



Health-related quality of life and emotional wellbeing improve in parents after their children have undergone epilepsy surgery – A prospective population-based study



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ABSTRACT

The objective was to compare parental health-related quality of life (HRQoL), anxiety, and depression at baseline and 2 years after epilepsy surgery in a population-based series of children and young people who underwent surgery between 1995 and 1999 and to compare with population norms. Fifty mothers and 44 fathers of 50 children and young people (age: 1–20 years) completed the Medical Outcome Study 36-item Short Form Health Survey (SF-36) and Hospital Anxiety and Depression (HAD) scale at baseline and at follow-up. Changes in SF-36 and HAD scores between baseline and follow-up were compared using Wilcoxon signed rank test. Scores on the SF-36 were compared with a reference sample from the Swedish population using the Mann Whitney *U* test. Factors associated with changes in SF-36 and HAD scores were analyzed using regression analysis. On the SF-36, the Physical Component Summary (PCS) scores were not significantly different between baseline and follow-up for mothers ($p = 0.177$) or fathers ($p = 0.054$). Mental Component Summary (MCS) scores improved significantly for mothers ($p = 0.008$) and fathers ($p < 0.001$). Mothers' baseline scores on seven of eight SF-36 domains were significantly lower than reference values. Scores at follow-up improved on these seven domains, but on three domains (primarily mental health domains), scores remained significantly lower than reference values. Fathers' baseline scores on four of eight SF-36 domains were significantly lower than reference values, and scores at follow-up remained significantly lower on the four primarily mental health domains. The proportions of mothers and fathers classified as HAD-A and HAD-D cases decreased at follow-up but did not reach statistical significance. Child epilepsy variables were in the main not associated with parental outcomes, but a greater reduction in AEDs was associated with a greater reduction in PCS scores. Parents of young people/children with seizure-free outcome were significantly more likely to have a reduction in depression scores than parents of young people/children with continued seizures. Many aspects of HRQoL and emotional wellbeing improved at 2-year follow-up for parents after epilepsy surgery on their children. There is a need to comprehensively identify factors associated with changes in parental HRQoL and emotional wellbeing to provide adequate support.

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1. Introduction

Parents of children with epilepsy have been reported to have lower HRQoL, higher levels of depression and anxiety, and increased parenting stress compared to parents of nonaffected children [1–3]. Poorer parental HRQoL and emotional difficulties in parents of children with epilepsy can have a significant negative impact on HRQoL in their children [1,4,5].

Both mothers and fathers of children with drug-resistant epilepsy report worse HRQoL compared with general population norms, while mothers are reported to have significantly more anxiety than fathers [6].

There is very limited research on the impact of pediatric epilepsy surgery on parental outcomes. In a convenience Canadian sample of 13 adolescents who had undergone epilepsy surgery, mothers reported their perceptions of change in areas including family function [7] although no standardized measures of functioning were used. In another Canadian study, which included 30 children who underwent surgery and 21 who were unsuitable for surgery, mothers completed a standardized measure of anxiety before and 1 year after surgery [8]. In a Dutch study, parenting stress was reported on by 31 parents (29 mothers) before and 2 years after their children's epilepsy surgery [9]. However, no previous

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studies of parental HRQoL or paternal emotional wellbeing before and after pediatric epilepsy surgery have been published to our knowledge. Understanding changes in parental functioning may contribute to our understanding of the broad psychosocial impact of epilepsy surgery in children and young people and their families and lead to the development of optimal support strategies.

The primary aim of the current study was to evaluate HRQoL, depression, and anxiety in mothers and fathers before and after their children have undergone epilepsy surgery. A secondary aim was to compare parental HRQoL before and after surgery with reference values from the Swedish norm population. The third aim was to identify factors significantly associated with change in HRQoL and parental emotional wellbeing.

2. Methods

2.1. Swedish National Epilepsy Surgery Register

All patients who undergo epilepsy surgery procedures in Sweden are prospectively reported to the population-based Swedish National Epilepsy Surgery Register (SNESUR). This was the basis for this prospective observational study. The study sample comprised a national sample of parents of children and young people (≤ 20 years) who underwent presurgical evaluation from 1995 to 1999 and subsequently underwent surgery. In SNESUR, information is collected longitudinally for each patient and contains baseline information about epilepsy history, preoperative seizure types, mean monthly seizure frequency during the year preceding the presurgical investigation, antiepileptic drugs (AEDs), preoperative investigations, psychosocial data, surgical data, and histopathologic diagnoses. Two-year follow-up data cover seizure types and frequencies, AEDs, and psychosocial data.

2.2. Outcome measures

Parents were asked to complete the questionnaires at the time of presurgical evaluation (baseline) and the same questionnaires 2 years postoperatively (follow-up). The questionnaires were distributed by the epilepsy nurses at the six Swedish epilepsy surgery centers and were self-administered. Respondents did not receive payment for participating.

