Prevalence of all epilepsies in urban informal settlements in Nairobi, Kenya: a two-stage population-based study

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Summary

Background WHO estimates that more than 50 million people worldwide have epilepsy and 80% of cases are in low-income and middle-income countries. Most studies in Africa have focused on active convulsive epilepsy in rural areas, but there are few data in urban settings. We aimed to estimate the prevalence and spatial distribution of all epilepsies in two urban informal settlements in Nairobi, Kenya.

Methods We did a two-stage population-based cross-sectional study of residents in a demographic surveillance system covering two informal settlements in Nairobi, Kenya (Korogocho and Viwandani). Stage 1 screened all household members using a validated epilepsy screening questionnaire to detect possible cases. In stage 2, those identified with possible seizures and a proportion of those screening negative were invited to local clinics for clinical and neurological assessments by a neurologist. Seizures were classified following the International League Against Epilepsy recommendations. We adjusted for attrition between the two stages using multiple imputations and for sensitivity by dividing estimates by the sensitivity value of the screening tool. Complementary log–log regression was used to assess prevalence differences by participant socio-demographics.

Findings A total of 56 425 individuals were screened during stage 1 (between Sept 17 and Dec 23, 2021) during which 1126 were classified as potential epilepsy cases. A total of 873 were assessed by a neurologist in stage 2 (between April 12 and Aug 6, 2022) during which 528 were confirmed as epilepsy cases. 253 potential cases were not assessed by a neurologist due to attrition. 30 179 (53·5%) of the 56 425 individuals were male and 26 246 (46·5%) were female. The median age was 24 years (IQR 11–35). Attrition-adjusted and sensitivity-adjusted prevalence for all types of epilepsy was 11·9 cases per 1000 people (95% CI 11·0–12·8), convulsive epilepsy was 8·7 cases per 1000 people (8·0–9·6), and non-convulsive epilepsy was 3·2 cases per 1000 people (2·7–3·7). Overall prevalence was highest among separated or divorced individuals at 20·3 cases per 1000 people (95% CI 15·9–24·7), unemployed people at 18·8 cases per 1000 people (16·2–21·4), those with no formal education at 18·5 cases per 1000 people (16·3–20·7), and adolescents aged 13–18 years at 15·2 cases per 1000 people (12·0–18·5). The epilepsy diagnostic gap was 80%.

Interpretation Epilepsy is common in urban informal settlements of Nairobi, with large diagnostic gaps. Targeted interventions are needed to increase early epilepsy detection, particularly among vulnerable groups, to enable prompt treatment and prevention of adverse social consequences.

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Introduction

Epilepsy is among the most common neurological disorders, affecting more than 50 million people worldwide.[1] The prevalence of active epilepsy is higher in low-income and middle-income countries, and is estimated to be about 12·7 cases per 1000 people in rural areas and 5·9 cases per 1000 people in urban areas compared with a median prevalence of about 4·9 per 1000 people in high-income countries.[1,2] Most epilepsy studies in Africa have focused on convulsive epilepsies in rural populations.

There are few studies of epilepsy prevalence in low-resource urban settings in Africa. Three of the studies available include one in informal settlements of urban Enugu in Nigeria,[3] one in a peri-urban district of Dakar in Senegal,[4] and the most recent one from Dar es Salaam, Tanzania.[5] The studies in Enugu (Nigeria) and in Dakar (Senegal), have provided prevalence figures for active convulsive epilepsy. However, these studies excluded high-risk groups such as children. The survey in Tanzania used a one-stage, 9-item screening questionnaire without confirming the diagnosis of epilepsy.[5]

A systematic review found the point prevalence of active convulsive epilepsy higher in low-income and middle-income countries at about 6·7 cases per 1000 people than in high-income countries at 5·5 per 1000 people.[6] The median prevalence of lifetime epilepsy (cumulative incidence) is 15 cases per 1000 people in sub-Saharan

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For more on the **Epilepsy Pathway Innovation in Africa project** see https://epina.web.ox.ac.uk/

Research in context

Evidence before this study

We searched PubMed for articles published from Jan 1, 2000, to March 22, 2024, using the terms ("prevalence of epilepsy" OR "epilepsy prevalence" OR "prevalence of active convulsive epilepsy" OR "prevalence of non-convulsive epilepsy") AND ("low- and middle-income countries" OR "developing countries" OR "sub-Saharan Africa") AND ("urban"). We did not apply any language restrictions to the search. Overall, several studies on the prevalence of epilepsy have been conducted in rural areas. Furthermore, evidence has shown that non-convulsive epilepsy might constitute up to half of all epilepsies, but most studies have only focused on active convulsive epilepsy.

Added value of this study

Our study provides the most recent and robust evidence on the prevalence of all epilepsies in an urban informal settlement in an African country. We used a two-stage population-based (census) approach in the Nairobi Urban Health and Demographic Surveillance Systems (NUHDSS), which ensured that all residents in the NUHDSS were approached for screening. The HDSS comprises two large informal settlements in Nairobi (Korogocho and Viwandani). Our analysis further accounted for attrition between the first and second stages using multiple imputation methods and adjusted the estimates for sensitivity of the screening questionnaire. A trained neurology team assessed and confirmed the diagnosis of all possible cases rather than participants self-reporting or cases being captured only by the screening questionnaire. Our study further estimates the epilepsy diagnostic gap in an urban setting.

