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ASSESSING KNOWLEDGE ATTITUDE AND PRACTICE OF COMMUNITY HEALTH WORKERS TOWARDS EPILPSY AND PEOPLE LIVING WITH EPILEPSY COMPARING TRAINED AND NON- TRAINED POPULATIONS IN RWANDA

**A CROSS-SECTIONAL STUDY**

*A dissertation submitted to College of Medicine and Health Sciences, School of Medicine and Pharmacy in partial fulfillment for the requirement of award of a Masters` degree in Internal Medicine, University of Rwanda.*

**By**

**Dr. Muhumuza Ndamage Stephen**

**SUPERVISORS:**

**Dr .TUEWEN Dirk UCB Belgium**

**Dr .SEBERA Fidèle, Honorary Senior Lecturer at UR, Senior Consultant Neurologist and Medical Director of the CARAES Neuropsychiatric Hospital.**

**Dr .DEDEKEN Peter, Neurologist and Consultant UCB, Belgium.**

**Dr .BITUNGUHARI Leopold, Lecturer at the University of Rwanda and Consultant Internal Medicine, Kigali University Teaching Hospital**

**13<sup>th</sup> June 2019**

## DECLARATION

I, Dr. MUHUMUZA NDAMAGE STEPHEN, to the best of my knowledge hereby declare and certify that the work presented in this dissertation entitled “**Assessing Knowledge, Attitude and practice of community health workers towards epilepsy and people living with epilepsy comparing trained and non-trained populations in Rwanda**” is entirely my own and original work and it has never been presented or submitted in whole or in part to any other university.

Dr. Muhumuza Ndamage Stephen

Signature: 

Date: ....13/06/19

### Supervisors:

We, hereby declare that this dissertation has been submitted with our approval as the supervisors.

Dr Tuewen Dirk

Signature: .....

Date: .....

Dr. Sebera Fidele

Signature: .....

Date: .....

Dr Dedeken Peter

Dr. Bitunguhari Leopold

Signature.....

Date: .....

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Dr. Muhumuza Ndamage Stephen

## **ABSTRACT**

KNOWLEDGE ATTITUDE AND PRACTICE OF COMMUNITY HEALTH WORKERS IN EPILEPSY AND PEOPLE LIVING WITH EPILEPSY IN TWO HEALTH DISTRICTS COMPARING TRAINED AND NON TRAINED GROUP CROSS-SECTIONAL STUDY.

### **BACKGROUND**

Epilepsy as a non- communicable disease is more prevalent in Sub-Saharan Africa where 80 % of 70 millions of affected people are found. Recent publications show high treatment gap of up to 78% and stigma rated at 70 % in some communities.

Though over time we have seen documented evidence of how community health workers have been partners in decreasing maternal and infant mortality rates case of Rwanda.

Could training of community health work in epilepsy replicate the success seen in other domain of infant and maternal mortality?

### **Method:**

With the Use of validated questionnaire containing questions regarding knowledge, perception, attitude of community health workers towards epilepsy and people living with epilepsy.

The researcher took a cohort of 103 non trained and 96 trained community health workers asked them to answer the questionnaire individually.

### **Results:**

It was clear both groups had basic baseline knowledge about epilepsy, there was less stigma in the trained group p value < 0.001 .the trained group was most likely to refer epileptic patient to a health facility p value < 0.05.

Surprisingly the non-trained group were mentioning more signs of epilepsy than the trained group, whether this was a confounder or not could be re -tested.

### **Conclusion:**

It is clear the trained group has less stigma more likely to refer epilepsy patient to a health facility.

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## **ABBREVIATIONS**

AED	Antiepileptic Drugs
CHW	Community Health Workers
DALY	Disability-Adjusted Life-Years
DC	Direct Costs
GBD	Global Burden of Disease
IC	Indirect Costs
iCCM	integrated Community Case Management
KAP	Knowledge, Attitude and Practice
LMIC	Low- and Middle-Income Countries
mhGAP	Mental Health Gap Action Programme
MNCH	Maternal, Newborn, and Child Health
NCD	Non-communicable Disease(s)
PBF	Performance-Based Financing
PI	Principal Investigator
PwE	Person(s) living with Epilepsy
ROAE	Rwandan Organization against Epilepsy
SSA	sub-Saharan Africa
SUDEP	Sudden Unexplained Death in Epilepsy.

## **.INTRODUCTION**

Epilepsy is a common neurological disorder and according to a recent publication 80% of the 70 million people living with epilepsy in the world live in sub-Saharan Africa [SSA].<sup>1</sup> In SSA, epilepsy is *associated* with a particular high burden of disease.<sup>2,3</sup>

The disease burden is often described as a '*double burden*'. The first burden is the greater prevalence of the disease compared with Western Europe, North America, Latin America and Asia mainly due to the presence of a higher number of combined risk factors such as cerebral malaria, neurocysticercosis, meningitis, HIV infection, toxocariasis, perinatal events, and traumatic brain injury.<sup>1, 2, 4, 5, 6</sup> Second, persons living with epilepsy [PwE] in SSA are also confronted with a poor healthcare infrastructure with limited resources and limited access to antiepileptic drugs [AEDs], and to significant cultural barriers leading to stigma and discrimination.<sup>7, 8, 9</sup>

The prevalence of this chronic non-communicable disease [NCD] varies between 5.2 to 14.2 people per 1,000 population world-wide; however, a notably higher prevalence in Rwanda has been described.<sup>6</sup> Indeed, this study, completed in 2005, identified a much higher prevalence of 49/1,000 people which was recently confirmed by a door-to-door survey in three villages in Musanze. [F Sebera, personal communication, 2018]

Although treatment for epilepsy is available in most countries, there remains a significant treatment gap and a recent study in Uganda revealed a treatment gap as high as 78%.<sup>10</sup> In addition, there is also an important gap in obtaining the correct diagnosis due to various factors, *e.g.*, limited number of neurologists, limited number of epilepsy-trained staff in primary health care centres and district hospitals, reduced awareness among PwE and their families of the disease itself and the stigma associated with the disease. These factors all contribute to hamper the confirmation of diagnosis by trained professionals.<sup>11, 12, 13</sup>

It is believed that the treatment gap is elevated because of the disease-associated stigma, the societal discrimination and the lack of knowledge of the disease. Indeed, persons living with epilepsy are discriminated at all levels of society ranging from job opportunities to the right to marry.<sup>6, 14</sup> People may believe that epilepsy is contagious or due to possession by evil spirits.<sup>15</sup> Moreover, persons living with epilepsy suffer more frequently from soft tissue injuries, burns, dental injuries, fractures and head injuries.<sup>16, 17, 18</sup>

A study completed in Zambia in 2001 showed epilepsy as one of the public health conditions in mental health that does require greater funding and attention. A community-based approach in epilepsy care was recognized as the most likely to decrease the diagnosis and treatment gap.<sup>15</sup>

In Rwanda, the community health workers (CHW) are considered key members of rural communities and are respected for volunteering to provide a service for members of their communities. They receive specific health care training in a selected number of medical communicable diseases. CHW are the bridge for patients to existing primary health care structures and they mobilize villagers to attend education sessions on, *e.g.*, maternal health, HIV and malaria. They actively participate in initiatives such as Rapid SMS (Short Message Service) in mother and child care. The structured approach in providing education at grassroots in Rwanda has, together with existing systems and infrastructures, helped the country to achieve, in 2015, the target 5A of Millennium Development Goals.<sup>19, 20</sup> For



example, Rwanda successfully decreased maternal mortality to 78% between 1990 and 2015. CHW have been instrumental in this success.<sup>19, 20</sup>

Given that these people are respected members of their communities, their presence in the community and their critical contribution in turning around the scourge of malaria and maternal death, their value and impact is undisputed. Could this success be replicated in closing the epilepsy treatment gap and waging the fight against the epilepsy-associated stigma?

## **1. MOTIVATION FOR THE STUDY**

Epilepsy as a non-communicable disease is more prevalent in Rwanda when compared with other sub-Saharan countries. The general population is often ignorant about this condition and is fearful of the disease due to many misconceptions and myths. This compromises early diagnosis and management.

Indeed, in a recent field study in Musanze, the average time between the first seizure and the diagnosis was calculated as 8.3 years. [F Sebera, personal communication, 2018] Stigma associated with the disease leads to a behaviour of hiding patients at home and to excluding children from school and adults from the workplace and marriage.

This study was motivated by the desire to enhance the understanding of the role of the CHW in the early referral of PwE.

## **2. HYPOTHESIS**

The understanding of epilepsy by CHW and by persons living with epilepsy is insufficient and focused training programs such as the training conducted by the Rwandan Organization Against Epilepsy (ROAE) could offer CHW the tools to reduce their misperceptions and to improve their knowledge.

## **3. RESEARCH QUESTION**

*Assessment of the knowledge, attitude and practice (KAP) towards epilepsy and persons living with epilepsy by CHW trained by the ROAE compared to a group of CHW who received no epilepsy training.*

## **4. OBJECTIVES**

### **4.1 General Objective**

The primary objective of this cross-sectional study was to assess differences, if present, in selected KAP parameters of CHW towards epilepsy and PwE having been administered an epilepsy training by the ROAE when compared with CHW without such epilepsy training.

### **4.2 Specific Objectives**

The specific objectives are:

- Assess basic knowledge, attitude and practice of epilepsy trained and non-trained CHW towards epilepsy and persons living with epilepsy
- Assess perception of CHW towards PwE.
- Compare the two groups

## 5. METHODS

### 5.1 Study design

This study was a cross-sectional non-interventional study and was carried out in Musanze and Rwamagana. Table 1 summarizes the catchment areas in the two health districts.

### 5.2 Study population

Group A consisted of 100 CHW from three sectors of the Musanze district as outlined in the Table 1. The CHW of Group A received an epilepsy training by the ROAE. Group B consisted of 100 CHW of Nyakariro sector where no epilepsy training had been given.

Table 1 summarizes the catchment areas in the two health districts.

	Group A	Group B
Province	Northern	Eastern
District	Musanze	Rwamagana
Sector	Muhoza, Musanze, Cyuve	Nyakariro
Cells	13	5
Villages	33	38

Table 1. Catchment areas in the Musanze and Rwamagana health districts.

In Musanze, the person responsible for the CHW provided the principal researcher [PI] with a listing of CHW in the Muhazo, Musanze and Cyuve sectors who attended the epilepsy training course by the ROAE. One nurse accompanied the principal investigator (PI) to the urban and semi-urban villages and CHW were invited into a room of the primary health care centre with the request to complete the questionnaire.

In the Nyakariro sector, the person responsible for the CHW informed the appropriate staff members in the 38 villages of the request to meet the PI in the villages to have the questionnaire administered. Three nurses accompanied the PM to the villages and CHW were invited into a room at three primary health care centres with the request to complete the questionnaire.

### 5.3 Inclusion and exclusion criteria

The inclusion criteria were:

For Group A, a CHW who signed the informed consent form to participate in the study and who attended the ROAE epilepsy training course;

For Group B, a CHW who signed the informed consent form to participate in the study and who had not previously attended an epilepsy training course.

