Addressing the treatment gap and societal impact of epilepsy in Rwanda — Results of a survey conducted in 2005 and subsequent actions

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ABSTRACT

This study, supported by the Rwandan Ministry of Health and the World Health Organization, was conducted in 2005 to determine the prevalence of epilepsy and its sociocultural perception in Rwanda, as well as epilepsy-related knowledge and practices of health-care professionals (HCPs). A cross-sectional, nationally representative survey was conducted throughout Rwanda by trained investigators. Participants were recruited by random cluster sampling based on the organization of administrative units in the country. Overall, 1137 individuals (62% from rural areas) were interviewed. The prevalence of epilepsy was estimated to be 49 per 1000 people or 41 per 1000 for active epilepsy. Onset of epilepsy before the age of 2 years was reported in 32% of the cases. Family history of epilepsy, head trauma, and premature delivery were reported in 53%, 50%, and 68% of the cases, respectively. Most (68%) patients did not receive any medical treatment for epilepsy; 21.5% had received some form of traditional treatment. According to responses from the general population, people with epilepsy should not be entitled to schooling (according to 66%), to work (according to 72%), to the use of public places (according to 69%), or to marriage (according to 66%). Furthermore, 50% believed that epilepsy was untreatable, and 40% thought that it was transmissible. Of the 29 HCPs interviewed, the majority knew the definition of epilepsy and status epilepticus, as well as basic treatment options and side effects. However, 90% believed that treatment was only necessary in the first week after a seizure. Living with epilepsy was associated heavily with stigma, and a significant treatment gap (68%) was identified. Following this study, numerous actions have been taken by the Rwandan government, the Rwandan League Against Epilepsy, and several nongovernmental organizations to increase awareness about epilepsy and to close the treatment gap. An overview of these activities is provided.

1. Introduction

Epilepsy is a common neurological condition worldwide; however, the incidence, the prevalence, and the burden associated with the disease are highest in low-income countries. Of the estimated 70 million people living with epilepsy globally, 80% are in developing countries [1].

In recent years, a number of studies have reported data on the prevalence of epilepsy in Sub-Saharan Africa, as well as on risk factors and the treatment gap. Up to 2004, epidemiological data on epilepsy in the Central African country of Rwanda were sparse. Rwanda is a landlocked country with an area of 26,338 km^2 and a population of approximately 12 million inhabitants [2]. In 2005, the prevalence of epilepsy in this country was reported to be 7 per 1000 [3]. This estimate was obtained from a survey on the prevalence and causes of musculo-skeletal impairment; questions about seizures were included at the request of Ministry of Health, since people with epilepsy often came to the attention of health services through treatment for trauma caused during seizures.

Our study, which was supported by the Rwandan Ministry of Health and the World Health Organization, ran almost concurrently to the one described above; however, its focus was exclusively on epilepsy. Furthermore, while the primary objective was to determine the prevalence of epilepsy in Rwanda, our study had several further objectives. Notably, we sought to identify the etiological factors of epilepsy in Rwanda and to evaluate the sociocultural perception and the level of knowledge and attitudes about epilepsy in the general population. We also assessed the level of knowledge and practices of health-care professionals (HCPs) caring for people with epilepsy.

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The data and insights gained from this survey were instrumental in developing a comprehensive program to increase awareness of epilepsy, to reduce the stigma associated with the disease, and to close the treatment gap. We provide the results of the cross-sectional survey, as well as an overview of the numerous actions taken by the Rwandan government, the Rwandan League Against Epilepsy, and several nongovernmental organizations since 2005 as the direct consequence of this survey.

2. Methods

This was a cross-sectional study conducted in September 2005 under the auspices of the Rwandan Ministry of Health in collaboration with the World Health Organization (WHO). Participation in the survey was entirely voluntary and anonymous. All investigators carried an authorization letter from the Ministry of Health, which also included an explanation of the rationale and the objectives of the survey.

The study consisted of three separate surveys. The first two surveys were conducted in the general population — the first one was used to determine the prevalence of epilepsy, and the second one was used to evaluate the sociocultural perception and the level of knowledge about epilepsy. The third survey, conducted among HCPs, assessed their level of knowledge and practices relating to epilepsy.

