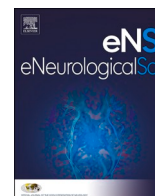


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## Decentralized, primary-care delivered epilepsy services in Burera District, Rwanda: Service use, feasibility, and treatment

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### ABSTRACT

**Background:** Integrating epilepsy care into primary care settings could reduce the global burden of illness attributable to epilepsy. Since 2012, the Rwandan Ministry of Health and the international nonprofit Partners In Health have collaboratively used a multi-faceted implementation program- MESH MH—to integrate and scale-up care for epilepsy and mental disorders within rural primary care settings in Burera district, Rwanda. We here describe demographics, service use and treatment patterns for patients with epilepsy seeking care at MESH-MH supported primary care health centers.

**Methods and findings:** This was a retrospective cohort study using routinely collected data from fifteen health centers in Burera district, from January 2015 to December 2016. 286 patients with epilepsy completed 3307 visits at MESH-MH participating health centers over a two year period (Jan 1st 2015 to Dec 31st 2016). Men were over twice as likely to be diagnosed with epilepsy than women (OR 2.38, CI [1.77–3.19]), and children under 10 were thirteen times as likely to be diagnosed with epilepsy as those 10 and older (OR 13.27, CI [7.18–24.51]). Carbamazepine monotherapy was prescribed most frequently (34% of patients).

**Conclusion:** Task-sharing of epilepsy care to primary care via implementation programs such as MESH-MH has the potential to reduce the global burden of illness attributable to epilepsy.

### 1. Introduction

Epilepsy is a common, chronic neurological disorder that disproportionately affects people living in low and lower-middle income countries, particularly sub-Saharan Africa [1,2]. Epilepsy accounts for over ten million disability adjusted life years (DALYs) globally, and severe epilepsy is among the 10% of disorders with the highest estimated disability weights, alongside AIDS and metastatic terminal cancer [3]. Treatment for epilepsy is highly effective, yet it is estimated that more

than three quarters of people living with epilepsy in low-resource settings do not receive treatment [4]. Significant barriers to effective treatment continue to exist, including a paucity of health workers trained and supervised in the diagnosis and treatment of epilepsy, challenges in antiepileptic medication supply chain management, limited access to diagnostic tools and equipment, and health systems which are poorly conducive to the integration of chronic care. Increasingly, task sharing or task shifting—the redistribution of responsibilities from higher trained health workers to less highly trained health workers

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in order to maximize efficiency of health workforce resources—is being adapted for the care of epilepsy in low-resource settings and in sub-Saharan Africa [5,6]. With regard to culture, due to stigma and fear embedded within communities and health systems, health care providers are still often reluctant to interact with or touch people living with epilepsy, due to fears of spiritual malaise or demonic possession [7]. From a policy perspective, the variable placement of epilepsy within non-communicable disease and mental health policies and frameworks in many countries may create the additional risk of further under-prioritization and inadequate resource allocation for epilepsy prevention and care. Despite these challenges, epilepsy remains a highly treatable condition.

Rwanda's current National Strategic Plan for Mental Health aims to address the country's burden of neuropsychiatric disorders by placing mental health and neurologic services, including epilepsy, within public district health systems, and decentralizing care from the national neuropsychiatric referral hospital into district continuums of care [8]. There is now at least one psychiatric nurse with training in epilepsy diagnosis and management at each district general hospital in the country [9], yet the treatment gap for epilepsy is estimated to remain at 68% across rural areas of the country [10]. The National Plan also advocates for the integration of mental and neurologic care into primary care settings, in order to expand evidence-based treatment for epilepsy to underserved areas of the country, and address ongoing limitations in the number of available specialized providers for neurologic and psychiatric disorders.

Partners In Health (PIH), an international non-governmental organization known locally as *Inshuti Mu Buzima* (IMB), has been working to support the health system strengthening in three rural districts in Rwanda since 2005, with mental health systems strengthening formally initiated in 2009. Beginning in 2012, IMB/PIH and the MoH collaboratively adopted a set of implementation strategies to integrate neuropsychiatric care into primary care, called the MESH-MH (Mentoring and Enhanced Supervision at Health Centers for Mental Health) implementation program. The program is based on an existing set of strategies designed to improve care quality in a variety of clinical domains in IMB-supported districts of Rwanda, including care for chronic non-communicable diseases [11]. MESH- MH has been described in detail elsewhere [9,12,13]. Between 2012 and 2016 services for severe mental disorders and epilepsy were scaled to 19 health centers across the rural district of Burera, Rwanda, supported by the MESH- MH implementation program.