Implications of all the available evidence

In 2022, WHO published the Intersectoral Global Action Plan (IGAP) on epilepsy and other neurological disorders, outlining five strategic objectives, including strengthening the public health approach to epilepsy (strategic objective 5). One of the crucial global targets under strategic objective 5 of the IGAP is to increase epilepsy service coverage by 50% by 2031. The denominator to compute service coverage is the number of people with epilepsy (prevalence). Our study contributes to this by providing data on the prevalence of epilepsy in urban settings in an African country, which, together with findings from other studies, can be used to estimate the total number of people with epilepsy in the absence of a nationally representative survey on epilepsy. Furthermore, targeted interventions are needed in informal settlements for early detection of epilepsy and prompt treatment to prevent future adverse social and economic consequences. Studies to examine risk factors and causes of epilepsy are also needed.

Africa,[7] compared with 4–7 cases per 1000 people in high-income countries. A study in rural African Health and Demographic Surveillance Systems (HDSS) sites in South Africa, Kenya, Tanzania, Uganda, and Ghana showed an age-standardised prevalence of active convulsive epilepsy ranging from 7·0 to 14·8 cases per 1000 people.[8] Most studies have focused on active convulsive epilepsy, yet non-convulsive epilepsies can contribute to up to 50% of all epilepsy cases.[9,10]

In this study, we aimed to estimate the prevalence of epilepsy in two urban informal settlements of Nairobi using a two-stage approach. This involved household screening of all residents available in the Nairobi Urban HDSS (NUHDSS),[11] followed by a neurologist's assessment to confirm final diagnosis at a health-care facility. We also examined epilepsy prevalence differences across the participants' socio-demographic profiles.

Methods

Study design and participants

The study was conducted in two informal settlements (Korogocho and Viwandani), which form the NUHDSS. An urban informal settlement, as used in this study, also means an urban slum. Similar to other urban informal settlements in Kenya, Viwandani and Korogocho lack basic infrastructure, have poor sanitation, and are overcrowded. There is high unemployment in the area, poverty is rife, and the health infrastructure is inadequate. Viwandani has a very transient population, and Korogocho is more settled, with most residents living there since birth. Detailed information about the NUHDSS has previously been published.[11]

This is a population-based cross-sectional study (census) in the NUHDSS with two stages of screening and is part of the Epilepsy Pathway Innovation in Africa (EPInA) project. EPInA was set up to improve epilepsy treatment pathways, including prevention, diagnosis, treatment, and awareness in Africa. The EPInA project also involves prevalence surveys in Kenya, Tanzania, and Ghana.

In stage 1, trained field interviewers administered a standardised 14-item screening questionnaire[12] in English with Swahili translation to heads of households or adult representatives to identify people with symptoms of epilepsy. The first part of the questionnaire collected data on socio-demographic characteristics, followed by the seizure-specific questions. Socio-demographic characteristics included education level, date of birth, sex (male or female), marital status, and employment status for each household member. Ten questions were used to identify cases with possible active convulsive epilepsy, while the remaining four questions were used to identify those with possible active non-convulsive epilepsy. The questions used to detect non-convulsive seizures were designed to capture possible focal seizures without impaired awareness, focal seizures with impaired awareness, absence seizures, and drop attacks. Those who responded positively to any screening questions and

a proportion of those screening negative were invited to stage 2, which was decided according to availability of resources and past research on testing a scale.[13] If they agreed, they were referred to a health facility for full assessment and definitive diagnosis by a specialist neurologist.

The sensitivity of the screening instrument was conducted by matching 40 controls (those with no epilepsy) with 120 cases (confirmed epilepsy cases) using propensity score matching (ratio 1:3). A neurologist assessed all these cases. They were matched by age, sex, marital status, education, employment, and site. The computation of the sensitivity and specificity is as previously defined.[8]

The study was approved by the Scientific Ethics Review Unit at the Kenya Medical Research Institute (reference number, KEMRI/RES/7/3/1). All participants provided written informed consent.

Procedures

The clinical phase of the study involved a neurologist (TK) supported by two postgraduate candidates in neurology (QM and AM) taking a history to elicit the semiology. TK directly supervised QM and AM and was responsible for the final diagnosis. TK, QM, and AM reviewed all cases seen daily and agreed on the final diagnosis. Epilepsy was defined as having at least two unprovoked seizures more than 24 h apart,[14] and diagnosis was categorised as epilepsy, not epilepsy, or unknown. Those in whom the neurologist could not definitively determine if they had epilepsy or not, were referred for an electroencephalogram (EEG) to aid diagnosis. Seizures and epilepsies were classified using the 2017 Internation League Against Epilepsy (ILAE) classification.[14,15] A patient was diagnosed with generalised epilepsy if they presented with any of the examples of seizure types listed in the ILAE positional paper[14] including absence, myoclonic, atonic, tonic, and tonic-clonic seizures. A diagnosis of focal epilepsy was made if a patient had focal aware seizures, focal impaired awareness seizures, focal motor seizures, focal non-motor seizures, or focal to bilateral tonic-clonic seizures.[14,15] Confirmed cases detected by questions on convulsive seizures were classified as

