

FULL-LENGTH ORIGINAL RESEARCH

Managing depression and anxiety in people with epilepsy: A survey of epilepsy health professionals by the ILAE Psychology Task Force

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Summary

Objectives: The Psychology Task Force of the Medical Therapies Commission of the International League Against Epilepsy (ILAE) has been charged with taking steps to improve global mental health care for people with epilepsy. This study aimed to inform the direction and priorities of the Task Force by examining epilepsy healthcare providers' current practical experiences, barriers, and unmet needs around addressing depression and anxiety in their patients.

Methods: A voluntary 27-item online survey was distributed via ILAE chapters and networks. It assessed practices in the areas of screening, referral, management, and psychological care for depression and anxiety. A total of 445 participants, from 67 countries (68% high income), commenced the survey, with 87% completing all components. Most respondents (80%) were either neurologists or epileptologists.

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Results: Less than half of respondents felt adequately resourced to manage depression and anxiety. There was a lack of consensus about which health professionals were responsible for screening and management of these comorbidities. About a third only assessed for depression and anxiety following spontaneous report and lack of time was a common barrier (>50%). Routine referrals to psychiatrists (>55%) and psychologists (>41%) were common, but approximately one third relied on watchful waiting. A lack of both trained mental health specialists (>55%) and standardized procedures (>38%) was common barriers to referral practices. The majority (>75%) of respondents' patients identified with depression or anxiety had previously accessed psychotropic medications or psychological treatments. However, multiple barriers to psychological treatments were endorsed, including accessibility difficulties (52%).

Significance: The findings suggest that while the importance of managing depression and anxiety in patients with epilepsy is being recognized, there are ongoing barriers to effective mental health care. Key future directions include the need for updated protocols in this area and the integration of mental health professionals within epilepsy settings.

KEYWORDS

mental health, psychiatric comorbidity, psychotherapy, screening, suicide, treatment

1 | INTRODUCTION

The prevalence of mental health comorbidities, particularly depression and anxiety, in people with epilepsy (PWE) is high and associated with suboptimal patient outcomes,^{1,2} such as reduced quality of life,³ pharmacoresistant seizures,⁴ suicide,⁵ injuries,⁶ and medication nonadherence.⁷ To comprehensively manage epilepsy and improve quality of life, both behavioral and seizure specific outcomes need to be addressed.⁸ Increasing awareness of the importance of and morbidity from mental health comorbidities in epilepsy has resulted in International League Against Epilepsy (ILAE) consensus statements by the ILAE Commission on the Neuropsychiatric Aspects of Epilepsy, and the Neuropsychobiology Commission,^{9,10} and recommendations of the inclusion of routine screening for depression and anxiety in PWE according to the American Academy of Neurology's quality indicators.^{11,12} It is also now strongly encouraged that depression and anxiety should either be treated by epilepsy healthcare professionals or they should be referred for appropriate external management.¹³

It remains unknown to what extent these recommendations and quality indicators have been adopted in clinical practice.^{14–16} For instance, a survey of 102 epileptologists in the United States found that less than half routinely screened for anxiety and that only 5% utilized a validated screening measure.¹⁷ Moreover, there is currently little international consensus about what role neurologists, epileptologists, and other epilepsy healthcare professionals should play in the management of mental health comorbidities, and no systematic approaches or protocols have been developed in this area.¹³

Key Points

- ILAE survey of epilepsy health professional's screening, referral, and management practices for depression and anxiety.
- Less than half felt adequately resourced to manage these comorbidities.
- Lack of consensus about which health professionals were responsible for screening and management.
- Ongoing barriers to mental health care, including a lack of trained mental health specialists and standardized procedures.
- Future directions include need for updated protocols and the integration of mental health professionals within epilepsy settings.

However, the recently launched ILAE roadmap for a competency-based educational curriculum includes the appropriate management of psychiatric emergencies (eg, suicidal ideation) and recognition of when to refer patients for treatment of mental health comorbidities as key competencies for epileptologists.¹⁸ This highlights the need to better examine the existing clinical landscape and determine what barriers exist to the management of mental health comorbidities in PWE.

The ILAE Psychology Task Force of the Medical Therapies Commission has been charged with improving

mental health care for PWE. To that end, this study aimed to inform the future direction and priorities of the Task Force by examining epilepsy healthcare professionals' current practical experiences, barriers, and unmet needs in relation to the screening, referral, and management of depression and anxiety in their PWE. We also aimed to examine differences in practice by low-, medium-, and high-income countries.

