


## RESEARCH ARTICLE

# Very high epilepsy prevalence in rural Southern Rwanda: The underestimated burden of epilepsy in sub-Saharan Africa

Ieme Garrez<sup>1</sup>  | Dirk E. Teuwen<sup>1</sup> | Fidèle Sebera<sup>2,3</sup> | Sylvestre Mutungirehe<sup>2</sup> | Arlene Ndayisenga<sup>4</sup> | Delphine Kajeneza<sup>3</sup> | Georgette Umuhoza<sup>2</sup> | Jeannine Kayirangwa<sup>5</sup> | Uta E. Düll<sup>6</sup> | Peter Dedeken<sup>1,7</sup> | Paul A. J. M. Boon<sup>1</sup>

<sup>1</sup>Department of Neurology, Ghent University Hospital, Ghent, Belgium

<sup>2</sup>Department of Neurology, Ndera Neuro-Psychiatric Teaching Hospital, Kigali, Rwanda

<sup>3</sup>Centre Hospitalier Universitaire Kigali, Kigali, Rwanda

<sup>4</sup>King Faisal Hospital, Kigali, Rwanda

<sup>5</sup>Ruhengeri Referral Hospital, Musanze, Rwanda

<sup>6</sup>Medicalized Health Center, Gikonko, Rwanda

<sup>7</sup>Heilig Hart Ziekenhuis, Lier, Belgium

## Correspondence

Ieme Garrez, Department of Neurology, Ghent University Hospital, Ghent, Belgium.  
Email: [ieme.garrez@ugent.be](mailto:ieme.garrez@ugent.be)

## Funding information

Fracarita Belgium and VLIR UOS; Fund for Scientific Research Flanders, Grant/Award Number: FWO—11K8722N

## Abstract

**Objectives:** Up to 85% of people living with epilepsy (PwE) reside in low-and middle-income countries. In sub-Saharan Africa, the lifetime prevalence of epilepsy is 16 per 1000 persons. In Northern rural Rwanda, a 47.7 per 1000 prevalence has been reported. As variations in prevalence across geographical areas have been observed, we studied the prevalence in Southern rural Rwanda using the same robust methodology as applied in the North.

**Methods:** We conducted a three-stage, cross-sectional, door-to-door survey in two rural villages in Southern Rwanda from June 2022 to April 2023. First, trained enumerators administered the validated Limoges questionnaire for epilepsy screening. Second, neurologists examined the persons who had screened positively to confirm the epilepsy diagnosis. Third, cases with an inconclusive assessment were separately reexamined by two neurologists to reevaluate the diagnosis.

**Results:** Enumerators screened 1745 persons (54.4% female, mean age:  $24 \pm 19.3$  years), of whom 304 (17.4%) screened positive. Epilepsy diagnosis was confirmed in 133 (52.6% female, mean age:  $30 \pm 18.2$  years) and active epilepsy in 130 persons. Lifetime epilepsy prevalence was 76.2 per 1000 (95% CI: 64.2–89.7‰). The highest age-specific rate occurred in the 29–49 age group. No gender-specific differences were noted. In 22.6% of the PwE, only non-convulsive seizures occurred. The treatment gap was 92.2%, including a diagnosis gap of 79.4%.

**Conclusion:** We demonstrated a very high epilepsy prevalence in Southern rural Rwanda, with over 20% of cases having only non-convulsive seizures, which are often underdiagnosed in rural Africa. In line with previous Rwandan reports, we reiterate the high burden of the disease in the country. Geographic variation in prevalence throughout Africa may result from differences in risk and aetiological factors. Case-control studies are underway to understand such differences and propose adapted health policies for epilepsy prevention.

## KEYWORDS

door-to-door, epilepsy, prevalence, Rwanda

## INTRODUCTION

Epilepsy is characterised by recurrent seizures with neurological, cognitive, psychological and social impact [1].

It is one of the most common neurological disorders affecting 70 million people worldwide, of whom 85% live in low- and middle-income countries (LMICs) [2]. In comparison to the estimated prevalence of five per 1000 people in high-income countries [3], the epilepsy prevalence in LMICs is two to three times higher [2]. The prevalence of active

**Sustainable Development Goal:** Good Health and Wellbeing; Reduced Inequalities

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Tropical Medicine & International Health* Published by John Wiley & Sons Ltd.

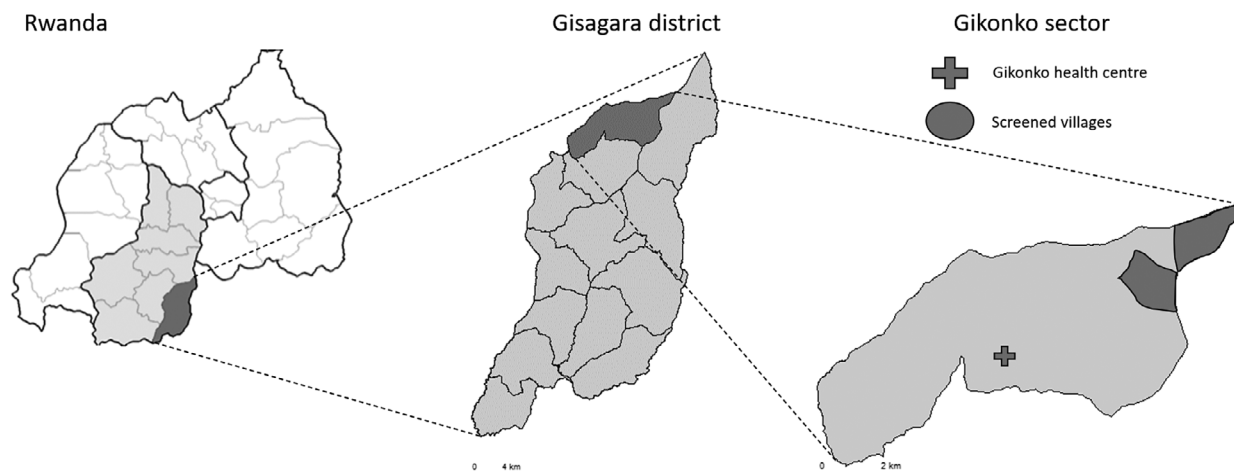


FIGURE 1 Study area.

and lifetime epilepsy in sub-Saharan Africa (SSA) has been estimated at 9 and 16 per 1000 people respectively, with numbers twice as high in rural as opposed to urban areas [4]. An even higher prevalence has been reported in Rwanda. A mental health survey from 2022 reported an epilepsy prevalence of 29 per 1000 [5]. A nationwide epilepsy survey with a clustered approach from 2005 reported a prevalence of 49 per 1000 people [6]. Another door-to-door epilepsy survey conducted in Northern rural Rwanda in 2017 observed a prevalence of 47.7 per 1000 [7].

Epidemiological studies on epilepsy in SSA often reveal a wide variation in prevalence, ranging from 7.4 per 1000 people estimated for the Eastern region of SSA to 30.2 per 1000 for the Central region. This variation is not only observed between but also within countries [4]. Besides a methodological component to this heterogeneity including differences in survey methods used, the nature of the epilepsy studied (lifetime or active), or definitions of active epilepsy applied, variability in prevalence across geographical areas may suggest clustering of people living with epilepsy (PwE). Geographical differences in the distribution of various risk or aetiological factors such as infectious diseases, traumatic brain injuries and genetic factors, may account for this clustering [4, 8]. As a variation in prevalence across geographical areas might apply, we studied the epilepsy prevalence in the topographically distinct Southern rural region of Rwanda using a similar two-stage methodology as applied in the North and including an additional case ascertainment stage for inconclusive cases [7]. In addition, we assessed the diagnosis and treatment gap in the region.

## METHODS

### Study area

We conducted a prospective, cross-sectional, door-to-door study from June 2022 to April 2023, to survey the entire

population of two neighbouring villages in the Gikonko sector, Gisagara district, Southern province of Rwanda (Figure 1). We selected the villages based on their rural character, total population, absence of previous epilepsy awareness campaigns and availability of known collaborators in the area. The villages are located 18 km from a paved road and 120 km from the capital city. The nearest district hospital is at 9 km walking distance, a primary health centre at 8 km and a secondary school at 7 km.

