

Quality of life and sense of coherence in young people and adults with uncomplicated epilepsy: A longitudinal study



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ABSTRACT

Objectives: The aim of the study was, in a ten-year follow-up, to describe and explore potential changes in quality of life and sense of coherence in relation to gender differences among persons with epilepsy in the transition from adolescence to adulthood.

Materials and methods: A longitudinal study of sense of coherence (SOC) and quality of life with repeated measurement design (1999, 2004, and 2009) was conducted in a population of persons ($n = 69$) who were aged 13–22 years in 1999 and 23–33 years in 2009. The Quality-of-Life Index (QLI) and the Sense of Coherence (SOC) scale were used.

Results: There was a significant decrease ($p \leq 0.001$) in seizures compared with the 2004 results, mainly among the women ($p = 0.003$). When comparing the total QLI scores, no significant differences were found between the three data collections and there were no differences in total scores between men and women. There was a decrease in the SOC total score over the 10-year period study. Total SOC was significantly higher among those being 30–33 years old compared to those being 23–29 years old ($p = 0.014$) and among those having a driving license ($p = 0.029$) compared to those not having a driving license.

Conclusions: Both quality of life and sense of coherence are important for maintaining health and well-being. Promoting health and well-being requires effective high-quality multidisciplinary person-centered care.

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1. Introduction

According to the World Health Organization (WHO), epilepsy is one of the world's most common serious brain disorders, affecting about 50 million people globally [1]. In Sweden, the prevalence of active epilepsy is approximately 0.6–0.7%, which means that about 60,000 people have epilepsy, of which 50,000 are adults and 10,000 are children [2]. However, reported incidence rates may vary because of differences in age structures among different countries [3] and because of an array of utilized age definitions. For example, the WHO [4] has defined adolescents as young people between the ages of 10 and 19 years, while the United Nations (UN) has defined youth to be people between 15 and 24 years [5]. Even if the goal of epilepsy treatment is to control seizures with minimum side effects [6], only about 70% of people with epilepsy achieve this goal with antiepileptic drugs (AEDs) [1].

Persons diagnosed with epilepsy are more likely to experience lower quality of life (QOL) than the general population because of seizures and medical–psychiatric and psychosocial problems [7] as well as perceived stigma and discrimination [1,7]. Women with epilepsy tend to have

lower QOL than men with epilepsy [8–10]. Age and duration of the epilepsy diagnosis can have a significant negative association with health-related QOL in epilepsy [11]. Seizure severity [12], treatment side effects [13], and depression [12] are all found to be clinically significant predictors of QOL. However, there are [13] no data to suggest that age, gender, education, family status, comorbidity, seizure type, age at seizure onset, and epilepsy duration significantly affect the overall QOL as measured with the Quality of Life in Epilepsy Inventory (QOLIE-31) [13].

Sense of coherence (SOC) reflects a person's ability to cope with difficult or stressful situations. SOC among young people and adults with epilepsy has been sparsely researched. The findings from the first data collection in this project indicate that females (13–22 years) have a lower SOC compared with males (13–22 years) ($p = 0.003$) [14].

A study following young people and adults over a 10-year period is of particular interest because it includes the transition from adolescent to adulthood. Though some gender differences regarding QOL and SOC have been noted in previous research, there is a need for a longer follow-up of this cohort.

The aim of the study was, therefore, in a ten-year follow-up, to describe and explore potential changes in quality of life and sense of coherence in relation to gender differences among persons with epilepsy in the transition from adolescence to adulthood.

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2. Materials and methods

2.1. Design

A prospective and longitudinal study of sense of coherence and quality of life with repeated measurement design was carried out.

2.2. Sample and data collection

At baseline, in 1999, all adolescents and young adults ($n = 193$) aged 13 to 22 years, who had been diagnosed with uncomplicated epilepsy (i.e., epilepsy with no initially associated neurological impairment) and registered as having an epilepsy diagnosis (defined as at least two unprovoked epileptic seizures), in four Swedish hospitals [15] were invited to participate. The inclusion criteria were having experienced at least one epileptic seizure during the last year and/or being on epileptic drug treatment for epilepsy. Individuals with additional neurological impairments, benign childhood epilepsy, or other diseases or handicaps that were considered to substantially impact on QOL were excluded, leaving 151 participants (78%) in the study: 84 females and 67 males [15].

In 2004, the first follow-up study with these persons, then 18–27 years old, was carried out, and a total of 102 out of 146 (69.9%) traceable persons of the 151 participants from 1999 returned the completed Quality-of-Life Index (QLI) questionnaires [16]. Medical information was extracted from the patients' records by two physicians. Ninety-seven persons out of the 146 (66.4%) returned completed questionnaires regarding their sense of coherence [17]. The two most common diagnoses in 2004, in accordance with the ICD-10, were “generalized idiopathic epilepsy and epileptic syndrome” (52.2%) and “partial symptomatic epilepsy and epileptic syndrome with complex partial seizures” (20.3%). Other diagnoses were epilepsy, nonspecified (14.5%); partial symptomatic epilepsy and epileptic syndrome with simple seizures (5.8%); grand mal seizures, nonspecified (4.3%); other generalized epilepsy and epileptic syndromes (1.4%); and other epilepsy (1.4%).

