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.

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 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.

Materials and methods

Study site

The Hai district lies on the slopes of Mount Kilimanjaro in northeast Tanzania, covering an area of approximately 1,300 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.[21] 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 30mg tablet. At this price the annual cost to a patient taking 120mg 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.

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 hours apart during the past five years, or currently using AEDs. Seizures and epilepsies were classified according to currently recommended criteria.[22] Full details of the prevalence study have been published elsewhere.[23]

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.[24] This tool has previously been used in several surveys conducted Africa.[25] Additional items relating to seizure severity, including a history of seizure-related injuries, were drawn from the Liverpool Seizure Severity Score [26]; pragmatic categories quantifying seizure frequency were drawn from a related study of seizure severity and quality of life.[27] 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.

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 healthcare-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.

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.

Results

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.

Access to medical care

A total of 253 cases (86.9%) had previously sought medical attention, 173 (68.4%) of whom stated they were taking treatment at the time of the study (59.5% of all cases). Demographic and clinical characteristics of these groups along with univariable ORs for seeking medical treatment and self-reported AED treatment are summarised in Tables 1 and 2. Binomial multivariable logistic regression models are summarised in Table 3. Cases identified as less likely to have sought medical treatment were those who had used traditional treatment (odds ratio (OR) for failure to seek treatment 2.62; 95% CI 1.00 to 6.83) or who drank alcohol (OR 4.20; 95% CI 1.63 to 10.82), while having completed primary education was a protective factor (OR 0.33; 95% CI 0.11 to 0.96) (Table 3). Among cases who had previously presented, factors associated with non-treatment were being male (OR 3.35; 95% CI 1.39 to 8.09), having a seizure-related injury (OR 2.64; 95% CI 1.12 to 6.19), believing that epilepsy has a supernatural cause (OR 5.44; 95% CI 1.48 to 19.94), having no expressed idea as to the cause (OR 5.29; 95% CI 1.60 to 17.52) or using alcohol (OR 3.93; 95% CI 1.29 to 12.01). Protective factors in this group were having epilepsy for 10 years or more (OR 0.28; 95%CI 0.09 to 0.90) and having previously been given a seizure-related diagnosis (OR 0.25; 95% CI 0.09 to 0.65) (Table 4). Of 102 cases with seizure-related injuries, 76 (74.5%) had burns. Seizure-related diagnoses included the Kiswahili terms *kifafa* or *degedege*. *Kifafa* is usually translated as meaning epilepsy, although in our experience is used to refer more specifically to generalised convulsive episodes with frothing at the mouth; *degedege* is usually translated as referring to febrile seizures in children, although is often used interchangeably with *kifafa*.

Current AED use and treatment gap

Out of the 291 PWE identified, 118 denied taking AEDs at the time of the study, and a conservative estimate of the ETG is therefore 40.5% (95% CI 34.9 to 46.2).

Out of 173 PWE who stated they were taking treatment, 147 (85.0%) were using one drug and 26 (15.0%) were using two in combination. Phenobarbitone (PB) was the most commonly identified AED, used by 134 (77.5%) of all treated cases. Other AEDs encountered were phenytoin (PHT) (28 cases, 16.2%), carbamazepine (CBZ) (22 cases, 12.7%) and sodium valproate (SV) (two cases, 1.2%). In 13 (7.5%) cases, we could not confidently identify the drug(s) used. The patterns of AED use are illustrated in Figures 1 and 2.

Data on self-reported compliance were available in 168 (97.1%) cases, of whom 122 (70.5%) were taking treatment daily when available, although 30 (24.6%) of these were using doses likely to be sub-therapeutic. The remainder were taking treatment only very infrequently; four cases (2.3%) reported taking AEDs only after a seizure had occurred.

Data on side effects from AED treatment were available in 159 (91.9%) of 173 treated cases, with 134 (84.3%) of these reporting no adverse effects. Of the 25 individuals that did report side effects, 17 cases complained of tiredness (13 using PB mono-therapy, three using PB and PHT, and one using an unidentified drug). Other adverse effects reported included dizziness (four cases on PB mono-therapy, one on an unidentified drug), headache (two cases, both using PB), rash (one case using CBZ and SV), memory problems (one case using PB), and unspecified behavioural disturbance (one case using PB).

Data on cost of AEDs were available from 146 (84.4%) cases, of whom 96 (65.8%) purchased their medication privately.

The majority of treated cases had poorly controlled seizures, with only 20 (11.6%) reporting to be seizure-free (defined as no seizures in the previous five years). Of the 153 treated cases with active seizures, 100 (65.4%) reported seizures on at least a monthly basis (Figure 3).

