

Sociodemographic correlates of health-related quality of life in pediatric epilepsy

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Abstract

In most chronic conditions, better health-related quality of life (HRQOL) is associated with higher socioeconomic status (SES) and ethnic majority status, with disadvantaged groups typically reporting lower HRQOL. In 163 children with intractable epilepsy, we evaluated the relationship between HRQOL and a broad spectrum of demographic variables (SES, parental education, gender, age, marital status, family size, and ethnic and linguistic status), in relation to known neurological and behavioral correlates of HRQOL. No demographic variable was found to be related to child HRQOL, except for marital status, where children from divorced/separated parents had lower HRQOL. However, marital status was not uniquely predictive of HRQOL when neurological and behavioral variables were taken into account. Exploratory analyses indicated that children of separated/divorced parents were more likely to have early epilepsy onset, lower adaptive/developmental levels, and worse seizure frequency, suggesting that severe epilepsy may be a risk factor for marital stress. In sum, contrary to research in other chronic conditions, sociodemographic variables in pediatric epilepsy were weak predictors of HRQOL in comparison to neurological and behavioral variables. The results are discussed with respect to epilepsy-specific determinants of HRQOL.

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1. Introduction

Research on chronic diseases has indicated that health-related quality of life (HRQOL) varies according to demographic characteristics such as income level, educational history, ethnicity, occupational status, age, and gender, with disadvantaged groups typically reporting lower HRQOL. This association has been reported for a host

of conditions including cancer [1–5], HIV infection [6,7], lupus [8], renal disease [9,10], traumatic brain injury [11], and psychiatric disorders [12–14]. Studies involving healthy populations also indicate that socioeconomic status (SES) is associated with HRQOL in adults and children, and that there is an inverse association between children's HRQOL and family variables such as low parental education, SES [15–19], and ethnic minority status [16,20], with low family income contributing to caregiver distress in families of children with chronic conditions [21]. Ethnicity is particularly important in the understanding and management of chronic diseases [22–25], as ethnicity appears to influence the perception of social burden, symptom reporting, knowledge about biopsychosocial contributions to health,

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and health outcomes [16,17,25–27]. Importantly, there is evidence that the predictive power of “ethnicity” may actually relate to factors such as level of acculturation, literacy, or quality of education, rather than ethnicity per se [26–28]. Indeed, limited parental proficiency in English has been associated with worse child health status and reduced likelihood of accessing necessary medical care [29], and some studies suggest that socioeconomic factors outweigh ethnicity in predicting HRQOL in conditions such as cancer [30]. Likewise, male gender, low education, and low degree of acculturation are all factors posited to influence delays in seeking treatment and, consequently, to adversely affect HRQOL [24].

In comparison to this extensive body of research, the field of epilepsy has a notable paucity of studies on demographic predictors of HRQOL, particularly in children [31]. Nevertheless, existing epilepsy studies indicate that there are differences in treatment, treatment response, and understanding of epilepsy between sociodemographic groups [32–36]. In particular, studies involving children and youth reveal a relationship between low socioeconomic status and poor HRQOL in adolescents with epilepsy [37], as well as in families of children with epilepsy [38]. Studying the effects of demographic variables on health outcomes such as HRQOL is an important goal given the potential future benefits for health policy initiatives with implications for minority groups [39].

To address the deficiencies in the epilepsy literature, we undertook an investigation of the relationship between demographic variables and HRQOL using data from a cohort of children with epilepsy followed at a tertiary care center that serves a multicultural population in Vancouver, Canada [40]. The goal of the study was to determine which specific demographic variables were associated with poorer HRQOL in children with epilepsy, and whether these variables contributed to the prediction of HRQOL over and above the influence of known neurological and behavioral correlates of HRQOL, including such variables as antiepileptic drug (AED) load, intractability, seizure severity, adaptive/developmental level, and attention deficit/hyperactivity disorder (ADHD) symptoms, factors identified as important correlates of HRQOL in prior research [41–44].

