilligan, 1998, 2000), and is an critical factor in positive adaptation and social integration (Drapeau, Saint-Jacques, Lepine, Begin, & Bernard, 2007; Johnson et al., 2000; Taub & Pearrow, 2006). As children with epilepsy

experience adversity attributed to their chronic illness, the education system can function as a protective factor to promote resilience (Gilligan, 1998, 2000; Elias et al., 2006). Although research has demonstrated that positive school experiences are important in promoting adaptation, a lack of research may contribute to a misunderstanding of how best to support students with epilepsy at school (Elias, et al., 2006). Due to the unique social and academic difficulties that often accompany epilepsy, children with epilepsy may endure negative school experiences if not provided with appropriate supports. To ensure positive adaptation and QOL, school personnel must help create positive school environments and experiences for these children.

Current epilepsy literature examining QOL has focused on children and adolescents' overall QOL, with a general inquiry of how epilepsy impacts physical, emotional/behavioural, social, and academic domains (Elliot et al., 2005). Although literature emphasizes the importance of schools in promoting children's psychological, social, and physical health (Johnson et al., 2000; Taub & Pearrow, 2006), there is a dearth of literature that examines their school experiences in detail. As these children spend the majority of their developmental years engaged with school systems, it is essential that this deficiency of research is addressed so educators can help create positive learning environments for children with epilepsy attending inclusive educational settings (Elliot & Shneker, 2008).

### *Purpose of the Study and Research Questions*

The purpose of this phenomenological study is to understand the school experiences of children with epilepsy. The specific objectives are to (1) identify children's perceptions and experiences of having epilepsy at school; and (2) gain insights to inform future studies. This study will be used as a platform to develop a larger study investigating the experiences of

teachers and primary caregivers in addition to children with epilepsy. It is the researcher's intention that findings from the larger study will be shared with school districts through the development of a school handbook so as to increase the communication between researchers and school personnel.

### *Delimitations*

Methodological restrictions influence research outcomes and are therefore imperative to identify and address. The present study contains the following delimitations that have impacted its design and outcome:

1. This study is limited to six children with epilepsy;
2. This study is limited to children ages seven to twelve;
3. This study is limited to children residing in Victoria, British Columbia, Canada;
4. This study is limited to children who received parental consent to participate in the interviews;
5. This study is limited to families involved with the Victoria Epilepsy and Parkinson's Centre
6. This study is limited to data gathered from April 2009 to August 2009.

### *Summary*

This chapter presented the need for an explicit examination of children with epilepsy to better understand how they experience school. The purpose of the study and accompanying research question was identified, and delimitations of the study were examined.

Chapter two examines existing epilepsy literature, specifically reviewing its influence on children's QOL and school experiences.

## Chapter 2: Review of Relevant Literature

In Canada, epilepsy is found in approximately 3 out of every 1000 children (Bumeo, Prasad, Corbett, & Sang, 2006; Pazzaglia, & Frank-Pazzaglia, 1976), making it one of the most frequently diagnosed neurological disorders affecting children (Ettinger, et al., 1998; Fejerman, 2002; Lagae, 2008). Epilepsy is characterized by recurring seizures, as well as by its effects on social, behavioural and cognitive development (Baker, 2002; Lagae, 2008). Seizures are caused by an electrical disturbance in the brain that changes an individual's sensation, awareness, and/or behaviour (Canadian Epilepsy Alliance, 2008).

Etiology and seizure classifications vary. Etiology of seizures can be distinguished as symptomatic or idiopathic (Lagae, 2008). Symptomatic seizures occur due to an underlying brain dysfunction, such as head trauma or brain tumours (Fejerman, 2002; Lagae, 2008). Idiopathic seizures, most commonly found among children, have no identifiable cause (Lagae, 2008).

Children with symptomatic epilepsy generally experience partial seizures (Lagae, 2008). That is, seizure onset is localized in a particular portion of the brain (Lagae, 2008). Symptomatic epilepsy may be temporary (Lagae, 2008). In addition to partial seizures, children with idiopathic epilepsy experience generalized seizures, in which seizure onset is dispersed throughout the brain (Lagae, 2008). This type of epilepsy is assumed to have a genetic background (Lagae, 2008). For both symptomatic and idiopathic epilepsy, seizures are further categorized by the presence or absence of consciousness (Lagae, 2008).

There are various ways in which individuals with epilepsy experience a seizure. During a seizure, individuals may become rigid and convulse, look dazed or stare blankly, wander aimlessly, or perform automatic movements such as smacking lips or picking at clothing (Canadian Epilepsy Alliance, 2008). A loss of bladder and bowel control or vomiting may

accompany some seizures (Canadian Epilepsy Alliance, 2008). After an episode has ended, an individual may have no memory of the seizure (Canadian Epilepsy Alliance, 2008).

### *Cognitive Functioning in Children with Epilepsy*

A great deal of research has focused on the cognitive and behavioural functioning of individuals with epilepsy. Although these effects have been reported in both adults and children, these two groups may experience effects on functioning differently, and as such, should be discussed separately. It has been suggested that childhood epilepsy may impact cognitive performance in a more general way as opposed to the modality-specific effects seen in adults (Williams et al., 1998). Jovic-Jakubi and Jovic (2006) suggest that this difference between children and adults may be due to differences in plasticity and ongoing maturation. As such, while the author will focus specifically on the cognitive and behavioural effects on children in this paper, it is important to note that effects may persist into or change in adulthood.

Extant research has frequently indicated impairments of cognitive and behavioural functioning in children with epilepsy. One of the most frequently reported cognitive impairment is in memory. As an essential component of learning, memory deficits can have a negative impact on a child's school experience.

Epilepsy can impact memory in a variety of ways. Children with epilepsy frequently have difficulties retaining information in short-term memory while processing incoming information, a process known as working memory (Hernandez et al., 2003). For example, in Hernandez et al.'s (2003) examination of cognitive functioning of children with epilepsy, 32 children aged eight to sixteen with frontal lobe, temporal lobe, and generalized absence epilepsy were compared with non-epileptic controls. The children participated in a continuous performance test in which they listened to a series of letters and were instructed to respond to a designated target

stimulus by raising their hand. To assess working memory, the investigators changed the target letters following the alphabetic sequence. Children with epilepsy, particularly those with frontal lobe epilepsy, performed worse on this task compared to healthy controls, thereby demonstrating weakness in working memory.

In addition to poor working memory, children with epilepsy often show short-term memory impairments. A study by Davidson, Donis, O'regan, and Zuberi (2007) found that children with idiopathic generalized seizures demonstrated poor initial learning efficiency compared to healthy controls. That is, the children with epilepsy required more trials to reach 90 percent mastery than children without epilepsy. This same study indicated that children with epilepsy have difficulty retrieving the same information after a delay of one week. Williams et al. (1998) found similar results after analyzing neuropsychological evaluations of 79 children with epilepsy. Performance on the Wide Range Assessment of Memory and Learning suggested problems with initial encoding of information (Williams et al., 1998).

Children with epilepsy can also experience memory impairments following a seizure (Elliot et al., 2005; Moffat et al., 2009; Northcott et al., 2007). Retention difficulties can persist for many hours after a seizure (Elliot et al., 2005; Moffat et al., 2009). Further, children with epilepsy frequently report that entire memories created before the seizure can be erased (Elliot et al., 2005), making learning a challenge for students with uncontrolled seizures.

In addition to memory impairments, attention and concentration difficulties are also prevalent in this population regardless of an attention-deficit hyperactivity disorder (ADHD) diagnosis (Fastenau et al., 2008; Selassie, Viggedal, Olsson, Jennische, 2008). In the study described above by Hernandez et al. (2003), children with epilepsy, particularly those with frontal lobe epilepsy, demonstrated difficulty sustaining attention on tasks requiring the child to

respond to a selected target stimulus. Children with frontal lobe epilepsy were also more impulsive in their responses. Observations by parents confirmed these attention difficulties by describing their children as distractible, nervous, and absentminded on the Child Behaviour Checklist. These attention and concentration difficulties can have a substantial impact on a child's ability to learn and succeed in school.

In addition to memory and attention deficits, children with epilepsy often have lower intelligence (Bailet & Turk, 2000; Titus et al., 2008; Williams et al., 1998). In an examination by Bailet and Turk (2000), children with idiopathic epilepsy aged eight to thirteen scored significantly worse than sibling controls on the Wechsler Intelligence Scale for Children-Revised. Specific subtests examined were Arithmetic, Vocabulary, Picture Arrangement, and Block Design (Bailet and Turk, 2000). This finding is consistent with other neuropsychological evaluations (Titus et al., 2008; Williams et al., 1998). Williams et al. (1998) suggest that the attention and encoding difficulties often found in children with epilepsy may contribute to a generalized pattern of lower IQ, but this hypothesis requires further investigation.

Impairments have also been reported in psychomotor speed (Hermann, Jones, Sheth, Dow, Koehn, & Seidenberg, 2006), processing speed (Hernandez et al., 2003), reaction time and vigilance (Aldenkamp, Weber, Overweg-Plandsoen, Reijs, & van Mil, 2005; Siren, Kylliäinen, Tenhunen, Hirvonen, Riita, Koivikko, 2007), perceptual organization, self-regulation, and attention (Hernandez et al., 2003). Although it is clear that children with epilepsy display cognitive and behavioural impairments, the literature is less clear on what causes these deficits.

A wealth of research exists that seeks to understand the influences on cognitive impairments in children with epilepsy. Although many studies have examined these influences, their relationships are unclear and inconsistent. Factors that have been found to influence

cognitive impairments include early age of onset (Berg et al., 2008; Fastenau et al., 2008; Jovic-Jakubi & Jovic, 2006), etiology, type of epilepsy (Aldenkamp et al., 2005; Berg et al., 2008), EEG discharge, polytherapy (Aldenkamp et al., 2005), poor seizure control (Wirrel, Sherman, Vanmastrigt, & Hamiwka, 2008), current age, and seizure type (Fasteneau et al., 2008). While many researchers have suggested one or more of these are related to with poor cognitive functioning, others argue that there is no relationship. For example, Jovic-Jakubi and Jovic (2006) demonstrated that type of epilepsy was significantly associated with test scores, Aldenkamp et al., (2005) found similar results and suggested that underachievement is primarily seen in children with localization-related epilepsy and symptomatic generalized epilepsy. Williams et al. (1998), however, did not find correlations between any medical factors, including type of epilepsy, and neurocognitive outcomes such as IQ, psychomotor speed, memory, and academic achievement. Discrepancies in the literature create a need for further research on how types of epilepsy and other medical factors influence cognitive functioning.

Discrepancies also exist around seizure intensity. Researchers have found that cognitive performance is improved when seizure activity is reduced or controlled (Deonna et al., 2000; Siren et al., 2007). Austin et al., (1999), however, found that children with high seizure severity continued to perform poorly on cognitive tasks regardless of seizure improvement. While some studies support this finding (Bailet & Turk, 2000), others argue that persistent cognitive impairments may be a result of permanent damage to cortical networks during development (Deonna et al., 2000) or the means by which the seizures are controlled, for example, antiepileptic drugs (AED) (Aldenkamp et al., 2005, Taras & Potts-Datema, 2005; Wirrell et al., 2008).

While an examination of all discrepancies is beyond the scope of this thesis, it is imperative to understand that researchers are not in agreement as to what factors influence cognitive functioning the most. Understanding the cognitive functioning of a child with epilepsy is a complex process, and it seems as though each individual circumstance is quite different. That said, there is consensus that cognitive impairments are prevalent in children with epilepsy. These cognitive impairments can have a substantial impact on a child's school experience, and in turn, their QOL (Elliot et al., 2005).

### *Pharmacological Treatment and Effects*

Although a range of management techniques exist, pharmacological treatment remains the foundational therapy for seizure control (Ben-Menachem & French, 2008). There are approximately twenty anti-epileptic medications (AEDs) used to treat epilepsy, half of which have appeared in the last fifteen years (MacDonald & Rogawski, 2008). AEDs control seizures by interacting with cellular targets such as ion channels, neurotransmitter transporters, neurotransmitter metabolic enzymes, and synaptic vesicle proteins (MacDonald & Rogawski, 2008). As an integral aspect of their lives, AEDs substantially impact the quality of life of individuals with epilepsy (Browne & Holmes, 2004).

A physician's decision to place a child on a particular AED extends beyond seizure control. Each AED bears a level of toxicity and numerous potential side effects (Browne & Holmes, 2004) that can greatly impact an individual's life. Side effects of AEDs vary for each individual child, and can be influenced by factors such as the type and number of AEDs, their interaction with other medication, seizure etiology, age of epilepsy onset, seizure frequency, interictal discharges, and individual response (Pellock, Nordli, & Dulac., 2008).

While AED side effects vary, they commonly impact a child's cognitive functioning. As Pellock et al., 2008 explains, epilepsy medications can positively or negatively impact a child's ability to concentrate, attend, learn, and perform, which ultimately influences school experiences. Due to seizure cessation, AEDs can have a positive influence on cognition, and have been shown to specifically improve neurocognitive functioning in such areas as fine motor fluency and visual memory (Siren et al., 2007).

While AEDs can have a positive effect on cognitive functioning, they can also cause impairments. Although it is difficult for researchers to distinguish the effects of AEDs independent of other disease-related psychosocial factors, studies have demonstrated deficits in reaction time (Mandelbaum, Burack, & Bhise, in press; Aldenkamp et al., 2005; Hoie 2006), verbal and working memory (Hoie 2006; Wirrell 2008; Sellassie 2008), executive functioning (Hoie, 2006), reading and math skills, attention (Wirrell, 2008), and nonverbal intelligence (Wirrell 2008; Sellassie 2008). Other side effects of AEDs that can greatly impact learning and overall QOL include fatigue (Elliot et al., 2005) and depression (Oguz, Kurul, Dirik, & Eylül, 2002). Negative effects of AEDs can be enhanced by treatment factors such as polytherapy (Aldenkamp et al., 2005; Oguz et al., 2002; Pellock et al., 2008; Selassie et al., 2008), elevated AED blood levels, and use of older AEDs (Ortinski & Meador, 2004), although studies examining the benefits of newer AEDs are minimal (Aldenkamp, Krom, & Reijs, 2003). For some children, side effects may be temporary, only occurring during the introduction of a drug or during the initial phase of dosage increases (Aldenkamp, 2001). While it is commonly understood that all AEDs have side effects (Pellock et al., 2008), studies have demonstrated that these side effects vary depending on the type of medication prescribed (Aldenkamp, 2001; Gates, 2000).

Although effects of AEDs have been recognized, there are few studies examining AED treatment on children (Loring & Meador, 2004). As children are particularly susceptible to the negative effects of drugs due to the effects they can have on their neurodevelopment (Ortinski, & Meador, 2004), it is important for researchers to consider the specific influence AEDs have on the younger population. As AEDs are an integral part of their lives, focusing on children would identify how medications affect their daily experiences, and provide an opportunity to promote positive quality of life.

### *Quality of Life*

The term “quality of life” (QOL) has been used for many decades, and has undergone vast changes in meaning. Before World War II, QOL was used to refer to the quality of external living conditions, placing great emphasis on material value (Musschenga, 1997). Aims of policy makers thus viewed economic growth as the means of improving QOL (Musschenga, 1997). Critics argued, however, that QOL should also incorporate internal qualities of human life (Musschenga, 1997). After World War II, policy makers began to embrace “happiness” and “well-being” as important influences, and thus “quality of life” research emerged as a discipline for designing social policies (Musschenga, 1997).

Interest in QOL became particularly popular in the field of medicine when it was suggested that health care and medicine can improve an individual’s QOL (Musschenga, 1997). As medical and technological advances emerged, individuals with diseases were able to prolong life expectancy (Roberts, 2000; Musschenga, 1997). QOL was, therefore, quantitatively measured using survival rates (Musschenga, 1997; Turnbull, Turnbull, Wehmeyer, & Park, 2003).

It was soon questioned if invasive treatments were more harmful than the disease itself, and whether individuals were truly happy with the prolongation of their life (Musschenga, 1997). As such, QOL began to integrate the effects of medical and non-medical treatments on patients' lives (Musschenga, 1997), thereby emphasizing the subjectivity of QOL definitions (Turnbull et al., 2003). Today, medicinal and technological advances not only increase survival rates, but also increase participation in daily activities (Musschenga, 1997). It is, therefore, imperative that QOL is considered when treating individuals with chronic illnesses.

Although increasing in popularity, QOL is not easily defined in the literature (Taylor, Gibson, & Franck, 2008; Turnbull et al., 2003). QOL is a personal concept, and its conceptualization is often ambiguous (Taylor et al., 2008). Researchers generally agree, however, that QOL encompasses such processes as well-being, social involvement, and opportunities to achieve one's potential (Hinds et al., 2004).

Epilepsy literature often uses health-related quality of life (HRQOL) and QOL interchangeably (Taylor et al., 2008). Although they are treated similarly, they are often comprised of very different meanings, ranging from seizure control and independent living, to embarrassment in social settings. It is, therefore, important that QOL is operationally defined in all research (Taylor et al., 2008).