Gisagara ranks as the second poorest district in Rwanda [9]. Literacy among adults is low, subsistence agriculture is the main income source. According to the 2022 housing census, the population is relatively young, with a mean and median age of 24.6 and 19 years (y) respectively. The district counts 397,051 inhabitants of whom 28,772 (52.1% female) live in the Gikonko sector [10].

### Survey preparation

Meetings were held with the Administrative Authority of the Gikonko sector, the responsible and the staff of the nearest health centre, the elders of the villages and the community health workers (CHWs) of the villages. The survey was authorised and CHWs, who are familiar with all villagers, were allowed to accompany enumerators to ensure screening completeness for each household [11]. The Administrative Authority provided the 2021 census data as a reference. CHWs provided recent data on the number of households and family members.

Enumerators received a one-day epilepsy training from a Rwandan neurologist with 10 years of experience in epilepsy (author: SM), and a resident-neurologist of Ghent University, Belgium (author: IG). Subsequently, enumerators were trained on the administration of the Limoges questionnaire, a validated questionnaire to screen for epilepsy in (sub)tropical areas developed by the Institute of Epidemiology and Tropical Neurology of Limoges, the Pan African Association of Neurological Sciences and the International League Against Epilepsy [12, 13].

The questionnaire was validated in Mauritania with a sensitivity and specificity of 95.1% and 65.6%, respectively [14], and has been translated and adapted to the Rwandan indigenous language and sociocultural context [6]. Questions were captured on the Research Electronic Data Capture (REDCap) mobile application which allows offline data collection and is connected to a secure, web-based database once online [15, 16].

## Survey process

The survey was conducted in three stages.

First, enumerators screened all individuals of households with a permanent residence in the selected villages during door-to-door visits using five screening questions (Table S1). The screening was supervised by the principal investigator (author: IG) and a Rwandan research assistant with experience in epilepsy research (author: GU). Household members were explained the survey's purpose and possible benefits/risks. Caregivers responded for minors or mentally ill persons. CHWs and enumerators planned a return visit if a family member was absent. If not at home during the return visit, the member was considered not screened.

Second, persons who answered positively to one or more screening questions were referred to a team of 4 Rwandan study neurologists (authors: FS, SM, AN, DK) for medical history taking including an in-depth description of all possible seizure types to confirm an epilepsy diagnosis if applicable.

Third, two neurologists (authors: IG, PD) reviewed case notes to confirm epilepsy diagnoses assigned by the study neurologists. In case of doubt, two study neurologists (authors: FS, SM) returned to the villages to separately retake medical history in inconclusive cases to reevaluate the diagnosis. In case of discrepancies between the neurologists, a consensus meeting among the two study neurologists provided a decision on diagnosis.

## Definitions

Epilepsy was defined as  $\geq 2$  unprovoked seizures occurring at least 24 h apart [17]. Lifetime epilepsy considered people who had epilepsy at any point in their life up to the survey. Active epilepsy considered PwE with at least one seizure in the previous 5 years or who were currently on antiseizure medication (ASM) [18]. Active epilepsy defined by a 1-year cut-off was additionally reported.

The treatment gap was defined as the proportion of people with active epilepsy, based on a 5-year cut-off, who were not adequately treated at the time of the survey. Adequate treatment included ongoing use of ASM regardless of the type or dose of ASM in relation to seizure classification.

The diagnosis gap was defined as the proportion of PwE who had never been diagnosed before the screening by a healthcare professional such as a physician, nurse or CHW, or a traditional healer.

## Statistical analysis

Statistical analyses were performed in RStudio (Version 2022.12.0–353, R Foundation, Inc.). The crude, unadjusted epilepsy prevalence was calculated as the number of epilepsy cases confirmed in stage III divided by the population screened in stage I, expressed per 1000 persons. Unadjusted prevalence and exact binomial 95% confidence intervals (CI) were calculated overall and by age and gender. Prevalence was adjusted by dividing the crude prevalence by the sensitivity of the screening questionnaire (0.951) [14, 19, 20]. As non-response between stages ought to have been low, imputation was not performed. Crude prevalence was age-standardised using the Rwandan standard population of 2022 [10], the United States standard population of 2000 [21] and the World Health Organisation world standard population of 2000–2025 [22].

Associations between demographics, prevalence and epilepsy characteristics were explored using Pearson's Chi-squared test, Fisher's exact test or Wilcoxon non-parametric rank-sum test. For post-hoc group comparisons, adjusted standardised residuals were calculated. According to Agresti, "an adjusted standardized residual having an absolute value that exceeds about 2 when there are few cells or about 3 when there are many cells indicates lack of fit of  $H_0$  in that cell" [23]. If the residual is positive and large, the observed count in that cell is larger than expected if the variables were independent, if it is negative and small, the observed count is smaller than expected. A  $p$ -value of  $<0.05$  was considered statistically significant. For multiple comparisons, Bonferroni correction was applied.

## Ethics

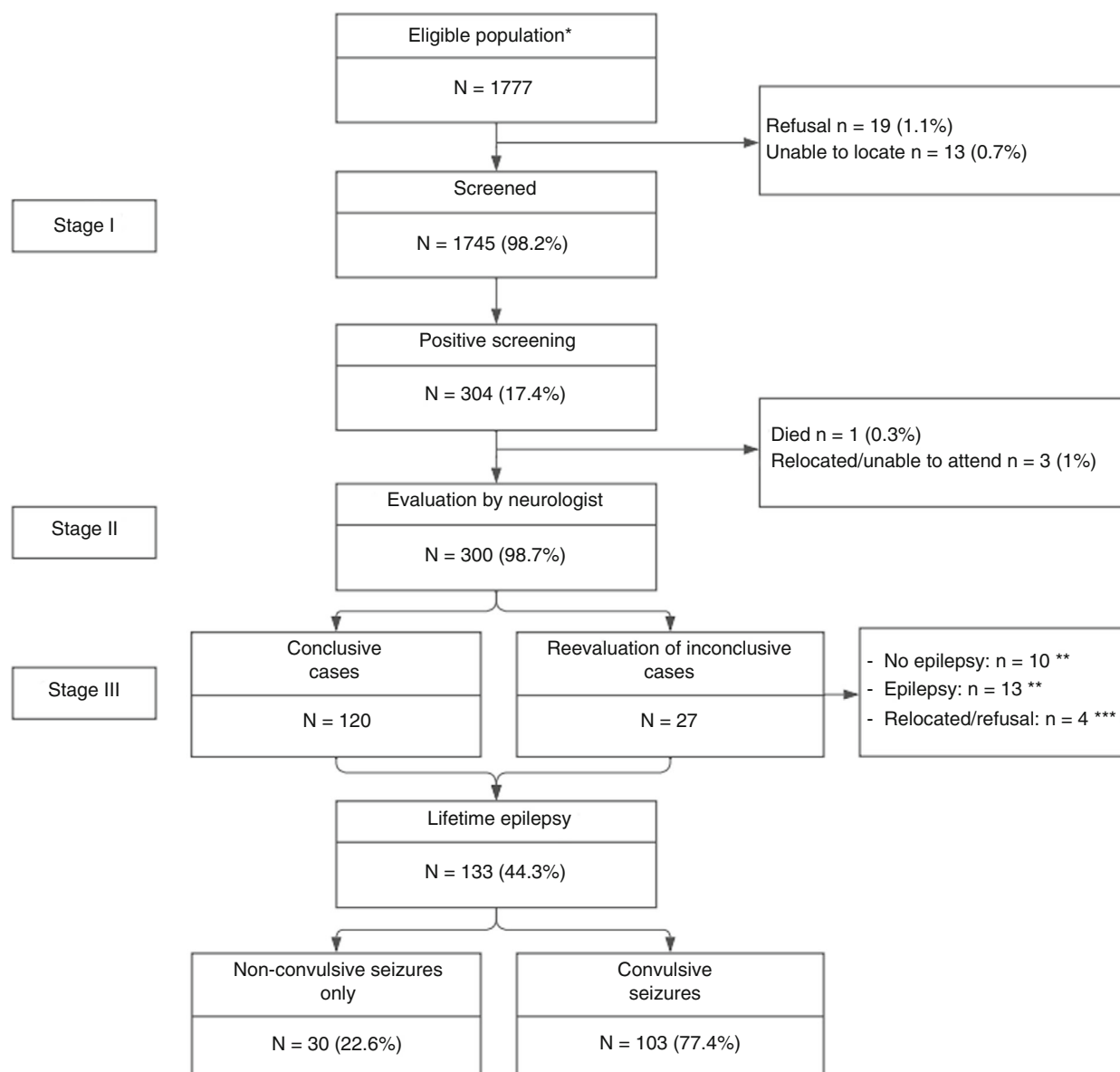
The Rwandan National Ethical Committee (No.27/RNEC/2022) and the Ethical Committee of Ghent University Hospital, Belgium (ONZ-2022-0403) approved the study protocol.

