



# Perceived epilepsy stigma mediates relationships between personality and social well-being in a diverse epilepsy population

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## ABSTRACT

**Introduction:** Perceived epilepsy stigma and reduced social well-being are prevalent sources of distress in people with epilepsy (PWE). Yet, research on patient-level correlates of these difficulties is lacking, especially among underserved groups.

**Materials and methods:** Racially/ethnically diverse adults with intractable seizures ( $N = 60$ , 62% female; 79% Black, 20% Hispanic/Latino, 8% White) completed validated measures of personality (NEO Five Factor Inventory, NEO-FFI-3), perceived epilepsy stigma (Epilepsy Stigma Scale, ESS), and quality of life (Quality of Life Inventory in Epilepsy, QOLIE-89). Controlling for covariates, ordinary least-squares (OLS) regression evaluated the total, direct, and indirect effects of NEO-FFI-3 neuroticism and extraversion scores on epilepsy-related social well-being (i.e., combination of QOLIE-89 social isolation and work/driving/social function subscales,  $\alpha = 0.87$ ), mediated through perceived stigma.

**Results:** In separate models, higher levels of neuroticism (N) and lower levels of extraversion (E) were significantly and independently associated with greater perceived stigma (N path  $a = 0.71$ ,  $p = 0.005$ ; E path  $a = -1.10$ ,  $p < 0.005$ ). Stigma, in turn, was significantly and independently associated with poorer social well-being (N path  $b = 0.23$ ,  $p < 0.001$ ; E path  $b = -0.23$ ,  $p < 0.001$ ). Bias-corrected bootstrap confidence intervals (CIs) showed that neuroticism and extraversion were indirectly associated with social well-being through their respective associations with perceived stigma (N path  $ab = -0.16$ , 95% CIs  $[-0.347, -0.044]$ ; E path  $ab = 0.25$ , 95% CIs  $[0.076, 0.493]$ ).

**Conclusion:** Higher neuroticism and lower extraversion covaried with stigma beliefs, and these may be markers of poor social outcomes in PWE. Mediation models suggest that targeting epilepsy stigma beliefs may be a particularly useful component to incorporate when developing interventions aimed at promoting social well-being in diverse PWE.

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## 1. Introduction

For people with epilepsy (PWE) with intractable seizures, feeling socially disconnected [1] and stigmatized [2] are prevalent sources of distress. Both PWE and caregivers report that the hardest part of living with epilepsy includes discrimination, social rejection, and feeling like a societal burden [3]. Importantly, however, not all PWE feel this way, and research suggests that such beliefs may relate to an underlying set of personality traits rather than epilepsy per se.

While there are many theories of personality, the Five Factor Model has identified five traits (neuroticism, extraversion, openness to

experience, agreeableness, and conscientiousness) believed to be biologically determined, temporally stable, and yet still reciprocally affected by life circumstances and social contexts [4]. In this way, one's psychosocial adjustment to a chronic illness – such as epilepsy – may be influenced by longstanding and relatively fixed patterns of thinking, emotional reactions, and behavior. This is implicated in Wilson et al.'s findings [5,6] that people with intractable epilepsy reporting high levels of neuroticism and low levels of extraversion also endorsed poorer mood states and difficulties with family functioning even after having achieved seizure freedom from epilepsy surgery. Additionally, higher levels of neuroticism were the strongest independent predictor of poorer general quality of life (QoL) among young adults with epilepsy and psychosocial difficulties, and showed moderate to strong effects of higher extraversion and lower neuroticism on better social functioning [7,8]. Despite this empirical support for the link between personality

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and psychosocial outcomes in PWE, the issue of *how* personality and social well-being are associated requires closer examination.

Prior work has linked both increased neuroticism and reduced extraversion to perceptions of epilepsy stigma [9], which may act as one mechanism through which personality affects psychosocial outcomes. Link and Phelan [10] defined stigma as a loss of status and power resulting from the separation of those stigmatized from the general population because of a characteristic that has been culturally defined as different and undesirable. Scambler and Hopkins [11] further emphasized the concept of “felt” or perceived epilepsy stigma, referring to the internalized shame of having epilepsy and the fear that one *may* encounter discrimination because of their illness.

Indeed, perceived epilepsy stigma is common. Almost half of Paschal et al.'s [12] sample of PWE felt that the general public held negative views about them, and 41% of those respondents stated that this belief negatively impacted how they viewed themselves. Within a sample of predominantly Caucasian, well-educated adults, perceived epilepsy stigma was significantly and negatively associated with QoL independent of depressive symptoms and seizures [13]. Furthermore, heightened levels of perceived epilepsy stigma have been associated with reduced participation in social activities, lower rates of marriage, unemployment, and feeling socially restricted [14] and socially isolated [15].

