



Perceived stigma in Korean adolescents with epilepsy: Effects of knowledge about epilepsy and maternal perception of stigma



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ABSTRACT

Purpose: There has been little research on whether the knowledge that adolescents with epilepsy (AWE) or their family have about the condition reduces their perception of stigma. In this study we determine the relation between AWE's perceived stigma of, and knowledge about, epilepsy and maternal perception of stigma.

Methods: This was a cross-sectional multicenter study involving AWE and their mothers from 25 secondary or tertiary hospitals in Korea. The level of knowledge about epilepsy was assessed using 34 medical items of the Epilepsy Knowledge Profile-General (EKP-M). Additional questionnaires included the Child Stigma Scale, Parent Stigma Scale, and the Maternal Disclosure Management Scale. **Results:** A total of 243 AWE and their mothers were included. The mean EKP-M score was 20.7 (range, 12–31) for AWE and 22.0 (range, 11–31) for their mothers. AWE and mothers had a neutral perception of stigma on average, but the maternal concealment behavior was high. Multiple linear regression indicated that AWE's knowledge about epilepsy was significantly related to their perception of stigma. Unexpectedly, AWE with a low level of knowledge reported a higher perception of stigma than those with a very low level of knowledge ($\beta = 0.280$, $p = 0.040$). In addition, higher maternal concealment behavior ($\beta = 0.070$, $p = 0.002$) and receiving polytherapy ($\beta = 0.240$, $p = 0.046$) were independent factors predicting higher perception of stigma in AWE.

Conclusion: The knowledge that the AWE had about their epilepsy, maternal concealment behavior, and receiving polytherapy were significantly related to the AWE's perception of stigma.

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1. Introduction

Epilepsy is associated with significant psychosocial difficulties and stigma, which is a psychosocial burden faced by people with epilepsy (PWE) that can indirectly affect their quality of life.^{1–5} The perception of stigma can have a great influence on psychosocial health and self-esteem,¹ especially in adolescents with epilepsy (AWE), because the development of self-identity and peer relationships is of critical importance in adolescence. Few studies have been made on perceived stigma in Korean AWE.⁶ According to one study, perceived stigma and social isolation from their peers

cause serious problems in Korean AWE's psychosocial adjustment.⁶

The relation between epilepsy and perceived stigma in AWE is complex and is likely to be mediated by a number of factors including seizure frequency and type, adverse effects of antiepileptic drugs, the family environment, school, and society at large.^{1,7} Feelings of stigma were more likely to be reported by PWE with more frequent seizures; however, non-seizure factors such as experience of actual discrimination, introverted personality, and problem solving controllability may also affect feelings of stigma.³ In Korea, non-seizure factors seem to be more important to generate the perceived stigma in PWE than seizures themselves. Our previous study showed that 21% of Korean PWE reported feelings of stigma despite having epilepsy in remission for a minimum of 2 years.³ Knowledge about epilepsy is an important non-seizure factor that is potentially related to perceived stigma of PWE.

Levels of knowledge about epilepsy among PWE differ significantly among countries.⁸ In general, PWE in developing

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¹ See Appendix A for Korean QoL in Epilepsy Study Group members.

countries have lower levels of the knowledge than in developed countries. No study has been made on the epilepsy knowledge among Korean AWE. However, a survey of Korean adolescents from the general population indicated a general lack of familiarity and knowledge about epilepsy as well as perceptions that reflect stigma.⁹ These findings describe how the peer social environment can be especially stressful for AWE. In addition, few educational treatment program for AWE has been developed in Korea.

A recent UK study suggested that some social avoidance of teenagers with epilepsy might be related to concerns about not knowing what to do if a seizure occurred.¹⁰ Therefore, improving the knowledge and understanding of AWE will improve success in coping with the disease, which, in turn, may prevent AWE from generating internalized stigma¹¹; however, there has been little research on whether or not the knowledge that AWE or their family have about epilepsy reduces the perception of stigma. Westbrook et al.¹² reported that approximately two thirds of AWE did not report feeling stigmatized, and suggested that specialized education and support in a teaching hospital setting may have helped them cope with living with epilepsy, perhaps resulting in fewer feelings of stigma.

Family environment is predictive of psychological wellbeing in AWE.^{13,14} Parental perception of stigma was correlated with depression of the child,¹⁴ which reflects the importance of the family environment in the development of child perceptions of stigma. In Korea, mother is the main caregiver of the adolescent patients while father's role as a caregiver is overlooked and insignificant. And family with an epilepsy child tends to conceal that their child has the disease from their neighbors and relatives. Therefore, mother's perception of the disease has the strongest impact on AWE's stigma.

