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Anxiety disorders in predominantly African American and Caribbean American adults with intractable epilepsy: The role of perceived epilepsy stigma

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ABSTRACT

Introduction: Anxiety disproportionately affects people with epilepsy (PWE) and leads to poor outcomes. Yet, risk factors are not well understood especially among underserved groups. This cross-sectional study aimed to identify epilepsy-specific predictors of anxiety disorders in predominantly African American and Caribbean American PWE.
Materials and methods: The prevalence of anxiety disorders was established via diagnostic interview (Mini-International Neuropsychiatric Interview (MINI)). We identified the extent to which aspects of seizure burden (seizure frequency, seizure severity, convulsive vs. nonconvulsive seizures), seizure worry, and perceived epilepsy stigma were associated with anxiety disorder diagnosis. Finally, logistic regression assessed the overall and independent contributions of significant risk factors.
Results: There were 60 participants (62% women, 52% African American, 27% Caribbean American, 20% Hispanic/Latino) with an average of 2 seizures per month. Nearly half of the sample (43%) had ≥1 anxiety disorder, with 62% of affected individuals qualifying for agoraphobia. Those with anxiety disorders tended to have convulsive seizures ($p = 0.037$) and endorsed greater seizure worry ($p = 0.012$), more general symptoms of anxiety ($p = 0.005$), and worse perceived epilepsy stigma ($p = 0.003$). Logistic regression accounted for 28% to 37.6% of the variance in anxiety disorder diagnostic status and correctly classified 73% of cases; however, only perceived epilepsy stigma made a unique contribution.
Conclusions: Anxiety disorders were prevalent in these predominantly African American and Caribbean American PWE. Epilepsy-specific risk factors included convulsive seizures, seizure worry, and perceived epilepsy stigma. Interventions aimed at treating anxiety disorders in diverse PWE may especially benefit from targeting stigma beliefs.

1. Introduction

Psychiatric disorders are common in people with epilepsy (PWE), with prevalence estimates ranging from 19% to 80% [1]. Depression has historically been considered the most common psychiatric comorbidity among PWE, with anxiety disorders a close second [2,3]. However, recent studies suggest that anxiety may be more prevalent than initially thought, with rates either comparable with depression [4–6], overshadowing it [7], or showing comorbidity in patients [8]. Nevertheless, anxiety and its predictors remain a relatively understudied area in epilepsy.

In the general population, lifetime prevalence of anxiety disorders ranges from approximately 2% to 5% [3]. Among PWE, estimates are higher with single samples yielding rates of 8% to 30% [2,6,9–11] and population-based appraisals falling between 11% and 52% [3,4,12]. Anxiety symptoms and disorders add to the set of difficulties experienced by PWE with strong links to ratings of overall disability [13]. Not surprisingly, anxiety disorders also covary with diminished quality of life (QoL) [7,9,14]. Even positive effects of epilepsy surgery on QoL can be attenuated by the presence of high anxiety over time [15]. Anxiety is also associated with suicidal thoughts and behaviors in PWE [8,16–18], even among seizure-free patients postsurgery [19].

Anxiety in PWE may be specifically related to the state of living with seizures rather than the effects of chronic illness in general, as having other chronic medical conditions has not been shown to significantly impact the degree of anxiety in PWE [20]. Yet, what aspect of epilepsy

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leads to disproportionate levels of anxiety remains unclear. Prior reports implicated the unpredictable nature of seizures [21–25], fearing seizure-related injuries or death [22–24,26], and having seizures in public places [27], which may account for high rates of agoraphobia in PWE [16]. In addition, other epilepsy-related factors may contribute. People with epilepsy often report reduced independence, diminished social well-being, and low self-esteem [5], as well as feeling stigmatized on the basis of their health [28–30]. Perceived epilepsy stigma (i.e., the internalized shame of having epilepsy and the fear that one may encounter discrimination because of their illness) negatively impacts mental health [31], and a recent meta-analysis found that the weighted average correlation between perceived stigma and anxiety was significant and moderate [32]. Epilepsy stigma beliefs are even common among people with new-onset seizures [33,34], with stigma significantly predicting anxiety severity at the time of epilepsy diagnosis and one-year postdiagnosis [30]; this illustrates the enduring effects of unaddressed stigma beliefs. Additionally, Taylor et al. [33] found that PWE who endorsed more severe perceived stigma reported greater seizure worry in addition to general anxiety symptoms.