2 | METHOD

2.1 | Procedure and materials

The ILAE Psychology Task Force developed an online survey. Six items were adopted, with permission, from a previous US survey of neurologist members of the American Epilepsy Society,¹⁴ and additional items following a review of the relevant literature. The survey consisted of 27 closed items, which included questions about 1. Professional training and epilepsy expertise (11 items); 2. Screening procedures (8 items); 3. Referral options (4 items); 4. Available treatments (2 items); 5. Access to psychological care (1 item); and 6. Requests for future services by the ILAE Psychology Task Force (1 item). A copy of the survey is included as a Appendix S1—Survey. At the end of the survey, participants were provided with a link to the ILAE Psychology Task Force Web site (www.ilae.org/patient-care/mental-health-care-resources), which contains resources about mental health care in epilepsy. The survey was reviewed by ILAE Psychiatry Commission members and approved for use and distribution to members by the ILAE Executive Committee.

The survey was piloted among epilepsy health professionals practicing in Australia. In order to reach these professionals, the Epilepsy Society of Australia (the Australian Chapter of the ILAE) emailed its members with an invitation and link to the survey. Recruitment took place between November 2018 and December 2018; two reminder emails were sent during this time. Following this successful acceptability pilot, the survey was opened internationally. No major changes were made. The survey was circulated via the ILAE Regional Chairs, who were asked to forward the questionnaires to individual ILAE Chapters for distribution. The survey was also promoted on the Web site for the 33rd International Epilepsy Conference in Bangkok (2019). The international survey remained open from April 2019 to December 2019.

Participants were invited to take part in the survey by means of an email including a secure link to a Qualtrics survey. This link directed potential participants to an information statement and consent form before they were able to proceed to the first item. The questionnaire was designed to take no more than 10–15 minutes to complete.

Participants were eligible if they were (a) At least 18 years of age; (b) A professional working with patients with

neurological disorders; (c) Had competence in English; and (d) Provided consent. The survey was approved by the Macquarie University Human Research Ethics Committee.

2.2 | Statistical analyses

Descriptive statistics were utilized to examine rates of endorsement on the survey items. Chi-square analyses were used to analyze significant differences between low/middle-income countries with high-income countries¹⁹ on questions with forced option responses. For comparison purposes, low- and middle-income countries were collapsed into one group (low/middle income). IBM SPSS Statistics program 24 was used for analyses.

3 | RESULTS

Of the 445 participants who commenced the survey, 388 (87.2%) completed it in its entirety. Respondents reflected participation from 67 countries (displayed in Table S1). According to World Bank classifications,¹⁹ most participants were from high income ($n = 304$; 68.3%), followed by middle-income ($n = 106$; 23.82%) and low-income countries ($n = 35$; 7.87 %). The countries with the highest number of participants included Brazil ($n = 52$), Australia ($n = 52$), Italy ($n = 35$), and Germany ($n = 33$).

3.1 | Health professionals' training and experience with epilepsy

As displayed in Table 1, most respondents were neurologists ($n = 204$; 46%) or epileptologists ($n = 149$; 33.6%) with the majority working in public hospitals ($n = 180$; 42.3%) and university healthcare systems ($n = 121$; 28.3%). Most respondents were fully trained ($n = 393$; 87.9%) and considered themselves an expert in epilepsy management ($n = 224$; 50.1%).

3.2 | Depression and anxiety management

3.2.1 | Importance and resources for management

The vast majority ($\geq 93\%$) of respondents indicated they “strongly agree” or “agree” that the management of depression and anxiety is integral to the comprehensive care of PWE. However, only 40% “strongly agree” or “agree” that their setting is adequately resourced to manage these mental health comorbidities.

TABLE 1 Characteristics of respondents

	Total n (respondents)	n	Percentage of respondents
Specialty ^a	443		
Neurologist		204	(46)
Epileptologist		149	(33.6)
Neuropsychologist		49	(11.1)
Clinical psychologist / psychologist		38	(8.6)
Nurse		31	(7)
Psychotherapist		19	(4.3)
Psychiatrist		17	(3.8)
Neuropsychiatrist		16	(3.6)
Social worker		5	(1.1)
Special professional interest in epilepsy	442		
Yes		425	(96.3)
No		17	(3.8)
Level of training in profession	443		
Fully trained (eg, attending)		393	(87.9)
In training (eg, intern, resident, fellow, postdoc)		50	(11.2)
Level of experience managing epilepsy	431		
Expert (>10 y)		224	(50.1)
Advanced (5-10 y)		102	(22.8)
Novice (<5 y)		105	(23.5)
Primary patient group ^a	431		
Children (0-18 y)		167	(38.7)
Adults (18-65 y)		304	(70.5)
Older adults (>65 y)		143	(33.2)
Patients with intellectual disability		138	(32)
Percentage of patients who have epilepsy	427		
<10%		32	(7.5)
>10% and <30%		94	(22)
>30% and <50%		60	(14.1)
>50% and <70%		98	(23)
>70% and <90%		63	(14.8)
>90% to 100%		80	(18.7)
Primary setting for working with PWE	427		
University Health Care System		121	(28.3)
Public Hospital		180	(42.3)
Private Hospital		52	(12.2)
Private Practice		30	(7.0)
Community Health Care Service		21	(4.9)
Other		23	(5.4)

^aResponses were not mutually exclusive, and participants could select more than one.

