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Extracurricular participation among children with epilepsy in Canada

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ABSTRACT

Introduction: Participation in extracurricular activities creates opportunities for children to foster friendships, promote a sense of belonging, and improve physical and mental well-being. The objective of this study was to determine the relationship(s) of personal factors, seizure variables, and social supports with extracurricular participation in children with epilepsy (CWE).
Methods: Baseline analysis of the QUALITÉ longitudinal study cohort of children aged 8–14 years (N = 426) was conducted. Variables hypothesized to be related to the participation of CWE were classified using the International Classification of Functioning, Disability and Health according to body functions (presence of generalized tonic–clonic seizures in the past month, on/off AEDs, and seizure severity), environmental factors (perceived social support from parents and friends), and personal factors (sex, age, family structure, and family income). Analysis of variables related to extracurricular participation was conducted with regression modeling.
Results: Personal factors of age, gender, and family structure as well as body function variables of generalized tonic–clonic seizures and seizure severity were found to be the most important to extracurricular participation based on how frequently they were included in the final models (16/16 and 13/16 times, respectively). When parental support was found to be related to participation, the association was negative in 6 out of 16 models.
Discussion: The personal factors that are related to extracurricular participation among children with epilepsy mirror samples based on the general population, although seizures also play an important role. The relationship between perceived parental support and actual participation levels warrants further exploration.

1. Introduction

Participation in extracurricular activities can have an important influence on the short- and long-term physical and emotional health of children with epilepsy (CWE) [1,2]. These activities can create opportunities for children to foster friendships, promote a sense of belonging, and improve physical and mental wellbeing [3,4]. Participation in extracurricular life in childhood has been found to impact future autonomy, independence, and quality of life in major life areas. These areas include employment and marriage, the average rates of which are lower in adults with childhood-onset epilepsy than in the general population [5,6].

Despite the benefits of extracurricular participation, CWE can often experience a disproportionate level of restriction in extracurricular activities relative to their risk of injury [1,7] and compared to controls [2] or to siblings [8]. Only one Canadian study was able to ascertain similarities in physical activity patterns between adolescents and young adults with and without epilepsy [9]. Previously explored seizure variables (e.g., frequency, antiseizure drugs (AEDs), neurotoxicity) have been empirically explored as potential predictors of participation with varying success [1,8].

The social factors that are empirically predictive of extracurricular participation among other samples of children remain unexplored in this group. For example, family income and family structure are found to influence participation levels in children with physical impairments [10–13]. Furthermore, the social support that children receive from their families and close friends is also known to influence their willingness to participate in activities outside of school [3].

Research exploring any association between extracurricular participation and seizure-related factors or social support factors might provide insight into possible interventions that could encourage such participation. Such an approach could, for example, help clinicians and service providers to tailor counseling about extracurricular activities according to the needs of the individual child with epilepsy and his/her

Abbreviations: CWE, children with epilepsy; GTC seizures, generalized tonic–clonic seizures; ICF, International Classification of Functioning, Disability and Health; AED, antiseizure drug.

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family. The objective of this study was to determine the relationships of seizure variables and social support to recreational, physical, social, self-improvement, and skill-based participation levels in CWE.

2. Materials and methods

2.1. Conceptual approach

We used the International Classification of Functioning, Disability and Health (ICF) as the conceptual framework to explore factors that were relevant to the child's participation [14]. This framework applies a holistic approach toward understanding health and disability and posits that biopsychosocial components of the child's functioning have an interrelated impact on their health. The independent variables were selected based on ICF components that are relevant to this group [15] from the QUALITÉ study. The variables are classified as body functions (presence of generalized tonic–clonic (GTC) seizures in the past month, on/off AEDs, and seizure severity), environmental factors (perceived social support from parents and friends), and personal factors (sex, age, family structure, and family income) (Fig. 1).

2.2. Participants

This study was conducted using the baseline data from the QUALITÉ longitudinal cohort [16]. Inclusion criteria for this study were the following: a diagnosis of active epilepsy by a child neurologist (defined as having a seizure in the past 12 months, or taking AEDs), a Peabody Picture Vocabulary Test — Third Edition (PPVT-III) standard score >70 to ensure the validity of self-reporting of participation, and an understanding of English or French. Informed consent/assent was obtained by all participants, and the study was approved from the Research Ethics Board at each site.

