

# THE SCHOOL EXPERIENCES OF CHILDREN WITH EPILEPSY: A PHENOMENOLOGICAL STUDY

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This research was supported in part by funding from REACH (Research in Early Childhood Care, Education and Health). A special thanks to Rachel Jalbert and Stephanie Helm for their editorial assistance.

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## ABSTRACT

In Canada, approximately three out of every 1,000 children have epilepsy, making it one of the most commonly diagnosed neurological conditions affecting children. It is therefore highly probable that educators will work with this population at some point in their careers. Epilepsy is linked to academic underachievement and social isolation, but 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 identify the school experiences of children with epilepsy. Specifically, this study identified children's perceptions and experiences of having epilepsy at school and acquired insights to inform future studies. Participants were six students (ages 7-12 years) who have a diagnosis of epilepsy and reside in Victoria, British Columbia, Canada. Data were gathered through open-ended, semi-structured interviews. These interviews were transcribed and analyzed to obtain the essential experiences of school children with epilepsy. Four categories emerged from these interviews: (a) seizures, (b) academics, (c) social belonging and (d) awareness. Implications for schools and directions for future research are discussed.

*Keywords:* school children, epilepsy, quality of life, seizures, health impairments

## **THE SCHOOL EXPERIENCES OF CHILDREN WITH EPILEPSY: A PHENOMENOLOGICAL STUDY**

Literature suggests that there is a correlation between the health of an individual and academic success (Taras & Potts-Datema, 2005). Epilepsy, in particular, is linked to academic underachievement (e.g. Aldenkamp, Overweg-Plandsoen, & Diepman, 1999) and social challenges (e.g. Baker, 2002). Despite these implications, little is known about how students with epilepsy experience school and how their experience impacts their quality of life (QOL). Epilepsy is one of the most commonly diagnosed neurological conditions affecting children (Fejerman, 2002), with approximately three out of every 1,000 children in Canada affected (Bumeo, Prasad, Corbett, & Sang, 2006). It is therefore likely that educators will work with this population during their career. With a service delivery model in most Canadian schools that expects inclusivity in classrooms, it is important that the school experiences of children with epilepsy are examined so as to best inform educators of these students' unique needs and how to improve their QOL during their time in school.

### **QUALITY OF LIFE**

Quality of Life (QOL) is not easily defined in the literature (Taylor, Gibson, & Franck, 2008), but is generally thought to encompass well-being, social involvement, and opportunities to achieve one's potential (Hinds et al., 2004). This study adopts Keith and Schalock's (1994) model of QOL, suggesting that satisfaction, well-being, social belonging, and empowerment/control are important components of an individual's QOL. Keith and Schalock's model has been used among various researchers to describe QOL of children with chronic health conditions (Roberts & Cairns, 1999; Roberts, Hayashi, Anderson, Martin, & Maxwell, 2003; Roberts, Massie, Mortimer, & Maxwell, 2005).

Children and adolescents with epilepsy have lower QOL than individuals without epilepsy (Montanaro, Battistella, Boniver & Galeone, 2004). Epilepsy can affect QOL directly by negatively impacting daily functioning, as well as indirectly, by reducing opportunities to engage in activities that support positive QOL (Bishop & Allen, 2003).

### **FACTORS THAT AFFECT QUALITY OF LIFE**

Seizures occur when there is an electrical disturbance in the brain that alters an individual's sensation, awareness, and/or behaviour (Canadian Epilepsy Alliance, 2008). Williams, Griebel, and Dykman (1998) suggest that childhood epilepsy may impact cognitive performance more generally, while adults experience modality-specific effects. Negative experiences and maladaptive functioning in physical, behavioural/emotional, social, and academic domains

have been attributed to the low QOL of many young children with epilepsy. Many of these factors can directly impact their school experience.