All participants gave their verbal informed consent during stage I and written informed consent during stage II. For individuals  $<18$  years of age or individuals with cognitive impairment, consent was obtained from their parents/caregivers. For illiterate individuals, a narrative approach was used.

## RESULTS

### Study population

Enumerators screened 1745 individuals from 476 households (54.4% female, mean age  $24y \pm 19.3$ , 3.67 persons per household), resulting in 98.2% of the estimated eligible population screened (Figure 2). At least one screening question was answered positively by 304 individuals (54.9% female, mean age  $30y \pm 19.6$ ). After attrition of four individuals, 300 were evaluated by a neurologist. Lifetime epilepsy was diagnosed



**FIGURE 2** Screening survey flow. \*Individuals of all ages with permanent residence in the selected villages during the door-to-door survey. \*\*No discrepancies in the re-evaluation of the two neurologists were noted. \*\*\*Conservatively excluded from the epilepsy cohort.

in 133 (52.6% female, mean age 30y  $\pm$ 18.2). The positive predictive value of the screening questionnaire was 44.3%. Figure 3 shows the demographic distribution by gender and age of the screened population and PwE.

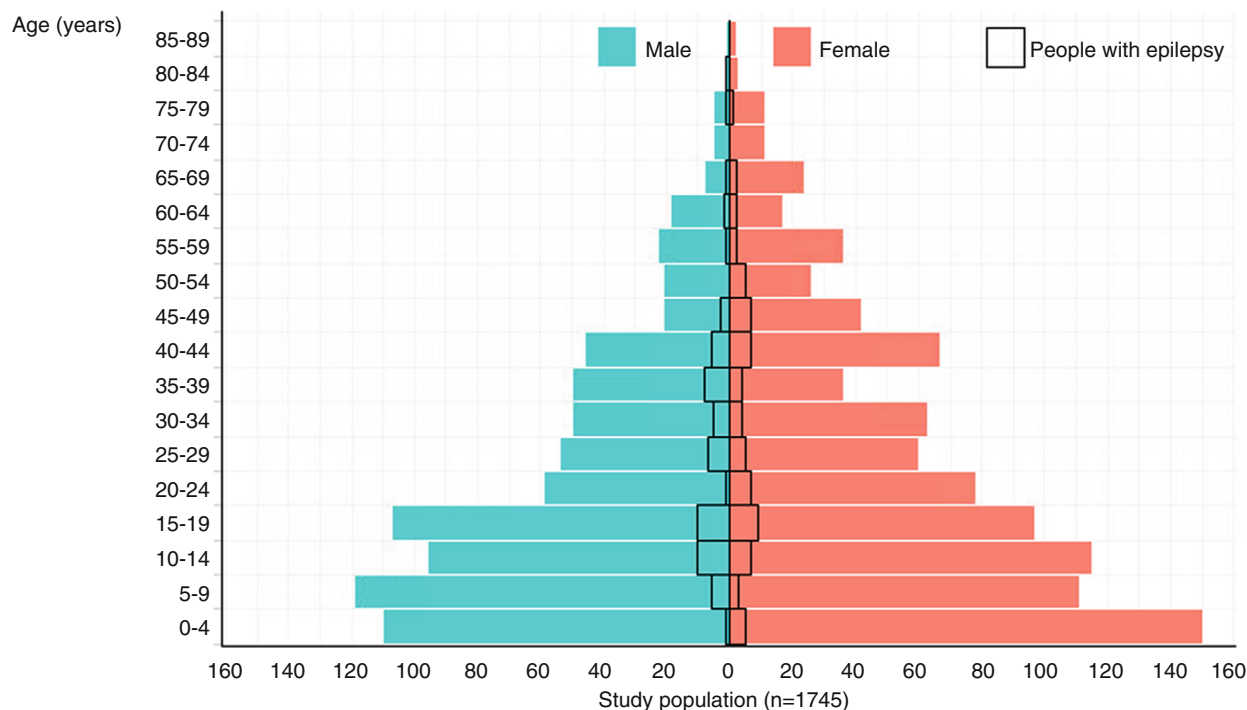
### Epilepsy prevalence and onset

The crude, unadjusted prevalence of lifetime epilepsy was 76.2 per 1000 people (95%CI: 64.2–89.7‰). The prevalence was 80.1‰ (95%CI: 66.9–93.6‰) when adjusted for screening sensitivity. The crude prevalence was 78.3‰ (95%CI: 64.8–91.7‰) when standardised to the age distribution from Rwanda [10]; 89.1‰ (95%CI: 71.3–107.0‰) from the

United States [21], and 85.3‰ (95%CI: 69.7–100.8‰) worldwide [22].

Unadjusted prevalence did not vary with gender ( $p = 0.673$ ) but did vary with age ( $p < 0.001$ ) (Table 1). A higher prevalence was observed in those aged 29–49y ( $p = 0.008$ ) (Figure 4). Peak age-specific prevalence for both women (100.5‰, 95%CI: 64.0–148.1‰) and men (135.6‰, 95%CI: 88.8–195.0‰) was at 29–49y. Table S2 summarises the age-specific prevalence by gender.

The mean age at first seizure was 18y  $\pm$ 16.2 without differences between males (17y  $\pm$ 17.1) and females (19y  $\pm$ 15.4) ( $p = 0.443$ ). The age at first seizure was most frequent between 0 and 5y in both women and men, having occurred between 0 and 5y in 29% of all PwE (Figure 4).



**FIGURE 3** Age and gender distribution of the population screened during the door-to-door survey. Black squares indicate the number of cases with lifetime epilepsy by gender in each age group.

**TABLE 1** Unadjusted prevalence of lifetime epilepsy per 1000 people, by age and gender.

	Screened in stage I (n)	Lifetime epilepsy (n)	Unadjusted prevalence (% [95% CI])	Adjusted standardised residuals	p-value
Gender					$p = 0.673$
Female	949	70	73.8 (57.9–92.3)		
Male	796	63	79.1 (61.4–100.1)		
Age groups <sup>a</sup> (y)					$p < 0.001$
0–5	310	7	22.6 (9.1–46.0)	<b>−3.92</b>	$p = 0.001^b$
6–12	294	18	61.2 (36.7–95.0)	−1.06	
13–18	265	26	98.1 (65.1–140.4)	1.46	
19–28	266	18	67.7 (40.6–104.8)	−0.57	
29–49	396	46	116.2 (86.3–151.9)	<b>3.41</b>	$p = 0.008^b$
50+	214	18	84.1 (50.6–129.7)	0.46	

Note: Bold values indicate statistically significant values.

<sup>a</sup>Age distributions were grouped as aligned with Ngugi et al. [8]. Age distributions grouped per lustrum/decade can be found in the Supplemental data.

<sup>b</sup>Bonferroni correction applied.

