Development of the perceived stigma scale and the concealment of epilepsy scale for the Turkish population

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ABSTRACT

The aim of this study was to develop two culture-specific scales to measure the level of felt stigma, and level of concealment of Turkish adult people with epilepsy (PWE). For this purpose, a 10-item felt-stigma scale and a 17-item disclosure of epilepsy scale were developed and then applied to 200 adult PWE. After item and factor analyses of the stigma scale, the 10 items with a one-factor solution explained 45.6% of the variance with a 0.86 internal consistency value. Higher scores represent higher felt stigma. The concealment of epilepsy scale has 17 items loaded on one factor, which explained 45.1% of the variance. Cronbach's alpha coefficient was found to be 0.92. The higher the score, the higher the concealment of illness by the participant. For convergent validity, the relationship between stigma and disclosure scales was examined, and a positive significant relation ($r = 0.64$, $p < 0.000$) was found.

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1. Introduction

Stigma has been defined as an "attribute which is deeply discrediting" or an "undesired differentness" by Goffman [1]. According to Morell, "Stigma is a mark of shame or discredit, a stain and an identifying mark or characteristic" [2, p. 21]. Jones et al. [3] defined certain dimensions of stigma, including concealability (whether the symptoms are visible to other people), the course of the mark (whether the prognosis is degenerative or salient over time), disruptiveness (whether the illness disrupts social interactions or not), aesthetics (other people's reactions to the unattractive sides of the stigmatized illness), origin (other people's attributes toward the origin of the illness: congenital, accidental, or intentional), and peril (the perceived threat of the disorder by others). Unfortunately, epilepsy fits almost all the definitions and dimensions of stigma. People with epilepsy (PWE) have been seen as dangerous and the illness seen as contagious or inheritable, and its origin even as demonic or ambiguous [4,5]. Depending on the type, seizures can interrupt social order and can be unesthetic and uncontrollable [6]. This is why, for centuries, PWE have suffered from the negative effects of both felt stigma, which is a fear of stigmatization and a fear of encountering enacted stigma, and enacted stigma, which is real discriminative experiences, simply because of having epilepsy [7–11].

There have been numerous attempts in the literature from different countries to investigate the level of, mostly, felt stigma [e.g., 8,12–15]. The most commonly used scale is the one developed by Jacoby [16], although, as even she stated [17], there is doubt over its cross-cultural applicability to measure felt stigma. Jacoby's scale was developed for British PWE, but since stigma is a cultural construct, the kinds and the degree of stigmatization will vary among cultures. In two of our previous studies in which we applied Jacoby's stigma scale [18,19], contrary to our clinical observations indicating higher felt stigma, such as feeling inferior and being ashamed of the condition, we were not able to measure it. However, in the first study in which we applied the present stigma scale [7], whose psychometric properties will be described in the present paper, we detected felt stigma in almost half of our participants, which was concordant with our clinical observations. Therefore, the first aim of this study was to describe the development process of a culture-specific scale to determine felt stigma for Turkish PWE.

The second aim of this study was to develop a scale in order to investigate the level of concealment of epilepsy from others. Other than seizures, PWE seem "normal" and "healthy" and conform to the expected standards of society. Because of this, most PWE do not disclose their illness [11], usually informing very few about their condition [20], and adopting concealment as the first strategy to battle against enacted stigma. In an earlier study, we found that almost half of Turkish PWE conceal their condition and most do so from their diagnosis [18], which indicates a long-term strategy to deal with stigma. Almost 90% stated felt stigma as the most important reason for their concealment behavior [18].

In most studies, concealment of the condition is regarded as a part of stigma and has been found to correlate with and predict stigma

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[e.g., 7,12,13]. Although a few studies found no relationship between stigma and concealment [e.g., 21], others showed that if an individual with epilepsy has observable seizures, such as tonic–clonic, this can contribute to stigma [14].

Interestingly, sometimes PWE disclose their condition, even though they feel stigmatized. For example, they reveal their epilepsy beforehand to avoid more negative consequences later, such as getting caught having a seizure in public, or so they can control the content of information, such as medicalizing their epilepsy, for example by saying they have low blood pressure, low blood-sugar level, or just saying having they have "fits," without specifying epilepsy. These disclosures were termed "preventive telling" [22]. In contrast, "pragmatic disclosure" is where PWE sometimes disclose their condition to obtain information about a doctor, a new treatment, or simply to assure themselves that they can get help during a possible seizure [23]. However, none of these disclosures necessarily mean that the person is free from felt stigma; rather, they are strategies to manage stigma.