The Swedish version of the Medical Outcome Study 36-item Short Form Health Survey (SF-36) was used to measure HRQoL [10]. The SF-36 is widely used and is a generic questionnaire that measures eight HRQoL domains: physical functioning (PF), role limitation-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limitation-emotional (RE), and mental health (MH). The domain scores range from 0 to 100; higher scores indicate better health status. Scores from the eight domains can be aggregated into two summary measures: Physical Component Summary (PCS) and Mental Component Summary (MCS). Two summary measures—MCS and PCS—are transformed to *t*-scores with a mean of 50 ($SD = 10$), where 50 represents the mean of the population. The Swedish version of SF-36 has shown good reliability and validity in both clinical- and community-based samples [11,12]. Both the principal component analysis and clinical group contrasts largely replicated U.S. findings, supporting the cross-cultural stability of the SF-36 in Sweden [11], and the performed criterion-validity tests support the cross-cultural stability of the SF-36 [12]. For comparisons of parents' HRQoL with population norms, a large reference sample ($n = 3764$; 52% females) comprising persons between 30 and 50 years was drawn from the Swedish SF-36 normative database (total $n = 8930$) [10].

The Hospital Anxiety and Depression (HAD) scale [13] is a very widely used instrument for assessing emotional symptoms in adults. It consists of 14 items measuring anxiety (HAD-A; 7 items) and depression (HAD-D; 7 items) in two separate subscales. Items are rated on a four-point Likert scale (0–3), and ratings are summed to give a score

ranging from 0 (no symptoms) to 21 (maximum distress) for both depression and anxiety. Cutoffs for 'possible' clinical cases (8–10 points) and 'probable' clinical cases (>10 points) have been established [11]. The HAD scale has been shown to have good psychometric properties in a Swedish sample of 1300 people aged between 30 and 59 years [14].

2.3. Parent and child characteristics

Information was gathered regarding parents' marital status ('married/living with partner' and 'divorced/widowed/single'), living arrangements ('living with partner and child' and 'living alone/alone with child/with a partner without child'), education level (high school degree/higher' and 'no high school degree'), and employment ('full-time employment' and 'nonfull-time employment', which included unemployment, part-time employment, sick leave, parental leave, and students). This information was gathered at baseline and follow-up.

Information about the children and young people before and 2 years after surgery was also collected including seizure frequency, seizure type, AED use, and intellectual disability (ID; $FSIQ < 70$) status. Intellectual disability status was based on results of cognitive assessments carried out as part of the children's presurgical workup. Seizure outcome was graded as seizure-free (seizure-free with or without auras during last year of follow-up), $\geq 75\%$ reduction, 50–74% reduction, and 0–49% reduction in seizure frequency or increased seizure frequency. For patients who were not seizure-free at the two-year follow-up, the mean monthly seizure frequency in the last year of follow-up was reported. For the purposes of this study, two categories were compared: seizure-free vs. nonseizure-free.

2.4. Ethics

The study was approved by the University of Gothenburg Regional Board of Medical Ethics, and informed consent was obtained from all parents.

2.5. Statistical analysis

Descriptive statistics were used to describe characteristics of the children and their parents. Mean (*M*) scores are reported for HAD and SF-36 scores before and at follow-up. Chi-square or ANOVA analyses were carried out to compare the characteristics of the children of responders and nonresponders. McNemar's analysis was also used to compare employment status, education level, living arrangements, and marital status in parents at baseline and follow-up.

Nonparametric statistical methods were used to analyze the HAD and SF-36 data due to the ordinal-level nature of the data. All analyses were performed for mothers and fathers, separately. Changes in HAD and SF-36 scores between baseline and follow-up were tested using the Wilcoxon signed rank test. Differences between the proportions of cases (Possible/Probable) vs. noncases of HAD-A and HAD-D respectively at baseline and follow-up were calculated using McNemar's analysis. Comparisons of SF-36 scores with Swedish reference values were made using the Mann-Whitney *U* test at baseline and follow-up. Results of the Wilcoxon signed rank and Mann-Whitney analyses for the SF-36 are reported before and after Holm-Bonferroni adjustment [15] for multiple comparisons.

Multiple regression applying generalized estimating equation modeling was used to identify factors associated with change (Δ) in maternal and paternal scores on the SF-36 MCS and PCS and HAD Depression and Anxiety. The predictors in the model were parent (mother vs. father), seizure outcome status (seizure-free vs. nonseizure-free), ID status (ID vs. non-ID), age of seizure onset in years, age at the time of epilepsy surgery in years, and change in AEDs (i.e., change in number of AEDs). Parental factors were tested to see if there were significant differences between baseline and follow-up. Parental employment was the only factor where there was a significant change, and change in

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