There exists a paucity of literature describing service use patterns for people with epilepsy receiving care within health systems focused on decentralizing mental health and neurologic care to primary care settings. We have previously examined mental health service use trends as services were moved from district specialized mental health clinics into primary care health centers [14]. People with epilepsy may have service needs which differ from other users of mental health services [15]. The aim of this work was to describe demographics, service use, and treatment patterns for patients with epilepsy receiving care from non-specialists in health centers in one rural district of Rwanda.

## 2. Methods

### 2.1. Study design

A descriptive retrospective cohort design was used and routinely collected data from all patients who received mental health care at health centers in Burera district supported by the MESH MH model were collated.

### 2.2. Study setting

The study was conducted in rural Burera District, Northern Province, Rwanda. Burera is a rural district with a population of about 340,000,

and is served by 19 primary care health centers throughout the district. The primary referral center for the health centers is the 150-bed public Butaro District Hospital. Approximately 1500 community health workers link rural communities to the health system via health center referrals, and engage in case finding, psychoeducation, treatment adherence and follow up support. Mental health and neurologic service provision in the district is provided at the district specialized mental health clinic, and at the primary care centers by non-specialist primary care nurses. Through the MESH-MH program, primary care nurses are equipped to perform patient assessments, provide treatment including basic medication management and psychoeducation, coordinate community support, and manage follow-up care. The program has focused primarily on four mental and neurologic disorders: epilepsy; schizophrenia; bipolar disorder; and severe depression. Complicated cases or patients requiring acute care are referred to the local government tertiary care center in the district, Butaro District Hospital. All clinical providers are employed by the government within Ministry of Health facilities. Mental health care delivery in the district is further supported by the IMB mental health team, which, at the time of the study, included one program manager, one community coordinator, one research coordinator, and several data officers, along with an expatriate psychiatrist, the Pagenel Fellow in Global Mental Health Delivery (<http://ghsm.hms.harvard.edu/education/fellowships#pagenel>). Together the IMB mental health team and the Pagenel Fellow are supported by a PIH cross-site mental health team, which includes several psychiatrists with extensive experience in mental health care delivery and system development.

### 2.3. Study population

All patients diagnosed with epilepsy who attended at least one visit to a health center supported by the MESH MH program between January 1st, 2015 and January 31st, 2016 were included in the analysis. The diagnosis of epilepsy was established by clinical history (at least two recurrent unprovoked seizures) and exam. The follow up period included visits occurring between January 2nd, 2015 and December 31st, 2016. Patients attending MESH MH supported health centers who were diagnosed with a mental disorder were also included as a comparison group in the analysis.

### 2.4. Data collection

Patient data were recorded by primary care nurses on mental health specific paper registers at each participating health center. The IMB supported data officers abstracted disaggregated patient variables from the paper registers into a centralized Microsoft Access Database (Microsoft Corp, Redmond, Washington, USA). Collected variables included: gender, age, health center name, patient residence (home village), primary and secondary diagnosis, antiepileptic treatment regimens, and the dates of individual patients' appointments.

### 2.5. Data analysis

Diagnoses recorded by the assessing clinician at the patient's first visit were used for analysis. Mental disorders other than epilepsy were combined into one category, labeled "non-epilepsy diagnoses". Age was divided into three categories comprised of young children (<10 years), older children and adolescents (10–19 years) and adults (>19 years). Distance from home to health facility was dichotomized into  $\leq 5$  km or  $> 5$  km. Service use was assessed by calculating the total number of visits for mental health and epilepsy care, at health centers during the two year study period. The number of patients with a second visit to any health center for care within 90 days of their first visit was calculated. The number of patients with at least five visits, each within 90 days of the previous visit, was also calculated. Individuals with missing data on a given factor were excluded from analyses of that variable. Numbers

**Table 1**

Characteristics of people with and without epilepsy receiving neurologic and mental health care at MESH-MH supported health centers in Burera District, Rwanda, January 2015 to January 2016.