The exclusion criteria were:

- CHW not signing the informed consent;
- CHW who were absent on the day of the interview; and
- CHW who relocated.

### 5.4 Sample size

A total of 100 CHW per group were to be enrolled and as this study is descriptive, no statistical power calculations were done to demonstrate differences.

## **6.STUDY CONDUCT.**

A structured questionnaire, based on an existing questionnaire taken from the literature, validated by the neurologist of the University Teaching Hospital of Kigali, was administered by PI to the CHW of selected villages.

The questionnaire contains an introductory statement and a total of 20 questions; two administrative questions and 18 multiple choice questions, with six questions where the CHW could tick more than one answer.

The major activities related to the research activities are outlined in [Appendix 1](#). The study budget is detailed in [Appendix 2](#) and the budget allowance for the mission and the accommodation was respected.<sup>21</sup>

## **7.DATA INSTRUMENT AND DATA COLLECTION**

The questionnaire was made available in Kinyarwanda [see [Appendix 3A](#) (Kinyarwanda version) and [Appendix 3B](#) (English version)].

In Musanze, the person responsible for the CHW provided the PI with a listing of CHW who attended the epilepsy training course by the ROAE. One nurse accompanied the PI to the urban and semi-urban villages on six consecutive days. CHWs were invited into a meeting room of the primary health care centres with the request to complete the questionnaire and the PI remained available to respond to questions of the CHWs.

In Nyakariro, the person responsible for the CHW informed the appropriate staff members in the rural villages with the request to meet the PI in the villages to complete the questionnaire. Three nurses accompanied the PI to the villages. CHWs were invited into a meeting room of three primary health care centres with the request to complete the questionnaire and the PI remained available to respond to questions of the CHWs.

The research was approved by the Institutional Review Board of the University of Rwanda and by the local administrative and medical authorities.

## **8.ETHICAL CONSIDERATION**

Within the framework of the ethical aspects the principal researcher considered following items:

- Obtain approval from the Institutional Review Board of the University of Rwanda and adapt the study protocol according to their recommendations;
- Prepare an informed consent and questionnaire for the CHW to be self-administered, in order to
  - explain the objective of the study;
  - explain the voluntary nature of the participation; and
  - explain that there is no risk of physical or mental impact for the participants;
- The PI would:
  - summarize the observation in a Master's thesis; and
  - provide a summary of the study results to the CHW prior to any publication.

## 9. DATA ENTRY AND ANALYSIS

The questionnaires were completed by the participants and collected by the principal research. An *ad-hoc* database was developed using Google Forms by staff of UCB. A double data entry was completed by an independent data specialist and an extraction of the data was done in Excel.<sup>22</sup> A search for data errors was completed with an error rate of 1.6% and corrections were made by a verification against the source data.

Analysis was performed with STATA 12 software packages. Qualitative variables were described as percentages and quantitative variables as means  $\pm$  standard deviation [SD]. The differences between means and the differences between proportions were evaluated using t-test and Chi-square.

## 10. REVIEW OF THE LITERATURE

### 10.1 Introduction

The objective of the review of relevant literature is to improve the understanding of the data available relevant to the research activities of the knowledge, attitude, and perception of epilepsy by community health workers. CHW are an essential and important part in the provision of health care service to persons living in the villages.

### 10.2 Global burden of epilepsy

There is a growing recognition that the burden of neurological disorders is disproportionately high in low- and middle-income countries (LMIC), where health-care services and resources are often scarce. The absolute burden of neurological disorders is six times higher in LMIC compared with high-income countries, largely due to epilepsy (14-fold higher), cerebrovascular disease (eight-fold higher), and migraine (six-fold higher).<sup>23</sup>

The neurological burden of disease is expected to grow exponentially in LMIC in the next decade. Despite the significant impact of neurological disorders on patients and society, knowledge of their burden remains limited. In addition to our limitations in epidemiological knowledge, there are major challenges in the assessment and management of people with neurological disorders.

As an important public health problem, epilepsy represents 0.8% of the global burden of disease (and 5% of the global neurological burden of disease).<sup>24, 25</sup> Epilepsy ranks fifth in the global burden of neurological diseases, behind stroke, migraine, dementia and meningitis.<sup>25</sup> Stroke was the leading cause of age-standardized disability-adjusted life-years (DALY) rates in 18 of 21 Global Burden of Disease (GDB) regions. The other top 6 conditions and the variation by region are listed in [Figure 1](#).

Stroke, migraine, meningitis, Alzheimer's disease and other dementias, and epilepsy each caused more than 1 million DALYs. Epilepsy caused the highest burden in children and young adults. The authors concluded that prevalence of epilepsy was higher in LMIC and that the prevalence was highest in central America, Chile, north Africa and the Middle East. It is not clear how supportive data from African GDB regions have been incorporated, although epilepsy is the only neurological condition with data sources for all 21 GDB regions.

Regions	Stroke	Migraine	Dementias	Meningitis	Epilepsy	Headache
Global	1	2	3	4	5	6
Southern sub-Saharan Africa	1	3	5	4	2	6
Eastern sub-Saharan Africa	1	4	5	2	3	7
Central Asia	1	2	3	7	4	6
Central Latin America	1	3	2	7	4	5
North Africa/Middle East	1	3	2	5	4	6
East Asia	1	3	2	7	5	6
Southeast Asia	1	2	3	4	5	8
Oceania	1	4	3	2	5	7
High-income Asia-Pacific	1	2	3	11	5	4
Southern Latin America	1	2	3	7	5	4
Caribbean	1	2	3	4	5	6
Andean Latin America	1	2	3	7	5	4
Central sub-Saharan Africa	1	4	3	2	5	6
Western sub-Saharan Africa	1	3	4	2	5	6
Central Europe	1	2	3	11	6	5
Eastern Europe	1	2	3	7	6	4
Australasia	2	1	3	12	6	5
Western Europe	2	1	3	12	6	4
High-income North America	2	3	1	12	6	4
Tropical Latin America	1	2	3	7	6	5
South Asia	1	2	4	3	6	7

**Figure 1:** Ranking of age-standardized DALY rates for six neurological disorders by 21 GBD regions in 2015 (ranked by importance of epilepsy)

Epilepsy particularly impacts people living in the lowest income countries where epilepsy incidence may be close to 10-fold higher than in the high-income countries. The median incidence of epilepsy was 50.4/100,000/year (interquartile range [IQR] 33.6–75.6), while it was 45.0 (IQR 30.3–66.7) for high-income countries and 81.7 (IQR 28.0–239.5) for LMIC.<sup>[26]</sup> A recent retrospective, observational U.S. claims database analysis reported an epilepsy incidence of 79.1 per100,000 people.<sup>27</sup> Epilepsy can appear at any age, but incidence rates show a bimodal distribution with higher incidences occurring in early childhood and in the elderly. Epilepsy incidence in children ranges from 41 to 187/100,000, with higher incidences in developing countries.<sup>28</sup>

The life-time prevalence of epilepsy in North-America has been recently recalculated at about 8.4 per 1,000 and an annual prevalence of 1.2 per 1,000 was estimated by the United States' Centers of Diseases Control and Prevention.<sup>27, 28</sup>

In SSA countries an average life-time prevalence rate of 15 in 1,000 has been described, varying between 7.8 per 1,000 to 48.7 per 1,000 person-years.<sup>1, 6</sup>

In Asian countries, median prevalence varies from 1.5 to 14.0 per 1,000 and is similar to that found in Europe and North America, although with wide variation and with significant prevalence differences between rural and urban areas.<sup>29, 30</sup>

From the literature review it transpires that the rate varies throughout each region, with the lifetime prevalence rates of epilepsy being 1.5–14.0 per 1,000 person-years in Asia, 5.1–57.0 per 1,000 person- years in Latin America, and 2.91–49 per 1,000 person- years in SSA.<sup>6, 30, 31, 32</sup>

It should be remembered that epilepsy can be completely controlled in most affected persons by inexpensive medications or cost-effective surgical procedures, and many forms of epilepsy can be prevented by appropriate public health interventions.

### **10.3 Burden of epilepsy in Africa**

The population in SSA is estimated at 1,126 billion representing 17% of the world population. The average annual income per capita is calculated at US\$ 1,871 with persons living in 26 countries not reaching US\$ 999 per year. The poverty rate is calculated at 47% with an unemployment rate of 11% and with youth unemployment likely to be much higher. The average Human Development Index for the 48 countries is 0.4837.<sup>33</sup>

The prevalence of epilepsy is highest in low-income and lower middle-income countries, which include over 80% of the countries of SSA.<sup>34</sup> The majority of PwE are not receiving appropriate care due to various reasons including shortages of trained health workers, limited diagnostic equipment, inadequate/inconsistent anti-epileptic drug supplies, cultural beliefs. Social isolation, stigma, beliefs and attitudes all contribute to the significant treatment gap for epilepsy.

The number of people living with epilepsy, particularly children, will continue to rise because of projected epidemiologic and demographic changes.

Based on the above data, it is understandable that access to quality epilepsy care for many persons in SSA countries is inadequate. Moreover, as many persons live in rural areas and 4 out of 10 persons in cities are experiencing situations of extreme poverty, access to quality care is further compromised. Educational achievements, employment rates, and quality of life are particularly low in patients living with epilepsy.

In SSA countries, the differences in the epilepsy incidence could be explained by the distribution of epilepsy-related environmental factors and etiologic factors, *i.e.*, various infections with neurologic sequelae, stroke, head injuries, obstetric and perinatal factors and genetic factors.<sup>2</sup> In addition, persons living with epilepsy have a mortality rate 2–3 times higher than the general population and the causes of death include status epilepticus, sudden unexplained death in epilepsy (SUDEP) and suicide.

A comprehensive review of the literature relative to prevalence and incidence data could not be conducted within the framework of this research project considering data span the period from 1980 until now. The methodologies of data collection differ significantly, but a recent article summarized the review of 83 relevant studies in detail.<sup>35</sup>

Active epilepsy was estimated to affect 4.4 million people in SSA, whilst lifetime epilepsy was estimated to affect 5.4 million. The prevalence of active convulsive epilepsy peaks in the 20–29 age group at 11.5/1000 and again in the 40–49 age group at 8.2/1000.

The epilepsy prevalence data are summarized in [Table 2](#).