2.1. Population and health-care professional sampling

The size of the sample from the general population was calculated based on the estimated 10 per 1000 expected prevalence of epilepsy, with an accuracy of 2.5% for an infinite population and a confidence level of 95%, taking into account a cluster 2 effect. The sample size needed for this survey was calculated to be 1137 people.

Survey locations were determined by random cluster sampling. Clusters were selected in three stages based on the units of administrative structures in Rwanda. In the first step, five administrative districts – one from each of the five provinces of the country (North, East, West, South, and City of Kigali) – were selected randomly. In the second step, five sectors – one from each of the five aforementioned administrative districts – were selected randomly. In the third step, 10 cells, two from each of the sectors, were selected randomly. Each cell consists of 110 households; consequently, with an average number of 4–5 people in a typical household and 1100 households targeted, the final number of possible inhabitants that could be reached was 4950.

Health-care professionals working in health centers serving in the districts where the population-based survey was conducted were randomly selected for participation in the survey. Seven such centers were targeted.

2.2. Investigators and questionnaires

All survey investigators (at least senior technician in Health Sciences) underwent specific training in epilepsy and the questionnaire overseen by the project researcher (F. Sebera) and representatives of the Ministry of Health and WHO.

The survey on the prevalence of epilepsy was conducted using a validated questionnaire for countries in tropical and subtropical areas developed by the Institute of Epidemiology and Tropical Neurology of Limoges, the Pan African Association of Neurological Sciences (PAANS), and the International League Against Epilepsy (ILAE) [4]. Briefly, the questionnaire consists of nine modules or chapters and is conducted in two stages. In the first stage, the entire survey population is screened using the first two modules (demographics and screening) in a door-to-door survey. In the second stage, all individuals screened as positive are examined by a physician to confirm epilepsy using the third module (epilepsy confirmation). If the individual was determined to have epilepsy by the physician, as well as depending on the specific objectives of the survey, the physician will fill out the six remaining modules (natural history of epilepsy, history of epilepsy, clinical examination, supplementary examination, etiologies and, antiepileptic treatment).

The second part of the current survey, relating to the perception of epilepsy in the general population, was carried out using a questionnaire developed by a team of clinical neurologists in Dakar, Senegal. The questionnaire consists of three parts: general knowledge about epilepsy, the experience of the population with epilepsy, and sociocultural implications of epilepsy. The questionnaire used for HCPs was developed by the ILAE and the International Bureau for Epilepsy (IBE) and consists of multiple choice questions relating to epilepsy training, clinical knowledge about epilepsy, and how people with epilepsy are treated and supported.

All questionnaires were translated into Kinyarwanda and were adapted to the sociocultural context of Rwanda.

2.3. Data collection, entry, and analysis

The general population survey was conducted in two phases. The first phase was a pilot, conducted in a single cell (Nonko) in the City of Kigali. Following this, the investigators and project researchers met to review and systematically rectify problems encountered during the presurvey. The second phase involved the actual collection of data through door-to-door visits of the households in the cells that had been selected randomly. Only individuals with permanent residence at the household were interviewed. If a given respondent was found to screen positive based on the epilepsy questionnaire, they were referred to a physician trained in epilepsy to confirm the diagnosis. The diagnosis of epilepsy was confirmed following a detailed history based on information provided by patients and their family, friends, or caregivers and a full clinical examination.

Data were double entered and analyzed using SPSS software (version 12.0). Chi-square tests were conducted to determine any association between epilepsy and demographic variables.

3. Results

3.1. Prevalence of epilepsy

A total of 1137 individuals from the general population were interviewed. Results from the randomly selected cells indicated that all socioeconomic strata of the country were represented, with 38% of the sample in urban areas and 62% in rural areas. Farmers and other agricultural workers accounted for just about half of the total population (n = 576, 50.6%). The second largest group was composed of people working from home and students or pupils (n = 212, 18.6%), followed by unemployed (n = 177, 15.5%) and professionals (n = 169, 14.8%). The mean age of those who were interviewed was 30.28 ± 16.2, and 52% were female.

