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The epilepsy treatment gap in rural Tanzania: A community-based study in adults

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ABSTRACT

Purpose: Most people with epilepsy (PWE) in low-income countries are not treated. We identified risk factors for the epilepsy treatment gap in rural Tanzania.
Methods: We identified adult PWE in a community-based prevalence study. Factors associated with failure to access or default from medical care were identified using logistic regression modelling.
Results: A total of 291 PWE were included, of whom 253 (86.9%) had presented to medical services. Failure to present was positively associated with using alcohol (odds ratio (OR) 4.20; 95% confidence interval (CI) 1.63 to 10.82) or attending traditional healers (OR 2.62; CI 1.00 to 6.83) and inversely associated with having completed primary education (OR 0.33; CI 0.11 to 0.96). Default from treatment was associated with being male (OR 3.35; CI 1.39 to 8.09), having a seizure-related injury (OR 2.64; CI 1.12 to 6.19), believing in a supernatural cause for epilepsy (OR 5.44; CI 1.48 to 19.94) or having no expressed knowledge of cause (OR 5.29; CI 1.60 to 17.52). Cases less likely to default had a duration of epilepsy greater than 10 years (OR 0.28; CI 0.09 to 0.90) or had previously received a seizure-related diagnosis (OR 0.25; CI 0.09 to 0.65). Of all 291 PWE included, 118 denied taking AEDs; the epilepsy treatment gap in this population was therefore 40.5% (95% CI 34.9 to 46.2).
Conclusion: Interventions to improve access to education and to support formal diagnoses may promote access to, and retention under, medical care for PWE in rural Tanzania and in other low-income countries.

1. Introduction

Over 90% of all people with epilepsy (PWE) live in low- and middle-income countries (LMICs), where the majority are not treated despite the availability of effective and affordable medication [1]. The epilepsy treatment gap (ETG) is defined as the proportion of people with active epilepsy who are not receiving treatment [2,3]. Recent estimates of the ETG in LMICs have ranged from 56% to over 75%, albeit with wide confidence intervals and considerable heterogeneity between studies [1,4]. A large proportion of PWE living in LMICs also discontinue treatment soon after initiation, a phenomenon known as the secondary treatment gap [5].

There is a paucity of data from LMICs on factors contributing to the ETG. In a systematic review, eight out of 27 eligible studies presented data on causes of the ETG [1], of which three were from sub-Saharan Africa (SSA) [6–8]. These studies were descriptive rather than analytic, and two included only small numbers PWE ($n = 45$ or 33). Health system factors contributing to the ETG were cost, distance, drug availability and a lack of medically skilled personnel, while patient factors included non-adherence and

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seeking traditional rather than medical treatment. This phenomenon is well-recognised in SSA, including in Tanzania, and is often associated with considerable costs to the patient [9–11]. More recently, factors contributing to the ETG were studied among PWE living in a coastal Kenyan community, with traditional beliefs and negative attitudes towards medical care, distance from health facilities, cost, learning disability, increased duration of epilepsy and having focal seizures all being associated with failure to seek medical treatment [12].

In addition to difficulties in accessing effective treatment, epilepsy in SSA is also associated with social isolation and reduced life-expectancy [13,14], outcomes which may be exacerbated by having uncontrolled seizures, making the condition more visible and more dangerous. Given access to appropriate and consistent anti-epileptic drug (AED) therapy, the prognosis of epilepsy can be favourable, with seizure-freedom being achievable in up to 75% of PWE within five years of diagnosis [15,16], including for those living in LMICs [11,17,18].

We conducted a community-based prevalence study of epilepsy in a rural district of northern Tanzania. We examined factors associated with failure to access or default from medical treatment, our aim being to identify contributors that would potentially be amenable to intervention. This is the first population-based analytical study of the ETG from Tanzania, and only the second study of this type from SSA. These data should be used to inform policy and interventions designed to reduce the epilepsy treatment gap.

