Community perceptions and attitudes regarding epilepsy and disease cost after implementation of a community-based epilepsy treatment program in onchocerciasis-endemic communities in the Democratic Republic of Congo

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Article info

Article history:
Received 23 September 2020
Revised 30 December 2020
Accepted 30 December 2020
Available online 27 January 2021

Keywords:
Epilepsy
Community-based
Antiepileptic
Stigma
Misconceptions
Sustainability

Abstract

Background: In October 2017, a community-based epilepsy treatment program (CBETP) was initiated in the Logo health zone (Ituri province, Democratic Republic of Congo), consisting mainly of community epilepsy education, provision of free antiepileptic drugs (AEDs), and monthly follow-up of persons with epilepsy (PWE). Prior to the implementation of the CBETP, qualitative research had revealed several misconceptions about the cause of epilepsy, major epilepsy-related stigma, and high economic cost for families of PWE mainly because of costly treatment by traditional healers. One year after the implementation of the CBETP, we assessed the perceived effect of this program on the community’s perceptions and attitudes regarding epilepsy and on disease costs.

Methods: Focus group discussions (FGD) and semi-structured in-depth interviews (SSI) were conducted with different target groups. Additionally, the cost associated with epilepsy was evaluated using questionnaires administered to 74 PWE and/or their families.

Results: Nine FGDs and 16 SSIs were conducted. There was a notable shift in perceptions and attitudes, as most community members no longer believed that epilepsy is contagious, while acknowledging that this condition can be treated in local health centers. Persons with epilepsy and their family experienced less epilepsy-related stigma and consulted less frequently traditional healers; the latter showed a growing willingness to collaborate with health professionals in the management of PWE. The direct and indirect costs for families caring for a PWE decreased by 95.2% and 95.7%, respectively.

Conclusion: The main perceived benefits of the CBETP were the decrease in misconceptions about epilepsy and epilepsy-related stigma. Families with PWE understood the benefit of seeking health care from trained health professionals rather than with traditional healers. The direct and indirect costs for families to take care of a PWE reduced considerably after the program. However, the cost-effectiveness and long-term sustainability of this approach remain to be assessed.

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1. Background

Of the estimated 50 million people worldwide living with epilepsy, more than 80% reside in low- and middle-income countries (LMICs) [1]. Despite being one of the most cost-effective neurological disorders to treat, epilepsy remains a major concern in low-income countries. If diagnosed properly and treated with proper
antiepileptic drugs (AEDs), up to seven in ten persons with epilepsy (PWE) could have their seizures fully controlled [2]. Although there are cheap AEDs on the market, about three quarters of PWE in LMICs are still not receiving appropriate treatment [1], mainly because of long distance to health facilities, lack of trained healthcare providers, cost of AEDs, cultural belief in traditional medicine, or unavailability of AEDs [3]. Bridging the treatment gap and fully controlling the seizures in PWE is still a big challenge in LMICs. A meta-analysis of 12 studies reported that 70% of PWE in LMICs do not get the appropriate AEDs [4].

Epilepsy poses an important economic burden for the health system as well as on the PWE and their family because it is associated with increased healthcare needs, premature death, and lost work productivity [5]. We previously showed that the cost of taking care of a PWE in the Logo health zone in Ituri province in the Democratic Republic of Congo (DRC), constituted almost half of the household income [6]: 68.2% of the direct epilepsy-related cost was spent only on traditional medicine. Other costs included cost of outpatient care, AED cost, and expenses for transport particularly from remote areas to healthcare facilities. A study in Burundi revealed that healthcare expenses among PWE were 6 times higher compared to the rest of the population, and that families with PWE had on average 5 times more disrupted days than other families [7].

In October 2017, a clinical trial was initiated in the Logo health zone to investigate whether ivermectin is able to decrease the frequency of seizures [8]. During that project, we also aimed at establishing a community-based epilepsy treatment program (CBETP) to treat all PWE in the area [9]. Before setting up this program, formative research was conducted to investigate the community’s knowledge, perception, and attitudes regarding epilepsy. Qualitative findings revealed several misconceptions about epilepsy, including the belief that epilepsy is a family-related disease, that it is contagious, transmitted by saliva, or by contact with a person during seizures, or caused by evil spirits [10]. In the latter study, the traditional healers were found to play an important role in spreading these misconceptions. The study also reported barriers to access AEDs, the lack of trained healthcare workers to diagnose and treat epilepsy, the high cost for medical treatment, and lack of drugs in the village health centers. The affected villages strongly advocated that a CBETP be set up to alleviate the sufferings of PWE [10]. Therefore, in December 2018, one year after setting up a CBETP, we re-evaluated the community’s perceptions and attitudes about epilepsy and experience with the program. Moreover, we re-evaluated the cost for a family to take care for a PWE among the participants in trial.