Of the people interviewed, 71 had a positive response in the PAANS screening questionnaire, in that they reported symptoms that may have corresponded to a seizure. These symptoms included loss of consciousness with or without fall/convulsions; loss of urine and/or saliva; tremor or uncontrollable movements of one part of the body without loss of consciousness; auditory or visual hallucinations; and 'strange' bodily feelings. Based on the positive results on the questionnaire, these individuals were referred to a physician to confirm the diagnosis of epilepsy.

Following detailed description of history and full clinical examination, fifteen (21%) individuals were found to present these symptoms in the context of concomitant diseases such as alcohol intoxication, fever, stress/anxiety, diabetes, pregnancy complications, and malaria and were, therefore, excluded. The remaining 56 (79%) individuals had reported these symptoms more than once and did not have any concomitant disease. Of these individuals, 42 reported that they had already been diagnosed with epilepsy. Overall, of the 1137 individuals in the survey population, 56 confirmed cases of epilepsy were

identified, corresponding to a prevalence of 49/1000. Our results also indicated that 47 of the 56 individuals had active epilepsy, corresponding to a prevalence of 41/1000. Having active epilepsy was defined as having experienced a seizure within 5 years before the survey.

With the exception of sex, a significant association between demographic characteristics and cases of suspected epilepsy was identified (Table 1). The highest cases of epilepsy were found among individuals 19 years of age or younger (12.6%), unemployed (12.4%), and single (7.4%).

3.2. Seizure type and history

Of the people with epilepsy, the majority (84%) had experienced at least one seizure during the last 5 years, and 14% reported having experienced an episode of status epilepticus at least once.

The majority (70%) of seizures were described as generalized tonic–clonic seizures based on detailed seizure history; however, given limited diagnostic facilities, it could not be ascertained whether these were primary or secondarily generalized seizures. Fourteen percent of seizures were identified as secondarily generalized seizures. Of the primary generalized seizures, 29% were determined as myoclonic, 29% as absence, 11% as atonic, and the remainder as unknown. Simple partial seizures were reported by 16% of the people and complex partial seizures by 14%. It is important to note that patients may have reported more than one type of seizure. People with epilepsy were also asked if they could identify specific factors that triggered their seizures. The most frequently reported factors were emotion (18%), light stimuli (18%), lack of sleep (14%), occurrence during sleep (13%), and upon waking (11%).

A substantial proportion of the people with epilepsy (n = 20, 36%) reported that the onset of their condition was before the age of 2 years (Table 2). For the vast majority (95%) of the cases, onset of epilepsy was at or before the age of 20 years.

3.3. Etiology

Based on patient history, the following factors were found to have significant association with epilepsy: consanguinity between parents; family history of epilepsy; mother taking medication during pregnancy; premature birth; encephalitis; severe measles; neurological sequelae of disease; contact with dogs, cats, and pigs; head trauma with loss of consciousness (all p < 0.001); and prolonged posttraumatic coma

Table 1
Distribution of epilepsy based on population demographics.

	N	Epilepsy cases (%)	p-Value
Sex			0.401
Male	549	4.4	
Female	587	5.5	
Age			<0.001
<19 years	273	12.6	
20–49 years	719	2.5	
≥50 years	145	2.7	
Marital status			<0.001
Married	606	1.8	
Single	523	7.4	
Length of stay in the region where the survey was conducted			<0.05
<5 years	430	3.3	
≥5 years	705	5.8	
Profession			<0.001
Professional	169	2.4	
Agricultural worker/farmer	576	2.4	
Home-based/student/pupil	212	7.5	
Unemployed	177	12.4	
Religion			<0.05
Christian	1074	4.7	
Other	51	11.8	

Table 2
Reported age of patients at onset of epilepsy.

Age	N (%)
≤2 years	20 (36%)
2–6 years	7 (13%)
6–12 years	9 (16%)
12–20 years	6 (11%)
≥20 years	11 (20%)
Unknown	3 (5%)

(p = 0.004). Overall, head trauma, family history of epilepsy, and premature birth were reported in 50%, 53%, and 68% of patients with epilepsy, respectively. Family members with a history of epilepsy mentioned most frequently were grandparents (5%), uncles and aunts (17%), and cousins (21%).

Potential causes of epilepsy mentioned most frequently by respondents were obstructed labor with fetal distress, serious childhood illness, and head trauma. The most common childhood diseases reported by the respondents were meningitis, measles, and malaria, while head trauma was most commonly reported as the consequence of road accidents, blows to the head, and occupational accidents.

