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Epilepsia®

SPECIAL REPORT

# Epilepsy research in Africa: A scoping review by the ILAE Pediatric Commission Research Advocacy Task Force

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## Abstract

**Objective:** Despite the high prevalence of epilepsy in Africa, evaluation of epilepsy research trends on the continent is lacking. Without establishing effective research, improvement in care for people with epilepsy cannot be effectively strategized or targeted.

**Methods:** A scoping review of the peer-reviewed literature on epilepsy from Africa (1989–2019) was conducted. The aim was to understand from this what areas are well researched versus underresearched based on published epilepsy topics.

**Results:** A total of 1227 publications were identified and assessed. A significant increase in publications occurred over the 30 years assessed. African author leadership was evident in most reports. Nine countries had >50 publications identified; the remaining 45 countries had <50 or no publications. Research studies were typically of lower quality (case series and observational studies). Research

themes were more focused on clinical epilepsy (descriptive observational studies) and social aspects (qualitative surveys). However, there were a number of unique and strong themes, specifically for neurocysticercosis and nodding syndrome, where strong research collaborations were evident, basic science understandings were explored, and interventional models were established.

**Significance:** Despite Africa being the continent with the most countries, it is lacking in the quantity, quality, and for some areas, relevance of research on epilepsy. Targeted approaches are needed to upskill the strength of research undertaken with more basic science, interventional, and randomized controlled studies. Themes of research need to promote those with unique African content but also to align with current international research areas that have impact on care delivery, such as epilepsy surgery and epilepsy genetics. For this to be possible, it is important to strengthen research hubs with collaborations that empower Africa to own its epilepsy research journey.

**KEYWORDS**

Africa, epilepsy, low- and middle-income countries, research, scoping review, treatment

## 1 | INTRODUCTION

Low- and middle-income countries, especially those in Africa, bear the highest burden of epilepsy.[1–4] A recent global burden of disease study reported that the decline in numbers of those living with epilepsy in high-income countries (HICs) is not evident for low-income regions, and particularly in sub-Saharan Africa.[4] The median prevalence of active epilepsy in HICs was 4.9 per 1000 compared to 12.7 per 1000 in rural areas of resource-limited countries.[3–5]

This significant disparity in numbers and outcomes can be attributed to increased prevalence of risk factors for epilepsy in resource-limited countries that include infectious diseases, preventable brain injuries, and poor access to and capacity of health care services.[2,3]

Despite the high prevalence, analysis is lacking that critiques epilepsy research trends in Africa. A recent focused review exploring epilepsy research trends in children with epilepsy from Kenya identified only 35 research papers from the region between 2004 and 2019.[6] Despite the exponential increase in epilepsy genetics research across resource-equipped settings, such data are largely unavailable in Africa.[7] HICs have documented trends in epilepsy research and patient experience that have directly led to improved epilepsy management and outcome in these settings.

Understanding the current trends in epilepsy research in Africa is important to identify regionally relevant focus themes as well as to strategize critical gaps in research that are necessary to optimize epilepsy care.[8] Expanding on existing knowledge of the epidemiology of epilepsy in Africa would be a first step in laying the foundation for robust advocacy within the region.[5]

**Key Points**

- There has been a significant increase in the number of epilepsy publications originating from Africa during 1989–2019
- West Africa had the highest proportion of publications, and Central Africa had the least, with significant variation evident within regions
- Fourteen African countries had no identified publications on epilepsy over the study period
- Basic science themes and interventional study approaches were evident in publications on neurocysticercosis and nodding syndrome
- The majority of the publications focused on clinical and social aspects of epilepsy, with an increase in qualitative studies over time

## 2 | MATERIALS AND METHODS

We applied the Joanna Briggs Institute's approach for conducting a scoping review,[9] which is a systematic five-step approach to searching, screening, and reporting. The steps included (1) identification of the research questions; (2) identification of relevant databases; (3) study selection;

(4) data extraction; and (5) result interpretation, summarization, and dissemination. A scoping review of literature on epilepsy from Africa published between 1989 and 2019 was conducted. This timespan was considered adequate to understand the trends of epilepsy research in Africa. The concept of an African study was regarded as a study based in an African country or countries on an epilepsy-related topic. Collaborative studies with additional non-African countries were included, but the focus of the data collection was on epilepsy in Africa.

This report was undertaken under the auspices of the Pediatric Commission of the International League Against Epilepsy (ILAE). The ILAE has six regional commissions, of which Africa falls into two, specifically the African Commission and the Eastern Mediterranean Commission. The working group for the task force elected to be inclusive of all countries in Africa for the report to be representative of the whole African continent. However, regional assessments were made, for example, specific to activities in North Africa, East Africa, sub-Saharan Africa, and so on.

To guide the search strategy and ensure that a broad range of literature was captured in this study, two research questions were formulated, namely: What is the epilepsy research conducted in Africa? What areas are underresearched based on published epilepsy topics? We were particularly interested in the types of research published, what the focus of the publications were, and the trends in frequency of these publications over time, to identify areas that were adequately represented and those that were not in comparison with international publication trends. In addition, we sought to determine regions with consistent research teams generating high-quality studies led by African researchers and to understand the evolution in funding grants awarded to African centers. A scoping review was hence selected as the most appropriate methodology to address these questions.

A computerized search was conducted in the following databases without methodological restrictions between January 1, 1989 and March 31, 2019: Embase, MEDLINE, and AJOL (African Journals Online). The search strategy included the following keywords: seizures, convulsions, epilepsy, epilep*, Africa, and specific African country names (such as Egypt, Tanzania, etc.) and regions (e.g., North Africa, West Africa). We included all study designs published between 1989 and 2019 in English, French, and Portuguese. We combined keyword terms and phrases related to epilepsy and Africa, including epidemiology, management, and outcomes, to identify the studies. Team members then tested our search terms, and consensus was attained regarding the search strategy (Appendix S1). The reference list of review studies was examined to determine whether other studies were not captured through the electronic search. Suitable titles were subsequently added if they met the criteria for review.

## 2.1 | Study selection

Seven researchers independently screened papers by title and abstract and identified those for full text review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews (Appendix S2).[10,11] Where there was lack of clarity regarding a specific study, this was discussed at the regular team meetings, and a consensus regarding inclusion was arrived at. Following evaluation, data were extracted and entered into the Research Electronic Data Capture (REDCap) platform (Vanderbilt and National Institutes of Health)[12] hosted at the Aga Khan University to allow all investigators to contribute to data entry, extrapolation, and analysis. All articles were imported into both Endnote and REDCap. Duplicates were removed. Three authors (P.S., J.S., and J.W.) rechecked the data entered for completeness and accuracy. We included peer-reviewed journal articles as well as case series with data from more than five cases, comparison studies, observational studies, surveys, and randomized control trials.