### **PHYSICAL FACTORS**

Physically, the most frequent complaint of children with epilepsy is excessive fatigue (Elliott, Lach, & Smith, 2000). Other somatic complaints include headaches, hair loss, visual disturbances, weight gain, dizziness (Moffat, Dorris, Connor, & Espie, 2009), soreness of the mouth, uncontrolled urination, and injuries from seizures (Elliott, Lach, & Smith, 2005). Many physical complaints are typically a result of medication side effects or seizure-related factors, and can interfere with daily functioning and participation in social activities in school (Elliott et al., 2005).

### **EMOTIONAL AND BEHAVIOURAL FACTORS**

Children and adolescents with epilepsy frequently experience negative emotional and behavioural effects as well (Elliott et al., 2005). Ettinger et al. (1998) found that 26 percent of children ages seven to 18 met criteria for depression, while 16 percent experienced elevated levels of anxiety. Medication side effects can impact mood and irritability (Benavente-Aguilar, Morales-Blanquez, Rubio, & Rey, 2004; Elliott et al., 2005). Other psychosocial factors may also contribute to psychological distress. For example, in a focus group, Moffat and her colleagues (2009) found that children with epilepsy had elevated frustration and anger when they lose control of their bodies during a seizure. Further, they found that some children express fear of injury or death during a seizure. In another study, because their condition may not remain confidential due to the unpredictability of seizures, some children with epilepsy felt anxious over potential embarrassment (Elliott et al., 2005). Epilepsy may also hinder the development of autonomy (Moffat et al., 2009). Adolescents, in particular, complain of restrictions on privacy and high rates of parental and teacher monitoring, thereby interfering with their desire for increased independence (McEwan, Espie, Metcalfe, Brodi, & Wilson, 2004). This loss of control and lack of independence has been shown to elicit frustration, anger, and sadness among young individuals with epilepsy (Elliott et al., 2005; Moffat et al., 2009).

### **SOCIAL FACTORS**

Many young people with epilepsy experience social isolation due to internal and external constraints (Elliott et al., 2005). Children with epilepsy have expressed that they feel “different” from their peers, contributing to feelings of social inadequacy (Elliott et al., 2005). Many children are unwilling or too embarrassed to disclose their conditions to peers (Moffat et al., 2009). Because

of this lack of shared information, many children also fear that peers will be unfamiliar with safety procedures that prevent injury during seizures, and therefore choose to withdraw from social interactions (Elliott et al., 2005). Many children with epilepsy also experience bullying and teasing. Further, restrictions and excessive monitoring by caregivers and educators, as well as illness-related factors, such as frequent doctor appointments, hinder children's ability to participate in social activities (Elliott et al., 2005; McEwan et al., 2004).

### **ACADEMIC FACTORS**

The academic difficulties that children with epilepsy experience are well documented in the literature (e.g. Aldenkamp, Weber, Overweg-Plandsoen, Reijs, & van Mil, 2005; Austin, Huberty, Huster, & Dunn, 1999). Memory (Elliott et al., 2005), attention (Fastenau, Shen, Dunn, & Austin, 2008), and learning challenges (Moffat et al., 2009) encountered by many individuals with epilepsy negatively impact academic experiences. For example, Elliott and her colleagues (2005) found that 70 percent of children and adolescents aged seven to 18 years old expressed struggles with memory impairments. Their study also revealed that students were frustrated with their postictal confusion, which impaired their ability to focus and attend to materials being learned in class.

Academic underachievement is prevalent among students with epilepsy (e.g. Aldenkamp et al., 2005). In children, epilepsy has been found to negatively impact intelligence (Bailet & Turk, 2000; Titus, Kanive, Sanders, & Blackburn, 2008), processing speed (Hernandez et al., 2003), vigilance (Aldenkamp et al., 2005; Sirén et al., 2007), perceptual organization, and self-regulation (Hernandez et al., 2003), all which are factors which affect academic achievement. Difficulties have been reported in mathematics (Wirrell, Sherman, Vanmastrigt, & Hamiwka, 2008), spelling, writing, reading, reading comprehension (Aldenkamp et al., 1999), and expressive language (Selassie, Viggedal, Olsson, & Jennische., 2008). Fastenau et al., (2008) studied 123 children with epilepsy and found that approximately 50 percent met criteria for a learning disability diagnosis based on low achievement and traditional definitions of IQ-achievement discrepancy. Academic challenges have been attributed to anti-epileptic medications (Wirrell et al., 2008), polytherapy, or the use of multiple medications (Selassie, et al., 2008), excessive fatigue (Elliott et al., 2005), or seizure localization (Aldenkamp, et al., 2005).