Our group previously showed that perceived epilepsy stigma predicted reduced social well-being in people with intractable seizures [35]. This relationship was at least partially driven by personality factors also associated with anxiety in PWE [34,36] and those without seizures [37–41]. Specifically, heightened levels of neuroticism and introversion predicted stronger stigma beliefs and poorer social well-being, with stigma beliefs mediating the relationships between these personality traits and social well-being [35].

The present study aimed to characterize the prevalence of anxiety disorders among a sample of racially diverse patients with intractable epilepsy, the majority of whom identify as African American or Caribbean American, and to elucidate epilepsy-specific factors associated with the presence of anxiety disorders in these individuals. In particular, we hypothesized that perceived epilepsy stigma would be a significant and independent predictor of anxiety disorders above and beyond other epilepsy-specific variables and general anxiety symptoms.

2. Methods

2.1. Participants and procedures

English speaking adults diagnosed with epilepsy for ≥1 year with ≥2 seizures in the preceding 6 months were recruited from the State University of New York (SUNY) Downstate Medical Center's Comprehensive Epilepsy Center. SUNY Downstate Medical Center serves a predominantly African American and Caribbean American urban population. Exclusion criteria included the following: diagnosis of a major comorbid illness 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, severe cognitive dysfunction, English 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, filled out self-report questionnaires, and completed a battery of clinician-administered tests and interviews over two study visits with master's level research assistants under the supervision of New York State Licensed Psychologists (L.N. and J.S.G.). 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, age at seizure onset, and seizure frequency were obtained via self-report. Information on epilepsy diagnosis, lateralization of seizures, and seizure classification was ascertained via medical chart review.

2.2.2. Seizure burden

2.2.2.1. Seizure frequency. Number of seizures in the preceding month was self-reported by participants, who often commented that they were unsure of the exact number of seizures they had unless witnessed by someone else because of amnesia.

2.2.2.2. Seizure Severity Questionnaire (SSQ) [42]. The SSQ is a 24-item questionnaire containing three sections that address aura/warning, ictal, and postictal symptoms for "typical seizures." Items cover the frequency and helpfulness of auras and address severity and bothersomeness of ictal movement/altered consciousness, as well as the cognitive, emotional, and physical aspects of postictal recovery. The SSQ has strong test–retest reliability [42]. In this study, the SSQ total score was derived using scoring criteria described by Cramer, de la Loge, Brabant, and Borghs [43]. Each item is rated on a 7-point scale from 1 (not severe/bothersome) to 7 (very severe/bothersome). Higher scores reflect greater perceived seizure severity.

2.2.2.3. Primary seizure type. In an effort to account for a more objective index of seizure burden than could be captured by self-report measures, participants' medical charts were reviewed to create a binary seizure classification according to whether their *primary seizure type* was convulsive = 1 or nonconvulsive = 0. Our group previously demonstrated that convulsive rather than nonconvulsive seizures were associated with worse patient-reported psychosocial outcomes [35].

2.2.3. Epilepsy Stigma Scale (ESS) [44]

This 10-item questionnaire assessed the degree to which respondents believe 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 stronger perceived epilepsy stigma. The ESS has excellent internal consistency [44].