2. Methods

2.1. Participants

All children had been referred for neuropsychological assessment from the Epilepsy Surgery Program and Seizure Clinic at British Columbia Children’s Hospital. Participants were classified by epilepsy syndrome according to ILAE criteria [45]. All necessary ethics and methods approvals from the hospital and university review boards were obtained to access these archival data. The sample was from a larger sample of children with intractable epilepsy whose neurological characteristics, adaptive levels, ADHD symptoms, and HRQOL have been previously reported [44]. Only patients with sufficient demographic information were included in the study; of the initial 203 cases reviewed, 163 had sufficiently complete

demographic information for inclusion in the study. At a minimum, each case had to have information on ethnicity, linguistic status, and parental occupation.

2.2. Measures

Demographic variables included age, gender, ethnicity, linguistic status, maternal and paternal education level, maternal and paternal occupation, marital status, and number of children in the household. All demographic information was provided by the parent at the time of the clinical evaluation on a standard background questionnaire, via open-ended response blanks. SES was calculated using Blishen and colleagues’ [46] occupational categorization scheme wherein numerical values are assigned to occupations according to Canadian Census-derived estimates of the educational requirement and remuneration for specific occupational categories. Familial SES was based on the highest occupational level attained by either the father or mother. Education level for mothers and fathers was coded in years. The Blishen Index of parental SES has established reliability and validity [47], and is used in a wide range of research contexts [48,49].

HRQOL was measured using the Impact of Childhood Illness Scale (ICI) [50]. The ICI is a 30-item parent-rated questionnaire that is divided into four sections: (1) impact of the disorder and its treatment, (2) impact on the child’s development and adjustment, (3) impact on parents, (4) and impact on the family. For each item, the parent rates how often the particular problem or situation occurs (Frequency score), as well as the amount of concern each one causes (Importance score). Scores for the two domains range from 0 to 60, with the total score ranging from 0 to 120. Higher scores reflect worse quality of life. The ICI is a generic instrument suitable for children with other illnesses or disabilities. The parent rates each item according to the degree of perceived frequency or impact on the parent and/or child. For Frequency ratings, the categories are “never or rarely true,” “sometimes true,” and “often or really true.” For Importance ratings, the categories are “a lot of concern,” “a bit of concern,” and “not much concern.” Validity in pediatric epilepsy is good [42].

All neurological data were extracted from health records at the time of the evaluation as part of routine clinical care; seizure frequency in the month prior to the evaluation was estimated based on health record information, and confirmed by parent report at the time of the evaluation. Behavioral measures included the Scales of Independent Behavior—Revised (SIB-R) [51] and the ADHD Rating Scale IV (ADHD-RS-IV) [52]. The SIB-R is a measure of adaptive behavior and developmental level that provides information on an individual’s ability to function independently in the home and community. Parents rate their children in several domains, including motor skills, social interaction and communication skills, personal living skills, and community living skills. Scores are presented in standard score format (mean of 100, SD of 15), with higher scores indicating better functional independence. The SIB-R Broad Independence standard score is the most reliable index score, reflecting the child’s overall adaptive level in the aforementioned domains. The ADHD-RS-IV is a parent inventory that evaluates attention and hyperactivity problems in the home setting. Ratings are translated into percentile ranks based on a normative sample, with higher percentiles indicating more severe ADHD symptoms. ADHD-RS-IV score patterns for the larger sample are described in detail elsewhere [44].

2.3. Data analysis

Because this was the first study of its kind to our knowledge and we wanted to minimize the risk of type II error, we adopted an a priori cutoff of $P < 0.05$, while being cognizant of the increased risk of type I error. First, correlational analyses between demographic variables and HRQOL were conducted (Pearson’s r for all analyses except those involving non-normal variables, where Spearman’s r was used instead), followed by a multiple regression analysis predicting HRQOL, where only variables with significant associations with HRQOL were included. The purpose of the

multiple regression analysis was to determine whether demographic variables added any additional unique variance to the prediction of HRQOL when neurological and behavioral variables were taken into account. Consequently, all identified predictors were entered simultaneously, and semipartial correlations were examined to determine the extent of unique variance shared between HRQOL and each predictor.