Continent					Ref
sub-Saharan Africa	Year	Sample size	Prevalence (%)	Age group	35
			5.09	≤9	
			5.98	10-19	
			11.5	20-29	
			4.31	30-39	
			8.2	40-49	
			7.84	50-59	
			3.1	≥60	
Countries					Ref
West Africa	Year	Sample size	Prevalence	Type study	
Benin – Tourou	2011	1,031	7.0	Door-to-door	36
Benin	2012	13,046	8.0	Door-to-door	4
Benin	2007	1,232	10.6	Cross-sectional	37
Benin Cotonou	2003	1,400	7.9	Cross-sectional	38
Benin – total	2007	11,668	10.5	Door-to-door	39
<i>Benin Agonhohoun</i>	2007	536	14.9	<i>Door-to-door</i>	39
<i>Benin Aligoudo</i>	2007	1,607	13.7	<i>Door-to-door</i>	39
<i>Benin Dona</i>	2007	532	16.9	<i>Door-to-door</i>	39
<i>Benin Hounvi</i>	2007	959	9.4	<i>Door-to-door</i>	39
<i>Benin Kome</i>	2007	958	11.5	<i>Door-to-door</i>	39
<i>Benin Madjavi</i>	2007	4,095	6.6	<i>Door-to-door</i>	39
<i>Benin Sanwlaƙpa</i>	2007	570	15.8	<i>Door-to-door</i>	39
<i>Benin Sovlegni</i>	2007	1,110	9.0	<i>Door-to-door</i>	39
<i>Benin Wogbaye</i>	2007	559	14.3	<i>Door-to-door</i>	39
<i>Benin Ye</i>	2007	742	13.5	<i>Door-to-door</i>	39
Benin Zinvié	2000	3,134	15.9	Door-to-door	40
Burkina Faso	1993	16,627	10.6	Cross-sectional	41
Burkina Faso	2012	888	43.9	Cross-sectional	42
Gambia	2002	16,200	4.26	Cross-sectional	43
Ghana	2013	129,812	4.9	Door-to-door	44
Ghana	2015	113,796	10.1	Cross-sectional	45
Ivory Coast	1990	309	74.4	Door-to-door	46
Ivory Coast	1995	929	59.7	Door-to-door	47
Ivory Cost	1988	1,176	7.6	Cross-sectional	48
Liberia	1983	4,436	28.0	Cross-sectional	49
Mali	2000	5,243	13.3	Door-to-door	50
Nigeria	1989	2,925	6.2	Cross-sectional	51
Nigeria	1982	903	37.0	Cross-sectional	52

Nigeria	1987	18,954	5.3	Cross-sectional	53
Nigeria – Enugu	2016	8,228	6.0	Cross-sectional	54
Nigeria	2015	6,800	4.3	Cross-sectional	55
Nigeria	2014	2,212	4.5	Cross-sectional	56
Nigeria	2017	1,802	20.8	DtD (Ø) rural	57
Nigeria	2014	2,212	4.7	DtD semi-rural	57
Senegal	1986	7,682	8.3	Cross-sectional	58
Senegal	2005	4,500	14.2	Cross-sectional	59
Togo	1959	5,264	16.7	Cross-sectional	60
Togo	2000	9,155	18.6	Door-to-door	61
Togo	2007	6,249	15.7	Cross-sectional	62
<b>Central-Africa</b>					
Cameroon – Keleng	2008	181	104.9	Door-to-door	63
Cameroon – Bilomo	2000	1,900	58.4	Door-to-door	64
Cameroon	2007	1,898	49.0	Cross-sectional	65
Cameroon	1989	500	70.0	Cross-sectional	66
<b>East Africa</b>					
Ethiopia	2006	1,154	37.2	Door-to-door	67
Kenya	2008	151,408	2.9	Door-to-door	68
Kenya	2008	10,218	10.7	Cross-sectional	69
Kenya	1994	7,450	5.6	Cross-sectional	70
Kenya	1988	2,960	20.2	Random-cluster	71
Kenya – Kilifi	2013	233,881	2.9	Cross-sectional	44
Kenya – Kilifi	2017	11,223	20.9	Cross-sectional	72
Rwanda	2008	6,757	7.0	Cross-sectional	73
Rwanda	2005	1,137	49.2	Random cluster	6
Tanzania	2015	14,583	20.5 (*)	Door-to-door	74
Tanzania	2012	38,523	2.9	Cross-sectional	75
Tanzania	2012	103,026	2.8	Cross-sectional	76
Tanzania	2013	104,889	3.5	Cross-sectional	44
Tanzania	2009	7,399	11.2	Door-to-door	77
Tanzania	1992	18,183	10.2	Cross-sectional	78
Uganda	1996	4,743	12.9	Cross-sectional	79
Uganda	2010	193,126	2.1	Cross-sectional	80
Uganda – Igangamayuge	2013	69,186	2.2	Cross-sectional	44
Uganda – Mukono	2016	3,000	13.3	Cross-sectional	81
<b>Southern Africa</b>					
Zambia	2004	55,000	14.1	Door-to-door	82
Madagascar	2004	925	27.0	Door-to-door	83
South Africa	2014	3,889	9.8	Cross-sectional	84
South Africa – Agincourt	2013	82,818	2.96	Cross-sectional	44
South Africa	2000	6,692	7.32	Door-to-door	85

**Table 02.** Summary of country epilepsy prevalence data grouped by region. (\*) Febrile seizures; (Ø) DtD: door-to-door



The prevalence of epilepsy in SSA with a mean of 9.39/1,000 population, varies significantly across the continent. The variation is dependent on many factors including type of study, rural vs. semi-rural vs. urban populations, case definitions, diagnosis by specialist medical staff, among others.

The prevalence of epilepsy in Rwanda is elevated when considered within the East African context. In addition, the data of the cross-sectional study have been confirmed in a door-to-door survey in three villages in the Musanze district.[F Sebera, personal communication, 2018].<sup>6</sup>

## 10.4 Epilepsy, misconceptions, stigma and social isolation in sub-Saharan Africa

### 10.4.1 Misconceptions

In 2001, a study was carried out in the district of Kiremba, Ngozi province, Northern Burundi with 784 persons being interviewed; 352 persons living with epilepsy and 428 healthy persons. The results illustrated that epilepsy is an important public health problem.<sup>86</sup>

People described epilepsy by their symptoms [Intandara, Igifúkunyi, Ibisazi, Ibidudaguzi, Ibihondanyi], by the onset of the epilepsy [Ivyubirizi, Igisahuzi, Akamashu, Igikange], by the origin of the epilepsy [Igisigo, Iridayimoni, Imizimu, Ibishetani, Ivyisi] and the organ involved [Ikinyamutwe]. The beliefs of PwE and healthy persons were compared and summarized in [Table 3](#).<sup>86</sup>

The authors confirm the observations made by other African researchers that epilepsy is considered contagious.<sup>87,88</sup> Furthermore the authors confirmed that the origin of epilepsy was considered supernatural, an observation also made by other African researchers.<sup>89,90</sup>

	<b>PwE</b> [n=352]	<b>Healthy persons</b> [n=428]	<b>p-value</b>
Epilepsy is contagious	40.3% [142]	37.2% [158]	NS
Epilepsy is incurable	56.0% [197]	52.3% [223]	NS
Epilepsy has supernatural characteristics	48.6% [171]	11.8% [50]	< 0.005
Transmission by aura	14.9% [44]	24.5% [104]	< 0.004
Schooling of child living with epilepsy not possible	43.8% [154]	59.3% [246]	< 0.001
Marriage not recommended	16.2% [57]	40.1% [166]	< 0.001

[Table 3](#). Beliefs on epilepsy of persons living with epilepsy and healthy persons.<sup>86</sup>

Whereas the above studies served as a basis, a review of the recent literature was completed with articles published between 2000 and 2017.<sup>91</sup> The review covered publications from Benin, Burundi, Cameroon, Democratic Republic of Congo, Ethiopia, Kenya, Malawi, Mali, Namibia, Nigeria, South Africa, Tanzania, Togo, Uganda, Zambia. (see [Table 4](#))

<b>Misconception categories identified on studies on epilepsy in SSA</b>		
<b>Examples</b>		<b>References</b>
Employment	PwE are insane	7, 92, 93
	PwE have no normal intelligence	80, 94, 95
	Economic losses related to missed work and epilepsy-associated physical disabilities	9, 96, 97, 98, 99
	No employment offered to PwE	36, 98, 99, 100, 101, 102
Restrictions, limitations and negative impact	Prefer PwE be in separate classes/schools.	36, 80, 95, 103, 104, 105, 106, 107
	Environmental safety with increased risk of burns, drowning and/or injuries	9, 18, 80, 99, 108, 109, 110, 111, 112
	PwE are excluded from marriage or remain unmarried	93, 95, 99, 100, 113, 114
	Parents are stigmatized because their children living with epilepsy	106, 115
Cause and nature of epilepsy	Epilepsy is destiny/has a supernatural cause	94, 116, 117, 118, 119
	Epilepsy is caused by witchcraft	15, 36, 86, 92, 104, 116, 119, 120, 121
	Epilepsy is due to demonic possession/evil spirit/adultery	15, 86, 95, 106, 116, 117, 119, 121, 122, 123
	Epilepsy is a mental disorder/madness/insanity	86, 92, 94, 102, 113, 117, 124, 125
	Epilepsy is hereditary	36, 116, 117, 125
	Epilepsy is transmitted by saliva	36, 116
	Epilepsy is contagious	15, 36, 86, 92, 94, 95, 100, 102, 117, 120, 125
	Epilepsy is a type of poisoning/bad blood	117, 126
	Epilepsy is transmitted when witnessing seizures	36
	Treatment	Should be treated by traditional healers
Wearing an amulet. talisman or complete a spiritual cultural diet		76, 116
Prayers		117, 127
Herbal medicine or others		116, 120, 122, 124, 128
Epilepsy is not curable		86, 87, 93, 116
First aid for seizures	Sacrifice to gods	116
	Call a doctor or nurse	117

	Put something into the mouth; smell the smoke of a lit match	117
	Move person with epilepsy away from harm	117
	Start praying	117
	Apply olive oil on the person	117
Integration into community	Objecting marriage to PwE	36, 101, 102, 113, 114
	PwE are vulnerable	95, 102
	PwE have less access to water	95
	PwE have less access to healthy food	95
	PwE are often physically abused	95, 101
	Women living with epilepsy have less children	95
	Women living with epilepsy are more often raped	95, 101
	Women living with epilepsy are more likely to be severely stigmatized	118
	PwE live more often in rural/ poorer areas/poor housing	95, 101, 114, 121, 124, 129
	PwE should not cook/drive/swim	100
	PwE should not play with normal people	93, 117

**Table 4.** Summary of possible misconceptions on epilepsy in African countries.

#### **10.4.2 Stigma and social isolation**

The burden of epilepsy in LMIC affects the person living with epilepsy, their family and communities.<sup>130</sup> PwE are highly impacted by physical dangers of a seizure that brings risk of various injuries and possible death.

There is also a psychological and social impact for persons living with epilepsy in rural areas as they and their families may be stigmatized and socially isolated in their communities due to the neurological condition.<sup>131</sup> A child living with epilepsy in a financially constrained family frequently cannot participate in the daily activities of family life, *i.e.*, collecting water for fear of drowning or cooking for fear of falling in the fire and subsequent burns.<sup>132</sup>

Financial security is at risk due to the cost of epilepsy medication and treatment and the cost associated with the travel and the consultations.<sup>9, 86, 133</sup>

Psychological and social development of persons living with epilepsy is no doubt affected by the stigma of the disease, which is present worldwide to some degree but most visible in the poorer regions of the world.<sup>114</sup> It is considered that psychosocial support groups can help bring PwE out of the shadows.<sup>134</sup> Across Africa, epilepsy is very frequently considered to result from demonic possession or a curse and epilepsy is thought to be contagious through the different body fluids. Epilepsy is often labelled as ominous and non-curable disease. PwE or their family sometimes choose to keep their condition secret.<sup>135</sup> Children living with epilepsy are sometimes locked inside their home, are deemed to have low intelligence, or are not allowed to play with other children or to attend school. Witchcraft and sorcery may be invoked to fight the suspected demonic origin of epilepsy, bringing an additional cost from the services of traditional healers.