	By site				By sex		
	All (n=56 425)	Korogocho (n=21 462)	Viwandani (n=34 963)	p value	Male (n=30 179)	Female (n=26 246)	p value
Sex	..	..	..	<0·0001	..	..	
Male	30 179 (53·5%)	10 834 (50·5%)	19 345 (55·3%)	..	..	..	..
Female	26 246 (46·5%)	10 628 (49·5%)	15 618 (44·7%)	..	..	..	..
Median age, years	24 (11–35)	22 (11–35)	25 (12–35)	<0·0001	26 (12–37)	23 (11–33)	<0·0001
Age groups	..	..	..	<0·0001	..	..	<0·0001
0–5	7580 (13·4%)	2940 (13·7%)	4640 (13·3%)	..	3868 (12·8%)	3712 (14·1%)	..
6–12	7582 (13·4%)	3416 (15·9%)	4166 (11·9%)	..	3821 (12·7%)	3761 (14·3%)	..
13–18	5631 (10·0%)	2817 (13·1%)	2814 (8·0%)	..	2755 (9·1%)	2876 (11·0%)	..
19–28	13 504 (23·9%)	4459 (20·8%)	9045 (25·9%)	..	6759 (22·4%)	6745 (25·7%)	..
29–49	17 915 (31·8%)	5773 (26·9%)	12 142 (34·7%)	..	10 303 (34·1%)	7612 (29·0%)	..
50 or older	4213 (7·5%)	2057 (9·6%)	2156 (6·2%)	..	2673 (8·9%)	1540 (5·9%)	..
Highest level of education*	..	..	..	<0·0001	..	..	<0·0001
Less than primary or no formal education	13 551/48 845 (27·7%)	7486/18 552 (40·4%)	6065/30 323 (20·0%)	..	6629/26 311 (25·2%)	6922/22 534 (30·7%)	..
Primary	18 163/48 845 (37·2%)	7297/18 552 (39·4%)	10 866/30 323 (35·8%)	..	9392/26 311 (35·7%)	8771/22 534 (38·9%)	..
Secondary	14 856/48 845 (30·4%)	3300/18 552 (17·8%)	11 556/30 323 (38·1%)	..	8911/26 311 (33·9%)	5945/22 534 (26·4%)	..
Post-secondary	2275/48 845 (4·7%)	439/18 552 (2·4%)	1836/30 323 (6·1%)	..	1379/26 311 (5·2%)	896/22 534 (4·0%)	..
Employment†	..	..	..	<0·0001	..	..	<0·0001
Not employed	11 119/37 385 (29·7%)	4619/13 142 (35·1%)	6500/24 243 (26·8%)	..	3490/20 605 (16·9%)	7629/16 780 (45·5%)	..
Employed full-time or part-time	8707/37 385 (23·3%)	821/13 142 (6·2%)	7886/24 243 (32·5%)	..	6515/20 605 (31·6%)	2192/16 780 (13·1%)	..
Self-employed	7234/37 385 (19·4%)	2430/13 142 (18·5%)	4804/24 243 (19·8%)	..	3639/20 605 (17·7%)	3595/16 780 (21·4%)	..
Informal employment	10 325/37 385 (27·6%)	5272/13 142 (40·1%)	5053/24 243 (20·8%)	..	6961/20 605 (33·8%)	3364/16 780 (20·0%)	..
Marital status†	..	..	..	<0·0001	..	..	<0·0001
Never married	11 173/37 385 (29·9%)	4429/13 142 (33·7%)	6744/24 243 (27·8%)	..	6601/20 605 (32·0%)	4572/16 780 (27·3%)	..
Married or cohabiting	22 196/37 385 (59·4%)	6586/13 142 (50·1%)	15 610 (64·4%)	..	13 103/20 605 (63·6%)	9093/16 780 (54·2%)	..
Separated, widowed, or divorced	4016/37 385(10·7%)	2127/13 142 (16·2%)	1889 (7·8%)	..	901/20 605 (4·4%)	3115/16 780 (18·6%)	..
Household size	4 (2–5)	4 (3–6)	3 (2–4)	<0·0001	..	..	..

Data are n (%), n/N (%), or median (IQR), unless otherwise specified. *Question only applicable to those aged 6 years or older. †Question only applicable to those aged 18 years or older.