The following types of publication were excluded: conference abstracts and posters, case reports and series with fewer than five cases, commentaries, policy briefs, editorials, opinion pieces, and debates. Also excluded were studies that did not contain extractable data on an African country, region, or the whole continent/subcontinent; studies of acute symptomatic seizures in nonepileptic patients; and studies that did not contain basic science or patient-derived data related to epilepsy.

## 2.2 | Data extraction

The data extraction for this study is summarized below.

## 2.3 | Data synthesis and dissemination

All studies included in this scoping review were analyzed using descriptive statistics and thematic analysis. Results were organized in tables and charts and presented into themes that reflect the review objectives. Tables were used to illustrate how epilepsy research has evolved from January 1, 1989 to March 31, 2019 in terms of themes, research design, authorship, and geography. The PRISMA flow chart (Figure 1) was used to summarize the included and excluded research studies. Supporting figures were

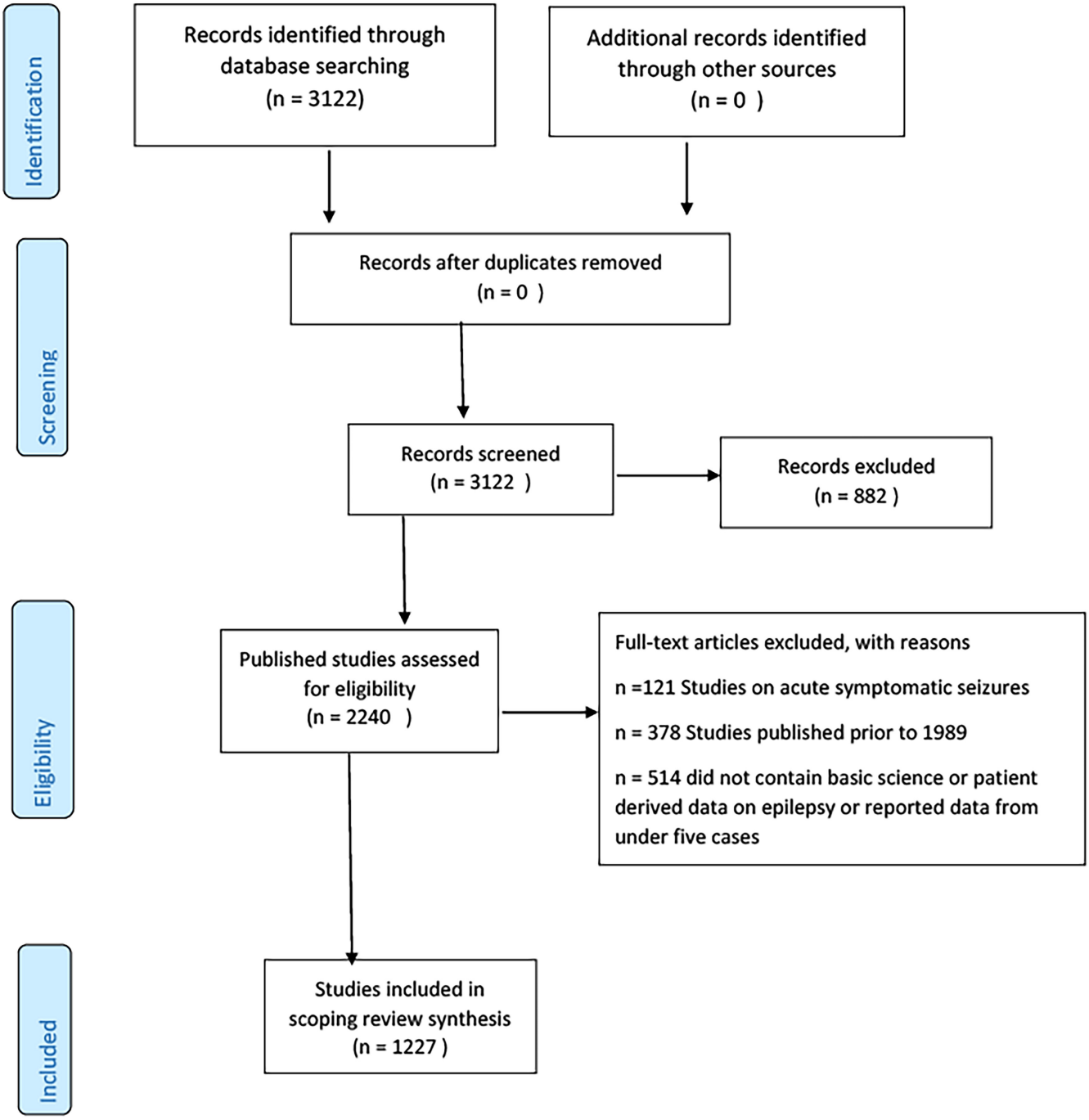


**FIGURE 1** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart

developed to present the synthesis with a focus on which to draw future research implications.

## 2.4 | Ethics approval and protocol registration

Ethical approval was not required, as no primary data were collected. The protocol for this scoping review was publicly published on the open science framework, and a DOI was assigned (DOI 10.17605/OSF.IO/6TGKM).

## 2.5 | Statistics

Statistical tests were performed using SPSS statistical software version 20.0 (IBM). Categorical data were presented as frequencies and percentages. Chi-squared test was used to compare the frequencies and percentages among

different groups, and Kruskal–Wallis test was used to compare between different time frames.

## 3 | RESULTS

A total of 3122 studies were identified through the database search. Following screening, studies were excluded as follows: 254 were conference abstracts, and 628 did not contain extractable data from an African country. At evaluation, 121 studies investigated acute symptomatic seizures in nonepileptic patients, 378 were published before 1989, and 514 did not contain basic science or patient-derived data on epilepsy or reported data from fewer than five cases. None of the Portuguese language studies met the inclusion criteria. The remaining 1227 studies were included in the scoping review (Figure 1 shows PRISMA study flow chart).