To summarise, as detailed in Table 4. the life of a PwE may be significantly impacted.

Personal health security is also threatened by epilepsy. Fear of injury, concern about the social consequences of having a seizure, and the stigmatization related to a diagnosis of epilepsy leads to social isolation.<sup>16</sup>

Stigma, in all forms, limits the personal, educational, and social opportunities of the PwE, leading to a significant impact on the quality of life of both the PwE and his or her family members.

Three forms of stigmatization associated with epilepsy have been described: ‘*enacted*’, ‘*felt*’, and ‘*courtesy*’ stigma.<sup>120</sup> ‘*Enacted*’ stigma occurs when the source of discrimination is another person. ‘*Felt*’ stigma results from a fear of being discriminated against. ‘*Courtesy*’ stigma occurs when someone close to a person living with epilepsy, in relation or proximity, feels stigmatized.

Studies have indicated that nearly half, and sometimes up to 78%, of PwE report ‘*feeling stigma*’ or ‘*fear of being stigmatised*’.<sup>2, 6, 9, 18, 91, 106, 110, 118, 130, 131, 134, 136</sup>

PwE who report greater felt stigma are more likely to suffer from low self-esteem, poorer psychological function, and more uncertainty about the future. Psychiatric co-morbidities, including depression and anxiety, are more prevalent in patients living with epilepsy who report greater felt stigma with an important associated decreased quality of life. PwE experience felt and enacted stigma via social exclusion, activity restriction, teasing/bullying, internalized negative feelings to epilepsy, concealment of epilepsy and parental stigma-coaching.<sup>137</sup> Higher stigma perceptions were significantly correlated with greater epilepsy concealment from others outside the family and greater negative effects around epilepsy-related communication within the home.

The different elements contributing to ‘*felt*’ stigma vary by region and culture, but the common denominators include worry about the occurrence of the next seizure, limited or absent social support, and severity of the seizures. Increased levels of ‘*felt*’ and ‘*enacted*’ stigma are associated with lower levels of education, lower socioeconomic status, minorities, and those with less exposure to PwE. Research activities should be initiated to improve the health of persons living with epilepsy, as recommended by the Institute of Medicine.<sup>138</sup>

Data on ‘*courtesy*’ stigma in epilepsy are very limited. As an illustration, an example of ‘*courtesy*’ stigma was recently reported in frontline health care workers returning from the Ebola outbreak in Western Africa.<sup>139</sup> They were met by an unforeseen risk of stigmatization upon their return home, related to others' fears of their infectious status. Media representations of the disease appear to have played a significant role in heightening societal perceptions of the risks associated with the returning health care workers, resulting in public hostility toward them. For participants, these social risks overtook concerns about biological risks during the immediate post-mission period. The participants developed different strategies to cope with ‘*courtesy*’ stigma, by rationalizing stigmatizing attitudes, educating people, or simply through an avoidance of others.

### **10.4.3 Diagnosis gap**

Health care providers and CHW in Africa are confronted with exceptional challenges to ensure access to care for PwE in their communities.

PwE often delay their first visit to a primary health care centre, and the duration of untreated epilepsy still needs to be better understood. It is important as a long duration of untreated epilepsy is considered a risk factor associated with a poor long-term outcome, a higher comorbidity and premature death.

Access to a medical diagnosis is not only dependent on the number of trained physicians and mental health nurses in a setting. The patient's background, age, gender, education level, employment, economic status and socio-cultural factors play equally important roles in the diagnosis gap. Also, the awareness and belief of the disease by persons living with epilepsy, alongside with the stigma associated with the disease, contribute to the diagnosis gap. Seeking help from traditional healers, religious healing or alternative medicine delays the access to quality care.

It will be important to focus interventions by improving access to education and epilepsy awareness of the persons living with the disease, their families and their communities.

#### **10.4.4 Co-morbidity**

PwE in a rural area of SSA had a high level of co-morbidity.

Children often demonstrate important cognitive impairment, behavioural disorders, motor difficulties, burns and soft-tissue injuries.<sup>140</sup> In a study in Nigeria, children suffered seizure-related injuries with multiple injuries in 24.8% of cases. The most frequent were skin/softtissue lacerations, followed by injuries to the tongue and softtissues of the mouth, minor head injuries, and dental injuries with tooth loss.<sup>112</sup> In addition, children living with epilepsy also suffer from burns, often necessitating longer hospitalisations.<sup>90, 104, 109, 111, 140</sup>

In adult PwE depression is very common with 1 out of 5 PwE suffering from depression. Anxiety is also a common condition. A long duration of epilepsy, frequency of the seizures and previous hospitalization from epilepsy are independent predictors of depression in person living with epilepsy.<sup>128</sup>

PwE suffer social deprivation and discrimination in education, employment, housing, marital life, and access to water and food.<sup>95, 100, 141</sup>

#### **10.4.5 Epilepsy treatment gap**

The epilepsy treatment gap is defined as the percentage of persons living with active epilepsy who are not being appropriately treated (either because of lack of access to treatment or being on inadequate treatment) in a given population at a given time.<sup>142</sup>

Cost-effective epilepsy treatments are available and an accurate diagnosis can be made without supportive technological equipment. Nonetheless, a clear majority of individuals with epilepsy in many resource-poor regions do not receive treatment. Untreated epilepsy is a critical public health issue, as people with untreated epilepsy face potentially devastating social and economic consequences and overall poor health outcomes. Due to stigma, many PwE have lower employment and education levels and lower socioeconomic status. In addition, persons with epilepsy have poor health outcomes, including greater psychological distress, more physical injuries such as fractures and burns, and increased mortality.<sup>142</sup>

Research has been conducted to understand the relative impact of various cultural (awareness of epilepsy and effectiveness of the treatment), demographic (access to quality care),

economic (affordability of care), and logistical factors (limited availability of treatments,) believed to be at the origin of the treatment gap in resource-poor settings.<sup>143</sup>

The determination of the epilepsy treatment gap is vital for health care planning in SSA, both at the public health level as well as at the individual level. This treatment gap is a major cause of suffering and death and contributes to the socio-economic burden of the disease.<sup>144</sup> Closing the epilepsy treatment is essential and an appeal to the international community was launched in 2001.<sup>11</sup>

In Ethiopia, it was determined that the proximity of a quality epilepsy service in local primary health centres decreased the cost of transportation for most of service users, hence improving access to quality care.<sup>145</sup> It should be remembered that most persons living with epilepsy and their caregivers in the villages continue to seek help from traditional healers. Most of the care received was focused on medication provision with limited information provided on how to manage their illness and its effects. Caregivers and service users spoke about the high emotional and financial burden of the disease and lack of ongoing practical and emotional support. Most participants reported clinical improvement on medication, which in over half of the participants was associated with ability to return to money generating activities. Task-sharing improved the accessibility of epilepsy care for PwE and caregivers and was perceived as having a positive impact on symptoms and productivity.

The treatment gap is a crucial health challenge for epilepsy care in LMIC. The reported size of the epilepsy treatment gap in SSA varies widely, ranging from 40.6% in rural Tanzania to 92.0% in Madagascar.<sup>6, 10, 45, 68, 76, 146, 147, 148, 149, 150</sup>

The treatment gap can be compounded by a low awareness of epilepsy, unaffordability and availability of care and treatment in the proximity, or likely stigma and social isolation surrounding the disease. Furthermore, health system issues such as absence of primary health workers trained to diagnose and treat epilepsy associated with limited access to the health facilities, especially in rural areas, may have been contributory

## 10.5 Economic burden of epilepsy

### 10.5.1 Economic burden of the epilepsy at global level

There are limited data on the global cost burden of epilepsy as a disease. Nor is there a standardized methodology so data sources resulting in estimates are difficult to compare.

### 10.5.2 Economic burden of epilepsy in high-income countries

Clearly, the economic costs of epilepsy are substantial, but estimates vary. Having epilepsy is about much more than having a seizure. PwE and their families face an array of challenges to daily living that varies with the severity and nature of the condition, and may change as the individual gets older. The negative effects on quality of life can be severe and involve family and social relationships, academic achievements and employment opportunities, housing opportunities, and the ability to function independently.<sup>151</sup>

In the United States, various studies have been conducted.

In 2004, the average direct healthcare cost of epilepsy in the USA was estimated at US\$ 4,325 per person per annum,<sup>152</sup> compared with US\$ 909 per person per annum based on an earlier US study (with costs adjusted for inflation to 2004).<sup>153, 154</sup> Overall lifetime productivity

decreases by 34% for men and 25% for women and as expected estimated overall costs are higher for persons living with refractory disease.<sup>153</sup>

For general epilepsy populations (comprising all clinically defined subgroups), total direct healthcare costs per person per annum ranged from US\$ 10,192 to US\$ 47,862 and epilepsy-specific costs ranged from US\$ 1,022 to US\$ 19,749. Four recent studies using claims data from large general populations yielded relatively similar epilepsy-specific annual cost estimates ranging from US\$ 8,412 to US\$ 11,354. Although more difficult to compare, studies examining direct cost differences for epilepsy sub-populations indicated a consistent pattern of markedly higher costs for those with uncontrolled or refractory epilepsy, and for those with comorbidities.<sup>154</sup>

A recent estimate of indirect and direct costs of epilepsy in the U.S. was US\$ 36.8 billion.<sup>155</sup> The indirect costs of epilepsy in terms of lost work and productivity are significant, with newer estimates ranging from 12% to 85% of total annual costs.<sup>156, 157</sup> The direct costs of in-patient and out-patient visits exceed the costs of AEDs.

In Europe, the economic studies on the cost burden of epilepsy are being supported by the European Brain Council.

Estimates of cost per case differ significantly across Europe, as indicated in a recent survey article that reported direct costs ranging from US\$ 2,000 per year to US\$ 11,500.<sup>157</sup> The total European 2010 cost of brain disorders, including epilepsy, was € 798 billion, of which 37% was related to health care costs, 23% was related to non- medical costs, and 40% was related to indirect costs. The average cost per inhabitant was € 5,550.

It was concluded that brain disorders overall are much costlier than previously estimated, constituting a major health economic challenge for Europe.

### **10.5.3 Economic burden of epilepsy in African low and low-middle income countries**

The effect of epilepsy extends well beyond those with a diagnosis and impacts families, communities and society.<sup>158</sup>

The quality of life of caregivers and siblings is often impacted by frequent and unpredictable seizures, a range of co-morbidities, behavioural and sleep disorders and stigma surrounding the diagnosis. In addition, the impact may be accentuated by the resilience of the PwE and resources available to families of those living with epilepsy. Beyond the immediate family and health care providers, the presence of a PwE may affect local communities by drawing additional resources from education or health-support systems.

