Effectiveness of Involvement of Community Health Workers in Identification and Referral of Persons Living With Epilepsy in Rural Rwanda

Fidele Sebera
CAREAS Neuropsychiatric Hospital
Peter Dedeken
H Hart Ziekenhuis
Jeannine Kayirangwa
Ruhengeri Hospital
Josiane Umwiringirwa
CARAES Neuropsychiatric Hospital
Delphine Kajeneza
CARAES Neuropsychiatric Hospital
Nicole Alves dos Reis
UCB Pharma SA
Dirk Edward Teuwen (dirk.teuwen@ucb.com)
Ghent University Hospital, Department of Neurology, Gent, Belgium. https://orcid.org/0000-0003-0668-600X
Paul Boon
Ghent University Faculty of Medicine and Health Sciences: Universiteit Gent Faculteit Geneeskunde en Gezondheidswetenschappen

Research

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Abstract

Introduction

As part of an interventional study on epilepsy and depression as co-morbidity, persons living with epilepsy (PwE) were enrolled in villages associated with three health centers (HCs) in the Musanze district, Rwanda. Due to slower than expected enrolment based on an estimated prevalence of 47.7‰, we engaged Community Healthcare Workers (CHWs) in the identification and referral of PwE.

Methods

CHWs of villages associated to three HC participated in a one-day training on epilepsy and on the Kinyarwanda version of the Limoges epilepsy screening questionnaire. CHWs returned to their villages and identified persons responding positive to one or more questions. After one week, CHWs accompanied possible PwE to their respective HC for clinical evaluation and diagnosis of epilepsy by neurologists

Results

A total of 1308 patients screened positive. Clinical diagnosis of epilepsy was confirmed in 589. We observed an unexpected effect of an additional 93 non-screened patients also presenting to HCs, all confirmed with epilepsy. The number of PwE increased from 48 persons prior to the intervention to 682 (a 14.2-fold increase). In the Gataraga, Kimonyi and Karwasa HC, the patient number increased from 18 to 161, 11 to 193 and 19 to 328, respectively. Relative increases at each HC were 8.9-, 17.5- and 17.3-fold, respectively.

Conclusion

This observation illustrates that involving CHWs, equipped with an easy-to-administer screening tool, enhances possible case detection and decreases epilepsy diagnosis and treatment gaps. The involvement of CHWs impacted the lives of many PwE.

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Introduction

In Rwanda, community health workers (CHWs) are considered key members of rural communities and are respected for volunteering to provide health services for members of their communities [1].

The Rwanda National CHW network consists of four CHWs in each village responsible for different community health related matters, *e.g.*, maternal health, human immunodeficiency virus, and malaria. CHWs live in the community, and have completed a minimum of primary school education. Each community is under the supervision of a health post or health center (HC), staffed with a nurse supervising community health activities in their catchment area. At the secondary district hospital (DH) there is a CHW supervisor in charge of the training of CHWs. The vast network of CHWs is managed by the Rwandan Ministry of Health. CHWs were organized in cooperatives to ensure accountability and income generation and may receive community performance-based financing [1,2].

CHWs receive specific healthcare training on a selected number of medical communicable diseases and they are often the link between patients and existing primary healthcare structures. They are key in mobilizing villagers to attend education sessions on health related topics. The structured approach to providing education at a grassroot level in Rwanda has, together with existing systems and infrastructures, helped the country to achieve, in 2015, target 5A of the Millennium Development Goals [1,2].

CHWs also actively participate in mobilisation initiatives, such as Rapid SMS (short message service) for mothers and childcare [1,2], resulting in a decrease in maternal mortality of 78% between 2005 and 2015 [3].

Up to now, CHWs have only been engaged in one large scale epilepsy project in Rwanda [4] aimed to improve the lives of persons living with epilepsy (PwE), including their mobilisation, increased access to treatment and better societal integration by involving all direct and indirect stakeholders. In total, 460 health professionals, 415 traditional healers, 564 religious leaders and 4429 CHWs of 85 HCs in four health districts were trained on epilepsy, resulting in identification of 6330 PwE of whom more than a 30% were on treatment after two years.

Within the framework of an interventional study on epilepsy and co-morbid depression, PwE were enrolled from villages associated with the HCs of the Cyuve/Gacaca, Gataraga and Kimonyi sectors in the Musanze district of Rwanda. We anticipated recruitment of 500 patients among an estimated number of around 3500 PwE, based on epilepsy prevalence data of 49‰ and an estimated population of 72,635 persons ([5.6]. Due to slow recruitment of only 48 PwE after three months and given the former success of CHW supported mobilization, we engaged CHWs for the identification and referral of PwE in a community-based approach.