Table 1: **Socio-demographic characteristics of study participants in Korogocho and Viwandani**

	Overall	Korogocho	Viwandani
Population	58 527	22 254	36 273
Total screened	56 425/58 527 (96·4%)	21 462/22 254 (96·4%)	34 963/36 273 (96·4%)
Possible epilepsy	1126/56 425 (2·0%)	349/21 462 (1·6%)	777/34 963 (2·2%)
Detected by convulsive epilepsy screening questions	682/1126 (60·6%)	297/349 (85·1%)	385/777 (49·5%)
Detected by only non-convulsive epilepsy screening questions	444/1126 (39·4)	52/349 (14·9%)	392/777 (50·5%)
Assessed by a neurologist	873/1126 (77·5%)	313/349 (89·7%)	560/777 (72·1%)
Diagnosed as positive			
All types of epilepsy	528/873 (60·5%)	239/313 (76·4%)	289/560 (51·6%)
Focal*	38/528 (7·2%)	11/239 (4·6%)	27/289 (9·3%)
Generalised*	306/528 (58·0%)	164/239 (68·6%)	142/289 (49·1%)
Combined generalised and focal*	105/528 (19·9%)	43/239 (18·0%)	62/289 (21·5%)
Unclassified*	79/528 (14·9%)	21/239 (8·8%)	58/289 (20·1%)
Convulsive or non-convulsive			
Convulsive epilepsy*	371/528 (70·3%)	202/239 (84·5)	169/289 (58·5%)
Non-convulsive epilepsy*	157/528 (29·7%)	37/239 (15·5%)	120/289 (41·5%)
Crude prevalence per 1000 people			
All types of epilepsy†	9·4 (8·6–10·2)	11·1 (9·7–12·6)	8·3 (7·4–9·3)
Focal*	0·7 (0·5–0·9)	0·5 (0·2–0·8)	0·8 (0·5–1·1)
Generalised*†	5·4 (4·8–6·1)	7·7 (6·5–8·8)	4·1 (3·4–4·8)
Combined generalised and focal*	1·9 (1·5–2·2)	2·0 (1·4–2·6)	1·9 (1·3–2·2)
Unclassified*†	1·4 (1·1–1·7)	1·0 (0·6–1·4)	1·7 (1·2–2·1)
Convulsive or non-convulsive			
Convulsive epilepsy alone*†	6·6 (5·6–7·6)	9·4 (7·6–11·3)	4·9 (3·8–5·9)
Non-convulsive epilepsy alone*†	2·8 (2·4–3·2)	1·7 (1·2–2·3)	3·4 (2·8–4·1)
Attrition-adjusted prevalence per 1000 people			
All types of epilepsy†	11·5 (10·7–12·4)	12·5 (11·4–14·0)	10·9 (9·8–12·0)
Focal*†	0·8 (0·5–1·0)	0·6 (0·3–0·8	1·0 (0·7–1·2)
Generalised*†	6·8 (5·9–7·3)	8·5 (7·3–9·7)	5·6 (4·7–6·4)
Combined generalised and focal*	2·2 (1·9–2·5)	2·2 (1·6–2·7)	2·3 (1·8–2·7)
Unclassified*†	1·7 (1·3–1·9)	1·2 (0·7–1·5)	2·0 (1·6–2·4)
Convulsive or non-convulsive			
Convulsive epilepsy*†	8·4 (7·8–9·3)	10·7 (9·3–12·0)	7·0 (6·1–8·1)
Non-convulsive epilepsy*†	3·1 (2·6–3·6)	1·8 (1·2–2·4)	3·9 (3·2–4·6)
Attrition-adjusted and sensitivity-adjusted prevalence per 1000 people			
All types of epilepsy	11·9 (11·0–12·8)	12·9 (11·8–14·4)	11·2 (10·1–12·4)
Focal*	0·8 (0·5–1·0)	0·6 (0·2–0·8)	0·9 (0·6–1·2)
Generalised*†	7·0 (6·1–7·5)	8·8 (7·5–10·0)	5·8 (4·8–6·6)
Combined generalised and focal*	2·3 (2·0–2·6)	2·3 (1·5–2·8)	2·4 (1·8–2·8)
Unclassified*†	1·8 (1·3–2·0)	1·2 (0·7–1·5)	2·1 (1·6–2·5)
Convulsive or non-convulsive			
Convulsive epilepsy*†	8·7 (8·0–9·6)	11·0 (9·6–12·4)	7·2 (6·3–8·4)
Non-convulsive epilepsy*†	3·2 (2·7–3·7)	1·9 (1·2–2·5)	4·0 (3·3–4·7)

(Table 2 continues on next page)

convulsive epilepsy. Confirmed cases that were detected by questions on non-convulsive seizures but were not classified as convulsive epilepsy, were generally classified as non-convulsive epilepsy.

Outcomes

The primary outcome of the study was prevalence of all epilepsies in two Nairobi informal settlements (Korogocho and Viwandani). This was estimated by the number of confirmed cases (stage 2) divided by the number of participants that were screened in stage 1. The secondary outcome of the study was an estimate of the epilepsy diagnostic gap. This was estimated as the proportion of participants confirmed as having epilepsy who did not previously know that they had epilepsy.