The unadjusted prevalence of active epilepsy decreased from 74.5‰ (95%CI: 62.6–87.8‰) to 67.6‰ (95%CI: 56.3–80.4‰) based on a 5- versus 1-year cut-off respectively (Table 2). Out of 118 PwE with at least one seizure in the preceding 12 months and/or with ongoing ASM, 78% had at least one seizure type with convulsions, resulting in a prevalence of active convulsive epilepsy of 52.7‰ (95%CI: 42.7–64.3‰). In all PwE, 30.8% had any type of non-convulsive seizures and 22.6% had only non-convulsive seizures.

## Epilepsy and sociodemographic characteristics

A new diagnosis was made in 79.4% of PwE without significant differences in gender, age or age at first seizure between previously and newly diagnosed PwE (Table 3).

The mean time between the first seizure and diagnosis was 3 years in previously diagnosed PwE and 12 years in newly diagnosed PwE. Of the previously diagnosed PwE, 75% had been diagnosed within a year after their first seizure compared to 6.9% of the newly diagnosed PwE.



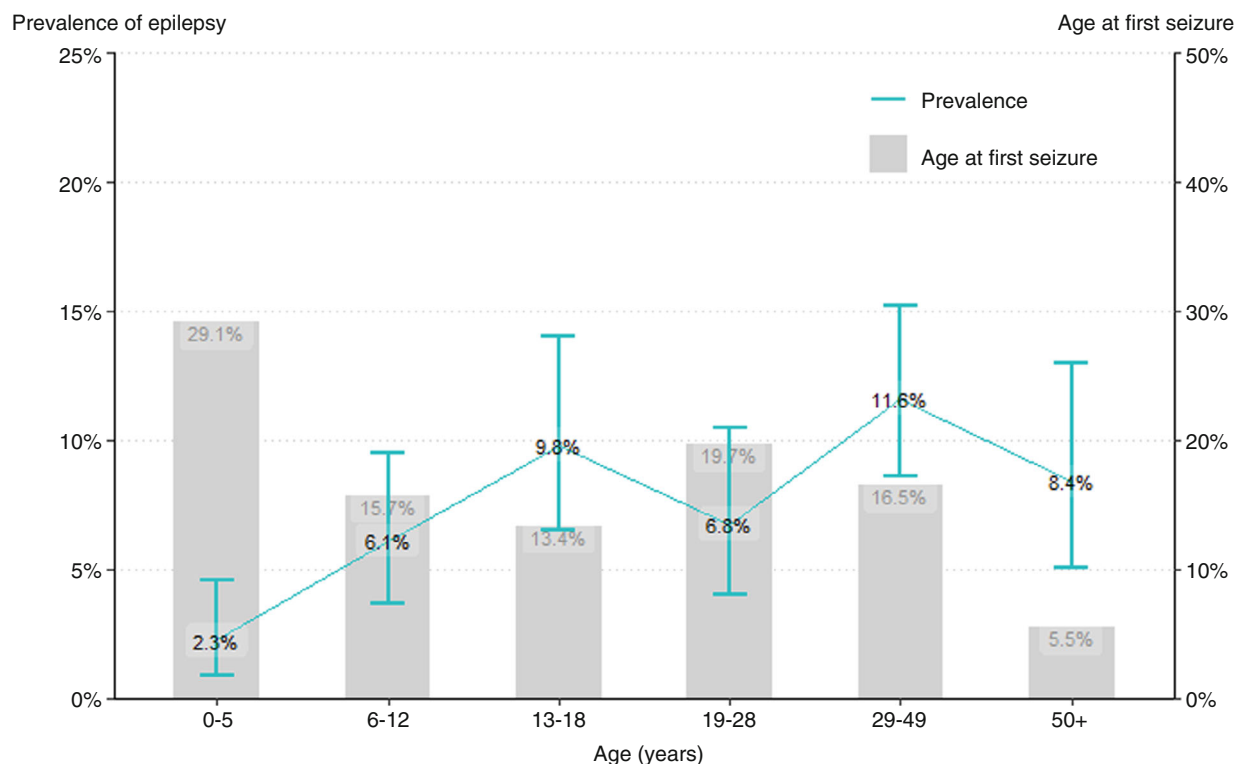


FIGURE 4 Age-specific prevalence of lifetime epilepsy and age at first seizure.

TABLE 2 Unadjusted prevalence of lifetime, active, and convulsive epilepsy per 1000 people.

Date of last seizure	Epilepsy			Convulsive epilepsy		
	<i>n</i>	Unadjusted prevalence (‰)	95% CI (‰)	<i>n</i>	Unadjusted prevalence (‰)	95% CI (‰)
Active (≤12 months)	118	67.6	56.3–80.4	92	52.7	42.7–64.3
Active (≤5 years)	130	74.5	62.6–87.8	100	57.3	46.9–69.3
Lifetime	133	76.2	64.2–89.7	103	59.0	48.4–71.1

Previously diagnosed PwE reported more frequently being single, unemployed and having had no education (Table 4). Up to 90% of all PwE had health insurance regardless of their diagnosis status.

Of 130 PwE with a seizure within the last 5 years, 92.2% were not adequately treated, of whom 52.5% were female (Table 3). In previously diagnosed PwE, 60% were not adequately treated: 40% never took any ASM and 60% had discontinued ASM. Financial reasons for treatment discontinuation were mentioned by three PwE, whereas ignorance, lack of efficacy, advice from a pastor and intolerance were each mentioned by one PwE. Two PwE mentioned seizure cessation, yet both had ongoing seizures at the time of the survey.

Ten PwE reported ongoing use of ASM including phenobarbital, valproate, diazepam and phenytoin, of whom two reported seizure-freedom and six reported >75% seizure reduction.

Of the three PwE without seizures for more than 5 years, two reported having used ASM in the past and became seizure-free under ASM. The third PwE had childhood-

onset epilepsy since the age of 2 years with seizure cessation at the age of 15.

Of all PwE, 54 (41.5%) had contacted traditional or religious healers, 10 (7.7%) had sought biomedical care and 11 (8.5%) had used both traditional and biomedical care in whom all but one traditional medicine was the initial point of care. In 55 PwE (42.3%), no biomedical nor traditional treatment had been sought. Of the 65 PwE who used traditional treatment, 61.5% reported a lack of efficacy and 54% had stopped the treatment at the time of the survey.

## DISCUSSION

The lifetime epilepsy prevalence of 76.2 per 1000 people observed in the present study reiterates the exceptionally high prevalence in Rwanda. While a few rates from SSA are similar or higher, ranging from 41 to 105 per 1000 [24–32], the prevalence we observed is high compared to the 15–16 per 1000 prevalence in SSA [4, 33].

TABLE 3 Epilepsy characteristics of people living with lifetime epilepsy.