We report the methodology, feasibility and impact of engaging CHWs in the mobilization of PwE, using an easy to administer screening tool.

Material And Methods

Screening tool

We used the Kinyarwanda version of the Limoges epilepsy screening questionnaire, part two [7,8,9]. This questionnaire was previously translated into Kinyarwanda and adapted to the sociocultural context of Rwanda. It has been used in a door-to-door survey by health care professionals [6].

Recruitment and engagement of CHWs

In June 2018, CHWs of all villages in the Cyuve, Gacaca, Gataraga and Kimonyi sectors, which are the full catchment areas of the three HCs, were invited to attend an one-day training session. In addition, and at the recommendation of the supervisor at the district hospital (DH), CHWs of selected neighbouring villages of the adjacent sectors of Shingiro and Busogo, Muhoza, Musanze, Muko, and Gacaca were also invited. (see **Figure 1**) Multiple preparatory meetings with the staff of the district hospital, executive secretaries and nurses in charge of the CHWs of concerned sectors preceded the training.

CHWs received the recommended *per diem*, as per the Official Gazette, for their attendance to the training as well as for the working days in their villages completing household surveys [10].

CHW training

Training on epilepsy, the screening questionnaire and project rationale, was administered by a neurologist and the project coordinator, a social worker (SW). CHWs were made familiar with signs and symptoms of epilepsy as well as with the epilepsy screening questionnaire. The questions were pre-tested with some CHWs to ensure clarity and understanding of the wording [11]. As part of the CHW training, a roll-play was organised on how all questions should be administered to household members in their communities.

Screening by CHWs in the village

The CHWs organised household visits according to a schedule agreed with the SW. Any person who responded positively to at least one question of the questionnaire was invited for a neurology consultation at the nearby HC. CHWs and SW scheduled the neurology consultations together.

Referral and epilepsy diagnosis of persons with positive screening

CHWs accompanied the persons with a positive screening for a neurology consultation by a neurologist or a resident-neurology. When epilepsy as diagnosis was confirmed, the SW registered demographic data of the PwE. Presence of lifetime epilepsy, both active and inactive, was considered.

If villagers attended the consultation without having been administered the screening questionnaire by a CHW, they were equally allowed to the neurology consultation. If epilepsy diagnosis was clinically confirmed, demographic data were also recorded but not included in demographic analyses.

Data collection and analysis

CHWs received a paper version of the questionnaire for each person and a paper form to record minimal demographic data for positive screened persons. The data collected by the CHWs were transferred into an Excel spreadsheet and matched with the data recorded by the SW during the neurology consultation. Descriptive analysis in Excel was performed.

Ethical considerations

The survey was approved by the College of Medicine and Health Sciences - Institutional Review Board (Kigali, Rwanda) [461/CMBS-IRB/2016]. Verbal consent was obtained before administration of the questionnaire.

Results

CHW recruitment and engagement

A total of 318 CHWs of 114 villages attended the epilepsy training, scheduled in groups of 50-60 CHWs over a 5-day period. CHWs from outside the catchment area of the respective HCs accounted for 12% (38/318).

Screening by CHWs

A total of 280 CHWs completed screening interviews in 101 villages and brought positive screened persons to the neurology consultation at the respective Karwasa, Gataraga and Kimonyi HCs. They performed screening during one day in their community. An average of 4.7 (range 1-27) positive screened persons was referred per CHW.

Epilepsy diagnosis and demographics

A total of 1308 persons who screened positive to at least one question, were referred by the CHWs to the neurology consultation at the Karwasa, Gataraga and Kimonyi HCs. Of those, 1,114 (85.2%) provided the results of their individual screening questionnaire, whereas in 14.8% results were lost or not recorded. Clinical diagnosis was confirmed in 589 (45%) persons (**Figure 2**). In total 277 (47%, 277/589) new cases were confirmed. Of the 312 patients with a previous diagnosis of epilepsy, only 48 (15.4%) were taking anti-epileptic treatment (AED).

The age distribution by gender, shows a male preponderance in the younger age group *vs.* a female preponderance in the older age group (see **Table 2**). The overall female:male ratio is 1,43:1,00. However, there are distinct differences between the three sectors, with many more women in Kimonyi. In addition, when combining PwE by 20-year age groups the female preponderance is clearly higher in with 3.61:1.00 vs. 0.70:1.00 in ≤20 age group (see **Table 2**).

The income level, labelled according to the Rwandan standards, demonstrates no gender difference. The social security coverage was only available for 41.4% of PwE, not differing by gender (see **Table 3**).

