



# Factors associated with increased felt stigma among individuals with epilepsy



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## ABSTRACT

**Purpose:** The aim of the study is to determine whether certain demographic, clinical, and psychosocial traits are associated with higher levels of felt stigma among persons with epilepsy (PWE) patients followed at a level 4 epilepsy center.

**Methods:** We performed a direct survey of 182 consenting patients that included the Epilepsy Stigma Scale.

**Results:** On univariate analysis, higher levels of perceived stigma were associated with age, marital status, race, driving, work status, seizure etiology, Quality of Life in Epilepsy-10 (QOLIE-10) scores, and health literacy. Among coping reactions, the use of denial, behavioral disengagement and venting were also associated with higher degrees of felt stigma.

Using multiple linear regression, being single, poorer QOLIE-10 scores, difficulties understanding written information, and the use of behavioral disengagement were independently associated with poorer scores on the Epilepsy Stigma Scale.

**Conclusion:** Our study paints a compelling profile of a PWE who has greater perceived stigma. Programs that increase the level of social support, improve health literacy, and enhance quality of life may also help decrease the amount of felt stigma among PWE.

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## 1. Introduction

The eminent sociologist Erving Goffman once defined stigma as a "...phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoil normal identity." [1]. A more recent definition of stigma is "... a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem." [2].

The fear of societal stigma remains one of the most important factors that lead to psychological suffering among people with epilepsy (PWE). Fisher and colleagues [3] showed that more than half of PWE experienced fear, depression, or anger as their initial reaction to the diagnosis of epilepsy and a quarter of them expressed serious concerns about social stigma and the fear of

others' reactions, often resulting in shame and loneliness. Another cross-cultural European study conducted in 1999 showed that more than half of PWE reported feeling stigmatized [4]. Stigma can be categorized into "enacted stigma" where actual discrimination takes place against PWE on the basis of their social unacceptability, and "felt" stigma which refers to the shame associated with having epilepsy and the fear of experiencing enacted stigma [5].

It behooves clinicians who manage PWE to understand the importance of stigma on overall wellness and the role it plays in impacting a patient's quality of life. Unfortunately, the impact of stigma on the lives of PWE is often underestimated by healthcare workers even though stigma affects quality of life even more than seizure frequency or the adverse effects of antiepileptic drugs (AEDs) [6–10].

In particular, an important question that remains unanswered is whether there are certain demographic, clinical, or psychosocial variables that are associated with enhanced felt stigma among individuals with epilepsy. More importantly, is there a certain psychosocial profile that is correlated with higher levels of perceived stigma? Knowing this would help identify those individuals who are having an especially difficult time coping with their condition. These PWE may benefit from added support and encouragement.

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In this study, we perform a direct survey of PWE who are followed at a Level 4 Comprehensive Epilepsy Program. The aim of the study is to determine those variables that are associated with a high degree of felt stigma and using multivariable analysis, to identify those that are independently significant. We opted to examine a large number of potential predictor variables in this study in order to create a comprehensive profile of a PWE who perceives a high level of felt stigma. In addition, new variables that until now have not yet or have only been rarely addressed in this context, such as health literacy, were included in this study.

## 2. Methods

The Institutional Review Board of the University of Florida Health Sciences

Center/Jacksonville (UFHSCJ) approved this study.

This study is an extension of a previous work that was detailed in an earlier publication [11]. We performed a direct survey on adult epilepsy patients who were being followed at the UFHSCJ-Comprehensive Epilepsy Program (CEP) outpatient clinics from February to June 2014. These patients had a diagnosis of localization-related epilepsy and had no history of non-epileptic events. They were their own primary caregivers and could complete the survey without assistance.

The UFHSCJ-CEP is a level 4 epilepsy center located in downtown Jacksonville, Florida and is a major referral center in the region. Around 42% of patients seen at the UFHSCJ-CEP are males, 58% are Caucasians and 31% are African-Americans. A significant portion of patients seen at the UFHSCJ-CEP come from the indigent population and 40% of patients are either uninsured, part of the city's indigent care program or recipients of Medicaid/Medicare HMO programs. Around 5% of patients have undergone epilepsy surgery and/or vagus nerve stimulator implantation.

A copy of the survey can be found in the supplementary section (Supplementary Material 1).

We obtained the following information:

Demographic information: age, gender, marital status, ethnicity (Hispanic versus non-Hispanic), race, educational attainment, annual household income, whether they drive, whether they receive disability benefits, current employment status.

