Psychosocial and sociodemographic associates of felt stigma in epilepsy

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ABSTRACT

Background: Lack of a sufficient range in socioeconomic status (SES) in most prior studies of felt stigma and epilepsy has hampered the ability to better understand this association.
Methods: We assessed the burden and associates of felt stigma in 238 individuals with prevalent epilepsy aged 18 and older, comparing low SES with high SES.
Results: Reported levels of stigma were higher in low SES than in high SES ($p < 0.0001$), and all psychosocial variables were associated with stigma, including depression severity ($p < 0.0001$), knowledge of epilepsy ($p = 0.006$), quality of life ($p < 0.0001$), social support ($p < 0.0001$), and self-efficacy ($p = 0.0009$). Stigma was statistically significantly associated with quality of life in the low SES group and with depression severity and social support in the high SES group.
Conclusions: Low SES alone did not account for felt stigma; rather, we found that quality of life, depressive symptoms, and social support have the greatest impact on reported felt stigma in individuals with prevalent epilepsy.

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1. Introduction

Approximately 2.2 million people worldwide have been diagnosed with epilepsy [1], and it is estimated that 1 in 26 individuals will develop epilepsy during their lifetime [2]. Operationally defined for use in epidemiologic studies, epilepsy is two or more unprovoked seizures occurring at least 24 h apart [3,4].

The IOM recommends that in order to relieve the burden of epilepsy, it is necessary to not only address prevention efforts in individuals with established risk factors of epilepsy and in people with epilepsy and depression but also reduce felt stigma in this population [1]. It is well established that stigma contributes to the burden of epilepsy and the individual's outcome. In particular, felt stigma, described as feared or perceived discrimination, is reported across studies of both prevalent [5–10] and incident [11,12] epilepsy in developed and developing countries [13]. Increased levels of felt stigma perceived by the individual with epilepsy may negatively affect health-related behaviors, including treatment, coping, and self-management.

Few studies have explored the relationship between socioeconomic status (SES) and felt stigma in people with epilepsy [6]; however, increased felt stigma in low SES populations has been identified in studies of other highly stigmatized illnesses. For example, individuals diagnosed with tuberculosis, leprosy, or HIV/AIDS, who reside in communities of low socioeconomic status, report more stigma compared with those residing in communities of high socioeconomic status [14–16]. Given that we know that high levels of felt stigma are reported in individuals with incident epilepsy who reside in a low-income community [11], we would expect that, similarly, in a population with prevalent epilepsy, the level of felt stigma would be greater in individuals residing in a community of low SES compared with high SES. Additionally, past research has identified associations between psychosocial risk factors and presence of felt stigma in individuals with both incident and prevalent epilepsy. These include depression [11,13,17–26], quality of life [12,13, 22,23,27], social support [12,17,18,26–30], knowledge of epilepsy [31–33], and self-efficacy [25,27,34,35].

As previously demonstrated in the "Epilepsy Care and Outcomes Study", low SES individuals with epilepsy experience more felt stigma compared with high SES individuals with epilepsy [28]. We extended this analysis and hypothesized that the relationship between low SES and stigma would exist even after adjusting for confounders. We explored whether multicollinearity was present in the data. We did not find large changes in estimated regression coefficients when we added or deleted any explanatory variables. We did not retain in the model any insignificant regression coefficients except for site, as site was our main predictor variable of interest. We constructed a correlation matrix for explanatory variables, and there was no indication of a possible multicollinearity, as 90% of the correlations were no greater than $r = 0.4$. We also examined the relationship between the level of felt stigma

and potential psychosocial predictors of stigma including depression, quality of life, social support, knowledge of epilepsy, and self-efficacy.

2. Methods

The methods are described elsewhere [28]. Briefly, the "Epilepsy Care and Outcomes Study" enrolled 437 subjects with prevalent epilepsy at two clinical sites in Houston, Texas. The two sites were Ben Taub, a public hospital serving a low SES community, and Kelsey-Seybold, a private hospital serving a high SES community. Participants diagnosed with epilepsy, aged 12 years and older, were included if they had no evidence of progressive cerebral disease or degenerative neurological disorder. A subset of 238 participants was interviewed to obtain longitudinal data on seizure characteristics, knowledge and attitudes about epilepsy, health-care use, and quality of life.

2.1. Measures

2.1.1. Felt stigma

Felt stigma was measured using a modified version of a scale developed by Austin et al. [36] and subsequently modified by Dilorio et al. [37] for adults with epilepsy. This 10-item scale assesses the degree to which epilepsy is perceived as negative and interferes with the relationships people have with others. Each item is rated on a 7-point scale from 1 = "strongly disagree" to 7 = "strongly agree." Higher scores indicate more perceived felt stigma, with alpha = 0.91 [37]. We analyzed felt stigma using the mean (SD) and median (IQR).