3.2.2 | Responsibility for screening and management

Most respondents believed that neurologists/epileptologists (n = 221; 54.3%) should be responsible for screening

for depression or anxiety in PWE, followed by general/family practitioners (n = 75; 18.4%; Figure 1). Just over a third thought neurologists/epileptologists (n = 150/420, 35.7%) should take primary responsibility for organizing the management of anxiety and depression, followed by

psychiatrists (n = 106, 25.2%), psychologists/neuropsychologists (n = 84, 20%) general/family practitioners (n = 64, 15.2%), and epilepsy or psychiatry nurse specialists (n = 16; 3.8).

3.2.3 | Screening / assessment practices

As displayed in Figure 2, screening practices for depression and anxiety were almost identical. Over 40% of respondents indicated they assessed for both comorbidities at every patient visit (ie, initially and at every follow-up). About one third based screening for depression (n = 114; 28%) and anxiety (n = 123; 30.7%) on spontaneous reports by the patient or a relative. In contrast, 58% (n = 231) only screened for suicidality if symptoms were spontaneously reported, and about 6% (n = 25) never screened suicidality. Most respondents reported that they included screening questions as part of their clinical interview for depression and anxiety ($\geq 75.6\%$). Fewer stated that they used a validated screening instrument ($\geq 23.3\%$) or delegated the use of a validated screening instrument to other staff ($\geq 8.1\%$).

3.2.4 | Barriers to screening

Over half of respondents reported a lack of time during clinic visits was a barrier to screening practices for both depression (n = 217; 54.1%) and anxiety (n = 203; 50.9%; Table 2). Other frequently reported barriers included lack of access to psychiatric / psychological treatment resources ($\geq 19.3\%$) and uncertainty about appropriate screening instruments ($\geq 17\%$). Over 20% of respondents reported

experiencing no barriers to screening and management for anxiety and depression.

3.3 | Referral practices and barriers

Respondents endorsed the following referral patterns: referral to a psychiatrist for both depression and anxiety ($\geq 55.6\%$), followed by referral to a psychologist ($\geq 41.5\%$). Less commonly, patients were started on psychotropic medication ($\geq 33.8\%$) or subjected to monitoring (“watchful waiting”; $\geq 26.9\%$; Table 3). The most commonly endorsed barriers to referring patients on for follow-up assessment/management included lack of mental health specialists trained to assess and manage PWE ($\geq 55.4\%$), standardized assessment procedures ($\geq 37.8\%$), and time to deal with the referral procedures ($\geq 29\%$).

3.4 | Treatments accessed and psychological care

The majority of respondents had patients who had accessed both psychological treatments with mental health professionals (≥ 78.3) and psychotropic medications ($\geq 74.7\%$) at some stage. Other common interventions included antiseizure medication (ASM) changes ($\geq 66.3\%$) and psychoeducation ($\geq 43.4\%$; see Table 4). The most common barrier was a lack of appropriately trained mental health specialists (n = 234; 60%), followed by patients’ inability to access treatment (n = 204; 52.3%) and lack of desire for psychological therapy (n = 197; 50.5%). An additional barrier reported was that intellectual/cognitive difficulties

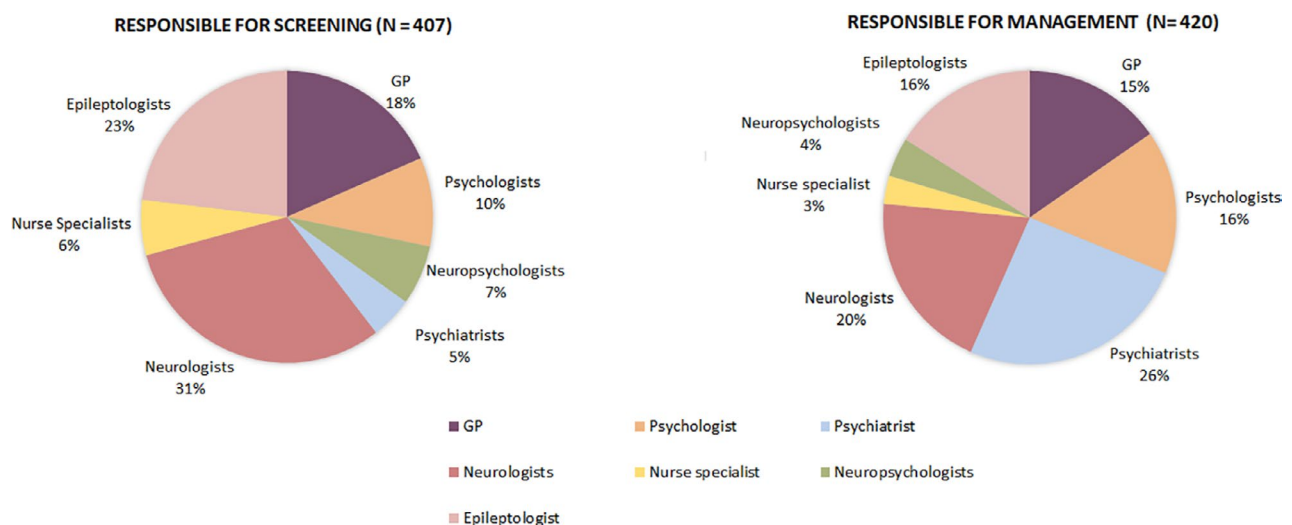


FIGURE 1 Clinicians believed responsible for the organization of the screening and management for depression and anxiety of patients with epilepsy.