2.2.4. Quality of Life in Epilepsy (QOLIE-89) [45]

This 89-item questionnaire assesses 17 multi-item scales that tap a variety of QoL concepts. In the present study, only the *seizure worry* subscale was analyzed. The seizure worry subscale consists of 5 items gauging how worried/fearful respondents are of having seizures, hurting themselves during a seizure, suffering embarrassment or other social problems because of seizures, and how bothered they are by seizures in general. This subscale has good internal consistency and test–retest reliability [45]. Lower scores reflect greater seizure worry.

2.2.5. Beck Anxiety Inventory (BAI) [46]

This 21-item questionnaire is designed to screen for anxiety and is widely used in epilepsy [3]. Respondents rate the extent to which they feel bothered by somatic symptoms of anxiety, a feature that allows for discrimination between states of anxiety vs. depression. Each item is rated on a scale from 0 (not at all bothered) to 3 (severely bothered); higher scores reflect greater anxiety. The BAI has excellent internal consistency and strong convergent validity with other established anxiety scales; its traditional cutoffs include scores of ≤7 (minimal), 8 to 15 (mild), 16 to 25 (moderate), and ≥26 (severe anxiety) [46].

2.2.6. Mini-International Neuropsychiatric Interview (MINI) [47]

This structured clinical interview is designed to diagnose Axis I psychiatric disorders based on criteria contained in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition text revision (DSM-IV-TR). The MINI has strong inter-rater reliability and test–retest reliability [48], as well as convergent validity with other established diagnostic interviews [47]. In the present study, only current diagnosis of

anxiety disorder was considered (1 = current diagnosis; 0 = no current diagnosis); frequencies of specific anxiety disorders were described, as well as rates of co-occurrence.

2.3. Statistical analyses

All analyses were conducted using IBM SPSS Statistics for Windows, Version 25.0 (IBM Corp., Armonk, NY). Descriptive statistics were computed to characterize the sample and determine prevalence of anxiety disorders, and associations between perceived epilepsy stigma and anxiety disorder diagnosis with age, education, and sex were explored. Inter-relationships and group differences were assessed among study variables using Pearson correlations, *t*-tests, and Chi-Square analyses as appropriate. Finally, significant epilepsy-specific variables from the univariate analyses were entered into a multivariate logistic regression model to assess their overall and relative contributions in predicting participants with anxiety disorders, independent of self-reported anxiety symptoms. For this analysis, all continuous variable raw scores were z-transformed using this sample's means (*M*) and standard deviations (*SD*).

3. Results

3.1. Demographic and illness characteristics

As shown in Table 1, participants were 60 racially and ethnically diverse women (62%) and men. The average participant was aged 42 years old and had a high school education. Thirty-three percent of participants were born outside of the continental U.S. Most identified as African American (51.7%) and Caribbean American (26.7%), with only a minority indicating White or mixed race (8.3% and 5%, respectively). Twenty percent self-identified as Hispanic/Latino. Additional information about participants' socioeconomic backgrounds was previously described [35].

As shown in Table 2, mean epilepsy duration was approximately 21 years, and 87% were diagnosed with a focal seizure disorder. Participants' primary seizure type was evenly split among nonconvulsive ($n = 30$) and convulsive seizures ($n = 30$). Participants reported an average of two seizures in the preceding month.

The mean SSQ total score was 3.53 ($SD = 1.84$). The mean seizure worry score was 2.88 ($SD = 0.69$), and the mean ESS score was 34.15 ($SD = 15.82$). On average, participants endorsed mild anxiety on the BAI; however, more than a quarter of the sample (26.7%) reported moderate-to-severe levels (Table 3).

3.2. Anxiety disorder diagnosis

As shown in Table 3, 43% of the sample qualified for ≥1 current anxiety disorder. Most of these individuals had one such condition (69%), whereas 31% had two or more comorbid anxiety disorders. The most prevalent anxiety disorders were agoraphobia (26%) and social phobia (10%), with 73% of people with an anxiety disorder qualifying for either or both conditions. There were fewer cases of generalized anxiety disorder (8%), obsessive–compulsive disorder (8%), posttraumatic stress disorder (5%), and panic disorder (3%). Among the 31% of participants with ≥2 comorbid anxiety disorders, all but one (87.5%) had agoraphobia.