Disparity in the literature emphasizes the importance for further research on the relationship between forms of epilepsy, medical factors, and their influence on cognitive functioning. It is evident that cognitive impairments are prevalent among children with epilepsy, which can have a significant impact on a child's school experiences, and in turn, their QOL (Elliott et al., 2005).

### **AIMS OF THE CURRENT STUDY**

As children spend a significant amount of time in the classroom, schools are among the most effective contexts for promoting the psychological, social, and physical health of school-age children (Weissberg, Caplan, & Harwood, 1991). Despite this opportunity, there is a lack of QOL research that specifically focuses on the school experiences of children with epilepsy which can help educators understand how to best support, accommodate, and prepare for these children in their classes. The purpose of this phenomenological study was to contribute to the existing literature by identifying the perceptions and school experiences of a small group of children with epilepsy.

### **METHODOLOGY**

To identify and describe the perceptions and school experiences of children with epilepsy, this study adopted a qualitative paradigm using children's narratives (Creswell, 1998; Wimpenny & Gass, 2000). Through the process of journal writing, the researcher implemented bracketing as a means of eliminating presuppositions of the phenomenon so that its essence can emerge without influence from existing theories, research findings, or personal biases (Ashworth, 1999). With presuppositions about the children's school experiences bracketed, the researcher engaged in conversations with children with epilepsy to develop a clearer understanding of the phenomenon (Berndtsson, Claesson, Friberg, & Ohlen, 2007). Although the researcher bracketed her presuppositions, findings continue to be subjective, and are therefore not generalizable, but are instead specific to the children in this study.

Throughout the study, interview discussions were recorded, extensively reviewed, and transcribed. Transcripts were coded for meaning units and themes (Creswell, 1998, 2005; Donalek, 2004). Participants were then asked to validate the emergent themes to confirm the truth-value of the interpretation (Donalek, 2004; Roberts & Cairns, 1999). The researcher continued to use a journal to reflect on her thoughts, responses, and decision-making process to establish credibility.

### **PARTICIPANTS**

Participants were recruited from two approaches: (a) opportunistic sampling from a larger study that involved families with children with epilepsy (Roberts & Whiting, 2011), and (b) typical sampling through a community partner at the Victoria Epilepsy and Parkinson's Centre. Six children between the ages of 7 and 12 years were interviewed for this study. Written consent was

Table 1

*Participant Demographics*

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

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

obtained from each parent and verbal consent was obtained from the child at the time of the interview.

Each participant had been diagnosed with epilepsy and was enrolled in school located in the Victoria, British Columbia region. At the time of the interview, three participants were enrolled in public schools, two attended private schools, and one was home-schooled. These children experienced absence, tonic clonic, or complex partial seizures (Table 1). According to Epilepsy Canada (2003), absence seizures occur when a child loses awareness, often appearing as daydreaming. During a tonic clonic seizure, the individual experiences stiffened muscles, convulsions, and becomes unconscious, causing him or her to fall to the ground. Complex partial seizures frequently are preceded by an “aura,” often described as complex motor and sensory action. An individual experiencing a complex partial seizure may look dazed, or perform repetitive movements.

**DATA COLLECTION**

Data were gathered through in-depth, semi-structured interviews based on Keith and Schalock’s (1994) QOL model, as modified by Roberts and Cairns (1999). Interviews took place at the participants’ homes or at a location of their choice. Interviews began with the children drawing a picture depicting what it is like to have epilepsy at school. This activity built rapport between the researcher and participant, and encouraged the child to reflect on school experiences and focus on the research question (Mauthner, 1997). Following this activity, participants were asked open-ended questions about the school

experiences. Clarifying and elaborating probes were used if a participant provided limited or ambiguous explanations.