	Persons with epilepsy diagnosis n (%)	Non-epilepsy diagnosis n (%)
Gender (n = 814)		
Male	163 (57.0)	189 (35.8)
Female	123 (43.0)	339 (64.2)
Age group (n = 754)		
< 10 years	72 (26.8)	13 (2.7)
10–19 years	68 (25.3)	54 (11.1)
≥ 20 years	129 (48.0)	418 (86.2)
Distance from home to the health facility (n = 764)		
< 5 km	235 (88.3)	448 (90.0)
≥ 5 km	31 (11.7)	50 (10.0)
Comorbidity (n = 286)		
None	256 (90%)	–
Depression	3 (1%)	–
Psychosis	7 (2%)	–
Other	20 (7%)	–

**Table 2**

Treatment regimens (n = 283)<sup>a</sup>

Anti-epileptic medication	N (%)
Carbamazepine/Tegretol	97 (34.2)
Phenobarbital	70 (24.7)
Depakine/Depakote	71 (25.1)
Other	7 (2.5)
Polytherapy	38 (13.4)

<sup>a</sup> Medication data were missing for three patients.

and percentages are reported for categorical variables; all reports regarding pairwise variable associations used a two-tailed Fisher's exact test with a 5% significance level. For age group, we computed a *p*-value for the association between each group and epilepsy diagnosis by aggregating all other groups and analyzing the resulting 2 × 2 table with Fisher's exact test. A multiple logistic regression analysis was used to determine whether, among patients with an epilepsy diagnosis, patient gender, age, distance from home to the health facility, and presence of co-morbidity, were significant predictors of follow up for a second and fifth visit. Data were analyzed using Stata v.15.1 (Stata Corp, College Station, Texas).

## 2.6. Ethics approval

This study, titled "Delivery of Non-Communicable Chronic Disease Care at PIH-supported Districts in Rwanda: Clinical and Programmatic Outcomes" received ethics approval from the Rwanda National Ethical Committee (RNEC).

## 3. Results

There were 286 unique patients with epilepsy seen at the fifteen health centers in Burera District participating in the MESH MH

**Table 3**

Patient follow up visit attendance by diagnosis.

Visit	Epilepsy diagnosis		Non-epilepsy diagnosis		Total		P-value
	n	% returning (n/N)	n	% returning (n/N)	n	% returning (n/N)	
Initial visit	286	–	529	–	815	–	–
Second visit*	233	81.5% (233/286)	375	70.9% (375/529)	608	74.6% (608/815)	<0.01
Fifth visit**	167	58.3% (167/286)	241	45.5% (241/529)	408	50.1% (408/815)	<0.01

\* Second visit defined as occurring within 90 days of first visit

\*\* Each visit from second to fifth occurred within 90 days of the previous visit

implementation program between January 1st 2015 and January 31st 2016. Patient characteristics are described in Table 1.

People with epilepsy represented 36% of the total number of patients receiving mental or neurologic care at MESH MH participating health centers during the same period. Men receiving services were over twice as likely to be diagnosed with epilepsy as women (OR 2.38, CI [1.77–3.19]). Epilepsy was the predominant diagnosis among children; children under 10 were thirteen times as likely to be diagnosed with epilepsy as individuals 10 and over (OR 13.27, CI [7.18–24.51]). Most (88%) patients attending services with epilepsy lived within a short walking distance (< 5 km) to a health center. There were no significant differences in the distance traveled to the health centers between those with epilepsy and those without epilepsy. Tegretol (carbamazepine) monotherapy was prescribed most frequently (34% of patients), followed by Depakote/Depakene (valproic acid) (27%) and phenobarbital (24%) (Table 2).

286 patients with epilepsy completed a total of 3307 visits for epilepsy care during the period from January 1st 2015 to Dec 31st 2016. Of these 286, 233 (81.5%) returned within 90 days for a second visit and 167 (58.3%) of total patients returned for at least five total visits, each within 90 days of the first. Patients with epilepsy were more likely to return for both a second and a fifth visit than patients with other diagnoses of a mental disorder (*p* < 0.01) (Table 3).

The effect of gender, age, distance from home to health center, or comorbidity on fifth visit attendance did not reach statistical significance in logistic regression analysis for patients with epilepsy (Table 4), although when all patients were analyzed the effect of distance on fifth visit attendance was highly significant (*p* < 0.01).

## 4. Discussion

Our study is one of the first to characterize demographics, service use and follow-up, and treatment patterns for patients with epilepsy receiving care in primary care settings in rural sub-Saharan Africa. Our findings reinforce the feasibility of task-sharing to deliver epilepsy care to populations without access to specialized services. According to the World Health Organization (WHO), one hundred million people worldwide will be diagnosed with epilepsy at some point in their lives, the majority of whom live in resource-limited settings, yet basic pharmacological and psychosocial care for epilepsy for the majority of these individuals has not been achieved [16]. The innovative PIH/MoH collaborative implementation program MESH MH addresses this treatment gap by using a set of basic implementation strategies to facilitate front-line public primary care nurses to provide basic care for patients with epilepsy and mental disorders.