Disease-related information: age at seizure onset, seizure duration, seizure frequency, whether they experience convulsions, whether they experience seizures while awake, seizure etiology, number of AEDs (antiepileptic drugs) they are currently taking, severity of side effects from their current AED regimen.

Psychosocial Data: Quality of Life in Epilepsy-10 (QOLIE-10) [12], Beliefs About Medicines Questionnaire-Specific (BMQ-S) [13], Screening Questions for Health Literacy [14], Brief Coping with Problems Experienced (Brief-COPE) Inventory [15], and the Epilepsy Stigma Scale (ESS) [16].

The QOLIE-10 is a shorter form that is derived from the QOLIE-89. It covers epilepsy-targeted and general aspects of mental and physical health as well as social and role functioning. Health related quality-of-life issues in patients with epilepsy are categorized into three distinct areas: (a) medication effects, (b) mental health, and (c) role functioning and seizure worry. Test-retest data shows significant Pearson's correlations for individual items (range,  $r = 0.48-0.81$ ). Scores range from 10 to 50 with higher scores indicating poorer quality of life [12].

The BMQ-S assesses commonly held beliefs about medicines. Subjects are given 10 statements that reflect different attitudes toward the use of prescribed medications with responses answered across a 5-point Likert scale. The items of the BMQ-S reflect both patient concerns about potential adverse effects of medications as well as beliefs in the necessity of their prescribed medications. Responses have been tested in patients across various disease states,

and the internal consistency of the BMQ-S ranges from 0.55 to 0.86 (Cronbach alpha) [13]. In this study, we obtained a BMQ-S Necessity minus Concerns score with higher scores indicating strong patient beliefs in the importance of their seizure medications.

We included three screening questions for health literacy taken from the Short Test of Functional Health Literacy in Adults (STOHFLA) ("How often do you have someone help you read hospital materials?", "How confident are you filling out medical forms by yourself?", and "How often do you have problems learning about your medical condition because of difficulty understanding written information?") [14]. When compared with overall STOHFLA scores, Chew and colleagues [17] showed that responses to each of these three questions correlate well with detection of inadequate health literacy.

The Brief-COPE is used to assess an individual's coping strategy. It is a 28-item self-reported questionnaire taken from the original COPE measuring 14 distinct subscales of coping reactions (2 questions each): self-distraction, active coping, denial, substance abuse, emotional support, instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Each item is scored from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot) and we obtained the total score of the 2 questions that reflect each coping mechanism. Thus, there is a minimum score of 2 and a maximum score of 8 for every coping reaction. Test-retest reliability for the various coping strategies ranges from 0.46 to 0.86 [15]. In this study, COPE questions were structured to assess *dispositional coping* which reflects stable coping tendencies, as opposed to *situational coping* which reflect those strategies employed for particular situations which may differ across various situations [18].

We assessed perceived stigma using the Epilepsy Stigma Scale (ESS). This scale was adopted by Dilorio and colleagues [16] from the Parent Stigma Scale earlier developed by Austin and colleagues [19]. It is a 10-item scale that assesses the degree to which a person believes that epilepsy is perceived as negative and interferes with one's relationships with others. Items are rated on a 7-point scale with higher scores indicating a higher degree of felt stigma. The alpha coefficient for responses to the ESS shows high internal consistency (0.91) [18].

## 3. Statistical analysis

Statistical analysis was performed with SPSS 15.0 at a 5% level of significance using a 2-tailed test. Interval variables were transformed, if necessary to satisfy the assumptions of parametric analysis.

We performed univariate analysis to determine the association between scores on the Epilepsy Stigma Scale and the various demographic, clinical, and psychosocial variables. Interval data and near-interval data were analyzed using Pearson correlation and Spearman's rho respectively. Categorical data was evaluated using analysis of variance with pair-wise comparison performed on significant variables using Bonferroni correction. Ordinal data was analyzed using Kruskal-Wallis.

Multiple linear regression was performed on significant variables identified by univariate analysis ( $p < 0.5$ ) to determine those that were independently associated with higher scores on the Epilepsy Stigma Scale.

## 4. Results

Over 95% of patients who met the study criteria agreed to participate in the study. One hundred and eighty two continuous consenting patients completed the survey and were included in this study. Table 1 details the characteristics of our study

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