The budget envelope of a person living with epilepsy can be calculated by direct and indirect costs. Direct costs (DC) include recurring costs like consultation, hospitalization, medication and investigation fees for the PwE. Indirect costs (IC) include decreased productivity due to absence from work for the PwE and relatives. The latter puts an important financial strain on the PwE and health care systems.

Four studies in Africa have addressed the treatment cost of neurological conditions in low-income and low-middle-income countries.

A first article reviewed children who had suffered from bacterial meningitis and had been seen at the Albert Royer Hospital in Dakar.<sup>159</sup> Sixty-eight children were located at their home

and caregivers interviewed about costs during the acute meningitis episode and due to meningitis sequelae, including productivity loss from caring for a disabled child. Lifetime costs were predicted by assuming a life expectancy of 30 years for disabled children. Seventy-one percent of the children had either minor or major sequelae. Mean discounted lifetime sequelae costs amounted to US\$ 34,895 (95% confidence interval: US\$ 67–96,755) per child. Discounted childcare costs amounted to US\$ 3,158 (9%), treatment costs US\$ 460 (1%) and productivity costs US\$ 31,276 (90%). No children were receiving rehabilitation services by the time the study was conducted. Caring for a disabled child is a considerable financial as well as emotional burden for the individual family. None of the families could afford the treatment they desired for their child.

A second study conducted in Burundi included a total of 1,056 patients, with 352 patients living with epilepsy and 704 controls.<sup>160</sup> The total annual cost of patients living with epilepsy was US\$ 11.0 against US\$ 7.3 for controls. The IC represented 75.8% of the total cost. For the 18 people with epilepsy taking AEDs, the annual average total cost became US\$ 48.4. The number of indirect lost days was 10.2 for the treated PwE and 2.0 days for the untreated PwE ( $p < 0.001$ ).

A third African study addressed the economic impact of epilepsy in 65 PwE aged  $35 \pm 17$  years who attended Neurology Clinic at UITH Ilorin (Nigeria).<sup>96</sup> Sixty-five patients (32 males, 33 females) participated in the study with age range of 16 to 74 years and mean (SD) of  $35 \pm 17$  years. Total clinic attendance was 314 days and 53 days were spent on admission. Almost 25% of PwE resided outside the Ilorin metropolis and the distance travelled to attend clinic varied from 4 to 200 km (mean =  $47 \pm 30.6$  km). The total annual cost per patient was ₦ 41,878 (US\$ 279.2). The DC and IC were ₦ 33,616 (80%) and ₦ 8,262 (20%), respectively. The three leading consumptive items in DC were: antiepileptic drugs (AEDs) at ₦ 24,138 (72%), investigations at ₦ 5,373 (16%) and transportation at ₦ 2,387 (2%).

The self-estimated monthly family income varied from ₦ 3,000 to ₦ 200,000 (median of ₦ 25,000). Only 23 patients (35.4%) bore the cost of care themselves. Of the IC, lost earnings due to absenteeism from work amounted to ₦ 6,177. The exchange rate at the time of the study was ₦ 150 = 1 US\$)

A third study in Africa was performed to evaluate the societal cost of epilepsy.<sup>97</sup> A total of 103 children were identified, predominantly (45.6%) in the 0–5 years age group. Most (61.3%) families belonged to the low socioeconomic class (Ogunlesi socio-economic scoring class IV and V) and resided (80.6%) in an urban setting.

The total of DC and IC per patient per annum was ₦ 292,794.50 / US\$ 1,157.29.

The total medical direct cost was 80.5%; with consultations (0.8% or ₦ 2,400.00 / US\$ 9.49), AED (14.6% or ₦ 42,862 / US\$ 169.41) and investigation (65.0% or ₦ 190,033.00 / US\$ 752.28). The direct non-medical cost was 5.0%; with transportation (3.3% or ₦ 9,751.00 / US\$ 38.54), feeding (0.8% or ₦ 2,396 / US\$ 9.47) and lodging (0.9% or ₦ 2,738.00 / US\$ 10.82). The indirect cost was 14.5% or ₦ 42,313.00 / US\$ 167.24.

Investigative procedures are the principal cost drivers accounting for 65% of the total direct cost. The authors concluded that out-of-pocket expenses may contribute significantly to catastrophic expenditures and worsening of secondary treatment gap in children living with epilepsy.



Another study in South Africa compared the cost for PwE consulting a clinic, the hospital and/or the traditional healers.<sup>161</sup> Direct out-patient, median costs per visit varied significantly ( $p < 0.001$ ) between hospital (2010 US\$ 9.08; IQR: US\$ 6.41-US\$ 12.83) and clinic consultations (US\$ 1.74; IQR: \$ 0–\$ 5.58). Traditional healer fees per visit were found to cost \$ 52.36 (IQR: US\$ 34.90–US\$ 87.26) per visit.

Average annual out-patient, clinic and hospital out-of-pocket costs were calculated at US\$ 58.41. Traveling to and from the hospital and waiting to be seen by the caregiver there took significantly longer than at the clinic. Fortunately, traditional healers were consulted less often as they were the most expensive mode of care. While higher out-of-pocket costs were incurred at hospital visits, more people with acute convulsive epilepsy visited hospitals than clinics for epilepsy care. Promoting increased use and effective care at clinics and reducing travel and waiting times could substantially reduce the out-of-pocket costs of outpatient epilepsy care.<sup>84, 161</sup>

## 10.6 Community Health Workers

### 10.6.1 Background on community health workers in Rwanda

Rwanda has achieved the Millennium Development Goal targets 4 and 5A. Target 5A required a reduction of 75% of the maternal mortality ratio by 2015. Rwanda accomplished 78%, ahead of schedule.<sup>162</sup>

The Government of Rwanda, in the context of its health vision 2020 and related health sector reforms and policies, invested in the essential health interventions for reducing maternal mortality, including family planning and access to other reproductive health services, skilled care during pregnancy and childbirth (including emergency obstetric care), post-partum care as well as post-abortion care, with special efforts to scaling up key maternal health services from 2005 to 2015.<sup>20</sup>

The role, objectives and training of CHW was outlined in a reform. It aimed to improve access to maternal health interventions nationwide.<sup>19</sup> the reform required a minimum of six years of primary education as eligibility criterion for CHW at village level.

Moreover, three CHW would be identified per village, including two general CHWs (a woman and a man), responsible for community health, health education, nutrition, HIV prevention, and a community health worker, known as ‘Mobilizer for Maternal Health’, a woman responsible for community-based interventions during and after pregnancy, as well as for child care.

In addition, the government of Rwanda has implemented community performance-based financing as a response to addressing issues of motivation and retention of the community health workers. They were organized in cooperatives to ensure accountability and income generation.<sup>19, 20</sup> there is a network of 45,011 community health workers, managed by the Rwandan Ministry of Health.

In 2011, Rwanda set up a short message (SMS)-based system to improve maternal and child health (MCH) using Rapid SMS, a free and open-source framework.<sup>163</sup> This was customized to allow interactive communication between a CHW involved in the follow up of mothers and babies at community level, a national centralized database, the health facility, and in case of emergency, the ambulance driver.

There was equally a strong performance discipline with clear communication lines between the different agencies. This has also resulted in strong performance-focused upward accountability measures. Professional standards are accomplished by:

- (i) Regular evaluation of primary health centres by district hospital staff for the performance-based financing (PBF);
- (ii) CHW in charge of maternal health are supervised by field coordinators who visit them in their homes and provide continuous training;
- (iii) monthly reporting on progress towards agreed performance goals, such as increased family planning, at every local health authority level.

Based on this success the government of Rwanda recently announced the implementation of a fourth community health worker in every village in charge of prevention and promotion. This will further strengthen the community-based integrated health model. Task-shifting for CHW in Rwanda has been well received and did not negatively impact the motivation, job satisfaction and outcome of the care provided.<sup>164</sup>

### **10.6.2 Introduction**

What is the role of the CHW in the health pyramid in Africa in bringing care at the community level?

This question cannot be answered in the framework of this research work; nevertheless, there is a need to redesign the management of CHW and their incorporation into a wider system of community health care as part of a general effort to shift health care from the clinics into the community.<sup>165</sup>

### **10.6.3 Community health workers and epilepsy in Rwanda**

In 2010, the Mental Health Gap Action Programme (mhGAP) was released by the World Health Organization (WHO). The mhGAP intervention guide, now also available in an application, provides description, an assessment, management and follow-up of patients with seven different mental health conditions and epilepsy. These recommendations rely mainly on health workers in decentralized care structures at the primary (e.g., local healthcare clinics) and secondary (e.g., district hospital) levels.<sup>133</sup>

For epilepsy, these guidelines are very suitable. The diagnosis can be clinically done by general practitioners or mental health nurses, and there are relatively inexpensive AEDs that are available at grass root level.

The role of CHW in access to epilepsy care is deemed important in the framework to reduce the epilepsy treatment gap.<sup>150, 168</sup>

In Rwanda the role of the CHW and their synergies with the mental health nurses in the primary health care centre in the treatment, adherence and follow-up of PwE is critical. Indeed, vulnerable PwE in rural Rwanda are clearly dependent on the local health structures, rather than on specialized medicine at the central level in tertiary hospitals or the capital.

In addition, the community health workers within the village are very well placed to assist the villagers living with epilepsy as stigma may socially and economically isolate these persons at the community level.

Therefore the Rwandan Organization Against Epilepsy (ROAE) planned the implementation of an epilepsy training model for CHW in the district of Musanze. [F Sebera, personal communication, 2018]. The training course was aimed to improve their knowledge of, attitude towards and practices in epilepsy. All CHW were invited to attend a one-day training course in the appropriate primary health care centres. A total of 1280 CHW participated and returned to their villagers.

Despite the training provided by the ROAE it transpired that only a marginal increase in PwE seeking care for their condition was observed. Therefore, given the importance of CHW in health matters, the idea of a research project evaluating the impact through a standardized questionnaire comparing trained and non-trained village CHW was established.

## 11.RESULTS

### 11.1 Demographic characteristics of the two study groups

A total of 199 CHW were interviewed and completed the questionnaire; 99 in Musanze (trained group), and 100 in Nyakiriro (non-trained group).