## DATA ANALYSIS

Interviews with the participants were extensively reviewed and transcribed verbatim, including all literal statements and non-verbal and paralinguistic communications, such as intonations, emphasis and pauses (Heyner, 1985). Significant statements that represented how participants experienced school were extracted and searched for themes (Heyner, 1985; Wertz, 2005). A theme was identified when two or more participants mentioned the topic in their interviews.

The researcher's interpretations were validated through a second interview with the participants (Roberts & Cairns, 1999). During this second interview, participants were able to provide feedback or additional comments. These comments were included in the analysis. Final analysis elicited a description of the school experiences of children with epilepsy. Pseudonyms are used to protect the privacy of the participants and ensure confidentiality.

## FINDINGS

In-depth interviews explored the narratives of children with epilepsy, and described their perceptions and school experiences. Seizures, academics, feelings of belonging, and others' awareness of their condition characterized the narratives. These four categories, as revealed through the interviews, illustrate how children with epilepsy experience school.

### SEIZURES

Seizures can be expressed differently among individuals affected by epilepsy and, as revealed through the interviews, their influence on school experiences can vary. Some children described their seizures as brief interruptions to their connections with reality, as depicted by Thomas, a 12 year-old student who has absence seizures:

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?'

Others identified seizures as a source of anxiety. For these individuals, their seizures created a dependence on others and an essential understanding of first aid. Emily demonstrated her experience of having a tonic clonic seizure through her drawing. In this picture, Emily illustrated herself seizing on the ground. A discussion of this illustration conveyed that Emily feels different from others when having a seizure, and described others as “sad” and “not happy,” stating that her teacher calls the ambulance. This experience is not the same as that of Thomas, and therefore stresses that examination of seizures is essential in understanding the experiences of attending school with epilepsy.

The children in this study discussed their perceptions of others’ reactions to their seizures. Many of the participants believed their teachers worried about their condition, and mentioned the anxiety their school community had around ensuring their safety during a seizure. Some children believed that this anxiety was manifested as overprotection, which in turn disrupted feelings of normalcy and belonging. The children also discussed their needs before, during, and after a seizure. These needs include steps to ensure seizure prevention, knowledge of seizure first aid, ongoing support, and empathy from teachers. These types of supports were identified as ways to promote positive school experiences for children with epilepsy.

Seizures were described as affecting the children’s well-being, specifically targeting their physical health. Post-seizure effects and medication changes were identified as taking a physical toll on the participants’ wellness. The children discussed the physical discomfort that can occur after a seizure, particularly postictal confusion and fatigue. Nicole described this experience:

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).

In addition to these post-seizure effects, medication was another source of physical hardship for many of the participants. Often, medication experimentation is necessary to obtain seizure control, but for some participants, these frequent changes caused illness and discomfort. Nicole discussed her frustration: “they were experimenting with various horrible medications that made my epilepsy even worse. I hm, back then I felt like a lab animal.” She described feeling “overheated and pukey” during this period of experimentation.

In addition to the physical effects, seizures were shown to cause negative effects on the emotional well-being of the children in this study. The participants described feelings of anxiety, anger, and frustration about living with epilepsy. These feelings were attributed primarily to having seizures, bullying, academic difficulties, and medication experimentation. For Emily, having a



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seizure frightened her: "Cuz if I have a seizure, I might have to go to the hospital and I don't like that." Academic difficulties were a stressor for Thomas, who stated that "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 these negative feelings, however, participants maintained a positive view of self, and described a sense of hope. Many of the children in this study stated that they would eventually outgrow their epilepsy, providing them with the hope of permanent recovery.

### ACADEMICS

Interviews with the children revealed mixed feelings about school; they reported both negative and positive experiences. A common source of frustration was academic difficulties, both in general as well as in specific subjects. For Thomas, academic challenges are more generalized and elicit daily frustration: "It takes longer to do things . . . Um, it's hard to be organized." These skills are essential for learning, completing, and submitting assignments, and affect all aspects of Thomas's school day. For other students, such as Rachel, difficulties are experienced in specific subject areas: "One concern I have at school is I get frustrated with math."