3. Results

Table 1 lists age at onset of epilepsy, epilepsy duration, seizure frequency, number of AEDs, and number of prior AEDs for the sample. Table 2 summarizes such demographic information as age, gender, ethnicity, linguistic status, maternal and paternal education, SES, parental marital status, and number of children in the household. Data were available for all 163 children on the majority of demographic variables, with the exceptions of marital status ($N = 110$), maternal education ($N = 106$), and paternal education for ($N = 96$).

In the sample, 18% of children were of an ethnic background other than Caucasian. The largest minority representation was for Chinese-Canadians (6.0% of the overall sample), followed by First Nations (3.0%) and Indo-Canadian (2.4%); the rest were from a variety of other different ethnic backgrounds. For the purposes of statistical analysis, ethnicity was dichotomized into two categories: Minority Status and Caucasian. In 31 households (19%) another language was spoken in addition to English; of these, 51% spoke an Asian language ($N = 18$; e.g., Cantonese, Mandarin, Vietnamese, Taiwanese, Korean), 11 spoke a European language (e.g., Italian, Spanish, German, Serbian), and 4

spoke an East Indian language (Punjabi or Hindi). The remaining children spoke other languages. Because of the wide variety of second languages spoken, linguistic status was dichotomized into two categories: Multilingual and Unilingual English-Speaking. Nineteen percent of the sample consisted of families in which parents identified as either separated or divorced. Two parents identified themselves as single; because it was not known whether these involved prior common-law relationships, these were excluded from analyses involving marital status. Parental marital status was dichotomized into two categories: Partnered (including common-law, married, and remarried) and Separated/Divorced.

Pearson's correlations between demographic variables and HRQOL indicated that all demographic variables, with one exception, were unrelated to HRQOL (all r 's $< \pm 0.10$). The one significant correlation involved a modest association between parental marital status and HRQOL, with separation/divorce associated with worse HRQOL ($r = 0.23$, $p = 0.02$). In terms of neurological variables, as expected, number of current and failed medications was moderately associated with HRQOL (Pearson's $r = 0.30$, $r = 0.32$, $P < 0.0001$), and Spearman's correlation between seizure frequency and HRQOL was also significant ($r = 0.31$, $P = 0.0001$). As we reported previously in the larger sample [44], worse ADHD symptoms and lower adaptive/developmental level were associated with lower HRQOL ($r = 0.34$, $r = -0.37$, $P = 0.0001$).

To determine whether demographic variables identified as predictors of HRQOL in the correlational analyses contributed any unique variance to the prediction of HRQOL when known predictors of HRQOL were considered, a regression equation combining the only significantly associated demographic variable (marital status) with the neurological and behavior variables showing associations with HRQOL (number of current and failed AEDs, seizure frequency, ADHD symptoms, and adaptive/developmental level) was constructed. Together, these six variables (marital status, number of current AEDs, number of failed AEDs, seizure frequency, ADHD symptoms, adaptive/developmental level) contributed significantly to the prediction of HRQOL ($R^2 = 0.38$, $P < 0.0001$). However, marital status did not contribute any unique variance to the prediction of HRQOL in this multivariate analysis (Table 3). The small semipartial correlation for marital status ($r = 0.14$,

Table 1
Neurological and behavioral variables and HRQOL

	Mean (SD)	Range
Age at epilepsy onset (years)	4.0 (3.9)	0–15.3
Duration of epilepsy (years)	7.7 (4.3)	0.5–17.5
Seizure frequency (seizures/month)	64.7 (195.5)	0–1710
Number of AEDs	1.7 (1.1)	0–5
Number of prior AEDs	4.5 (3.5)	0–14
SIB-R Broad Independence	68.6 (37.4)	4–155
ADHD-RS-IV total score (percentile rank)	73.8 (26.2)	1–99
ICI total score	48.6 (26.3)	0–103