3.4. Treatment

Of the 56 people with epilepsy, 38 were not receiving treatment for their condition, resulting in a treatment gap of 67.8% (Fig. 1). Fourteen patients had been treated with traditional medicines, which were mostly of plant origin, but also included some of animal origin, minerals, and a mix. A total of 16 patients were on antiepileptic drugs (AEDs). Overall, 13 (23%) patients were receiving AEDs alone; of these, nine (16%) had received AEDs from the very start of their treatment, while four (7%) had started treatment with traditional options and then switched to AEDs. Of the remaining patients, three (5%) were receiving a mix of traditional medicine and AEDs, while the treatment history of two patients was unknown.

Of the respondents who were receiving medical treatment in the form of AEDs, only 49% managed to take the AEDs on a regular basis. The main reasons for not taking AEDs regularly were lack of funds (56%), unavailability of drugs (22%), personal reasons (11%), and unknown (11%). The most frequently used AEDS were phenobarbital (33%), valproic acid (44%), carbamazepine (44%), ethosuximide, vigabatrin, and gabapentin (22%); respondents could report taking more than one AED.

Among those who used traditional medicine, 82% had received their treatment from a traditional healer, while the remainder had obtained the treatment themselves. Most traditional medicines were administered orally (84%); other routes of administration were dermal (6%) and inhalation (3%). Scarification was also used as a method of treatment by 3% and, finally, prayers or incantations by a further 3%. Traditional treatment was considered effective by 48% of the respondents who used them and by 65% of their family members.

3.5. Sociocultural perceptions of epilepsy in the general population

While the majority (84%) of respondents expressed a fear of epilepsy, responses also revealed some understanding of the causes of epilepsy, with 45% indicating that epilepsy was due to brain infection and 39% reporting that it was the result of complications during childbirth. However, a substantial proportion reported that epilepsy was also due to evil spirits (53%), casting of an evil spell (32%), or evil thoughts (28%). Respondents were allowed to indicate more than one cause.

Responses also revealed a deep stigma associated with epilepsy. According to 66% of the respondents, people with epilepsy should not be entitled to schooling (66%), to work (72%), to the use of public places (69%), or to marriage (66%). Half the respondents also believed that
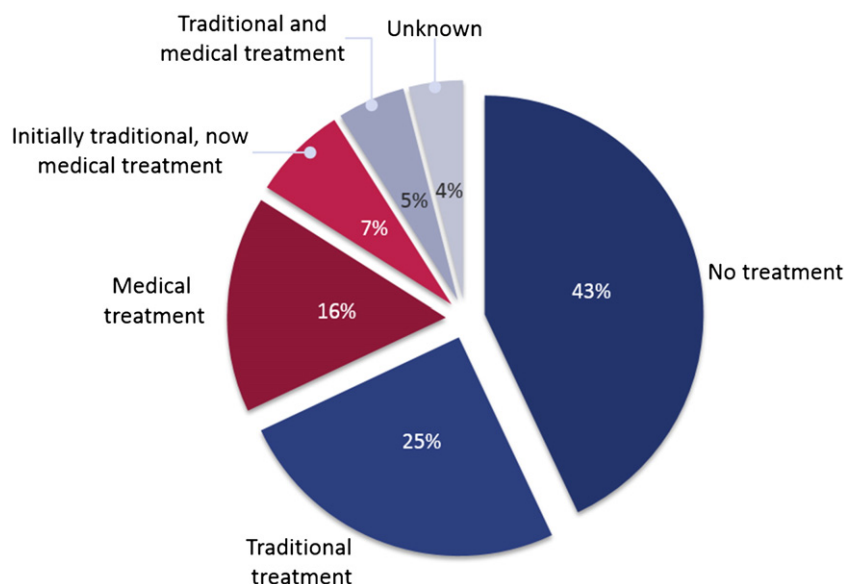
Fig. 1. Treatment pattern of patients with epilepsy in Rwanda in 2005.

epilepsy was untreatable, and 40% thought that it was a transmissible disease.