3.3. Associations between demographics and key variables of interest

Perceived epilepsy stigma was not significantly associated with age or education ($r = -0.141$, $p = 0.283$ and $r = -0.132$, $p = 0.316$, respectively) nor were there significant differences across males and females (Males: $M = 33.44$, $SD = 17.06$; Females: $M = 34.59$, $SD = 15.22$; $t[58] = -0.274$, $p = 0.785$). Likewise, there was no significant difference in the rate of anxiety disorders across sex ($\chi^2[1] = 0.27$, $p = 0.604$) nor were there significant differences across those with and without anxiety disorders in terms of age (Anxiety Disorder: $M = 41.54$, $SD = 14.48$; No Anxiety Disorder: $M = 41.91$, $SD = 12.89$; $t[58] = 0.105$, $p = 0.916$) or education (Anxiety Disorder: $M = 12.17$, $SD = 2.94$; No Anxiety Disorder: $M = 12.99$, $SD = 2.94$; $t[58] = 1.242$, $p = 0.219$).

3.4. Inter-relationships among predictor variables

Self-reported anxiety symptoms on the BAI were significantly and positively associated with seizure frequency ($p = 0.012$) and perceived epilepsy stigma ($p = 0.025$); the relationship between high scores on the BAI and greater seizure worry was approaching statistical significance ($p = 0.069$). Greater seizure worry was significantly associated

Table 1
Study variable descriptive statistics (N = 60).

Variable	N (%)	M (SD)	Range
Sex			
Male	23 (38.3)		
Female	37 (61.7)		
Age (years)	60	41.75 (13.48)	20–75
Education (years)	60	12.63 (2.52)	4–18
Country of origin			
USA	40 (66.7)		
Jamaica	5 (8.3)		
Haiti	4 (6.7)		
Guyana	2 (3.3)		
Trinidad	2 (3.3)		
Colombia	1 (1.7)		
Czech Republic	1 (1.7)		
Granada	1 (1.7)		
Nigeria	1 (1.7)		
Puerto Rico	1 (1.7)		
St. Vincent	1 (1.7)		
United Kingdom	1 (1.7)		
Race			
Black/African American	31 (51.7)		
Black/Caribbean American	16 (26.7)		
White	5 (8.3)		
Mixed race	3 (5.0)		
Other	5 (8.3)		
Hispanic/Latino ethnicity	12 (20.0)		

Table 2
Illness characteristics (N = 60).

Variable	N (%)	M (SD)	Range
Duration of epilepsy (years)	60	20.8 (14.5)	1–48
Age at seizure onset (years)	60	20.9 (15.8)	0–66
Epilepsy syndrome	60		
Temporal lobe epilepsy	44 (73.3)		
Frontal lobe epilepsy	7 (11.7)		
Generalized epilepsy	3 (5.0)		
Unclassified	4 (6.7)		
Juvenile myoclonic epilepsy	1 (1.7)		
Parietal lobe epilepsy	1 (1.7)		
Lateralization of seizures	56		
Right hemisphere	22 (39.3)		
Left hemisphere	19 (33.9)		
Bilateral	11 (19.6)		
Unclassified	4 (7.1)		
Primary seizure type			
Convulsive seizures	30 (50.0)		
Partial seizure with secondary generalization	19 (31.7)		
Generalized tonic–clonic seizure	10 (16.7)		
Myoclonus with secondary generalization	1 (1.7)		
Nonconvulsive seizures	30 (50.0)		
Complex partial seizure	22 (36.7)		
Simple partial seizure	6 (10.0)		
Absence seizure	1 (1.7)		
Myoclonic jerks	1 (1.7)		
Seizure frequency (past 1 month)		1.9 (2.9)	0–16

Table 3
Descriptive statistics for study measures (N = 60).

