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Injuries from seizures are a serious, persistent problem in childhood onset epilepsy: A population-based study



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ABSTRACT

Purpose: Document the frequency, types and risk factors for injuries caused by seizures for people with childhood onset epilepsy.

Method: We contacted patients with all types of epilepsy except childhood absence from the Nova Scotia Childhood Epilepsy population-based cohort. Seizure onset was between 1977 and 1985. Patients and parents were asked about serious injuries resulting from a seizure, defined as severe enough for an urgent physician or dentist visit.

Results: Of 595 eligible patients, we contacted 472 (79%). During an average follow up of 23.9 ± 8 years, 52 (11%) experienced ≥ 1 serious injury for a total of 81 injuries. Of all injuries, 24 (30%) were lacerations requiring sutures, 15 (19%) fractures, 11 (14%) broken teeth, 8 (10%) concussions, 4 (5%) burns, and 20 (25%) other. "Other" included 1 fatal drowning, 2 near-drownings, 3 shoulder dislocations and 1 severe eye injury. Four injuries occurred with the first seizure; all others after a long gap from seizure onset (range 1.5–30 years). Injuries occurred in all epilepsy syndromes, most commonly with symptomatic generalized epilepsy (17% vs. 11% $p = 0.03$) and intractable epilepsy (28% vs. 8% $p < 0.0001$). Most injuries occurred during normal daily activities and were judged not to be easily preventable.

Conclusions: During ~ 24 years of follow up 1 out of 10 patients with childhood onset epilepsy had a serious injury as the result of a seizure. Most injuries occurred years after the initial diagnosis and were more common when seizures were more frequent. The only practical solution to injury prevention is better seizure control.

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1. Introduction

Children with epilepsy may be injured during seizures. Any seizure that alters consciousness or leads to loss of motor control may lead to a variety of accidental injuries including falls, drowning, driving accidents or being struck by a vehicle, crashes with others or equipment during sporting events. Additional injuries from seizures may be the result of the seizure itself such as shoulder dislocation from severe muscle contraction during a generalized tonic-clonic seizure or tongue biting from tonic masseter contraction [1]. Children with epilepsy may have other neurological or behavioral problems that might increase the risk of an accident such as ataxia or ADHD (attention deficit and hyperactivity disorder). Physicians, parents and patients may be

very concerned about the risk of seizure related accidents and limit activities in an effort to prevent them [2].

In this study we have attempted to document how often seizures result in injuries during many years of follow up of a population-based cohort of children with new onset epilepsy. We have focused exclusively on injuries which occurred as the direct result of a seizure.

2. Methods

Patients were selected from the Nova Scotia population-based childhood epilepsy cohort. The cohort includes only incident (newly diagnosed) cases. The methods for the case finding of this cohort have been published previously [3,4]. Patients included all those in the Province of Nova Scotia between 1 month and 16 years of age who developed epilepsy (≥ 2 unprovoked seizures) between 1977 and 1985. Excluded were patients with progressive brain disorders such as a malignant brain tumor, neurodegenerative disease or metabolic disease. The entire cohort includes 692 patients

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with the complete array of epileptic disorders; however, for the current study those with epilepsy primarily characterized by absence seizures were excluded, because we have already published details about their seizure-related injuries [5].

The authors personally contacted parents and patients for a semi-structured telephone interview several times over their clinical course with a final interview for most patients at 20–30 years after the initial diagnosis of epilepsy. The interview lasted about 45 min and consisted of a series of questions including several about accidents that occurred during a seizure. Data from the last available interview are reported in this paper. We included only those accidents that were sufficiently concerning that they lead to an emergency room visit or a visit with a family physician or a dentist. We accepted the parent or patient's impression that the accidents occurred during an actual seizure.

To show the time between onset of epilepsy and time of injury, follow up was divided into intervals of 0–5 years, >5–10, >10–15, >15–20, >20. The number of patients with active epilepsy (i.e. those not beginning a terminal remission) was estimated for each interval.

