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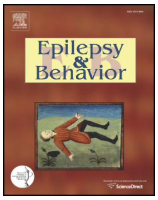

Brief Communication

Perceived stigma and adherence in epilepsy: Evidence for a link and mediating processes

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ABSTRACT

Objective: This study tested whether perceived epilepsy-related stigma is associated with adherence in people living with epilepsy and if information, motivation, and behavioral skills are potential pathways underlying the stigma–adherence link.

Methods: We surveyed persons living with epilepsy between the ages of 18 and 65 ($N = 140$) using an online questionnaire to assess medication adherence and perceived epilepsy-related stigma. In addition, participants reported their level of information, motivation, and behavioral skills.

Results: Higher perceived epilepsy-related stigma was associated with lower medication adherence ($r = -0.18$, $p < .05$). Higher perceived stigma was associated with lower levels of information ($r = -0.28$, $p < .05$), motivation ($r = -0.55$, $p < .05$), and behavioral skills ($r = -0.41$, $p < .05$), and the link between stigma and adherence was fully explained by information, motivation, and behavioral skills, i.e., the effect of stigma on adherence was fully mediated ($c = -0.18$, $p < .05$ reduced to $c' = 0.06$, $p = .48$).

Conclusion: Perceived epilepsy-related stigma is problematic for maintaining the prescribed medication regimen in people living with epilepsy. The information–motivation–behavioral skills model is a useful framework for understanding the pathways linking perceived stigma and adherence in this population.

1. Introduction

Despite a broad array of FDA-approved antiepileptic medications, many patients with epilepsy do not achieve complete control of their seizures. One reason is inadequate medication adherence [1–3]. Although the exact definitions of inadequate adherence vary widely, from missing at least 25% of the time to missing a single time [4], inadequate adherence has been linked to worse health outcomes [2,5]. Poor adherence rates among patients with epilepsy range between 30% and 60% [5–7], similar in frequency with other chronic medical conditions like type 2 diabetes and hypertension [8,9]. Consequently, over 30% of seizures are precipitated by nonadherence to medication [10], contributing to increased health-care costs [7,11].

Disease-related stigma may be one cause for inadequate adherence. Perceived stigma relates to worse health and health behavior in general [12] as well as decreased self-control [13]. Patients perceiving higher levels of stigma reported greater difficulty managing epilepsy, expected more negative outcomes from treatment, and had lower levels of medication management and adherence [14]. Among adults with epilepsy, stigma was associated with impaired self-efficacy and sense of mastery and greater perceived helplessness [14–17]. The act of taking AEDs itself can remind patients of epilepsy-related stigma, leading them to avoid pill-taking in public or veiling the pills' purpose [18]. Incorrect and/or insufficient knowledge about were shown to stigmatize the condition in the community and influence when individuals sought care and patients disclosed their condition [19].

One theoretical framework that could explain the stigma–adherence link in patients with epilepsy is the information–motivation–behavioral skills (IMB) model, which was originally developed around adherence to HIV medication. This approach postulates that adherence-related information, motivation, and behavioral skills (conceptualized as a combination of self-efficacy and objective skills) are determinants of adherence. The IMB model has generated evidence-based interventions to improve adherence, though it has never before been applied to epilepsy [20]. Individuals who increased their information and motivation and built behavioral skills within interventions were more likely to adhere to their treatment regimen [21,22].

There is already evidence from research in epilepsy that information, motivation, and skills may mediate the relationship between stigma and adherence in patients with epilepsy [23–28]. Patients with epilepsy perceiving stigma demonstrated insufficient knowledge about epilepsy

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and related services [23–25]. Stigma may undermine seeking adherence information because patients may not talk about their condition with others as much as in nonstigmatized conditions [19]. Thus, they may have less adherence information, i.e., less knowledge about how to adhere to treatment and about medication side effects and interactions. Stigma can undermine motivation because it is related to a negative view of the self [23] and interfere with seeking social support for disease management [26]. Patients who have lower levels of information and motivation due to stigma may develop less behavioral skills (including actual skills and self-efficacy) that are necessary for daily epilepsy management [21,23,24]. Because of the negative self views, stigma may also lead to less feelings of competence and mastery, further undermining skill development [16].

Accordingly, we tested three hypotheses in this study of adults living with epilepsy. First, higher perceived epilepsy-related stigma would be associated with lower medication adherence (Hypothesis 1). Second, higher perceived epilepsy-related stigma would be associated with lower levels of information, motivation, and behavioral skills (Hypothesis 2). Third, the link between perceived epilepsy-related stigma and adherence would be mediated by information, motivation, and behavioral skills (Hypothesis 3).