Table 2
Demographic characteristics

	Mean (SD)	Range	N (%)
Gender (% female)			72 (44)
Age	11.8 (3.7)	4.06–20.23	
Maternal education (years)	13.6 (2.6)	5–22	
Paternal education (years)	13.8 (3.1)	7–22	
Blishen SES Index	51.3 (15.7)	23.41–101.74	
Minority ethnic background			30 (18)
Bilingual/multilingual household			31 (19)
Parents separated/divorced			20 (19)
Number of adults in household	1.95 (0.5)	1–4	25 (15) ^a
Number of children in household	2.2 (0.8)	1–5	51 (31) ^b

^a One-parent households.

^b Families with more than two children.

Table 3
Regression equation values for the prediction of HRQOL combining marital status and neurological/behavioral variables

Predictor	B	SE	β	P	Semipartial r
AEDs	8.95	2.11	0.38	0.0001	0.37
Failed AEDs	2.84	0.80	0.35	0.001	0.31
ADHD symptoms	0.25	0.10	0.25	0.01	0.22
Marital status	5.16	3.14	0.15	0.11	0.14
Adaptive level	-0.11	0.07	-0.15	0.16	-0.12
Seizure frequency	-0.01	0.01	-0.06	0.52	-0.06
Constant	10.71	12.90	—	0.41	—

$P = 0.11$) indicates that marital status is a weak, nonsignificant predictor of HRQOL that contributed no meaningful unique variance to the prediction of HRQOL over and above the contribution of the other predictor variables.

Because the unique association between a predictor (marital status) and a dependent variable (HRQOL) can be reduced in the presence of common variance with the other predictors in the regression equation (i.e., a variable's multivariate association with HRQOL may be lower than its bivariate association because it measures an overlapping domain similar to that of the other predictors in the multiple regression), we explored the extent to which marital status was related to the neurological and behavioral variables included in the regression equation. Examining correlations between marital status and these variables revealed that parental divorce was associated with higher seizure frequency (Spearman's $r = 0.20$, $P < 0.04$); no other associations between divorce and neurological or behavioral variables were found. We then divided children into two groups based on the timing of parental separation/divorce (before epilepsy onset vs after epilepsy onset; $N = 9$ and 11 , respectively) and examined group differences in HRQOL predictors. Children whose parents separated/divorced after seizure onset had an earlier age at seizure onset ($t = 2.28$, $P = 0.04$), lower adaptive/developmental level ($t = 3.20$, $P = 0.006$), and higher seizure frequency (Mann–Whitney $U = 9.0$, $P = 0.015$).

4. Discussion

In contrast to an extensive health literature documenting a relationship between HRQOL and demographic factors such as SES, ethnicity, and parental education, we found that almost no demographic variable was associated with HRQOL in the context of intractable pediatric epilepsy. One exception was marital status; children from families characterized by parental separation/divorce had lower HRQOL, but this demographic variable was of negligible importance in a regression-based prediction of HRQOL when other more potent neurological and behavioral variables were included. These findings indicate that in severe pediatric epilepsy, the powerful effects of epilepsy-related factors and comorbid behavioral conditions (particularly ADHD) take precedence over demographic variables in contributing to HRQOL. Thus, compared with other health conditions, HRQOL in intractable pediatric epilepsy may be more neurologically and behaviorally determined than in other conditions where sociodemographic variables play a larger role. In this study, extent of polytherapy, number of failed attempts at controlling seizures with new medications, low functional independence, and severity of ADHD symptoms were the most potent predictors of poor HRQOL, as we have reported previously [41,44], with demographic factors accounting for virtually no additional variance in HRQOL. The association between neurological variables and HRQOL has been documented elsewhere [53,54], and low adaptive functioning and

ADHD symptoms are known correlates of poor HRQOL in other populations of children [55,56]. Overall, this study illustrates the importance of developing condition-specific HRQOL models that identify the relative importance of HRQOL predictors, because these may differ across chronic conditions.

