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The Stigmatizing Impact of Perceived Epilepsy Stigma

Original Article Citation

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Background and Purpose: Stigma is a pervasive barrier for people living with epilepsy (PLWE) and can have substantial negative effects. This study evaluated clinical correlates of perceived stigma in a research sample of PLWE considered to be at high risk due to frequent seizures or other negative health events. Methods: Analyses were derived from baseline data from an ongoing Centers for Disease Control and Prevention (CDC)-funded randomized controlled trial (RCT) testing an epilepsy self-management approach. Standardized measures assessed socio-demographics, perceived epilepsy stigma, epilepsy-related self-efficacy, epilepsy self-management competency, health literacy, depressive symptom severity, functional status, social support, and epilepsy-related quality of life. Results: There were 160 individuals, mean age of 39.4, (Standard deviation/SD = 12.2) enrolled in the RCT, 107 (66.9%) women, with a mean age of epilepsy onset of 23.9 (SD 14.0) years. The mean seizure frequency in the prior 30 days was 6.4 (SD 21.2). Individual factors correlated with worse perceived stigma were not being married or cohabiting with someone ($p = .016$), lower social support ($p < .0001$), lower self-efficacy ($p < .0001$), and lower functional status for both physical health ($p = .018$) and mental health ($p < .0001$). Perceived stigma was associated with worse depressive symptom severity ($p < .0001$). Multivariable linear regression found significant independent associations between stigma and lower self-efficacy (β 0.05; $p = .0096$), lower social support (β 0.27; $p = 2.4 \times 10^{-5}$, and greater depression severity (β 0.6; $p = 5.8 \times 10^{-5}$). Conclusions: Perceived epilepsy stigma was positively correlated with depression severity and negatively correlated with social support and self-efficacy. Providers caring for PLWE may help reduce epilepsy stigma by screening for and treating depression, encouraging supportive social relationships, and providing epilepsy self-management support. Awareness of epilepsy stigma and associated factors may help reduce some of the hidden burdens borne by PLWE.

Commentary

People living with epilepsy (PLWE) often state the impact of their seizures on their everyday lives can be more problematic than the seizures themselves. The Institute of Medicine (IOM) recognized that the complexity of the illness of epilepsy is challenging to convey to the general public, as described in a 2012 report that recommended interventions to address epilepsy stigma and create a more inclusive and supportive community.[1] The World Health Organization (WHO) has also emphasized stigma as a hidden burden of disease that impacts mental and physical health as well as social opportunities.[2] Stigma has been found to correlate with important clinical outcomes, such as depression and quality of life. Despite these reports and efforts to define and promote awareness of the impact of the stigma associated with epilepsy, stigma continues to pose a significant burden negatively impacting the quality of life.

The article highlighted in this commentary examined how certain demographic and clinical factors correlated with perceived epilepsy-related stigma. The authors re-analyzed data from a CDC-funded prospective study of a self-management program (SMART) for people with epilepsy experiencing frequent seizures and epilepsy complications.[3] Participants were ≥18 years and had at least one negative health event (NHE) within the last 6 months, defined as a seizure, emergency room (ER) visit, hospitalization, or self-harm attempt. Perceived stigma was measured using the Epilepsy Stigma Scale (ESS), a validated 10-item scale that assessed the degree to which a person believes epilepsy is perceived as negative and interferes with their relationships. Depression was measured using the Patient Health Questionnaire (PHQ-9). Epilepsy control was self-reported seizure frequency. Quality of life was assessed with the QOLIE-10. Epilepsy-related self-efficacy, a person's belief that they have the ability to perform actions that will help achieve their objectives, was measured using the Epilepsy Self-Efficacy Scale (ESES). Social support was measured using the Multidimensional Scale of Perceived Social Support

(MSPSS), a 12-item scale that measured an individual's global perception of social support provided by family and friends and satisfaction with that support. Epilepsy Self-Management was measured using the Epilepsy Self-Management Scale (ESMS), a 38-item scale that assessed the frequency of use of epilepsy self-management practice. The sample consisted of 160 adults with a mean age of 39.4 (SD 12.2) years; 66.9% ($N = 107$) were women and 82.5% (N = 132) were white. The mean seizure frequency was 6.4 in the last 30 days and the mean NHE count was 29.9 (SD 72.0) in the last 6 months, with seizures comprising >95% of NHE types.