In our study, patients with epilepsy were more likely to be children, and 85% of children under 10 who were seen at the MESH MH supported services were diagnosed with epilepsy. Globally, the burden of epilepsy is high among children [17]. In sub-Saharan Africa, it is estimated that over 90% of people with epilepsy are younger than 20 years old [1], and the prevalence of epilepsy in children is estimated to be between 3.6 and 44/1000, with higher rates in rural areas [17]. The most common risk factors for epilepsy in resource-limited countries has been attributed to birth-related trauma, traumatic brain injuries, and central nervous system (CNS) infections, as well as inadequate access to quality health

**Table 4**  
Predictors of attendance at a second and fifth visit for people with epilepsy<sup>\*,\*\*</sup>

	2nd Visit						5th Visit					
	Attended n (%)	Did not attend, n (%)	Unadjusted Odds Ratio [95% CI]	Unadjusted p-value	Adjusted Odds Ratio [95%CI]	Adjusted p-value	Attended n (%)	Did not attend, n (%)	Unadjusted Odds Ratio [95% CI]	Unadjusted p-value	Odds Ratio [95%CI]	p-value
Gender (n = 286)												
Male	130 (55.8)	33 (62.3)					94 (56.3)	69 (58.0)				
Female	103 (44.2)	20 (37.7)	1.31 [0.68–2.55]	0.44	1.66 [0.79–3.45]	0.18	73 (43.7)	50 (42.0)	1.07 [0.65–1.77]	0.81	1.18 [0.69–2.00]	0.55
Age group (n = 269)												
< 10 years	61 (27.6)	11 (22.9)	1.28 [0.59–2.97]	0.59	1.39 [0.61–3.15]	0.18	47 (29.7)	25 (22.5)	1.45 [0.80–2.67]	0.21	1.35 [0.74–2.47]	0.32
10–19 years	54 (24.4)	14 (29.2)	0.79 [0.38–1.71]	0.58	0.92 [0.41–2.05]	0.83	41 (26.0)	27 (24.3)	1.09 [0.60–2.00]	0.78	1.36 [0.73–2.53]	0.033
≥ 20 years	106 (48.0)	23 (47.9)	1.00 [0.51–1.97]	1.00	0.83 [0.22–1.91]	0.43	70 (44.3)	59 (53.2)	0.70 [0.42–1.18]	0.17	0.63 [0.37–1.06]	0.08
Distance from home to health facility (n = 266) <sup>a</sup>												
< 5 km	197 (89.1)	38 (84.4)					146 (91.2)	89 (84.0)				
≥ 5 km	24 (10.9)	7 (15.6)	0.66 [0.25–1.95]	0.44	0.65 [0.22–1.91]	0.43	14 (8.8)	17 (16.0)	0.50 [0.22–1.14]	0.08	0.53 [0.23–1.24]	0.14
Comorbidity (n = 286)												
No	209 (89.7)	47 (88.7)					147 (88.0)	109 (91.6)				
Yes	24 (10.3)	6 (11.3)	0.99 [0.35–2.49]	1.00	1.05 [0.40–2.78]	0.92	20 (12.0)	10 (8.4)	0.90 [0.42–1.91]	0.86	0.96 [0.46–2.03]	0.93

\* Odds ratios and *p*-values based on both Fisher tests of pairwise variable associations (“unadjusted”) and a multiple logistic regression involving all predictors (“adjusted”).

\*\* Although the effect of distance on fifth-visit attendance does not reach statistical significance in analysis of people with epilepsy alone, when all patients are analyzed the effect of distance is highly significant ( $p < 0.01$ ). There is no interaction between epilepsy diagnosis and distance ( $p = 0.9$  in a separate multiple logistic regression analysis not shown here), so it would be justified to base analysis of the effect of distance on the entire patient population.

services [1]. Children with epilepsy are at risk for behavioral disturbances [18] and reduced school attendance, as well as other consequences such as burns, falls and drowning. Service provision for children with epilepsy should focus not only on optimal seizure control, but also family psychoeducation and addressing the significant morbidity and social stigma which is associated with epilepsy [17].