Evaluation of unscreened patients

In addition to the positively screened subjects, 93 persons, who had not been attended by a CHW nor had been administered the screening questionnaire, presented voluntarily and unexpectedly to the neurology consultation. 100% were clinically confirmed PwE. Of those, 41.9% were previously diagnosed with epilepsy, yet none were on AED. 63 PwE (67.7%) came from within the catchment area.

Impact of the CHW engagement

Prior to the CHW epilepsy training, only 48 PwE were enrolled in the aforementioned study at the three HCs combined. Following the mobilization campaign, a total of 682 persons were confirmed PwE. The intervention resulted in a 14.2-fold increase in number of PwE in these sectors. The increases were 17.3, 8.9 and 17.5-fold at the HCs of the Karwasa, Gataraga and Kimonyi HCs, respectively. (**Figure 3**)

Discussion

The project demonstrated the impact of the use of the Limoges screening questionnaire administered by CHWs in the identification of PwE in a rural population associated with three HCs in Northern Rwanda. A community-based intervention with the grass root CHWs was critical in bringing persons with possible epilepsy forward to the neurology consultation; persons often hidden in the shadow of epilepsy stigma and social isolation. Their commitment and motivation resulted in a more than 14-fold increase in the overall number of PwE being referred to the HCs. A total of 682 PwE were offered treatment for their condition, or were referred for technical investigations at the secondary and tertiary referral hospitals.

The pivotal role of CHWs has already been recognised in communicable diseases, *e.g.*, HIV, Ebola, malaria, tuberculosis, among others, as well as non-communicable diseases, *e.g.*, hypertension, diabetes, among others [12,13,14]. Providing specific training enable CHW to engage their communities, build resilience, strengthen health structures and support emergency response capacity [13]. The impact of training of CHWs in epilepsy has only very rarely been documented [4,15]. More recently, a study described the use of the mhGAP and the impact of a successful engagement of CHWs on mental healthcare and epilepsy in Mozambique [16].

In contrast to a previous mobilisation project for PwE which used only training of CHWs [4], we combined training with an easy to administer validated screening tool [17]. This different methodology may explain a higher number of confirmed cases per trained CHW (2.1; 589PwE/280CHWs) in our project compared to the former project (1.5; 6330PwE/4429CHWs). The positive predictive value of the screening tool was 45% (589/1308). This yield needs further analysis as future screening or mobilisation projects may want to increase both human resource allocation and screening tool utility.

CHWs demonstrated high engagement and ensured that persons who were administered the Limoges screening questionnaire attended their scheduled appointment with the neurology team. It confirms the impact to engage them following training to administer a tool in the households of their communities and ensure appropriate referral. On the other hand, we observed a high variability in the number of patients brought to the HC from 1 to 27 persons per CHW. Possible explanations include epilepsy training effect and interpretation, bias in administration of the screening tool or motivational aspects. The effect and importance of repeated training needs to be investigated further. Future projects may also improve reporting tools and measures to prevent loss of data, as we observed up to 15% missing questionnaires.

The diagnosis gap in screened and clinically evaluated patients was 47.0% considering 312 out of 589 persons were previously diagnosed with epilepsy. The treatment gap amongst those previously diagnosed with epilepsy was 84.6% considering only 48 persons out of 312 have access to regular AED treatment, in line with previous findings in Rwanda [6,18].

With an overall female:male ratio of 1.43:1.00, we observed large age-dependent gender difference, with male preponderance in the age group below 20 years, changing to female preponderance in older age groups. This age related shift has been observed in Zambia as well, suggested to be aetiology dependent [19]. In our project, CHWs were not instructed to conduct a solid door-to-door approach and may have missed household members when executing screening during daytime, possibly resulting in a selection bias. As PwE often stay at home, more older females involved in the household and younger boys not attending school may have been detected.

Based on income, nearly two out of three PwE were in the lower two tier income levels, with nearly 25% in the poorest economic class, which may not be exceptional in a rural setting. Six in 10 PwE had no access to social security, although this is recommended. This may explain the low number of previously diagnosed PwE adhering to treatment and may contribute to the diagnosis gap as care seeking patterns are impeded by financial concerns. In order to address their financial situation, a dedicated financial support for PwE was established during the project for the organization of psycho-educative groups and individualised psycho-economic activities through micro-financing credits.

Interestingly, we observed a spill-over effect of the project within and outside the catchment area since non-screened persons presented unexpectedly to the neurology consultation. It was found that the word of a specialized neurologist consultation had been spreading fast. In total, 93 additional patients were diagnosed with epilepsy, accounting for nearly 14% (93/681) of all confirmed cases. This may reflect a high need for epilepsy care also in the neighboring regions and needs to be addressed in future projects. Of note, all voluntarily presenting unscreened patients were clinically confirmed PwE, suggesting that epilepsy as a disease may be recognized yet does not necessarily lead to care seeking.