Statistical analysis used SPSS version 15. Comparisons are Chi-squared and *t*-tests. "Multivariate analysis was not performed, given that correlates of injuries would be expected to be only variables related to seizure frequency/control."

This study was approved by the IWK Health Center Research Ethics Board.

3. Results

3.1. Sample description (Table 1)

Of 595 eligible patients, 472 (79%) answered questions about injury resulting from a seizure. Information came from parents + patient in 55%, patient alone in 18.3% and parents alone in 26.8%. No patient or parent refused participation. Ninety percent of patients were followed for ≥ 10 years. Follow up was <10 years in 10%, 10–20 years in 13%, 20–30 years in 58% and >30 years in 19%. The average age at seizure onset was 6.1 ± 4.6 years and at final follow up was 30 ± 9.7 years. Duration of follow up averaged

23.9 ± 8 years. Intellectual disability was present in 124 (26%) and 87 (18%) had a severe neurological deficit that interfered with activities of daily living.

Epilepsy syndromes were: focal 274 (58%), rolandic 39 (8%), juvenile myoclonic 26 (5.5%), generalized tonic-clonic only 40 (8.4%), symptomatic generalized epilepsies 65 (13.8%) and other 28 (5.9%). We used the 1989 ILAE Classification [6] rather than the 2010 ILAE suggestion of organization [7] in order to group patients, as fewer than 50% of patients with epilepsy have a syndrome accepted by the 2010 schema [8].

There were 125 (26.5%) individuals who experienced ≥ 1 seizure in the last year of follow up. Over the course of follow up, 62% had remission of their seizures (seizure-free and no longer receiving AED treatment) with an average terminal remission from seizures of 19.5 ± 9 years.

4. Injuries

Overall, 52 (11%) patients had ≥ 1 injury as the result of a seizure; 34 had 1 injury, 7 had 2 injuries and 11 had ≥ 3 . The total number of injuries was 81. The types of injury are outlined in Table 2. About 70% of the injuries consisted of lacerations requiring sutures, bone fractures, broken teeth or concussion. There was one fatality – a 35-year-old woman with Juvenile Myoclonic Epilepsy (JME) who drowned during a seizure in a supervised swimming pool. None of the accidents were the result of falls from bicycles and none occurred during sporting activities. In our judgment, all of the accidents occurred during normal daily activities and none was easily preventable. Others have noted that helmet use is not particularly effective in preventing facial or dental injuries, although we did not document the frequency of their use [9].

Not surprisingly, patients with more frequent seizures were more likely to sustain an injury. Those with persistent epilepsy (no remission) were significantly more likely to be injured than those with remission (21.3% vs. 4.8%, $p < 0.0001$) (Table 1). Likewise, people with intractable epilepsy had significantly more injuries than those without intractable seizures (27.7% vs. 7.6%, $p < 0.0001$) (Table 2). Children with "symptomatic generalized epilepsy" had more injuries than those with all other syndromes (16.9% vs. 11.3%, $p = 0.03$). Children with intellectual disability were more likely to be injured (Table 1), but this is likely the result of the strong association of intellectual disability with symptomatic generalized epilepsy and intractability [10].

For 47 of the 52 patients with injury, the age at the first injury was well documented. Injuries occurred throughout the clinical course (Fig. 1) and only ~5% of injuries occurred with the first seizure. Of first injuries, 70% occurred more than 5 years after the onset of epilepsy.

5. Discussion

The main findings of our study are that significant injuries occur as the result of seizures throughout the clinical course and, not surprisingly, are more likely to occur in those with more frequent

Table 1
Description of sample $n = 472$.