The present study adopts Keith and Schalock's (1994) model of QOL, which identifies satisfaction, well-being, social belonging, and empowerment/control as important components. According to Keith and Schalock (1994), satisfaction is an individual's overall contentment over the particular circumstance. Well-being encompasses an individual's view of his or her life situation (Keith & Schalock, 1994). Social belonging includes involvement in activities, social interaction, and relationship development (Keith & Schalock, 1994). Finally, empowerment

relates to an individual's opportunity to exercise control of, and make choices in, his or her life (Keith & Schalock, 1994). Together, these components are thought to influence an individual's QOL. It is Keith and Schalock's (1994) integrative model of QOL that guides this research.

The QOL model developed by Keith and Schalock (1994) has been used to describe QOL experiences in other research. For example, Roberts and Cairns (1999) developed their interview questions from Keith and Schalock's QOL model to examine the experiences of children with HIV/AIDS. Using this model, Roberts and Cairns (1999) interviewed families of children with HIV/AIDS using questions that elicited information about their satisfaction, well-being, social belonging, and empowerment. While open-ended questions were explored, the participants continuously provided information that fell into one of Keith and Schalock's four components of QOL. Other studies support the use of this QOL model (Roberts, Hayashi, Anderson, Martin, & Maxwell, 2003; Roberts, Massie, Mortimer, & Maxwell, 2005). Various components of Keith and Schalock's model have been verified in other studies seeking an understanding of QOL (Hinds et al., 2004).

### *Quality of Life and Epilepsy*

Living with a chronic illness has vast implications on developmental trajectories, daily functioning and, subsequently, QOL (Bishop & Allen, 2003; Roberts, 2000; Roberts et al., 2003; Ronen, Rosenbaum, & Streiner, 1999; Taylor et al., 2008; Taras & Potts-Datema, 2005). Because of a reduction in positive life experiences and personal control, children and adolescents living with chronic illnesses also experience low QOL (Devins, Blinik, Hutchinson, Hollomby, Barre, & Guttman, 1983). Interestingly, studies have demonstrated that young people with epilepsy have lower QOL than individuals without epilepsy (Montanaro, Battistella, Boniver and Galeone, 2004), and those with other chronic health conditions, such as asthma (Austin et al.,

1998). Low QOL among individuals with epilepsy is seen cross-culturally (Au et al., 2002; Choi-Kwon et al., 2003; Yong, Chengye, & Jionge, 2006).

Epilepsy can reduce QOL both directly and indirectly (Bishop & Allen, 2003). As a direct influence, epilepsy affects functioning in domains deemed important to QOL (Bishop & Allen, 2003). As an indirect influence, epilepsy reduces opportunities to engage in activities that improve QOL (Bishop & Allen, 2003). Personal values and experiences influence QOL as well (Bishop & Allen, 2003).

Research on QOL has demonstrated the mediating effects of physical, behavioural/emotional, social, academic domains (Elliot et al., 2005). Negative experiences and maladaptive functioning in these domains have attributed to the low QOL experienced by many children and adolescents with epilepsy (Bishop & Allen, 2003; Elliot et al., 2005; Fastenau et al., 2008; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004; Moffat, Dorris, Connor, & Espie, 2009; Ronen et al., 1999; Sherman, Slick, & Eyrl, 2006; Suurmeijer et al., 2001). Integrated throughout these domains is children's longing for normalcy (Elliot et al., 2005). That is, children with epilepsy tend to feel different from their peers, in terms of their physical, emotional/behavioural, social, and academic experiences (Elliot et al., 2005). These differences appear to contribute to low QOL. To understand epilepsy's influence on QOL according to current research, a discussion of each domain is appropriate.

### *Physical Domain*

Physically, children with epilepsy experience a number of problems that interfere with daily functioning. The most frequent physical complaint is excessive fatigue (Bishop & Allen, 2003; Choi-Kwon et al., 2003; Elliot, Lach, & Smith, 2000; Elliot et al., 2003; McEwan et al., 2004; Moffat et al., 2009; Yong et al., 2006). Excessive fatigue can occur directly after a seizure

or for many hours following (Elliot et al., 2000; Elliot et al., 2005). Side effects of anti-epileptic medications can also enhance fatigue, causing a general lack of energy (Elliot et al., 2000, 2005). Children's ability to participate in some physical and social activities is subsequently limited (Elliot et al., 2003). In many cases, extra sleep is essential, making frequent naps and earlier bed times necessary (Elliot et al., 2003).

Children and adolescents with epilepsy also express somatic complaints due to medication side effects or seizure-related factors (Bishop & Allen, 2003; Elliot et al., 2003; Moffat et al., 2009). Somatic complaints include headaches, hair loss, visual disturbances, clumsiness, increased appetite, weight gain, and dizziness (Moffat et al., 2009). Soreness of the mouth, uncontrolled urination, and injuries from seizures are also experienced by some individuals (Bishop & Allen, 2003; Moffat et al., 2009). Somatic complaints not only enhance children's feelings of abnormality, they also interfere with daily functioning (Elliot et al., 2005). For example, concentration difficulties from persistent headaches can affect social and academic functioning. The physical domain, therefore, acts as an important influence on QOL.

#### *Emotional/Behavioural Domain*

Children and adolescents with epilepsy also experience effects within emotional/behavioural domains (Au et al., 2002; Bishop & Allen, 2003; Choi-Kwon et al., 2003; Elliot et al., 2000; Elliot et al., 2005; Ettinger et al., 1998; McEwan et al., 2004; Moffat et al., 2009; Yong et al., 2006). In fact, in a study of children and adolescents with epilepsy ages seven to eighteen, Ettinger et al., (1998) found that 26 percent of participants met criteria for depression. In addition, 16 percent of participants demonstrated elevated anxiety (Ettinger et al., 1998). Similarly, Elliot et al.'s (2005) interviews suggest that many children with epilepsy experience periods of intense emotional distress and intermittent sadness. These trends are

consistent among the literature (Baker et al., 2005; Conant, Morgan, Muzykewicz, Clark, & Thiele, 2008; Cushner-Weinstein et al., 2008; Montanaro et al., 2004). As such, rates of suicide and suicide attempts in children, adolescents and adults with epilepsy are relatively high compared to the general population (Jones, Hermann, Barry, Gilliam, Kanner, & Meador, 2003).

Medication side effects can impact mood and irritability, and increase sadness and anxiety (Benavente-Aguilar, Morales-Blanquez, Rubio, & Rey, 2004; Elliot et al., 2005). Other psychosocial factors, however, contribute to increased rates of psychological distress among children with epilepsy. For example, a loss of physical control over their bodies during a seizure creates elevated frustration and anger (Au et al., 2002; Elliot et al., 2005; Moffat et al., 2009). Because children with epilepsy cannot control when and where their seizures occur, illness confidentiality cannot be guaranteed. Anxiety over potential embarrassment is, therefore, persistent, with subsequent effects on social interaction and self-esteem (Au et al., 2002; Bishop & Allen, 2003; Choi-Kwon et al., 2003; Elliot et al., 2000; Elliot et al., 2005; Ettinger et al., 1998; McEwan et al., 2004; Moffat et al., 2009; Yong et al., 2006).

Particularly in adolescences, epilepsy may hinder the development of autonomy (McEwan et al., 2004; Moffat et al., 2009; Wilde & Haslam, 1996). Restrictions on privacy and high rates of parental monitoring disrupt adolescents' development of independence (Elliot et al., 2000, 2005; McEwan et al., 2004; Moffat et al., 2009; Wilde & Haslam, 1996). Although they understand parents' safety concerns (Elliot et al., 2005), high levels of parental involvement enhance feelings of abnormality (Elliot et al., 2000, 2005; McEwan et al., 2004; Moffat et al., 2009). This trend is also seen among children, where parental restrictions reduce their participation in activities such as sleepovers and pool parties (Elliot et al., 2000, 2005; McEwan et al., 2004; Moffat et al., 2009; Wilde & Haslam, 1996). Frequent loss of control in their lives

creates a great deal of frustration, anger, and sadness among children and adolescents with epilepsy (Elliot et al., 2005; McEwan et al., 2004; Moffat et al., 2009).

Fear of seizures also contributes to increased psychological distress (Au et al., 2002; Bishop & Allen, 2003; Elliot et al., 2000; Elliot et al., 2005; McEwan et al., 2004; Moffat et al., 2009). Young people with epilepsy often worry that they will sustain an injury, or even die, during a seizure (Moffat et al., 2009). Extant literature also explains that many individuals with epilepsy frequently worry about the side effects of medications, and the implications of forgetting to take them (Elliot et al., 2005; Moffat et al., 2009; Wilde & Haslam, 1996). As such, children and adolescents tend to rely on parental reminders to take medications. Dependence on others to ensure safety negatively affects the development of autonomy, and exacerbates feelings of abnormality (Wilde & Haslam, 1996).

Many children with epilepsy view seizures as a restriction to future accomplishments (Elliot et al., 2005; Moffat et al., 2009). As such, certain careers and activities (for example, driving) are perceived as unattainable. This negative outlook contributes to the sadness and helplessness experienced by children with epilepsy.

### *Social Domain*

Social support is defined as an exchange of social, emotional, and/or instrumental resources between an individual and the social environment (Suurmeijer, Reuvekamp, & Aldenkamp, 2001). Because it enhances the well-being of individuals, social support is a contributor to QOL outcomes (Baker et al., 2005; Suurmeijer et al., 2001). Unfortunately, young people with epilepsy experience profound social isolation, which negatively impacts their social support, and subsequently, their QOL (Au et al., 2002; Baker et al., 2005; Bishop & Allen, 2003; Caplan et al., 2005; Elliot et al., 2005; McEwan et al., 2004; Moffat et al., 2009).

Barriers to inclusion arise from internal constraints (imposed by the individual), and external constraints (imposed by other individuals or circumstances) (Elliot et al., 2005). Internal constraints, such as low self-confidence, have a profound impact on social inclusion (Conant, et al., 2008; Elliot et al., 2005; Jalava, Sillanpaa, Camfield & Camfield, 1997; Moffat et al., 2009). Children with low self-confidence tend to withdraw from social interactions (Elliot et al., 2005; Jalava et al., 1997; Moffat et al., 2009).

Children with epilepsy also tend to feel “different” from their peers, which enhances feelings of social inadequacy (Elliot et al., 2005; Moffat et al., 2009). Many feel they do not belong to, or fit in with, peer groups, and worry about rejection should they have a seizure in the presence of peers (Elliot et al., 2005). Embarrassment of taking anti-epileptic medication also restricts full participation in peer groups (Moffat et al., 2009).

Yet another internal constraint creating social isolation is the inability for children with epilepsy to rely on their bodies (Elliot et al., 2005). The inability to depend on their bodies creates anxiety over social embarrassment and personal safety (Elliot et al., 2005). For example, in their study of childhood epilepsy and perceived QOL, Moffat et al., (2009) found that half of the participants were unwilling to disclose their condition to peers, due to fears of embarrassment and rejection. As such, participants were frequently anxious about seizing in the presence of peers, as the secrecy of their illness meant peers were unfamiliar with their situation, and subsequently, safety procedures that prevent injury during a seizure (Elliot et al., 2000). Because children cannot predict or prevent seizures in the presence of peers, withdrawal from social interactions often results (Baker et al., 2005; Elliot et al., 2005; Moffat et al., 2009; Jalava et al., 1997).

External constraints are also major contributors to the social isolation experienced by young people with epilepsy. Many of these constraints are imposed by peers (Au et al., 2002; Bishop & Allen, 2003; Caplan et al., 2005; Elliot et al., 2005; McEwan et al., 2004; Moffat et al., 2009; Suurmeijer et al. 2001) and are attributed to the stigma attached to epilepsy (Baker et al., 2005; Choi-Kwan et al., 2003; Elliot et al., 2000; Yong et al., 2006). Extant research has demonstrated the frequent acts of bullying and teasing towards children with epilepsy (Bishop & Allen, 2003; Choi-Kwan et al., 2003; Conant et al., 2008; Elliot et al., 2005; Moffat et al., 2009; McEwan et al., 2004). In fact, 19 out of 22 participants in a study examining the QOL and psychosocial development in adolescents with epilepsy reported incidences of bullying (McEwan et al., 2004).

While not all children with epilepsy experience bullying, research suggests that peer rejection occurs more frequently among young people with epilepsy than the general population (Bishop & Allen, 2003; Choi-Kwan et al., 2003; Conant et al., 2008; McEwan et al., 2004; Moffat et al., 2009). For example, adolescents with epilepsy experience fewer romantic relationships than those without epilepsy (McEwan et al., 2004). This trend is seen in adult relationships as well (Jalava et al., 1997), and may be more prominent in some cultures (Yong et al., 2006).

McEwan et al., (2004) suggests that rejection from peers is due to a lack of knowledge about epilepsy and what to do in the event of a seizure. Others argue that the frequency of externalizing behaviour (EB) problems among this population contributes to peer rejection (Caplan et al., 2005; Hoie et al., 2008). Children with EB problems, such as attention-deficit hyperactivity disorder (ADHD), are often rejected or avoided by their peers (Hymel, Vaillancourt, McDougall & Renshaw, 2004). Children with epilepsy demonstrate elevated levels

of EB problems, which may thus contribute to peer rejection (Caplan et al., 2005; Tse et al., 2007). These children subsequently lack opportunities to practice appropriate social interaction, thereby exacerbating EB problems (Tse et al., 2007; Hymel et al., 2004).

External constraints are also imposed by caregivers. Both parents and children with epilepsy report that parental restrictions and excessive monitoring hinder children's ability to participate in social activities (Bishop & Allen, 2003; Elliot et al., 2000, 2005; McEwan et al., 2004; Moffat et al., 2009). Children with epilepsy report restrictions on such activities as swimming (Elliot et al., 2005), sleepovers, visiting friends (Moffat et al., 2009) and driving (Bishop & Allen, 2003). Restrictions and excessive monitoring increases loneliness, and exacerbates alienation (Moffat et al., 2009).

Illness factors also contribute to social isolation (Caplan et al., 2005). For example, frequent school absences due to doctor appointments can restrict relationship development (Caplan et al., 2005). Additionally, children with epilepsy report that leaving class or interrupting recess to take medication causes them to miss out on play with peers (Elliot et al., 2005; Moffat et al., 2009).

### *Academic Domain*

School experiences have important influence on children's current (Bishop & Allen, 2003; Choi-Kwan et al., 2003; Elliot et al., 2005; Lewis & Parsons, 2008) and future (Ross & Van Willigen, 1997) quality of life. The academic difficulties of children with epilepsy are well documented in the literature (e.g. Aldenkamp et al., 1999; Aldenkamp et al., 2005; Austin et al., 1999; Berg et al., 2008; Caplan et al., 2006; Chaix et al., 2006; Fastenau et al., 2008; Hermann et al., 2001; Katzenstein et al., 2007; Northcott et al., 2007; Seidenberg et al., 1986; Selassie et al., 2008; Williams, 2003; Wirrell et al., 2008). Problems with memory (e.g. Chaix et al., 2006;

Elliot et al., 2005; Moffat et al., 2009; Northcott et al., 2007; Selassie et al., 2008; Williams, 2003), attention (e.g. Elliot et al., 2005; Fastenau et al., 2008; Selassie et al., 2008; Williams, 2003), and/or learning (e.g. Aldenkamp et al., 1999; Aldenkamp et al., 2005; Austin et al., 1999; Bender et al., 2008; Berg et al., 2008; Fastenau et al., 2008; Moffat et al., 2009; Selassie et al., 2008; Smith, Elliot, & Lach, 2002; Williams, 2003; Wirrell et al., 2008), negatively impact academic achievement, and subsequently self-worth (Caplan et al., 2005). For example, many students with epilepsy report memory impairments following a seizure (Elliot et al., 2005; Moffat et al., 2009; Northcott et al., 2007). Retention difficulties can persist for many hours after a seizure (Elliot et al., 2005; Moffat et al., 2009). Further, children with epilepsy frequently report that entire memories created before a seizure can be erased (Elliot et al., 2005). As such, learning is often a challenge for students with epilepsy.

Attention and concentration difficulties are also prevalent among this population (Elliot et al., 2005; Fastenau et al., 2008; Selassie et al., 2008; Williams, 2003), regardless of an ADHD diagnosis (Fastenau et al., 2008; Selassie et al., 2008). These impairments enhance learning difficulties (Elliot et al., 2005; Fastenau et al., 2008; Selassie et al., 2008; Williams, 2003), and negatively affect self-esteem (Caplan et al., 2005).

Academic underachievement is also prominent among children with epilepsy (e.g. Aldenkamp et al., 1999; Aldenkamp et al., 2005; Austin et al., 1999; Elliot et al., 2000, 2005; Fastenau et al., 2008; Hermann et al., 2001; Katzenstein et al., 2007; Selassie et al., 2008; Williams, 2003; Wirrell et al., 2008) and is persistent over time (Austin et al., 1999). Difficulties in mathematics (Wirrell et al., 2008), spelling, writing, reading, reading comprehension (Aldenkamp et al., 1999; Aldenkamp et al., 2005; Bender et al., 2008; Berg et al., 2008; Moffat et al., 2009; Seidenberg et al., 1986; Williams, 2003), and expressive language (Selassie, et al.,

2008) have been identified in the literature. These difficulties may be attributed to anti-epileptic medications (Taras & Potts-Datema, 2005; Wirrell et al., 2008), polytherapy (Selassie, et al., 2008), excessive fatigue (Elliot et al., 2005), or seizure localization (Aldenkamp, 2004). Of note, extreme fatigue, seizure attacks, and memory impairments contribute to discontinuous learning experiences (Elliot et al., 2005), and may therefore affect a child's academic success in school.