Diagnosis status ( <i>n</i> [%])	All PwE	Previously diagnosed 27 (20.6)	Newly diagnosed 104 (79.4)	All PwE 131 (100.0)	
Gender					<i>p</i> = 0.496
	Female	16 (59.3)	54 (51.9)	70 (53.4)	
	Male	11 (40.7)	50 (48.1)	61 (46.6)	
Age groups					<i>p</i> = 0.835
	0–5	2 (7.4)	5 (4.8)	7 (5.3)	
	6–12	4 (14.8)	13 (12.5)	17 (13.0)	
	13–18	5 (18.5)	21 (20.2)	26 (19.8)	
	19–28	5 (18.5)	13 (12.5)	18 (13.7)	
	29–49	7 (25.9)	38 (36.5)	45 (34.4)	
	50+	4 (14.8)	14 (13.5)	18 (13.7)	
Age at first seizure (y) (mean ± SD)		<i>n</i> = 26	<i>n</i> = 101	<i>n</i> = 127	
	All PwE	17 ± 17.9	18 ± 15.8	18 ± 16.2	<i>p</i> = 0.534
Time between first seizure and diagnosis (y) (mean ± SD)		<i>n</i> = 20	<i>n</i> = 101	<i>n</i> = 121	
	All PwE	3 ± 4.7	12 ± 11.3	11 ± 11.1	
Gender					
	Female	3 ± 5.2	13 ± 12.7	11 ± 12.4	
	Male	2 ± 4.3	12 ± 9.7	10 ± 9.7	
Adequate treatment in active epilepsy ( <i>n</i> [%])		<i>n</i> = 25	<i>n</i> = 103	<i>n</i> = 128	
	Yes	10 (40.0)	0	10 (7.8)	
	No	15 (60.0)	103 (100.0)	118 (92.2)	

Heterogeneity in prevalence from community-based studies in SSA can partly be attributed to methodological factors. First, stigma and discrimination of PwE might impede the capture of persons at risk during screening stages resulting in low screening coverage of the eligible population or high attrition between stages [34]. Although some studies report >85% coverage [8, 35–37], and adjust prevalence for non-response [8, 30, 35, 37–39], others report coverage of 55% and non-response in up to 52% [30]. Considering our elevated prevalence, 98.2% screening coverage and low attrition, we assume to accurately portray the epilepsy burden in the region. Second, several studies only include active epilepsy defined by either a 1- or 5-year cut-off resulting in prevalence differences between studies [4]. When reporting both cut-offs, the prevalence in one study increased by 0.2 per 1000 [35], whereas our prevalence increased from 67.6 to 74.5 per 1000. Third, the preponderance of SSA studies including only convulsive seizures, which are more easily detected in resource-limited settings [40], leaves non-convulsive seizures underrated. Most screening questionnaires exclude non-convulsive seizures a priori [41–44]. The epilepsy prevalence in a study in urban Tanzania more than doubled when including non-convulsive seizures [45], and a study in rural Kenya reported an overall epilepsy

prevalence three times that of active convulsive epilepsy [46]. Using a screening tool able to detect non-convulsive seizures [12–14], we identified non-convulsive seizures in 30.8% of all epilepsies, similar to 28.4% of PwE with non-motor seizures in a Northern Rwandan survey [7]. The paucity of epidemiological data on epilepsy including non-convulsive seizures underestimates the epilepsy burden in LMICs, complicates comparison with high-income countries, and affects resource allocation for epilepsy care. Nonetheless, even our active convulsive epilepsy prevalence of 52.7 per 1000 is far higher than most active convulsive epilepsy rates in SSA ranging from 7.0 to 14.8 per 1000 [8].

The currently found prevalence also exceeds the 7 per 1000 estimate of a Rwandan cross-sectional survey from 2008 and the 29 per 1000 of a Rwandan mental health survey from 2022 [5, 47]. Methodological incongruities again prevail as the latter study included participants aged 14–65 years only and both studies did not have epilepsy as their primary focus. Without instruments validated to screen for epilepsy nor neurologists involved in the diagnosis, both studies presumably underestimated the prevalence. Two other Rwandan community-based studies did report a prevalence in the vicinity of our observations. A study in Northern rural Rwanda from 2017 and a nationally

TABLE 4 Sociodemographic characteristics of people living with lifetime epilepsy.

Living arrangement ( <i>n</i> [%])		Previously diagnosed <i>n</i> = 27	Newly diagnosed <i>n</i> = 104	All PwE <i>n</i> = 132
Alone		0	6 (5.8)	6 (4.5)
With partner		7 (25.9)	44 (42.3)	51 (38.6)
With relatives		20 (74.1)	54 (51.9)	75 (56.8)
Marital status ( <i>n</i> [%])		<i>n</i> = 27	<i>n</i> = 104	<i>n</i> = 132
Single		7 (25.9)	9 (8.7)	16 (12.1)
Married		3 (11.1)	24 (23.1)	27 (20.5)
Co-habitation		3 (11.1)	19 (18.3)	22 (16.7)
Separated/Divorced		4 (14.8)	10 (9.6)	14 (10.6)
Widowed		1 (3.7)	6 (5.8)	7 (5.3)
Underage (<18y)		9 (33.3)	36 (34.6)	46 (34.8)
Employment ( <i>n</i> [%])		<i>n</i> = 24	<i>n</i> = 99	<i>n</i> = 124
Farmer		10 (41.7)	63 (63.6)	73 (58.9)
Student/Underage for labour force		9 (37.5)	33 (33.3)	43 (34.7)
Unemployed		4 (16.7)	1 (1.0)	5 (4.0)
Other		1 (4.2)	2 (2.0)	3 (2.4)
Health insurance ( <i>n</i> [%])		<i>n</i> = 27	<i>n</i> = 104	<i>n</i> = 131
Yes		24 (88.9)	94 (90.4)	118 (90.1)
No		3 (11.1)	10 (9.6)	13 (9.9)
Education ( <i>n</i> [%])		<i>n</i> = 27	<i>n</i> = 103	<i>n</i> = 130
<6 years		2 (7.4)	5 (4.9)	7 (5.4)
No education		10 (37.0)	14 (13.6)	24 (18.5)
Primary school not completed		6 (22.2)	54 (52.4)	60 (46.2)
Primary school ongoing		5 (18.5)	16 (15.5)	21 (16.2)
Primary school completed		3 (11.1)	10 (9.7)	13 (10.0)
Secondary school ongoing		1 (3.7)	4 (3.9)	5 (3.8)
Secondary school completed		0	0	0
Socio-economic classification (ubudehe) <sup>a</sup> ( <i>n</i> [%])		<i>n</i> = 27	<i>n</i> = 103	<i>n</i> = 130
1		13 (48.1)	41 (39.8)	54 (41.5)
2		12 (44.4)	48 (46.6)	60 (46.2)
3		2 (7.4)	14 (13.6)	16 (12.3)
4		0	0	0

<sup>a</sup>Ubudehe process involves categorising all households into four categories reflecting their degree of social and economic vulnerability starting from the most vulnerable who are categorised as one.

representative survey in rural and urban areas from 2005 reported a lifetime epilepsy prevalence of 47.7 per 1000 (CI: 39.8–56.8) and 49 per 1000 respectively [6, 7]. However, our prevalence of 76.2 per 1000 (CI: 64.2–89.7) still differs, despite the commonality in methodology employed. In concordance, a survey across five SSA centres reported considerable differences in prevalence between sites, despite their consistent methodology [8]. Others have reported similar geographical heterogeneities, even across small geographical areas [35, 37, 45]. Methodological disparities alone can therefore not account for these differences [2].

A documented relation between the prevalence gradient across SSA and the distribution of risk factors of epilepsy

has suggested variation in prevalence due to clustered exposure to environmental or genetic risk factors [8]. Higher estimates of heterogeneity in rural areas underline the possibility of spatial clustering of, for example, parasitic infections or genetic factors as relatives in rural areas tend to live in proximity [2]. The disparity in prevalence between Northern and Southern rural Rwandan areas might therefore highlight geographical differences in risk factors. For instance, malaria prevalence in Rwanda ranges from 17% in the East, 11% in the South to 1% in the North [48]. Further, a Northern Rwandan study documented a *Taenia solium* seropositivity in children of 13.3% [49], while a Southern study reported a general seropositivity of 18.4% with almost



a quarter of PwE considered as neurocysticercosis cases [50]. The clustering of risk factors is particularly evident given the higher prevalence in rural areas where factors such as poor perinatal care, poor sanitary conditions with higher transmission rates of infections, and poverty are all pervasive [2, 4]. The distribution of public services favours urban regions at the expense of rural areas where health centres with meagre resource allocation are cited. Rural dwellers have less access to healthcare which implies decreased and delayed presentation of risk factors [51, 52]. The higher prevalence in rural settlements calls for intensive efforts on epilepsy at the grassroots to take epilepsy out of the shadows.

## Demographic characteristics

Like most studies from high-income countries and LMICs, we found a non-significant slightly higher prevalence in men [3, 33]. Contrary, the Northern Rwandan study did report a significant and precedented female-to-male ratio that inverted after childbearing age from low to high [7, 53]. Whether these gender differences represent divergent aetiologies and gender-dependent risk factors within these various regions or whether they are an artefact of case ascertainment or competing mortality risks remains to be determined [53, 54].