Variable	N (%)	Range	M (SD)	SE
MINI anxiety disorders	26 (42.6)			
AG	16 (26.2)			
SP	6 (10)			
GAD	5 (8.2)			
OCD	5 (8.2)			
PTSD	3 (4.9)			
PD	2 (3.3)			
Comorbidities (% of cases with current anxiety disorders)	8 (30.7)			
AG + PD	2 (25)			
AG + SP	2 (25)			
AG + GAD	1 (12.5)			
AG + OCD	1 (12.5)			
AG + SP + GAD	1 (12.5)			
OCD + PTSD + GAD	1 (12.5)			
BAI		0–39	11.65 (8.90)	1.15
Minimal	21 (35)		3.24 (2.41)	
Mild	23 (38.3)		11.26 (2.34)	
Moderate	11 (18.3)		12.09 (2.43)	
Severe	5 (8.3)		32.40 (5.55)	
Seizure worry		1.60–4.20	2.88 (0.69)	0.09
Seizure severity		0.50–7.00	3.53 (1.84)	0.24
Perceived stigma		10–67	34.15 (15.82)	2.04

Note. MINI = Mini Neuropsychiatric Interview; AG = agoraphobia; SP = social phobia; GAD = generalized anxiety disorder; OCD = obsessive–compulsive disorder; PTSD = posttraumatic stress disorder; PD = panic disorder; BAI = Beck Anxiety Inventory total score; Minimal = BAI ≤7; Mild = BAI between 8 and 15; Moderate = BAI between 16 and 25; Severe = BAI ≥26; Seizure severity = Seizure Severity Questionnaire total score; Seizure worry = Quality of Life in Epilepsy Inventory — Seizure Worry subscale; Perceived stigma = Epilepsy Stigma Scale.

with stronger perceived epilepsy stigma ($p = 0.031$) and showed a trend with seizure frequency ($p = 0.072$). In contrast, perceived epilepsy stigma was not significantly related to seizure frequency ($p = 0.392$). There were no significant relationships with seizure severity (p's ≥ 0.215) (Table 4).

Participants with primarily convulsive rather than nonconvulsive seizures were not significantly more likely to self-report anxiety symptoms on the BAI (Convulsive: $M = 12.87$, $SD = 9.54$; Nonconvulsive: $M = 10.43$, $SD = 8.18$; $t[58] = -1.060$, $p = 0.293$) or endorse greater seizure frequency (Convulsive: $M = 2.17$, $SD = 3.49$; Nonconvulsive: $M = 1.77$, $SD = 2.13$; $t[58] = -0.537$, $p = 0.594$), seizure severity (Convulsive: $M = 3.64$, $SD = 1.81$; Nonconvulsive: $M = 3.44$, $SD = 0.73$; $t[56] = -0.425$, $p = 0.672$), seizure worry (Convulsive: $M = 2.81$, $SD = 0.66$; Nonconvulsive: $M = 2.95$, $SD = 0.73$; $t[58] = 0.779$, $p = 0.439$), or perceived epilepsy stigma (Convulsive: $M = 33.73$, $SD = 15.66$; Nonconvulsive: $M = 34.57$, $SD = 16.23$; $t[58] = 0.202$, $p = 0.840$).

3.5. Group comparisons across PWE with and without anxiety disorders

Individuals whose primary seizure type was convulsive rather than nonconvulsive were significantly more likely to qualify for an anxiety disorder ($\chi^2[1] = 4.344$, $p = 0.037$). In contrast, those with anxiety disorders did not report significantly more seizures in the preceding month than those without (Anxiety Disorder: $M = 2.42$, $SD = 1.62$; No Anxiety Disorder: $M = 1.62$, $SD = 2.00$; $t[58] = -1.001$, $p = 0.324$). Likewise, participants with anxiety disorders did not report significantly more perceived seizure severity than those without (Anxiety Disorder: $M = 3.53$, $SD = 1.801$; No Anxiety Disorder: $M = 3.55$, $SD = 1.90$; $t[56] = 0.50$, $p = 0.960$).