Traditional treatment

Data on the use of traditional treatment were available from 276 (94.8%) cases, of whom 133 (48.2%) had attended a traditional healer at some point. Of these, 90 (67.7%) could recall details of the diagnosis or explanation given to them by traditional healers: no specific explanation was given in 33 cases (36.7%), a supernatural explanation was used in 23 cases (25.6%), 13 (14.4%) were diagnosed as *degedege* and 10 (11.1%) as *kifafa*; 11 cases (12.2%) described a range of other explanations relating to various physical or emotional causes. Eighty-five people provided an estimate of the cost to themselves or their families of traditional treatment, with 20 (23.5%) having spent at least 100,000 Tanzanian Shillings (about 50 USD), often selling livestock or other possessions to raise funds. Modes of treatment described included taking inhalations and purgatives, wearing amulets and talismen, participating in spiritual ceremonies and scarification.

Discussion

The ETG in adult PWE living in this part of Tanzania is 40.5%. This is considerably lower than recent estimates from comparable populations in this region. Elsewhere in northern Tanzania, for example, 76% of PWE identified in a community-based study had never received AED treatment, despite living close to a hospital where AEDs are available [28].

The lower ETG in Hai may be due in part to its proximity to the large towns of Arusha and Moshi, where numerous private clinics and non-governmental healthcare providers are located, and to a large referral hospital (KCMC), where neurology services are available. The influence of bias, however, must also be considered. Firstly, we know that epilepsy is a highly stigmatising condition in this population [13], and it can be assumed that more marginalised individuals are less likely to have been detected by the study. Secondly, our prevalence study detected only PWE with active convulsive epilepsy [23], reflecting the difficulty in identifying non-convulsive epilepsy in door-to-door surveys in low-income settings. This issue has previously been acknowledged in study design [29], and is reflected in the consistently low proportions of non-convulsive epilepsies that have been described in community-based cross-sectional studies.[30] It can be assumed that PWE belonging to either or both of these groups are less likely to be diagnosed and treated and would, therefore, have contributed to the ETG estimate had they been included. Finally, the utility of self-reporting in estimating the ETG has recently been questioned by a study from Kenya in which self-reported adherence had a sensitivity and specificity of 38.1% and 80.8% when compared to detection of AEDs in blood.[12] With these potential biases in mind, and considering the high proportion of treated patients who were taking AEDs only very infrequently, along with the large burden of uncontrolled and frequent seizures observed in this group of PWE, we suggest that the ETG in Hai of 40.5% is likely to represent a considerable underestimate of those not receiving appropriate or regular treatment.

Beyond estimating the ETG, we sought to identify factors associated with access and adherence, components of the ETG that may have different implications in terms of interpretation and, ultimately, intervention.[31] Cases less likely to have presented to medical services were those who had visited traditional healers and those who used alcohol; having completed primary education was associated with a greater likelihood of having sought medical treatment. While lack of education and alcohol use could represent socio-economic markers predictive of a lower level of engagement with services in general, they may also be factors that are present more frequently as the result of having epilepsy. With regards to education, we are more inclined to believe the latter, as qualitative studies of adults and children with epilepsy in this population have identified exclusion from school due to epilepsy as a recurring theme.[13,32] This is supported by quantitative data locally, with 50% of children with epilepsy in the Hai DSS not attending school regularly compared to none of a group of age-matched controls[33], while elsewhere in Africa 43.2% of 2,170 PWE in five countries (Ghana, Kenya, South Africa, Tanzania and Uganda) reported lack of education, almost double the proportion seen in controls.[34] Improving access to education for PWE may therefore be an intervention that helps to reduce the ETG in the long term, and for this reason we are currently pursuing public engagement activities with parents and teachers in order to further understand these issues.[35]

Only 38.3% of PWE who had previously sought treatment in this population recalled receiving a diagnosis compatible with epilepsy or seizures. The fact that continued use of AEDs is associated with having received a diagnosis speaks plainly to the need to equip local healthcare workers with the knowledge, skills and confidence to make what may be a very stigmatising diagnosis. It has been proposed that interventions at a local level should address the training of health care workers, enabling them to diagnose and manage epilepsy, to counsel PWE about their diagnoses, and to make appropriate referrals.[36] Such programmes have been successful in improving the diagnosis and management of epilepsy in communities in India, Zimbabwe and Ethiopia.[37–39] In communities similar to Hai, where nearly one third of PWE that initially present to treatment services are not retained, such educational interventions would clearly also be appropriate.