### 3.1 | Publication characteristics of epilepsy research in Africa

Location, funding, and authorship characteristics are included in Table 1. There has been a steady increase in publications, with the majority of reports between 2013 and 2019 (Figure 2A,B). Over three consecutive time frames, statistical difference ($p = .001$) was evident for the numbers of publications during 2009–2019 (801, 65%, 95% confidence interval [CI] = 62.5%–67.9%) compared to 1989–1998 (125, 10%, 95% CI = 8.6%–12.0%) and 1999–2008 (301, 24%, 95% CI = 22.2%–27.0%). The period with the least published research was 1989–1998, specifically 1989, with a total of five published studies. Of the 1227 published studies, 824 (67%, 95% CI = 64.4%–69.8%) studies were published in international journals, whereas 403 (33%, 95% CI = 30.2%–35.6%) studies were published in African journals, with little change in this over the years.

A total of 746 (61%) studies were exclusively written by African authors, whereas 81 (7%) studies did not include any African authors. A total of 762 (62%) studies had an African author in both the first and last authorship position, 257 (21%) studies had an African author in the first or last position, and 208 (17%) studies did not have an African author in either first or last position (Figure 2A,B).

Fourteen African countries had no identified publications on epilepsy over the study period (Angola, Republic of Congo, Chad, Comoros, Cape Verde, Djibouti, Eritrea, Equatorial Guinea, Lesotho, Western Sahara, Somaliland, Somalia, Sao Tome and Principle, and Swaziland). The heat map of Africa (Figure 3A) demonstrates the proportions of reports in the remaining 40 countries. Figure 3B illustrates the trends in the most prolific countries with >50 publications over the consecutive decades.

Overall, West Africa had the highest proportion of research conducted ($n = 428$, 35%), whereas Central Africa had the least ($n = 90$, 7%). Multicenter African studies accounted for 27% ($n = 333$). In West Africa, the majority of studies ($n = 274$, 22%, out of 1227 for all of Africa) took place in Nigeria, whereas Niger, Liberia, and Gambia only had one study published from each country. In Central Africa, the majority of studies ($n = 56$, 5%) were conducted in Cameroon compared to four studies from the Central African Republic. In East Africa, the majority of studies ($n = 80$, 7%) were published from Uganda, followed by Tanzania and Ethiopia, whereas Rwanda had the lowest number of studies with only seven identified. In North Africa, 72 (6%) studies were conducted in Egypt, whereas the fewest studies were conducted in Libya, with four reports. Lastly, in Southern Africa, South Africa had the most studies ($n = 119$, 10%), whereas Namibia, Reunion Island, and Botswana had the fewest studies published, with two each.

Of the 361 funded studies, 232 (64%) studies were externally funded such as via seed grants and contributions in kind of time and effort, whereas 110 (30%) studies were funded through research grants, 15 (4%) studies were funded from various associations (e.g., the ILAE, International Child Neurology Association, International Brain Research Organization), and only four among these studies were related to sponsored pharmaceutical work.

Regarding types of studies, descriptive and observational studies dominated, with 161 (13%) case series, 572 (47%) observational studies, 286 (23%) surveys, and 78 (6%) reviews. There were 120 (10%) comparison studies and only 10 (1%) randomized controlled trials.

Subject and research characteristics of included studies are reported in Table 2. Research themes are reported in Figure 4. Of the 1227 studies, there were 694 (56%) descriptive clinical epilepsy studies, 314 (26%) studies analyzing social components related to individuals with epilepsy, 90 (7%) interventional studies, 74 (6%) basic science studies, 47 (4%) diagnostic studies, and eight (1%) systematic reviews about epilepsy. Some subjects were frequently investigated focus areas, namely etiology ($n = 266$, 22%), clinical features ($n = 280$, 23%), epidemiology ($n = 196$, 16%), and drug management findings ($n = 147$, 12%). Conversely, epilepsy surgery ($n = 15$, 1%), neuroimaging ($n = 56$, 5%), genetics ($n = 50$, 4%), long-term outcomes ($n = 73$, 6%), and electroencephalographic features ($n = 77$, 6%) were explored less frequently. There was a balance between studies specifically investigating adults ($n = 345$, 28%) and children ($n = 332$, 27%), with 452 (37%) reports including all ages. There were 18 (2%) studies on women. A total of 472 (38%) studies noted unique Africa themes (Table 3).

**TABLE 1** Data extraction framework

| Key domains | Description |
|---|---|
| Year published | Year of publication |
| Type of journal | International |
| | African |
| Author | Indicate where the lead author is based (e.g., African based in Africa, non-African in Africa, African based outside of Africa, and non-African not based in Africa) |
| Number of African authors | Percentage of authors of African origin in each study |
| Author composition | Single author or multiple authors on the paper |
| Study location | The region the study was completed in and the respective countries within the region |
| Type of study | Case series[a] |
| | Comparison study |
| | Observational study |
| | Survey |
| | Randomized control trial |
| | Review article |
| Research theme or focus | 1. Clinical epilepsy<br>• Epidemiology—prevalence and incidence of epilepsy of the study participants<br>• Etiology<br>• Clinical features<br>• EEG features<br>• Neuroimaging<br>• Genetics<br>• Drug management<br>• Epilepsy surgery<br>• Long-term outcomes<br>1. Research subject characteristics<br>• Children, adults, women, or mixed populations<br>• Number of study subjects<br>• Comorbidities (i.e., anxiety, ADHD, ASD, learning disability)<br>1. Etiologies of special interest to Africa<br>• HIV<br>• Sickle cell disease<br>• Nodding syndrome<br>• Neurocysticercosis<br>• Tuberculosis<br>• Cerebral malaria<br>• Trauma<br>• Birth asphyxia |
| Funding for research | Pharma driven |
| | Research grants |
| | Association funding (i.e., ILAE) |
| | Other |

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; EEG, electroencephalographic; ILAE, International League Against Epilepsy.

[a]Data from more than five cases.

## 3.2 | Topics of special relevance to Africa

Among the 194 studies describing etiologies of special interest to Africa, nodding syndrome ($n = 53$, 27%), neurocysticercosis ($n = 65$, 34%), cerebral malaria ($n = 15$, 8%), and human immunodeficiency virus ($n = 12$, 6%) were key themes. Birth asphyxia ($n = 2$), sickle cell disease ($n = 1$), tuberculosis ($n = 1$), and trauma ($n = 1$) had less frequent reports. The following topics expand on areas of special relevance to Africa, illustrating that unique, targeted, and evolving research can be done well, especially in the African setting.