High incidences of learning disabilities (LD) are found in students with epilepsy (Fastenau et al., 2008). In a study of 123 children with epilepsy by Fastemua et al., (2008), approximately 50 percent of the sample met criteria for LD based on low achievement and traditional definitions of IQ-achievement discrepancy (Fastenau et al., 2008). This puts children with epilepsy at further risk for early school drop-out, psychosocial issues around learning, and peer relationship difficulties (Morrison & Cosden, 1997), which impact QOL.

In addition to epilepsy's direct effects, school absences due to doctor appointments, hospitalization, or seizure-related factors, also negatively impact learning and achievement (McEwan et al., 2004; Moffat et al., 2009). Many students with epilepsy miss lessons or exams due to frequent absences, making learning discontinuous. These situations also exacerbate alienation from peers (Elliot et al., 2005; Moffat et al., 2009). Additionally, many children with epilepsy feel teachers are unsupportive and unfair (McEwan et al., 2004; Moffat et al., 2009). For example, children in a study by Moffat et al., (2009) described overprotective and unfair treatment by teachers, such as activity restriction. Research suggests that overprotection and unnecessary restrictions are due to stigma and misunderstandings surrounding epilepsy.

Epilepsy research has suggested that physical, behavioural/emotional, social, academic domains mediate QOL (Elliot, Lach, and Smith, 2005). Negative experiences and maladaptive functioning in these domains can negatively affect the school experiences (Weissberg, Caplan, &

Harwood, 1991), and have attributed to the low QOL experienced by many children and adolescents with epilepsy (Bishop & Allen, 2003; Elliot et al., 2005; Fastenau et al., 2008; McEwan et al., 2004; Moffat, et al., 2009; Ronen et al., 1999; Sherman et al., 2006; Suurmeijer et al., 2001). Schools are among the most effective contexts available to promote the psychological, social, and physical health of school-age children (Weissberg, Caplan, & Harwood, 1991). The lack of QOL literature focusing specifically on the school experiences of children with epilepsy is, therefore, counterintuitive. As resilience literature demonstrates that positive school experiences foster resilience in children faced with adversities (Elias, et al., 2006; Gilligan, 1998, 2000), it is important that researchers examine how to promote positive experiences. With specific focus on the school experiences of children with epilepsy, educators will understand how to best support, accommodate, and prepare for students with epilepsy. This study will contribute to the existing literature by identifying the school perceptions and experiences of a small group of children with epilepsy.

### Chapter Three: Methodology

Chapter three outlines the methodology used to identify children's perceptions and experiences of having epilepsy at school. The research approach, design, data collection methods, and analysis are presented below. The chapter will finish with a description of ethical considerations.

#### *General Approach*

This study aims to understand the school experiences of children with epilepsy by identifying their perceptions and experiences of having epilepsy at school. This exploration will employ a qualitative methodology. Qualitative inquiries aim to interpret, understand, explain and bring meaning to central phenomenon (Arsenault & Anderson, 1998). The idea that natural observation and in-depth conversation can lead to a deep understanding of the world is a fundamental assumption of this research paradigm (Arsenault & Anderson, 1998). Research using qualitative inquiries also assumes that (a) participants' voices are important; (b) general, open-ended questions in places familiar to participants are valuable; and (c) advocating for change and improvement is a responsibility of research (Creswell, 2005). As this study seeks an in-depth understanding of children's experiences with epilepsy, a qualitative methodology will be used.

#### *Research Design*

Qualitative research employs various paradigms, each adopting its own assumptions, criteria, and methods of inquiry (Arsenault & Anderson, 1998). As each paradigm offers a unique perspective into the phenomenon, it is essential to choose one that meets the needs of the particular inquiry. As this study aims to identify the perceptions and experiences of school children with epilepsy, a qualitative paradigm that elicits a description of their experiences is

necessary. The present study, therefore, will adopt a phenomenological research design to understand the school experiences and perceptions of children with epilepsy.

Phenomenological designs aim to acquire a comprehensive understanding of a phenomenon (Barnett, 2005; Creswell, 1998; Donalek, 2004; Giorgi, 2006; Lopez & Willis, 2004; Wertz, 2005; Wimpenny & Gass, 2000). This is typically accomplished by listening to the narratives of those who have experienced the phenomenon in question (Creswell, 1998; Wimpenny & Gas, 2000). Thorough examination of these narratives provides a description of the lived experience, and elicits the essence or central meaning of the phenomenon (Donalek, 2004; Wimpenny & Gas, 2000). The end product allows for a deeper understanding of the participants' lived experiences.

There are two main phenomenological approaches: eidetic, or descriptive phenomenology, and hermeneutic, or interpretive phenomenology (Lopez & Willis, 2004). The latter searches for meaning rooted in common-life practices (Lopez & Willis, 2004). This approach focuses on describing the *meaning* of everyday experiences and analyzing how it impacts choices (Lopez & Willis, 2004). The former, and that which this study adopts, seeks only a *description* of the perceived world through the narratives of participants (Lopez & Willis, 2004). Several assumptions accompany the eidetic approach to phenomenology. The first assumes that experiences perceived by individuals are of importance and should be studied (Lopez & Willis, 2004). The second believes that any lived experience holds universal essences, or common features (Lopez & Willis, 2004). Last, eidetic approaches assume that the true nature of the phenomenon is revealed through a description of these essences (Lopez & Willis, 2004). This study, therefore, uses eidetic phenomenology to create an exhaustive description of the

perceptions and experiences of school children with epilepsy by listening to their narratives and identifying universal essences.

### *Entering Assumptions*

The researcher plays an essential role in phenomenological research. As Donalek (2009) emphasizes, research is not truly phenomenological unless the researcher's beliefs are acknowledged throughout the study. Without the reflection and bracketing of one's presuppositions of a phenomenon, the essence of the phenomenon cannot truly emerge (Ashworth, 1999; Donalek, 2009). Bracketing, a means of suspending presuppositions of the phenomenon under investigation, allows the lived experiences of the participants to emerge without influence from existing theories, research findings, or personal biases (Ashworth, 1999). As such, the researcher must suspend all beliefs and assumptions of what school is like for children with epilepsy so as to have the children's lived experiences surface into clarity (Ashworth, 1999).

Many of the participants in this study were recruited from the *Tools for Success* tutoring program coordinated by the Victoria Epilepsy and Parkinson's Centre (VEPC). The researcher is actively involved in this program, and has developed a relationship with many of the participants. As such, it is possible that the researcher holds personal assumptions and biases about the phenomenon under study. Further, the researcher has completed a graduate-level course in which the cognitive effects of children with epilepsy were explored. As such, the researcher has knowledge of current literature on the experiences of children with epilepsy. To ensure the essence of the phenomenon is truly understood, the researcher will bracket her assumptions and biases, and document these in a journal. This journal will also be used to record

and reflect on any thoughts, responses, and decisions made throughout the research process (Donalek, 2009). This procedure ensures the credibility of the study.

### *Data Collection Methods*

Phenomenology is used to explore areas where little is known, or where content is sensitive (Donalek, 2004; Giorgi, 2006; Wertz, 2005). Phenomenological data collection may occur in a variety of forms, such as journal writing (Donalek, 2004) or, more commonly, interviewing (Wimpenny & Gass, 2000). Data collection extracts experiences from participants so the phenomenon of interest is exposed (Wimpenny & Gass, 2000). Through bracketing presuppositions of the phenomenon (Creswell, 1998, 2005; Donalek, 2004; Wertz, 2005; Wimpenny & Gass, 2000), talking and listening to individuals who have experienced it, and observing their environments, one can develop a true understanding of the phenomenon (Berndtsson, Claesson, Friberg, and Ohlen, 2007).

In phenomenological interviews, it is important to establish the context of the interview, construct the experience, and reflect on its meaning (Wimpenny & Gass, 2000). The interest of the researcher is also essential. It is necessary that the researcher is passionate about understanding the phenomenon, as the researcher's ability to listen is equally important as the participants' ability to express themselves (Wimpenny & Gass, 2000),

For this study, interview discussions were recorded, extensively reviewed, and transcribed. During this process, the researcher was immersed in the data, and reflected on all possible meanings and perspectives derived from the narratives (Donalek, 2004; Wertz, 2005). Transcripts were searched for meaning units, and eventually, themes (Creswell, 1998, 2005; Donalek, 2004). Once identified, the participants were asked to validate emergent themes to ensure the truth value of the interpretation (Donalek, 2004; Roberts & Cairns, 1999). As each

researcher brings a unique perspective to the data (Berdtsen et al., 2007), credibility was established through ongoing and extensive reflections about the researcher's thoughts, responses, and decision-making processes (Donalek, 2004). These reflections were documented in a journal.

### *Sampling and Recruitment*

Both opportunistic and typical sampling was used in the recruitment processes. Opportunistic sampling allows the study's sample to surface during the initial inquiry, and occurs after investigations have begun (Creswell, 2005). That is, opportunistic samples manifest from events that unfold during the initial data collection (Creswell, 2005). This sampling process captures the developing or emerging nature of qualitative research, and can lead to unanticipated findings (Creswell, 2005).

Using opportunistic sampling, this study recruited children from families involved in a larger study which used parent interviews to understand the school experiences of children with epilepsy. As children bring a unique perspective in understanding how they experience school, families participating in this larger study were asked if their child would like to be involved in a separate interview.

As not all families from the larger study wanted their child interviewed, typical sampling was used to recruit additional participants. In typical sampling, participants and sites are intentionally selected to enable a complete understanding of the phenomenon of interest (Creswell, 2005). To understand the school experiences of children with epilepsy, therefore, the researcher recruited only those students living with epilepsy.

To facilitate the recruitment process, Isa Milman, a community partner from VEPC, contacted families involved in the organization to inform them of the study and invite their child's participation. A letter was provided for Ms. Milman to facilitate the recruitment process

(see Appendix A). Recruitment was done via mail, email, telephone or in person during VEPC assemblies. The investigator was provided the contact information of those who wished to participate.

All interested individuals were sent a letter of introduction (see Appendix B) outlining the purpose and specific objectives of the study. Letters described the interview process, and emphasized the voluntary nature of participation. Families were also informed of data analysis procedures and ways in which findings would be disseminated. Contact information of the primary investigator, the research assistant, and the Associate Vice President Research at the University of Victoria was provided if the family had additional questions or wanted to verify the ethical approval of the study. The families were then contacted by phone to arrange an interview at their convenience.

Before interviews were conducted, primary caregivers were asked to sign a consent form (see Appendix C). Consent forms outlined the purpose and objectives of the study, the study's rationale, and the reason the child had been asked to participate. The consent form assured confidentiality and explained that the family may withdraw at any time. Interview and data analysis procedures were described, and the time commitment involved was addressed. Potential benefits and inconveniences were discussed, as well as the process for ongoing consent. Finally, families were told how information from the study would be disseminated. Contact information of the Associate Vice President Research of the University of Victoria was provided so families could verify ethical approval. Verbal consent was also obtained from the child at the time of the interview (see Appendix D).

### *Participants*

Six children between the ages of 7 and 12 years were recruited for this study. This age range assures children have the cognitive ability to reflect on and self-report emotional experiences (Yule, 1993). Participants had a diagnosis of epilepsy and were enrolled in a school district in the Victoria, British Columbia region. Three participants attended a public school, and two attended a private school. One participant was being home-schooled at the time of the interview. Types of seizures that these children experienced were petite mal, absence, grand mal, and complex partial. All but one child took medication to control his or her seizures (Table 1).

### *Data Collection*

Over a period of five months, the researcher interviewed six children with epilepsy in the Victoria, BC region. Interviews took place in the homes of the participants, or at a location of their choice. If children or caregivers were uncomfortable with one-on-one interviews, caregivers were given the option to be present during the interview. None of the participants requested this option. Before proceeding with the interview, the researcher established rapport by talking with the child about their interests.

Data was gathered through in-depth, semi-structured interviews. The interview guide was based on Keith and Schalock's (1994) quality of life model, and was modified from Roberts and Cairns (1999) (see Appendix E). Initial interviews lasted between fifteen minutes and sixty minutes, and began by asking the participants to draw a picture of what it is like to have epilepsy at school. Beginning with this activity allowed the researcher to build rapport with the child, and prompted the child to reflect on his or her school experiences (Mauthner, 1997). This method has also been shown to help children focus on the research question (Mauthner, 1997)

Open-ended questions that pertain to quality of life experiences and interactions with the

Table 1

*Participant Demographics*

Pseudonym	Age in Years	Age of Onset in Years	Type of Seizure	Current Medication
Rachel	7	3	Petite Mal	Levetiracetam
Bradley	9	6	Absence	Zarontin
Emily	8	4	Grand Mal	Keppra
Thomas	12	11 <sup>a</sup>	Absence	Lamictal and Epival
Nicole	11	5	Complex Partial	Unmedicated
Anna	11	7	Grand Mal	Keppra

<sup>a</sup> Diagnosis obtained at age 11, but parent reported symptoms started at age 3.

school systems followed the activity. If a child did not understand a question, simplified language was used. If the participant provided short or ambiguous explanations, clarifying and elaborating probes were used (see Appendix E). This process was informed by research that suggests young children can better reflect on emotional experiences when provided with more structured questions (Zeman, et al., 2007).

The investigator periodically updated the families about the progress of the study. This was done by phone. During these updates, children and families were reminded that participation is voluntary and that they may choose to withdraw at any time.

*Reflexivity*

As the researcher was emotionally and professionally invested in the lives of children with epilepsy due to her involvement with VEPC, it was essential for her to bracket her presuppositions and document her thoughts and decisions throughout the entire process. To

address this component of the study, the researcher kept a journal that was used throughout the entire process. As is evident from the researcher's first reflection, becoming aware of personal biases is an important step in eliciting the truth of a phenomenon:

*My literature review has been interpreted as having a 'negative' feel to it – meaning that children with epilepsy typically have bad experiences. I think this interpretation is correct. My current belief is that epilepsy hinders school experiences, and that most children with epilepsy have negative experiences. I really need to bracket these presumptions so that I can truly get a sense of what school is like for children with epilepsy. It is equally as possible that children with epilepsy have great school experience (May 2, 2009).*

Throughout the study, the researcher discussed her beliefs and assumptions, particularly before an interview or a day of analysis. This was particularly important since the researcher was involved in another study that spoke with parents of children with epilepsy. As such, it was necessary to acknowledge the parents' experiences and set aside biases and beliefs that were developed from those interviews.

*I am doing another child interview today with one of the children from the tutoring program. I feel like she will talk about her positive experiences. This may be because she has never mentioned any problems at tutoring, and her mother also mentioned she had a positive experience during her interview. I need to push these assumptions aside and allow her to talk about her experiences without any presuppositions from me (May 5, 2010).*

Decision-making processes were also documented in the journal so as to ensure the credibility of the study. The following quotation illustrates the thought process behind her decision to supplement the word “epilepsy” in her interview with “having seizures”:

*I do, however, want to discuss with my supervisor the possibility that the children don't understand what 'epilepsy' is. Perhaps it would be best to word it 'having seizures' instead. In my experience, I've seen children know that they have seizures, but not understand the term 'epilepsy.' I will discuss all this with my supervisor (June 5, 2010).*

### *Data Analysis*

Phenomenological data analysis allows for the essence of a phenomenon or experience to be revealed (Creswell, 1998; Donalek, 2004; Giorgi, 2006; Hyener, 1985; Wertz, 2005; Wimpenny & Gas, 2000). To ensure the essence of the phenomenon emerged from the interviews during analysis, the researcher bracketed her presuppositions of the phenomenon and maintained openness to emergent themes (Creswell, 1998, 2005; Donalek, 2004; Hyener, 1985). Of course, a complete phenomenological reduction is impossible, and to suggest that the research and analysis is objective is misleading (Hyerner, 1985). To ensure that bracketing was attempted, the researcher continuously reflected on her perceptions of the phenomenon, as well as decisions that were made. These reflections were documented in a journal (Hyener, 1985).

After completing the initial interviews with participants and bracketing presuppositions, the researcher extensively reviewed and transcribed the interviews verbatim. This included all literal statements, as well as any non-verbal and paralinguistic communications, such as intonations, emphasis and pauses (Hyener, 1985). Typed transcripts had a large margin for notes on meaning units and themes (Hyener, 1985).

To gain a sense of the participants' overall meaning, the researcher immersed herself in the data and extensively reviewed the transcriptions (Roberts & Cairns, 1999). The researcher extracted significant statements that represent how the participants experience school (Colaizzi, 1973; Heyner, 1985; Roberts & Cairns, 1999; Wertz, 2005). Statements were then searched for patterns, or themes, that formed a comprehensive understanding of the participants' experiences (Colaizzi, 1973; Creswell, 1998, 2005; Roberts & Cairns, 1999; Wertz, 2005). Themes were categorized and labelled according to their most central meaning (Roberts & Cairns, 1999). Due to the small sample size, if two or more participants mentioned an issue or topic in their interviews, it was considered a theme. Throughout this process, the researcher continued to reflect on and record her thoughts in a journal.