Not surprisingly, participants with an anxiety disorder tended to endorse more symptoms on the BAI than those without an anxiety disorder (Anxiety Disorder: $M = 15.23$, $SD = 8.61$; No Anxiety Disorder: $M = 8.91$, $SD = 8.22$; $t[58] = -2.891$, $p = 0.005$). Those with an anxiety disorder tended to report more seizure worry than those without an anxiety disorder (Anxiety Disorder: $M = 2.62$, $SD = 0.63$; No Anxiety Disorder: $M = 3.07$, $SD = 0.69$; $t[58] = 2.593$, $p = 0.012$). They also reported worse perceived epilepsy stigma (Anxiety Disorder: $M = 40.85$, $SD = 13.36$; No Anxiety Disorder: $M = 29.03$, $SD = 15.81$; $t[58] = -3.134$, $p = 0.003$).

Table 4
Pearson correlations among study variables (N = 60).

	Seizure worry	Stigma	Seizure frequency	Seizure severity
BAI	−0.236	0.290*	0.322*	0.133
Seizure worry	–	−0.279*	−0.234	−0.165
Perceived stigma	–	–	0.112	0.020

Note. BAI = Beck Anxiety Inventory total score; Seizure Worry = Quality of Life in Epilepsy Inventory — Seizure Worry subscale; Perceived Stigma = Epilepsy Stigma Scale; Seizure Severity Questionnaire.
* $p < 0.05$.

3.6. Logistic regression predicting anxiety disorder diagnosis

Multivariate logistic regression assessed the combined and relative impact of those epilepsy-specific factors showing significant univariate associations with anxiety disorder diagnosis, independent of general symptoms of anxiety. The model contained four variables (BAI total score, primary seizure type, seizure worry, and perceived epilepsy stigma). The full model containing all predictors was statistically significant ($\chi^2[4] = 19.762$, $p = 0.001$), indicating that the model distinguished between participants who did and did not qualify for a current anxiety disorder. The model explained between 28.1% (Cox & Snell R^2) and 37.6% (Nagelkerke R^2) of the variance in diagnostic status and correctly classified 73.3% of cases. However, as shown in Table 5, only perceived epilepsy stigma made a unique statistically significant contribution to the model (Odds Ratio (OR) = 2.058, *95%* Confidence Interval (CI) = 1.053, 4.059, $p = 0.035$). To this end, each standard deviation increase in perceived epilepsy stigma corresponded to a greater than twofold likelihood that respondents had an anxiety disorder, independent of anxiety symptoms on the BAI ($p = 0.132$), primary seizure type ($p = 0.056$), and degree of seizure worry ($p = 0.150$).

4. Discussion

The present study sheds light on the prevalence of anxiety disorders in a sample of predominantly African American and Caribbean American PWE from socioeconomically disadvantaged backgrounds

Table 5
Logistic regression predicting anxiety disorder diagnosis (N = 60).

Predictor	β	SE	Wald	df	*p*	OR	95% CI	
							Upper	Lower
BAI	0.515	0.342	2.274	1	0.132	1.674	0.857	3.271
Seizure type	−1.220	0.637	3.666	1	0.056	0.295	0.085	1.029
Seizure worry	−0.468	0.325	2.070	1	0.150	0.626	0.331	1.185
Perceived stigma	0.722	0.342	4.462	1	0.035	2.058	1.053	4.019
Constant	0.223	0.432	0.267	1	0.605	1.250		

Note. All continuous data were converted to z-scores using the sample's means and standard deviations for these analyses. BAI = Beck Anxiety Inventory total score; Seizure type = binary classification of primary seizure type (convulsive = 1, nonconvulsive = 0); Seizure worry = Quality of Life in Epilepsy Inventory — Seizure Worry subscale; Perceived stigma = Epilepsy Stigma Scale.