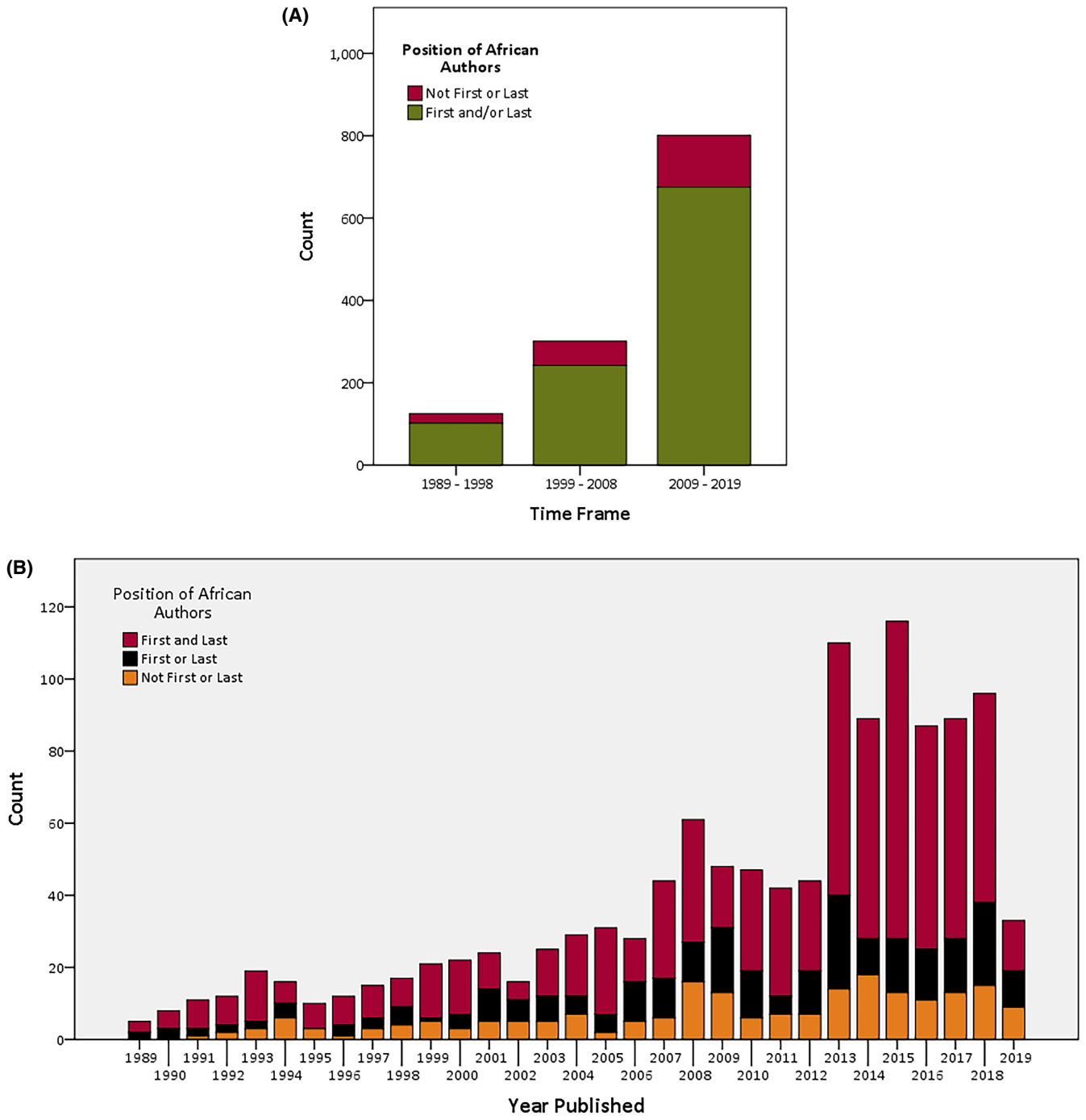


**FIGURE 2** (A) There was a statistically significant difference in publications across three time frames but with no proportional variance in lead authorship positions. (B) Detailed illustration of trends in publication numbers and African lead authorship between 1989 and 2019

### 3.2.1 | Traditional healers

Studies relating to traditional healers frequently reported that people with epilepsy chose traditional healers over health care professionals as their preferred practitioners to manage their epilepsy. This was often driven by beliefs about the underlying cause of the epilepsy, as well as traditional healers having more cost-effective payment methods and better availability.[13–17] Trends in research over time moved toward working with traditional healers to build on resources to support people with epilepsy[18–20] and to develop models to improve pathways to care.[21–25] Traditional healers are notable for their cultural understanding and use of plants in the management of epilepsy as well their ability to provide detailed clinical descriptions of event semiology.[26,27] Exploring the preferred use of traditional healers led Millogo et al. to note that traditional healers can impart useful messages, namely their