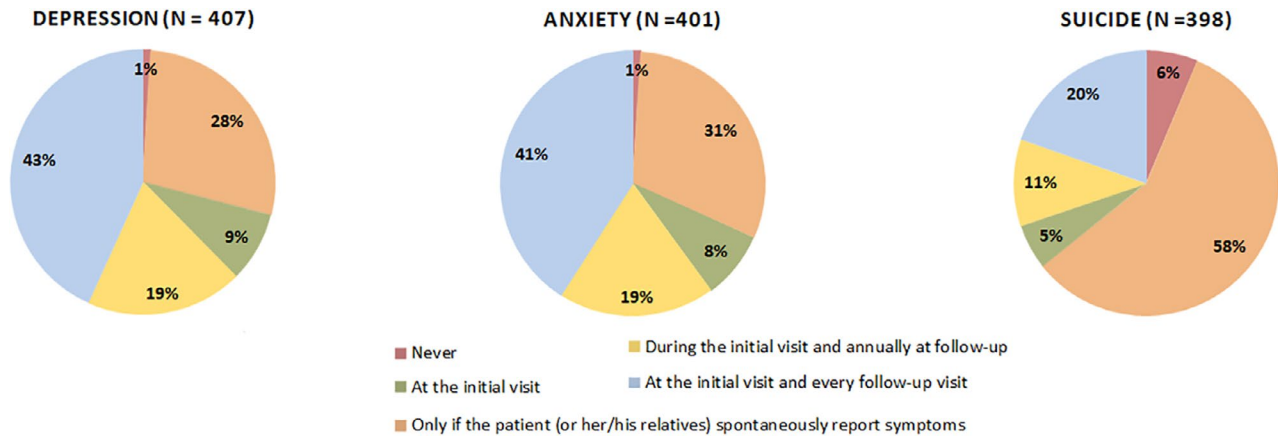


FIGURE 2 Frequency of screening practices

limit the benefits of psychological treatment for PWE (n=160; 41%; see Table 4).

3.5 | The ILAE psychology task force's role

A majority of respondents felt the ILAE Psychology Task Force should create guidelines for referring/managing depression/anxiety in PWE (n = 311; 80.2%), followed by the provision of epilepsy educational resources for mental health professionals (n = 270; 69.6%), creation of registries of mental health professionals specializing in epilepsy (n = 265; 68.3%), and lastly the provision of mental health educational resources for neurologists (n = 244; 62.9%).

3.6 | Comparison between responses from low/middle-, and high-income countries

No significant differences among countries were observed in relation to importance of and resources for the management of depression and anxiety or screening practices. However, there were significant differences in who was believed to be responsible for screening ($\chi^2 = 22.72$, $P < 0.001$) and management of anxiety and depression ($\chi^2 = 16.89$, $P < 0.001$). Specifically, more respondents from low/middle-income than high-income countries considered a psychiatrist responsible for screening (n = 15/132; 11.36% vs n = 4/275; 1.5%). However, the endorsed responsibility for neurologists/ epileptologists for mental health screening was very similar between low/middle-income and high-income countries (n = 74/132; 56.1% vs n = 147/275; 53.5%).

In addition, fewer respondents from low/middle-income than high-income countries considered a GP responsible for the management of depression and anxiety in PWE (11/137; 8% vs 53/283; 18.7%). However, endorsement of the role of

neurologists/ epileptologists in the context of management of mental health comorbidities was similar between low/middle (n = 54/137; 39.4%) and high-income countries (n = 96/283; 33.9%).

4 | DISCUSSION

The ILAE Psychology Task Force has been charged with improving mental health care for PWE. This survey aimed to inform the future direction and priorities of the Task Force by exploring the current clinical practices of epilepsy health-care professionals across the globe, through ILAE chapters, in the management of depression and anxiety in their patients with epilepsy. Encouragingly, almost all survey respondents (87%) believed the management of both depression and anxiety was integral to epilepsy care. However, less than half felt they were adequately resourced to manage these comorbidities themselves. The survey responses uncovered key trends and barriers in relation to the responsibilities and management practices (eg, screening, referral, psychological care) for mental health comorbidities and highlighted several important areas for future consideration.