Statistical analysis

We estimated an unadjusted prevalence with a 95% CI by dividing the number with a positive diagnosis in the second stage by the number of cases screened in the first stage. Attrition was estimated as the proportion of individuals screened as probable cases in stage 1 who were not assessed in stage 2. Multiple imputation was used to adjust estimates for attrition between the two stages. Multiple imputation was based on the logit model with age, sex, education level, employment status, marital status, and participants' responses on the history of convulsion or epilepsy attacks included as the covariates. Detailed information on the multiple imputation model is outlined in appendix 1 (p 2). To compare the age-specific prevalence estimates, we used the age distribution proposed in a previous study in five African countries.[8] We used a complementary log–log (*cloglog*) regression to test for differences in prevalence by age, sex, site, education level, marital status, and employment. We report prevalence ratios with 95% CIs. p values less than 0·05 were considered significant. We used the *cloglog* model instead of the traditional logistic regression because it is preferred for rare outcomes.[16] Bivariate associations are examined using χ^2 test (categorical variables) or *t* test (continuous variables). Attrition-adjusted and sensitivity-adjusted prevalence data were obtained by dividing the attrition-adjusted prevalence by the sensitivity value. Data management and analysis were performed in Stata (version 17.1) and R version 4.2.3.

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

We screened 56 425 residents from 24 615 households between Sept 17 and Dec 23, 2021, and their socio-demographic characteristics are presented in table 1. The sensitivity for the screening questionnaire was 97%, and the specificity was 43% (appendix 1 p 5).

34 963 (61·9%) of the participants were from Viwandani, and 30 179 (53·5%) were male and 26 246 (46·5%) were female. The median age was 24 years (IQR 11–35), and slightly more than one-third had completed primary education. A third of Viwandani participants were in full-time or part-time employment compared to 6% from Korogocho. More than half of those surveyed were married or living with a partner. The median household size for Korogocho was 4 (IQR 3–6) compared with a median of 3 (2–4) for Viwandani. The median age for males was 26 years (IQR 12–37), and for females was 23 years (11–33). A higher proportion of females (31%) than males (25%) had no formal education. A higher proportion of females (45%) compared with males (17%) were not employed but a higher proportion of males (32%) than females (13%) were in full-time or part-time employment. About one in every five females (19%) compared with 4% of males were separated, or widowed, or divorced.

Of the 56 425 residents screened, 1126 were positive (stage 1) and deemed possible epilepsy cases, of whom 682 were screened positive by the items on convulsive epilepsy and 444 by items on non-convulsive epilepsy. In stage 2 (conducted between April 12 and Aug 6, 2022), 873 (77·5%) of the 1126 were evaluated by a neurologist, of whom 230 were classified as negative, 517 as positive, and 126 were not determined as a confirmed case. 100 of 126 undetermined cases underwent EEG recordings, and 11 tested positive (confirmed epilepsy). In total, 528 (60%) of 873 were diagnosed with epilepsy: 371 (70%) with convulsive epilepsy and 157 (29·7%) of 528 with non-convulsive epilepsy (table 2). Of the 528 confirmed cases, 239 were from Korogocho and 289 were from Viwandani (figure). Overall, of the 528 epilepsy cases, 38 (7%) were classified as focal epilepsy, 306 (58%) were classified as generalised epilepsy, and 105 (20%) were classified as generalised and focal epilepsy. There was insufficient information to classify epilepsy type in 79 (15%) participants.

Crude prevalence of all types of epilepsy was 9·4 cases per 1000 people (95% CI 8·6–10·2), convulsive epilepsy was 6·6 cases per 1000 people (5·6–7·6), and non-convulsive epilepsy was 2·8 cases per 1000 people (2·4–3·2; table 2). Crude prevalence for focal epilepsy alone was 0·7 cases per 1000 people (95% CI 0·5–0·9), generalised epilepsy was 5·4 cases per 1000 people (4·8–6·1), and combined focal and generalised epilepsy was 1·9 cases per 1000 people (1·5–2·2). Overall, the prevalence of all types of epilepsy adjusted for attrition was 11·5 cases per 1000 people (95% CI 10·7–12·4) and was 11·9 cases per 1000 people (11·0–12·8) when adjusted for attrition and sensitivity. Attrition-adjusted and sensitivity-adjusted prevalence of focal epilepsy was 0·8 cases per 1000 (95% CI 0·5–1·0), was 7·0 per 1000 (6·1–7·5) for generalised epilepsy and was 2·3 cases per 1000 (2·0–2·6) for combined generalised and focal epilepsy. Attrition-adjusted and sensitivity-adjusted prevalence of convulsive epilepsy was 8·7 cases per 1000 people (95% CI 8·0–9·6), and non-convulsive epilepsy was 3·2 cases per 1000 people (2·7–3·7). Overall, the prevalence was slightly higher in Korogocho than in Viwandani (p=0·0010) and varied by village (p<0·0001; appendix 1 p 6). Factors associated with the heterogeneity were not investigated in this study.

	Overall	Korogocho	Viwandani
(Continued from previous page)			
Diagnostic gap (n=528)†			
Previously knew their diagnosis*	108/528 (20·5%)	68/239 (28·5%)	40/289 (13·8%)
Did not previously know their diagnosis (diagnostic gap)*	420/528 (79·5%)	171/239 (71·5%)	249/289 (86·2%)
Diagnostic gap by type of epilepsy†			
Convulsive epilepsy	263/371 (70·9%)	134/202 (66·3%)	129/169 (76·3%)
Non-convulsive epilepsy	157/157 (100·0%)	37/37 (100·0%)	120/120 (100·0%)

Data are n/N (%) or cases per 1000 people (95% CI). Attrition-adjusted and sensitivity-adjusted prevalence was obtained by dividing the attrition-adjusted prevalence by the sensitivity value (0·97). *The denominator is the number of cases diagnosed as positive for all types of epilepsy. †Estimate is significantly different between the two sites at 5% significance level.