and elucidates epilepsy-specific factors associated with anxiety disorders in these individuals. Over a quarter endorsed moderate-to-severe anxiety, and nearly half qualified for an anxiety disorder on diagnostic interview. This is much higher than diagnostic rates observed in the general population and at the upper limit of estimates reported in prior studies of PWE [2–4,6,9–11]. Additionally, such high rates of anxiety disorders are in contrast to those exhibited by people from African American and Caribbean American backgrounds in general [49]. Importantly, however, when such individuals do meet criteria for an anxiety disorder, they tend to experience worse symptom severity and greater functional impairment compared with Whites [49].

It is unclear whether our findings are specific to racial/ethnic minorities with epilepsy, as the present study appears to be the first of its kind in a predominantly African American and Caribbean American sample. Our results are consistent with De Oliveira et al.'s work [50] describing 96 patients with temporal lobe epilepsy from Brazil (46.6% White, 41.1% mixed race, and 12.3% Black); they reported an anxiety disorder prevalence of 40.6% using the MINI without significant differences across racial/ethnic groups. It seems unlikely that their study's and our use of MINI-based diagnoses account for these relatively high rates. The Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (SCID) has yielded rates ranging from 8% to 35% in PWE from Turkey, Brazil, Germany, Poland, and the U.S. [51–59]. The Schedules for Clinical Assessment in Neuropsychiatry (SCAN) and Composite International Diagnostic Interview (CIDI), which overlap with the International Statistical Classification of Diseases and Related Health Problems (ICD-10), have produced rates of 36.3% and 45.1% in PWE from Oman and England [60,61]. Therefore, the MINI's published rates of 14.9%–52.1% across PWE from Italy, Cuba, Brazil, India, and the U.S. are comparable [4,50,54,62–64].

Since the aforementioned estimates exceed prevalence rates of anxiety disorders found in the general population, identifying which aspects of living with seizures are most associated with the presence of anxiety disorders is important for screening, diagnosis, and care. This is especially the case since anxiety often goes unrecognized and untreated in primary and secondary healthcare settings [65,66], including epilepsy specialty clinics [67]. Furthermore, a recent meta-analysis of studies centered on PWE argued for better anxiety screening techniques [6].

Whereas recent seizures [2,22,26,68] and low perceived control over seizures [69] have been found to relate to higher anxiety, neither seizure frequency nor perceived seizure severity were associated with having an anxiety disorder in the current sample. In this study, PWE with an anxiety disorder tended to have convulsive seizures, endorse greater seizure worry, and report stronger perceived epilepsy stigma. As anticipated, perceived epilepsy stigma was independently associated with having an anxiety disorder even though other epilepsy-specific factors and general symptoms of anxiety did not make unique contributions.

Whereas long-term anxiety may decrease if seizures remit [70], and with successful epilepsy surgery in particular [71], moderate-to-severe anxiety has been associated with a nearly 3-fold increased risk of poor adherence to antiepileptic drugs (AEDs) [72]. Prior work from our group suggests that many PWE struggle with AED adherence, which we have found is associated with maladaptive beliefs about medications [73], memory difficulties [74], and limited medication management capacity [75]. Such issues may perpetuate a vicious cycle with poor adherence leading to worse seizures, which triggers heightened anxiety, in turn threatening adherence further. Making matters worse, racial/ethnic minorities are generally reluctant to consider epilepsy surgery [76]. Taken together, these data reinforce the importance of developing effective interventions to treat anxiety in this high-risk group of patients.

