



## Frequency and predictors of psychological distress after a diagnosis of epilepsy: A community-based study



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### ARTICLE INFO

#### Article history:

Received 31 March 2017

Revised 26 July 2017

Accepted 26 July 2017

#### Keywords:

Epilepsy  
Depression  
Anxiety  
Stigma  
Family function

### ABSTRACT

**Objective:** The objective of the study was to determine the frequency and predictors of psychological distress after a diagnosis of epilepsy.

**Methods:** The Sydney Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC) was a prospective, multicenter, community-based study of people of all ages with newly diagnosed epilepsy in Sydney, Australia. Analyses involved multivariate logistic regression and multinomial logit regression to identify predictors of psychological distress, assessed using the Hospital Anxiety and Depression Scale (HADS) and the Strengths and Difficulties Questionnaire (SDQ), as part of structured interviews.

**Results:** Psychological distress occurred in 33% (95% confidence interval [CI] 26 to 40%) and 24% (95% CI 18 to 31%) of 180 adults at baseline and 12 months, respectively, and 23% (95% CI 14 to 33%) of 77 children at both time points. Thirty adults and 7 children had distress at baseline who recovered at 12 months, while 15 adults and 7 children had new onset of distress during this period. History of psychiatric or behavioral disorder (for adults, odds ratio [OR] 6.82, 95% CI 3.08 to 15.10; for children, OR 28.85, 95% CI 2.88 to 288.60) and higher psychosocial disability (adults, OR 1.17, 95% CI 1.07 to 1.27) or lower family functioning (children, OR 1.80, 95% CI 1.08 to 3.02) were associated with psychological distress (C statistics 0.80 and 0.78).

**Conclusions:** Psychological distress is common and fluctuates in frequency after a diagnosis of epilepsy. Those with premorbid psychological, psychosocial, and family problems are at high risk of this adverse outcome.

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### 1. Introduction

Epilepsy, a common neurological condition, is often associated with depression and anxiety [1]. The psychological impact of epilepsy may relate to reduced quality of life [2] and impaired cognition [3]. Among adults with epilepsy, the prevalence of psychological distress is higher than in the general population [1], and affected children and adolescents report high rates of depression, anxiety, and behavioral problems

[4]. Identifying those most at risk of psychological distress could optimize management strategies to improve the control of seizures [5], quality of life [6], adherence to medication [7], response to pharmacological or surgical treatments [8,9], and reduce suicide risk [10].

Previous studies of psychological distress after epilepsy have been undertaken in people with first seizure [11], epilepsy of uncertain duration [12–14], chronic epilepsy [15], and those undergoing surgery [9], or with self-reported epilepsy or “seizure disorder” [16]. Moreover, they have usually been cross-sectional [12–14], identifying associations between anxiety and unemployment [12], stigma and poor seizure control [13], and depression and unemployment, stigma, poor seizure control [13], neuroticism, poor functioning, limited social support, history of depression, and stressful life events [14]. We undertook the Sydney

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Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC) to provide a reliable assessment of the frequency and predictors of psychological distress in people of all ages with newly diagnosed epilepsy.

## 2. Methods

### 2.1. Overview

The SEISMIC study is registered at Australia New Zealand Clinical Trial Registration database (ANZCTR12609000059268), and details of the study methodology have been published [17]. In brief, SEISMIC recruited a prospective cohort of people with a new diagnosis of epilepsy in Sydney, Australia. Initially, a population-based incidence study of residents in the central eastern area of Sydney was planned, but because of lower than predicted case identification and recruitment, the geographical area was broadened to the whole of the metropolitan region of Sydney in 2011. Participants were enrolled over an initial 6-month pilot phase from July 2008, and over a 3.5-year main phase from June 2010 to December 2013. Participants or their proxies were interviewed within 28 days, or as soon as possible (baseline), and at 4 and 12 months after their diagnosis. If the baseline assessment was undertaken beyond the 28-day period, participants were asked to recall their situation within the first month of diagnosis; the 4-month interviews were not applied to participants whose baseline interviews were completed longer than 4 months after their diagnosis.

### 2.2. Ethical approval

Full ethical approval was provided by the Human Research Ethics Committee/08/RPAH/258 (lead committee) of the Sydney South West Area Health Service (SSWAHS) for protocol No X08-0152 on 10 July 2008 and from local institutional research governance offices for each clinical center or principal investigator (PI). Written informed consents were obtained from participants or their proxies.

