

Brief Communication

Perceived need for restrictions on activity for children with epilepsy

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ABSTRACT

Background: Children and youth with epilepsy have long been subjected to excessive restrictions on extracurricular activities due to concerns over risk of injury. Over time physicians and medical regulatory associations have liberalized the advice given for people with epilepsy to promote independence, self-esteem and general health benefits of physical activity. Current evidence suggests that few restrictions are needed for children with epilepsy beyond water-related precautions and avoidance of very high-risk activities. However, more stringent restrictions on daily activities may be imposed by caregivers. This study was aimed at exploring current perceptions of parents regarding restrictions on activity for children with epilepsy and the child's perspective on restrictions related to the diagnosis.

Methods: A self-administered questionnaire was offered to a sample of parent-child dyads of children/youth with epilepsy attending summer camp for children with epilepsy age 8–18 years. A 10-item validated HARCES Parent Scale of Childhood Epilepsy was completed by the parent/guardian and a modified-HARCES completed by the child. The primary objective was to assess the degree of restrictions placed on children with epilepsy from the perspective of child and parent assessed independently. Agreement of perceived restrictions between parent-child dyads was also determined.

Results: 21 parent/guardian-child pairs were recruited with mean age of children/youth 12.7 years (range 9–16 years). Total HARCES scores for parents and guardians ranged from 11–26 ($x = 16.5$; SD 4.9) while total scores for children with epilepsy similarly ranged from 10–25 ($x = 15.2$; SD 4.9). There were no differences in total parent scores when analyzed by child's age (<13 or >13 years), gender, age of seizure onset, seizure frequency or seizure type. Total HARCES scores showed no agreement between parent and child pairs with correlation of 0.2798 (95% CI -0.173 – 0.635).

Conclusions: Children and youth with epilepsy often face activity restrictions based on fear of perceived risk of injury. This small sample shows evidence that even more permissive parents and his/her children still feel limited by such restrictions. Parents and children do not perceive these restrictions in the same way despite similar education by physicians highlighting an important secondary role of epilepsy camps in targeting misperceptions and educating families on appropriate precautions.

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1. Introduction

Epilepsy is the single most common neurological disorder worldwide affecting an estimated 40 million individuals globally. The burden of epilepsy extends beyond its implications on health and has been shown to negatively impact quality of life. Historically children with epilepsy were advised to avoid many physical and sporting activities due to a perceived high risk of injury during a seizure [1]. In recent decades evidence has emerged that the risk of injury was only minimally elevated over the general population for many sporting activities [2]. In the 1970s and 1980s new position statements were released from the American Medical Association (AMA)

and the American Academy of Pediatrics, which liberalized the policies around participation of people with epilepsy in sports and physical activity [3,4]. The AMA considered this change an improvement in the patient's adjustment to school, society and to the disorder itself [3]. This led epilepsy experts and the International League Against Epilepsy to promote more physical activity for people with epilepsy in order to foster independence and self-confidence [5,6]. However, physician and parental fears over the theoretical risk of injury related to seizures are still prevalent. This is of course exacerbated by the unpredictable nature of seizures and social stigma surrounding epilepsy. Long-term consequences of such well-intentioned restrictions can be significant: parental anxiety, reduced quality of life and further social isolation for the child with epilepsy. Furthermore, undue restrictions perpetuate the stigma associated with the condition and exclude people with epilepsy from the general health benefits of regular physical activity.

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Evidence suggests that few restrictions are needed in childhood activities beyond water-related safety and avoidance of very high-risk activities such as scuba diving and sky-diving [6]. Van den Broek showed that most accidents due to seizures were minor with contusions and minor wounds being most common [7]. Parents are typically educated about this at initial diagnosis of epilepsy to understand when precautions are necessary. Current practice encourages participation in regular physical activity including contact sports and supervision for water sports, harnessed climbing and horse-back riding [8]. However, more stringent and excessive restrictions may be imposed by the parent or guardian in daily activities. In 2001, Aytch et al. reported heightened parental vigilance and monitoring of the child's activities for parents of children with epilepsy [9]. They also observed parental reluctance to leave the child in the care of others. Such hyper-vigilance may have negative impact on the child's social development and self-esteem with enduring consequences.

We were interested in exploring the current practices and perceptions of parents regarding restrictions on activity for his or her child with epilepsy. Our study also examined the child's perspective on restrictions due to the diagnosis of epilepsy. If a wide gap in physician advice regarding restrictions and parent/child beliefs still exists, more educational campaigns will be necessary to liberalize restrictions and avoid their damaging psychosocial and health consequences.