The children discussed their experiences with educational services, such as learning support teachers, and described the helpfulness of adaptations and accommodations they were afforded in the classroom. Nicole suggested that flexibility was an important adaptation for her: "One thing I suggest for school, is to (pause) is to give um, is to give not really timed events like in Grade 1 like try and make it stress-free as possible." Additional support from classroom and learning support teachers was also valued by many of the participants. When supports were appropriately provided, the participants had a positive view of their educational experiences.

### SOCIAL BELONGING

A recurrent theme among the interviews was the importance of socialization and acceptance at school. Some children identified feelings of frustration due to social isolation and bullying experiences, and many discussed the value of their friendships and support from their peers. Nicole described her experiences with bullying: "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." Emily described instances of physical bullying:

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. And they, they use a stick, punch, and (pause) *hit me in the back* [whispered]

The narratives from these children also emphasized the importance of positive social relationships, suggesting its importance in positive school experiences. Friendships were often characterized by the support they provided: "Cuz I have um, lots of friends. And they all when I have seizures 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" (Emily).

Feelings of normalcy were essential to a positive school experience, and because of their seizure control, many children in this study felt their school experiences were "typical." At times, this was attributed to seizure control through medication: "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). Thomas' experiences were similar: "I have to, like, take, uh (pause) five pills every day. And I have like I haven't had one of those [absence seizures] in like, well I don't like usually have them anymore. But I used to have them like eight times every day." That said, the children believed there were limitations placed on them because of their epilepsy. For example, Nicole described an incident when she wanted to participate in a running activity, but because she was recovering from a cold, was asked by her teachers to "do it at a slowed pace." Some children also described feelings of aberration, and referred to differential treatment, which they felt was due to their diagnosis. Nicole stated that her teacher unreasonably believed that she had special learning needs. Anna, however, felt that she was treated better than her peers because of her diagnosis:

[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 [the 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.

The children in this study identified this differential treatment, both negative and positive, as a threat to their feelings or normalcy.

## **AWARENESS**

Building awareness and educating their school community about epilepsy was deemed important to most of the children in this study. The children suggested that awareness goes beyond simple recognition of the conditions' presence

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in the school, and includes education about epilepsy and its effects on the individual. Through education, the participants believed that misconceptions about epilepsy would be alleviated, and would aid in spreading awareness of what seizures look like, how they can be triggered, and how to help in the event of a seizure. For example, Anna stated that her teachers failed to recognize her absence seizures, and instead misinterpreted them as daydreaming: “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 daydreaming.” The participants also believed that education would aid teachers in understanding the types of supports needed for side effects and other challenges, such as academic difficulties. Through a discussion about his illustration, Thomas described how he felt his teachers did not know how to help him with his academic challenges: “And [my 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 children described the importance of the school’s awareness of seizure triggers:

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

To alleviate some of these challenges at school, some children recommended having a nurse or community advocate provide training and education to school personnel and peers. Anna suggested that schools should:

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.

It was also suggested that schools participate in Purple Day, which is an international campaign that focuses on building epilepsy awareness and support.

The children in this study discussed the importance of disclosure to their school experiences. Contrary to other chronic illnesses, epilepsy is typically visible at school, especially if seizures have not yet been controlled by medication. As such, disclosure to peers is not only unavoidable, but can be an essential key to maintaining safety. This was not viewed as a challenging task by most of the participants; in fact, the children believed it was necessary to inform their peers about their epilepsy so as to elicit their classmates’ support and understanding. It was also seen as an opportunity to prepare their peers in the event that a seizure occurs in their presence. Some participants, however, said their disclo-

tures were met with unpleasant reactions from peers, eliciting feelings of stigmatization. Anna described her experience of disclosing her condition to her friends:

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.