To validate interpretations of the interviews, photocopies of the transcribed interviews, along with notes and analysis, were reviewed with participants during a second interview (Roberts & Cairns, 1999). These interviews were between ten and sixty minutes in duration, and allowed participants to provide feedback or additional comments. The majority of the participants added additional comments, and as such, these comments were recorded and included in the analysis. Only two participants clarified the meaning of statements in the initial interview. This procedure ensured the truth value and credibility of the analysis. Final analyses generated themes that presented a description of the school experiences of children with epilepsy.

### *Ethical Considerations*

Vital to any research project is the ethical consideration of the study. Approval from the Human Research Ethics Board ensured that the study's benefits outweighed any risks involved. In this study, a number of potential risks existed. Participants could feel sad or angry if they have

had negative school experiences. It was expected, however, that the research would be of no greater risk than what the child would encounter in daily life. Participants were never forced to discuss negative experiences. The researcher was careful to pace the interviews according to the child's needs.

As interviews required up to two hour with each participant, the child and his/her family may have been inconvenienced. To alleviate some of this inconvenience, families had the opportunity to choose the time and location of the interview. Further, although participants were encouraged to share their school experiences as fully as possible, they were never forced to remain in the interview.

Another essential ethical consideration was receiving consent from parents/guardians, and the children. After initial contact with the families, the investigator distributed consent forms to the primary caregivers of individuals interested in participating. Children were asked to give verbal consent at the time of the interview.

Ongoing consent is also necessary in any investigation. In this study, the investigator periodically updated participating families about the progress of the study by phone. During these updates, children and families were reminded that participation is voluntary.

Discussion of anonymity and confidentiality of participants is also necessary. Ensuring anonymity means that responses cannot be associated with individual participants. Confidentiality refers to the protection, access, control and security of participants' identity, as well as his or her data and personal information. Confidentiality is considered during recruitment and data collection, as well as when disseminating findings.

Although this study could not guarantee anonymity due to the nature of data collection, the researcher ensured confidentiality. Data was kept in strictest confidence. The participants'

identities were never revealed, and at all times, the data was kept in a locked file cabinet. Once collected, the data was analyzed anonymously. No names, only a code number, were attached to this data. Although the findings may be published in academic journals, university lectures, or professional workshops, the names and identifying features of participants will never be used in the dissemination of the findings. Documents will be shredded and audio recordings will be incinerated five years after completion of the study. These issues and procedures were discussed in the consent forms that were distributed to the families of the participants.

### *Summary*

Chapter three outlined the research approach and design used to identify children's perceptions and experiences of having epilepsy at school. An overview of specific data collection methods and analysis was also provided. The chapter ended with a discussion of the ethical considerations for this study.

Chapter four will describe the findings obtained from the interviews. A synopsis of essential structure of the perceptions and experiences will be provided, as well as the thematic, cluster, and categorical representations. Additionally, participant quotations are presented so as portray the meaning of the children's lived experiences.

## Chapter Four: Findings

Chapter four describes the findings of the data analysis. A description of the participants and an outline of their essential experience and perception of having epilepsy at school will be provided. An explanation of the thematic, cluster, and categorical representations will follow. Quotations from the interviews will be presented in the final section so as to portray the meaning of the children's lived experience of having epilepsy at school.

### *Participant Profile*

Six children between the ages of 7 and 12 years participated in this study. Each child was currently enrolled in an elementary school in the Victoria region and had a diagnosis of epilepsy. Table 1 provides the children's demographical information. To ensure confidentiality, pseudonyms are used (Table 1).

### *Essential Experience*

The school experiences and perceptions of six children with epilepsy were explored through in-depth interviews. Interviews aimed to elicit an accurate and detailed illustration of these children's school experiences. The children's narratives were characterized by their seizure experiences, education experiences, feelings of belonging, as well as others' awareness of their condition. As revealed through the interviews, it is these four categories that illustrate how school is experienced by children with epilepsy.

For the children in this study, seizures added to the complexity of the school experience. As seizures can be experienced quite differently among individuals, their influence on school experiences can vary. For some of the participants, seizures were described as brief interruptions to their connection with reality. For others, seizures were a source of anxiety, and created a dependence on others and an urgent need for first aid knowledge.

The participants also discussed how they perceived others' perceptions and reactions to their seizures. Many of the participants felt their epilepsy worried their teachers, creating anxiety within the school community around how to maintain their safety. This anxiety often manifested as overprotection, which disrupted feelings of normalcy and belonging.

Seizures also influenced the children's well-being, specifically their physical and emotional health. Seizures were described as taking a physical toll on the children's wellness, particularly with regards to post-seizure effects and medication changes. The children described their experiences with physical discomfort following a seizure, particularly the confusion and fatigue that can occur after some seizures. Medications were another source of physical discomfort for the participants. While medication experimentation is necessary to obtain seizure control, frequent changes often caused illness and discomfort. Epilepsy also influenced the participants' emotional well-being. The children spoke to their feelings of anxiety, anger, and frustration of living with epilepsy. These negative feelings were attributed to their seizures, bullying experiences, academic difficulties, and medication experimentation. Despite the negative influences on their physical and emotional health, many participants maintained a positive view of themselves, particularly in the school setting. A sense of hope was also evident among the participants. Many of the participants stated that they would outgrow their epilepsy, giving them hope of permanent recovery.

Participants also discussed their specific needs before, during, and after a seizure. These needs surrounded seizure prevention, seizure first aid, ongoing support, and empathy from teachers. The participants felt that support in these areas contributed to positive school experiences.

The children in this study held both positive and negative views of their educational experience. Academic frustration was discussed by many of the participants, both in general as well as in specific subject areas. The children explained their involvement with educational services, such as learning support teachers, as well as the many adaptations and accommodations they experience in the classroom on a daily basis. When these supports were appropriately provided, the children generally had a positive view of their educational experience.

A common topic during the interviews was the importance of socialization and acceptance at school. While some commented on their frustration caused by social isolation and bullying, many spoke of the value of their friendships and the support they received from peers. The children also discussed issues of normalcy. Because of their seizure control, many felt their school experiences were “typical.” The children realized, however, that there were limitations on activities because of their epilepsy. Other children described their feelings of abnormality, and stated they felt they received differential treatment because of their diagnosis.

Building awareness and educating their school community about epilepsy was important to many of the participants. The children felt that education would alleviate the misconceptions that people have about their condition, and help spread awareness of what seizures look like, how seizures can be triggered, and how to help in the event of a seizure. The children recommended that nurses or community advocates educate school personnel and their peers. They also suggested that schools participate in Purple Day, an international campaign that builds epilepsy awareness.

An important part of the children’s school experiences was disclosure of their condition. Peer disclosure was not viewed as a difficult task by many of the participants. Children who discussed their disclosures felt it was necessary to inform their peers about their epilepsy to gain

their support and understanding, as well as to prepare them in the event that a seizure occurs in their presence. For some, disclosures were met with unpleasant reactions from teachers and peers, and many felt stigmatized.

The participants also felt a need to build their own awareness of their epilepsy. Some of the children discussed their attempt to learn more about the condition so as to help others understand what epilepsy is, and how to support them. Others described their awareness of the signals their bodies give them prior to a seizure. Building their knowledge of epilepsy not only allows them to understand their personal needs, but also helps them explain and advocate for themselves.

#### *Categorical, Clusters, and Thematic Structures*

The findings of this study were used to understand the perceptions and experiences of school children with epilepsy. Data analysis of the interviews revealed four categories: (1) The Seizure Experience, (2) The Educational Experience, (3) Social Belonging, and (4) Awareness. Within each of these categories are clusters made up of two or more themes. Table 2 provides an overview of the categorical and cluster structures derived from the analysis.

#### *Category One: The Seizure Experience*

Living with epilepsy adds to the complexity of a child's school experience, particularly when seizures occur in the school setting. Seizures were discussed by many of the participants, making the seizure experience an important component of their overall school experience. The seizure experience encompasses the physical and emotional experience of having a seizure, as well as the specific needs that arise when seizures occur. This category is comprised of two thematic clusters: a) Seizures at School b) Impact on Wellness, and c) Needs of the Child (Table 2). Although each seizure experience is unique to the individual, when considered together, an

Table 2

*Categories and Clusters Derived from Data Analysis*

Categories			
The Seizure Experience	The Educational Experience	Social Belonging	Awareness
Clusters within each Category			
1. Seizures at School	1. School Experiences of the Child	1. Interpersonal Relations of Child	1. Awareness of School Community
2. Impact on Wellness	2. Academic Issues	2. Issues of Normalcy	2. Awareness of Child
3. Needs of the Child			3. Issues of Disclosure

illustration of the children's lived experiences emerges.

*Cluster One: Seizures at School*

Many children interviewed for this study described their personal seizure experiences, particularly when the seizures occurred at school. The discussion centred around two main themes: i) Experience of the Child, and ii) Perceptions and Experiences of the School (Table 3). The themes illustrate how the children perceive seizures to impact their school experiences.

Each child in the study has been diagnosed with epilepsy. As there are various forms of epilepsy, children's seizures can be experienced quite differently, and can thus impact their experiences in varying ways. This diversity was portrayed in the narratives of the participants. While some participants described, in detail, their seizures' impact on their educational experiences, others did not mention their seizures at all. For those who chose to discuss their seizures during the interview, their various influences were depicted. For Thomas, a grade five student with childhood absence epilepsy, seizures interrupt his connection with reality:

I've no clue because half the time I'm not there... Well I just kinda, well the type of epilepsy that I have I go like, like you could be talking to me I could you could be talking to you right now, all of a sudden I could like (pause) [*imitates a blank stare*]... And y- you could go like [*snaps fingers*] Thomas, Thomas and you could go like that and I'd be like 'what?'

Thomas's seizures cause him to "just go black," which he expressed as having an impact on how he experiences school, both academically and socially, due to his brief disconnect with the world.

Emily, a grade two student who has Tonic Clonic seizures, illustrated her seizure experiences through her drawing (see Figure 1). In her picture, Emily drew herself lying on the ground having a seizure. Interestingly, she drew herself using an orange marker, while her teachers and peers were drawn in brown. Through discussion of this illustration, Emily conveyed that she feels different than others when having a seizure. She further described the people around her as "sad" and "not happy," and stated that the tall figure, a teacher, was going to call an ambulance. The way Emily experiences her seizures is different than the how they are experienced by Thomas. This demonstrates the diversity of seizure manifestations, highlighting their varying influence on how one perceives and experiences school. As such, examining the seizure experience is an essential component in understanding these children's lived experiences of attending school with epilepsy.

As part of their seizure experience, some children described the warning signs of an oncoming seizure, and how this affects their seizure experiences at school. For some children with epilepsy, their bodies send warning signals that a seizure is about to occur. For Anna, a grade six student, this warning allows her to ask for assistance before a seizure occurs:



Figure 1. What it is like to have epilepsy at school. Illustration by Emily, age 8.

Table 3

*Clusters and Themes for “The Seizure Experience”*  
 (% = percentage of participants who addressed each theme)

Clusters		
Seizures at School	Impact on Wellness	Needs of the Child
Themes within the Cluster		
Experience of the Child (67%)	Physical Wellness (33%)	Teacher Support (33%)
Perceptions and Experiences of the School (50%)	Emotional Wellness (67%)	Empathy (50%)
	Hope (33%)	

And like I had a small seizure and like I knew it was going to happen so like I was telling like everybody that was coming up to me asking what was wrong I was telling them to go find the teacher and get her to come into the class. And I really didn't like that teacher cuz she was really rude and stuff but she was really helpful that day cuz like, well kind of helpful. She, it was perfect timing that she got there cuz she got there right as I was like falling off my chair? And like it didn't last that long it was like five seconds or so.

For some children with epilepsy, these warning signs can provide a sense of control in an otherwise uncontrollable situation. By understanding their bodies, the children have time to ask for assistance, thereby ensuring their own safety and giving them a sense of control.

While the children in this study illustrated their personal perceptions and experiences of having a seizure, they also provided insight as to how they believe others perceive and experience their seizures. As mentioned above, Emily portrayed a sense of anxiety in her picture by describing her peers and teacher as “not happy” and “sad” during her seizures. This negative perception was described by other participants. Nicole, who is currently home-schooled, recalled

her experiences in the public system. She believed that the school overreacted to her seizures, stating, “usually when I was having seizures they’d freak out like I was hm, like I was p- like I’d be puking and stuff and they’d just stick me in the emergency room and call ambulances all the time.” In her perspective, Nicole believed the school’s decision to call emergency personnel was unnecessary and melodramatic. Nicole’s discussion of her drawing also portrayed this perception: “That’s like me having a seizure...And the teachers would just kind of, panic, like.”

Anna also talked about the anxiety that the school has around her seizures. She commented that when she has a seizure, “everybody all like ru- rushes to you like trying to remember what to do from like stuff.” Anna’s comment conveys a sense of anxiety among teachers and peers around seizure first aid. The perceptions elicited from many of the participants conveyed an overall sense of anxiety among school personnel.

#### *Cluster Two: Impact on Wellness*

Many of the children in this study described the impact epilepsy has on their wellness. Three themes arose in this cluster: i) Physical Wellness, ii) Emotional Wellness, and iii) Hope (Table 3). Each of these themes contributed to a detailed illustration of how seizures can impact these children’s physical and emotional well-being.

As seizures are a physical experience that the body endures, it is not surprising that the children in this study detailed the physical impact of their epilepsy. Some participants chose to discuss post-seizure effects. Following a seizure, some of the participants felt confused and lethargic, as described by Nicole:

Kind of confused, kind of like ‘what the hell are they doing with me right now?’

Especially when I was in postictal confusion and I was in the ambulance, I just kind of mildly struggled then I’d kind of be conked out (laughs).

These effects made a recovery period essential to their well being. This need was conveyed by Nicole: “And I, and the worst part, I get so I get many seizures cuz I get, keep getting sick without the chance to recover.”

Nicole further describes her frustration with medication experimentation: “and they were experimenting with various horrible medications that made my epilepsy even worse. I hm, back then I felt like a lab animal.” Nicole went on to say that changing medications made her feel “overheated and pukey.” She stated she felt “sick most of the time so [she] just kinda got the hm kind of slimy feeling you get when you’re sick. That was the kind of feeling I had cuz I was sick *all the time*.” For children with epilepsy, medication changes occur quite frequently, as it is important to find a drug and dose that is compatible with your body. As portrayed in Nicole’s description, these changes can have a negative impact on one’s physical well-being.

Rachel, a student in grade two, was concerned about maintaining a healthy lifestyle through physical activity and a nutritious diet. Rachel made several comments about getting “tons of exercise” and eating nutritious food. These concerns demonstrate the need maintain a body healthy by making healthy choices in their day to day life.

In addition to the physical impact of epilepsy, many participants referred to their emotional experiences in their discussion. These emotional experiences varied, but when considered mutually, convey a sense of anxiety and frustration. For example, Emily discussed how having a seizure frightened her. Her fear is evident when she states: “Cuz if I have a seizure, I might have to go to the hospital and I don’t like that.” While feelings of anxiety emerge from the occurrence of a seizure for some children, others feel anxiety and frustration as a result of the various effects epilepsy can have on their daily experiences. For example, Nicole commented on the emotional impact of changing medications: “Often times I felt (pause) emotional-wise I felt

like a lab animal.” Her statement reveals feelings of frustrations during her hunt for seizure control. Feelings of frustration were also illustrated in other statements concerning bullying and academic concerns. Nicole conveyed how angry she was about the bullying incidents through her statement:

Well I had a really good hm friend named Scott and it was a boy, and the older snot kids that was older brother’s friends? And they kept teasing me and teasing me. One time I hm, hm I ended up chasing them and rip- hm, like chasing them and grabbing them...

Thomas said he felt school was stressful, and went on to comment that “there’s a bunch of, there’s a bunch of, there’s stuff that hasta be handed in and I, like, do it and I, forget to do it and then I have to hand it in and then, everything gets all, mixed up.”

Despite the negative impact on their emotional well-being, some of the participants said they held a positive view of themselves as students. Thomas’s positive sense of self was developed through comments by his teachers on his report card: “Well, on my report card all my teachers said I was really...enthusiastic.” Others agreed with Thomas, stating that they felt “good” at school.

When meeting for the validation process, some of the participants stated that they believed their epilepsy was temporary. Thomas discussed how he plans on stopping his medication at age 15, and that there was a point in which he will experience permanent recovery. Bradley mentioned that his seizures are “starting to go away.” Their perceptions of epilepsy as a temporary condition convey a strong sense of hope among some of the children.

### *Cluster Three: Needs of the Child*

Many of the children discussed their personal needs when experiencing a seizure. This cluster contained two themes: i) Teacher Support, and ii) Empathy (Table 3). Enforcing seizure

prevention was important to many of the participants. For example, Anna detailed her teacher's support in preventing her seizures from occurring. Her photosensitivity creates a problem when her peers bring toys with flashing lights to school. Anna describes her teacher's support during a time when her classmates brought flashing pins to school: "Like sometimes I like whenever they do I tell the teacher. M- the good one that I like she um does something about it..." Anna's comment illustrates the importance of the school's support in maintaining a learning environment safe of seizure triggers.