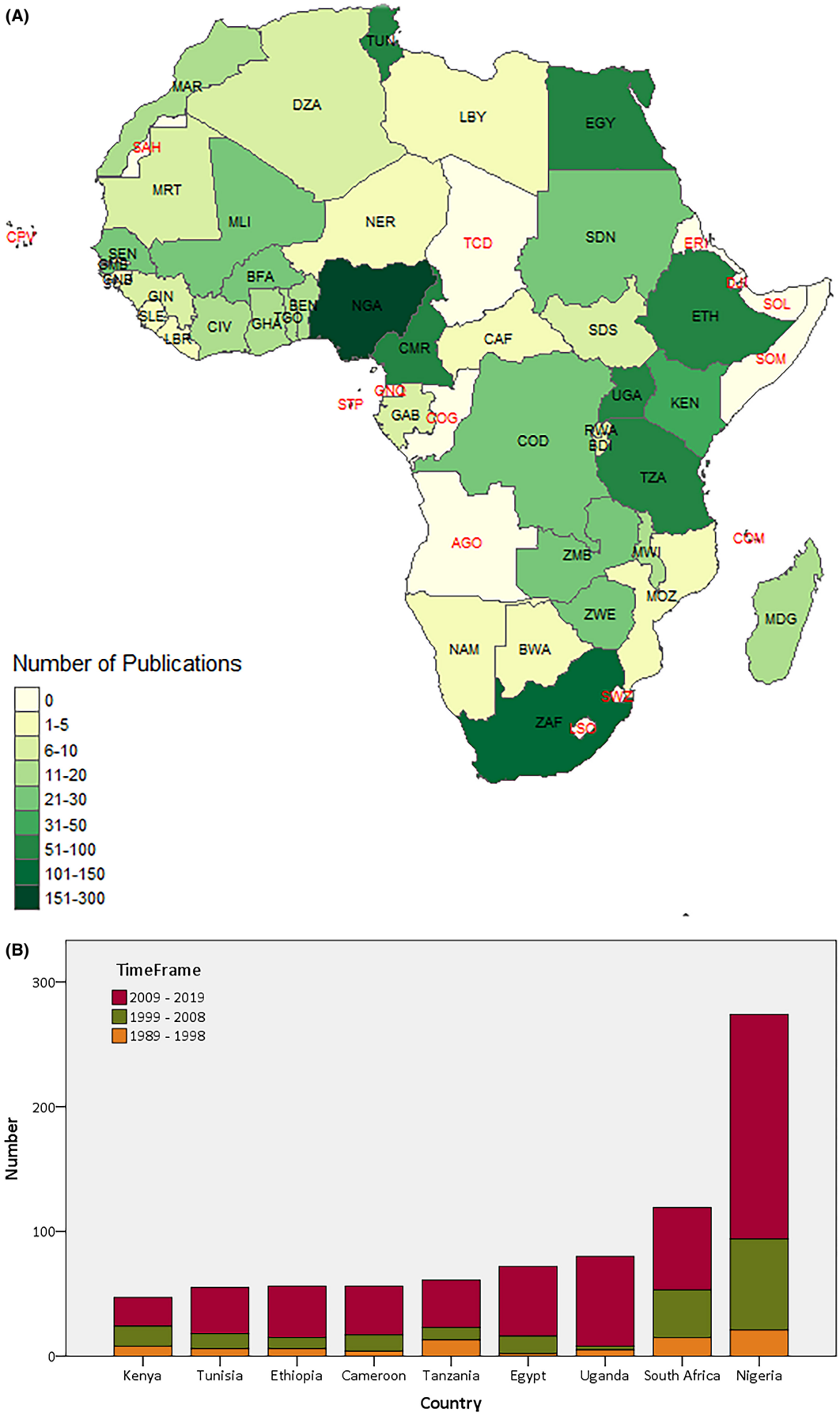


**FIGURE 3** (A) Heat map to illustrate the range of publications on epilepsy generated over 1989–2019 in African countries. (B) African countries with >50 publications on epilepsy topics, illustrating the increase in publications with each decade, especially 2009–2019

**TABLE 2** Location, funding, and author characteristics of included studies

| Characteristics, $N = 1227$ | *n* (%) |
|---|---|
| Year published | |
| 1989–1999 | 146 |
| 2000–2009 | 328 |
| 2010–2019 | 753 |
| Type of journal | |
| African journal | 403 (33) |
| International journal | 824 (67) |
| Research funding, $n = 361$ | |
| Pharma driven | 4 (1) |
| Research grant | 110 (30) |
| Associations | 15 (4) |
| Other | 232 (64) |
| Region of Africa published from | |
| East Africa | 292 (24) |
| West Africa | 428 (35) |
| Sub-Saharan Africa | 177 (14) |
| Central Africa | 90 (7) |
| North Africa | 181 (15) |
| Multisite | 177 (14) |
| Authors of study | |
| Multicenter | 406 (33) |
| Africa and other countries | 543 (44) |
| Other | 278 (23) |
| Authorship of African authors | |
| Not first nor last | 208 (17) |
| First or last | 257 (21) |
| First and last | 762 (62) |

advice to people with epilepsy to stay away from fires and to avoid eating pork.[28] Although limited at many other treatment levels of epilepsy care, implementation of these two aspects would have significant impact for prevention of seizure injury and prevention of neurocysticercosis in endemic regions.

### 3.2.2 | Ethnopharmacology

The study of ethnopharmacology is very exciting in the African context, with overlap in the field of traditional healers' practice, as this group often has extensive knowledge of and is involved in the clinical application of plant-based products for people with epilepsy.[26,27] Early animal models (typically mice) were used to explore the role of products such as the West African black pepper water extract[29] and ethanolic extract of the leaves of *Maprounea africana*.[30] Sehlare sa Seebana is a trditional Nothern Sotho herbal remedy for epilepsy which consisted of aqueous and ethanol extracts of six plants adminstered by inhalation of smoke. This product was effectively tested in a γ-aminobutyric acid type A ($GABA_A$)–benzodiazepine receptor binding assay.[31] *Rhus chirindensis* stem-bark extract is used in South African traditional medicines and produces its antiseizure effect by enhancing GABAergic neurotransmission and/or action in the brain. The authors proposed that the plant could be a natural supplementary remedy in the management of childhood seizures.[32] *Searsia dentata* and *Searsia pyroides* are used in traditional South African medicine to treat convulsions and epilepsy. In a mouse model study, the N-methyl-D-aspartate (NMDA) receptor antagonistic effect was demonstrated for the crude ethanolic extracts of these two South African medicinal plants.[33] Another study on the same plant species, collected from the Botanical Garden at the University of KwaZulu-Natal, confirmed the specificity of the plants and justified their use in traditional medicine for the treatment of epilepsy.[34] Nigerian studies on the aqueous leaf extract of *Albizia glaberrima* found that the product enhanced GABAergic inhibitory actions[35] and suggested that the methanol leaf extract of *Laggera aurita* possesses antiseizure properties.[36] A study from Cameroon found that *Senna spectabilis* possesses antiseizure activity, hypothesizing that the plant decoction could interact with $GABA_A$ complex receptor probably at the GABA and benzodiazepines sites.[37] Overall, although there is common and ongoing use of plant products by traditional healers for people with epilepsy, research on this at a scientific level continues to be on mouse models.[30–36] In settings where access to antiseizure medications is often challenging, to identify effective and sustainable local remedies would be ideal.

### 3.2.3 | Nodding syndrome

Over the past decade there have been >50 reports on nodding syndrome, a condition that has undergone unique clinical, electroclinical, biomedical, and epidemiological assessments.[38–41] This condition is prevalent in specific regions of Africa, especially Uganda, Tanzania, and Sudan, with variations in phenotypic expression.[42] Affected children have an occasional nodding of the head, which can correlate with seizure activity and is often triggered by eating.[43]

Although the pathogenesis has not been completely delineated, a role of *Onchocerca volvulus*, the parasitic filarial worm responsible for river blindness that is highly endemic in these areas, is suspected. The result of the careful correlation of nodding syndrome with high prevalence of