2. Methods

2.1. Data source

Between September 2011 and March 2012, we conducted an internet-based study. To detect correlations between stigma, adherence, and its social–cognitive predictors, we estimated that a sample size of at least 85 participants would allow detection of medium-to-large effect sizes ($r \geq .30$) with 80% power and that a sample size of 153 participants would allow detection of small-to-moderate correlations ($r \geq .20$) with 70% power ($\alpha = .05$, two-tailed tests) [29,30]. Thus, the current sample size seems adequate for detecting clinically meaningful effects. Potential subjects were recruited through Epilepsy Foundation online message boards and PatientsLikeMe.com, where information regarding our study was posted. Additionally, we recruited outpatients and inpatients treated at the Columbia Epilepsy Center to participate in this study (12% of the sample); for these patients, we were able to independently verify their epilepsy diagnosis. All patients were screened for eligibility via telephone or in-person interview. Our inclusion criteria included patients 18 years of age or older, who spoke English, who had a diagnosis of epilepsy, and who were taking antiepileptic medications.

Each patient meeting our eligibility criteria was given a randomly generated study ID, which they could use to log on to our online survey to read additional details about the study. After reading the details about the study, patients signed the informed consent online. The participants were e-mailed a $15 gift card upon completion of the 60-minute survey. The Columbia University Institutional Review Board granted approval. After completing the informed consent, a link to the PsychData survey was sent to participants via e-mail.

2.2. Measures

2.2.1. Adherence

Participants reported medication adherence on the Knobel brief adherence questionnaire [31]. This questionnaire consists of 6 items such as "Thinking about the last *week*, how often have you *NOT* taken your medicine?" Answer options were 1 = never, 2 = 1–2 times, 3 = 3–5 times, 4 = 6–10 times, or 5 = more than 10 times. Items were reversed, if applicable, so that higher scores indicated higher adherence; were averaged; and then were rescaled to a 0 to 10 scale. The reliability of the Knobel was satisfactory in this sample (Cronbach's $\alpha = 0.68$).

2.2.2. Stigma

The Epilepsy Stigma Scale evaluates perceptions of stigma both in close relationships and from society in general [32]. Participants rated items on a 7-point scale (1 = strongly disagree to 7 = strongly agree; example item, "People who know that I have a seizure condition treat me differently"). The 10-item scale has a possible range of scores from 10 to 70, with higher scores indicating higher perceived epilepsy-specific stigma. Reliability was good in this sample (Cronbach's $\alpha = .86$).

2.2.3. Information, motivation, and behavioral skills

Items assessing levels of adherence information, motivation, and behavioral skills for taking antiretroviral HIV medications [20,33] were adapted for people living with epilepsy. Parallel to the original measure, the adapted scale consisted of three subscales with 10 items assessing adherence information (e.g., "I know what to do if I miss a dose of any of my epilepsy medications (for example, whether or not to take the pill(s) later)."), 10 items assessing adherence motivation (e.g., "It frustrates me to think that I will have to take these epilepsy medications every day for the rest of my life."), and 14 items assessing adherence behavioral skills (e.g., "How hard or easy is it for you to make your epilepsy medications part of your daily life?"). All items showed good internal consistency in our sample (all Cronbach's $\alpha \geq .70$).

2.3. Data analysis

All measures were recoded to a 0 to 10 scale for easier comparison. We then calculated zero-order correlations between perceived stigma, adherence, and information, motivation, and behavioral skills and then conducted mediation analyses [34,35]. Mediation analysis is a statistical approach to determine how much of a predictor–outcome link is explained by process variables using a series of regression analyses [34]. In a first step, a link between predictor and outcome variable is estimated and tested for significance—perceived stigma and adherence in this analysis. In a second step, the predictor is shown to be correlated with the mediating variables—perceived stigma with information, motivation, and behavioral skills. In a third step, the mediating process variables are added to the predictor–outcome regression. If the predictor–outcome link is reduced in this third regression model, we can conclude that the process variables explain a certain percentage of this link. For testing the three theoretically derived process variables, we followed the recommendations by Hayes [36]. To describe the effect size for the total indirect effect of stigma on adherence, we computed the proportion of the total effect of adherence that was mediated by information, motivation, and behavioral skills (percent mediated) by dividing the total indirect effect by the total effect [35]. Statistical Package for the Social Sciences (SPSS) 21.0 software was used for all analyses.

3. Results

3.1. Sample characteristics

Table 1 gives an overview of participant characteristics. Participants ($N = 140$) were between 20 and 65 years old (age: $M = 38.51$ years). More female than male patients participated (62% were female). The sample was predominantly White (71%), but a wide range of minority patients also participated (10% Hispanic or Latino, 3% Asian, 5% Black or African American, 3% Native Hawaiian or Other Pacific Islander, 8% Other). Participants showed, on average, relatively high adherence ($M = 7.05$ on a 0 to 10 scale), with 25% of participants reporting perfect adherence and the other 75% of the sample reporting some adherence problems such as skipping medications in the past month and on weekends. Information, motivation, and behavioral skills were high, above the scale midpoint on a 0 to 10 scale (information: $M = 7.07$; motivation: $M = 5.46$; behavioral skills: $M = 6.49$; all ranges: 0–10). The mean score for perceived epilepsy-related stigma was 4.93 ($SD = 2.25$), indicating that patients varied widely in their stigma