During the review of the training records it emerged that three persons in Musanze had not attended the epilepsy training. Subsequently, they were moved to the non-trained group, bringing that total to 103 persons (. The findings are summarized in [Table 5](#)

	Trained group	Non-trained group	p-value
<b>Gender</b>			
Female - n (%)	66 (68.8)	70 (68.0)	0.05
Male - n (%)	30 (31.2)	33 (32.0)	
Total - n (%)	96 (100)	103 (100)	
<b>Age</b>			
Mean age (y)	45.0	40.0	<0.001
Median age (y)	45.15	40.10	
Range (y)	24-86	25-65	
<b>Urban vs. rural</b>			
Urban - n (%)	83 (86.5)	3 (2.9)	
Rural - n (%)	13 (13.5)	99 (96.1)	
Missing - n (%)	0 (0)	1 (1.0)	
Total - n (%)	96 (100)	103 (100)	
<b>Education level</b>			
Primary school - n (%)	42 (43.8)	81 (78.6)	
Secondary school - n (%)	45 (46.9)	14 (13.6)	<0.001
Vocational school - n (%)	9 (9.4)	7 (6.8)	
Missing - n (%)	0 (0)	1 (1.0)	

[Table 5](#).demographic characteristics of the two study populations

There are three important differences between the two groups (see [Table 5](#)). First, it is noted that 86 CHW in Musanze came from the urban area and 13 come from semi-urban areas (villages around Musanze); hence, the population has a predominance of persons living in town. The population in Nyakariro is an entirely rural population. Only three non-trained

CHW came from urban areas. Second, significantly more CHW in Musanze completed the secondary school level when compared with the CHW in Nyakariro. Third, the mean age for CHW in Musanze is higher when compared with the mean age in Nyakariro.

There was no difference in the female/male ratio between the two study groups.

## 11.2 Familiarity with epilepsy

The questionnaire addressed whether CHW were familiar with epilepsy. In the event the community health worker had observed a seizure, they were asked to describe the seizure event through six signs or symptoms, i.e., confusion, tongue biting, uncontrolled urine loss, convulsion, stiffness and staring of the eyes. The CHW could mark more than one sign or symptom.

The results are summarized in [Table 6. Familiarity with epilepsy](#)

	Trained group n (%)	Non-trained group n (%)	p-value
<b>Have you heard/read about epilepsy?</b>			
Yes	95 (99.0)	91 (88.3)	<0.05
No	1 (1.0)	12 (11.7)	
<b>Do you know a person with epilepsy?</b>			
Yes	81 (84.4)	72 (69.9)	0.06
No	13 (13.5)	26 (25.2)	
Not familiar	2 (2.1)	5 (5.9)	
<b>Have you ever witnessed seizure attack?</b>			
Yes	93 (96.9)	89 (86.4)	0.07
No	3 (3.10)	9 (8.7)	
Not familiar	0 (0)	5 (4.9)	
<b>Number of symptoms seen during an attack (*)</b>			
1 symptom	12 (12.5)	4 (3.9)	<0.001
2 symptoms	19 (19.8)	6 (5.8)	
3 symptoms	22 (22.9)	18 (17.5)	
4 symptoms	28 (29.2)	16 (15.5)	
5 symptoms	7 (7.3)	26 (25.2)	
6 symptoms	5 (5.2)	19 (18.4)	
Missing data	3 (3.1)	14 (13.6)	

[Table 6.](#) Familiarity with seizures (\*) more than one answer was allowed

The questions on familiarity with epilepsy identified a difference of CHW in Musanze having heard about epilepsy significantly more when compared with the non-trained CHW.

There are no differences in the responses for the three other questions, except for the difference, although significant, between only one symptoms observed during a seizure. It is

interesting to observe that the percentage of CHW listing all six symptoms was higher in the non-trained group.

### 11.3 Knowledge

The questionnaire addressed the epilepsy knowledge level of community health workers. A summary of the differences between the two groups can be found in [Table 7](#).

	Trained group n (%)	Non-trained group n (%)	p-value
<b>Which age group is most affected (*)</b>			
0-4	7 (7.2)	27 (24.3)	
5-9	21 (21.6)	34 (30.6)	<0.05
≥10	67 (69.1)	48 (43.5)	
Missing	2 (2.1)	2 (1.8)	
Subtotal	97 (100)	111 (110)	
<b>How long should the treatment be given (**)</b>			
For one week	3 (3.0)	11 (10.7)	
For one year	5 (5.0)	7 (6.8)	
For two years of seizure freedom	45 (45.0)	17 (16.5)	<0.05
For life	45 (45.0)	67 (65.0)	
Missing	2 (2.0)	1 (1.0)	
Subtotal	100 (100)	103 (100)	
<b>What is the cause of epilepsy? (*)</b>			
Brain injury	86 (41.7)	61 (43.6)	
Genetic trait	14 (6.8)	21 (15.0)	
Birth injury	59 (28.6)	13 (9.3)	<0.05
Excessive worry	27 (13.1)	15 (10.7)	
Blood disorders	17 (8.3)	0 (0)	
Witchcraft	1 (0.5)	1 (0.7)	
Curse of God	0 (0)	0 (0)	
Spirit possession	1 (0.5)	8 (5.7)	<0.05
Not familiar	1 (0.5)	20 (14.3)	
Missing	0 (0)	1 (0.7)	
Subtotal	260 (110)	140 (100)	
<b>Is epilepsy... (*)</b>			
Madness	6 (5.3)	9 (7.6)	
Spirit possession	12 (10.5)	13 (11.0)	
Mental retardation	3 (2.6)	5 (4.2)	
Brain disease	93 (81.6)	78 (66.1)	

Missing	0 (0)	13 (11.0)
Subtotal	114 (100)	118 (100)

**Table 7.** Epilepsy knowledge of CHW. (\*) more than one answer was allowed; (\*\*) some CHW selected two answers

In the four questions relative to knowledge only four differences could be noted (see [Table 7](#)). There is knowledge difference between the two groups for the age group 5-9 years-old at which seizures are observed, how long the treatment should be given, whether epilepsy is a birth defector a spirit possession. The trained group was able also to list more correct answers (i.e., brain injury, genetic trait or birth injury) than the non-trained group.

It is noteworthy to observe that the non-trained CHW more often responded ‘not familiar with epilepsy’ or did not complete the question and were listed as ‘missing’.

#### 11.4 Stigma

The epilepsy awareness of CHW was evaluated through six questions (see [Table 8](#)).

	Trained group n (%)	Non-trained group n (%)	p-value
<b>Would you allow your child to play with a child living with epilepsy</b>			
Yes	93 (96.9)	84 (81.4)	
No	3 (3.1)	7 (6.8)	<0.001
Not familiar	0 (0)	12 (11.7)	
<b>A child living with epilepsy should never attend school?</b>			
True	11 (11.5)	16 (15.5)	
False	80 (83.3)	70 (68.0)	<0.001
Sometimes true	5 (5.2)	4 (3.9)	
Do not know	0 (0)	12 (11.7)	
Missing data	0 (0)	1 (1.0)	
<b>May your son marry a woman living with epilepsy?</b>			
Yes	80 (83.3)	51 (49.5)	<0.001
No	15 (15.6)	38 (36.9)	
Not familiar	0 (0)	13 (12.6)	
Missing data	1 (1.0)	1 (1.0)	
<b>May your daughter marry a man living with epilepsy?</b>			
Yes	84 (87.5)	52 (50.5)	<0.001
No	12 (12.5)	40 (38.8)	
Not familiar	0 (0)	11 (10.7)	

<b>Can you give a job to a person living with epilepsy?</b>			
Yes	91 (94.8)	68 (66.0)	<0.001
No	5 (5.2)	34 (33.0)	
Missing data	0 (0)	1 (1.0)	
<b>Epilepsy is contagious</b>			
Always	1 (1.0)	7 (6.8)	
Sometimes	16 (16.7)	29 (28.2)	
Never	77 (80.2)	64 (62.1)	0.06
Missing data	2 (2.1)	3 (2.9)	

**Table 8.** Epilepsy awareness and stigma of CHW

Whereas the trained CHW present less stigma when compared with non-trained CHW as evidenced by the p-values with the two questions relative to marriage standing out most between the two groups (see [Table 08](#)).

Nevertheless, there are some unexpected observations.

First, there are 11 trained CHW who responded that children living with epilepsy should not attend school. Second, for the question whether epilepsy is a contagious disease, 17 trained CHW selected the answers always/sometimes. It is unclear whether this is a result of the cultural or traditional belief and that the training did not change that perception.

### 11.5 Treatment recommendation

Two questions dealt with the epilepsy treatment recommendation (see [Table 9](#)).

	<b>Trained group</b> n (%)	<b>Non-trained group</b> n (%)	<b>p-value</b>
<b>If a person found on the road what would you do? (*)</b>			
Health facility	95 (99.0)	84 (76.4)	<0.001
Traditional healer	0 (0)	3 (2.7)	
Chinese medicine	0 (0)	3 (2.7)	
Praying session	0 (0)	5 (4.5)	
Do nothing as there is no treatment	0 (0)	5 (4.5)	
Do not know	1 (1.0)	4 (3.6)	
Not familiar	0 (0)	6 (5.5)	
Subtotal	96 (100)	110 (100)	
<b>What would you recommend for treatment for a family member living with epilepsy? (*)</b>			
Health facility	96 (90.6)	92 (75.4)	<0.05
Traditional healer	0 (0)	8 (6.6)	
Chinese medicine	2 (1.9)	3 (2.5)	

Prayers	8 (7.5)	11 (9.0)
No, as epilepsy cannot be treated	0 (0)	2 (1.6)
Do not know what to do	0 (0)	1 (0.8)
Not familiar	0 (0)	4 (3.3)
Missing data	0 (0)	1 (0.8)
Subtotal	106 (100)	122 (100)

**Table 9.** Treatment recommendations. (\*) more than one answer was allowed

Questions on treatment recommendations shows a difference in the two groups, although the number of non-trained CHW responding ‘not familiar’, ‘do not know’ and ‘missing’ may have created a bias. Non-trained CHW are less likely to send a person with a seizure to the health facility.

## 12.DISCUSSION

The ‘Assessment of the knowledge, attitude and practice (KAP) towards epilepsy and PwE’ by CHW trained by the ROAE compared with a group of CHW who received no epilepsy training was addressed by the administration of a questionnaire to trained and non-trained community health workers. Five categories of responses were identified, i.e., demographic characteristics, familiarity with epilepsy, knowledge, stigma and treatment recommendation.

This is a descriptive study using a questionnaire and a comprehensive review of the literature guided the interpretation of the results. The timing of the execution of the roll-out of the questionnaire did not allow for the pre-testing of the questionnaire and it transpired that some questions could have been formulated differently.

The demographic characteristics between the trained and the non-trained groups are somewhat different. Indeed, the trained CHW are more often living in urban areas, are older and have completed secondary school. These differences were unexpected as the overall profile of CHW in the Musanze and the Rwamagana health districts are very similar.

Both groups illustrate a similar familiarity with epilepsy and may have a similar baseline knowledge of the disease. Of note is the observation that non-trained CHW were more likely to report five or all six symptoms. It may be hypothesized that the non-trained CHW confused a convulsion with a syncope and psychosomatic signs and symptoms to a seizure episode. In contrast, trained CHW were able to differentiate and hence identified fewer symptoms.