The interpretation of our data related to prevalence calculations is limited as neither prevalence nor incidence can be derived. CHWs were not asked to apply a stringent door-to-door methodology and did not record the number of persons and households interviewed.

Second, CHWs may not have visited all households in the village or have screened all members of a household, resulting in missed households/household members because of agricultural activities or school attendance. From a scalability perspective of a mobilization campaign, we feel that the balance between well planned home visits, may be more feasible compared to a scientific and a state-of-the-art door-to-door approach, even at the risk of missing cases. The observed spill over-effect of 63 unscreened patients from within the catchment area presenting to the neurology consultation may offset missed persons during screening.

In conclusion, this project supports the mhGAP recommendation to engage CHWs in mental and neurological health activities. Our project demonstrated the feasibility and scalability of both training on epilepsy and use of an easy-to-administer screening questionnaire. We would recommend targeted scaling-up mobilisation campaigns given the high prevalence of epilepsy in Rwanda, if adequate access to care and treatment is guaranteed.

Declarations

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Availability of data and materials

[contact editorial office]

Authors' contributions

Conceptualisation: FS, JK, PD

Data curation: FS, DK, JK, JU

Formal analysis: DT

Funding acquisition: FS, JU

Investigation: FS

Methodology: FS, DT

Resources: FS

Software: PD, NAdR, DT

Supervision: PAJMB

Validation: PD

Visualization: NAdR, DT

FS and DT drafted the manuscript. NAdR, DT and PD conducted the statistical analysis. All authors critically revised and approved the manuscript.

Authors' information

This article is part of the PhD research of FS. The study was presented at the 4th African Neurology Conference held in Entebbe, Rwanda (August 2019).

Consent for publication

Consent for publication was obtained from FS, DET, NAdR, JK, JU, DK, PD, PAJMB.

Competing interests

[contact editorial office]

DET is an employee of UCB Pharma. PD received consultancy fees from UCB Pharma and Novartis Pharma. PAMJB has received speaker and consultancy fees from UCB Pharma and various other pharmaceutical companies, and research grants through his institution. DK received an unrestricted grant from the UCB Corporate Societal Responsibility department to complete the Master of Neurology training at the University of Cheikh Anta Diop (Dakar, Senegal).

Other authors have no competing interests.

Ethical approval and consent to participate

The survey study was approved by the College of Medicine and Health Sciences - Institutional Review Board (Kigali, Rwanda) [461/CMBS-IRB/2016], the Institutional Review Boards of the CARAES Neuro-Psychiatric Hospital of Ndera (Kigali, Rwanda) and the Ruhengeri Referral Hospital (Musanze, Rwanda).

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Tables

Table 1: CHWs per health center and their relative contribution to an identification of PwE and persons without epilepsy using the Limoges screening questionnaire.

Health Center	Karwasa	Kimonyi	Gataraga	Total
	n (%)	n (%)	n (%)	n (%)
CHW	169 (60.4)	56 (20.0)	55 (19.6)	280 (100)
Persons screened positive	660 (50.4)	369 (28.2)	279 (21.3)	1308 (100)
PwE	299 (22.9)	159 (12.2)	131 (10.0)	589 (45.0)
Persons without epilepsy	361 (27.6)	210 (16.1)	148 (11.3)	719 (55.0)
Contribution of CHW (n) to identify				
PwE	138 (81.7)	48 (85.7)	46 (83.6)	232 (82.6)
Persons without epilepsy	133 (78.7)	56 (100)	45 (81.8)	238 (85.0)

Table 2: PwE and female:male ratio by sector and by age group. ([a]) gender not known in two persons

Health Center	Total PwE[a]	Female	Male	female:male ratio
	n (%)	n (%)	n (%)	
Karwasa	297	150 (50.04)	147 (49.5)	1.02:1.00
Kimonyi	159	118 (74.2)	41 (74.2)	2.88:1.00
Gataraga	131	77 (58.8)	54 (41.2)	1.43:1.00
Total	587	345 (58.8)	242 (41.2)	1.43:1.00
Age group (y)	Total PwE[a]	Female	Male	female:male ratio
	n (%)	n (%)	n (%)	
00-19	262	116 (44.3)	146 (55.7)	0.79:1.00
20-39	159	99 (62.3)	60 (37.7)	1.65:1.00
≥ 40	166	130 (78.3)	36 (21.7)	3.61:1.00
Total	**587**	**345 (58.8)**	**242 (41.2)**	**1.43:1.00**