2.3. Child self-report measures

The Children's Assessment of Participation and Enjoyment (CAPE) [17] is a scale designed to measure how children between the ages of 6 and 21, with or without impairments, participate in everyday activities outside of their mandated school activities. The CAPE subscales used in this study evaluate recreational, active physical, social, self-improvement, skill-based, informal, and formal forms of participation. An overview of item content is found in Appendix A.

Scores for Diversity (the breadth of types of activities) and Intensity (amount of time spent on each activity) were calculated across the five subscales. A Diversity score and an Intensity score were calculated for each subscale. Internal consistency and test–retest reliability have been demonstrated as acceptable among typical children and children with various levels of cerebral palsy [18].

The Social Support Scale for Children (SSSC) [19] was designed to measure the perception of the social supports that children between ages 8 and 18 receive from their parents and peers. The instrument consists of four subscales based on the source of support (parent, classmate, teacher, close friend), and each subscale contains six questions. In this study, the parent and close friend scales were included in the analyses as the authors wanted to capture only the child's self-perceived social support outside the school environment. Adequate internal consistency and validity of the scale have been published by the developer and in independent studies [20].

2.4. Data analysis

All analyses were conducted with SPSS for IBM Version 21.0. Means, standard deviations, kurtosis, and skew were checked for all child-report measures. Zero-order correlations among independent variables <0.3 were deemed as free from multicollinearity.

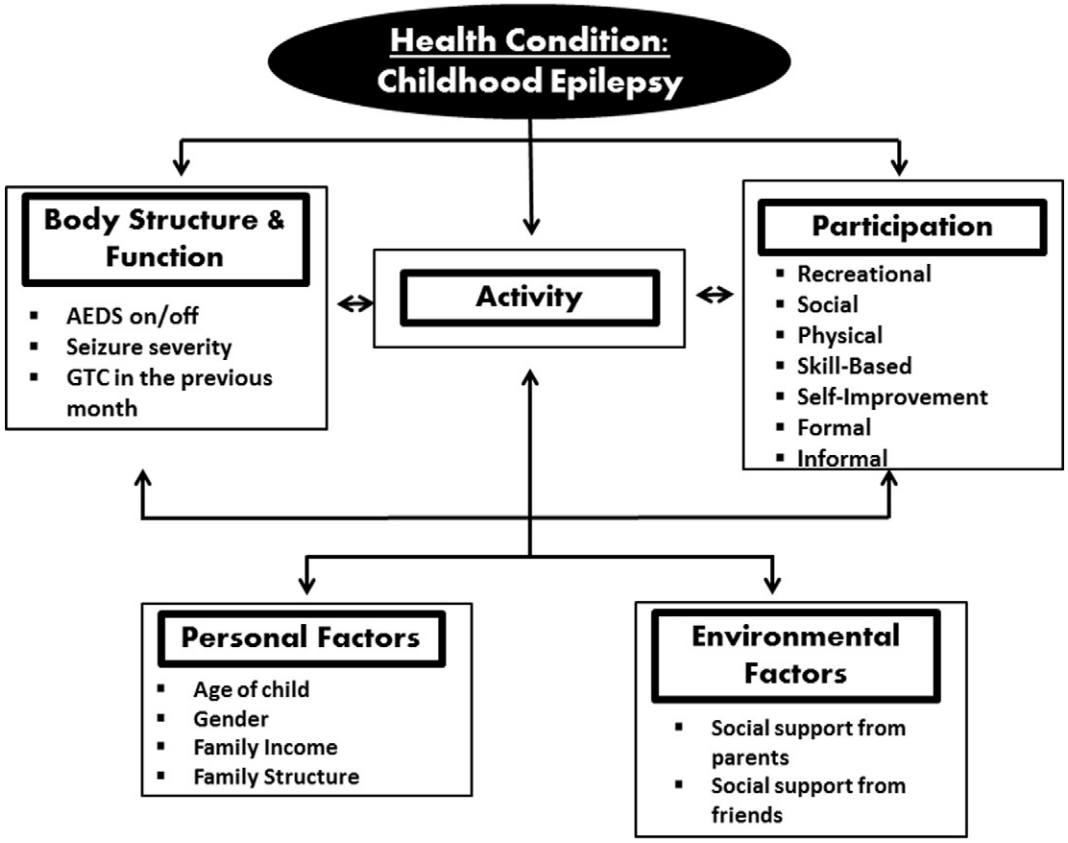

Fig. 1. ICF as framework to understand the influence of personal, body structure and function, and environmental factors on participation.