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Quality of life in epilepsy in Bhutan

Altaf Saadi [a], Bryan Patenaude [b], Damber Kumar Nirola [c], Sonam Deki [c], Lhab Tshering [c], Sarah Clark [d], Lance Shaull [d], Tali Sorets [d], Guenther Fink [b], Farrah Mateen [d,e,*]

[a] Partners Neurology Residency, Massachusetts General Hospital and Brigham and Woman's Hospital, Boston, USA
[b] Harvard T. H. Chan School of Public Health, Boston, USA
[c] Jigme Dorji Wangchuck National Referral Hospital, Thimphu, Bhutan
[d] Massachusetts General Hospital, Boston, USA
[e] Harvard Medical School, Boston, USA

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ABSTRACT

Purpose: To assess the quality of life in epilepsy (QOLIE) among adults in the lower middle-income country of Bhutan and assess the potential demographic and clinical associations with better QOLIE.
Methods: People with clinically diagnosed epilepsy were prospectively enrolled at the Jigme Dorji Wangchuck National Referral Hospital in Thimphu (2014–2015). Regression models were constructed to assess the potential impact of age, sex, residence in the capital city, wealth quintile, educational attainment, seizure in the prior year, seizures with loss of consciousness, self-reported stigma score, and need for multiple antiepileptic drugs.
Results: The mean Bhutanese QOLIE-31 score among 172 adults (mean age 31.1 years, 93 female) was $48.9/100 \pm 17.7$. Younger age, lower educational attainment level, and increased self-perceived stigma were each observed to have an independent, negative association with QOLIE ($p < 0.05$), while a patient's wealth quintile, sex, seizure frequency, seizure type and number of antiepileptic drugs were not. Education appeared to be most strongly associated with QOL at the high school and college levels.
Conclusions: There are potentially modifiable associations with low QOLIE. Addressing the educational level and self-perceived stigma of PWE may have an especial impact. The low QOLIE in Bhutan may reflect cultural approaches to epilepsy, health services, or other factors including those outside of the health sector.

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1. Introduction

Relatively little is known regarding the quality of life (QOL) among people with epilepsy (PWE) in low- and middle-income countries (LMICs), even though 80% of PWE live in the developing world [1]. While QOL in epilepsy has been summarized in a systematic review of 86 studies in 2011, 61 of those 86 were derived from Europe and North America, all of which were higher income settings [2]. In that review, seizure frequency; seizure severity; and depression, anxiety, and other comorbidities were strongly associated with a lower QOL. The evidence for educational level, employment, and antiepileptic drugs (AEDs) as predictors of QOL was inconclusive.

Available data from high-income countries may not transpose readily to LMICs for several reasons: (1) higher levels of absolute poverty, (2) limited access to health care and medications, (3) a dearth of specialized healthcare workers; (4) increased perceived stigma toward PWE, (5) fewer AEDs generally available, (6) available AEDs often being older generation medications that may have more side effects, and (7) employment and its relationship to wealth being considerably different [1,3,4]. Mitigating these factors may be a stronger sense of community and social support as well as an overall higher QOL in the general population in some LMICs [5].

The present study aims to clarify the relationship between wealth, education, and QOL alongside the more generally studied clinical and demographic predictors of QOLIE. Using data from a prospective cohort in the lower middle-income country of Bhutan, a landlocked country in the Himalayan Mountains, we report the predictors and relationship of social, economic, clinical, and demographic variables with QOL in PWE.

* Corresponding author at: Massachusetts General Hospital, 165 Cambridge St #627, Boston, MA 02114, USA. Tel.: +617 724 8653; fax: +1 617 726 6991.
E-mail addresses: asaadi@partners.org (A. Saadi), bryanpatenaude@gmail.com (B. Patenaude), drnirola@yahoo.com (D.K. Nirola), somkey90@gmail.com (S. Deki), tsheringlhab999@gmail.com (L. Tshering), sclark0929@gmail.com (S. Clark), lrshaull@gmail.com (L. Shaull), tsorets@bbns.org (T. Sorets), gfink@hsph.harvard.edu (G. Fink), fmateen@mgh.harvard.edu (F. Mateen).

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2. Methods

2.1. Ethics approvals

This study was approved by the Research Ethics Board of Bhutan, the University of Ottawa Research Ethics Board, and the Partners Healthcare Institutional Review Board.