2. Materials and methods

2.1. Study site

The Hai district lies on the slopes of Mount Kilimanjaro in northeast Tanzania, covering an area of approximately 1300 km^2. Agriculture, commercial mining and cottage industries are the main economic activities [19]. Hai was established as a demographic surveillance site (DSS) by the Tanzanian Adult Morbidity and Mortality Project in 1994 [20], and thus represents a well-defined study population. The DSS is comprised of 59 villages, with a total population after the most recent census in 2009 of 161,119 people living in 43,794 households. Government-funded healthcare in the district is delivered via three tiers: 24 dispensaries catering for village to ward level (up to 10,000 inhabitants), four health centres at administrative divisional level (up to 50,000 inhabitants) and one district hospital [19]. The AEDs phenobarbitone and phenytoin are available in village dispensaries and carbamazepine is available at Hai District Hospital. At the time of the study, PB was also available to patients via the Mental Health Association of Tanzania, a non-governmental organisation providing support to patients with various psychiatric disorders, at a cost price of 15 Tanzanian Shillings (TSh) per 30 mg tablet. At this price the annual cost to a patient taking 120 mg of PB per day would be 21,900 TSh, or about 10 US Dollars (USD). Neurology services are available at Kilimanjaro Christian Health Centre (KCMC), a large referral hospital in the nearby town of Moshi. Sodium valproate is also available at KCMC.

2.2. Participants and study design

During 2009 and 2010 adult PWE aged 15 years or above were identified in a door-to-door prevalence study in the Hai DSS. Epilepsy diagnoses were confirmed by the research doctor (EH), with active epilepsy being defined either as either having two or more unprovoked seizures at least 24 h apart during the past five years, or currently using AEDs. Seizures and epilepsies were classified according to currently recommended criteria [21]. Full details of the prevalence study have been published elsewhere [22].

All PWE completed a standard questionnaire which asked about current or previous access to medical care and/or AED treatment, use of traditional healers or medications, and the associated costs of any treatments used. From cases taking AED treatment, we sought to ascertain the identity, dose and pattern of use of AEDs. Where drug names could not be spontaneously volunteered, prompts were offered and, wherever possible, any patient-held and/or health facility records or prescriptions were scrutinised. The ETG was defined as all cases with active epilepsy who were not taking any form of AED treatment at the time of the study.

The questionnaire was derived from a proforma designed to collect standardised data in epidemiological studies of epilepsy in tropical low-income countries [23]. This tool has previously been used in several surveys conducted Africa [24]. Additional items relating to seizure severity, including a history of seizure-related injuries, were drawn from the Liverpool Seizure Severity Score [25]; pragmatic categories quantifying seizure frequency were drawn from a related study of seizure severity and quality of life [26]. The research doctor conducted all interviews in the field, assisted by a UK medical student (SC). A Tanzanian research nurse (JR) provided interpretation between English and Kiswahili. Interviews were held in private at a local health facility, other community centre or in the homes of PWE. A collateral history from a relative or carer was also taken wherever possible.

2.3. Statistical analysis

Data were analysed using the Statistical Package for Social Sciences (SPSS) version 20. We used Pearson's χ^2 to measure associations between demographic, clinical, patient and health-care-related variables and two binary outcomes: previous presentation to medical services and, for those who had presented previously, self-reported current AED use. We further investigated univariate associations with each of the two outcomes using multivariable binary logistic regression models constructed using a backwards stepwise elimination strategy based on the likelihood ratio test. Predictor variables with a p-value of >0.1 were excluded at each step; those with a value of ≤ 0.05 were retained in the final models. Missing values were considered to being missing completely at random and we did not impute for missing data. The 95% confidence interval (CI) for the ETG was calculated for a binomially-distributed observation using the standard error of a proportion.

2.4. Ethics

The ethics review committee of the Tanzanian National Institute of Medical Research approved the study (ref. NIMR/HQ/R.8a/Vol.IX/786; 09/02/2009). Written informed consent was obtained from all PWE participating in the study. All PWE identified during the study were either started on treatment or were counselled in order to optimise treatment, in liaison with the Hai District Community Health Management Team.

3. Results

3.1. Participants

Two-hundred and ninety-one PWE were included in the study: 155 (53.3%) were male and the median age of all cases was 30 years (range 15 to 85 years; IQR 21 years). All PWE included in the study were suffering from active convulsive epilepsy with either primary or secondary generalisation, with no cases of non-convulsive epilepsy identified.