2.1.2. Socioeconomic status (SES)

We classified Ben Taub Hospital as low SES and Kelsey-Seybold Hospital as high SES based upon significant differences in education, employment, income, and health insurance status found between these two patient populations [28].

2.1.3. Depression

Depressive symptoms were measured using the well-validated Center for Epidemiologic Studies Depression Scale (CES-D) for adults, which has been demonstrated to have high internal consistency (alpha = 0.80) and adequate convergent validity compared with other measures of depression. We used previously published cutoff points categorized as "no symptoms" (scores of <15), "moderate symptoms" (scores of 15–23), or "high symptoms" (score of at least 24) [38,39].

2.1.4. Quality of life

Scores from a 10-item limited activity scale and a 5-item daily activity scale from the SF-36 [40] were aggregated to measure the overall quality of life. Reported Cronbach's alpha on variables in the SF-36 ranges from 0.76 to 0.90. We analyzed quality of life using the mean (SD) and median (IQR) of these 15 items.

2.1.5. Social support

To assess social support, we used the Personal Resource Questionnaire 85 Part 2 (PRQ 85-2), which is a 25-item scale that assesses intimacy, assistance, affirmation of worth, social integration, and nurturance [41,42]. Construct validity has been established against the Beck Depression Inventory and the Trait Anxiety Scale. Reported Cronbach's alpha is between 0.87 and 0.90 and as high as 0.92. We analyzed social support using the mean (SD) and median (IQR) of the 25 items.

2.1.6. Knowledge of epilepsy

We analyzed knowledge of epilepsy using the three categories of 'true', 'false', and 'I don't know' on the Epilepsy Knowledge Scale [33], a 19-item scale ranging from 0 to 100 with Cronbach's alpha = 0.72.

2.1.7. Self-efficacy

The Epilepsy Self-Efficacy Scale [43] is a 33-item scale with an 11-point rating scale, ranging from 0 (I cannot do at all) to 10 (Sure I can do it). Self-efficacy was analyzed using the mean (SD) and median (IQR) of the 33 items. Content and construct validity have been assessed in a 25-item version of this scale with alpha coefficients ranging from 0.91 to 0.94.

The Institutional Review Board at the University of Texas (Houston) approved this study. This study was considered exempt by the Columbia University IRB as all data received were deidentified.

2.2. Statistical analyses

Using two-sample t-tests, we analyzed the mean felt stigma score, comparing participants on the following factors: age category, gender, race/ethnicity, and SES. This analysis was repeated separately for participants from Ben Taub General Hospital and for those from Kelsey-Seybold Clinic.

To examine the stigma scale, we calculated the mean of the 10 items per subject and used that as the subject's felt stigma score as had been done by Austin et al. [44]. This approach suggests that the average score across items reflects the burden of felt stigma. We used two-sample t-tests to compare felt stigma through bivariate factors and ANOVA when a factor has more than two categories. Descriptive statistics were used to determine the mean (SD) and the median (IQR) level of felt stigma according to the presence of depressive symptoms and knowledge of epilepsy, both categorical variables. Correlation coefficients were used to determine the association between felt stigma and the level of quality of life, social support, and self-efficacy, all continuous variables. All tests were performed at the 0.05 two-sided significance level.

Linear regression models were used to determine the associations between psychosocial and sociodemographic factors and felt stigma. First, we examined the whole cohort together to determine whether each of the factors was associated with felt stigma. Second, we examined the high SES subsample and the low SES subsample separately. All predictors significant at $\alpha < 0.10$ were included in each initial multivariable model and retained if they were significant at $\alpha = 0.05$ level. Socioeconomic status as indexed by ascertainment site was included in all models.

All statistical analyses were conducted via SAS 9.2 (SAS Institute, Cary, NC, U.S.A.).

3. Results

3.1. Participant demographics

There were 238 participants included in this analysis — 71 (29.8%) from Ben Taub and 167 (70.2%) from Kelsey-Seybold. There were no differences between ascertainment site for age (p = 0.2) or gender (p = 0.9); however, statistically significant differences were identified for race/ethnicity (p < 0.0001), education (p < 0.0001), insurance (p < 0.0001), and marital status (p < 0.0001) (Table 1).

3.1.1. Ben Taub

Of the 71 participants ascertained from Ben Taub, the low SES site, almost half were 18–40 years old, about 40% were male, and almost half were Black/non-Hispanic.

3.1.2. Kelsey-Seybold

Of the 167 participants ascertained from Kelsey-Seybold, the high SES site, half were 18–40 years old, about 42% were male, and almost two-thirds were White/non-Hispanic.