The differences in knowledge of epilepsy are present especially in the understanding of the cause of the condition where the trained CHW perform better. In addition, the trained CHW also perform better on the duration of the treatment to be provided to PwE. Although there is also a difference in the knowledge between the trained and non-trained CHW in the presentation of epilepsy by age group, it should be recognized that the possible answers to the questions could have been structured differently. Indeed, the adult group from 15 years of age was not referenced in the possible answers. This omission could not be corrected for. In addition, an in-depth review of the training material provided by the ROAE found that the training on the knowledge was rather limited.

The reduction of stigma in trained CHW is significant and the outcome of the training course and understanding of the disease burden is remarkable. Nevertheless, there are some unexpected observations. The unexpected findings that some trained CHW responded that



children living with epilepsy should not attend school and that epilepsy is a contagious disease deserve further attention. It is likely that cultural and traditional beliefs persisted, and that future training programme need to emphasize these particular aspects.

The recommendation relative to treatment choices is better in trained community health workers. Nevertheless, an interesting observation could be made between the treatment choice for a family member living with epilepsy or a person presenting a seizure in the street. Trained CHW tend to recommend more rapidly a person with a seizure to the health facility than a family member living with epilepsy who is referred to the health centre combined with prayers.

Our research activities investigating the epilepsy knowledge, attitude and practice by CHW illustrate how continued training of CHW for this non-communicable disease can change the life and perspective of PwE. The training enabled CHW to better understand the stigma and to decrease the level of stigma as well to ensure that PwE are correctly referred to the health centre for diagnosis and treatment follow up. This approach of training grass root CHW has also contributed to the success of the fight against communicable diseases, such as HIV, tuberculosis, malaria, infant and maternal mortality, among others.

An in-depth analysis of the epilepsy training material for the CHW training and a further coaching of the teachers is to be investigated in order to improve the knowledge gap and further reduce the stigma barriers. This way the quality of life of PwE could be further improved.

In view of the demonstrated benefits of training to CHW and of the proximity and social acceptability of CHW to the villagers, access to care will further advance, stigma will reduce, social integration will improve at both work and at school, and hence the quality of life of these PwE will improve. This is particularly important for Rwanda given the observation that the prevalence of epilepsy is high when compared the average prevalence in sub Saharan Africa.<sup>6</sup>

The benefit of an epilepsy training was clearly illustrated by the training program for the diagnosis and management of generalized tonic-clonic seizures offered to nursing staff and environmental technicians responsible for community health education in the Banket health district in Zimbabwe.<sup>168</sup> Also, the impact of patient-education pamphlets on drug compliance, seizure frequency, and clinic attendance were evaluated. A 74 % increase of new patients was observed in the six-month period after the training.

Information in the pamphlets may have helped to alter an erroneous presumption of cure after a brief period of chemotherapy that often underlies patient default from drug therapy in developing countries. The use of the pamphlets did not, however, lead to a significantly increased frequency of clinic-attendance among non-defaulters, when compared with controls.

The data on drug compliance suggested that education of CHW led to a marked reduction in non-compliance in the randomly selected patients tested. In addition, the use of patient-information pamphlets did not lead to any significant difference in the degree of non-compliance.

Overall, these findings suggest that health information delivered orally by the community health worker is more effective in improving patient drug compliance than is the information gleaned from information pamphlets.

CHW are also critical in reducing the treatment gap, reported at 68%.<sup>6</sup> Several interventions to address the causes of the diagnosis and treatment gaps have been published.<sup>3, 167, 168, 169</sup> CHW can contribute to close the diagnosis and treatment gaps. Indeed, their key position in the communities and villages should enable them to provide guidance and refer PwE to the primary health care centres, if well trained.<sup>150</sup> They are also key in creating the awareness of care available to PwE and mobilise the communities to reduce the stigma associated with the condition. Their role in observing early co-morbidities of epilepsy, e.g., depression, suicidality, needs to be carefully considered and future training might need to give them some key indicators to help them to help persons within their communities.<sup>145</sup> Based on the studies performed in Zimbabwe and Zambia, CHW should be offered tools to deliver orally the key information on epilepsy and co-morbidities.

CHW are best placed to help PwE on how they can improve adherence to the anti-epileptic treatment, when and how to take anti-epileptic treatment and how to improve the self-esteem of PwE in their communities by reducing their stigma and social exclusion.<sup>3, 171</sup> These actions can be further supported by smart phone applications to help differentiate by simple questions whether a person experienced a seizure and requires referral or whether a person experienced a non-epileptic condition as it was demonstrated in India.<sup>171</sup> Although such applications are not yet available in Rwanda, they deserve further investigation on how to improve educational interventions for the grass root health workers.

During the field work and discussions with CHW the need of additional and a broader education was suggested. Provided the complexity of the disease, the challenges in access to care, especially in rural areas of Rwanda, and the stigma arising from superstitious beliefs of the condition, such broader training and education should include PwE, their parent and/or families, their communities, teachers in schools, traditional and faith healers.<sup>106</sup> The ROAE recently completed an epilepsy training of over 1,300 accredited traditional healers in Musanze and is an additional step in improving access to care for PwE. [F Sebera, personal communication, 2018]

### **13. CONCLUSION**

The exploration of the knowledge of epilepsy, the disease aetiology, management and attitude towards the disease and the PwE of trained and non-trained CHW revealed several interesting observations.

The training improved, no doubt, the knowledge and attitude of CHWs. Importantly the understanding on stigma has also improved in trained CHWs.

Further assessments of the impact of the training and the outcome for the PwE are recommended and easy to perform pre-tested KAP questionnaires should be applied more readily. It would be of interest to conduct a nation-wide KAP analysis of CHWs in all provinces in order to better understand diagnosis and treatment gaps relative to epilepsy. Indeed, when CHWs are well informed, PwE are likely to face less stigma, be in better neurological and physical health and will be better integrated in their communities.

### **14. KEY POINTS**

- To the best of our knowledge, this is the first epilepsy KAP analysis in CHW in Rwanda;

- An epilepsy-focused training benefitted CHW in their knowledge, attitude and practices towards this stigmatizing disease;
- Future training should (i) enhance the capabilities of CHW in understanding the importance of referral to primary health care centres; and (ii) improve the understanding of the individual signs and symptoms of a seizure;
- An assessment of the effectiveness of the referral process of PwE by CHW may be warranted; and,
- Pre-testing of the questionnaire in future knowledge, attitude and practices studies is strongly recommended.

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## APPENDIX 1: Study design

<b>#</b>	<b>Activity</b>	<b>Timeframe</b>
1.	Protocol elaboration	August 2017
2.	IRB submission and approval	September 2017
3.	Search for funds	October – November 2017
4.	Field Study	March – April 2018
5.	Data entry	October 2018
6.	Data analysis	October 2018
7.	Report Writing	June – November 2018
8.	Master thesis	October – December 2018
9.	Presentation results to community health workers	February 2019
10.	Presentation at conference	August 2019
11.	Publication in peer reviewed journal	October 2019

APPENDIX 2: Research Budget (in RwF)

<b>0. Logistics</b>			
Province	Northern	Eastern	
Reason of travel	Data collection	Data collection	
Intended days of stay	11	11	
Transportation	330,000	330,000	
Mission/Days	7,200	7,200	
Mission fee 11 days	79,200	79,200	
Accommodation	47,700	37,200	
Total accommodation	524,700	409,000	
Total cost [RWF]	933,900	818,400	1,752,200
<b>1. Personnel</b>			
Compensation community health workers			400,000
<b>2. Stationary</b>			
Total			115,000
<b>3. Miscellaneous</b>			
Total			200,000
<b>4. Transportation for informing community health workers</b>			
Total			300,000
<b>Grand total</b>			<b>2,767,300</b>



Kigali ....mutarama 2018

**Kwemera kwitabira ubushakashatsi**

Jyewe, Dr Muhumuza Ndamage Stephen, ndi kwiga kuba inzobere mu ndwara zo mu mumubiri muri Kaminuza y'u Rwanda. Ndi gukora ubushakashatsi ku bijyanye "nu bumenyi ,imyitwarire n'icyo umujyanama w'ubuzima ya korera umuntu ubana kyangwa urwaye igicuri".

Intengoy, ububushakashatsi nukumenya uko abantu babana n'igicuri bavurwa, n'okumenya ubumenyi bwumujyana w'ubuzima kundwara y'igicuri.

Nkumuganga w'indwarwa zo m'umubiri nifuza kumenya uko umujyanama w'ubuzima y'itwara imbere y'ububurwayi budakira .mugihe nazuraga ntabonye ko abantu babana n'igicuri bahabwa akato ,bagahabwa amahirwe make y'akazi .

Ndasaba kowakwitabira gusubiza ibibizo biri muri ubu bushakashatsi buvuzwe haruguru. Ibikubiye muri ubu bushakashatsi bizagirwa ibanga hagati yanjye [Umushakashatsi] n'usubiza [Uwitabiriye ubushakashatsi].

Mukazamenyeshwa ibyavuye mur'ububushakashatsi mbere y'uko bwazandikwa mubitabo, no kumbuga z'ubushakashatsi.

Njye ndemeza yuko nasobanukiwe ibijyanye n'ubu bushakashatsi, nemeye gusubiza ibibazo muri ubu bushakashatsi, kandi mfite uburenganzira bwo kudakomezanya n'ubushakashatsi igihe cyose mbyifuriye.

Habaye hari ibindi bisobanuro, cyangwa hataribyo wishimiye muri ikigihe cyubushakashatsi , ushobora kwiyambaza abakuriye ubushakashatsi muri kaminuza y'uRwanda kuri telefoni 0788490522 cyangwa uwungirije kuri tel: 0783340040.