Consistent with most reports from SSA including Rwanda [6, 33, 55], 60% of our cases had their first seizure before the age of 18 years. The first seizure occurred most frequently between the ages of 0–5 years, though this frequency might have been overestimated due to imprecise recall which hinders differentiation with the onset of febrile seizures. Seizure onset at a young age could be related to perinatal insults, central nervous system infections including cerebral malaria, or genetically determined epilepsies [8, 33, 35].

Contrary to most SSA studies which show a higher prevalence in adolescents and young adults [35, 53, 55–57], we found a peak in adulthood suggesting few cases lost to spontaneous remission or premature mortality [2, 40, 58]. This peak might also indicate the importance of later-onset epilepsy as peaks in adulthood have been linked to preventable environmental factors including infectious aetiologies such as neurocysticercosis [8, 59], simply due to increasing exposure over a lifetime. Furthermore, the shift from mostly young PwE documented in Rwanda in 2005 [6], towards older PwE after several years may hypothetically indicate a reduction of epilepsy incidence in children due to changes in aetiologies over time, although it may as well reflect under-ascertainment of younger PwE.

## Diagnosis and treatment gap

In addition to a high prevalence, we observed a treatment gap of 92.2% into the bargain, in line with the gap of 91.5% in

Northern rural Rwanda [7]. While the treatment gap exceeds 75% in many reports from low-income countries [30, 52, 60], our numbers are among the highest published [53, 54, 56, 61, 62]. Predominant reasons to explain the gap are limited access to health facilities and a lack of resources, including low supplies, excessive drug costs, or a lack of trained health professionals [51, 63, 64]. The dearth of adequate care is particularly valid in rural areas where the treatment gap is higher [52]. Truly, the Rwandan study that surveyed both urban and rural areas, reported a lower gap of 68% [6]. Furthermore, many PwE do not seek care, either since they do not recognise the significance of the disorder and the need for treatment or they are prevented from doing so in light of the stigma associated with the disease. Misconceptions about the disease may lead to negative attitudes towards PwE resulting in discrimination and social isolation [63–65]. In Northern rural Rwanda, approximately 40% of PwE had received a diagnosis prior to the study [7]. In the present study, only 20% of our cases were previously diagnosed, of whom 60% discontinued treatment or never took any ASM. Half of our PwE did seek traditional treatment as animistic religious beliefs in the origin of the disease impel many to seek relief from traditional remedies [65]. Although over 60% considered these traditional interventions ineffective.

Several initiatives have been implemented by the Rwandan government, non-governmental organisations (NGOs), and multilateral developmental sponsors to enhance epilepsy awareness, reduce stigma, and narrow the treatment gap. Examples include the availability of ASM including carbamazepine, phenobarbital, phenytoin and valproate in the central pharmacy, educational seminars for healthcare professionals in district hospitals, and an epilepsy knowledge and awareness campaign in four Rwandan districts by the NGO Handicap International [66]. Despite these initiatives, our results stress the persistent need for further efforts that address the diagnosis and treatment gap. Proposed solutions include the involvement of CHWs to promote epilepsy care and the implementation of educational initiatives in communities to reduce the stigma of the disease. Sustained supplies of affordable ASM need to be ensured and prescribed by staff skilled to diagnose and treat the condition, and trained traditional healers as potentially effective stakeholders in epilepsy management should be considered.

## Limitations

The prevalence observed in the present study ranks among the highest in SSA. Higher rates were only documented in regions that are hyper-endemic for onchocerciasis or in villages where locals repeatedly claimed ample presence of epilepsy [24–32]. Specific aetiological factors may influence surveys conducted in geographically isolated areas. The question therefore remains whether small-scale studies, which often yield the highest prevalence, overestimate the real prevalence [2]. Although we selected our study area primarily based on the absence of

previous epilepsy awareness campaigns and the availability of supportive resources, the endemic nature of potential risk factors such as *T. solium* [50], might impair external validity.

Although all suspected epilepsy cases were evaluated by neurologists experienced in eliciting the protean and subtle manifestations that seizures entail, the demarcation of epileptic seizures from mimics including syncope and psychogenic non-epileptic seizures (PNES) may be difficult by history taking only. PNES is associated with previous trauma such as physical, sexual, or emotional abuse, minor head trauma, and physical or emotional neglect [67]. A Rwandan report documented women being subjected to physical and sexual violence in 37% and 23%, respectively, and men in 30% and 6% [68]. This violence may have triggered PNES. Although PNES can occur in 10%–20% of patients referred to epilepsy centres [69–71], population-based studies are scarce, data on PNES in Rwanda is non-existent and the diagnostic gold standard, video-EEG monitoring, is unavailable.

## CONCLUSION

We report an extremely high epilepsy prevalence in Southern rural Rwanda and reiterate the massive burden of this disease in the country. These data call for immediate action to improve epilepsy diagnosis and management in Rwanda. Further, geographical variation in prevalence between Northern and Southern areas might indicate case clustering due to the combined effect of differential exposure to environmental and genetic factors. As many causes for epilepsy in SSA are preventable, case-control studies are underway to ascertain the risk factors and aetiologies of epilepsy in Rwanda, critical to propose national policies for epilepsy prevention.

## ACKNOWLEDGEMENTS

The authors thank all patients and villagers and are extremely grateful for the support and perseverance of the community health workers Julianne Ahobantegeye, Josephine Bankundiye, Philemon Kagemanyi, Aphrodice Karenzo, Béatha Mukeshimana and Jean Marie Vianney Shyirambere, the social worker Nathalie Nyirahitimana and the mental health nurses of Medicalized Health Center, Gikonko, as well as the enumerators Liliane Gashagaza, Didier Kwizera, Providence Mujawamariya, Diane Ntakirutimana, Anne Shumbusho, Angélique Uwamahoro, Anastase Wacu and the volunteers Alexine Billet and Jean van Haaren.

## CONFLICT OF INTEREST STATEMENT

This research has received funding from Fracarita Belgium and VLIR UOS. Ieme Garrez holds a fundamental research fellowship at the Fund for Scientific Research Flanders (FWO—11K8722N). Dirk Teuwen has received consultancy fees from UCB Pharma. Fidele Sebera has received research grants through his institution. Peter Dedeken has received

consultancy fees from UCB Pharma, Merck, Pfizer and Novartis. Paul A. J. M. Boon has received speaker and consultancy fees from UCB Pharma, LivaNova and Medtronic, and research grants from the same companies through his institution. Other authors have no conflicts of interest to disclose.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request to the corresponding author. Data will be disclosed upon study team agreement within a reasonable timeframe. The data are not publicly available due to privacy or ethical restrictions.