We found that males attending MESH MH supported services were more than twice as likely as women to carry a diagnosis of epilepsy. This may be because men have a higher burden of epileptic disorders in Rwanda, and our data agrees with epidemiologic studies demonstrating that men may be marginally more likely to have epilepsy [19]. For example, higher rates of epilepsy among males have been associated with risk factors such as increased rates of head injuries [20]. Trends toward gender differences may also be seen in some common epilepsy syndromes, as well as other seizure sequelae [19]. Further characterization of the types of epilepsy seen at MESH MH supported services and their etiologies, and better understanding of the epidemiology of service-seekers versus the population prevalence of epilepsy, could better characterize both prevalence and gender differences among those with epilepsy in our catchment area. While most cases of epilepsy worldwide are idiopathic with no identifiable cause, questions remain as to potential specific characteristics and sources of epilepsy in Burera District (i.e., post-head injury, infectious—viral, bacterial, protozoal or parasitic, genetic or other), that may be reflective of its unique geographic, natural, historical or cultural context [2,21].

Our data reflected low levels of comorbid psychiatric diagnoses, particularly depression, among patients with epilepsy, with only 1% of patients in our study diagnosed with both epilepsy and a depressive disorder. Depression is estimated to be the most common comorbid psychiatric disorder with epilepsy, with estimated point prevalence ranging from 4% of seizure free patients in community settings, up to 58% in those with medically intractable epilepsy [22]. People with epilepsy are at high risk for depression stemming from psychosocial factors such as stigma, but also neurological, with site and lateralization of seizure focus both possible contributors to the development of depression in patients with epilepsy [23]. Depression is undertreated across high income countries as well as resource limited settings, but may be more undertreated in epilepsy populations due to under-recognition of depressive symptoms, as well as potential concerns about drug interactions and the risks of exacerbating seizures with antidepressant therapy. Our low recorded prevalence of depression in patients with epilepsy likely indicate that comorbid psychiatric diagnoses are being overlooked in patients with epilepsy served by the MESH MH program, and quality improvement measures to improve care for people with epilepsy should include basic screening and treatment protocols for depression and other psychiatric disorders.

The most common medications prescribed for epilepsy treatment in our study were carbamazepine, valproate or phenobarbital monotherapy regimens, which together accounted for 84% of treatment regimens administered by MESH MH supported services. These treatment regimens are aligned with World Health Organization treatment guidelines for standard antiepileptic treatment regimens, which include strong recommendations for these three medications in addition to phenytoin as initial treatment for convulsive epilepsy [24]. With basic treatment, seizure control can likely be achieved in up to 50% of patients and significant improvements in seizure frequency in up to 25% more, although the success rate depends on the type of seizure and extent of associated neurological abnormalities [25]. Further data on treatment adherence, seizure frequency, and functional status is needed to more accurately assess the efficacy of MESH MH services in improving the lives for people with epilepsy.

In our study, people with epilepsy were significantly more likely to return to care than those with other diagnoses. This may be because families are more likely to return to care with their children, or because people perceive the treatment as being more effective than for other disorders. Distance to the health center may also play a role in return to

care, as other IMB clinical programs in rural Rwanda have found that return to care is lower when patients have to travel farther for care [26]. Although the effect of distance on fifth-visit attendance did not reach statistical significance in analysis of people with epilepsy alone, when all patients were analyzed the effect of distance on fifth-visit attendance was highly significant ( $p < 0.01$ ). It is possible that decentralization of health services to facilities nearer to patients' homes via MESH MH has resulted in better follow up for all people with mental disorders, as well as those with epilepsy. Further research however is needed to explore the reasons for loss to follow up and to demonstrate whether the decentralization of mental health services to health centers via MESH MH has improved adherence to follow up care for people with epilepsy throughout the district.

The primary limitation of this study is that it is a retrospective review of routinely collected with missing data and variation in data quality and completeness. Our study was also limited to data available in paper records at public health facilities throughout Burera district, and did not include specific data on clinical outcomes for people with epilepsy. However, despite the limitations, our study represents one of the first description of demographics, service utilization, and treatment patterns for patients with epilepsy receiving care from non-specialists in health centers in one rural district of Rwanda. Our results can be used to inform the gaps in epilepsy care that still exist in a rural Rwandan district and could be applied to other similar contexts.

## 5. Conclusion

There remains a great need to increase global awareness of the burden of epilepsy on individuals and their families, and its treatable nature. Implementation programs such as MESH MH, focused on accurate diagnosis and treatment of epilepsy, including medication as well as psychosocial services, have the potential to reduce the occurrence of neurological sequelae and improve the quality of life for people living with epilepsy. Further research is needed to validate our findings and analyze patient level clinical outcomes and experiences of care, in order to inform programs and systems designed to bring decentralized, task-sharing in epilepsy care to scale.

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