3.6. Epilepsy knowledge and practices of health-care professionals

Our study sample included 29 HCPs: 26 state nurses, two social workers, and one senior technician in mental health. Most (86%) of the respondents were familiar with epilepsy and status epilepticus, as well as basic treatment options and their side effects. When asked to describe the cause(s) of epilepsy, 41% reported that the most common cause could not be detected, 38% cited brain tumor, and the remaining 21% reported that epilepsy was caused by a reduction in cerebral blood flow.

Respondents knew that antiepileptic treatment was not curative. However, the majority (90%) believed that treatment was only necessary in the first week after a seizure; only 10% reported that treatment was required for at least 2 years. Only 38% reported that urgent medical intervention was necessary if the duration of a seizure exceeds 15 min. Of those, 90% chose phenobarbital as first-line therapy in status epilepticus, and 10% chose diazepam.

4. Discussion

4.1. Implications of the results — putting the findings in perspective

Based on the results of this cross-sectional survey, the prevalence of epilepsy in Rwanda is estimated to be 49 per 1000 people, or 41 per 1000 if only active epilepsy is considered. Results also reveal a treatment gap of 68%. However, it is important to note that the survey was conducted in 2005 — should it be repeated today, the results will most likely be different, especially the treatment gap.

The prevalence of 49 per 1000 people ranks among the highest in Sub-Saharan Africa. In a review of 28 door-to-door studies published between 1982 and 2004, a higher prevalence of epilepsy was reported in only two countries [5]. Two studies conducted in Cameroon reported estimates of 70 and 58 per 1000 in 1989 and 2000, respectively, and two studies from Ivory Coast reported estimates of 74 and 59 per 1000 in 1990 and 1995, respectively [5]. A third study from Ivory Coast conducted in 1988 reported a prevalence of only 7.6 per 1000, while a recent study in Cameroon reported an even higher prevalence of 105 per 1000 [6]. However, the survey was conducted in a geographically isolated area, hyperendemic for onchocerciasis. As noted by the review

authors, such divergence was also noted in two Nigerian studies conducted among the same ethnic community living 20 km apart using the same protocol; in one study, the prevalence was 5.3 per 1000, and, in the other, 37.0 per 1000 [5]. In another review of 32 studies conducted up to 2012, prevalence values ranging from 0 to 36 per 1000 were reported [7]. The large variation in the prevalence of epilepsy across Sub-Saharan Africa is further demonstrated in a large-scale study conducted across five countries: Kenya, South Africa, Uganda, Tanzania, and Ghana [8]. The prevalence of active convulsive epilepsy ranged from 7.0 per 1000 in South Africa to 14.8 per 1000 in Tanzania. The investigators attributed this variation to the distribution and types of risk factors rather than methodology since they had used the same cross-sectional and case–control study design in all five countries.

The prevalence estimate in our survey was also substantially higher than the 7 per 1000 reported in the only other survey conducted in Rwanda [3]. However, as noted, there are several important differences in the methodology of the two surveys. The primary focus of the survey by Simms and colleagues was the prevalence and causes of musculo-skeletal impairment. For detection of epilepsy, respondents who answered 'yes' to any of the following during screening, "Do you ever have fits, involuntary movement, rigidity, or loss of consciousness?", were examined in more detail by a physiotherapist using the diagnostic section of the questionnaire. For the current survey, we used the validated PAANS epilepsy screening questionnaire [4], and the survey investigators underwent specific training in epilepsy. The questionnaire was overseen by the project researcher and representatives of the Ministry of Health and WHO. In fact, 42 of the 56 patients subsequently confirmed as having epilepsy had already been diagnosed with the disease, and only 14 new cases were identified in the survey. Our survey also included people in urban regions where there is a higher level of health education and awareness compared with rural regions, which can facilitate the reporting of the disease. These observations underscore the robustness of our study.

