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Clinical correlates of negative health events in a research sample with epilepsy☆

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ABSTRACT

Aims: In spite of advances in care, people with epilepsy experience negative health events (NHEs), such as seizures, emergency department (ED) visits, and hospitalizations. Being able to identify characteristics that are associated with NHE risk can help inform care approaches that reduce complications and burden. This analysis using baseline data from a larger randomized epilepsy self-management clinical trial assessed the relationship between demographic and clinical variables vs. seizure-related complications among people with epilepsy.

Methods: Data were derived from a baseline sample of a larger prospective study of 120 individuals with epilepsy who experienced an NHE within the last 6 months. Demographic characteristics, depression assessed with the 9-item Patient Health Questionnaire (PHQ-9) and the Montgomery–Asberg Depression rating scale (MADRS), quality of life assessed with the 10-item Quality of Life in Epilepsy Inventory (QOLIE-10), self-efficacy assessed the Epilepsy Self-Efficacy Scale (ESES), social support assessed with the Multidimensional Scale of Perceived Social Support (MSPSS), self-management assessed with the Epilepsy Self-Management Scale (ESMS), and stigma assessed with the Epilepsy Stigma Scale (ESS) were all examined in association with past 6-month NHE frequency and 30-day seizure frequency.

Results: Except for lower levels of education and lower levels of income being associated with higher 30-day and 6-month seizure frequency, demographic variables were generally not significantly associated with NHEs. Higher 30-day seizure frequency was associated with greater depression severity on PHQ-9 ($p < 0.01$) and MADRS ($p < 0.01$). Higher 6-month seizure frequency was also associated with greater depression severity on PHQ-9 ($p < .001$) and MADRS ($p = 0.03$). Both 30-day and 6-month seizure frequency were significantly negatively associated with QOLIE-10 ($p < 0.001$). Both 30 day ($p = 0.01$) and 6-month ($p = 0.03$) seizure frequency were associated with worse stigma on ESS. Total NHE count was associated with more severe depression on PHQ-9 ($p = 0.02$), and MADRS ($p = 0.04$), worse quality of life on QOLIE-10 ($p < 0.01$), and more stigma on ESS ($p = 0.03$).

Conclusions: Consistent with previous literature, more frequent seizures were associated with worse depression severity and quality of life. A finding that is less established is that higher seizure frequency is also associated with worse epilepsy-related stigma. Epilepsy self-management approaches need to address depression and stigma as well as seizure control.

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1. Introduction

Lifetime prevalence of epilepsy in the United States is estimated to be 1.2 to 2.9%. People with epilepsy have a significantly increased risk

of injury, and a threefold higher risk of death from any cause compared with the general population. In spite of advances in antiepileptic drugs (AEDs) and other therapies, many people with epilepsy experience negative health events (NHEs), such as accidents and emergency department (ED) visits, diminished quality of life, and poor mental health. Minorities and individuals of lower socioeconomic status may be particularly likely to have NHEs and reduced quality of life related to epilepsy [1–4].

Psychological factors and poor mental health have sustained and negative effects on people with epilepsy [5,6]. Comorbid affective

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disorders, in particular depression and anxiety, are major risk factors for poor quality of life in people with epilepsy [7]. Some studies found depression to be a more robust predictor of quality of life than seizure frequency, seizure duration, seizure type, number and adverse effects of AEDs [8,9]. Furthermore, the presence of depression and other psychiatric disorders may make epilepsy treatments less effective. One study of 890 patients with epilepsy found that individuals with psychiatric disorders were more than three times less likely to be seizure-free with AEDs than patients without [10]. A study of 121 patients who underwent temporal lobectomy found worse postsurgical seizure outcomes in patients with a psychiatric history than those without [11]. Given these findings, it is not surprising that depression and other mental health conditions have become an increasing focus of clinical care and research in epilepsy as well as a priority for public health and health policy recommendations [12,13].

In addition to depression and the stress of living with an unpredictable neurological condition, people with epilepsy experience social isolation and stigma [14,15]. Reports from surveys in 2010 and 2013 found that at least one out of five U.S. adults with epilepsy lives alone [16]. The stigma associated with epilepsy could be more harmful than the condition itself in that higher levels of stigma perception are associated with lower levels of self-efficacy in epilepsy management, worse treatment outcomes, less adherence to treatment regimens, and lower life satisfaction [17]. Additionally, the social disadvantages that many people with epilepsy face (e.g., unemployment, loss of income, requirement for caregiving in some cases) can further deflate self-esteem and marginalize people with epilepsy, compounding stigma [18].

