Predictors of disclosure management behavior at the end of 1-year follow-up in Korean adults with newly diagnosed epilepsy

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ABSTRACT

Purpose: Epilepsy is a concealable stigmatizing condition. We investigated the factors predicting disclosure management behavior in Korean adults with newly diagnosed epilepsy.
Methods: This longitudinal multicenter study included Korean adults with newly diagnosed epilepsy. Using statistical analyses, we determined at the end of a 1-year follow-up whether Disclosure Management Scale (DMS) scores were predicted by demographic, clinical, and psychosocial variables, including felt stigma, stress coping style, personality traits, social support, and experienced discrimination from society.
Results: Of a total of 121 participants, 69% reported that they often or sometimes kept their diagnosis a secret from others and rarely or never talked to others about their epilepsy. The average DMS score was 5.8 (SD = 2.9, range 0–11). In univariate analyses, DMS scores were significantly associated with an emotion-focused coping style ($r = 0.320$, $p < 0.001$), social support ($r = -0.185$, $p < 0.05$), and experienced discrimination ($p < 0.05$). Emotion-focused coping was the only independent predictor of a higher DMS score. Felt stigma, personality traits, and seizure freedom were not related to the DMS score.
Conclusions: Two-thirds of Korean adults with newly diagnosed epilepsy often or sometimes keep their epilepsy a secret. Emotion-focused coping is the most important predictor of concealment of epilepsy diagnosis at the end of a 1-year follow-up, although social support and episodes of experienced discrimination are also associated with disclosure management strategies.

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1. Introduction

Epilepsy is considered a stigmatizing condition [1]. The burden of the diagnosis, including the risk of a public seizure and negative public attitudes toward the label "epilepsy", may have significant consequences, including psychosocial difficulties, social exclusion, and eventually a significant impact on the quality of life of people with epilepsy [2–4]. Despite improvements in public attitudes toward epilepsy due to the worldwide "Out of the Shadows" campaign, people with epilepsy continue to suffer from social stigma and discrimination, not only in the developing world, but also in the supposedly enlightened West [5,6].

Because epilepsy has a concealable stigmatized identity, people with epilepsy can choose themselves whether to conceal their epilepsy diagnosis or disclose it, as long as no conspicuous seizures occur in public [7]. Felt stigma associated with epilepsy is considered one of the important factors affecting disclosure management strategies [8]. Felt stigma not only refers principally to the fear of discrimination against people with epilepsy but also encompasses a feeling of shame associated with being epileptic [9]. When individuals with epilepsy have greater felt stigma, they anticipate more negative social consequences of disclosing their condition. Furthermore, their fear of the anticipated negative consequences of disclosure plays a crucial role in their ultimate decision to disclose or conceal their epilepsy from others [5,7]. In a Turkish study [10], 90% of adult participants who concealed their epilepsy diagnosis reported felt stigma to be a reason for their concealment. In contrast,

Westbrook et al. [11] did not find a relationship between the tendency to conceal and perceived stigma in a sample of adolescents with epilepsy. Similarly, we did not find a strong association between felt stigma and concealment of epilepsy in adults with epilepsy [8]. These inconsistent findings support the speculation that many factors play significant roles in the decision to disclose or conceal epilepsy [12].

Westbrook et al. [11] suggested that personality traits, self-perceptions, cognitive evaluations, and general coping styles may buffer or accentuate the effects of epilepsy-related attributes on perceived stigma and disclosure management. Schneider and Conrad [13] also stated that individuals adopt different types of behavioral management according to personal characteristics and overall confrontation coping styles. Recently, Benson et al. [12] systematically reviewed the disclosure practices of children living with epilepsy and their parents. They found that children with epilepsy and their parents adopt varying disclosure management strategies, from concealment to voluntary disclosure, and that only a limited number of factors that enable disclosure are known.

Although epilepsy is considered a stigmatizing condition [1], there is little evidence on disclosure management in adults living with the condition [8,12]. Furthermore, exploration of the disclosure behaviors of adults with newly diagnosed epilepsy is of particular interest given that, due to the time elapsed since diagnosis, their disclosure management strategies are less complicated by potential factors. Therefore, we investigated the factors predicting disclosure management strategies at the end of a 1-year follow-up in Korean adults with newly diagnosed epilepsy, focusing on the effects of a stress coping style, personality traits, social support, and experienced discrimination from society on their disclosure management strategies.