The high prevalence may be confounded by the lack of additional diagnostic tools; indeed, lack of EEG was one of the main limitations of this study. However, in their analysis of epilepsy surveys in Sub-Saharan Africa, Paul et al. note that diagnosis should be confirmed by a HCP with expertise in epilepsy, using available medical history, seizure description, and neurologic examination and that lack of diagnostic instruments should not preclude the diagnosis of epilepsy [7]. The diagnosis of the epileptic nature of a seizure can be based on the description of the episode by the patient and witnesses and may

not require any specific investigation [9]. In fact, investigations such as a brain scan by magnetic resonance imaging or an EEG recording should not be used as screening tests owing to the presence of both false positives and negatives; they should only be used to corroborate clinical suspicion [10]. To confirm the diagnosis of epilepsy in our survey, patients who had a positive screen underwent a clinical examination by a physician and a detailed history was taken not only from the patients but also from their family, caregivers, and friends. Witness descriptions are mandatory for diagnostic purposes as they are more informative than the patients', given seizure-related loss of awareness, confusion, or amnesia [10].

It has been proposed that while door-to-door studies are considered to be the best available method for obtaining disease prevalence data, they are unlikely to recognize all forms of epilepsy, but rather only the most dramatic cases, and could, therefore, underestimate the true prevalence [7]. In the case of a study conducted in Benin, the prevalence was estimated to be 10.2% based on the results of a door-to-door survey and 38% based on a capture–recapture method [11]. After an 18-month follow-up during which health-care professionals, members of the general population, and village leaders in the study area were asked to identify suspected cases of epilepsy, the final prevalence was estimated to be 12% based on the combination of methods [11].

The majority (70%) of people with epilepsy in our survey reported that they experienced generalized tonic–clonic seizures. Given limited diagnostic facilities, a clear distinction could not be made in all cases. Nonetheless, the predominance of generalized tonic–clonic seizures has been reported in many other studies from Sub-Saharan Africa, notably because such seizures are more easily identifiable compared with other seizure types [5]. Use of EEG or scanning techniques could provide different results. In a recent study from Tanzania, 291 people with active epilepsy were offered investigation with a CT scan and EEG, the results of which were reviewed by neurologists in the UK [12]. At 71.5%, the predominant seizure type was found to be focal onset. In a survey from Cameroon, 52.6% of the cases had been classified as generalized, and 47.4% had been classified as focal epilepsy; after EEG investigation, generalized seizures were confirmed in 35.3% of the cases and focal in 64.7% [6]. However, according to the ILAE guidelines for epidemiological studies, EEG is not necessarily required for this classification [13].

In a substantial proportion of cases (36%) in our study, the onset of epilepsy was reported to be before the age of 2 years, with a further 13% reporting onset before 6 years of age. Young onset, perinatal complications, and premature encephalitis are all associated predominantly with primary generalized seizures. Indeed, patient histories revealed that family history of epilepsy, mother taking medication during pregnancy, and premature birth were significant etiological factors associated with epilepsy, as well as diseases such as encephalitis and severe measles; contact with dogs, cats, and pigs; head trauma with loss of consciousness; and prolonged posttraumatic coma. The reported potential causes of epilepsy are also in line with the findings from a large study in Kenya, South Africa, Tanzania, Uganda, and Ghana [8].

A family history of febrile or nonfebrile convulsions and previous head injury in adults were important preventable factors. In children, perinatal events and their mother being a widow were possible risk factors [14]. With regard to symptomatic epilepsy, potential causes of epilepsy mentioned most frequently by respondents were obstructed labor with fetal distress, serious childhood illness, and head trauma. The most common childhood diseases were meningitis, measles, and malaria. Head trauma was most commonly reported as the consequence of road accidents, blows to the head, and occupational accidents. Infectious diseases caused by close contact with certain animals are also important preventable causes of epilepsy. Recent evidence suggests that neurocysticercosis is associated with a considerable proportion of late-onset epilepsy in southern Rwanda [15]. Indeed, contact with pigs, the intermediate host of the causative agent *Taenia solium*, was one of the etiological factors identified in the survey. Human

toxocariasis caused by the larval stages of *Toxocara canis* and *Toxocara cati*, the common roundworm of dogs and cats, respectively, is also associated with epilepsy [16]. A significant association between toxocariasis and epilepsy was observed in neighboring Burundi [17]; results of our survey suggest an association in Rwanda, which requires confirmation through additional research. Results of a meta-analysis of eight studies from west (Benin and Nigeria), central (Cameroon and Central African Republic), and east Africa (Uganda, Tanzania, and Burundi) also suggested an association between epilepsy and onchocerciasis [18]; however, an association was not found in another study conducted in Tanzania [19].