Another issue related to concealment is its psychological cost on the person. Hiding an illness that usually manifests itself without warning or that cannot be controlled causes great anxiety and requires continuous efforts to keep it hidden. Consequently, many PWE live in constant fear and anxiety of being caught out and make endless efforts to disguise their condition. Hence, it is believed that concealment of epilepsy is worth measuring and evaluating separately from stigma.

Therefore, the aims of the study were to describe the development process of culturally specific felt stigma and the concealment of epilepsy scales and to provide their psychometric evaluation.

2. Method

2.1. Procedures followed for the development of epilepsy stigma scale and concealment of epilepsy scale

The items for both scales were developed in three phases: (1) formative research and concept development, (2) item development, and (3) data collection, reliability, and validity assessment. The first step included a literature review to obtain background information about the stigma, specifically felt stigma related to epilepsy [20,24,25]. The present paper's first author's clinical experience with PWE and her personal notes from previous studies, such as how PWE feel about having epilepsy and how they see their condition, were also used during item generation. Items for the concealment of epilepsy scale were created to understand to what extent PWE conceal their epilepsy from others, such as people in the outer social circle, like acquaintances, colleagues, coworkers, and/or from their inner social circle, like romantic partners, relatives, and close friends. The first author's notes from previous studies related to concealment and disclosure strategies by Turkish PWE were also used.

In step two, the items were generated for both stigma and concealment scales according to their conceptualizations stated above. Ten items were created for the stigma scale, and 17 items were created for the concealment scale. In order to evaluate the content validity, readability, and clarity of the scales, they were evaluated by three academics, each with a Ph.D. in psychology, and 20 PWE volunteers. Following feedback, some wording changes were made to increase the clarity of the items.

2.2. The scoring system of the scales

For both the scales, a five-point Likert scoring system was used. Response options were "completely agree," "agree," "not sure," "disagree," and "completely disagree." Responses were combined to create a five-point Likert scale whose higher scores indicate higher felt stigma and higher concealment of epilepsy.

On the cover page, demographics and clinical characteristics of the participants were requested (duration of epilepsy, seizure frequency, number of antiseizure medications used, and the existence of comorbidity).

2.3. Data collection

Two hundred adult PWE participated in the study. The first source of data collection was Dokuz Eylül University, School of Medicine, Department of Neurology. This group consisted of 103 volunteer PWE who attend for regular control visits. The second source was the official website of the Turkish Epilepsy Association. Ninety-seven PWE registered with the Association completed online versions of the scales.

The details related to the participants and the data collection procedure have been reported elsewhere [7]. The study was approved by the Izmir University of Economics Ethics Board (May 14, 2013, meeting no. 28, p. 66), and each patient gave informed consent for their participation.

3. Results

3.1. Data analysis

For all statistical analyses, SPSS for Windows, version 21 (SPSS Inc., Chicago) was used. Factor analysis using varimax rotation was performed to determine the factor structure of the scales. The internal consistency of the scales was analyzed by using Cronbach's alpha (α). Correlation analysis was used to evaluate the relationship between the stigma scale and the concealment scale.

3.2. Clinical and demographic characteristics of the participants

The age range of the participants varied between 18 and 68 years (M = 31.68, SD = 11.17); more than half were female (60.5%), and most were single (53%). There was a high level of unemployment (35%). More than a quarter had no seizures (33.9%), and more than half (53.5%) were on polytherapy. The demographic and clinical characteristics of the participants are summarized in Table 1.

3.3. Psychometric properties of the scales

3.3.1. Factor analysis

The necessary items were reverse coded before the factor analyses. Before we conducted the factor extraction, the Kaiser–Meyer–Olkin (KMO) value was examined to see whether the dataset supported

Table 1
Demographic and clinical characteristics of the participants.

	Participants (n = 200)
Sex (%)	
Female	60.5
Age (SD)	31.68 (11.17)
Year of education (SD)	10.70 (3.28)
Marital status (%)	
Single	53
Married	42.5
Divorced/widow	4.5
Occupational status (%)	
Employed	35
Unemployed	35
Housewife	8
Student	17
Retired	4.5
Duration of the illness (SD)	13.03 (9.95)
Number of seizures per month (%)	
No seizures	33.9
1–3	38.3
4–5	13.9
6+	13.9
Number of AEDS (%)	
Monotherapy	46.5
Polytherapy	53.5