Table 2: **Prevalence of epilepsy in two informal settlements in Nairobi**

Of the 528 cases diagnosed with epilepsy, 420 (80% [95% CI 76·1–83·0]) had epilepsy diagnosed for the first time (a diagnostic gap of about 80%). None of those who had non-convulsive epilepsy were previously diagnosed, and the convulsive epilepsy diagnostic gap was 71%.

Epilepsy prevalence and prevalence ratios disaggregated by the socio-demographic characteristics are presented in table 3. Prevalence among those aged 6–49 years was about twice as high as for those aged 0–5 years and those older than 50 years. Prevalence was highest among those aged 13–18 years (15·2 cases per 1000 people [95% CI 12·0–18·5]) and lowest among those younger than 5 years (6·8 cases per 1000 people [4·9–8·7]). Prevalence was 5·2 times higher among those with no formal education than in those with secondary education. For those who had only completed primary education, the prevalence was 2·6 times higher than in individuals who had completed secondary school. Prevalence was 2·2 times higher among those who were separated or divorced and 1·5 times higher among those who had never married than in those who married. Prevalence was 3·3 times higher among the unemployed than those in full-time or part-time employment. The difference in prevalence between the unemployed and those in full-time or part-time work was more pronounced in Viwandani than in Korogocho (appendix 1 p 5).

Discussion

Our findings show a high prevalence of epilepsy in two urban informal settlements in Nairobi, with non-convulsive epilepsy contributing to about one-third of observed cases. Eight people in every ten had not been

See Online for appendix 1

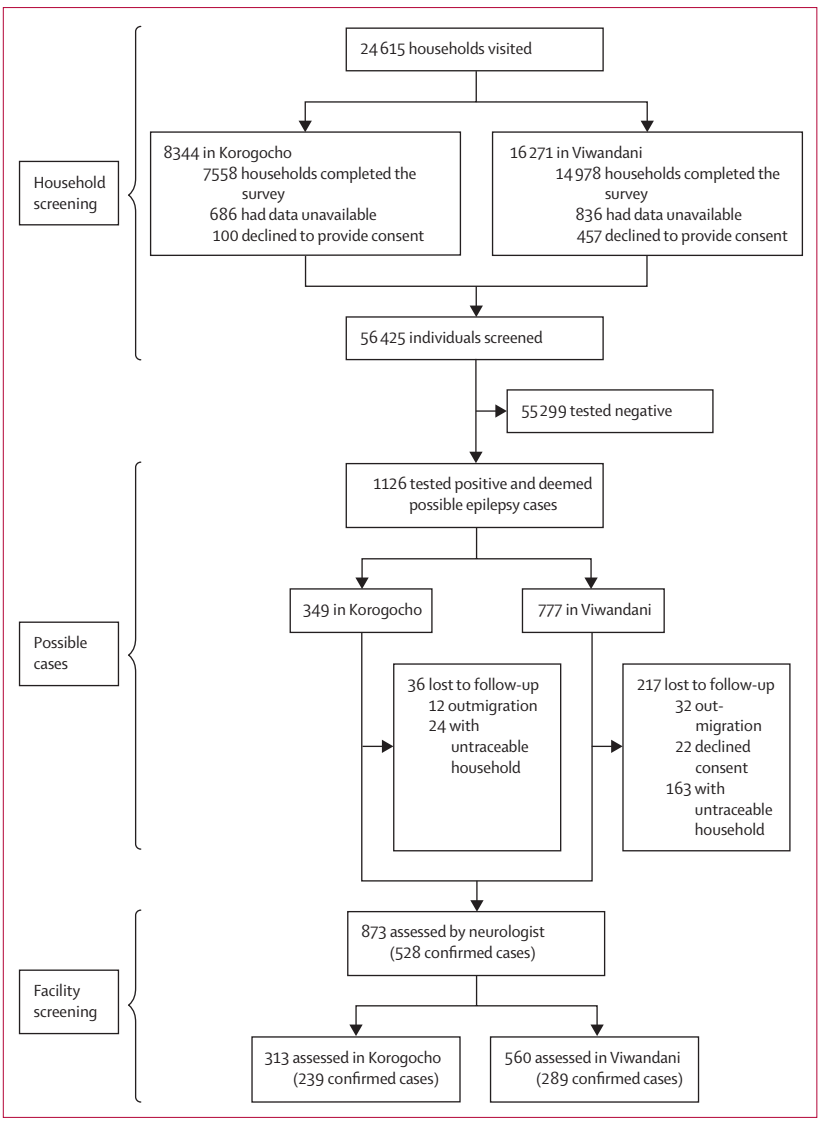

Figure: **Study profile**
Flow diagram of epilepsy screening from the Health and Demographic Surveillance Systems (stage 1) and diagnosis (stage 2).