Table 3. PwE by the income level (four categories from poor [level 1] to wealthy [level 4]) and access to social security coverage

Income level by category	Female	Male	Total
	n (%)	n (%)	n (%)
1	84 (24.3)	52 (21.5)	136 (23.2)
2	182 (52.8)	113 (46.7)	295 (50.3)
3	73 (21.2)	74 (30.6)	147 (25.0)
4	0 (0.0)	0 (0.0)	0 (0.0)
Unknown	6 (1.7)	3 (1.2)	9 (1.5)
Total	**345 (100)**	**242 (100)**	**587 (100)**
Access to social security	**Female**	**Male**	**Total**
	n (%)	n (%)	n (%)
Accessible	147 (42.6)	142 (39.7)	243 (41.4)
No access	193 (55.9)	96 (58.7)	335 (57.1)
Unknown	5 (1.4)	4 (1.7)	9 (1.5)
Total	**345 (100)**	**242 (100)**	**587 (100)**

Figures

Figure 1

Musanze health district [20]

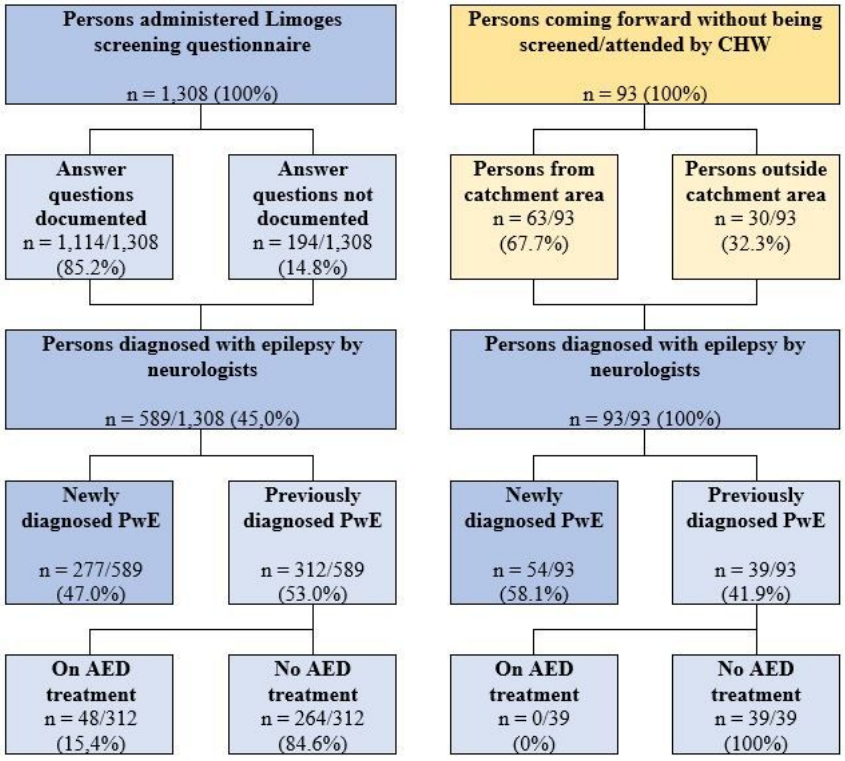

Figure 2

Flow diagram of the persons seen during neurology consultations at the health centers as a function of one or more positive answers to the Limoges screening questionnaire

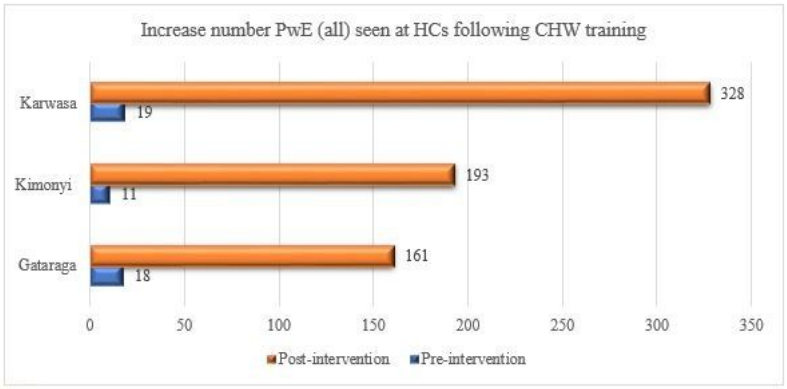

Figure 3

Impact on recruitment of PwE subsequent to an engagement of CHWs per health center