Murakoze

Umukono w'uwitabiriye ubushakashatsi

Itariki ...../...../ 2018

## Appendix 1b: Questionnaire [Kinyarwanda]

Questionnaire|...||...|

**Ibibazo.**

### **Ku mujyanama w'ubuzima**

*Uru rutonde rwibibazo bigamije kumenya ubumenyi, imyitwarire, icyo umujya nama w'ubuzima y;itwara imbere y'umuntu ubana indwara y'igicuri. Biragutwara iminota 15 gusubiza ibibazo bikurikira .*

*Urahabwa amafaranga 2,000RWF nyumayogusubiza , ibibazo.*

*Amakuru a zava muri isuzuma bumenyi aza tunganywa ku bufatanye bwa kaminuza y'urwanda n'ibitaro byindwara zo mumutwe CAREAS Ndera amakuru azavamo, azadufasha gutegura imfasha nyigisho zigenewe abajyanama b'ubuzima kugirango abantu babana n'uburwayi bwigicuri barusheho kubaho neza .Tubashimiye ubufasha bwanyu .*

Tanga amakuru kuri ibi bikurikira:

1. Umudugudu  
.....
2. Amazina yawe: Ryimuryango: ..... Irya kabiri: .....
  - o Imyaka yawe \_\_\_\_\_
  - o Igitsina       Gabo       Gore
3. Amashuri wize
  - amashuri abanza
  - amashuri y'isumbuye
  - amashuri y'imyuga
4. Aho mutuye
  - Mumuji
  - Mucyaro
5. Wari wigera wumva cyangwa usoma Indwara yitwa "Igicuri"?
  - a.  Yego
  - b.  Oya
6. Wigeza umenyana nu Muntu urwaye Igicuri?
  - a.  Yego
  - b.  Oya
  - c.  Ntago nsobanukiwe iyindwara y' Igicuri
7. Wari wabona umuntu Ufashwe n' Igicuri?
  - a.  Yego - Niba ari Yego, wavuga mubyo wabonye muri ibi bikurikira

- i.  Gucanganyikirwa
  - ii.  Kwiruma ururimi
  - iii.  Kwihagarika [ibyoroshye/Ibikomeye]
  - iv.  Kubura ubwenge
  - v.  Kugangarara
  - vi.  Gukanura amaso cyane
- b.  Oya
- c.  Ntago nsobanukiwe liyindwara y' Igicuri
8. Ese umuntu urwaye Igicuri bamuzanye murugo iwanyu, Nyuma ukamenya ko afite Iyi ndwara y' Igicuri; Wakora iki?
- a.  Nashaka umuvuzi Gakonda
  - b.  Ubuvuzi gakondo bwagishinwa
  - c.  Nahamagara Abasenga bakamusengera
  - d.  Ntacyo nakora kuko nubundi ntamuti Igicuri kigira
  - e.  Ntago nzi icyo gukora
  - f.  Ntago nsobanukiwe Iyindwara y' Igicuri
9. Ese gufatwa n'Igicuri bikunze kugaragara mukihe cyiciro cy'Imyaka?
- a.  Abana bato kuva kumyaka 1 kugera 5
  - b.  Abana bato kuva kumyaka 5 kugera 10
  - c.  Abantu bakuru
10. Umuntu uzwineza ko arwaye Igicuri bamusanze kunzira cyamufashe, bamuzana murugo Iwanyu; ese wabyakira ute?
- a.  Namushyikiriza Umuganga
  - b.  Namushyikiriza umuvuzi gakondo```
  - c.  Ubuvuzi gakondo bwagishinwa
  - d.  Nahamagara Abasenga bakamusengera
  - e.  Ntacyo nakora kuko nubundi ntamuti Igicuri kigira
  - f.  Ntago nzi icyo gukora
  - g.  Ntago nsobanukiwe Iyindwara y' Igicuri
11. Kwivuza Igicuri byakorwa mugihe cyingana iki?
- h.  Icyumweru kimwe nyuma yuko cyamufashe
  - i.  Mubuzima bwe bwose/Iminsi yose akiriho
  - j.  Umwaka umwe [1] gusa
  - k.  Nibura Imyaka ibiri [2] kitaragaruka

10. Ese wakunda ko umwana wawe akina namugenziwe urwaye igicuri?
- Yego
  - Oya
  - Ntago nsobanukiwe iyindwara y' Igicuri
11. Umwana urwaye Igicuri ntagomba kujya kwishuri.” Iyi mvugo;
- Nukuri
  - Nibinyoma
  - Rimwenarimwe nukuri
  - Ntago nsobanukiwe iyindwara y' Igicuri
12. Ese wakunda ko Umuhungu wawe ashaka Umukobwa urwaye Igicuri?
- Yego
  - Oya
  - Ntago nsobanukiwe iyindwara y' Igicuri
13. Ese wakunda ko Umukobwa wawe ashakwa n' Umugabo urwaye Igicuri?
- Yego
  - Oya
  - Ntago nsobanukiwe iyindwara y' Igicuri
14. Ese watanga akazi kumuntu urwaye Igicuri?
- Yego
  - Oya
15. “Igicuri nuburwayi bumeze...” [*Hitamo byose ubona aribyo*]
- Nkibisazi
  - Gufatwa nimyuka mibi/abadayimoni
  - Kudakura neza
  - Indwara ifata Ubwonko
  - Ntago nsobanukiwe iyi ndwara y' Igicuri
16. Igicuri kirandura [*hitamo kimwe ubona aricyo*]
- Ibihe byose
  - Rimwenarimwe
  - Ntanarimwe
17. Ese utekereza ko Igicuri giterwa niki? [*Hitamo byose ubona aribyo*]
- Gukomereka ku Bwonko
  - Biva mumuryango

- c.  Gukomereka uvuka
- d.  Guhangayika bikabije
- e.  Amaraso adatembera neza mumubiri
- f.  Amarozi
- g.  Waravumwe n' Imana
- h.  Imyuka mibi
- i.  Ntago nsobanukiwe iyi ndwara y' Igituri

18. Ese uramutse ufite umuvandimwe cyangwa mwenewanyu urwaye igituri wamugira inama yo kwivuzza ate ?

- a.  kujya kwa muganga
- b.  kureba umuvuzi gakondo
- c.  Ubuvuzi gakondo bwagishinwa
- d.  Nahamagara abasenga bakamusengera
- e.  Ntacyonakora kuko nubundi ntamuti igituri kigira
- f.  Ntabwonzu icyogukora
- g.  Ntago nsobanukiye iyindwara y'igituri

Mwakoze kugira uruhare muri irikusanya makauru, mubaye mufite ibitekerezo turabyakira. Mwabyandika hepfo hakurikira.



*Kigali, .. January, 2018*

**RE: INFORMED CONSENT**

**This informed consent supports the data collection of the study topic ‘KNOWLEDGE, ATTITUDE AND PRACTISE OF COMMUNITY HEALTH WORKERS TOWARRDS PERSONS LIVING WITH EPILEPSY IN BOTH RURAL AND URBAN AREAS OF RWANDA ‘.**

**The goals of this study is to understand the care offered to persons living with epilepsy and evaluate the knowledge of community health workers towards epilepsy as a disease.**

**By agreeing to participate in this study you agree to respond to the questions that I will ask you based on a questionnaire approved by my supervisors.**

**As a physician, I am interested to learn more on the community health approach of this important chronic disease. During my training I learned that persons living with epilepsy are very often stigmatized and excluded from their communities.**

**Also, as the principal researcher, I am committed to use the data collected only for the purpose of this study. You will be informed on the outcome of the study when the analysis and reporting has been done.**

**In the event you would have a complaint or have misunderstood the purpose of the study and the way the questions were raised, you may contact the chairperson of the IRB at 078 849 05 22 or deputy chairperson IRB at 078 334 00 40.**

**By signing below, I, \_\_\_\_\_ confirm that I understand the content of this document and the nature of this research project and I consent to participate in this research project. I do understand that I have the liberty to withdraw from the project at any time without any consequence.**

**Provider Signature**

**Witness Signature**

**Date: ...../...../ 2018**



**Questionnaire**|....||....|

*Dear Community Health Worker*

*This questionnaire is designed to better understand your understanding, your attitude and your practice towards epilepsy. We will be completing this questionnaire in roughly 15 minutes.*

*You will receive a financial compensation of 2,000RWF after completing the questionnaire.*

*The information of the questionnaire will be processed jointly at the University of Rwanda and the CARAES neuropsychiatric hospital of Ndera and will allow us to better target educational programmes for community health workers in the nearby future. It is important that persons living with epilepsy receive quality care. Your assistance is very much appreciated and we thank you for kind and generous assistance.*

4. Village [nom]

.....

5. Community health worker

Initials            Family Name:..... First  
name.....

○ Age \_\_\_\_\_ [year]

○ Gender     Male         Female

6. Highest grade attained.

Primary level

Secondary level

Vocational level

4. Where do you live ?

Town

Village

5. Have ever heard or have you ever read about a disease called “epilepsy”?

a.  Yes

b.  No

6. Do you know or have you ever known a person with “epilepsy”?

a.  Yes

b.  No

c.  Not familiar with epilepsy

7. Have you ever witnessed someone with an epileptic attack ?

a.  Yes - if yes what signs did you see during that attack mention all that apply

- j.  Confusion
  - ii.  Tongue biting
  - iii.  Uncontrolled urine loss
  - iv.  Convulsion
  - v.  Stiffness
  - vi.  Staring of eyes
- b.  No
- c.  Not familiar with epilepsy
8. When someone with epileptic attack is brought at your home, and you really know that he is an epileptic, what would you do?
- a.  Visit a traditional healer
  - b.  Consult Chinese traditional medicine
  - c.  Advise to seek prayer healing session
  - d.  Do nothing cause no treatment anyway
  - e.  Don't know what to do
  - f.  Not familiar with epilepsy
9. Epilepsy is common in which age group ?
- a.  Children from 1 to 5 years
  - b.  Children from 5 to 10 years
  - c.  Adult
10. When someone with epileptic attack is found on the road brought at your home and you really know that he is an epileptic, what would you do ?
- a.  Visit a health facility
  - b.  Visit a traditional healer
  - c.  Consult Chinese traditional medicine
  - d.  Advise to seek prayer healing session
  - e.  Do nothing cause no treatment anyway
  - f.  Don't know what to do
  - g.  Not familiar with epilepsy
11. Epilepsy treatment should be taken for how long ?
- h.  For one week after the attack
  - i.  For the rest of his/her life
  - j.  For one year
  - k.  For two years of seizure freedom

10. Would you allow your child to play with a child who has epilepsy?
- a.  Yes
  - b.  No
  - c.  Not familiar with epilepsy
11. "A child with epilepsy should never attend school." This statement is
- a.  True
  - b.  False
  - c.  Sometimes true
  - d.  Do not know as I am not familiar with epilepsy
12. Would you allow your son to marry a girl with epilepsy?
- a.  Yes
  - b.  No
  - c.  Not familiar with epilepsy
13. Would you allow your daughter to marry a man with epilepsy ?
- a.  Yes
  - b.  No
  - c.  Not familiar with epilepsy
14. Can you give a job to an epileptic patient ?
- a.  Yes
  - b.  No
15. "Epilepsy is a form of..." [*Please tick all that apply*]
- a.  Madness
  - b.  Spirit or demon possession
  - c.  Mental retardation
  - d.  Brain disease
  - e.  Not familiar with epilepsy
16. Epilepsy is a contagious condition [*Please tick one*]
- a.  Always
  - b.  Sometimes
  - c.  Never
17. What do you think is the cause of epilepsy? [*Please tick all that apply*]
- a.  Brain injury
  - b.  Runs in families

- c.  Birth injury
  - d.  Excessive worry
  - e.  Blood disorder
  - f.  Witchcraft
  - g.  Curse from God
  - h.  Spirit possession
  - i.  Not familiar with epilepsy
18. If you happen to have a relative with epilepsy how would you advise that person to seek treatment? [*Please tick all that apply*]
- a.  Visit a health facility
  - b.  Visit traditional healer
  - c.  Chinese traditional medicine
  - d.  Seek praying healing session
  - e.  No recommendation as epilepsy has no treatment
  - f.  Don't what to do
  - g.  Not familiar with epilepsy

Thank you for participating in this survey. We welcome any comments you have regarding this survey. Please place them below.

Online certificate attached



Certificate of Completion

The National Institutes of Health [NIH] Office of Extramural Research certifies that Muhumuza Stephen successfully completed the NIH Web-based training course:

**“Protecting Human Research Participants”**

Date of completion: 08/10/2017

Certification Number: 22434912