Other than alcohol use, a different set of associations with default from treatment were observed. Men were more than three times more likely to default than women, an

association that has not been described previously in the epilepsy literature from low-income countries. Contributory factors not measured and/or adjusted for in our study may include a poorer initial response to treatment, economic reasons or stigma. It may also be that women benefit from additional protective factors with regards to engaging with treatment. It has been suggested, for example, that women in Tanzania are more health-conscious then men, being accustomed to attending maternity and child-care clinics and speaking openly about health issues.[28] This may contribute to increased retention under care for chronic conditions such as epilepsy. Further work is warranted to reproduce this result in other populations and to further understand the specific barriers to long-term treatment faced by men with epilepsy in SSA.

Individuals who had suffered a seizure-related injury (most frequently burns) were more than twice as likely to default. This contrasts with data from elsewhere in Africa which suggest a positive association between current AED treatment and burns.[34] While our finding may point to the higher risk of injury in untreated epilepsy we were also told during field work, anecdotally and on numerous occasions, that when a PWE sustains a burn this would be taken as a sign that the condition had become untreatable. It may be that this apparently commonly held belief leads to default rather than encouraging compliance. Further investigation of such cultural issues, and of the temporal association between the incidence of injury and adherence to treatment, is warranted.

Individuals who believed either that epilepsy has a supernatural cause or who had no expressed knowledge of the cause were five times more likely to default. Taking this together with the observed association between failure to access treatment and use of traditional healers, we suggest that community-level sensitisation and education are warranted in order to increase the likelihood of incident cases presenting to medical services and continuing with treatment. In support of this, it has been demonstrated that supernatural and medical ideas about the causes of epilepsy can co-exist in African communities [10], and there are also precedents for establishing collaborative relationships between medical services and traditional healers.[40] In order to be successful, such initiatives would require sound ethnographic understanding of such treatment providers and their place within the community.[41]

Factors associated with a reduced likelihood of default from treatment in our study were having epilepsy for more than 10 years, and having previously received a diagnosis compatible with seizures or epilepsy. The first of these findings contrasts with those of a cross-sectional study of the risk factors associated with the ETG in rural Kenya.[12] Failure to seek treatment in that study was associated with duration of epilepsy of 10 years or more, while AED use of greater than five years was associated with non-adherence. While the authors postulate that PWE with a longer duration of epilepsy may have learned to cope with their condition, our alternative finding could indicate that people who have lived with epilepsy for longer may have learned the benefits of treatment. It may also be that those PWE who do not comply with treatment are less likely to survive with epilepsy for 10 years. We are following our cohort prospectively with regards to mortality, amongst other outcomes, and may be able to clarify this issue. Finally, it must also be considered that these contradictory findings, which are difficult to interpret, may also be spurious associations seen as a result of residual confounding that has not been controlled for in the analysis.

At least 65.8% of PWE taking AED treatment were buying their own drugs. Although the local cost of PB, used by 77.5% of PWE, was potentially as little as 10 USD per year, availability and affordability are nevertheless likely to be factors contributing to the ETG in this population, where nearly one half of people live on less than 1.90 USD a day, measured against 2011 international prices.[42] This assumption is supported by a secondary analysis of health-facility based surveys in 34 LMICs, including Tanzania, in which the availability of all AEDs in the public sector was less than 50% and adjusted per patient costs of generic AEDs were up to 17.5 times higher than international reference prices.[43] Furthermore, cost was found to be an independent predictor of failure to seek medical treatment among PWE living in rural Kenya.[12] Our limited data on traditional treatment also suggest that many patients are faced with significant upfront costs, which may represent catastrophic spending for families living below the poverty line. Although AEDs are available locally, either for free or at relatively low cost, problems of availability coupled with the poor treatment outcomes we observed may mean that they are not seen as being a viable alternative to traditional treatment, or one that represents better value for money. These issues warrant further investigation, particularly as financial protection is one of the tenets of universal health coverage now being promoted by the WHO as part of the post-2015 development agenda.[44]

In treated cases with uncontrolled seizures, 30.1% reported having seizures at least weekly and 65.4% at least monthly. Retrospective reporting of seizure frequency at up to two months has been shown to be consistent between patients and carers [45], and the high seizure frequencies among PWE in Hai point to a need to further optimise treatment for those who are taking AEDs. Conversely, 11.6% of cases who stated that they were taking treatment reported that they had been free of seizures for five years or more. This group of patients represents the challenge of advising on and supervising a safe withdrawal of treatment in this context. While it has been demonstrated in the UK that 59% of PWE who have been seizure-free for two years while taking AEDs will remain in remission following withdrawal of treatment, there are no comparable data from Africa and little published clinical experience. Encouragingly, in Ethiopia 20% of 64 patients who had stopped attending a nurse-led epilepsy clinic were found to be in remission off treatment.[39]

The majority of cases using AEDs (84.3%) did not report any side effects, and none complained of serious problems leading to withdrawal of treatment. This corresponds with other observational studies conducted in resource-poor settings, including SSA, which have consistently demonstrated the efficacy and tolerability of PB in routine clinical use.[15, 45,46] The Hai cohort is now under follow-up, allowing for prospective evaluation of treatment outcomes, including adherence, tolerability and efficacy.