Despite increasing calls by international experts and multidisciplinary ILAE Task Forces for neurologists/epileptologists to increase their responsibility for the screening and management of mental health symptoms in their patients,^{8,17} there were large discrepancies in who should have the primary responsibility to do so in clinical practice. While more than half the sample believed it was the role of the neurologist/epileptologist to screen for mental health comorbidities, only one third believed either a neurologist (20%) or epileptologist (16%) was responsible for organizing management. Five percent believed psychiatrists should screen for mental health comorbidities, with slightly more acknowledgment of the role of psychiatrists in screening from participants in low/middle-income countries. These

TABLE 2 Depression and anxiety screening practices and barriers.

	Depression N (%)	Anxiety N (%)
Method of screening ^a	407	401
I include screening question(s) as part of my clinical interview	307 (75.6)	304 (76.0)
I administer/score validated screening instrument	114 (28.0)	93 (23.3)
Other clinic staff administer/ score validated screening instrument	33 (8.1)	35 (8.8)
Other	40 (9.9)	41 (10.2)
Barriers to screening ^a	401	399
Lack of time during clinic visit	217 (54.1)	203 (50.9)
There are no accessible psychiatric/psychological treatment resources in setting	81 (20.2)	77 (19.3)
Uncertainty about appropriate screening instruments	69 (17.2)	84 (21.1)
Uncertainty about where to refer patients for treatment, if dep/anx identified	59 (14.7)	58 (14.5)
Treatment of dep/anx is not part of my role in the management of PWE	53 (13.2)	56 (14.0)
Allowing patients to initiate concerns first	52 (13.0)	49 (12.3)
Uncertainty about the treatment of dep/anx	37 (9.2)	51 (12.8)
Addressing dep/anx was not part of training	46 (11.5)	40 (10.0)
Inaccessibility to appropriate screening instruments	40 (10)	42 (10.5)
Discomfort or uncertainty with suicidal ideation	37 (9.2)	-
Discomfort or uncertainty about initiating discussions about dep/anx	22 (5.5)	20 (5.0)
Assessing dep/anx is not part of my role in the management of PWE	19 (4.7)	23 (5.8)
No barriers	82 (20.4)	88 (22.1)

Abbreviations: anx, anxiety; dep, depression; PWE, patients with epilepsy.

^aResponses were not mutually exclusive, and participants could select more than one.

findings may suggest there is some misconception about the role of psychiatrists given psychiatrists are trained to diagnose not screen mental health comorbidities and screening is typically the responsibility of all other health professionals. If a screen is positive, a provider will ideally refer to a mental health professional who makes a definite diagnosis as a valid basis for treatment initiation. However, in areas where resources are not as intense, an epilepsy healthcare professional may have to take on the role of more assessment to determine whether a diagnosis is warranted. Interestingly, respondents rarely endorsed neuropsychologists as having a role in the management (7%) or screening (4%) of depression and anxiety. Neuropsychologists in epilepsy centers are typically employed to conduct comprehensive evaluations of PWE²⁰ but do not treat depression or anxiety, despite some recognition within the discipline they are ideally situated to do so.²¹ More commonly the assessment and management of mental health comorbidities from providers other than neurologists/epileptologists involves clinical psychologists, psychiatrists, or general practitioners. Taken together, it appears there is a lack of clarity about the roles of neurologists/epileptologists and other health professionals in the management of mental health comorbidities of epilepsy, which likely vary by countries and resources.

In relation to the frequency of screening for both depression and anxiety, very few respondents never screened, and over 40% screened at the initial and every follow-up visit, as suggested by the 2017 AAN quality measurement guidelines.^{11,12} However, screening only following spontaneous reporting of symptoms was also high, in particular in the case of suicidal ideation (58%). This finding is very concerning given that patients typically underdisclose symptoms of depression to their physicians,²² with more depressive symptoms leading to reduced odds of patients disclosing.^{23,24} Moreover, the risk of death by suicide in PWE is three times higher than the general population²⁵ and an increased risk of suicide has been found among PWE with no recorded psychiatric diagnosis history.²⁶ Therefore, screening for suicidal ideation is strongly recommended⁹ and managing suicidal ideation is a key competency area of the new ILAE educational roadmap for epileptologists. Of note, very few respondents (<10%) reported that they experienced any discomfort or uncertainty when asking about suicidality as a barrier to screening for depression. Thus, it remains unclear why routine screening for suicidal ideation is so low, illustrating that further work is needed in this area.

In relation to screening methods, most respondents incorporated screening questions into their clinical interview.