Despite elevated rates of psychiatric disorders among PWE, nearly one-third of patients fail to receive either pharmacologic or nonpharmacologic psychiatric treatment [77]. Additionally, some anti-anxiety medications (e.g., benzodiazepines) may not hold much promise in treating anxiety in PWE [78]. Although this argues for nonpharmacologic approaches to ameliorating anxiety symptoms in such individuals, the historical failure to account for epilepsy-specific factors, such as stigma beliefs, may help explain why Cognitive Behavioral Therapy (CBT) has not yet been effective in reducing anxiety in people with seizures [79,80]. Cognitive Behavioral Therapy may be a particularly effective means of challenging stigma beliefs and the extent to which they influence behavior in PWE. Targeting stigma beliefs in CBT interventions may be especially helpful for PWE from racial/ethnic minority communities.

Although causality and directionality cannot be inferred on the basis of these data alone, the importance of perceived stigma may relate to why the most frequent anxiety conditions in this sample were agoraphobia and social phobia, with nearly three-quarters of affected individuals qualifying for either or both conditions. While it is possible that PWE who have anxiety are simply more likely to perceive higher levels of stigma, patients' stigma beliefs may contribute to anxiety about social situations and public places. To this end, internalized stigma beliefs may prompt inadequate strategies and efforts to cope with seizures. This could mimic an anxiety disorder but may not reflect organic psychopathology per se.

Complicating matters, a significant proportion of Black Americans with a psychiatric disorder endorse relying on informal support, rather than professional services, which points to potentially unmet behavioral health needs [81]. This is reinforced by epidemiologic findings that both Black and Hispanic/Latino Americans with psychiatric disorders are indeed less likely to access behavioral health care compared with non-Hispanic Whites [82]. Additionally, there is evidence that African Americans drop out of treatment with greater frequency [83]. Analogous sociodemographic issues may affect willingness to engage in epilepsy-related care [84], as more than three-quarters of individuals attending epilepsy support groups in the U.S.'s Pacific Northwest were White and nearly 40% of nonattenders were Black.

It is plausible that the social aspects inherent to accessing behavioral health services may be viewed negatively by people with fear of public places and of leaving home, social phobia, other behavior-restricting anxieties, and/or internalized stigma beliefs. Thus, future research should investigate whether internet-delivered psychosocial interventions, such as those that have proved helpful for PWE and comorbid depressive disorders [85], benefit PWE and co-occurring anxiety disorders. Such approaches may do well to specifically target maladaptive illness-related beliefs, including perceived stigma, to promote better psychosocial outcomes in diverse patients.

5. Limitations

Our results should be considered in the context of the strengths and weaknesses of our design. The use of structured diagnostic assessments, such as the MINI, allows for greater accuracy in classifying anxiety disorders than can be expected from patient-reported symptoms alone [6]. However, as the English language version of the MINI was validated in

the U.S. and Europe, its classification accuracy may be more limited in immigrant populations, such as those represented by a third of our sample. Although the high rates of anxiety disorders observed in our study are broadly consistent with a racially/ethnically diverse sample of PWE from Brazil [50] and a multicenter study conducted across the U.S. [4], our modest sample size and focus on patients with ≥2 seizures in the preceding 6 months recruited from a single tertiary epilepsy center may limit generalizability of these findings to the broader population of PWE. Also, given our small sample size, we are unable to speak to specific differences in anxiety disorder prevalence and stigma perception across racial/ethnic groups in a statistically/clinically meaningful way. Likewise, our cross-sectional design precludes drawing causal inferences about the relationships among epilepsy-specific variables – such as perceived stigma – and anxiety disorders. Therefore, larger and prospective studies with more representative samples of PWE are needed to replicate these findings and better understand how these associations unfold over time and differ across racial/ethnic groups. Such research may help inform interventions with at-risk patients, such as those described here.

6. Conclusions

The present study found that anxiety disorders were prevalent in this sample of predominantly African American and Caribbean American people with intractable seizures. Risk factors included convulsive seizures, seizure worry, and perceived epilepsy stigma. Perceived epilepsy stigma made a unique contribution, which argues for targeting stigma beliefs when developing psychosocial interventions aimed at treating anxiety disorders in diverse PWE.

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