2. Methods

2.1. Subjects

This study was conducted using a database constructed for a previously published article, which was a 1-year longitudinal study of factors contributing to the development of felt stigma in people with newly diagnosed epilepsy [14]. The participants were enrolled from eight tertiary hospitals in Korea during 2010 and 2011.To be eligible for the study, patients had to meet the following inclusion criteria: age 18–60 years, new diagnosis of epilepsy within 4 years after the first seizure, completion of the 1-year follow-up period of the study, and completion of a set of questionnaires. If patients had only experienced a single unprovoked seizure, diagnosis of epilepsy required confirmation by electroencephalography or magnetic resonance imaging [15]. Patients were excluded if they had a neurological deficit (e.g., hemiparesis, ataxia, gait problems, dysarthria, dysphagia, and 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. The participants were asked to complete the questionnaires on the day they visited their neurologist at the outpatient clinic. Demographic and clinical data were collected by interview and medical file review. Written informed consent was obtained from all subjects. The study was reviewed and approved by the Institutional Review Board of Asan Medical Center.

2.2. Measures

Disclosure management strategies were assessed at the end of the 1-year follow-up period using the Disclosure Management Scale (DMS), which was originally developed by Westbrook et al. [11]. It consists of four items. Three are rated on a four-point Likert-type scale, ranging from zero (no concealment of epilepsy) to three (full concealment of epilepsy), but item 3 is scored on a 0–2 scale. The score was summed across all items to produce a total score (ranging from 0 to 11), with higher scores indicating greater concealment of epilepsy diagnosis. Cronbach's alpha coefficient in the study was 0.766, showing acceptable internal consistency.

Social support and experienced discrimination from society were also assessed at the end of the 1-year follow-up period using the Social Support Scale [16] and a questionnaire evaluating episodes of discrimination [2]. The Social Support Scale consists of 25 items and measures four areas of social support, namely, emotion, information, material, and evaluation [16]. Each item is scored on a five-point Likert scale, and a higher score represents a higher level of social support. A questionnaire on episodes of discrimination [2] asked participants whether, because of their epilepsy, they experienced actual discrimination from other people in their daily life. The questionnaire consisted of 10 items, three job-related items (getting a job, being treated unfairly at work, and getting fired), three items related to discrimination by members of the opposite sex (being rejected from dating, getting separated or divorced, or being treated unfairly by a spouse), and four items related to friends, neighborhood acquaintances, and close relatives (being shunned or avoided, being refused a meeting, being disinvited to a meeting, and being insulted). Each item required a simple yes/no response. Participants were categorized as "discriminated" if they answered "yes" to at least one question.

Felt stigma was measured at baseline and reassessed 1 year later using the three-item Stigma Scale for Epilepsy [1]. Each item requires simple yes/no responses: whether they feel other people are uncomfortable with them, treat them as inferior, or prefer to avoid them because of their condition. Participants were categorized as "stigmatized" if they answered "yes" to at least one question. Cronbach's alpha coefficient in the study was 0.837, showing good internal consistency.

Psychological data collected at baseline included the stress coping style, personality traits, self-esteem, and symptoms of depressive mood and anxiety. Stress coping was assessed using the Way of Stress Coping Checklist [17], which has a validated and modified Korean version [18]. It measures two coping styles, problem-focused and emotion-focused, each consisting of 24 items rated on a four-point Likert scale. The total score of each domain ranges from 12 to 48. A higher score means higher problem- or emotion-focused stress coping. Personality traits were assessed using the short form of the Korean version of the Eysenck Personality Questionnaire [19], which is composed of 48 items made up of four scales (psychoticism, extraversion-introversion, neuroticism, and lie) with 12 items each. Self-esteem was assessed using the Korean version of the Rosenberg Self-esteem Scale [20], which is composed of 10 items (five positive and five negative), each scored on a four-point Likert scale. A higher score indicates greater self-esteem. Symptoms of anxiety and depression were assessed using the Korean version of the Hospital Anxiety Depression Scale (HADS), which consists of 14 items, seven related to anxiety (HADS-A subscale) and seven related to depression (HADS-D subscale) [21]. Higher scores represent a higher level of depression and anxiety.

2.3. Statistical analysis

Data are expressed as the number and percentage of patients, the mean and SD in the case of normally distributed data, and the median and interquartile range (IQR) in the case of not normally distributed data. To compare group characteristics, statistical analyses were performed using a Student t-test or one-way analysis of variance (ANOVA) with Scheffé post hoc test. To determine correlations between variables, Pearson's or Spearman's correlation tests were conducted.

We determined whether disclosure management strategies were predicted by study variables. The dependent variable was the DMS score. Independent variables included social variables (education, employment, economy, and marital status), clinical variables (prediagnosis duration, type of epilepsy, number of seizures before diagnosis, presence of only nocturnal seizures, presence of generalized tonic–clonic seizures, seizure freedom after diagnosis, and antiepileptic treatment), and