	Injury with seizure	No injury with seizure	<i>P</i>
Sex			
Female	27 (12.3%)	192	NS
Male	25 (11%)	228	
Epilepsy syndrome			SGE vs. all others $P = 0.03$
Focal ^b	29 (10.6%)	245	
Rolandic	2 (5.4%)	37	
JME ^a	6 (23%)	20	JME vs GTC only $P = 0.07$
GTC only ^a	3 (7.5%)	37	
SGE ^a	11 (16.9%)	54	
Other and unclassified	1 (3.6%)	25	
Intellectual disability	21 (16.9%)	103	0.02
Normal intelligence	31 (8.9%)	316	
No terminal remission	38 (21.3%)	140	0.0000001
Terminal remission	14 (4.8%)	280	
Intractable	23 (27.7%)	63	0.0000003
Not intractable	29 (7.6%)	355	

JME, juvenile myoclonic epilepsy; GTC only, epilepsy with generalized tonic clonic seizures only; SGE, symptomatic generalized epilepsy.

^a Well defined self-limited epilepsy syndromes of childhood with focal features were considered separately.

Table 2
Types of injuries $N = 81$.

24 (30%)	Lacerations requiring sutures
15 (19%)	Bone fractures
11 (14%)	Broken teeth
8 (10%)	Concussions
4 (5%)	Burns
3 (4%)	Shoulder dislocations
16 (20%)	Other including 1 fatal drowning, 2 near drownings, 1 severe eye injury with permanent loss of vision, 1 cervical disk herniation

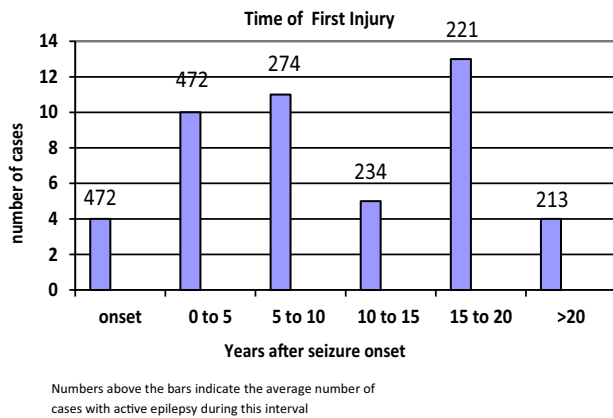


Fig. 1. Time of first injury

seizures. Overall, at least one child in ten with epilepsy will eventually have an injury related to a seizure that is serious enough to require medical assessment. Most injuries appear to occur more than 5 years after seizure onset.

There are a large number of publications about injuries involving people with epilepsy which have been thoroughly reviewed by Wirrell [11]. In general, the literature finds that accidents from all causes are only modestly increased in people with epilepsy compared to controls and most of that increase is related to accidents directly caused by seizures. A recent large, population-based, database study in the United Kingdom illustrates this concept [12]. 11,934 people with active epilepsy beginning at age 1–24 years were compared with 46,598 people of the same age without epilepsy. Both groups were followed for a median of 2.6 years. People with epilepsy had an 18% increase in their risk of fracture, 49% increase in the risk of thermal injury and 247% increase in the risk of poisoning. Poisoning was primarily with AED drugs; however, it was not possible to ascertain how many of the fractures and “thermal” injuries were directly caused by seizures.

Accidents in children and adults with epilepsy are not only the direct result of seizures. Concomitant neurological problems may include co-ordination problems with a greater chance of falling. AED intoxication results in significant ataxia. Comorbid ADHD may lead to impulsive behavior and risk taking. Intellectual problems may lead to poor judgment in dangerous places. However, the important issue for most physicians and caregivers and people with epilepsy is an injury which results directly from a seizure. Several studies have suggested that in otherwise normal children with epilepsy, the risk of injury over time is no higher than sibling controls [13] or normal control populations [14,15]; however, some of these normal children clearly have significant injuries due to a seizure. These seizure-related injuries are not frequent enough to stand out from injuries in the general control population. For the caretaker and the individual with epilepsy, concern about an injury from a seizure is still relevant and we think may lead to concern, anxiety and alterations in life style.

Several recent studies have addressed the risk of injury from a seizure. A prospective United Kingdom study noted that 12% of 198 children with newly diagnosed children with epilepsy had already had a seizure-related injury; however, only 16% of these injuries lead to medical assessment [16]. In the Connecticut study, 501 patients underwent a careful review 9 years after epilepsy onset that included questions about lifetime injuries [13]. About 50% answered affirmatively to the question: “Have you ever suffered any of the following injuries seriously enough to require medical attention?” Injuries included head injury, burns/scalds, fractures, dental injury and other types. An identical proportion of siblings without epilepsy reported injuries. However, only about

8% of the children with epilepsy had an injury related to a seizure; most of their injuries were from other causes.