Our study had several limitations. Due to limited resources, we were unable to collect objective data on distance from health facilities, the importance of which is well recognised.[12,25] Similarly we could not validate our estimate of the ETG through comparison of self-reported treatment with blood levels of AEDs, which has been shown to be meaningful.[12] Furthermore, we did not use any standardised measure of adherence, although this was not helpful when compared with measurement of AEDs in blood in the Kenyan study cited above. As our study was questionnaire-based, reporting and recall bias are likely to have occurred, and the influence on our findings of data missing at random is difficult to assess. To the best of our knowledge, however, this is the first community-based study of epilepsy in this population, and despite the acknowledged limitations represents a valuable baseline assessment of the experience of PWE in this part of Tanzania.

Conclusion

Despite the availability of effective and affordable drugs, at least two fifths of PWE in this rural area of Tanzania are not currently taking regular AED treatment. We have identified a combination of patient- and healthcare-related factors associated with failure to seek and default from medical treatment. Some of these are potentially modifiable through educational interventions targeting patients, healthcare workers and the community. Any interventions should, however, be informed by further detailed and nuanced characterisation of the various factors influencing treatment-seeking and delivery of care. A deeper understanding these issues will benefit PWE in the Hai DSS as well as elewhere in Tanzania, SSA and low-income countries in general.

Author declarations

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EH and RW conceived and designed the study. EH, JR, SC and AJ collected the data. Epilepsy diagnoses and classifications were made by EH, MJ and RGW. EH, WG and RW analysed and interpreted the data. RW, RJQM, EA and DM supervised the study. EH wrote the manuscript. All authors provided critical revision of intellectual content and approval for submission.

None of the authors has any competing interests to declare.

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

Tables and figures

	Previously sought medical treatment										
	Yes (N=253)		No (N=38)								
	n	(%)	n	(%)	Odds ratio (95% CI)						p-value
Demographic factors											
Age band											
15-24	91	(36.0)	12	(31.6)	1.0						
25-34	60	(23.7)	7	(18.4)	1.14	(	0.25	to	5.16	)	0.87
35-44	41	(16.2)	8	(21.1)	2.25	(	0.40	to	12.74	)	0.36
45-54	33	(13.0)	5	(13.2)	0.81	(	0.09	to	7.37	)	0.85
55+	16	(6.3)	4	(10.5)	0.56	(	0.06	to	4.79	)	0.59
Male sex (vs. Female)	132	(52.2)	23	(60.5)	0.97	(	0.33	to	2.81	)	0.95
Christian (vs. Muslim)	199	(78.7)	24	(63.2)	0.57	(	0.16	to	2.02	)	0.39
Missing values	8	(3.2)	1	(2.6)							
Chagga tribe (vs. Other)	194	(76.7)	26	(68.4)	1.26	(	0.31	to	5.13	)	0.75
Missing values	12	(4.7)	4	(10.5)							
Education											
None/incomplete primary	113	(44.7)	22	(57.9)	1.0						
Complete primary	103	(40.7)	8	(21.1)	0.20	(	0.04	to	0.97	)	0.05
Any secondary/tertiary	27	(10.7)	1	(2.6)	0.17	(	0.01	to	2.27	)	0.18
Missing values	10	(4.0)	7	(18.4)							
Literate (vs. Not literate)	126	(49.8)	15	(39.5)	1.23	(	0.27	to	5.51	)	0.79
Missing values	9	(3.6)	6	(15.8)							
Marital status											
Single (never married)	159	(62.8)	19	(50.0)	1.0						
Married/widowed	67	(26.5)	14	(36.8)	1.55	(	0.30	to	7.95	)	0.60
Divorced/separated	19	(7.5)	3	(7.9)	1.84	(	0.20	to	16.92	)	0.59
Missing values	8	(3.2)	2	(5.3)							
Main occupation											
Farming/herding	80	(31.6)	16	(42.1)	1.0						
Trade/skill/salaried	30	(11.9)	3	(7.9)	0.84	(	0.16	to	4.47	)	0.84
Other	81	(32.0)	7	(18.4)	0.31	(	0.06	to	1.50	)	0.15
Unable to work	58	(22.9)	11	(28.9)	0.81	(	0.14	to	4.62	)	0.81
Missing values	4	(1.6)	1	(2.6)							
Clinical factors											
Duration of epilepsy											
≤5 years	41	(16.2)	8	(21.1)	1.0						
6-10 years	33	(13.0)	8	(21.1)	1.96	(	0.24	to	16.22	)	0.53
>10 years	174	(68.8)	20	(52.6)	1.14	(	0.17	to	7.77	)	0.89
Missing values	5	(2.0)	2	(5.3)							
Focal-onset seizures (vs. Gen./undefined)	181	(71.5)	27	(71.1)	0.67	(	0.21	to	2.13	)	0.50
Seizure-related Injury (vs. No injuries)	90	(35.6)	12	(31.6)	0.50	(	0.15	to	1.67	)	0.26
Cognitive impairment (vs. No impairment)	75	(29.6)	13	(34.2)	0.98	(	0.18	to	5.18	)	0.98
Family history of epilepsy (vs. None)	44	(17.4)	7	(18.4)	1.29	(	0.38	to	4.36	)	0.68
Patient/healthcare-related factors											
Beliefs about cause of epilepsy											
Medical cause	45	(17.8)	5	(13.2)	1.0						
Supernatural cause	62	(24.5)	9	(23.7)	1.59	(	0.37	to	6.76	)	0.53
Doesn't know	110	(43.5)	10	(26.3)	0.93	(	0.25	to	3.48	)	0.92
Missing values	36	(14.2)	14	(36.8)							
Traditional treatment (vs. No trad. Rx)	112	(44.3)	21	(55.3)	2.81	(	0.92	to	8.59	)	0.07
Missing values	10	(4.0)	5	(13.2)							
Drinks alcohol (vs. Doesn't drink)	40	(15.8)	13	(34.2)	4.33	(	1.30	to	14.40	)	0.02