TABLE 3 Referral practices and barriers for depression and anxiety

	Depression N (%)	Anxiety N (%)
Responders (N)		
Typical next steps when identified with depression/ anxiety ^a	398	394
Refer patients to a psychiatrist	254 (63.8)	219 (55.6)
Refer patients to a psychologist	165 (41.5)	174 (44.2)
Place patients on psychotropic medications	139 (34.9)	133 (33.8)
Monitor (watchful waiting)	107 (26.9)	117 (29.7)
Refer patients to a psychotherapist	96 (24.1)	95 (24.1)
Refer patients back to primary health practitioner	89 (22.4)	90 (22.8)
Provide literature on mental health	58 (14.6)	63 (16.6)
Suggest patients seek help themselves	65 (16.3)	54 (13.7)
Barriers to follow-up assessment and management ^a	397	392
Lack of mental health specialists trained to assess/ manage PWE	219 (55.2)	217 (55.4)
No standardized procedures around these issues in place of practice	150 (37.8)	148 (37.8)
Lack of time to deal with the referral procedures	115 (29.0)	116 (29.6)
Limited funding for referral procedures	70 (17.6)	78 (19.9)
Referrals for follow-up is the role of other services (eg, epilepsy advocacy groups, general practitioner)	40 (10.1)	34 (8.7)
No barriers	76 (19.1)	76 (19.4)
Other	23 (5.8)	22 (5.6)

^aResponses were not mutually exclusive, and participants could select more than one.

However, it is an important limitation of this survey that the adequacy of these questions was not assessed qualitatively. Mental health assessment involves asking patients about specific symptoms of anxiety and depression, as opposed to simply asking “are you depressed or anxious,” which can underestimate endorsement, and thus prevalence.¹³ For PWE, it is also important to distinguish between cognitive and somatic symptoms of these disorders and overlap with seizure phenomena and ASM side effects.²⁷ A recent meta-analysis found that the rate of anxiety disorders in studies relying on clinical judgment was only 8%, compared with 27% among studies utilizing a structured or validated clinical interview.²⁸ Approximately only a third of respondents in the current study used validated screening instruments to screen for depression and anxiety, with screening practices almost identical for these two comorbidities. Consistent with previous surveys,^{14,29} lack of time was the most significant barrier for screening for both depression and anxiety. Additional barriers included lack of accessible psychiatric/psychological treatment resources for depression and uncertainty about screening devices for anxiety. There have been significant efforts to develop, translate, and promote the use of the epilepsy-specific depression screening instrument,

such as the Neurological Disorders Depression Inventory for Epilepsy^{10,30} which serves as an excellent suicidality screening instrument.³¹ In 2019, an epilepsy-specific anxiety screening was published (the Brief Epilepsy Anxiety Screening Instrument),³² which may aid in screening.

The most common typical next step once PWE were identified with depressive and/or anxiety symptoms was a referral to psychiatrist (>55%) followed by a psychologist (>41%). Unfortunately, psychiatrists and clinical psychologists seldom form part of interdisciplinary epilepsy teams.³³ As a result, it may not be surprising that one third reported placing patients on psychotropic medications. However, it remains unclear why another third (>26%) endorsed watchful waiting. Notably, watchful waiting is not recommended¹⁰ and suggests an underestimation of the need to initiate treatment of mental health comorbidities. Anecdotal evidence suggests that some neurologists/epileptologists may interpret symptoms of depression and anxiety as the logical consequence of the burden of epilepsy in severely affected patients rather than a mental health comorbidities requiring or amenable via specific intervention. Compared to a prior study in which anxiety was screened and managed less often than depression,¹⁴ our study highlights that the importance of anxiety

TABLE 4 Treatment options and barriers to psychological treatment

	Depression N (%)	Anxiety N (%)
Responders (N)		
Treatment options patients have accessed ^a	392	392
Psychological treatment with a mental health professional	313 (79.8)	307 (78.3)
Psychotropic medications	313 (79.8)	293 (74.7)
Antiepileptic medication changes	294 (75)	260 (66.3)
Psychoeducation	170 (43.4)	173 (44.1)
Advocacy / self-help groups	100 (25.5)	92 (23.5)
Information brochures	90 (23)	98 (25)
None	10 (2.6)	15 (3.8)
Barriers to psychological treatment for depression/anxiety ^a	390	
Lack of appropriately trained mental health specialists	234 (60)	
Patients cannot access psychological treatment (eg, costs, travel restrictions)	204 (52.3)	
Patients do not want psychological treatment (eg, stigma)	197 (50.5)	
Intellectual/cognitive difficulties limit the benefits of psychological treatment	160 (41)	
Difficulties identifying when to refer PWE to psychological treatment	101 (25.9)	
Limited knowledge about appropriate psychological treatment options	86 (22.1)	
Therapist fears of patients having seizures in session	68 (17.4)	
Psychological treatments (eg, CBT) have limited benefit in patients with epilepsy	35 (9.0)	
None	37 (9.5)	

^aResponses were not mutually exclusive, and participants could select more than one.

in PWE is becoming more widely recognized, as at least equivalent to that of depression. Unfortunately, significant barriers to treatment for mental health comorbidities are the lack of standardized procedures around referral practices and the inability to identify or uncertainty for when to refer PWE for psychological treatment. The last consensus on clinical practice statements for the treatment of neuropsychiatric conditions is almost a decade old,¹⁰ suggesting a need for more updated recommendations, similar to neuropsychological

assessment in epilepsy surgery.²⁰ Of note, >80% of respondents noted that creating such recommendations should be a priority of the ILAE Psychology Task Force.