Some of the participants described their dependence on teachers and peers during a seizure. Many of the children spoke of their need for the school's flexibility after a seizure occurs. Nicole conveyed this when she discussed a positive aspect of being home-schooled: "I can, I have access to all sorts of stuff when I get seizures." In her picture (see Figure 2), Anna illustrated two individuals bending down to help her during a seizure. She described how she relies on her teachers and peers to help her during this vulnerable time. Other participants also expressed appreciation for their teacher's willingness to help. During his interview, Thomas described his teachers' support, stating: "Like um, like when you have to explain to them what you have [epilepsy], they like take it and like they do as much as they can to help you."

The participants also revealed their desire for empathy from teachers and peers. As Emily conveys in her statement, empathy is an important part of her seizure recovery: "They help when, when, when I get sick. They come to the hospital every time I get sick. And they give me a card. That's what they always do." Emily's comment demonstrates the importance of having a caring school community to create a positive educational experience for children with epilepsy.

### *Category Two: The Educational Experience*

Throughout each of their interviews, the children discussed their perceptions and experiences within the school. This category is characterized by the children's general feelings about their experiences at school, as well as the various academic challenges and support they experience in the classroom. The children in this study came from a mixture of private and public education systems. For some, an opportunity to experience both public and private systems offered a unique perspective, allowing them to compare and contrast their experiences in both systems. The participants' descriptions also focused around the academic difficulties that are so often experienced by children with epilepsy. Their inimitable perceptions offer insight to their frustration and acceptance of their daily challenges in the classroom. This category envelops two thematic clusters: a) School Experiences of the Child, and b) Academic Issues (Table 2).

#### *Cluster One: School Experiences of the Child*

Cluster one is made up of two themes: i) Positive Experience, and ii) Negative Experience (Table 4). Throughout the interviews, the participants spoke of their positive and negative experiences with their current or previous school. For many of the children, they had a positive experience, particularly if they attended a private school. In Thomas's discussion, he said "I don't know my school's a really good, private school so it's good." This comment portrays many of the participants' positive feelings about their private school. Others who attended public educational systems also believed they had positive experiences, as portrayed through Emily's comment: "Uh, I like school. And it's fun to have friends".



Figure 2. What it is like to have epilepsy at school. Illustration by Anna, age 11.

Other students felt that the public school systems provided them with a negative experience, as shown through Nicole's comment when asked how she felt about school: "It depends on the school. If it's home school, oh good heaven. But if it's public school? *No way* you're sending me there." A picture drawn by Emily illustrates negative feelings about having epilepsy at her school (see Figure 1). When asked about her picture, Emily stated: "that's supposed to be sad." The varied feelings create a need to investigate the specific aspects that encompass these children's school experiences.

#### *Cluster Two: Academic Issues*

The narratives of the participants described experiences related to their academic success and challenges. Two themes comprised this cluster: i) Academic Difficulties, and ii) Academic Support (Table 4).

Some interviews elicited discussions of the academic challenges the children experience at school. While academic challenges were common, the way they were experienced varied between participants. For Thomas, academic difficulties are more generalized and are a daily frustration: "It takes, it takes longer to do things...Um, it's hard to be organized." Thomas also describes his forgetfulness as a source of frustration: "I forget things a lot...Uh, I can't find things." Thomas's challenges affect all aspects of the school day, as these skills are essential for learning, completing, and submitting assignments. Other students, however, experience difficulties in specific academic areas. Rachel states, "One concern, one concern I have at school is I get frustrated with math." Rachel felt confident about her overall academic achievement, but expressed concern over her abilities in math. Despite the individual challenges that were discussed in the interviews, it was evident that many school experiences were accompanied by academic difficulties.

Table 4

*Clusters and Themes for “The Educational Experience”*  
 (% = percentage of participants who addressed each theme)

Clusters	
School Experiences of the Child	Academic Issues
Themes within the Cluster	
Positive Experience (67%)	Academic Difficulties (50%)
Negative Experience (33%)	Academic Support (83%)

Suggestions for academic adaptations and accommodations were made by many of the participants. The participants felt these supports have helped their academic success, or would be helpful if they were to be implemented. Nicole made several suggestions about being flexible with the amount of time to complete schoolwork: “One thing I suggest for school, is to (pause) is to give um, is to give not really times events like in grade one like try and make it stress-free as possible.” Bradley spoke of the specific adaptations that were made to his assignments, mentioning that “she’ll [the teacher] give us easier sheets.” These discussions not only revealed the children’s desire for support in the classroom, but also demonstrated their understanding of their own academic needs.

In addition to specific adaptations, many of the children spoke of the additional support they received from their teachers. This support helped the children feel a sense of success in the classroom. Emily spoke highly of her teacher’s support when she commented, “And I- I like my teacher a lot. She’s nice to me and, she helps me sometimes.” Throughout his interview, Thomas mentioned the extensive support he received from his learning support teacher: “And I can’t do math I don’t, like, I can do, I I can do math, anybody can do math, but like, I just, like she helps

me with it.” These quotations demonstrate the importance of the teacher’s support in promoting safe learning environments and positive school experiences.

### *Category Three: Social Belonging*

Each child in the study discussed their social experiences at school. This category explores how the children relate to their peers, and feel a sense of belonging in their school community. The frequency with which the participants mentioned interpersonal relationships is indicative of its importance to the school experiences of these children. The children spoke of their experiences with peer acceptance, as well instances of social isolation and bullying. The social belonging category is comprised of two thematic clusters: a) Interpersonal Relations, and b) Issues of Normalcy. Each thematic cluster was used to illustrate the social experiences of children with epilepsy.

#### *Cluster One: Interpersonal Relations*

Narratives elicited during the interviews provided insight as to how these children experience interpersonal relations at school. As such, cluster one is comprised of two themes: i) Bullying, and ii) Friendships (Table 5).

The children’s narratives revealed instances of bullying. Two of the participants spoke repeatedly of negative treatment by their peers. While some bullying was verbal in nature, other instances of bullying were physical and violent. Nicole conveyed her feelings of being socially isolated and bullied when she stated: “Uh, I have a couple good friends but apart from (pause) and, but apart from that most of the kids kind of tr- hm, bullied me and treated me like a freak.” Nicole often used the term “freak” to describe how her peers, and teachers, treated her, and illustrated this perception in her drawing (see Figure 3). Emily experienced a more physical form of bullying and described these instances many time during her interview:

I always get arguments because people call me bad words, I have to go office. People call me, like “F” word and to go office. Some people punch me in the back, I had to go to office. Someone hit me in the basketball in the head I had to go to the office. Floor hockey when I fall I have to go office. An they, they use a stick, punch, and (pause) *hit me in the back* [whispered].

When she was asked to validate the analysis, Emily reiterated that these instances of bullying occurred quite frequently. The narratives of these children convey the social isolation and negative interpersonal relations that many of the participants experience at school.

Despite instances of bullying and mistreatment, all of the participants indicated they have positive social relationships. Each narrative emphasized the importance of positive social relations, suggesting its key role in positive school experiences. As Rachel explains, going to school provides an opportunity to develop positive social relationships: “*Interviewer*: Ok, so how do you feel about school?” *Rachel*: ‘Good...Because I get to play outside...And get to have new friends.’” Rachel’s narrative emphasizes the interconnectedness of her positive relationships and positive feelings at school.

Having a few close personal relationships was important to all of the children in this study. Bradley’s comment portrays the importance placed on having a best friend: “because they’re [peers] nice or mean so we got to get the best friends that you need?” Thomas spoke of a specific relationship he has with a peer who also has special needs. Thomas comments, “He’s he’s funny he’s really funny, but he just kinda, I help him, with stuff, a lot, cuz he always yells out stuff and, I have to kind of, cuz his mom wanted me to help him so I help him.” Having close

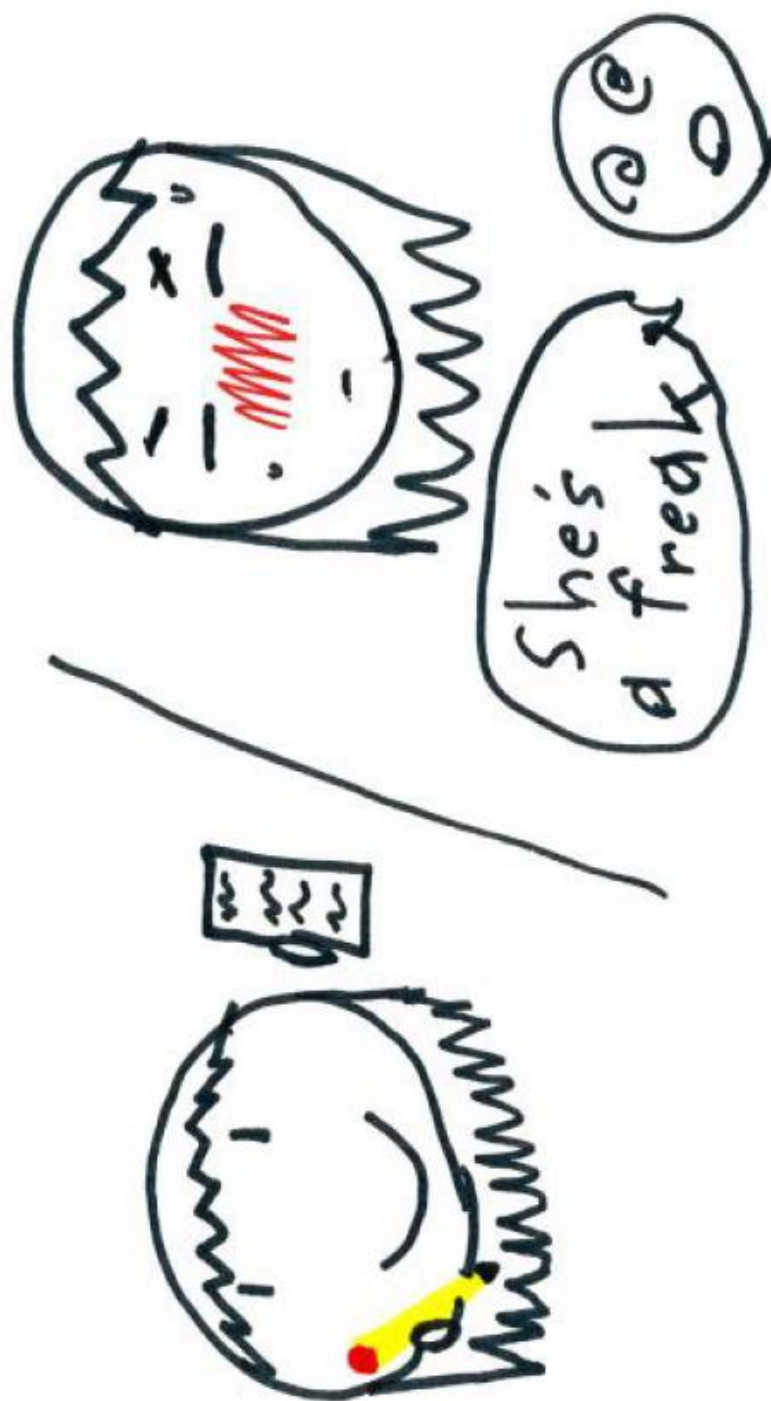


Figure 3. What it is like to have epilepsy at school. Illustration by Nicole, age 11. This drawing depicts Nicole's perceptions and experiences of having epilepsy at public school (right) and home school (left).

Table 5

*Clusters and Themes for “Social Belonging”**(% = percentage of participants who addressed each theme)*

Clusters	
Interpersonal Relations	Issues of Normalcy
Themes within the Cluster	
Bullying (33%)	Feelings of Normalcy (50%)
Friendships (100%)	Seizure Control (33%)
	Feeling Different (67%)
	Differential Treatment (33%)

relationships provide the children with a sense of social belonging in their community.

The children’s friendships were often defined by the support they provide. As illustrated in Emily’s comments, peer support was particularly important during a seizure: “Um, cuz I have um, lots of friends. And they all when I have seizures they they always help me and they tell the teacher... They run and tell the teacher, and then they’ll show tea- the teacher where I am.”

Having friends who understand their needs was also important to the children. Anna’s comment demonstrates the support she felt from her friends when she felt “shaky” and couldn’t participate in recess activities: “But me and my friends usually just like sit around whenever that happens cuz they understand and stuff.” As conveyed in this comment, support and understanding was an important component of friendship for these children.

*Cluster Two: Issues of Normalcy*

Throughout the interviews, the children discussed issues around maintaining a sense of normalcy. Although they recognize the need for restrictions and limitations because of their epilepsy, many viewed their school experiences as typical. Others felt different than their peers and believed they received differential treatment because of their epilepsy. Issues of Normalcy is comprised of five thematic clusters: i) Feelings of Normalcy, ii) Seizure Control, iii) Feeling Different, and v) Differential Treatment (Table 5).

Despite their diagnosis of epilepsy, many of the participants felt that their school experience was typical, and viewed themselves as “normal.” Anna conveyed this message when she said, “Um well, I just feel like a normal kid cuz like, I always take my pill and stuff and my friends are, they act normal around me they don’t like go like act weird or anything.” Anna’s sense of normalcy was attributed to the positive effects of her seizure medication. For Rachel, school allows her to “feel free from home,” offering a sense of normalcy and independence. Two of the participants believed that their school experiences were typical, but were still aware of their unique needs. These needs, however, did not seem to threatened their normalcy.

I don’t have a very, like the epilepsy that I have it’s not very bad. So the only way it effects me, like I’m not, like a really heavy ahh I need to have it’s (laughs) hard to explain but, I’m not just like really heavy duty it’s it’s not that bad it’s just, I have these things, when it happens, you know I need to go with the learning assistant. And that’s basically it. – Thomas, Grade 5

Anna has a similar reaction to her epilepsy, stating that her school experiences were typical, except when a seizure occurs: “Well, it’s kind of like a normal kid...Except for like of course you have epilepsy and it’s not that different? Except for when something happens.” Despite their

unique needs and occasional seizures, the children in this study conveyed feelings of normalcy. Participants often attributed their sense of normalcy to their seizure control.

With the exception of one child, all participants were taking medication to control their seizures. The seizure control obtained from taking the medication was a way for the children to maintain a sense of normalcy in their lives. Anna's comment conveys this message: "Um well, I just feel like a normal kid cuz like, I always take my pill and stuff and my friends are, they act normal around me they don't like go like act weird or anything." Anna's seizure control decreases the symptoms of her condition so that her epilepsy is not visible to her peers. This enhances her sense of normalcy. Thomas experiences a similar sense of normalcy: "And, I have to, like, take, uh (pause) five pills every day. And I have like I haven't had one of those things [absence seizures] in like, well I don't like usually have them anymore. But I used to have them like eight times every day." By controlling his absence seizures, Thomas feels more present in his daily interactions, thereby increasing his sense of normalcy

While many of the children in this study felt a sense of normalcy, others felt a sense of aberration. Thomas commented on his drawing (see Figure 4), stating that he "feels self-conscious" at school. In his picture, Thomas drew himself looking confused about a concept he being taught in class, while his peers say "this is easy." In terms of academic ability, Thomas felt different than his peers.

