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Original Article

Outcomes Trajectories in Children With Epilepsy: Hypotheses and Methodology of a Canadian Longitudinal Observational Study

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ABSTRACT

BACKGROUND: The impact of childhood epilepsy can only be appreciated by understanding that epilepsy comprises a set of complex neurobehavioral conditions with significant social consequences, and not simply disorders of recurrent seizures. Our objective is to describe the hypotheses and methodology behind a large prospective longitudinal study that is based on a conceptual framework for understanding health outcomes. The study will quantify the specific influences—direct, mediating or moderating—that various epilepsy, co-morbid, child, and family variables exert on health over the early life course. **METHODS:** The target population is 8- to 14-year-old children with epilepsy and their caregivers from across Canada. Children, caregivers, and health professionals are completing 17 measures at five visits over a 28-month period. We have selected measures based on content, the source of the items, psychometric properties, and provisions for child self-report. Our cross-sectional and longitudinal design includes a relational model for structural equation modeling of specific biomedical and psychosocial variables with hierarchical direction of influence. To measure change over time, we will use hierarchical linear modeling. **SIGNIFICANCE:** This article reports the framework for interpreting future data. We believe that it will help researchers consider their methodology and encourage them to plan and execute longitudinal studies. Furthermore, the article will help clinical readers identify what to look for when evaluating outcomes research. It is our belief that the next generation of research to understand life-course effect in the lives of children and youth with chronic conditions and their families must occur over real time.

Keywords: childhood epilepsy, health outcomes, health-related quality of life (HRQOL), participation, conceptual framework of determinants, moderators and mediators, psychosocial adjustment, self and proxy reports

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Introduction

Epilepsy is not simply a disorder of recurrent seizures but a set of complex neurobehavioral conditions with significant social consequences. Children and youth with epilepsy (CYWE) have levels of emotional, behavioral, social, and academic difficulties that are both higher[1-4] and more persistent[5-7] than youth with other chronic health conditions or youth in general. Consequently, outcomes research

The QUALITÉ group includes health professionals from across Canada committed to research on health outcomes in childhood epilepsy.

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into CYWE is a challenging and complex undertaking that needs to incorporate sophisticated methodologies and modern concepts of patient-reported outcomes.

Pediatric neurologists have come to recognize that the broad goal of management and care is to empower CYWE and their families to lead a life as free as possible of the adverse medical and psychosocial complexities of this condition.[8] The evidence base for achieving optimal outcomes in childhood epilepsy is underdeveloped. Most studies to date have focused on targeted clinical management, emphasizing the relative success of various treatments in achieving seizure control while minimizing adverse side effects. Interventions concerned with the long-term adjustment and wellbeing of individuals and their families have received less attention. Psychosocial adjustment and health-related quality of life (HRQOL) are multidimensional constructs that have been shown to have high internal variability among their different domains for any individual child, highlighting that an apparently similar medical condition can affect individuals in many different ways.[9]

There is increasing evidence that health outcomes associated with a variety of chronic conditions are not solely attributable to the nature of disease and its treatment.[10-14] Some people with significant health problems are highly satisfied with at least some aspects of their lives (the so-called "disability paradox")[15] and demonstrate success in these same areas of functioning. Others, with few or no apparent problems, are highly dissatisfied with their lives[16] and do not demonstrate the same level of achievement. Therefore, although managing the components of disease severity is necessary, by itself it is limited in scope because additional factors influence these outcomes in CYWE. Multiple biological, psychological, developmental, and socioecological processes act together to contribute to the variability in children's health and wellbeing.[17]

We conceptualize health outcomes as changes in the global health or any of its core dimensions of an individual, group, or population, attributable to an intervention or series of interventions. In thinking about outcomes, one needs to identify and include the objective (health status) and the perceived subjective health (HRQOL) on a continuum between "good health" and "poor health"; in addition, one should attempt to incorporate the person's own life goals as influenced by a multitude of factors at any point in that person's lifespan (quality of life).[18] This broad viewpoint goes beyond the traditional notion of health, even the one expressed by the International Classification of Functioning, Disability and Health framework that includes environmental and personal factors, and identifies "activity" and "participation" as goals worthy of attention.[19]

In recognizing that wellbeing is different from disease control, it is imperative that professionals pursuing outcomes research in childhood epilepsy expand their view of health determinants. In addition to the important biomedical treatment targets that are always being developed, we should consider the nonbiomedical factors at the personal and family levels that may be (1) important determinants of the overall outcomes of CYWE and (2) appropriate matches for effective interventions. In this project, the trajectories and end results refer to both objective indicators of functional status and participation[20] as well as subjective indicators of HRQOL.[8,21] We have based this study on the understanding that the relationship between the morbidity of any condition (e.g., epilepsy) and outcomes is neither proportionate to severity nor linear. Neither objective nor subjective indicators of outcomes can be explained by epilepsy variables alone.[22] We are therefore interested in the role that other factors play in the expression of these important outcomes.

This article describes the hypotheses and methodology of a prospective longitudinal study that addresses current methodological concerns. It does not review the current literature on what is known on childhood epilepsy outcomes research or report results; rather, it serves to aid researchers in conceptualizing outcomes and planning future studies as well as providing a baseline for future reporting of our study findings.

Hypotheses

We hypothesized that mental health, intellectual difficulties, and child and environmental factors will explain more of the variance in outcomes of CYWE than epilepsy and seizure-specific variables. In addition, changes in children's outcomes over time will be related more strongly to child and environmental psychosocial factors than to epilepsy-specific variables. Our model of outcomes determinants (Fig) is conceptually complementary to the International Classification of Functioning, Disability and Health framework[18]; it is based on theoretical concepts and empirical knowledge that have accumulated both within and outside the field of epilepsy.[23,24] Consistent with

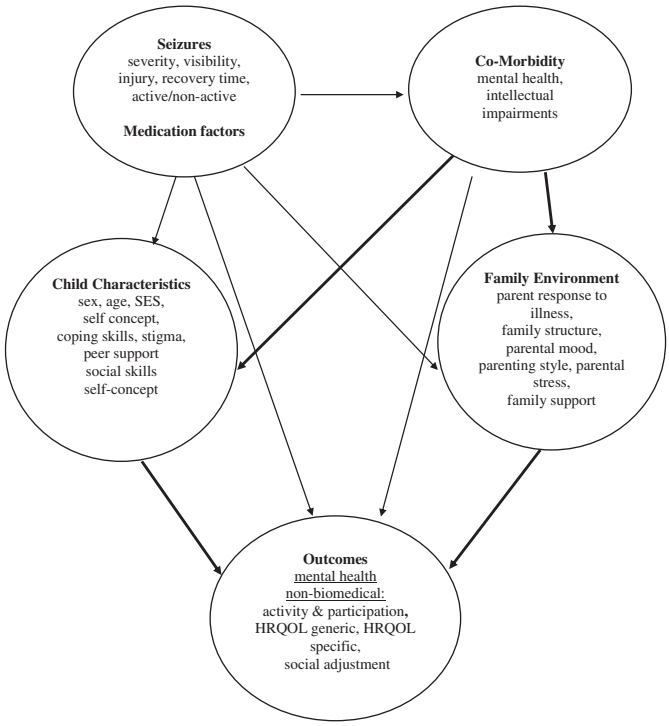

FIGURE.
Operational model of outcomes in children and adolescents with epilepsy: Illustrating factors to be considered in structural equation modeling analyses. HRQOL = Health-related quality of life; SES = socioeconomic status.

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