Approximately three quarters of respondents reported that their PWE, who had problems with depression or anxiety, had accessed psychotropic medications or psychological treatment with a mental health professional at some point in their lifetime. There was also high endorsement of changing ASMs to manage depression (75%) and slightly less for anxiety (66%). These findings are moderately encouraging as neurologists/epileptologists can play a critical role in selecting treatment strategies that take account of mental health comorbidities by adjusting ASMs known to exacerbate psychiatric symptoms.¹⁰ However, the field appears to continue to favor medication adjustments over psychological therapies despite evidence that psychological therapies can be effective.³⁴ Notably, there were several commonly endorsed barriers to psychological treatments with over half the sample reporting a lack of appropriately trained mental health specialists, accessibility difficulties, and patients not wanting psychological/psychotropic treatment. Tackling these barriers is of particular relevance to the ILAE Psychology Task Force, and some potential solutions are explored.

The findings strongly suggest more efforts are needed to identify and train mental health specialists to work with PWE, including the creation of registries of mental health professionals specializing in epilepsy, improving epilepsy resources and educational opportunities for mental health professionals and vice versa. One solution is the improvement of neurology and psychiatry residency programs with expanded curricula covering neurologic aspects of psychiatric disorders and vice versa to reduce this competency-related barrier.¹³ In relation to psychologists, there has also been recognition that some specialist training may be needed for the optimal delivery and tailoring of psychological interventions for PWE.^{35–37} For instance, it has been recommended that mental health professionals, especially those working in medical settings, should have basic knowledge about epilepsy and psychological interventions should ideally be implemented by professionals in direct contact with the medical epilepsy specialists treating the patients.^{10,34} In addition, it is recommended that psychological interventions are modified to accommodate common cognitive difficulties common in PWE,³⁷ including the use of written handouts.

The integration of mental health specialists (eg, psychologists, psychiatrists, qualified therapists, and social workers) within epilepsy care settings,^{14,34} which is, unfortunately, not currently common practice³³ would solve many of the barriers revealed in the current study. Many other chronic health teams have implemented more integrated care models for decades, where patients are offered psychological treatments by a psychologist, including HIV,³⁸ chronic pain,³⁹ and cancer.⁴⁰ Psycho-oncology is

now a required subspecialty of oncology dedicated to assisting patients manage the psychosocial(-spiritual) impact of cancer,⁴¹ which is critical to patient health outcomes. However, neurology is lagging behind this integrated model of care,⁴² which could help address treatment gaps for mental health comorbidities and work to improve overall self-management and quality of life of PWE.^{43,44} Another benefit of integrated care is that it is often more attractive to patients and family members who are concerned with the stigma associated with mental healthcare services⁴⁵ and accessibility issues. An excellent example of an integrative care model in an outpatient pediatric epilepsy center in the United States is outlined by Guilfoyle and colleagues.^{46,47} This service involves all children with epilepsy being seen by a pediatric psychologist during routine epilepsy visits soon after diagnosis, with screening of mental health comorbidities occurring every six months. This preventative and proactive model ensures timely screening and referrals for outpatient treatment to prevent the exacerbation of symptoms. This service has been found to be highly acceptable to patients and did not add to overall healthcare charges related to improving patients' quality of life.^{48,49}

Over the past decade, there have been significant developments in the remote delivery of psychological treatments via the Internet, videoconferencing, and telephone as a way of overcoming accessibility difficulties to psychological treatments. There is now substantial evidence for the effectiveness and acceptability of these interventions for common mental health^{50,51} and some physical health conditions.^{52,53} Several trials of remotely delivered interventions to improve mental health outcomes in PWE have yielded very encouraging results,⁵⁴⁻⁵⁶ and these treatments can be optimized for people with cognitive difficulties.^{54,57}

This study has several limitations, including online survey administration, which likely yielded lower participation rates (<10%) for countries who have lower resources and poor Internet access. While online survey administration was practical, relatively accessible and time and cost-efficient, study findings are likely biased toward more middle- to high-income countries and health systems. Several countries were also represented by only a single participant (eg, Japan, Uganda), which may have introduced some bias. The survey was also written in English, which may have also presented as a barrier to some international respondents. Furthermore, it is possible that some people and ILAE chapters have reached an "online survey fatigue" with requests for these types of studies growing in popularity over recent years. This may explain the lower response rate to this survey compared with other ILAE-promoted surveys.⁵⁸ However, it should be noted that the current number of responders is higher than previous surveys in the area of mental health comorbidity.³³ Thus, the lower response rate may instead reflect less interest in this subject area. Respondents also worked across varying health systems,

which may have very different funding and organizational processes, particularly in lower income countries. Unfortunately, it was not possible to perform detailed comparisons between low/middle- and high-income countries on most of the multiple response data collected. It is also not clear whether our findings differed between those working in adult versus pediatric epilepsy health settings. Finally, the survey also failed to assess types and intensity of psychological treatments PWE had accessed or access to social workers and occupational therapists who often provide mental health care. Given the survey was mainly promoted through the ILAE networks, it is not surprising that most respondents had a special interest in epilepsy. Furthermore, it is likely that those who did respond also had a special interest in mental health comorbidity, and the results may be biased toward professionals who believe this is an important area and therefore have more favorable management and procedures in place.

