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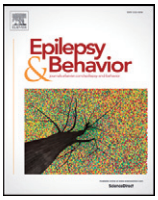

Disclosure management behaviors in Korean adults with well-controlled epilepsy: Their relation to perception of stigma

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ABSTRACT

Purpose: In spite of the fact that epilepsy is a concealable stigmatized identity, there is little evidence pertaining to disclosure management in adults living with epilepsy. We determined the factors contributing to disclosure management strategies in adults living with well-controlled epilepsy.
Methods: This was a cross-sectional multicenter study. Korean adults whose seizures had remitted for at least one year participated in this study. Using statistical analyses, we determined whether disclosure management behaviors measured using the Disclosure Management Scale (DMS) were related to demographic, clinical, and psychosocial variables. The Stigma Scale and Hospital Anxiety Depression Scale (HADS) were used.
Results: Of a total of 225 participants, 76% stated that they often or sometimes kept their epilepsy a secret, while 24% reported that they never or rarely kept their diagnosis hidden. The mean DMS score was 6.1 (SD = 2.4). In univariate analyses, the DMS scores were significantly related to the HADS depression scores ($r = 0.187$, $p = 0.005$) and the presence of perceived stigma ($p = 0.001$). In linear regression analyses, perceived stigma was identified only as an independent factor associated with DMS scores ($p = 0.031$), while HADS depression lost significance ($p = 0.057$). The presence of perceived stigma explained only 4.6% of the variance in DMS scores.
Conclusions: Our study shows that over 70% of Korean adults with well-controlled epilepsy often or sometimes keep their epilepsy a secret. Although perceived stigma is associated with concealment behaviors, it accounts for only a small proportion of the variance in disclosure management.

1. Introduction

Epilepsy, characterized by epileptic seizures, is one of the most common neurological disorders and can affect individuals of all ages. Because of the stigmatized nature of epilepsy, people with epilepsy commonly experience significant psychosocial difficulties, discrimination, and/or social exclusion around the world [1–4]. A large European study conducted in 15 countries showed that 51% of people with epilepsy experienced feelings of stigma associated with this condition [2]. This perception has a significant impact on the quality of life of people with epilepsy [2,5].

Epilepsy is a concealable condition as long as no conspicuous seizures occur in public [6]. When individuals feel a perception of being stigmatized upon disclosing their conditions, such as epilepsy, they are at risk of adverse psychosocial outcomes [7]. Recently, Benson et al. [8] systematically reviewed the disclosure practices of children living with epilepsy and their parents. They found that only one of the 32 studies they reviewed had disclosure of epilepsy as the primary research aim, and they noted that disclosure of epilepsy has been largely neglected to date [8].

As long as persons with epilepsy are in seizure remission, they can choose to conceal their epilepsy diagnosis or disclose it. People with nonvisible stigma attempt to set defensive goals and limit information about their condition to others so they can avoid stigmatization, especially in social settings [9]. A previous study showed that adolescents with better seizure control have significantly less open communication with friends about their epilepsy diagnosis [10], suggesting that individuals with controlled epilepsy are more likely to choose concealment and a selective disclosure strategy because they have a lower probability of seizure recurrence in public. In spite of the fact that epilepsy has a concealable stigmatized nature, there is little evidence pertaining to disclosure management in adults living with epilepsy. Furthermore, exploring the disclosure behaviors of adults with well-controlled epilepsy is of particular interest given that a high level of seizure control renders individuals more capable of concealing their epilepsy from others. Therefore, the aims of our present study were twofold: (1) to determine the frequencies of disclosure management strategies in adult Koreans with epilepsy with at least a 1-year seizure remission and (2) to determine whether their disclosure management is associated with demographic, clinical, and psychosocial variables.

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2. Methods

2.1. Subjects

This was a cross-sectional, multicenter study involving 19 secondary or tertiary hospitals in Korea. Inclusion criteria were as follows: age > 18 years, having a diagnosis of epilepsy, taking antiepileptic medication, being seizure-free for at least one year, and being willing to complete self-reported questionnaires. Epilepsy was defined as a history of two or more unprovoked seizures. Patients were excluded if they had a neurological deficit that affected their quality of life (e.g., hemiparesis, ataxia, gait problems, dysarthria, dysphagia, hemianopsia), if they were taking regular medication for active psychiatric or medical disorders that would have a negative impact on their quality of life, or if they were unable to read or understand the questionnaires. Hypertensive or diabetic patients without overt cardiovascular complications were not excluded.

A total of 225 participants whose seizures had remitted for at least one year participated in this study. These subjects were asked to fill out questionnaires on the day they visited their neurologist at the outpatient clinic. Demographic and clinical data were collected by interviews and by reviewing medical files. Written informed consent was obtained from all participants. The study was reviewed and approved by the Institutional Review Board of Asan Medical Center.

2.2. Questionnaires

Disclosure management strategies were assessed using the 4-item Disclosure Management Scale (DMS), which was originally developed by Westbrook et al. [11]. The items except one were scored on a four-point scale, ranging from zero (no concealment of epilepsy) to three (full concealment of epilepsy). Item 3 was scored on a 0–2 scale. The score was summed across all items to produce a maximum total score of 11 points. The Cronbach's alpha coefficient of the Korean version of DMS was 0.711, showing acceptable internal consistency.