Some of the children in this study described eventual acceptance among their peers, while others admitted continuous stigmatization at school.

In addition to building others' awareness of epilepsy, the participants reported that increasing their own awareness of their condition was important as well. Some children described their desire to learn more about epilepsy so they could assist with building the awareness of others, and advocate for their needs. Thomas described his desire to talk to others about his epilepsy: "I just feel kind of awkward cuz, whenever someone comes over it's like Oh, why do you take 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?'" Knowledge of the signals their bodies give them prior to a seizure was also important to some children in this study, and allowed them to seek support and ensure safety. Anna who has tonic clonic seizures describes the importance of her awareness of her body:

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.

Although participants recommend educating the school community through discussions with school nurses and community advocates and organizations, the children were equally convinced that their own knowledge of their condition would attribute to increased school awareness about epilepsy.

## DISCUSSION

While there is a general understanding of how epilepsy affects physical, emotional/behavioural, social, and academic domains across various contexts (Elliott et al., 2005), there is a lack of research that focuses on these children's

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school experiences. This study provided children with epilepsy the unique opportunity to describe their school experience and perceptions.

Four themes emerged from their narratives: seizures, academics, social belonging and awareness. Seizures and their academic difficulties negatively impacted the QOL of children with epilepsy. Children described how their seizures often affected their physical and emotional well-being, as well as impacting their feelings of normalcy. The children expressed their frustration with their academic difficulties but also explained how educational services were helpful for them. They further discussed how their interpersonal relationships have both helped and hindered their QOL, offering detailed descriptions of their social belonging and aberration within the school context. Finally, the children suggest ways to improve their QOL by disseminating information about their condition throughout the school community, and provide insight into their personal needs and challenges at school.

The opportunity for these children to speak openly about their school experiences offers a unique perspective on the lives of children with epilepsy. This study, therefore, offers new insight that can inform future studies and increase our understanding of the school experiences of children with epilepsy.

#### **EDUCATIONAL IMPLICATIONS**

Literature stresses the importance of promoting psychological, social, and physical well-being (Weissberg et al., 1991); however, children with epilepsy revealed how their condition limited their opportunities to improve their QOL in school. Understanding student needs and effects of epilepsy will allow teachers to provide appropriate supports at school. The perceptions of the children in this study can offer insight into how to create positive school environments for children with epilepsy. In particular, some children with epilepsy would benefit from adaptations to support their program at school, including flexible time to complete assignments. As identified in this study, medication side effects, negative interpersonal relationships, and academic difficulties were a major cause of anxiety and frustration for many of the children. These concerns have also been found in the literature (e.g. Elliott et al., 2005; Ettinger et al., 1998). Awareness within the school community can enhance understanding of children's needs and required supports (Johnson & Thomas, 1999), as well as reduce stigma and misconceptions about epilepsy (Wilde & Haslam, 1996).

#### **FUTURE RESEARCH**

Semi-structured interviews provided important information on how children with epilepsy experience school. Although the children were told the purpose of the study, questions did not explicitly ask how epilepsy impacted their

school experiences, with the exception of asking the children to draw a picture of what it is like to have epilepsy at school. These open-ended questions allowed the children to discuss their experiences at school without assuming that condition influenced school experiences. Categories that were elicited from discussions with the children included: Seizures, Academics, Social Belonging, and Awareness. Future research may use these categories to formulate specific questions pertaining to how children with epilepsy experience school. Doing so would provide more structure to the interview, which research has shown is helpful for younger participants (Yule, 1993). Additionally, future research should explore the categories that were obtained in the narratives of children with epilepsy to see how they affect the QOL of children with epilepsy.

Although discussions with children with epilepsy provide valuable information on how they experience school, the perceptions of other individuals, such as parents and school personnel, would offer additional insight (Johnson & Thomas, 1999; Ronen, Streiner, Rosenbaum, & The Canadian Pediatric Epilepsy Network, 2003). Most importantly, better understanding the lives of these children from various perspectives would provide educators with additional information on how to support, accommodate, and prepare for students living with epilepsy.

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