	Prevalence per 1000 people (95% CI)	Prevalence ratio (95% CI)	p value
Age, years			
0–5	6·8 (4·9–8·7)	1 (ref)	..
6–12	12·7 (10·1–15·2)	1·8 (1·3–2·6)	<0·0001
13–18	15·2 (12·0–18·5)	2·2 (1·6–3·1)	<0·0001
19–28	13·1 (11·1–15·1)	2·0 (1·4–2·7)	<0·0001
29–49	12·4 (10·8–14·1)	1·9 (1·4–2·5)	<0·0001
50 or older	9·1 (6·2–12·0)	1·3 (0·9–2·0)	0·20
Sex			
Male	11·5 (10·3–12·8)	1 (ref)	..
Female	12·3 (10·9–13·6)	1·1 (0·9–1·2)	0·54
Marital status*			
Married or living with a partner	9·6 (8·2–10·8)	1 (ref)	..
Never married	15·9 (13·4–18·2)	1·5 (1·2–2·0)	<0·0001
Separated or divorced	20·3 (15·9–24·7)	2·2 (1·7–2·9)	<0·0001
Employment*			
Employed full-time or part-time	6·2 (4·5–7·8)	1 (ref)	..
Not employed	18·8 (16·2–21·4)	3·3 (2·3–4·2)	<0·0001
Self-employed	11·6 (9·2–14·2)	2·0 (1·4–2·8)	<0·0001
Informal employment	12·2 (10·0–14·3)	2·0 (1·4–2·8)	<0·0001
Education*			
Secondary	5·9 (4·8–6·9)	1 (ref)	..
Post-secondary	10·0 (5·8–14·1)	1·5 (0·9–2·4)	0·13
Primary	14·1 (12·4–15·9)	2·6 (2·0–3·4)	<0·0001
Less than primary or no education	18·5 (16·3–20·7)	5·2 (3·9–7·1)	<0·0001
Site			
Viwandani	11·2 (10·1–12·4)	1 (ref)	..
Korogocho	12·9 (11·3–14·4)	1·2 (1·0–1·4)	0·082

All estimates are adjusted for attrition and sensitivity of the screening questionnaire. *Results adjusted for age, sex, and site.

Table 3: **Prevalence of epilepsy disaggregated by the socio-demographic characteristics**

diagnosed with epilepsy before, suggesting a wide diagnostic gap for epilepsy in these settings. The gap was more pronounced among those with non-convulsive epilepsy. Treatment gaps, reported as high as 90% in parts of Africa,[17] mainly result from the diagnostic gap, as a diagnosis is usually the entry point for starting medication. The wide gap could be due to inadequate knowledge, lack of epilepsy awareness, and limited capacity among and shortage of primary health-care providers to diagnose epilepsy, especially non-convulsive epilepsy. Other studies under the EPInA programme have tested mobile-based diagnostic tools to help primary health-care providers accurately diagnose active convulsive epilepsy.[18]

There were differences in the diagnostic gap between the two informal settlements. The gap was higher in Viwandani than Korogocho. This could be explained by the demographic differences between the two sites. Korogocho has a more settled population, with most residents living there since birth. Viwandani, conversely, consists of a younger and more transient population, most of whom are casual workers in industries in the neighbouring Nairobi industrial area.

Our overall prevalence is about half of the latest prevalence estimate of all types of active epilepsies reported in Kilifi (rural), Kenya in 2021.[9] We did not find a previous study on the incidence of epilepsy in Nairobi. However, we hypothesise that the difference might be explained by the high incidence of symptomatic epilepsy in the Kilifi region. Our prevalence estimate of active convulsive epilepsy is slightly higher than that reported in Kilifi in 2013,[8] but the distribution of prevalence by age is similar to that reported in Kilifi.

Compared with findings from other urban settings in Africa, the prevalence of epilepsy in Nairobi is twice as high as that reported in a metropolitan area of Enugu in Nigeria (6·0 cases per 1000 people)[3] and slightly lower than what was reported from a study in a Senegalese peri-urban district (14·2 cases per 1000 people).[4] The Nigerian study excluded children, a group in which epilepsy is common. When we compare similar age groups between the Nigerian study and ours, our prevalence estimate was still higher.[3] This is probably because we assessed all types of epilepsy by adding specific questions to detect non-convulsive epilepsy, which might have been missed by other studies that focused only on active convulsive epilepsy. The study in urban Dar es Salaam[5] used a methodological approach of sampling with only one stage of screening and no confirmatory stage by a neurologist, and reported a slightly higher prevalence.

Compared with other rural sites outside Kenya, our overall prevalence estimate of active convulsive epilepsy is within the range in four rural HDSS sites in 2013, which reported an adjusted prevalence ranging from 7·0 cases to 14·8 cases per 1000 people.[8] This prevalence range is higher than that reported in rural Zambia in 2004.[19] Those studies[8] implemented a similar methodology to ours but were based in rural settings and only focused on active convulsive epilepsy,[8] but our study screened for all seizure types.