2. Materials and methods

A self-administered questionnaire was offered to a convenience sample of parent–child dyads of children/youth with epilepsy attending a Maritime region overnight summer camp for children with epilepsy. Children/youth with epilepsy were eligible for the camp if they were aged 8–18 years and had a minimal developmental age of 8 years. Children attending the camp and their respective parent/guardian were included. Pairs were excluded if the parent or child was unable to read English or the child was unable to understand the modified HARCES questionnaire without parental assistance.

At the start of the camp, a parent/guardian and child were asked to complete one brief questionnaire together including demographics of age, age of seizure onset, current seizure frequency and seizure classification. This was followed by a 10-item validated HARCES Parent Scale of Childhood Epilepsy (Suppl 1) completed by the parent or guardian and a modified HARCES version administered to the child/youth (Suppl 2). The HARCES questions follow a score of 1–4 where 1 = none, 2 = a little, 3 = some and 4 = a lot. Children and youth with epilepsy were

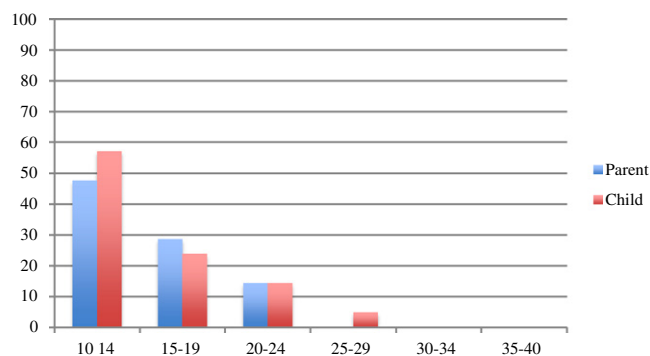


Fig. 1. Distribution of score frequencies on the Modified-HARCES in 21 parents and children. Scale range: 10 (least severe) to 40 (most severe score possible).

also asked to state which of the HARCES restriction items they felt was the worst; selecting from sports, gym class, swimming, staying overnight, and going to parties. The questionnaires were given a parent–child dyad numerical code to maintain anonymity. Completion of the questionnaire implied consent to participation in the research study.

The primary objective was to assess the degree of restrictions placed on children and youth with epilepsy from the perspective of child and parent independently. We also compared the agreement of perceived restrictions between parent and child dyad pairs. The HARCES parent-rated scale was scored according to published methodology and the modified HARCES child-rated questionnaire was scored similarly noting that it has not been formally validated. However, the questions have been modified only for age-related language. These scores represent the primary outcome measures and were also analyzed according to the baseline variables of age, gender, age at seizure onset, seizure frequency and seizure classification as categorical variables. We compared the agreement between parent-rated HARCES scores versus child-rated modified HARCES using correlation coefficients. The study was approved by the institutional Research Ethics Board.

3. Results

We recruited 21 parent/guardian–child pairs at a camp for children with epilepsy. One youth was excluded because no parent or guardian was available to complete the corresponding questionnaire. Of parent questionnaires, 18 were completed by mothers, 2 fathers and 1 guardian (grandparent). There were 11 male (52%) children respondents. The mean age of children and youth participating was 12.7 years (range 9–

Table 1
Demographic and clinical variables of children with epilepsy.

Variable	Outcome
Mean age	12.7 years (SD 2.5)
Gender	11 male (52%) 10 female (48%)
Mean age at seizure onset	4.8 years (SD 3.1)
Mean duration of epilepsy	8.0 years (SD 4.3)
Seizure types	
Generalized tonic–clonic	10 (48%)
Absence	7 (33%)
Atonic	1 (5%)
Myoclonic	1 (5%)
Simple partial	6 (29%)
Complex partial	7 (33%)
Seizure frequency	
Daily	4 (19%)
Weekly	3 (14%)
Monthly	4 (19%)
Yearly or less	10 (48%)

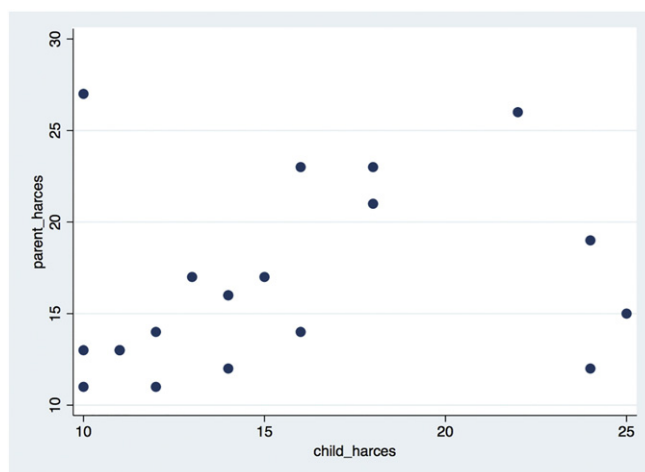


Fig. 2. Scatter plot of parent–child dyad HARCES total response scores.

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