Table 1: Univariable associations with failure to seek medical treatment for epilepsy

	Self-reported current treatment				Odds Ratio (95% CI)					p-value
	Yes (N=173)		No (N=80)							
	n	(%)	n	(%)						
Demographic factors										
Age band										
15-24	63	(36.4)	28	(35.0)	1.00					
25-34	43	(24.9)	17	(21.3)	0.76	(0.23	to	2.55	)	0.66
35-44	27	(15.6)	14	(17.5)	0.94	(0.17	to	5.13	)	0.95
45-54	24	(13.9)	9	(11.3)	1.53	(0.28	to	8.38	)	0.62
55+	16	(9.2)	12	(15.0)	1.15	(0.24	to	5.48	)	0.86
Male sex (vs. Female)	82	(47.4)	50	(62.5)	3.70	(1.38	to	9.94	)	0.009
Christian (vs. Muslim)	138	(79.8)	61	(76.3)	0.49	(0.15	to	1.45	)	0.19
Missing values	5	(2.9)	3	(3.8)						
Chagga tribe (vs. Other)	136	(78.6)	58	(72.5)	0.80	(0.26	to	2.47	)	0.70
Missing values	6	(3.5)	6	(7.5)						
Education										
None/incomplete primary	73	(42.2)	40	(50.0)	1.00					
Complete primary	75	(43.4)	28	(35.0)	0.61	(0.19	to	2.01	)	0.42
Any secondary/tertiary	18	(10.4)	9	(11.3)	0.51	(0.08	to	3.10	)	0.46
Missing values	7	(4.0)	3	(3.8)						
Literate (vs. Not literate)	88	(50.9)	38	(47.5)	0.71	(0.21	to	2.44	)	0.59
Missing values	6	(3.5)	3	(3.8)						
Marital status										
Single/never married	112	(64.7)	47	(58.8)	1.00					
Married/widowed	41	(23.7)	26	(32.5)	1.67	(0.37	to	7.52	)	0.51
Divorced/separated	14	(8.1)	5	(6.3)	0.58	(0.07	to	5.18	)	0.63
Missing values	6	(3.5)	2	(2.5)						
Main occupation										
Farming/herding	55	(31.8)	25	(31.3)	1.00					
Trade/skill/salaried	22	(12.7)	8	(10.0)	0.40	(0.07	to	2.24	)	0.30
Other	56	(32.4)	25	(31.3)	2.52	(0.74	to	8.54	)	0.14
Unable to work	36	(20.8)	22	(27.5)	2.55	(0.62	to	10.49	)	0.20
Missing values	4	(2.3)	0	(0.0)						
Clinical factors										
Duration of epilepsy										
≤5 years	24	(13.9)	17	(21.3)	1.00					
6-10 years	20	(11.6)	13	(16.3)	0.76	(0.18	to	3.17	)	0.71
>10 years	126	(72.8)	48	(60.0)	0.27	(0.06	to	1.15	)	0.08
Missing values	3	(1.7)	2	(2.5)						
Focal-onset seizures (vs. Gen./undefined)	121	(69.9)	60	(75.0)	0.69	(0.24	to	1.96	)	0.49
Seizure-related injuries (vs. No injury)	61	(35.3)	29	(36.3)	3.50	(1.32	to	9.25	)	0.01
Cognitive impairment (vs. No impairment)	48	(27.7)	27	(33.8)	2.03	(0.65	to	6.31	)	0.22
Family history of epilepsy (vs. No history)	31	(17.9)	13	(16.3)	0.68	(0.20	to	2.26	)	0.53
Patient/healthcare-related factors										
1st presentation ≤1 year from onset (vs. >1 year)	63	(36.4)	33	(41.3)	1.15	(0.47	to	2.81	)	0.77
Missing values	16	(9.2)	12	(15.0)						
Previous diagnosis										
None/no recall	70	(40.5)	44	(55.0)	1.00					
Epilepsy/*kifafa*/*degedege*	78	(45.1)	19	(23.8)	0.24	(0.09	to	0.66	)	0.006
Other	23	(13.3)	16	(20.0)	2.11	(0.65	to	6.85	)	0.22
Missing values	2	(1.2)	1	(1.3)						
Beliefs about cause of epilepsy										
Medical cause	36	(20.8)	9	(11.3)	1.00					
Supernatural cause	42	(24.3)	20	(25.0)	9.10	(2.01	to	41.23	)	0.004
Doesn't know	78	(45.1)	32	(40.0)	7.52	(1.96	to	28.85	)	0.003
Missing values	17	(9.8)	19	(23.8)						
Traditional treatment (vs. No trad. Rx)	79	(45.7)	33	(41.3)	0.78	(0.31	to	1.97	)	0.60
Missing values	7	(4.0)	3	(3.8)						
Drinks alcohol (vs. Doesn't drink)	17	(9.8)	23	(28.7)	4.91	(1.36	to	17.64	)	0.02