## ORCID

Ieme Garrez  <https://orcid.org/0000-0003-2190-0799>

## REFERENCES

1. Fisher RS, Cross JH, D'Souza C, French JA, Haut SR, Higurashi N, et al. Instruction manual for the ILAE 2017 operational classification of seizure types. *Epilepsia*. 2017;58(4):531–42.
2. Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia*. 2010;51(5):883–90.
3. Fiest KM, Sauro KM, Wiebe S, Patten SB, Kwon CS, Dykeman J, et al. Prevalence and incidence of epilepsy: a systematic review and meta-analysis of international studies. *Neurology*. 2017;88(3):296–303.
4. Owolabi LF, Adamu B, Jibo AM, Owolabi SD, Isa AI, Alhaji ID, et al. Prevalence of active epilepsy, lifetime epilepsy prevalence, and burden of epilepsy in sub-Saharan Africa from meta-analysis of door-to-door population-based surveys. *Epilepsy Behav*. 2020;103:106846.
5. Kayiteshonga Y, Sezibera V, Mugabo L, Iyamuremye JD. Prevalence of mental disorders, associated co-morbidities, health care knowledge and service utilization in Rwanda—towards a blueprint for promoting mental health care services in low- and middle-income countries? *BMC Public Health*. 2022;22(1):1858.
6. Sebera F, Munyamututsa N, Teuwen DE, Ndiaye IP, Diop AG, Tofighy A, et al. Addressing the treatment gap and societal impact of epilepsy in Rwanda—results of a survey conducted in 2005 and subsequent actions. *Epilepsy Behav*. 2015;46:126–32.
7. Dedeken P, Sebera F, Mutungirehe S, Garrez I, Umwiringirwa J, Van Steenkiste F, et al. High prevalence of epilepsy in northern Rwanda: exploring gender differences. *Brain Behav*. 2021;11(11):e2377.
8. Ngugi AK, Bottomley C, Kleinschmidt I, Wagner RG, Kakooza-Mwesige A, Ae-Ngibise K, et al. Prevalence of active convulsive epilepsy in sub-Saharan Africa and associated risk factors: cross-sectional and case-control studies. *Lancet Neurol*. 2013;12(3):253–63.
9. National Institute of Statistics Rwanda, Ministry of Finance and Economic Planning. Rwanda—integrated household living conditions survey (EICV5), 2016–2017, Cross-sectional sample. Kigali, Rwanda: NISR; 2018. p. 273 Report No.: RWA-NISR-EICV5-CS-2016-2017-V0.1.
10. National Institute of Statistics Rwanda, Ministry of Finance and Economic Planning. Rwanda—fifth Rwanda population and housing census, thematic report: population size, structure, and spatial distribution. Kigali, Rwanda: NISR; 2023.
11. Sebera F, Dedeken P, Kayirangwa J, Umwiringirwa J, Kajeneza D, Dos Reis NA, et al. Effectiveness of community health workers on identification and mobilization of persons living with epilepsy in rural Rwanda using a validated screening tool. *Hum Resour Health*. 2022; 20(1):10.
12. Quet F, Rafael F, Ngougou EB, Diagana M, Druet-Cabanac M, Preux PM. Investigating epilepsy in Africa: 10 years of data collection using a standardized questionnaire in 2269 peoples with epilepsy. *Epilepsia*. 2011;52(10):1868–76.

13. Preux PM. Questionnaire in a study of epilepsy in tropical countries. *Bull Soc Pathol Exot.* 2000;93(4):276–8.
14. Diagona M, Preux PM, Tuillas M, Ould Hamady A, Druet-Cabanac M. Dépistage de l'épilepsie en zones tropicales: validation d'un questionnaire en Mauritanie. *Bull Soc Pathol Exot.* 2006;99(2):103–7.
15. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009 Apr;42(2):377–81.
16. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al. REDCap consortium, the REDCap consortium: building an international community of software partners. *J Biomed Inform.* 2019 May 9;95:103208. <https://doi.org/10.1016/j.jbi.2019.103208>
17. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia.* 2014;55(4):475–82.
18. Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, et al. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia.* 2011;52(Suppl 7):2–26.
19. Lang Z, Reiczigel J. Confidence limits for prevalence of disease adjusted for estimated sensitivity and specificity. *Prev Vet Med.* 2014; 113(1):13–22.
20. Rogan WJ, Gladen B. Estimating prevalence from the results of a screening test. *Am J Epidemiol.* 1978;107(1):71–6.
21. Klein RJ, Schoenborn CA. Age adjustment using the 2000 projected U.S. population. *Healthy People 2010 Stat Notes.* 2001;2001(20):1–10.
22. Ahmad OB, Boschi-Pinto C, Lopez AD, Murray CJL, Lozano R, Inoue M. Age standardization of rates: a new WHO standard. Vol 9. Geneva (CH): World Health Organization; 2001. p. 10.
23. Agresti A. An introduction to categorical data analysis. 2nd ed. New York (USA): John Wiley & Sons, Inc.; 2007.
24. Lenaerts E, Mandro M, Mukendi D, Suykerbuyk P, Dolo H, Wonya-Rossi D, et al. High prevalence of epilepsy in onchocerciasis endemic health areas in Democratic Republic of the Congo. *Infect Dis Poverty.* 2018;7(1):68.
25. Levick B, Laudisoit A, Tepage F, Ensoy-Musoro C, Mandro M, Bonareri Osoro C, et al. High prevalence of epilepsy in onchocerciasis endemic regions in The Democratic Republic of the Congo. *PLoS Negl Trop Dis.* 2017;11(7):e0005732.
26. Raimon S, Dusabimana A, Abd-Elfarag G, Okaro S, Carter JY, Newton CR, et al. High prevalence of epilepsy in an onchocerciasis-endemic area in Mvolo County, South Sudan: a door-to-door survey. *Pathogens.* 2021;10(5):599.
27. Prischich F, De Rinaldis M, Bruno F, Egeo G, Santori C, Zappaterreno A, et al. High prevalence of epilepsy in a village in the Littoral Province of Cameroon. *Epilepsy Res.* 2008;82(2–3):200–10.
28. Siewe Fodjo JN, Tatah G, Tabah EN, Ngarka L, Nfor LN, Chokote SE, et al. Epidemiology of onchocerciasis-associated epilepsy in the Mbam and Sanaga river valleys of Cameroon: impact of more than 13 years of ivermectin. *Infect Dis Poverty.* 2018;7(1):114.
29. Nitiéma P, Carabin H, Hounton S, Praet N, Cowan LD, Ganaba R, et al. Prevalence case-control study of epilepsy in three Burkina Faso villages. *Acta Neurol Scand.* 2012;126(4):270–8.
30. Angwafor SA, Bell GS, Ngarka L, Otte W, Tabah EN, Nfor LN, et al. Incidence and prevalence of epilepsy and associated factors in a health district in north-West Cameroon: a population survey. *Epilepsy Behav.* 2021;121:108048.
31. Njamnshi AK, Sini V, Djientcheu VDP, Ongolo-Zogo P, Mapoure Y, Yepnjio FN, et al. Risk factors associated with epilepsy in a rural area in Cameroon: a preliminary study. *Afr J Neurol Sci.* 2007;26(2):18–26.
32. Efon-Ekangouo A, Nana-Djeunga HC, Nwane P, Lisongue-Tonga E, Domche A, Sumo L, et al. Prevalence of epilepsy in Ndom Health District (Littoral region, Cameroon) after long-term ivermectin-based preventive chemotherapy for the control of onchocerciasis. *Epilepsy Behav.* 2022;136:108939.
33. Preux PM, Druet-Cabanac M. Epidemiology and aetiology of epilepsy in sub-Saharan Africa. *Lancet Neurol.* 2005;4(1):21–31.
34. Atlas: epilepsy care in the world [Internet]. Geneva: World Health Organization; 2005 [cited 2023 July 20]. <https://apps.who.int/iris/handle/10665/43298>
35. Edwards T, Scott AG, Munyoki G, Odera VM, Chengo E, Bauni E, et al. Active convulsive epilepsy in a rural district of Kenya: a study of prevalence and possible risk factors. *Lancet Neurol.* 2008;7(1):50–6.
36. Debrock C, Preux PM, Houinato D, Druet-Cabanac M, Kassa F, Adjien C, et al. Estimation of the prevalence of epilepsy in the Benin region of Zinvié using the capture-recapture method. *Int J Epidemiol.* 2000;29(2):330–5.
37. Ae-Ngibise KA, Akpalu B, Ngugi A, Akpalu A, Agbokey F, Adjei P, et al. Prevalence and risk factors for active convulsive epilepsy in Kintampo, Ghana. *The Pan African medical journal.* 2015;21:29.
38. Watila MM, Balarabe SA, Komolafe MA, Igwe SC, Fawale MB, Otte WM, et al. Epidemiology of epilepsy in Nigeria: a community-based study from 3 sites. *Neurology.* 2021;97(7):e728–38.
39. Hunter E, Rogathi J, Chigudu S, Jusabani A, Jackson M, McNally R, et al. Prevalence of active epilepsy in rural Tanzania: a large community-based survey in an adult population. *Seizure.* 2012;21(9):691–8.
40. Ngugi AK, Bottomley C, Fegan G, Chengo E, Odhiambo R, Bauni E, et al. Premature mortality in active convulsive epilepsy in rural Kenya: causes and associated factors. *Neurology.* 2014;82(7):582–9.
41. Vergonjeanne M, Auditeau E, Thébaud C, Boumediene F, Preux PM. Instruments for investigation of epilepsy in low- and middle-income countries: a systematic review. *Epilepsy Res.* 2022;180:106865.
42. Ngugi AK, Bottomley C, Chengo E, Kombe MZ, Kazungu M, Bauni E, et al. The validation of a three-stage screening methodology for detecting active convulsive epilepsy in population-based studies in health and demographic surveillance systems. *Emerg Themes Epidemiol.* 2012;9(1):8.
43. Anand K, Jain S, Paul E, Srivastava A, Sahariah SA, Kapoor SK. Development of a validated clinical case definition of generalized tonic-clonic seizures for use by community-based health care providers. *Epilepsia.* 2005;46(5):743–50.
44. Giuliano L, Cicero CE, Crespo Gómez EB, Padilla S, Bruno E, Camargo M, et al. A screening questionnaire for convulsive seizures: a three-stage field-validation in rural Bolivia. *PLoS One.* 2017;12(3):e0173945.
45. Stelzle D, Schmidt V, Ngowi BJ, Matuja W, Schmutzhard E, Winkler AS. Lifetime prevalence of epilepsy in urban Tanzania—a door-to-door random cluster survey. *eNeurologicalSci.* 2021;24:100352.
46. Kariuki SM, Ngugi AK, Kombe MZ, Kazungu M, Chengo E, Odhiambo R, et al. Prevalence and mortality of epilepsies with convulsive and non-convulsive seizures in Kilifi, Kenya. *Seizure.* 2021;89: 51–5.
47. Simms V, Atijosan O, Kuper H, Nuhu A, Rischewski D, Lavy C. Prevalence of epilepsy in Rwanda: a national cross-sectional survey. *Trop Med Int Health.* 2008;13(8):1047–53.
48. Rwanda Malaria Indicator Survey [Internet]. Washington, DC: USAID; 2017 [cited 2023 April 26]. <https://dhsprogram.com/methodology/survey/survey-display-540.cfm>
49. Acosta Soto L, Parker LA, Irisarri-Gutiérrez MJ, Bustos JA, Castillo Y, Perez E, et al. Evidence for transmission of *Taenia solium* Taeniasis/Cysticercosis in a rural area of northern Rwanda. *Front Vet Sci.* 2021;8:645076.
50. Rottbeck R, Nshimiyimana JF, Tugirimana P, Düll UE, Sattler J, Hategekimana JC, et al. High prevalence of Cysticercosis in people with epilepsy in southern Rwanda. *PLoS Negl Trop Dis.* 2013;7(11): e2558.
51. Mbuba CK, Ngugi AK, Fegan G, Ibinda F, Muchohi SN, Nyundo C, et al. Risk factors associated with the epilepsy treatment gap in Kilifi, Kenya: a cross-sectional study. *Lancet Neurol.* 2012;11(8):688–96.
52. Meyer AC, Dua T, Ma J, Saxena S, Birbeck G. Global disparities in the epilepsy treatment gap: a systematic review. *Bull World Health Organ.* 2010;88(4):260–6.