This analysis, using baseline data from an ongoing randomized controlled trial (RCT) testing a novel self-management approach for epilepsy, evaluated demographic and clinical correlates of NHEs. We were particularly interested in the potential associations between factors relevant to epilepsy self-management as they relate to complications of epilepsy such as recurrent seizures, injuries or accidents, ED visits, and hospitalizations. Previous work has suggested that individuals with epilepsy and serious mental illness comorbidity are more likely to experience NHEs compared with individuals that do not have mental illness comorbidity [19]. Being able to characterize factors that indicate elevated risk for NHEs may help inform care approaches that reduce epilepsy complications and burden.

2. Methods

The RCT from which the data for this analysis is derived is a Centers for Disease Control and Prevention (CDC) funded project testing a novel intervention “Self-management for people with epilepsy and a history of negative health events” (SMART). The SMART intervention is intended to reduce NHEs and improve health outcomes in people with epilepsy, and is specially focused on high-risk subgroups with epilepsy who have recently experienced seizures or epilepsy-related complications. The study design is a prospective 6-month randomized comparison of SMART vs. 6-month wait-list control. Study inclusion criteria included a self-reported diagnosis of epilepsy, adults 18 years of age and older, having experienced an NHE within the last 6 months of initial contact/screen, and being able to provide written informed consent and participate in study procedures. The NHEs were defined as seizures, accidents or traumatic injury, self-harm attempts, ED visits, and hospitalizations. Participants were excluded if they were at immediate risk of self-harm, have dementia, were pregnant, and were unable to read/understand English. Recruitment was conducted in an urban setting in northeastern Ohio. All participants provided written informed consent and the study was approved by the local institutional review board (IRB).

2.1. Assessments

This analysis used screening and baseline data collected immediately prior to intervention randomization in this RCT. We collected

information on demographic variables of age, gender, ethnicity, race, socioeconomic status, marital status, level of education, and employment status.

2.2. NHEs

We evaluated self-reported events relevant to epilepsy self-management including the frequency or count of seizures in the last 30 days and last 6 months. We also assessed number of hospitalizations (for any cause), number of self-harm attempts, and number of accidents/traumatic injuries, all within the past 6 months. In this analysis, NHEs were all counted independently. A total NHE count was derived by summing the number of NHEs in each category.

2.3. Depression

Depressive symptoms were assessed using the 9-item Patient Health Questionnaire (PHQ-9), a widely used and validated self-rated depression scale [20]. The PHQ-9 incorporates diagnostic and statistical manual (DSM) diagnostic criteria, with scores ranging from 0 to 27. Higher PHQ-9 scores indicate worse depression severity. The PHQ-9 total scores of 5, 10, 15, and 20 represent the lower-limit thresholds of mild, moderate, moderately severe, and severe depression respectively. Depression was also assessed with the rater-administered Montgomery–Åsberg Depression rating scale (MADRS), a ten-item rater-administered questionnaire with scores ranging from 0 to 60 [21]. Like the PHQ-9, higher scores indicate worse depression severity.

2.4. Functional status

The SF-36 is a multi-purpose, short-form health survey with 36 questions that yields two psychometrically based components: a physical component summary (PCS) and mental component summary (MCS) [22]. Scores range from 0 (lowest or worst possible level of functioning) to 100 (highest or best possible level of functioning). It is a generic measure of health status, and has proven useful for conducting surveys and comparing the relative burden of diseases.

2.5. Epilepsy severity

Epilepsy severity was assessed with the standardized Liverpool seizure severity scale [23]. The 12-item Liverpool seizure severity scale has scores ranging from 1 to 40, with lower scores indicating more severe seizures.

2.6. Quality of life

Quality of life was assessed with the 10-item Quality of Life in Epilepsy (QOLIE-10), instrument a self-administered questionnaire developed from the original QOLIE-89 with scores ranging from 0.1 to 5.1 and higher scores indicating worse quality of life [24]. It comprises 7 components, including seizure worry, overall quality of life, emotional wellbeing, energy-fatigue, cognitive functioning, medication effect, and social function. Studies suggest that the QOLIE-10 has good test-retest reliability and correlates well with longer versions of this instrument [25].

2.7. Other assessments

Self-efficacy was measured using the 33-item Epilepsy Self-Efficacy Scale (ESES) with scores ranging from 0 to 330 and higher scores indicating better self-efficacy [26,27]. Social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS), a 12-item scale that measures an individual's perception of social support provided by family and friends, as well as satisfaction with that support [28]. The MSPSS score ranges from 1 to 84 with higher

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