Within a predominantly racial/ethnic minority sample of PWE in New York City, perceived epilepsy stigma was the strongest independent predictor of general QoL [16]. Furthermore, earlier reports from this population noted that these PWE had negative beliefs about antiepileptic drugs (AEDs) and associated medication nonadherence, placing them at increased risk of poor seizure control [17]. Additionally, 51% of individuals from this population with no prior history of neurosurgery stated that they would not consider epilepsy surgery even if they were guaranteed that seizures would stop and that they could be promised no subsequent deficits [18]. These findings are especially important given that nonwhite race [19], unemployment and low educational attainment [20], and chronic seizures place PWE at increased risk for heightened stigma perception and poor psychosocial outcomes.

The present study examined interrelationships among neuroticism, extraversion, perceived epilepsy stigma, and perceived social isolation and social functioning in a sample of adults with intractable epilepsy drawn from this same predominantly racial/ethnic minority and socioeconomically disadvantaged population of patients.

## 2. Methods

### 2.1. Participants and procedures

English speaking adults diagnosed with epilepsy for  $\geq 1$  year with  $\geq 2$  seizures in the preceding 6 months despite prescription of AEDs were recruited from the State University of New York (SUNY) Downstate Medical Center's Comprehensive Epilepsy Center between 2012 and 2015. The SUNY Downstate Medical Center serves a predominantly racial/ethnic minority and socioeconomically disadvantaged urban population. Approximately 600 adults are treated in the epilepsy center annually. Exclusion criteria included the following: diagnosis of a major medical illness or comorbid psychiatric disorder that would have interfered with attendance at study visits or the ability to provide informed consent, plans to undergo epilepsy surgery or another major medical intervention during the study period, or severe cognitive dysfunction, English language illiteracy (determined by participants' ability to comfortably read and paraphrase the informed consent form and complete study measures independently in writing), or communication deficit that would have precluded informed consent.

All participants provided informed consent, completed self-report questionnaires, and a battery of clinician-administered neuropsychological tests and clinical interviews over two study visits with Master's level research assistants under the clinical supervision of New York State Licensed Psychologists (L.N. and J.S.G.). The measures used in the

present study were completed in writing and took participants an average of 1 h to complete. The Institutional Review Board at SUNY Downstate Medical Center approved all study procedures.

### 2.2. Measures

#### 2.2.1. Demographic and illness-related variables

Information on age, sex, educational attainment, race, ethnicity, country of origin, cultural identity, languages spoken, annual household income, age of seizure onset, and seizure frequency were obtained via self-report. Information on relationship status, household composition, as well as epilepsy diagnosis, lateralization of seizures, and seizure classification was ascertained via medical chart review.

#### 2.2.2. NEO Five Factor Inventory (NEO-FFI-3) [21]

A 60-item personality inventory measuring personality domains of neuroticism, extraversion, and openness to experience, agreeableness, and conscientiousness on a 5-point scale from 1 (strongly disagree) to 5 (strongly agree). In general, six-month test-retest reliability is strong among adults ( $r$ 's = 0.80 to 0.87) [22]. Only the domains of neuroticism and extraversion were analyzed in the present study, both of which have been shown to have good internal consistency ( $\alpha$ 's = 0.86 and 0.79, respectively) [21].

#### 2.2.3. Epilepsy Stigma Scale (ESS)

A 10-item questionnaire assessing the degree to which a person believes that epilepsy is perceived as negative and interferes with relationships with others. Each item is rated on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree). A total score was computed as the sum of all items; higher scores reflect worse perceived stigma. The ESS has been shown to have excellent internal consistency ( $\alpha = 0.91$ ) [23].

#### 2.2.4. Quality of Life Inventory in Epilepsy (QOLIE-89) [24]

An 89-item questionnaire assessing 17 multi-item scales that tap the following QoL concepts: health perception, seizure worry, physical function, medication effects, role limitations – physical, role limitations – emotional, pain, emotional well-being, energy/fatigue, attention/concentration, memory, language, social support, work/driving/social function, social isolation, health discouragement, and overall QoL.

The social isolation and work/driving/social function subscales have previously been shown to have moderate to strong internal consistency and test-retest reliability [24] ( $\alpha = 0.88$ ; 21-day test retest reliability:  $r = 0.73$  and  $\alpha = 0.86$ ; 21-day test retest reliability:  $r = 0.86$ , respectively). In an effort to assess only social aspects of QoL while also conserving power, we combined these subscales into a unitary measure in the current study. The combined measure was reduced from its original composition (initial  $\alpha$  in the current sample = 0.43) to a psychometrically optimal number of items based on associated increases in Cronbach's alpha following systematic deletion of suboptimal items.

Ultimately, 5 items were deleted (all of which originated in the work/driving/social function subscale); they were the following: QOLIE-89 item #26 (“During the past 4-weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?”), #68 (“how much during the past 4-weeks has your epilepsy or antiepileptic medication caused trouble with driving?”), and a series of three items that gauged how much respondents were bothered by “driving limitations” (#76), “work limitations” (#77), and “social limitations” (#78). These deletions resulted in a final 8-item scale, which had strong internal consistency (final  $\alpha$  in the current sample = 0.87) and good face validity as an epilepsy-related social well-being construct. Higher scores reflect greater social well-being.

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