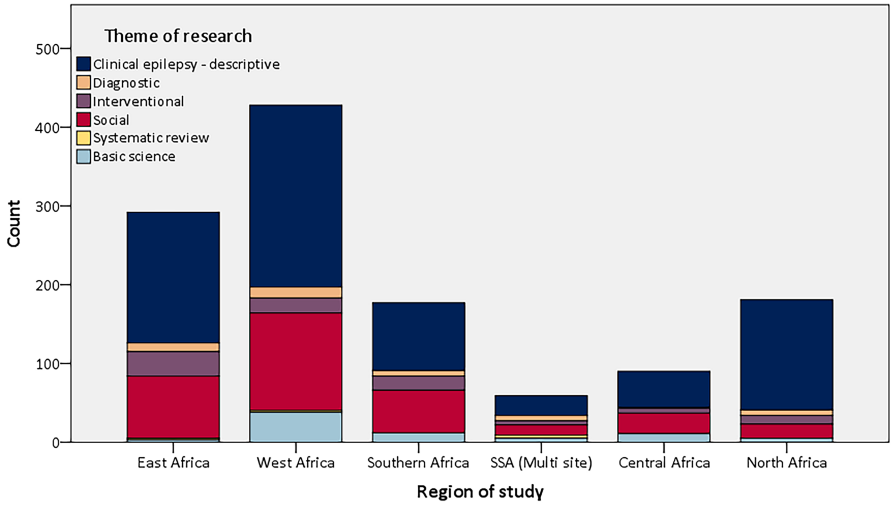


**FIGURE 4** Regional breakdown of research themes illustrating across Africa the focus on descriptive clinical epilepsy studies and research related to social issues compared to the more limited focus on diagnostic, interventional, and basic science research. SSA, sub-Saharan Africa

onchocerciasis has led to community-directed treatment with ivermectin, such that there was a significant decrease in the incidence of nodding syndrome between 2012 and 2017.[44] Similar conclusions were drawn from community studies in Cameroon.[45,46] More recent reports have highlighted the correlation of malaria with disease expression and outcome in children with nodding syndrome.[2,47] This led to promotion of intervention with doxycycline to eradicate or prevent malaria in children with nodding syndrome.[47,48] Nodding syndrome is also considered to be a neuroinflammatory disorder, triggered by antibodies to *O volvulus* or its symbiont, *Wolbachia*, which cross-react with human neuron proteins. Doxycycline may have a treatment role, as it is hypothesized to kill *Onchocerca* through effects on *Wolbachia*.[47]

Numerous other etiologies have been explored, such as autoimmune encephalitis, which was considered unlikely based on negative anti-NMDA and anti-voltage-gated potassium channel receptor antibodies in affected patients.[49] Metabolic derangements were not evident[50] as a cause, nor was the consumption of mycotoxins in contaminated foods.[51]

As the course and phenotype of the disease was understood, symptomatic guidelines were developed by the leading African clinicians and successfully implemented.[52] The debate about the correlation of the movements (head nods) and seizures was carefully delineated via neurophysiological studies.[53] The social challenges and burden of disease were noted as well as caregiver perceptions and the involvement of traditional healers.[54]

### 3.2.4 | Neurocysticercosis

Neurocysticercosis is also an established public health challenge affecting regions in Africa and beyond. It is related to poor pigpen management and contamination of food products. Epidemiological studies confirmed that in some regions, especially rural locations, neurocysticercosis was the predominant cause of epilepsy in adults.[55,56] Studies confirmed the high number of disability-adjusted life-years impacted by neurocysticercosis.[57,58]

Interventional public health programs have been implemented and identified further challenges to change community practices.[59] Serial vaccination of pigs with the TSOL18 vaccine and medication with oxfendazole eliminated *Taenia solium* transmission by pigs in a study in Uganda.[60] The World Health Organization (WHO) includes addressing *T solium* as one of the 2030 goals, noting the debate between biomedical interventions (human and pig treatment and pig vaccination) compared to improved husbandry, sanitation, and meat inspection with insight into the need for sustainable solutions for severely resource-constrained endemic settings.[61] A computer-based *T solium* educational program, "The Vicious Worm," was rolled out to primary school students in Zambia and led to significantly increased knowledge after the educational component, particularly regarding parasite transmission and disease prevention.[62]

Despite the public health awareness of the spread of cysticercosis, much remains unknown about many key pathogenic aspects of the disease, including how cerebral infection with *T solium* results in the development of seizures.[63] Eloquent basic science research suggests that *Taenia* larval acetylcholinesterases can interfere with cholinergic signaling in the host, potentially contributing to pathogenesis in neurocysticercosis.[64]

## 4 | DISCUSSION

This scoping review addresses the trends of data published on epilepsy in Africa over a 30-year period to identify the number of publications, the predominant themes

**TABLE 3** Subject and research characteristics of included studies

| Characteristics, $N = 1227$ | $n$ (%) |
|---|---|
| Type of study | |
| Case series[a] | 161 (13) |
| Comparison study | 120 (10) |
| Observational study | 572 (46.5) |
| Survey | 286 (23) |
| Randomized control trial | 10 (1) |
| Review article | 78 (6.5) |
| Theme of research | |
| Clinical epilepsy–descriptive | 694 (56.5) |
| Diagnostic | 47 (4) |
| Interventional | 90 (7) |
| Social | 314 (25.5) |
| Systematic review | 8 (1) |
| Basic science | 74 (6) |
| Clinical epilepsy | |
| Epidemiology | 196 (16) |
| Etiology | 266 (22) |
| Clinical features | 280 (23) |
| EEG features | 77 (6) |
| Neuroimaging | 56 (4.5) |
| Genetics | 50 (4) |
| Drug management | 147 (12) |
| Epilepsy surgery | 15 (1) |
| Long-term outcomes | 73 (6) |
| Research subjects | |
| Children | 332 (27) |
| Adults | 345 (28) |
| Women | 18 (1.5) |
| Children and adults | 452 (36.5) |
| Etiologies of special interest to Africa, $n = 194$ | |
| HIV | 12 (6) |
| Sickle cell disease | 1 (.5) |
| Nodding syndrome | 53 (27) |
| Neurocysticercosis | 65 (33.5) |
| Tuberculosis | 1 (.5) |
| Cerebral malaria | 15 (8) |
| Trauma | 1 (.5) |
| Birth asphyxia | 2 (1) |
| Other | 54 (28) |

Abbreviations: EEG, electroencephalographic; HIV, human immunodeficiency virus.