### 2.3. Participants

Subjects were children of age more than 44 weeks postconception and adults (no upper age limit) who were given a new diagnosis of epilepsy. Those who had a severe language disorder or cognitive impairment (as determined by their clinician) were eligible provided they had a proxy who could give informed consent and complete the assessments on their behalf. People were excluded if their seizures were due to an acute reversible cerebral insult or a reversible metabolic cause. Written informed consent was obtained from each participant or, where appropriate, an approved proxy.

### 2.4. Definitions

Epilepsy was defined as two or more unprovoked seizures, defined according to the International League Against Epilepsy (ILAE) Commission on Epidemiology and Prognosis as “a transient occurrence of signs or symptoms due to abnormal excessive or synchronous neuronal activity in the brain”.

### 2.5. Case-finding procedures

A ‘hot pursuit’ surveillance system was established across hospitals in Sydney: Bankstown Hospital, Prince of Wales Hospital, Royal Prince Alfred Hospital, St. Vincent’s Hospital, Sydney Children’s Hospital at Randwick, Westmead Hospital including Westmead Children’s Hospital, Concord Repatriation General Hospital, and Canterbury Hospital. This approach involved regular review of the records of all patients who presented to each of 3 main hospital areas—neurology outpatient clinics and departments, EEG labs, and emergency departments; outpatient attendees to the Brain and Mind Centre of the University of Sydney;

referrals from private consulting rooms of several epileptologists, neurologists, pediatricians, and general practitioners; and cases referred directly from Epilepsy Action Australia, a not-for-profit nongovernment organization. A lead clinician at each referral site acted as a PI maintained a screening log of all potentially eligible patients and documented when consent was obtained.

### 2.6. Assessment and data collection

Trained researchers extracted key sociodemographic, clinical, and contact information from medical records, and undertook structured, face-to-face, age-sensitive interviews with participants. For adults, this generally involved direct interviews with participants, whereas interviews were with a parent for those under 18 years. The interview involved the collection of information pertaining to the clinical pattern of seizures, investigations, and management, including the use of antiepileptic drugs (AEDs). Sociodemographic and other clinical information were obtained with particular attention to history of psychological or behavioral problems and their treatment, level of education, employment, household financial situation, and features of self-stigma. Histories of depression, anxiety, agitation, psychosis, use of antidepressants, sedatives or sleeping tablets, medication for anxiety/anxiolytics/benzodiazepines, major tranquilizers, and counseling or psychotherapy for psychological problems were asked. Any answer of ‘yes’ to these areas was defined as a history of psychological or behavioral problems. Self-stigma was determined by a single question of whether the participant thought that other people are uncomfortable, treat him/her differently, or preferred to avoid him/her.

We measured family function using the Family Adaptation, Partnership, Growth, Affection, and Resolve (APGAR) questionnaire [18], where there are 5 questions on a 3-point scale (1 “hardly ever” to 3 “almost always”; LONGSCAN scoring method) [18]. The consumption score from the Alcohol Use Disorders Identification Test [17,19] of the World Health Organization (WHO) was used to assess alcohol consumption among adult participants. Alcohol consumption at a level defined as ‘at risk’ was indicated by a total score of  $\geq 5$  for males or  $\geq 4$  for females [17]. Job strain, measured by the Job Content Questionnaire (JCQ) [20], was defined as high demands (e.g., long hours, too much work) and low control (e.g., limited or no choice concerning how or what work was completed). The JCQ has shown good internal consistency [20] and moderate construct validity [21]. Psychosocial disability was assessed using the 12-item WHO Disability Assessment Schedule (WHODAS 2.0), with responses ranging from 1 “none” to 5 “extreme” [22].

### 2.7. Psychological distress

The presence of anxiety and depression in adults was measured using the subscales of the Hospital Anxiety and Depression Scale (HADS) [23], which contains 14 items, each answered on a 4-point scale (0 “not at all” to 3 “very often”). Scores ranging from 0 to 21 (high score indicating more symptoms/worse outcome) were computed for the 7 items in the anxiety (HADS-A) and depression (HADS-D) subscales: score  $\geq 8$  in HADS-A and/or HADS-D indicated a case of anxiety and/or depression [23], and given the term ‘psychological distress’ [24]. The score for a single missing item on a subscale was inferred by using the mean of the remaining six items; if more than one item was missing, the subscale was deemed invalid. The HADS has shown good internal consistency for the anxiety (Cronbach’s alpha 0.88) and depression subscales (Cronbach’s alpha 0.82) in a community sample of people with epilepsy [5], and has been validated [25] and widely used [12,13] in epilepsy studies.

The presence of psychological distress in children (i.e., between the age of 2 and 17 years) was assessed using the parent-completed Strengths and Difficulties Questionnaire (SDQ) [26], which comprises five scales covering hyperactivity, psychological symptoms, conduct

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