Our study is limited by recall and other social biases inherent to surveys. Causative factors associated with epilepsy were evaluated based on self-reported data using questionnaires, which may be subject to recall bias and variability in the interpretation of questions. Furthermore, given the retrospective cross-sectional design of the survey, as well as the absence of EEG and other diagnostic tests to corroborate the self-reported findings, firm conclusions on the association between the causative factors and epilepsy cannot be drawn.

The treatment gap of 68% in our survey while high is relatively similar to those reported from recent studies across Sub-Saharan Africa, notably 70% in Kenya [14] and 76% in Southeast Nigeria [20]. In a study from Tanzania, the treatment gap was 76%, rising to 86% among patients with active epilepsy [21]. In another study from Tanzania, the treatment gap was reported to be 95%; however, this was in rural areas only [22]. Once again, it is important to reiterate that the 68% treatment gap was noted in 2005; given the measures described in Section 4.2, the current treatment gap is likely to be substantially smaller.

The predominant reasons explaining the treatment gap not only in Rwanda but also in other low-income countries are lack of resources, whether low supplies and high cost of drugs or lack of adequately trained HCPs [23–25]. Only 16% of the patients in our survey were receiving AEDs, and, of these, only 49% took them on a regular basis. The main reasons for not taking AEDs regularly were lack of funds (56%) and unavailability of drugs (22%). Another important reason for the treatment gap is that many individuals with epilepsy do not seek treatment, since they may not recognize that treatment can help or they are prevented from doing so in light of the substantial stigma associated with the disease [24,25]. Indeed, epilepsy was associated with significant stigma in our survey (see below). Traditional beliefs in the cause of epilepsy lead many to seek relief from traditional remedies. In Sub-Saharan Africa, as in many other poor regions, there is heavy reliance on traditional healers for health-care needs, and people with epilepsy have almost always sought care from healers before they are seen by HCPs [26]. In our survey, 26% of the patients had or were receiving some form of traditional treatment, whether oral remedies, scarification or prayers and incantations. While many (52%) of them did not consider these interventions effective, the majority (65%) of their family members did. These observations suggest that the treatment gap could be reduced substantially by ensuring adequate supplies of AEDs and educational initiatives to change attitudes to epilepsy, thereby reducing the stigma of epilepsy, which is a powerful barrier to effective care.

As noted above, the results of our survey unearthed substantial stigma associated with epilepsy, similar to observations in other countries in Sub-Saharan Africa. Epilepsy-associated stigma has been described as a devastating burden to people with epilepsy in Sub-Saharan Africa, with traditional healers identified as key figures in perpetuating the stigma [26]. However, in a survey of traditional healers in Cameroon, despite certain negative practices and attitudes, the majority reported that they would readily refer a patient to the hospital [27]. The authors suggest that collaboration between modern and traditional health-care systems to bridge the epilepsy treatment gap is possible.

The majority (84%) of respondents in our survey expressed a fear of epilepsy, while also revealing some understanding of the causes of epilepsy, with 45% indicating that epilepsy was due to brain infection and

39% reporting that it was the result of complications during childbirth. Some respondents also thought that epilepsy was due to evil spirits, casting of an evil spell, or evil thoughts. A similar supernatural and scientific divide was noted in a study conducted in Tanzania; 46.7% of the respondents thought that epilepsy was due to supernatural causes, while 51.5% assumed that epilepsy is a neurological condition or is inherited [28]. These observations indicate a gradual shift in the understanding and awareness of epilepsy, in that while attitudes may be changing, traditional beliefs are deeply entrenched, and educational initiatives are necessary. Indeed, despite some awareness of the causes of epilepsy, many respondents reported that people with epilepsy should not be entitled to schooling, to work, to the use of public places, or to marriage. Half the respondents also believed that epilepsy was untreatable, and 40% thought that it was a transmissible disease. Epilepsy has also been reported to be a contagious disease by 41% of people in Tanzania and 35% in Senegal [29,30].

4.2. Consequences of the survey findings — initiatives to combat epilepsy in Rwanda

Following the first disclosure of the results of this survey to the Rwandan government in 2005, numerous actions were taken to increase awareness of epilepsy, to reduce the stigma associated with the disease and to close the treatment gap. The initiatives have been carried out by different stakeholders, such as the Rwandan government, several nongovernmental organizations (NGOs), and personal commitment of individuals and funded or coordinated by bilateral or multilateral developmental sponsors.