[a]Data from more than five cases.

published, characterization of authorship, and where research is occurring, as well as the gaps in research topics and locations. Epilepsy in Africa is a significant challenge, particularly in children, who make up at least 50% of the population in most regions.[2–4] Compared to better resourced regions, availability of data on epilepsy from Africa is wanting, and strategies to reverse these trends are needed urgently.[65,66]

Africa has many unique challenges related to the prevention and management of epilepsy, ranging from low availability of skilled health workers, the smallest global proportion of neurologists, poor availability of efficacious antiseizure medications with fewer side effects, low public awareness of epilepsy and resultant stigma, and significant barriers to research.[65–68]

It is reassuring to see the steady increase in publications, especially over the past decade, and that two thirds of the reports are included in peer-review international journals. In addition, African researchers appear to be taking the lead in the majority of reports, although the ratio of African lead versus non-African lead has shown little variance over the past 30 years. Some regions and countries are leaders in this and could represent research hubs and focal areas to be pivotal in upscaling epilepsy research in the future. This is especially the case for Nigeria, South Africa, Uganda, Egypt, Tanzania, Cameroon, Ethiopia, Tunisia, and Kenya. It is worrying that many countries had either no or minimal research publications. Some regions tend to publish on relatively narrow themes and are yet to branch out into broader epilepsy themes. However, the expertise evident from these groups, for example, nodding syndrome, illustrates how a uniquely African condition can be explored from bench to bed, resulting in effective interventional studies and in real change in practice.[44–46,48]

Some 30% of the studies were supported by diverse funding resources. In the setting of scarce resources and busy clinical practices, access to funding support can be critical to enable study completion. Similarly strengthening collaborations both across Africa and with international colleagues can lead to innovative and effective outcomes. This includes assistance with the development of study methodology, meticulous data capturing, and accurate analysis and interpretation of findings. It is imperative that these collaborations are also learning and training opportunities that consistently build the capacity at the level of the African center.[66]

The quality of the research was of concern but not surprising based on the resource constraints. Most studies were observational and often survey based. There were few randomized controlled trials. Interventional studies were scarce, and much of the research was driven by clinical epilepsy descriptions (e.g., etiology, clinical profiles, and diagnostics). There were some very strong studies addressing epidemiology that had critical implications for confirming the burden of disease in regions,[3,5,69] as well

as large community-based studies exploring expression of key diseases such as nodding syndrome and prevalence of onchocerciasis.[70,71] However, these studies tended to be the exception, and compared to activity across resource-equipped settings, the overall quality of the studies was not comparable. Further, internationally topical epilepsy research areas, such as epilepsy surgery and genetics, were scarce, reflecting the limited access to these resources across the continent.[72,73] The importance of region-specific genetic studies in epilepsy is well understood, and with the significant genetic diversity represented on the continent, genetic studies in epilepsy would foster the possibility of precision medicine, with targeted interventions for patients, as well as potentially contributing to further understanding of the etiology of epilepsy in this region. There is a high burden of brain injury in Africa, especially for children, resulting in structural insults that often have lesional implications, for which epilepsy surgery may be remedial and have significant impact on resolution of epilepsy for these patients.

The data in Figure 5A illustrate the limitations in H index for countries in Africa (neuroscience papers published 1996–2020). Compared to H indexes for combined regions, Africa is second to last despite having the most countries (Figure 5B). The Organization for Economic Co-operation and Development combined 34 of the wealthiest

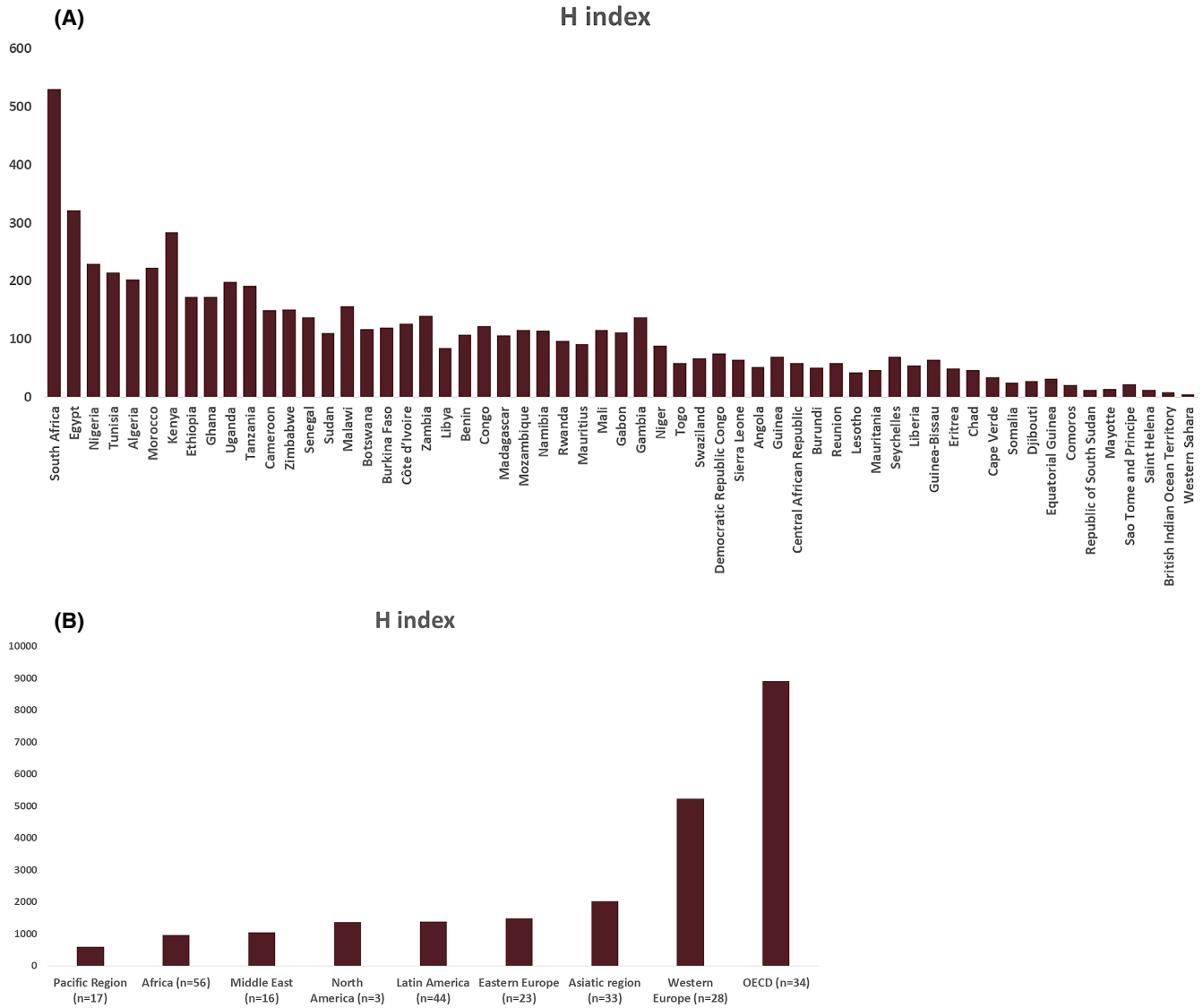


**FIGURE 5** (A) H index for countries in Africa from neuroscience papers published 1996–2020. Accessed at https://www.scimagojr.com/countryrank.php?region=Africa, September 25, 2021. (B) H indexes of Africa other regions of the world, demonstrating that Africa is second to last, despite having the most countries. Furthermore, the combined resource-equipped countries of the Organization for Economic Co-operation and Development (OECD) have the highest H index. Accessed at https://www.scimagojr.com/countryrank.php?area=2800, September 25, 2021