Although demographic predictors did not contribute *additional* information when neurological and behavioral measures were included, this did not mean that demographic variables had no association with HRQOL. While acknowledging that the association was modest, we found that a two-parent familial unit (common-law, married, or remarried) was associated with higher child HRQOL. In exploring this association in the small number of patients whose parents had separated or divorced, we found that children whose parents were divorced or separated after epilepsy onset tended to have an earlier age at onset of seizures, lower adaptive/developmental level, and higher seizure frequency, variables that are all associated with catastrophic epilepsy. Although replication in a larger sample is required before extrapolating from this finding, it does suggest that chronic epilepsy may exert a considerable burden on marital relationships in families of children with intractable seizures, thus increasing the likelihood of divorce/separation while also reducing child HRQOL. This is consistent with research indicating that chronic illnesses in children adversely affect the quality of marital relationships both directly and indirectly [57,58]. The relationship between marital stress and child HRQOL is likely complex and multifactorial, as parental adjustment also influences perceptions of child HRQOL, as measured via parental ratings such as those used in this study. It is also possible that marital status is a proxy variable for other variables such as family income or other economic indicators, which we did not study here; however, this seems less likely given the lack of association between SES and HRQOL in this study. Lastly, causative links between many of these variables may be bidirectional (e.g., low child HRQOL may be a source of marital stress, whereas marital stress may simultaneously reduce child HRQOL). In the future, more sophisticated analytic techniques, such as path analysis, could be considered to address these issues.

One limitation of this study is that it was necessarily restricted to families fluent in English because of the language requirements of the questionnaires administered and, therefore, does not apply to unilingual, non-English-speaking families such as new immigrants. As well, although the findings are relevant for those in other tertiary care centers serving children with severe epilepsy, they would not necessarily apply in community-based settings or other health care settings where children with less severe forms of epilepsy are seen. Self-report HRQOL data would also have helped disentangle some of the complex relationships between parental perceptions of child HRQOL and actual child HRQOL, in the context of neurological and behavioral variables.

In summary, minority status, low SES, and multilingualism were *not* identified as risk factors for poor HRQOL in this group of children, an unexpected finding because it runs contrary to much of the North American literature on chronic conditions, where these variables are associated with lower HRQOL. For example, in the United States, speaking a language other than English in the home and limited parental English proficiency are associated with a host of adverse outcomes, including poor health status, lower pediatric care, and lower access to care for children with chronic conditions [29]. Indeed, many US studies report a link between sociodemographic factors such as ethnicity, SES, linguistic status, and education and poor HRQOL, which may relate to intertwined sociodemographic/socioeconomic disparities. In European countries such as Britain and Italy, countries with universal health care, some studies report that socioeconomic factors are only minimally related to HRQOL [14,59,60]. On the other hand, in other European countries with strong social programs and universal health care such as Switzerland, Austria, and The Netherlands, sociodemographic factors such as low parental education are still identified as posing a risk for reduced HRQOL in childhood [18]. In this Canadian sample, it is possible that the lack of SES-, education-, or ethnicity-related associations with HRQOL may relate in some way to the Canadian sociocultural context or to the specific cultural/linguistic context of the Vancouver area where this study took place. According to a report released by the Government of Canada, families of Asian descent, groups with high representation in our minority sample, “are noted to have cultural histories and traditions that emphasize family-centeredness ... [with] a high level of ‘social capital’, or relational support that can buffer many family challenges” [61], and where benefits include pooling of resources and child care [62–65]. At a much more basic level, the lack of ethnicity/linguistic HRQOL disparities may reflect the effectiveness of a particular hospital environment aimed explicitly at patient-centered health care, and multiculturalism or to other factors not fully captured in this study. Whether hospital, local or national contexts mitigate some of the disparities that contribute to poor HRQOL in children is an important question deserving of systematic study. Regardless of the underlying reasons for the relationships we observed, there is a need for population-based studies, as well as international studies, to determine whether our results generalize to other regions and cultural milieus or apply to children with less severe forms of epilepsy. These are questions for future research.

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