53. Birbeck GL, Kalichi EM. Epilepsy prevalence in rural Zambia: a door-to-door survey. *Tropical Med Int Health*. 2004;9(1):92–5.
54. Winkler AS, Kerschbaumsteiner K, Stelzhammer B, Meindl M, Kaaya J, Schmutzhard E. Prevalence, incidence, and clinical characteristics of epilepsy—a community-based door-to-door study in northern Tanzania. *Epilepsia*. 2009;50(10):2310–3.
55. Ba-Diop A, Marin B, Druet-Cabanac M, Ngoungou EB, Newton CR, Preux PM. Epidemiology, causes, and treatment of epilepsy in sub-Saharan Africa. *Lancet Neurol*. 2014;13(10):1029–44.
56. Dent W, Helbok R, Matuja WB, Scheunemann S, Schmutzhard E. Prevalence of active epilepsy in a rural area in South Tanzania: a door-to-door survey. *Epilepsia*. 2005;46(12):1963–9.
57. Rwiza HT, Kilongo GP, Haule J, Matuja WB, Mteza I, Mbena P, et al. Prevalence and incidence of epilepsy in Ulanga, a rural Tanzanian district: a community-based study. *Epilepsia*. 1992;33(6):1051–6.
58. Levira F, Thurman DJ, Sander JW, Hauser WA, Hesdorffer DC, Masanja H, et al. Premature mortality of epilepsy in low- and middle-income countries: a systematic review from the mortality task force of the international league against epilepsy. *Epilepsia*. 2017;58(1):6–16.
59. Houinato D, Yemadje LP, Glitho G, Adjien C, Avode G, Druet-Cabanac M, et al. Epidemiology of epilepsy in rural Benin: prevalence, incidence, mortality, and follow-up. *Epilepsia*. 2013;54(4):757–63.
60. Kakooza-Mwesige A, Ndyomugenyi D, Pariyo G, Peterson SS, Waiswa PM, Galiwango E, et al. Adverse perinatal events, treatment gap, and positive family history linked to the high burden of active convulsive epilepsy in Uganda: a population-based study. *Epilepsia Open*. 2017;2(2):188–98.
61. Coleman R, Lopy L, Walraven G. The treatment gap and primary health care for people with epilepsy in rural Gambia. *Bull World Health Organ*. 2002;80(5):378–83.
62. Balogou AA, Grunitzky EK, Belo M, Sankaredja M, Djaigba DD, Tatagan-Agbi K, et al. Management of epilepsy patients in Batamariba district, Togo. *Acta Neurol Scand*. 2007;116(4):211–6.
63. Chin JH. Epilepsy treatment in sub-Saharan Africa: closing the gap. *Afr Health Sci*. 2012;12(2):186–92.
64. Newton CR, Garcia HH. Epilepsy in poor regions of the world. *Lancet*. 2012;380(9848):1193–201.
65. Baskind R, Birbeck GL. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy Behav*. 2005;7(1):68–73.
66. Finel E. Fighting against epilepsy in Rwanda: an efficient patient-centred experience. Kiyovu, Rwanda: Handicap International Rwanda; 2012. p. 62 Report No.: SD/LL/04.
67. Yang T, Roberts C, Winton-Brown T, Lloyd M, Kwan P, O'Brien TJ, et al. Childhood trauma in patients with epileptic vs nonepileptic seizures. *Epilepsia*. 2023;64(1):184–95.
68. National Institute of statistics of Rwanda (NISR) [Rwanda], Ministry of Health (MOH) [Rwanda], and ICF. Rwanda demographic and health survey 2019–20 final report. Kigali, Rwanda, and Rockville, Maryland, USA: NISR and ICF; 2021.
69. Asadi-Pooya AA, Emami Y, Emami M. Psychogenic non-epileptic seizures in Iran. *Seizure*. 2014;23(3):175–7.
70. Alsaadi TM, Marquez AV. Psychogenic nonepileptic seizures. *Am Fam Physician*. 2005;72(5):849–56.
71. Martin R, Burneo JG, Prasad A, Powell T, Faught E, Knowlton R, et al. Frequency of epilepsy in patients with psychogenic seizures monitored by video-EEG. *Neurology*. 2003;61(12):1791–2.

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Garrez I, Teuwen DE, Sebera F, Mutungirehe S, Ndayisenga A, Kajeneza D, et al. Very high epilepsy prevalence in rural Southern Rwanda: The underestimated burden of epilepsy in sub-Saharan Africa. *Trop Med Int Health*. 2024;29(3): 214–25. <https://doi.org/10.1111/tmi.13963>