high-income countries, which through this collaboration work together with governments, policymakers, and citizens on establishing evidence-based international standards and finding solutions to a range of social, economic, and environmental challenges. It is striking that this well-resourced collection achieved the highest combined H index.

As illustrated, Africa has some truly unique areas of research, namely nodding syndrome and neurocysticercosis, which have included basic science and laboratory-based analysis, epidemiological studies, and subsequently interventional research leading to disease-changing outcomes. Africa-based studies with strong international collaboration on nodding syndrome illustrate an effective model that encompasses understanding disease expression and epidemiology, exploring the etiology in depth, reviewing biomedical markers, understanding the socioeconomic implications, and implementing pathways to both treatment and prevention. In similar fashion, research on neurocysticercosis spans the range of bench to bedside interventions as well as the community and socioeconomic aspects of the condition, which has led to preventive efforts and formulation of effective evidence-based management of epilepsy resulting from neurocysticercosis.

The African setting carries a significant burden of disease from stigma and has undertaken extensive research into this area and various approaches not just to measure the extent of the issue but also the effective models of intervention to lead to change.[8,74–77] The continent is also well placed for exploring novel approaches to disease that may not be acceptable in resource-equipped settings; these could include a role for traditional healers[21] as well as ethnopharmacology and the field of neuropharmacognosy.[36,37,65,78] Not surprisingly, almost half the reports on specifically African themes addressed these high-burden etiologies and social challenges for people with epilepsy.

Overall, the focus of reports for minority groups was disappointing, with less than one third of the studies addressing children specifically and very few related to women with epilepsy.

Developing successful research programs that progress beyond preclinical and observational studies is challenged by many barriers in the African setting.[66] These barriers and potential solutions are addressed in the WHO/ILAE report, specifically the chapter, "Research on Epilepsy."[79] The conceptual model devised by Franzen et al. featured a three-pronged approach to develop sustainable health research capacity in low- and middle-income countries.[66] This focused on the needs of the individual, namely being aware of research and trials, becoming motivated to lead or work on trials, gaining knowledge and skills through this process, and being able to take on trial leadership capabilities. At an operational level, these researchers and other stakeholders should be able to form collaborations, as well as acquire resources inclusive of trial operations and implement relevant policy. The combined result would enable strengthening at the macro and institutional level with national grants and the expansion of networking platforms.

Despite some innovative researchers, basic science research was proportionally low, and is a key area that needs to be promoted. There are hubs of activity across Africa, and the International Brain Research Organization (IBRO) has further facilitated neuroscience in the African region via the Society of Neuroscientists of Africa (SONA), especially with the development of neuroscience training schools in Morocco and South Africa. The founding of the SONA in 1993 opened exciting avenues for upscaling African neuroscience research.[65] The IBRO provided critical support to the establishment and growth of the SONA through conference and workshop support as well as research fellowship opportunities. Various other groups have been critical in supporting the advance of African neuroscience, including the International Child Neurology Association, ILAE, International Society for Neurochemistry, National Institutes of Health, World Federation of Neurology, and World Federation of Neurosurgical Societies. Although this international support remains essential, African neuroscientists have a role in engaging in policy and decision-making to persuade governments to fund studies that address the unique regional needs in Africa.

Basic neuroscience research on local African fauna and animal models of brain disorders offers novel and innovative opportunities. This has supported the field of neuropharmacognosy and the implications for disease-modifying benefits of administering plant extracts to experimental animals.[80]

## 5 | STRENGTHS AND LIMITATIONS OF THIS STUDY

This scoping review only synthesizes research publications over 30 years (1989–2019). There may be equally important articles before this period or published after this period. Research publications in other languages (i.e., those outside of English, French, and Portuguese) were not used but may contain valuable information. However, the main languages spoken in Africa are English and French, with six countries speaking Portuguese. The keywords used were broad and may not have identified specialized studies. Regardless, this study will serve as a benchmark for future epilepsy research in Africa. Finally, this study having only one lead reviewer for individual papers is a

limitation that may have had an impact on the quality of the data collected.

## 6 | CONCLUSIONS

Epilepsy research in Africa has increased over the past 30 years, but there remains a great need to enhance the capacity of the region both for the quality of the studies and to encompass broader relevant areas. This would include more research focused on vulnerable groups, such as children, women, and the elderly, and increasing high-quality interventional studies to implement change in practices for high-burden areas, as successfully illustrated for nodding syndrome and neurocysticercosis, in addition to increasing research into areas underresearched and still relevant, such as the role for epilepsy surgery and the expression of epilepsy genetics in the region. For this to be possible, although strong international collaboration remains essential and joint funding projects should be promoted, the lead for these studies should come from Africa, led by Africans. To enable this, training is critical for neuroscientists and clinicians spanning from the laboratory to the clinical setting. In line with the International Global Action Plan for Epilepsy and other Neurological Disorders, Africa should increase its footprint by significantly upscaling epilepsy research within Africa, by Africans. Only with this model can relevant, viable, and sustainable practice change be implemented. As stated by Bentivoglio et al., have powerfully and rightfully advocated for the need to have African problems resolvedthrough goal-directed basic neuroscience research conducted in Africa to addressregion specific disorders.[81]

### AUTHOR CONTRIBUTIONS

Pauline Samia, Jo Wilmshurst, Jane Hassell, Jessica Hudson, Charles Hammond, and Stéphane Auvin were involved in conceptualizing the study. All authors were involved in evaluation of the raw data. Jasmit Shah provided statistical support. All authors provided intellectual input and approved the final manuscript.

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### CONFLICT OF INTEREST

S.A. and J.W. are associate editors for *Epilepsia*. None of the other authors has any conflict of interest to disclose.

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## SUPPORTING INFORMATION

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

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