The results demonstrated being married or cohabiting ($p = .016$), having social support ($p < .0001$), and self-efficacy ($p < .0001$) were negatively correlated with perceived stigma (measured by the ESS). Depression severity was positively correlated with perceived stigma ($p < .0001$). Notably, 33.9% of the variation in ESS was explained by social support, self-efficacy, and depression. Associations between stigma, social support, self-efficacy, and depressive symptom severity remained significant when adjustment was made for multiple variable testing.

This study builds on prior literature on stigma in epilepsy and reinforces that higher levels of stigma correlate with increased depression scores and lower quality of life scores and improve with greater self-efficacy and stronger social support.[4] However, in this study, no other significant correlations were found between demographic factors and stigma, aside from being married or cohabiting. While lower income, unemployment, and education level were previously found to be associated with greater stigma in prior studies,[4] these characteristics were not correlated in this sample. Stigma was not correlated with rurality in this sample, which included a significant number of people living in rural regions in Iowa and Ohio. Prior studies have also shown associations between stigma and the severity of epilepsy or age of epilepsy onset.[4] While this was also not redemonstrated in this study, all study participants had relatively recent NHEs and relatively high seizure frequency base rates.

Depression is the most common mental health diagnosis in PLWE[5] and has significant associations between perceived stigma, social support, and self-efficacy. Despite this well-established association, delays in depression diagnosis and under-recognition and under-treatment persist. Screening for depression in PLWE is critical to help recognize patients at high risk for complications and poor outcomes that include worsened stigma burden. Social support or committed personal relationships can provide protection against the negative impact of chronic diseases, while social isolation is associated with lower quality of life. While social support can be provided by friends, family, healthcare providers, and on-line communities, it has also been demonstrated that self-management programs like SMART have a positive impact, through the utilization of trained peers who can provide empathy and encouragement related to shared experiences and provision of instrumental support through practical advice. Epilepsy self-management support programs have been shown to improve self-efficacy and may be a tool for decreasing epilepsy stigma and improving outcomes and quality of life. Thus, this study further supports the need to develop more formal peer support programs that can help improve health outcomes and reduce epilepsy stigma.

A major limitation of this study includes the relatively small sample and the reliance on self-report for NHEs, including seizure count. The lack of correlation between demographic factors, epilepsy severity, and stigma may have been due to a small sample size and/or a homogeneous sample with regard to epilepsy severity. Additionally, the individuals in this study volunteered for a research study and may not represent the full spectrum of PLWE. It is possible that those who experience the most severe stigma burden may not volunteer for an epilepsy clinical trial. Lastly, the article appears to suggest that depression and lack of social support led to stigma, but perhaps this relationship is bidirectional.

This publication reinforces the importance of the relationships between stigma, depression, social support, and self-efficacy. PLWE often suffer from depression, social isolation, and loss of self-efficacy, which may worsen the effects of stigma and quality of life. While this article did not specifically trial an intervention to target stigma in epilepsy, the findings inform concrete interventions that can be taken that may alleviate stigma. Providers may help reduce epilepsy stigma by screening for mood disorders and treating depression, encouraging supportive social relationships, and referring PLWE to evidence-based epilepsy self-management programs. The epilepsy community should be familiar with these treatment options and should actively discuss and recommend their use for appropriate patients. Improving education, communication, and access to available resources addressing these factors will ultimately help to reduce epilepsy-related burden and improve quality of life.

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Declaration of Conflicting Interests

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