Emily also felt a sense of aberration. In her drawing (see Figure 1), Emily drew herself with orange, whereas the rest of her peers were brown. While discussing her picture during the validation process, Emily said that she feels different than her peers. An extreme sense of abnormality was conveyed in Nicole's interview. Nicole used the term "freak" throughout the interview to describe how others perceive her. She states: "But when they did notice [me having

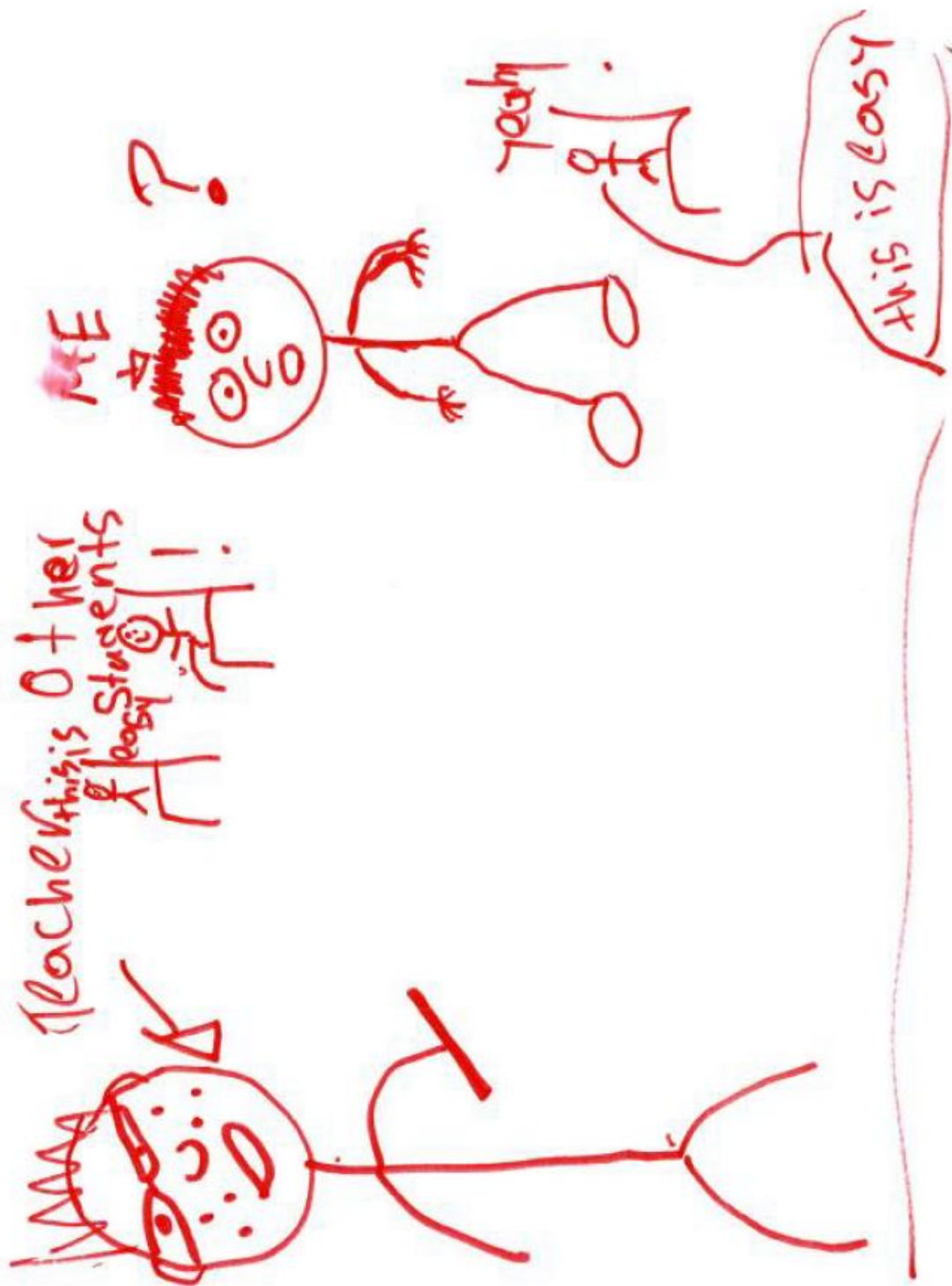


Figure 4. What it is like to have epilepsy at school. Illustration by Thomas, age 12.

a seizure] they [the teachers] tr- they treated me like a freak... They treated me like I had some sort of serious disease or something.”

Feelings of normalcy can be discouraged by restrictions and limitations on activities. Some of the participants conveyed that, although they feel they have a typical school experience, there are limitations as to the activities they can participate in because of their epilepsy. Anna illustrated this when she said, “... school’s perfectly normal and like I can do everything that everybody else can except for like running around too much can make me um feel a little shaky sometimes.” Similarly, Nicole recalled a time when she wanted to participate in a running activity, but was asked by her teachers to “do it at a slowed pace” because she was recovering from a cold. Although some of the participants understood why limitations were enforced, they can threaten the normalcy that the children desire in their lives.

Throughout the interviews, many of the children also commented on the differential treatment by their teachers, and attributed this to their epilepsy diagnosis. As illustrated in Nicole’s comment, some of the participants felt their teachers treated them in a negative way: “[they] didn’t treat kids equally. They treated other kids better.” Nicole also perceived differential treatment by her teachers, who she said viewed her unnecessarily as having special learning needs. This label contradicted her desire for normalcy and created hostility towards her teacher: “Yeah she tried to be hm, I think she was trying to use me to get as a special needs child in order to hm get some more relaxation cuz hm they get assistance when there’s a special needs child in the classroom? So essentially I was just treated like a freak.”

While some children experienced negative differential treatment, others felt they were treated “better” than their peers. Anna conveys this message when she shared the following statement:

[The teacher] treats people with like, i- if she was like um uh my friend has a heart problem and like I have epilepsy she treats them [students with a condition] a little better than she treats normal people...she's not *as* mean as she would be to everybody else...and like she lets us like phone home a lot more often than other people.

Although this may seem to portray empathetic teachers, the children felt that it threatened their normalcy, and desired to be treated equally to their peers.

#### *Category Four: Awareness*

The importance of epilepsy awareness and education was a common occurrence during the interviews. Each participant felt that it was necessary to education teachers and peers about epilepsy so as to avoid misunderstandings, and create a safe environment for the children to learn in. The participants also saw value in their own knowledge and understanding of their epilepsy. The Awareness category discusses the importance of epilepsy education throughout the school community, and is comprised of three thematic clusters: a) Awareness of the School Community, b) Awareness of the Child, and c) Issues of Disclosure (Table 2).

##### *Cluster One: Awareness of the School Community*

The children in this study continuously discussed the importance of the school's awareness of epilepsy, particularly when a child who attends the school has the condition. The children, however, were adamant that this awareness goes beyond simple knowledge of the presence of epilepsy in the school. Education about epilepsy was deemed important, not only to evaporate misconceptions about the condition, but to ensure that the teachers know what to do during a seizure, how to prevent one from occurring, as well as how to handle the symptoms and side effects, such as academic difficulties. This cluster consists of three themes: i)

Misconceptions of Epilepsy, ii) Safety, and iii) Faculty and Peer Awareness and Education (Table 6).

Some of the interviews detailed the misconceptions that their school had about epilepsy. The children described these misunderstandings as frustrating. Nicole stated that her teachers assumed her diagnosis of epilepsy meant she had special academic needs: “I think the stress was making me not learn, very properly. And they also had kind of stuff under my learning level?” For others, teachers failed to recognize the symptoms of her epilepsy. In Anna’s experience, her teachers misinterpreted her seizures for daydreaming: “Well they don’t really realize it when like people have when like some of the kids have like zone outs like I do... They just kind of think it’s like day dreaming.” Misunderstandings such as these can also affect how the teacher’s react to symptoms, as is conveyed in Anna’s comment: “Cuz like sometimes I feel like I start to get a headache and stuff. But like my other teacher thinks that people sometimes fake it? So like she’s just like ‘Ok drink some water, go back to your work.’” Many participants suggested that teacher education and awareness of epilepsy would help eliminate these misconceptions.

While the participants agreed that teachers had knowledge of their diagnosis, many felt it was important to go beyond simple acknowledgement its presence, and believed their school should be educated about epilepsy. Unfortunately, many of the children felt that their school was not adequately educated about their condition. As Thomas illustrated in his picture, his teachers did not understand how to help him with his academic difficulties that were caused by his epilepsy. Thomas explained his picture by stating: “And they’re [peers] are saying it’s all easy and, that’s the teacher like ‘hey, I don’t know what to do, I don’t know how to teach people [with epilepsy].”” Other participants commented on their teachers’ minimal understanding about seizure triggers. For Anna, this is a major concern:

Table 6

*Clusters and Themes for “Awareness”**(% = percentage of participants who addressed each theme)*

Clusters		
Awareness of the School Community	Awareness of the Child	Issues of Disclosure
Themes within the Cluster		
Faculty and Peer Awareness and Education (50%)	Child’s Awareness of Epilepsy (33%)	Disclosure to Peers (33%)
Misconceptions of Epilepsy (33%)	Child’s awareness of Personal Needs (33%)	Stigma (50%)
Safety (50%)		

Well like sometimes when like the lights are flashing like I have seizures from that. Like if the if they’re flashing like really fl- fast like they’re dying or something? They [the school] should probably replace it a lot fast than, oh let me see, five days.

Some participants stated that their teachers may not recognize when a seizure was occurring.

This concern was illustrated in Nicole’s description, “In grade one I had seizures various times while doing school, while maybe sometimes when I was doing school work and the teachers wouldn’t even notice.” Nicole stated her teachers were also not educated about post-seizure effects. As such, her teacher often viewed effects such as postictal confusion, as part of the seizure, rather than a side effect.

To alleviate these issues, the participants suggested educating the staff about epilepsy. Education should include general information about epilepsy, as well as what to do if a seizure occurs at school. Anna's comment conveys this message:

I think that like they should like set something up at like the beginning of the year if there's people in the school with um uh epilepsy like all the teachers like have a meeting and stuff to like get told what like it's all about and stuff cuz a lot of people have epilepsy. But like no none like half the teachers don't really know what it is so like, they should get like a health nurse or something to tell them what it is.

The participants felt that if the teachers were educated on their condition, their overreactions would be eliminated, and their safety would be increased:

I'd advise that maybe they just try to educate the teachers a bit more about epilepsy? So that they know what to do when the teachers are when the kid's having a seizure and and they're not just like '*Bah! What the hell's happening I'm taking you to the emergency room!*'" - Nicole

Some of the participants suggested educating their peers as well. Anna had an epilepsy educator from the community talk to her classmates about her condition. Anna suggested that other classes, particularly those who host a student with epilepsy, educate their peers: "Like they did with my grade three class my mom set something up and we all got like a bookmark or something." One way to educate the school community, the children suggested, is through participation in Purple Day, which is a day that aims to create awareness around epilepsy. Anna recommended "making it like a spirit day or something" in order to build community awareness of epilepsy.

Teacher awareness and education would help ensure the safety of children with epilepsy. The participants spoke of the importance of a school safety plan. Communication procedures between home and school, as well as within the school community, should be included in this safety plan. Emily's discussion of the school's protocol during her seizure conveys her school's safety procedure:

And they [friends] all when I have seizures they they always help me and they tell the teacher... They run and tell the teacher, and then they'll show the teacher where I am... Then the teacher will call my mother, and my mom will call the ambulance.

Anna was concerned that not all staff was aware of her epilepsy. This created a fear that many would not know how to help in the event of a seizure. She stated, "None of them even know what it [epilepsy] is so they don't *know* what to do to help." Despite her perception that many teachers were not educated about epilepsy, she appreciated that her own classroom teacher, as well as her peers, knew what to do when she had a seizure in class: "Well she got there at the exact time, she got one of the kids to press the emergency button she knew exactly what to do."

#### *Cluster Two: Issues of Disclosure*

As part of their school experience, disclosing their epilepsy to their peers was an important part of the children's diagnosis. While some participants felt their peers embraced their epilepsy, others felt that they were stigmatized, particularly until their peers became more educated. This cluster envelops two themes: i) Disclosure to Peers, and ii) Stigma (Table 6).

Unlike many chronic illnesses and conditions, epilepsy is typically visible during school, particularly when seizure control has not been maintained. For students with epilepsy, disclosing their condition to peers is not only inevitable, it is an integral part of their safety. For Thomas, disclosing his condition was not difficult: "Everybody knows that I do [have epilepsy]."

Having peers who had experience with epilepsy made it easier to disclose, as portrayed in Anna's comment: "Like a few of them [friends] have like Dads and like cousins and uncles and stuff that have epilepsy so they know... what to do [when I have a seizure] and when some don't then I tell them what to do, and stuff." Anna's disclosure created curiosity among her peers. To portray her experiences and answer some of their questions, Anna decided to use art: "I wanted to show my friends and they were like well how can you really remember it? ... And I was like well maybe I can draw something." Like Anna, many of the participants felt that they could explain their epilepsy to their peers, making disclosing to peers a comfortable process.

Unfortunately for some participants, disclosures were met with hostility, and the participants found themselves attached to the stigma of their condition. When Anna initially told her friends she had epilepsy, her disclosure created fear among her peers: "Well like, at the first part my friends were kind of like concerned and stuff, so like they kind of stayed away for a little while and then like I, I like started to talk to them and say like it's not contagious and stuff cuz that's what they were probably thinking." Stigma was also created from peers' parents, who felt anxious around the idea of caring for a child with epilepsy. Thomas states:

Um, but uh, the medication, it's they're sometimes like really big, pills, I have to take three big pink pills, and then two small white ones, and it's it's really hard cuz sometimes when I go over to friend's house I have to like pull my pills out, and I have to take them. And the parents are like 'Ah!'

While many of the children shared that their peers began to accept their condition, others continued to feel stigmatized at school.

*Cluster Three: Awareness of the Child*

In addition to wanting teachers and peers to be aware of their condition, the participants in this study desired to increase their own awareness of epilepsy. This cluster is comprised of two themes: i) Child's Awareness of Epilepsy and ii) Child's Awareness of Personal Needs (Table 6).

Throughout the interviews, the children spoke of their determination to understand their epilepsy. For some, a general understanding of epilepsy was important. Nicole stated that she has "been studying about seizures and stuff and gotten very knowledgeable." Other children felt being aware of their personal situation was important. For example, Anna's understanding of her epilepsy allows her to recognize the messages her body is sending her. Throughout her interview, she spoke of getting a "shaky" feeling before her seizures occurred. This awareness of her body has helped her ask for help during a seizure: "And like I had a small seizure and like I *knew* it was going to happen so like I was telling like everybody that was coming up to me asking what was wrong I was telling them to go find the teacher and get her to come into the class." Knowledge of their condition also allowed the children to spread awareness: "Well some [teachers] knew what epilepsy was some didn't. Like my grade four teacher she had like no clue what it was I had to explain it to her like I had to explain it to mostly every, each one of my friends..." (Anna). As this quotation portrays, understanding their condition provided the children with the tools to build awareness in others, thereby alleviating misconceptions and promoting safety.

Knowledge of their condition allowed the children to be aware, and advocate, for their personal needs. As Anna explains, she feels teachers need to listen to children with epilepsy, as

they have a great understanding of their bodies' needs: "...sometimes when I feel a little shaky I get forced to still like go outside and like, do stuff."

While the children appreciated their parents educating others on their condition, some participants felt that they were knowledgeable enough to talk about it themselves. As Thomas explains, he was frustrated by the lack of trust others had in his own knowledge of his epilepsy: "I just feel kind of awkward cuz, whenever someone comes over it's like Oh, why do you take the medication? And then they like whisper to my mom and I'm like [whispers] 'I'm right here, why don't you just ask me?'" While the participants stated that the school community should be educated about epilepsy, many of them felt that they were knowledgeable enough to explain their condition and contribute to the school's awareness.

### *Summary*

Chapter four presented the findings derived from each interview. The participants' demographics were provided, and the children's essential experience was detailed. Categories, clusters and themes were explored using participant quotations to further illustrate their experiences.

Chapter five will discuss the findings of the investigation as it relates to current literature. Limitations and implications of the study will also be explored. As an objective of this study is to inform future investigations, directions for further research will be discussed.

## Chapter Five: Discussion

Chapter five provides an overview of the present investigation and its findings. The study's contribution to research will also be outlined. The findings will be then discussed in relation to the purpose of the study, and will take place in the context of relevant literature. Following this discussion, the limitations and implications of the study will be provided. Chapter five will close with suggested directions for future research, and a final summary of the investigation.

### *Summary*

Following a phenomenological methodology, this study sought to understand the school experiences of children with epilepsy. Interviews with six participants identified children's perceptions and experiences of having epilepsy at school, and provided insight to inform future studies.

### *Research Contributions*

Existing literature examining QOL of children with epilepsy has focused on a general understanding of how epilepsy impacts physical, emotional/behavioural, social, and academic domains as a whole in various contexts (Elliot et al., 2005). Although literature emphasizes the importance of schools in promoting children's psychological, social, and physical health (Weissberg, Caplan, & Harwood, 1991), there is a deficiency of research that specifically examines these children's school experiences.

Through individual discussions with children with epilepsy, this study offers a unique examination of their school experiences and perceptions. Specifically, this study illustrated children's experience of seizures in the school setting, and how they perceive their condition influences their educational experience. An intimate discussion of their interpersonal

relationships offered a detailed description of their social belonging and feelings of both normalcy and aberration within the school context. The interviews also revealed the children's desire to have their condition disseminated throughout the school community, offering insight into their personal needs and challenges at school.

Of note, the questions asked were not aimed specifically at eliciting information about their experiences with epilepsy. Instead, interviews offered the children an opportunity to speak generally about their school experiences. As such, this study provides a unique perspective on the lives of children with epilepsy, and offers new insights to inform future studies and help fill the dearth of literature on school experiences of children with epilepsy.

*Purpose One: Identify Children's Perceptions and Experiences of Having Epilepsy at School*

Through intimate discussions with children, this study identified children's perceptions and experiences of having epilepsy at school. Since the participants took time to describe or illustrate their seizures, particularly as they occurred at school, the experience of having a seizure can be viewed an important part of these children's school experiences. The fear, anxiety, and annoyance that some children described suggest that their seizures are viewed as a negative aspect of their school experience. Feelings of fear, anxiety, and sadness about seizures has been found in other literature (Hightower, Carmon, & Minich, 2002; Lewis & Parsons, 2008).

Research suggests, however, that when young people reflect on their past seizures, they are more fearful than they were at the time of the seizure (Lewis & Parsons, 2008). Others have attributed anxiety and fear to the expectation of potential seizure onset (Galletti, Rinna, & Aquafondata, 1998). Further investigation on the children's emotional responses to their seizures would contribute greatly to our understanding of these children's experiences.