The aims of this study were twofold, as follows: (1) to determine the level of knowledge about epilepsy and the perception of stigma in Korean AWE and their mothers; and (2) to determine whether poor knowledge about epilepsy and maternal perception of stigma influence the presence of stigma among AWE.

2. Materials and methods

2.1. Subjects

This was cross-sectional multicenter study involving 25 secondary or tertiary hospitals in Korea. Subjects were individuals aged 13–18 years (middle or high school students) with any type of epilepsy who had been treated for at least one year. Epilepsy was defined as a history of two or more unprovoked seizures or a single seizure with evidence of epileptiform activity recorded by electroencephalogram or structural lesions documented by brain imaging. Subjects were excluded if they had reported a seizure in the 48 h before completing the questionnaires, if they had a neurological deficit that affected daily living activities, if they had received treatment for active psychiatric or medical disorders, or if they were unable to read or understand the questionnaires.

All the patients fulfilling the criteria were asked to participate in the present study on the day they visited their pediatric doctors or neurologists at the outpatient clinic. They were recruited consecutively. Demographic and clinical data were collected by interviews and from information in medical files, and were used as confounding variables in the statistical analysis. Demographic data were age and sex of the AWE, their mothers' age, educational level, and economic status. Epilepsy-related data were onset age, duration, type of epilepsy, frequency of both generalized and focal seizures, generalized tonic clonic seizure frequency, and number of antiepileptic drugs. All AWE and their mothers were

asked to fill out questionnaires at the outpatient clinic. Written informed consent was obtained from all subjects.

2.2. Questionnaires

The Epilepsy Knowledge Profile-General (EKP-G), which was developed by Jarvie et al.¹⁵ to assess general knowledge of epilepsy, consists of 55 items (34 medical knowledge items and 21 social knowledge items), with participants asked to answer "true" or "false" to each statement. Our study used the 34 items relating to medical knowledge (EKP-M), which include knowledge of features of epilepsy, etiology, medication, and management, with the total possible score ranging from 0 to 34. Both AWE and their mothers were asked to fill out the EKP-M. It usually takes about 8–15 min to complete EKP-M. The 21 social knowledge items of the EKP-G were not used in this study. Translation of EKP-M into Korean was done by the corresponding author (Lee SA).

Perception of stigma in AWE and their mothers was measured using the Child Stigma Scale (CSS) and the Parent Stigma Scale (PSS), respectively, both of which were developed by Austin et al.¹⁶ The CSS consists of eight items related to feelings of being different, embarrassment because of the seizures, and disclosure such as keeping the seizure condition a secret. The AWE were asked to rate how often they felt or acted in the ways described in each item on a five-point scale, ranging from one (never) to five (very often). The PSS consists of five items that reflect the parent's perceptions of how others might view their child because of the epilepsy. The mothers were asked to rate how much they agreed with each item on a five-point scale, ranging from one (strongly disagree) to five (strongly agree). In both the CSS and the PSS, the score for all items are summed and divided by the number of items in the scale. A higher score reflects a greater perception of stigma.¹⁶

The Disclosure Management Scale (DMS), which was developed by Westbrook et al.¹² was originally designed for PWE; however, it was modified for the mothers of AWE for use in this study. For example, a question such as "Do you keep your epilepsy a secret from others?" was modified to "Do you keep your son's/daughter's epilepsy a secret from others?" The DMS consists of four items and the mothers were asked to rate each of the items on a four-point scale, ranging from zero (no concealment of epilepsy) to three (full concealment of epilepsy). The score was summed across all items to produce a maximum total score of 11 points.¹²

2.3. Statistical analysis

We determined whether the AWE's perception of stigma (CSS score) was related to their medical knowledge about epilepsy (AWE EKP-M score) and their mother's medical knowledge about epilepsy (maternal EKP-M score), perception of stigma (PSS score), and disclosure management (DMS score). The dependent variable was the CSS score. Independent variables were the AWE EKP-M, the maternal EKP-M score, the PSS score and the DMS score. To analyze the effects of knowledge on perceptions of stigma, the participants were divided into three groups, according to the 33rd and 66th percentiles of the EKP-M score. We performed univariate linear regression, and then multiple linear regression with variables that had *p*-values <0.05 in the univariate analysis. Confounding variables included in the analysis were demographic (age and sex of the AWE), epilepsy-related (onset age, duration, type of epilepsy, frequency of both generalized and focal seizures, generalized tonic clonic seizure frequency, number of antiepileptic drugs), and maternal variables (age, economic status, educational level). *P*-values <0.05 were considered statistically significant. Data were analyzed using SPSS version 21.0 (SPSS Inc., Chicago, IL, USA).

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