5 | CONCLUSIONS

This study highlighted the ongoing underserved diagnostic and treatment needs for mental health comorbidities in PWE, underscoring that less than half of respondents felt adequately resourced to manage depression and anxiety in their patients. The results identify a number of important areas for improvement, including the need for updated protocols to help guide epilepsy services on how to best manage mental health comorbidities in PWE and for training/education of more mental health professionals in the area of epilepsy and more epilepsy providers in mental health screening and management. It also highlights the value of including mental health professionals on epilepsy teams and integrated care models for psychological care, particularly those involving remote treatment options. While the importance of managing mental health aspects of epilepsy appears to be well recognized by epilepsy community clinicians, much more work on management and implementation of mental health care is needed to provide care for PWE. These findings have informed the priorities of the ILAE Psychology Task Force by identifying practice and education gaps.

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CONFLICTS OF INTEREST




Author Gandy, Modi, Wagner, LaFrance, Reuber, Tang, Valente, Donald, and Michaelis received a travel stipend from the ILAE to attend the 33rd International Epilepsy Congress in Bangkok Thailand (June 2019), during which the Task Force had one-day meeting where the promotion and results of the survey were discussed. Author Gandy is supported by a Macquarie University Research Fellowship. She develops and evaluates psychological treatment programs for adults with neurological disorders, including epilepsy. These clinical trials follow CONSORT reporting standards and are ethics committee-approved and peer-reviewed to address any potential bias. Author Modi receives research funding from the National Institutes of Health for clinical trials related to psychological treatments for youth with epilepsy. These clinical trials follow CONSORT reporting standards and are ethics committee-approved and peer-reviewed to address any potential bias. Author Wagner receives research funding from the National Institutes of Health for clinical trials related to psychological treatments for youth with epilepsy. These clinical trials follow CONSORT reporting standards and are ethics committee-approved and peer-reviewed to address any potential bias. Author LaFrance receives author royalties for the seizure treatment book *Taking Control of Your Seizures: Workbook*, Oxford University Press, 2015. He studies evidence-based nonpharmacological interventions for people with seizures and receives funding from the US Congressionally Directed Medical Research Programs (CDMRP) (Award Number W81XWH-17-1-0619) that are ethics committee-approved and peer-reviewed to address any potential bias. Author Reuber is responsible for developing and supervising a team of psychotherapists working in a clinical neurology department and provides treatment to people with epilepsy. He therefore has an interest in demonstrating the effectiveness of psychotherapy. However, this potential bias is outweighed by his interest in the development of evidence-based treatments, encouraging him to assess the existing evidence as objectively and impartially as possible. Author Tang works as a clinical psychologist in a public hospital in Hong Kong under the Hospital Authority (“HA”). The views expressed are those of the author, and not necessarily those of the HA. She has received honoraria for speaking, and educational activities not funded by industry. She has no conflicts of interest to report. Author Valente receives personal grant from the National Council for Scientific and Technological Development (307817/2019-9) and is responsible for four projects with grants from The Sao Paulo Research Foundation (2019/04956-8; 2018/23798-1; 2018/03228-6; 2017/09870-9). Author Donald works in a clinical environment where she sees and manages children with epilepsy, developmental, and intellectual disabilities and challenging behavior. She has received funding for unrelated research projects supported by the South African National

Research Foundation and Medical Research Council, by an Academy of Medical Sciences Newton Advanced Fellowship (NAF002\1001), funded by the UK Government’s Newton Fund, by the National Institutes of Health (NIAAA, NIMH); UK MRC (MR/T002816/1) and by the US Brain and Behaviour Foundation Independent Investigator grant (24467). She has no conflicts of interest. Author Goldstein has received honoraria for speaking, and educational activities not funded by industry; she receives royalties from the publication of *Clinical Neuropsychology* (Wiley, 2004, 2013) and *The Clinical Psychologist’s Handbook of Epilepsy* Cull 1997. This work represents independent research part-funded by the NIHR Maudsley Biomedical Research Centre (BRC) at South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, Psychology and Neuroscience, King’s College London. The views expressed are those of the author, and not necessarily those of the NHS, the NIHR or the Department of Health.

ETHICAL APPROVAL

We confirm that we have read the position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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