Among the first of actions of the Rwandan government was to include the diagnosis and treatment of epilepsy in the minimal activity package of primary health-care centers, as well as to develop treatment guidelines. This was followed by ensuring availability of classic AEDs (carbamazepine, phenobarbital, phenytoin, and valproate) in the central pharmacy in Rwanda and access to phenobarbital in primary health-care centers. Other short- and medium-term goals included organizing educational seminars for HCPs, strengthening existing neuropsychiatric facilities in the reference center in Kigali and the two centers outside Kigali, and making EEG available in neuropsychiatric reference centers. The ministry of health has developed and validated a national strategic plan for mental health, which also includes epilepsy. A more comprehensive action plan on nontransmissible chronic diseases – diabetes, asthma, epilepsy, mental illnesses, and stroke – is under development.

Following the survey, Handicap International, an independent NGO, developed and implemented a vertically integrated epilepsy program between 2008 and 2012 in four districts: two in the west, one in the south, and one in the east of Rwanda [31]. The objectives of this program were to overcome stigma by changing the attitude of the community towards epilepsy and changing the perception of people with epilepsy regarding self-esteem and treatment adherence. This was achieved through training of volunteers within the community by raising community influencers' awareness and providing psychological and education support to patients and caregivers. Psychoeducational groups were also set up to encourage economic inclusion and to generate income.

Between 2008 and 2012, 6330 people with epilepsy have been identified in the four districts, with 2314 currently under medical treatment. A total of 460 health-care professionals have been trained, and 415 traditional healers and 563 religious leaders have been educated on epilepsy and its management. Importantly, 931 children with epilepsy have been integrated into regular primary schools.

The Rwandan League Against Epilepsy (RLAE) was created in 2009, subsequently becoming the local chapter of the ILAE in 2013 [32]. The initial objectives of the RLAE were identified as cascading centrally available resources to the districts, providing educational information to the general public about epilepsy, and strengthening capacities at the primary care level. The RLAE currently consists of 41 members,

including physicians, nurses, and people with epilepsy and their families, who are closely involved in the development of programs to raise awareness about epilepsy and the fight against social exclusion of people with epilepsy.

In 2012, the RLAE set up an 'educational caravane' in collaboration with Fracarita (http://www.fracarita-belgium.org/) – a Belgian NGO – and with the hospital of Ndera, Kigali. The aim of the caravane, which consists of a group of medical staff from the Ndera hospital, is to build capacity for the diagnosis and treatment of individuals with epilepsy in the Northern province. Physicians and nurses from district hospitals (N = 156) and primary care centers (N = 79) were trained in (differential) diagnosis of epilepsy, initiation of treatment, and identification of patients requiring referral to secondary or tertiary centers. Future initiatives aim to include rural HCPs to ensure identification of cases in more remote areas of the country.

It is very encouraging to observe the impactful consequences of the initial epidemiological research, which will ultimately improve the lives of patients with epilepsy in Rwanda. Continued efforts are needed to develop capacities of HCPs and AED access programs; to raise awareness within the community; to educate people with epilepsy, their caregivers, and the whole community; and to eliminate the root causes of stigma.

5. Conclusion

Based on the results of this survey conducted in 2005, the prevalence of epilepsy in Rwanda prevalence was found to be 49 per 1000 people, which ranks among the highest in Sub-Saharan Africa. Living with epilepsy was associated heavily with stigma, and a significant treatment gap (68%) was identified. Following this study, actions have been taken by the Rwandan government, the RLAE, and several NGOs to increase awareness about epilepsy and to close the treatment gap. While much has been accomplished in a relatively short period of time, continued efforts are needed to ensure that the momentum is not lost.

Conflicts of interest

Fidèle Sebera has received educational grant support from UCB Pharma. Dirk Teuwen, Azita Tofighy, and Peter Dedeken are employees of UCB Pharma, Brussels, Belgium. Professor Paul Boon has received support from UCB Pharma in the form of grants and speaker and consultancy fees. The remaining authors report no conflicts of interest relating to this study.

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