Interestingly for many of the participants, much of the anxiety and frustration came from the effects of epilepsy, rather than the actual occurrence of seizures. For example, medication side effects, negative interpersonal relationships, and academic difficulties were a major source of anxiety and frustration for many participants. These concerns have been found throughout the literature (e.g. Elliot et al., 2005; Ettinger et al., 1998). Fortunately, schools can help alleviate some of these challenges by understanding the child's needs, and offering an effective support system.

In addition to describing their seizures, the participants spoke of the support required from their teachers and peers before, during, and after seizures. Specifically, the children depended on their school community to assist with seizure prevention measures, keep them safe during a seizure, and provide an opportunity for the child's body to recover. In addition, the participants felt that teachers should be flexible academically, as seizures disrupt the learning process. Despite the importance for teacher and peer support, many of the participants perceived their teachers as anxious and unconfident during their seizures. Johnson and Thomas (1999) confirmed this perception in their study examining school responses to pupils affected with epilepsy. Johnson and Thomas (1999) reported that teachers expressed anxiety, fear, and a lack of confidence about having a child with epilepsy in their class. Due to their inexperience dealing with epilepsy, these teachers questioned their effectiveness in the event of a seizure (Johnson & Thomas, 1999). As Lewis and Parsons (2008) found, students with epilepsy feel reassured when their teachers understand their condition and know how to handle their situation safely, and sensitively. It therefore seems appropriate for schools to learn to deal with seizures effectively so they can not only ensure the safety of the child, but can provide comfort and support to a child

who may be anxious over the possibility of a seizure. One way to build this confidence is through teacher education.

Because of the reliance on teachers and peers, the children in this study felt that it was important for everyone in the school community to be aware and educated about epilepsy so that the appropriate procedures and supports can be implemented. Safety procedures can ensure a child is kept safe during a seizure, and may relieve some of the anxiety expressed by the participants. Awareness and education may also discourage stigma and misconceptions (Wilde and Haslam, 1996), and enhance understanding of these children's needs, and how to support them (Johnson & Thomas, 1999).

The children in this study discussed disclosing their condition to their peers. The participants were willing to make the disclosure, and in fact felt that it was necessary so as to ensure their peers were able to understand and help them in the event of a seizure. Research on epilepsy demonstrates mixed findings on willingness to disclose. In contrast to the findings of this study, Lewis and Parsons (2008) revealed that many children aged 7-18 actively maintained the invisibility of their illness to avoid stigma. Reluctance to disclose seems to continue into adulthood, as indicated by Troster (1998), who found increased reluctance if negative social consequences were anticipated. In contrast, however, Hightower et al. (2002) found that children with epilepsy disclose their epilepsy to peers and educate them about seizures. This study further found that educating peers led to greater peer acceptance of their condition (Hightower et al., 2002). To alleviate these contrasts in understanding, Galletti & Sturniolo (2004) suggest that the child's privacy should be respected if seizure occurrence is not foreseen during the school day, but should be disseminated in the event that seizure control is not achieved. Students with epilepsy, however, are often frustrated with the silence surrounding their

condition (Lewis & Parsons, 2008), suggesting a desire for openness about epilepsy. This was suggested by participants in the present study, who recommended that schools participate in Purple Day to spread awareness of epilepsy, despite the fact that many have obtained seizure control. Perhaps the reluctance found in other studies stems from the stigma attached to the condition, rather than a concern for their personal safety. Further investigation on disclosure experiences would provide insight as to how to ensure the child's safety, while also respecting personal confidentiality issues.

A major finding of the present study was the importance the children placed on their social belonging. Many participants spoke of friendships, describing the support and understanding that they received from these relationships. These discussions demonstrated the dependence that the children have on their friends, not only for assistance in the event of a seizure, but also for daily emotional support. Hightower et al. (2002) found similar results in which children with epilepsy chose best friends who provided them with acceptance and advocacy.

Interestingly, the way the participants viewed friendships was variable. Some participants mentioned having many friends, while others mentioned maintaining a close relationship with one "best" friend. Despite this variability, each participant described their friendships and relationships as satisfactory. This variability may be due to the meaning the children attach to friendship (Elliot et al., 2005). In their study, Elliot et al., (2005) found that to children, friendships either meant socializing with a single peer, socializing with many peers, having friendships only at school, or having friendships outside the school setting. As social belonging was unanimously important to the participants, an examination of how children with epilepsy

define friendship, and whether epilepsy-related factors contribute to this definition, would be valuable.

Although the participants felt satisfied with their friendships, their narratives presented themes of social isolation. Some of the participants in this study described instances of teasing and bullying, both physical and verbal. As evident from their discussions, these instances have negative implications on their school experiences. Evidence of bullying among children with epilepsy has been found in extant research (Elliot, Lach, & Smith, 2005; McEwan et al (2004), Ronen et al., 1999; Wilde & Haslam, 1996). Hamiwka, Yu, Hamiwka, Sherman, Anderson & Wirrel, 2009) disagree with claims linking epilepsy and bullying. Although Hamiwka et al. (2009) did not find that specific epilepsy factors put children at risk for bullying, 42 percent of their population reported that they were victims of bullying. Further, children with epilepsy were more frequently bullied than children with chronic kidney disease and healthy children (Hamiwka et al., 2009). It is possible that other factors related to epilepsy, such as stigma and awareness of epilepsy, and/or academic difficulties, put the children in this study at an increase risk for bullying. Further investigation on why children with epilepsy tend to be the victims of bullies is needed to obtain a complete understanding of these children's experiences.

Much of the children's narratives centered on issues of normalcy. Feelings of both normalcy and aberration were revealed. For some, abnormality was emphasized by experiencing a seizure, differential treatment from others (both positive and negative), others' misconceptions and stigmatizing behaviours, activity limitations, and learning difficulties. Feelings of aberration have been revealed in other studies. Elliot et al., (2005) found that seizures played a considerable role in the participants' identities, and therefore acted as a barrier to normalcy. This sense of abnormality negatively influenced the physical, emotional, social, and academic aspects of their

lives, and the participants were in an ongoing pursuit of normalcy. Similarly, Lewis and Parson (2008) found participants' feelings of abnormality were largely due to their inability to participate in the same activities as their peers.

The negative impacts of epilepsy on normalcy expressed in Elliot et al., (2005) and Lewis and Parson (2008) were less profound in the present study. When discussing how they viewed themselves at school, many children in this study acknowledged that there were certain aspects of their lives that differed from that of their peers, but generally felt a sense of normalcy at school. That is, most perceived themselves as "normal kids", but were aware that certain aspects of their epilepsy made them different. This poses some interesting questions about normalcy in children with epilepsy. Primarily, how do children with epilepsy define normalcy? While current research suggests that children with epilepsy feel different, and therefore abnormal, the children in the present study did not emphasize a connection between being different and abnormality.

Secondly, what role does seizure control have on feelings of normalcy in children with epilepsy? While some argue that seizure control may influence these feelings (Aldenkamp et al., 1998), others disagree. For example, Galletti et al., (1998) found that after a patient has reached seizure remission, feelings of abnormality may continue to persist. Interestingly, some children emphasized the temporary nature of their condition, expressing hope of eventual permanent recovery. This expectation and sense of hope has been found in other children with epilepsy (Lewis & Parsons, 2008). Believing in the temporary nature of their condition may, perhaps, promote feelings of normalcy. Examining the influence seizure cessation has on normalcy may promote a better understanding of how to provide these children with positive school experiences.

Examining current methodologies of obtaining information about normalcy would benefit our understanding as well. Elliot et al., (2005) and Lewis and Parsons (2008) asked their participants specific questions regarding their epilepsy. Both these studies found a strong sense of abnormality among their participants. In contrast, the present study, which did not elicit strong feelings of abnormality, offered the children an opportunity to discuss their school experiences without directly asking them to reflect on their epilepsy. Is it possible that direct questioning influences children to focus on their epilepsy rather than their general experiences? Perhaps children feel a sense of aberration when specifically reflecting on their condition, but when considering school experiences in general, feel a sense of normalcy. Further investigation as to how to elicit accurate information about normalcy is required.

Participants in this study also discussed the physical and emotional effects of their epilepsy. Most of the descriptions were negative in nature, expressing physical discomfort and feelings of fear and anxiety. These findings are consistent in the literature. For example, Elliot et al. (2005) found that the participants' frustration and anger was attributed to their seizures, medications, and perceptions of overprotection. Participants in the present study related their fear and anxiety to seizures and medication, but also to the bullying and academic difficulties that they experience at school. Research consistently demonstrates that physical and emotional problems can interfere with a child's learning, socialization, and overall QOL (Bishop & Allen, 2003; Elliot et al., 2005; Moffat et al., 2009), and is therefore important to consider when integrating a child with epilepsy into a school community.

While some participants expressed physical and emotional influences of their epilepsy, others did not. The absence of this discussion raises some important questions when viewed in the context of current research. While these children may not have experience any physical or

emotional effects of their condition, thereby contradicting the literature, there may be alternative explanations. Is it possible that, although physical and emotional effects occur, these children do not view them as influencing their school experiences? This finding demonstrates the importance of considering individual needs when assessing how epilepsy will influence school experiences.

Extant literature suggests a correlation between health and academic success (Ross & Van Willigen, 1997; Tara & Potts-Datema, 2005; Thies, 1999). Students with chronic illness experience many daily challenges that can impact their learning and socialization at school (Tara & Potts-Datema, 2005; Thies, 1999). In fact, students with chronic health conditions experience more academic difficulties than those who are healthy (Thies, 1999). As Thies (1999) explains, children whose condition directly affects their central nervous system (brain and spinal cord) often exhibit impairments of visual scanning, spatial abilities, attention, and memory, each of which have strong implications on academic success.

Many participants in this study described academic experiences, some of which specifically related academic problems to their epilepsy. Academic difficulty in children with epilepsy is well documented in the literature (eg. Aldenkamp et al., 1999; Aldenkamp et al., 2005; Austin et al., 1999; Berg et al., 2008; Caplan et al., 2006; Chaix et al., 2006; Fastenau et al., 2008; Hermann et al., 2001; Katzenstein et al., 2007; Northcott et al., 2007; Seidenberg et al., 1986; Selassie, Viggedal, Olsson, & Jennische, 2008; Williams, 2003; Wirrell et al., 2008). The children's narratives in this study suggest that educators should be aware of the academic challenges that many children with epilepsy encounter, as well as the various adaptations that can be implemented to help these students experience success in the classroom. As many of the participants in this study stated, academic adaptations and support are an important component of their positive school experiences. Teachers should be cautious, however, that some children

diagnosed with epilepsy do not have learning challenges, and feel that adaptations are unnecessary. It is therefore important to conduct appropriate academic assessments and discuss ideal teaching and learning methods and conditions so as to best understand children's academic needs and promote school success.

Throughout the interviews, each child examined their overall experience of school, expressing both positive and negative feelings. While there were mixed findings between participants and within individual narratives, a noticeable distinction can be made. Children who attended public schools expressed both positive and negative school experiences. Interestingly, children who attended private or home school, expressed only positive experiences. Although further investigation is needed to understand this finding, some speculations can be made. Private schools tend to have and smaller class sizes, allowing teachers to work more closely and intensely with students requiring additional support. Research has suggested that student-teacher interactions have a profound influence on learning and academic success (Elias et al., 2006). As such, perhaps small class sizes characteristic of private schools support positive student-educator relationships, thereby fostering resilience (Elias et al., 2006). Additionally, private schools often have more funds for teaching resources, promoting the use of approved academic and social programs that help children feel successful. There are many other variables, such as socio-economic status, that may have influenced these children's experiences. This study's findings could also be a coincidence that would normalize with a larger sample size. Further investigation into the role that private and public systems play in creating positive school experiences for children with epilepsy is needed.

Individual differences among the children's experiences emphasize the importance of understanding that children experience epilepsy in various and unique ways. Much of their

experience may depend on their individual experiences outside the classroom. The bi-directional nature of the E-T framework of resilience (Stewart, 2007) suggests that other processes (biological, social, and cultural) can influence the children's school experiences, as well as the experience of having epilepsy. As such, when understanding the school experiences of children with epilepsy, it is important to consider individual differences that may impact how school is experienced.

*Purpose Two: Gain insights to inform future studies*

This study will be used as a platform to develop a larger study investigating the experiences of teachers and primary caregivers in addition to children with epilepsy. The present investigation, therefore, can offer insight as to how future studies can obtain a greater understanding of how these children experience school.

This investigation used in-depth, semi-structured interviews based on Keith and Schalock's (1994) quality of life model, and was modified from Roberts and Cairns (1999) (see Appendix E). Questions were open-ended and pertained to the children's quality of life experiences and interactions with the school systems. While children were told the purpose of the study, and with the exception of asking the children to draw a picture of what it is like to have epilepsy at school, questions did not explicitly ask how the participants' condition impacts their experiences at school. This allowed the children to discuss their school experiences without the assumption that their epilepsy influences their school experience. As evident from the findings, many children chose to speak about their epilepsy, and how it impacted their school experiences. Categories that were elicited from these discussions (The Seizure Experience, The Educational Experience, Social Belonging, and Awareness) could be used formulate specific questions pertaining to the influence that epilepsy has on children's school experiences. This

would provide more structure to the interview, which research has shown is necessary for younger participants (Yule, 1993). Nevertheless, the openness of these interviews was valuable to the extraction of their school experiences, and should continue to be used in any study wanting to elicit the lived experiences of children with epilepsy.

Future studies should expand on this investigation by examining the perceptions of other individuals involved in these children's school experiences. That is, parents and school personnel, specifically teachers, could offer valuable insight into these children's school experiences (Johnson & Thomas, 1999; Ronen, Streiner, Rosenbaum, & the Canadian Pediatric Epilepsy Network, 2003). Ronen et al. (2003) found that parent-proxy responses complemented children's report when administered to children with epilepsy who are at least eight years of age. Ronen et al. (2003) suggests that, although perspectives may differ, a combination of both parent and child would contribute to a better understanding of childhood epilepsy. Similarly, Johnson and Thomas (1998) found value in speaking with teachers about their experiences. As teachers are with these children for a large portion of the day, and are a direct link to their experiences at school, listening to the narratives of teachers would provide valuable insight as to how schools can promote positive experiences for children with epilepsy.

### *Limitations*

A number of limitations exist for this study, and thus influence the findings and implications of the investigation. First, participant demographics limit our understanding of the school experiences of children with epilepsy. This study was limited to six participants aged seven to twelve years from Victoria, British Columbia. The findings in this study can therefore not be generalized to the wider community affected with epilepsy. Further, the study examined children diagnosed with epilepsy. As such, the information gained from this study cannot be used

to understand children with other chronic illness, or those who experience seizures due to other health-related issues.

Recruitment procedures also limit the extent to which these findings can be interpreted. The families used in this study were recruited from the VEPC. As such, the children came from families who have actively sought out a support group, and are currently being supported and advocated for by an organization that specializes in helping families with epilepsy. As such, these families may experience their child's condition differently than families who do not have support systems in place. Findings, therefore, cannot be generalized to children who are not involved with VEPC.

The length of the interview can also be viewed as a limitation of this study. These children live with epilepsy each day, and expressing their experiences during a short interview may not have elicited an exhaustive description of the phenomenon. These children were also not aware of the questions prior to the interview, and in fact, initial contact was only made with parents. As such, the children may not have had ample time to reflect on their experience of attending school with epilepsy. Future studies should consider providing children with the interview questions in advance to allow them time to process the questions and provide exhaustive descriptions.

A final limitation of this study is the lack of information that was collected regarding the school services that the children are receiving. The researcher is unaware of any learning support or other special educational resources that the children may be receiving that could greatly influence their school experiences. Future studies should obtain this information prior to data analysis.

### *Implications*

The majority of the children in this study desired for increased awareness and education about epilepsy among the school community, including all staff as well as peers. Educating staff and peers about epilepsy ensures the safety of the student, particularly in the event of a seizure. It would also help the school community understand how to successfully support these students physically, emotionally, socially, and academically. As many participants mentioned, misconceptions and stigma contribute to negative experiences. Building awareness and educating teachers and peers about epilepsy would alleviate these problems, and may promote positive school experience and overall QOL.

The participants' descriptions of physical and emotional wellness have important implications. Many of the narratives expressed physical discomfort and feelings of fear and anxiety. Physicians should be prepared to discuss the effects of seizures and AEDs on patients' physical and emotional health. In addition, support systems should be in place to help children cope with the negative physical and emotional effects of epilepsy.

As academic difficulties were highlighted in this study, and have been indicated in other epilepsy research, schools need to be prepared to support these students academically. As difficulties can vary, conducting appropriate assessments can help teachers determine specific areas of need. Further, appropriate adaptations should be implemented to ensure each child's academic success.

Understanding what school is like for children with epilepsy creates an opportunity to ensure these children have positive experiences throughout their years at school. Resilience literature has consistently demonstrated that positive school experiences foster resilience in children faced with adversities (Elias, et al., 2006; Gilligan, 1998, 2000). As children with

epilepsy can experience adversity attributed to their chronic illness, the education system can function as a protective factor to promote resilience (Gilligan, 1998, 2000; Elias et al., 2006). Understanding the children's experiences offers an opportunity to create positive school experiences, and ensures that the education system acts as a protective factor that contributes to their resilience. In this way, resilience can be viewed as a path to positive QOL, as it promotes positive developmental outcomes and discourages maladaptive outcomes under adverse circumstances (Winslow et al., 2006), and therefore contributes to the children's satisfaction, well-being, social belonging, and empowerment.