Perceived stigma was measured using the Stigma Scale for epilepsy [12], which consists of three items and requires simple yes/no responses. Persons with epilepsy were asked to indicate whether they felt other people were uncomfortable with them, treated them as inferior, or preferred to avoid them because of their condition. Subjects score one for each item with which they agree. As the score of the Stigma Scale is the sum of their positive responses, the measure of Stigma Scale is a continuous variable. In this study, however, subjects were categorized as "stigmatized" if they said "yes" to at least one of these questions due to noteworthy ceiling effects of the Stigma Scale [13]. The Cronbach's alpha coefficient was 0.844, showing good internal consistency. Symptoms of anxiety and depression were assessed using the HADS (Hospital Anxiety Depression Scale), which consists of 14 items, 7 related to anxiety (HADS-A subscale) and 7 related to depression (HADS-D subscale) [14]. Higher scores represent a higher level of symptoms of depression and anxiety. The sensitivity of the Korean version was 89.2% for the HADS-D and 78.8% for the HADS-A and its specificity 82.5% both for the HADS-D and HADS-A when the cutoff scores were set at 8 points [15].

2.3. Statistical analysis

We determined whether disclosure management strategies were related to demographic, clinical, and psychosocial variables. The dependent variable was the DMS score. Independent variables included demographic (age, sex), clinical (age at onset, duration of epilepsy, duration of seizure remission, types of epilepsy, antiepileptic treatment), and psychosocial variables (education, employment, economic and marital status, HADS-D and HADS-A scores, and presence of perceived stigma) (Table 1). Based on univariate analyses using the Pearson correlation test, Student's *t*-test, or one-way ANOVA, multiple linear regression analysis was performed with the variables that showed *p*-values <0.05 in the univariate analyses. The significance level was set at $p < 0.05$. Data were analyzed using SPSS version 21.0 (SPSS Inc., Chicago, IL).

Table 1
Patient characteristics ($n = 225$).

Male/female, n	116/109
Age, years, mean (SD)	35.6 (10.4)
Education level, n (%)	
Middle school or below	21 (9.3)
High school	71 (31.6)
University or above	133 (59.1)
Economic status, n (%)	
Low	47 (20.9)
Middle or high	178 (79.1)
Married, n (%)	115 (51.1)
Unemployed, n (%)	44 (19.6)
Duration of seizure freedom, years, mean (SD)	3.1 (2.9)
Seizure onset, years, mean (SD)	22.0 (10.8)
Duration, years, mean (SD)	13.6 (10.1)
Epilepsy syndrome, n (%)	
Idiopathic generalized/undetermined	60 (26.7)
Symptomatic partial	61 (27.1)
Cryptogenic partial	104 (46.2)
Monotherapy, n (%)	133 (59.1)
Questionnaire measures	
Disclosure Management Scale, mean (SD)	6.1 (2.4)
HADS-D subscale, mean (SD)	5.7 (3.6)
HADS-D ≥ 8, n (%)	63 (28.0)
HADS-A subscale, mean (SD)	6.1 (3.7)
HADS-A ≥ 8, n (%)	70 (31.1)
Presence of perceived stigma, n (%)	56 (24.9)

HADS-A, Hospital Anxiety Depression Scale-Anxiety subscale; HADS-D, Hospital Anxiety Depression Scale-Depression subscale; SD, standard deviation.

3. Results

3.1. Subjects

A total of 225 participants were included in this study. There were 116 men (51.6%) and 109 women (48.4%) (Table 1). The mean age was 35.6 years (standard deviation [SD] = 10.4), the mean age at seizure onset was 22.0 years (SD = 10.8), and the mean duration of seizure freedom was 3.1 years (SD = 2.9). The Hospital Anxiety Depression Scale (HADS)-Depression (HADS-D) and HADS-Anxiety (HADS-A) scores were ≥8 in 63 (28.0%) and 70 (31.1%) patients, respectively. There were 56 participants (24.9%) who reported feelings of stigma.

3.2. Disclosure management strategies

Of the 225 participants, 76% stated that they often or sometimes kept their epilepsy a secret (Table 2), while 24% reported that they never or rarely kept their diagnosis hidden. More than half (57.8%) of the participants said at least some of their friends knew they had epilepsy. Slightly more than half (52%) reported voluntary disclosure of their epilepsy between seizures, 32% reported that they disclosed their epilepsy only because they had a seizure in public and had to explain what happened, and only 16% said that someone else usually told others of their diagnosis. Two-thirds of the participants rarely or never talked to others about their epilepsy.

Disclosure management strategies were compared between patients with and without perceived stigma using the chi-square test. Participants with perceived stigma were more likely to keep their epilepsy a secret from others ($p = 0.004$) and less likely to disclose their epilepsy voluntarily ($p = 0.004$) than those without a perception of stigma (Table 2). In addition, participants with a perception of stigma tended to be less likely to talk about their epilepsy to others ($p = 0.067$) compared to those without a perception of stigma.