



# The relationship between illness severity, sociodemographic factors, general self-concept, and illness-specific attitude in Swedish adolescents with epilepsy

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## KEYWORDS

Epilepsy;  
Illness attitude;  
Illness Severity Scale;  
Self-concept;  
Adolescence;  
Young people

**Summary Purpose:** The aim of this study was to describe the relationship between the epilepsy condition (illness severity), sociodemographic factors, general self-concept, and illness-specific attitude in adolescents with uncomplicated epilepsy. **Methods:** Adolescents, aged 13–22, fulfilling criteria registered in four Swedish hospitals, answered questionnaires ( $n = 149$ ). The instruments “I think I am” and “Sense of coherence” measured the patients’ general self-concept. The “Child Attitude Toward Illness Scale” measured illness-specific attitude. A summary score (index) calculated from seizure frequency, seizure type, and antiepileptic drug (AED) with side effects measured “Illness Severity”. **Results:** Illness severity was significantly related to the participants’ general self-concept, as well as to their attitude toward their condition; i.e. higher illness severity scores were correlated with lower sense of coherence (SOC), poorer self-esteem, and a more negative attitude towards the epilepsy condition. Females had more severe illness according to the Illness Severity Index, with almost 80% found in the moderate and high severity groups as compared to 63% of males in the moderate/high severity groups. **Conclusions:** It was concluded that the severity of the epilepsy condition was related to the adolescents’ general self-concept and illness-specific attitude, but further research is needed to understand the causality of the relationship. The brief assessment of illness severity, constructed and used in this study should be addressed and developed further.

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## Introduction

Few studies in the epilepsy population concern the life situation and quality of life (QOL) of adolescents with epilepsy, especially those suffering from an uncomplicated condition, i.e. epilepsy only. Factors that have been found to relate to aspects of poor QOL and stigma in children and adolescents with epilepsy are high illness severity,<sup>1–3</sup> own or parents' negative attitude to the epilepsy condition,<sup>2,4–6</sup> "older age" (i.e. adolescents in late adolescence),<sup>3,7</sup> lower socio-economic status, and symptoms of neurotoxicity.<sup>3</sup> Corresponding factors in the adult epilepsy population are high seizure frequency,<sup>8–11</sup> use of avoidance or concealment as a coping strategy,<sup>8,9</sup> feelings about life as a whole and worry about epilepsy, psychological stress,<sup>9,11,12</sup> unemployment, and living alone or unmarried.<sup>8,13</sup> Compared to the general population, people with epilepsy have a poorer quality of life and more psychosocial problems.<sup>1,8–10</sup> This is in accordance with our findings concerning Swedish adolescents living with uncomplicated epilepsy.<sup>7</sup>

Psychological and social dimensions of health are related to a person's general self-assessment and can be described by his/her self-esteem<sup>14</sup> and sense of coherence (SOC)<sup>15</sup> i.e. the sense of meaning a person experience, and how he/she can understand and manage situations in life. It has been reported that persons with a strong SOC has a strong self and can handle stress better than those with a weak SOC.<sup>16–18</sup> According to Austin and Huberty<sup>4</sup> children with epilepsy and asthma related the feelings they had about themselves to their feelings about their chronic conditions indicating that also attitudes toward illness could relate to psychological and social dimensions of health.

This study is part of a larger study on the life situation of adolescents with uncomplicated epilepsy. The aim of this present study was to describe relations between the epilepsy condition (illness severity), sociodemographic factors, general self-concept, and illness-specific attitude in adolescents with uncomplicated epilepsy. Another aim was to find accurate but simple, basic components for the development of a new Illness Severity Scale for clinical use.

## Method

### Health-care system and study area

The study was carried out in the regional areas of four major hospitals in central Sweden: the Linköping University Hospital, the Örebro Regional

Hospital, and the County Hospitals of Jönköping and Karlstad. The total population of the four studied areas was approximately 125,000 in the age group 13–22, and the epilepsy care given was principally administrated by the clinics involved in this study.

### Inclusion/exclusion criteria

To be included, the adolescents should either have had at least one epileptic seizure during the last year, and/or be on antiepileptic drug (AED) treatment due to epilepsy.<sup>19</sup> The adolescents also had to be familiar with the Swedish language. Exclusion criteria were additional neurological impairments (most common; mental retardation, motor impairments) or other diseases (most common; asthma, diabetes, all diagnosed psychiatric conditions), or handicaps (most common; major physical handicap, obesity), which were considered to have a substantial impact on a person's quality of life ( $n = 65$  of totally 258 patients). All patients ( $n = 7$ ) with the diagnosis "benign childhood epilepsy" were excluded. The reason to exclude children with benign childhood epilepsy was the intention to have optimal conditions for comparisons between groups. The underlying hypothesis was that benign childhood epilepsy, having an excellent prognosis, could have a substantial positive impact on a person's general self-concept, through own and parents experience of the epilepsy condition as terminal. These children were too few ( $n = 7$ ) to form a group of their own, and if they had been included they would all have ended up in the youngest age groups, which might have had an impact when comparing groups. Three patients were excluded as they had been living abroad for 1 year or more.

### Subjects

All adolescents, aged 13 through 22, registered 28 February 1999 with an epilepsy-diagnosis in the paediatric or neurological departments, were invited to participate. Of 193 patients fulfilling the criteria, 158 (82%) returned mailed questionnaires. Seven patients with "benign childhood epilepsy" were excluded during the detailed record evaluation by one of the authors (B.S.) and two other subjects were excluded due to unspecified seizures (see under Illness Severity Index). This left 149 participants, 83 girls and 66 boys. One boy had undergone epilepsy surgery 1 year prior to this study; otherwise AED was the only epilepsy treatment. Of those who declined the invitation to participate, nine persons gave a reason why. In four cases the parents did not want their child to participate, and five patients stated that they "had other things to do". There

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