A prospective multi-centered European study compared 951 people with active epilepsy recruited from hospital clinics to age and sex matched controls [14]. Patients (all older than 5 years) and controls kept a diary for ~1400 person years or approximately 1.5 years/person. The cumulative probability of accidents for patients was 17% at 12 months and 24% at 24 months after study entry, which was slightly increased over controls. The increased number of injuries was due to 77 seizure-related accidents (~8% of patients). It is unclear if there was any special seizure-related accident risk for the 233 children (ages 5–15 years).

The types of accidental injuries that we noted have been previously emphasized in the literature and have included mainly lacerations, fractures, dental injuries, head injuries and burns. Shoulder dislocation has been frequently discussed and reviewed [17]. A meta-analysis of the fracture risk in epilepsy found that fractures were approximately twice as common as controls [18]. There has been concern that enzyme inducing AEDs might increase the risk of osteoporosis and pathological fractures. Our cohort was gathered during an era when enzyme-inducing AEDs were commonly used (for example, phenobarbital, phenytoin and carbamazepine). Unfortunately, we did not collect any information that would indicate if this mechanism played a role in any of our patients’ fractures.

The strength of our study is the long follow up, which gives a glimpse at the lifelong risk of a seizure-related injury. The major weakness of our study is the retrospective nature of the data collection. It is very likely that parents and patients simply did not remember all accidents. It is interesting that the frequency of injury related to a seizure in our patient population was similar to several other publications [13,14]. We suspect that if we had surveyed our patient population at more frequent intervals the number of reported injuries would have been greater. Nonetheless, the 11% risk experienced by our patients over 20–25 years is close to the 8% risk over 9 years reported in the Connecticut study [13]. In addition, we did not include patients with childhood absence epilepsy. In a previous study we found that their risk of a seizure related accident sufficient to lead to medical attention was 14% [5]. Adding this result to the present study would have increased the risk of accident slightly from 11.0% to 11.3%.

We did not have any formal criteria for judging if an accident was preventable in any straight forward fashion and we freely admit that our study does not firmly establish that the accidents were or were not preventable. Nearly all accidents related to seizures occurred during normal daily activities, so restrictions on specific activities would not likely have had an effect. The one patient who died from drowning was a normally intelligent 30-year-old adult who was swimming in a pool with a life guard, an arrangement that might have been judged as a sufficient precaution. Possibly if she had alerted the lifeguard before swimming and was accompanied by an adult with life saving skills, this tragic outcome might have been prevented. Our data collection did not provide the very detailed information on every accident that might have allowed us to judge if an environmental change such as different furniture would have prevented the injuries. We postulate that seizure-related injuries can only be significantly reduced by better seizure control. Adherence to effective medication is important as well as early intensive efforts to treat refractory seizures. If complete seizure control is not possible then a lifetime of vigilance to attempt to avoid injury is the only option.

We suspect that most families and patients worry about of the possibility of an injury from a seizure. They may need guidance to decide if there are activities that should be altered or avoided to reduce this risk. We do not know if the patients in our study altered their activities to avoid injury. There are a few reasonable

restrictions for people with active epilepsy such as avoiding sky diving, scuba diving or “free” rock climbing [8]. Other restrictions do not seem justified for most patients. It is unclear how long a patient should be seizure-free before engaging in high risk activities. Since accidents may occur many years after seizure onset, it is possible that a few obviously dangerous activities should be avoided indefinitely or until there is confidence that the seizures are “gone” and the patient can be said to no longer have epilepsy. A recent proposal from the ILAE suggests this should be 10 years seizure-free including the last 5 years without AED treatment [19].

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Conflict of interest

The authors have no conflicts of interest related to this paper.

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