In 2009, a second follow-up data collection on sense of coherence and quality of life was carried out. The individuals from previous data collections were identified by a research assistant, and they were invited to participate in this follow-up study. In addition to the questions included in the previous follow-up, questions regarding personality and quality of care were included; these were consequently not part of the longitudinal study and will be reported elsewhere. The questionnaire with a prestamped envelope was mailed to the individuals. Written information about the study was included. After about one month, a reminder was sent to those who had not responded. Those who still did not respond were contacted by phone by the research assistant. If they agreed to participate, another copy of the questionnaire was sent to them. In total, eighty-seven out of 128 traceable persons (53.9%) responded. Sixty-nine persons had now responded to both the QLI and SOC scale at all three data collection periods (Fig. 1).

2.3. Questionnaires

The self-administered generic version of the Quality-of-Life Index (QLI) developed in 1984 by Ferrans and Powers [18] was used. The QLI comprises a total of 68 items phrased as questions. The first section is related to satisfaction with specific areas of life (34 questions), while the second section is related to the importance, to the individual, of these same areas of life (34 questions). The 6-point response scale ranges from 1 = very dissatisfied/very unimportant to 6 = very satisfied/very important. Total scores range from 0 to 30, with higher scores indicating better QOL. In this study, Cronbach's alpha values [19] for the QLI were 0.89 (baseline in 1999), 0.97 (first follow-up in 2004), and 0.96 (second follow-up in 2009).

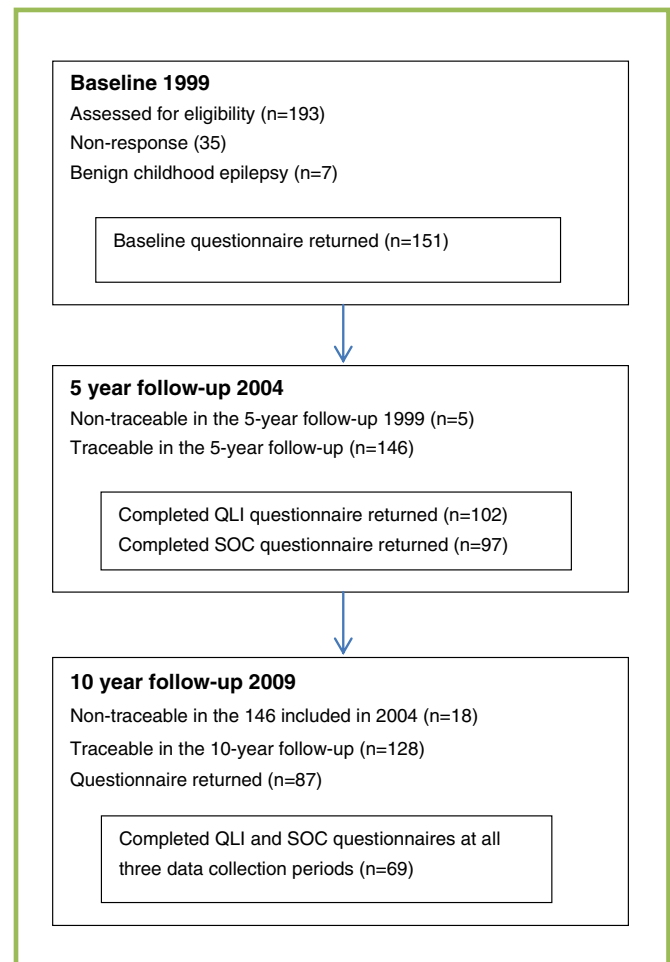


Fig. 1. Flow chart.

The Sense of Coherence (SOC) scale developed by Antonovsky comprises comprehensibility, manageability, and meaningfulness [20]. In this study, the 13-item version [21] was used at all three occasions. The 7-point response scale ranges from 1 to 7, with higher scores representing higher sense of coherence. The total SOC score was calculated by adding each item's score, ranging from 13 to 91, with higher scores representing stronger SOC. In the present study, Cronbach's alpha values were 0.51 (baseline in 1999), 0.89 (first follow-up in 2004), and 0.87 (second follow-up in 2009). In addition, some background and study-specific questions were included in the questionnaire (see Table 1).

2.4. Analysis

Statistical analyses were performed using SPSS, version 20.0. Descriptive statistics with frequencies, percent, range, mean, and standard deviation were used to describe the study sample. Estimates of internal consistency were established with Cronbach's alpha [19]. The mean SOC score and mean QLI score from the first (1999), second (2004), and third (2009) data collection points were compared using Friedman's two-way analysis of variance by ranks test and the Wilcoxon signed-rank test, while differences between two independent groups were analyzed using the Mann–Whitney U-test [22]. For nonparametric-related samples, McNemar's test was used. The correlation between QLI and SOC was tested with Spearman's rho.

The epilepsy diagnoses were categorized based on the ICD-10 codes used in 2004: “focal seizures” (ICD-10 code 40.1 or 40.2); “generalized

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