2.2. Study setting and population

The Jigme Dorji Wangchuck National Referral Hospital (JDWNRH) provides tertiary care to people from all 20 districts of the Kingdom of Bhutan. PWE are referred to the country's only psychiatrist for epilepsy management at the JDWNRH. In a 2014 Human Resources for Health country profile of Bhutan, there were 41 medical specialists for a total of approximately 742,000 inhabitants [6]. There are no neurologists.

183 adult participants were enrolled. Eleven participants were subsequently excluded for not meeting diagnostic criteria for epilepsy, having had only one seizure each. Table 1 summarizes demographic and clinical characteristics of the 172 remaining subjects; there was no statistically significant difference between sexes.

The assets and wealth survey found that nearly all households of PWE used electricity in Bhutan; however, only a third of households owned their homes (Table 2).

Table 1
Clinical and demographic characteristics.

	Total sample ($N = 172$)
Age (years)	
Mean ± SD	31.1 ± 11.2
Range	19–75
Gender	
Female (n)	93
Distribution of age (%)	
19–35	124 (72%)
35–60	42 (25%)
>60	6 (3%)
Highest educational attained	
None	47
Primary	44
Secondary	24
High School	33
College	24
Age of seizure onset (years ± SD)	18.8 ± 11.1
Seizure type	
Focal	42
Secondary generalized	130
Seizure frequency	
Seizure within the last year	112
Mean (range)	2.05 (0–60)
25th percentile	0
50th percentile	0.04
75th percentile	2
90th percentile	4.25
Number of AEDs	
0	10
1	103
2	42
>2	17
AED type	
Carbamazepine	63
Benzodiazepines	10
Phenytoin	66
Sodium valproate	37
Phenobarbital	38
Levetiracetam	23
Lamotrigine	7

Table 2
Summary of household economics survey.

Mean % monthly income spent on food	47
% of households that use	
Electricity	91
Liquefied petroleum gas	94
Wood	12
Other	4
% of households where cooking is done in the home	94
% of households that have	
Electricity	99
TV	88
Refrigerator	72
Mobile phone	97
Car/truck	37
Bike	12
% of households that owns home	41
% of households with livestock	37
% of households with bank account	88
% of households that did not earn money in the last month	13

2.3. Data collection and tools

Bhutanese outpatients, ages 19 years and older, were interviewed prospectively (August 2014–April 2015). Participants were included if they had diagnosed or suspected epilepsy. Each patient was interviewed by a neurologist and/or psychiatrist and screened for non-epileptic behavioral events to reduce the likelihood that participants had psychogenic non-epileptiform seizures (PNES). Participants with associated psychiatric disorders that were not epilepsy were excluded. Structured surveys were provided on paper in English, the working written language in Bhutan, or were offered as an oral translation into Dzongkha, the official and more commonly spoken language. Collected data also included socio-demographic characteristics and clinical parameters of epilepsy diagnosis and management. Patients were asked directly to rate their perception of epilepsy stigma on a 1 through 5 scale, and this "perceived epilepsy stigma" value was used as the predictor of interest in regression analyses.

2.3.1. Quality of life measurement

The QOLIE-31 is a widely-adopted, epilepsy-specific, 31-question inventory developed in the United States to assess seven domains relevant to PWE: overall quality of life, seizure worry, emotional well-being, energy/fatigue, cognitive, medication effects, and social function [7]. Overall health is reported in an additional question. The inventory has been validated and translated into at least 12 languages [8–19]. Since a minority of the cohort drives motor vehicles, the QOL question relating to driving was eliminated and scoring was re-weighted in that sub-scale to the number of available questions.

The scoring procedure converts raw numeric values of items to scores of 0–100, where higher scores reflect a better QOL. An overall score is obtained by using a weighted average of the multi-item scale scores [20]. Scoring of responses was entered into a secure, centralized database. All score calculations were confirmed by two independent reviewers.

2.3.2. Economic assessment

Each participant was invited to complete a household assets survey. This survey was based on the Multiple Indicator Cluster Survey (MICS) used by UNICEF [21] and refined by the authors to be relevant for PWE as well as the Bhutanese context.

A wealth index was created using polychoric principal components analysis based upon questionnaire responses. Wealth is composed of all household assets (agricultural and other) and

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