Table 2: Univariable associations with default from treatment having previously presented

	Adj. OR	(95% CI)				p-value
Failure to present						
Demographic factors						
Completed primary education	0.33	(	0.11	to	0.96	) 0.04
Patient/healthcare-related factors						
Traditional healer/treatment	2.62	(	1.00	to	6.83	) 0.05
Drinks alcohol	4.20	(	1.63	to	10.82	) 0.003
Default from treatment						
Demographic factors						
Male sex	3.35	(	1.39	to	8.09	) 0.007
Clinical factors						
Duration of epilepsy > 10 years	0.28	(	0.09	to	0.90	) 0.03
Seizure-related injury	2.64	(	1.12	to	6.19	) 0.03
Patient/healthcare-related factors						
Prev. seizure diagnosis (*kifafa*/*degedege*/other)	0.25	(	0.09	to	0.65	) 0.004
Believes aetiology supernatural	5.44	(	1.48	to	19.94	) 0.01
No ideas/knowledge of aetiology	5.29	(	1.60	to	17.52	) 0.006
Drinks alcohol	3.93	(	1.29	to	12.01	) 0.02

Table 3: Multivariable models of factors associated with failure of PWE to seek treatment, and default from treatment in those who have previously presented

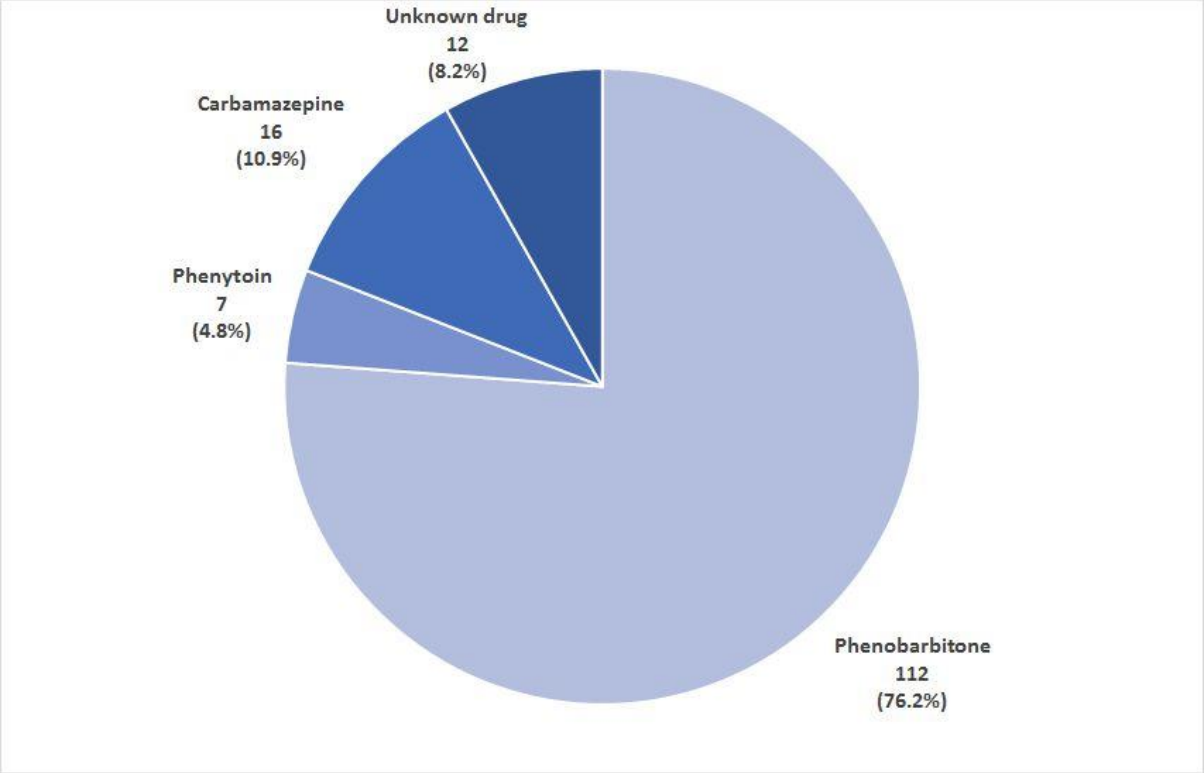

Figure 1: Pattern of AED monotherapy in adult PWE in the Hai DSS (n=147)