### *Directions for Research*

This study offers many areas for further investigation. Addressing the limitations of this study would enhance our understanding of the school experiences of children with epilepsy, and allow for more generalizations. Further, examining perspectives of parents, teachers, and peers would offer unique insight into the lives of these children.

Findings of this investigation provide numerous directions for research. Awareness and education was of great importance for many of the participants in this study. Building awareness and providing epilepsy education to staff and peers could alleviate some of the challenges these children face in terms of safety, support, and stigma. Literature has repeatedly demonstrated, however, the reluctance that children have around disclosing their condition to their peers (Elliot et al., 2005). Future research would find value in examining why children with epilepsy choose to disclose their condition to their peers, and how schools can ensure a child's safety while also respecting personal confidentiality issues.

During their interviews, many children illustrated their seizures, often describing the fear and anxiety they feel during that experience. Further investigation should explore children's

emotional responses to their seizures so as to best understand how seizures impact their school experiences, as well as to ensure appropriate support for these young students.

Bullying is a concern found in many schools; however instances of bullying seem elevated among children with epilepsy. Some research suggests that epilepsy factors are not specifically responsible for instances of bullying among this population. As being bullied can lead to anxiety, depression, and social difficulties (Bond, Carlin, Thomas, Rubin, & Patton, 2001), investigation on why children with epilepsy tend to be victims of bullying would be valuable in promoting positive school experiences.

Future research should also inquire as to why the children in public schools expressed more negative experiences than those in private schools. There is a dearth of literature examining the effects of private and public systems on the experiences of children with special needs. This information could not only contribute to a better understanding of the school experiences of children with epilepsy, but may also provide insight as to what aspects of the school promote success in children with special needs.

### *Final Summary*

With up to 0.6 percent of Canadian children under the age of 18 affected by epilepsy (Epilepsy Canada, 2003), it is likely that educators will teach a child with epilepsy during their career. Epilepsy is consistently linked to academic underachievement (e.g., Aldenkamp, Overweg-Plandsoen, & Diepman, 1999) and social difficulties (e.g. Baker, 2002). Unfortunately, a dearth of research examining how students with epilepsy experience school makes their unique needs less familiar to school personnel. The purpose of this phenomenological study, therefore, was to understand the perceptions and experiences of school children with epilepsy. Specifically, interviews aimed to identify children's perceptions and experiences of having epilepsy at school,

and gain insights to inform future studies. In-depth interviews described the school experiences of children with epilepsy. Four categories were elicited from the children's narratives: (1) The Seizure Experience, (2) The Educational Experience, (3) Social Belonging, and (4) Awareness.

The children's seizures added to the complexity of their school experiences. As seizure types and effects may vary, their influence on school experiences is diverse. For some of the children in this study, seizures were described as brief disruptions of consciousness. For others, seizures elicited anxiety, and created a dependence on others' first aid knowledge. The participants' felt that their teachers continuously worried about their safety, creating a sense of anxiety within the school. This anxiety often manifest as overprotection, which disrupted feelings of normalcy and belonging.

Narratives also suggested that seizures influenced the children's well-being, specifically their physical and emotional health. Physicians should be prepared to discuss the effects of seizures and AEDs on patients' physical and emotional health. In addition, support systems should be in place to help children cope with the negative physical and emotional effects of epilepsy.

Participants spoke of their specific needs before, during, and after a seizure. These needs surrounded seizure prevention, seizure first aid, ongoing support, and empathy from teachers. The participants felt that support in these areas contributed to positive school experiences.

Academic frustration was common for many of the participants. The children discussed their involvement with educational services, as well as classroom adaptations and accommodations. When these supports were appropriately provided, the children had a positive view of their educational experience. As such, schools need to be prepared to support these students academically and provide appropriate classroom adaptations. Because specific

difficulties vary, conducting appropriate assessments will help teachers determine specific areas of need.

Social belonging was an important part of the children's school experiences. While experienced frustration caused by social isolation and bullying, many discussed the value of friendships and support from peers. While the participants acknowledged that there were certain aspects of their lives that differed from that of their peers, they generally felt a sense of normalcy at school. Some children, however, expressed feelings of aberration, and felt they received differential treatment because of their diagnosis.

Some children discussed their experiences with disclosing their condition to friends. They described the importance of informing peers about their epilepsy so as to gain support and understanding, as well as to prepare them in the event that a seizure occurs in their presence. For some, however, disclosures were met with unpleasant reactions from teachers and peers, and many felt stigmatized.

The children felt that education would alleviate the misconceptions that people have about their condition. Education would also spread awareness of what seizures look like, how seizures can be triggered, and how to help in the event of a seizure. The children suggested that nurses or community advocates educate school personnel and their peers. Educating staff and peers about epilepsy ensures the safety of the student, and may help educators understand how to successfully support these students physically, emotionally, socially, and academically. Epilepsy education would also alleviate misconceptions around this condition.

Many also described the value in building their own knowledge of epilepsy. The children explained that personal knowledge not only provides them with a better understanding of their personal needs, but also helps them explain and advocate for themselves.

This investigation offers many directions for future research. Addressing the limitations of this study would enhance our understanding of the school experiences of children with epilepsy, and allow for more generalizations. As well, examining perspectives of parents, teachers, and peers would offer unique insight into the lives of these children, and provide educators with more information on how to support, accommodate, and prepare for students with epilepsy.

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## APPENDIX A

Recruitment Letter for Isa Milman to Inform Members About Study

April 1, 2009

Isa Milman  
Victoria Epilepsy & Parkinson's Centre  
813 Darwin Ave.  
Victoria, BC  
V8X 2X7

Dear Mr. & Mrs. (name),

I'd like to tell you about a research study on children with epilepsy in school and ask if you would be interested in taking part. You and your spouse/partner and children are in the group of families who have school children with epilepsy. We would like to learn from your child's experience so we can help schools better prepare, support, and accommodate children with epilepsy. Hearing your child's thoughts and experiences would be valuable for this study and having a chance to educate others may be of interest to your family. Taking part in this study would involve two interviews with your child that would last for about one hour.

The person doing the interviews would be Jillian Roberts' research assistant. Dr. Roberts is the Associate Dean Administration of the Faculty of Education at the University of Victoria and her assistant is a graduate student at the university. Your child's name will never be published, and your family's confidentiality will be protected. The interviews would be arranged at a time convenient for both family and interviewer. Interviews could take place in your home or another place of your choosing where privacy and quiet can be ensured."

There are some good reasons to choose to participate. The main reason is that professionals need to learn from children's experiences. Many children with epilepsy struggle with learning and social relationships in the school setting. These school experiences have been shown to be an important influence on children's current and future quality of life. Schools must be prepared to meet the needs of these children and their families, however this remains an under-researched area, and as such, there are few resources available to teachers. In the age of inclusive education, where teacher training, individualized programming, and family-centered practice are paramount, it is clear that additional research in this area is necessary in order to provide schools with the most useful and applicable information possible. The current study has been designed to fill such a gap in professional knowledge. Participating in this study allows your child to have a say and share his or her voice with policy makers.

If you are interested in having your child share his/her experience, or have any questions, please contact Cheryl Whiting at the University of Victoria by phone, (250) 853-3210, or through email at [cwhiting@uvic.ca](mailto:cwhiting@uvic.ca). Please feel free to contact me as well.

Thank you for your time and consideration,

Isa Milman  
Epilepsy Program Coordinator  
(250) 475-6677  
imilman@vepc.bc.ca

## APPENDIX B

Letter of Introduction from the University of Victoria

## THE UNIVERSITY OF VICTORIA

## Department of Educational Psychology and Leadership Studies

April 1, 2009

Dear Mr./Ms. Participant:

My name is Dr. Jillian Roberts. I am the Associate Dean Administration of the Faculty of Education at the University of Victoria. I am writing to provide information regarding a research project entitled “The Quality of Life Experiences of School Children with Epilepsy: A Pilot Study”.

The purpose of this study is to better understand the school experiences of children with epilepsy, and to share this information with school districts. The specific objectives are to:

- (1) Identify the perceptions and experiences of children with epilepsy regarding their interaction with the schools which impact their quality of life;
- (2) Clarify how families think schools can best support, accommodate, and prepare for these children; and
- (3) Use this pilot research as a platform to develop a larger study, which will investigate the experiences of primary caregivers, teachers, and children with epilepsy and examine their interactions with the school system. It is our intention that this information will be shared with school districts through the development of a school handbook.

As part of the study your child will be asked to discuss school experiences that have an impact on his/her quality of life. This discussion will be audio-recorded, transcribed, and searched for patterns of themes. At a later date, your child will be asked to evaluate and/or validate the themes derived from his/her interview. Once collected, this data will be analyzed anonymously. No names, only a code number, will be attached to this data. Moreover, this data will be kept in a locked file cabinet.

**Participation in this study is completely voluntary. Your child can withdraw at any time without any negative consequences.** If your child chooses to withdraw, the information derived from his/her interviews will not be used in data analysis.

The ultimate goal of this research is to share your child’s experiences with as many people as possible. I will provide you with regular updates and I will present and/or publish the results in scholarly meetings, in journals, and possibly, (as mentioned above) in a final school handbook.

If you have any questions, please feel free to contact me at (250) 721-7759 or email me at [jjrobert@uvic.ca](mailto:jjrobert@uvic.ca). You may also contact the research assistant, Cheryl Whiting, at (250) 853-3210. Moreover, if you have additional questions or concerns about participating in this study, you can contact the Associate Vice President Research of the University of Victoria (250) 721-

5416. Two copies of the consent form are provided. Please return one signed copy to me and retain the other copy for your records.

Thank you for your cooperation.

Most sincerely,

Jillian Roberts

Enclosures

## APPENDIX C

Human Research Ethics Consent Form

Your child is being invited to participate in a study entitled “The Quality of Life Experiences of School Children with Epilepsy: A Pilot Study” that is being conducted by Dr. Jillian Roberts. Dr. Roberts is the Associate Dean Administration of the Faculty of Education at the University of Victoria. You may contact her if you have further questions by calling her at (250) 721-7759. You may also contact her research assistant, Cheryl Whiting, at (250) 853-3210.

The research is being funded by HELP-UVic: Reach.

The purpose of this pilot study is to better understand the quality of life of school children with epilepsy and their families. The specific objectives are to:

- (1) Identify the perceptions and experiences of children with epilepsy regarding their interaction with the schools which impact both the child and family’s quality of life;
- (2) Clarify how children think schools can best support, accommodate, and prepare for these children and families; and
- (3) Use this pilot research as a platform to develop a larger study, which will investigate the experiences of primary caregivers, teachers, and children with epilepsy and examine their interactions with the school system. It is our intention that this information will be shared with school districts through the development of a school handbook.

This research is important because in Canada, epilepsy is found in approximately 3 out of every 1000 children, and is one of the most frequently diagnosed neurological disorders affecting children. Many children with epilepsy struggle with learning and social relationships in the school setting. These school experiences have been shown to be an important influence on children’s current and future quality of life.

Literature on resilience has consistently demonstrated the importance of positive school experiences as a critical protective factor in promoting resilience. As such, planning for school transition is critical to children’s success, and schools must therefore be prepared to meet the needs of students with epilepsy attending inclusive educational settings.

Your child is being asked to participate in this study because you and your spouse/partner and children are in the group of families who have children with epilepsy who attend school. We would like to learn from your child’s experience so that we can help schools better prepare, support, and accommodate children with epilepsy. Hearing your child’s thoughts and experiences would be valuable for this study.

If your child agrees to voluntarily participate in this research, his/her participation will include two interviews lasting about one (1) hour. The interviews would be arranged at a time convenient for both family and interviewer. Interviews could take place at your home or another location of your choice, where privacy and quiet can be ensured. The conversation will be audio recorded, and later transcribed. These transcriptions will not include any identifiable information about your child or your family. The researchers will use these transcriptions to search for themes of

experiences. These themes will be brought back to you at a later time (the second interview) for your child to review.

Participation in this study may cause some inconvenience to your child and some potential risks, including sad or angry feelings if he/she has had negative school experiences. Participants will be encouraged to share their school experiences as fully as possible. However, they will never be forced to remain in the interview (they may stop at any time), nor will they be forced to discuss negative experiences if they choose not to. The interviewer will be careful to pace the interviews according to the child's needs.

The potential benefits of your child's participation in this research include informing policy makers about the school experiences of children with epilepsy. Many children with epilepsy struggle with learning and social relationships in the school setting. These school experiences have been shown to be an important influence on children's current and future quality of life. Schools must be prepared to meet the needs of these children and their families, however this remains an under-researched area, and as such, there are few resources available to teachers. In the age of inclusive education, where teacher training, individualized programming, and family-centered practice are paramount, it is clear that additional research in this area is necessary in order to provide schools with the most useful and applicable information possible. The current study has been designed to fill such a gap in professional knowledge. Participating in this study allows your child to have a say and share his/her voice with policy makers

Your child's participation in this research must be completely voluntary. If your child does decide to participate, he/she may withdraw at any time without any consequences or any explanation. If your child does withdraw from the study, his/her data will not be included in final analysis.

To make sure that your child continues to consent to participate in this research, I will periodically update your family about the progress of the study by phone or written correspondence. During these updates, I will remind you and your child that participation is voluntary and that he/she can choose to withdraw without any negative consequences.

In terms of protecting your child's anonymity, no names, only code numbers, will be attached to the data derived from his/her interviews.

Your family's confidentiality and the confidentiality of the data will be protected by never revealing your child's identity and by keeping the data locked file cabinet at all times. Other planned uses of this data may include using it in university lectures or professional workshops.

Data from this study will be disposed of after five years. The transcribed interviews will be shredded and the audiocassettes will be incinerated.

It is anticipated that the results of this study will be shared with others in the following ways: I will present and/or publish the results in scholarly meetings, in journals, and possibly in a final school handbook.

In addition to being able to contact the researcher at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice President Research at the University of Victoria (250) 721-5416. Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

PARENT'S SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

**A COPY OF THIS CONSENT WILL BE LEFT WITH YOU, AND A COPY WILL BE TAKEN BY THE RESEARCHER**

## APPENDIX D

Verbal Consent Form for Children

My name is Cheryl Whiting (*research assistant*). I am a student at the University of Victoria. I am doing a study so that I can understand how children with epilepsy feel at school. I want to share this information with schools so that they can help children with epilepsy.

As part of this study, I am going to ask you to talk about your experience at school. The answers you give will be anonymous, which means no one will know your name or the answers that you gave.

This study is important because some children with epilepsy have difficulties at school. I want to learn how children with epilepsy experience school so that we can tell schools how to help children with epilepsy so they have good experiences.

I will ask you to talk about your school experiences because I think you have some valuable things to say about what it is like having epilepsy at school that will help with my study.

If you do not want to participate, that is fine. If you choose to participate and later decide you do not want to, that is fine too. If you decide you do not want to finish the interview, we will stop and I will not use your answers in the research. You never have to answer a question if you do not want to.

The goal of this study is to help schools understand how to help children with epilepsy at school.

Would you like to help me with this study?

*(Obtain Verbal Consent)*

## APPENDIX E

Interview Guide for Children

UNIVERSITY OF VICTORIA  
Department of Educational Psychology and Leadership Studies

I invite you to tell me about school. I want to learn what school is like for you, so that we can teach schools how to help children with epilepsy. I will ask you to tell me anything that comes to mind, and then will ask you a few other questions. Please let me know if the questions do not make sense. I will say them in a different way. (*\*The interviewer will simplify questions as needed and as appropriate*)

<b>QOL Component</b>	<b>Question</b>	<b>Simplified Language</b>	<b>Prompt</b>
Open question	Draw a picture of what it is like to have epilepsy at school	Draw a picture of you at school.	Please explain X?
Open Question	What is it like for you being at school?	Tell me about school.	Please tell me more.
SATISFACTION	How do you feel about school?	What do you think about school?	Please explain why X.
WELL BEING	How would you describe yourself at school?	What are you like at school?	Please tell me more.
SOCIAL BELONGING	How do you feel about your relationships and friendships at school?	How do you get along with the kids at school? How do you fit in at school?	Please tell me more about that.
EMPOWERMENT	Tell me about the things at school that you may or may not have control of	What are some things that you have or don't have ( <i>power over/are in charge of/a say over</i> ) at school.	Please tell me more about X.
Remind participant of the purpose of the study: "I want to learn what school is like for you, so that we can teach schools how to help children with epilepsy"			

Open question	Please share with me any other comment, suggestions, or concerns you may have about school.	Please tell me anything else about school.	Please tell me more about X.
Remind participant of the purpose of the study: "I want to learn what school is like for you, so that we can teach schools how to help children with epilepsy"			
Open question	What are some ways that the school meets your needs?	What are some things your school has done that helps ( <i>supports/is good for</i> ) you?	Please explain X.
Open question	What are some ways that your school does not meet your needs?	What are some things your school has done that are not helpful ( <i>do not support/do not help/are bad</i> ) for you?	Please explain X.
Open question	What could your school do differently that would help you?	What are some things at school you think need to be changed?	Please explain X.