Our findings show that epilepsy was more common among those separated or divorced, those with no formal education, and those not employed. These could plausibly be consequences of epilepsy rather than risk factors. It has previously been reported that older people with health problems are more likely to leave urban areas,[20] which might explain the lower prevalence among the older population. One limitation is that being a cross-sectional study, most of these findings (apart from age-related findings) might result from stigma-related reverse causality. Epilepsy might have led to separation or divorce, but we can only speculate as we did not assess the onset of epilepsy or the timing of marriage. Children with epilepsy might not have attended a school or might have dropped out of school, potentially owing to cognitive impairment and having to miss classes due to seizures or stigmatisation. Employers are less likely to hire people with epilepsy, as shown in a previous study.[21] These findings are also consistent with those from a recent systematic review that found that the prevalence of epilepsy was correlated with low socio-economic status,[22] age, employment status, and education level.[6,23] These findings highlight the psychosocial challenges of those with epilepsy, which can be worse if undiagnosed and untreated.

Our study has strengths. A neurology team confirmed the diagnosis (gold-standard) rather than patients self-reporting a diagnosis or one being identified only at screening. In our analysis, we accounted for attrition between the two stages using multiple imputations and adjusted estimates for the sensitivity of the screening questionnaire. This gives confidence in the robustness of the estimates reported. The cases were detected using screening tools with a high sensitivity, thus enabling the detection of nearly all types of epilepsy. We incorporated four questions in the questionnaire to detect non-convulsive epilepsy. Difficulty in detecting non-convulsive epilepsy in epidemiological studies is documented,[9,10] but our findings suggest that it is possible to detect these cases reliably. Another strength is that we used a population-based approach, which ensured that residents were all approached for screening.

However, there were limitations. Between stage 1 and stage 2, there was a high attrition of almost a quarter. This was accounted for using multiple imputations used in previous studies.[2,9] More than half of the detected cases were classified as generalised, but some, if not many, could have focal to bilateral tonic-clonic seizures (secondarily generalised). EEG, which could have detected more focal epilepsies, was only used selectively in those in whom there was a diagnostic challenge. The specificity of the screening questionnaire was low. However, this did not affect our prevalence estimates because the interest was in detecting all true positives, which was addressed by accounting for the tool's sensitivity. There was a high number of unclassified seizures. The screening tool for non-convulsive epilepsy was validated alongside convulsive epilepsy. We recommend further work to develop more robust validated tools for screening for non-convulsive seizures. Two trainee neurologists supported the senior neurologist on the team. Although this could be a potential limitation, the senior neurologist, as the gold-standard, was responsible for the final diagnosis. Future work to examine risk factors for epilepsy in urban settings is needed. This study showed differences between the two informal settlements but did not collect sufficient data to determine what could explain the difference. Future work might consider qualitative data to explore factors associated with the demographic and epilepsy-type heterogeneity observed between the two sites.

In conclusion, epilepsy is common in urban informal settlements of Nairobi, although estimates are lower than those of rural settings. We found a higher prevalence among those who were separated or divorced, with no formal education, and unemployed. A sizeable diagnostic gap was observed, with four-fifths not receiving a diagnosis before the survey and thus not on appropriate antiseizure medication. The diagnostic gap was 100% among those with non-convulsive epilepsy. The high diagnostic gap, especially for non-convulsive epilepsy, indicates that there is urgent work needed to build the capacity of health-care workers and create awareness among the public on the presentation of different types of epilepsy. Targeted interventions are needed in informal settlements for early detection of epilepsy and prompt treatment to prevent future adverse social and economic consequences. Studies to examine risk factors and causes of epilepsy are also required.

EPInA Study Group
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Contributors
DMM contributed to the methodology, conceptualisation, and data curation; conducted the formal analysis; and drafted the manuscript. DMM, DTK, and POO accessed and verified the data. DTK, ICK, GOM, SI, JWS, and CRN provided supervision, contributed to the conceptualisation and methodology of the study, guided the analysis, and reviewed the manuscript. POO, DMM, and JWK supervised data collection, conducted data curation, and reviewed the manuscript. FMW, JWK, SI, SMK, and GDJ reviewed and edited the manuscript. TK was the neurologist supported by QM and AM. CRN, DTK, SMK, JWS, AS, and GA contributed to funding acquisition, supervision, and project oversight, and critically reviewed the manuscript. CRN was the lead investigator for the Epilepsy Pathway Innovation in Africa (EPInA) study, and GA was the principal investigator at the Nairobi site. All authors read and approved the final version of the manuscript. CRN, DTK, and GA are the guarantors. All authors are members of the EPInA study that generated the data used, confirm they had access to all the data in the study, and accept responsibility for the decision to submit for publication.

Equitable partnership declaration
The authors of this paper have submitted an equitable partnership declaration (appendix 2). This statement allows researchers to describe how their work engages with researchers, communities, and environments in the countries of study. This statement is part of *The Lancet Global Health's* broader goal to decolonise global health.

See Online for appendix 2

Declaration of interests
We declare no competing interests.

Data sharing
We welcome collaborations. The data used in this study are part of the EPInA Project, which is under way in Kenya, Tanzania, and Ghana. The data collected for this study, including data collection tools and study protocol, will be made available at the end of the survey upon reasonable request to the EPInA lead principal investigator, Charles R Newton, and the Nairobi site's principal investigator, Gershim Asiki.

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