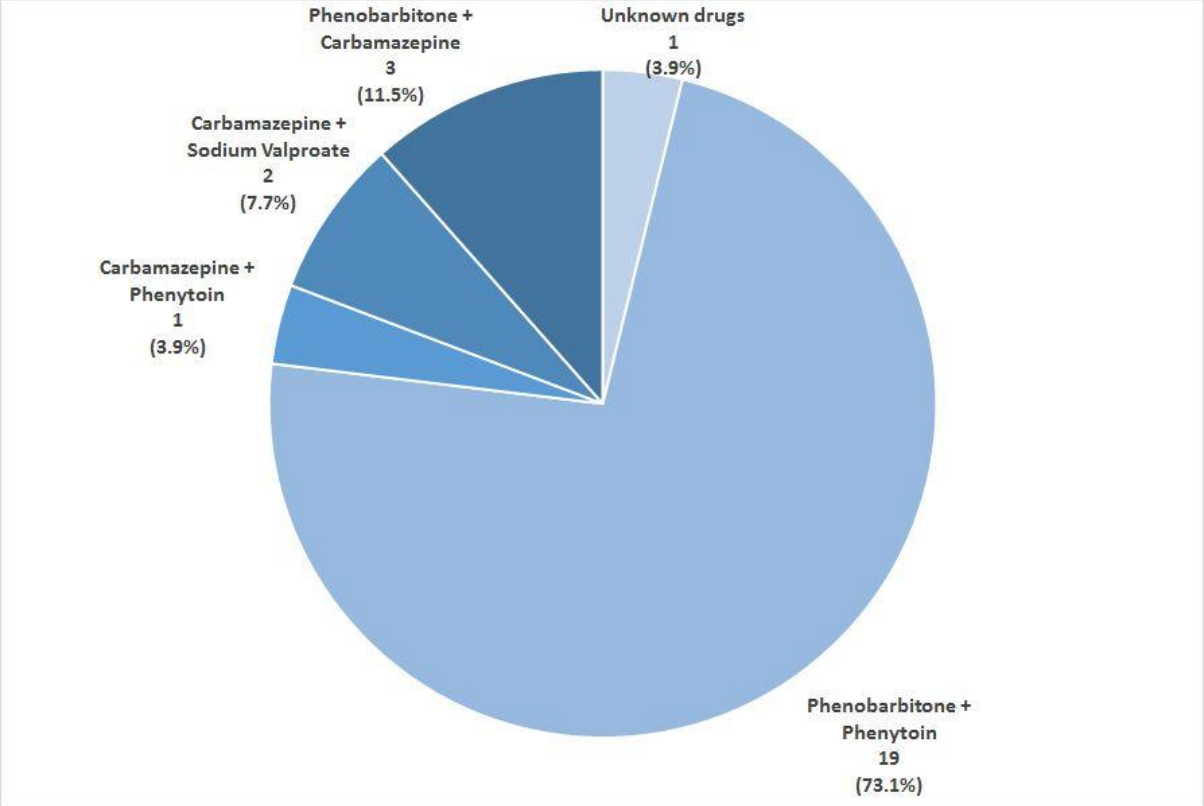

Figure 2: Pattern of AED dual therapy in adult PWE in the Hai DSS (n=26)

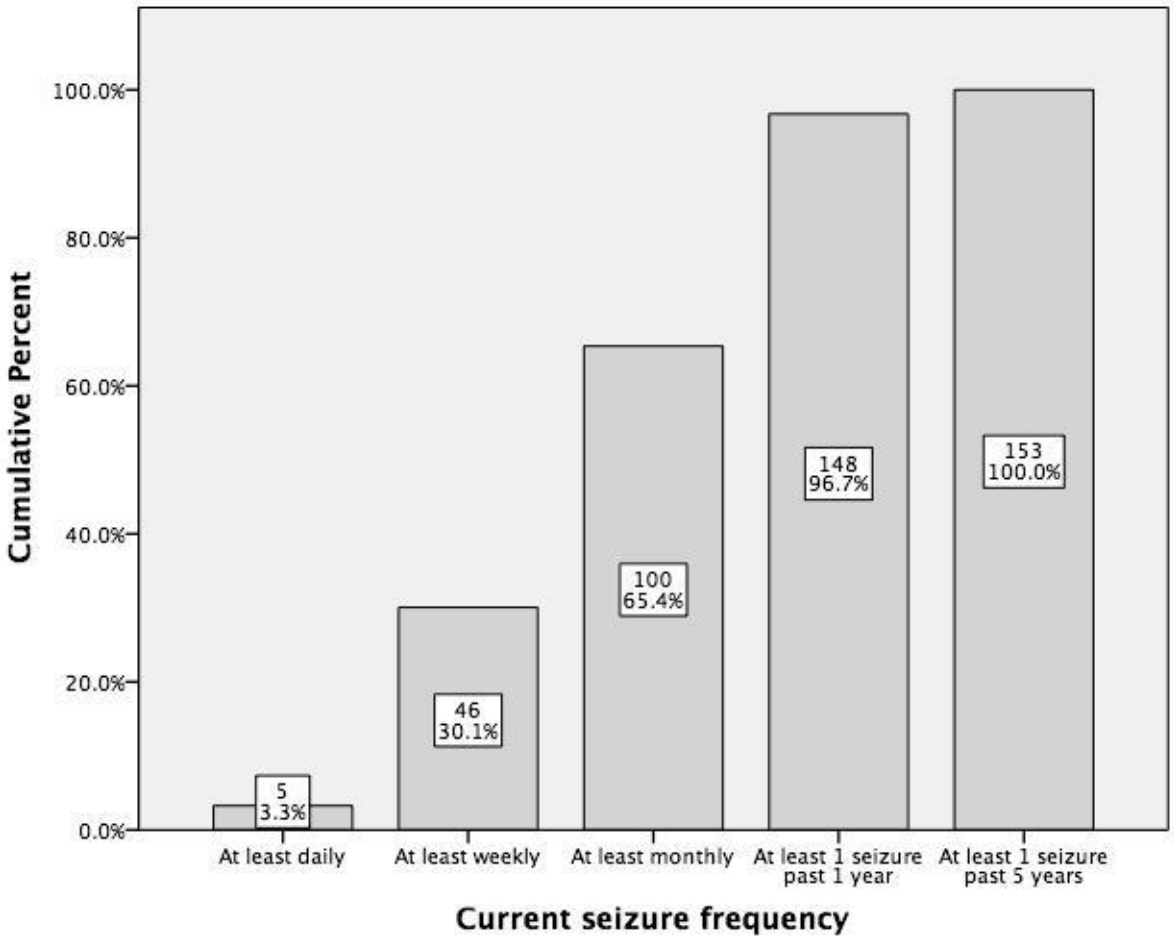

Figure 3: Cumulative seizure frequency in PWE with active seizures reporting to be taking AEDs (N=153)

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