2. Methodology

2.1. Study site

This study was conducted in Draju, Kanga, and Thedeja health areas in the Logo health zone, an onchocerciasis-endemic area with a high epilepsy prevalence of 4.6% and where ivermectin for onchocerciasis control had never been distributed [11]. The Logo health zone has only one reference hospital with five doctors, and 26 health centers headed by nurses [6]. The zone is located not far from the Ugandan border, therefore Ugandan shillings (USH) is the currency commonly used in the area. The majority of residents in this zone are from the Alur ethnic group (around 98%) and speak the Alur language which is the Dhu-Alur. The most practiced religion is Catholicism (80%) with a growing popularity of traditional religions such as “Mungu lonycon” or “Karwo” who believe that God is able to solve all problems in response to the prayers and whose leaders are preaching against all modern practices (modern medicines).

2.2. The community-based epilepsy treatment program

Prior to the start of the CBETP, local authorities, study participants, nurses, community healthcare workers known as relais communautaires (RECO), and teachers at the local schools were contacted to introduce the epilepsy treatment program and were asked to participate. Consenting individuals were trained by two neurologists. RECO were trained to screen persons suspected to have epilepsy using a pre-tested validated questionnaire with five questions [9]. All persons suspected to have epilepsy were referred to the trained local healthcare workers who took a detailed medical history and performed a clinical examination to confirm the diagnosis of epilepsy. All persons with confirmed epilepsy were offered free AED treatment. First line AED treatment was phenobarbital. Onchocerca volvulus-infected PWE were asked to participate in a randomized clinical trial to evaluate the effect of ivermectin on the frequency of seizures [12]. Ivermectin was administered orally and directly observed by the healthcare worker, while weekly home visits were conducted by the RECO to ensure that AEDs were taken daily as prescribed.

2.3. Community perceptions, attitudes and experience about epilepsy and the CBETP

Focus group discussions (FGD) were carried out among PWE and their families, RECO, teachers, and local residents without any PWE in their household (Table 1). Semi-structured in-depth interviews (SSIs) were performed with PWEs and their families, nurses at the local health centers, and local known traditional healers. The interviews were conducted in the presence of a principal investigator (M.M), supported by one or two moderators (moderators were trained healthcare professionals who were native of the study area and fluent in the local languages: Alur and Swahili). All interviewees were informed of the interviewer’s background and qualifications, and the motivations for undertaking the research project. The interview topic guides used for the FGDs and SSIs are presented in supplemental material 1.

Purposive sampling was used to ensure that interviewees were diverse in demographics, clinical expertise, and relationship with PWE. The FGD and SSI participants’ inclusion criteria are presented in Table 1. In each participating village, FGDs were conducted separately with RECO and teachers, PWE and their families, and traditional healers. Participants were contacted one day before the interview to identify a suitable time frame to meet with the research team. At the end of each FGD and SSI, the moderator summarized the discussions in French to enable the principal investigator (M.M) to ask additional questions. Both FGDs and SSIs were audio recorded.

2.4. Qualitative analysis

FGDs and SSIs were transcribed by trained staff and translated verbatim from the local languages to French by a professional local translator. All the interviewees were assigned pseudonyms during transcribing. The analysis started at the end of all planned interviews. Initially, A.D and H.D independently read and highlighted the transcripts to first familiarize themselves with the data and then to identify emergent themes and understand and report positive and/or negative changes from the baseline data (Fig. 1) (see Dolo et al. [10]). The codes were reviewed and confirmed by M. M, J.N.S.F, R.C, and S.C. Transcripts were then uploaded to NVivo 12 (QSR International, Pty, Doncaster, Victoria, Australia), which was followed by second level, line-by-line coding of text by A.D and H.D. A framework analysis as described by Srivastava and Thomson [13] was used. The SSIs and FGD transcripts were processed and analyzed according to the five key stages of framework qualitative data analysis (familiarization, identifying a thematic
framework, indexing, charting, mapping, and interpretation) [14], and reported in accordance with standards for reporting qualitative research (SRQR) [15]. Transcript analysis was completed in French to ensure fidelity and consistency of findings. During the process of data analysis, A.D and H.D frequently communicated with M.M who was involved in data collection and was in closer contact with local team to discuss emerging codes and categories, as well as the interpretation of key texts. Quotes included in this article were translated from French to English by A.D and confirmed by H.D (authors who are bilingual) and were verified for cultural accuracy by M.M who participated in fieldwork.

2.5. Cost related to epilepsy

Some PWE and their family members who participated in a clinical trial to evaluate the added value of ivermectin on the frequency of seizures in *O. volvulus* infected PWE [8,16] were asked to participate in a study to evaluate the epilepsy-related cost for the family. The direct and indirect costs due to epilepsy were assessed by interviewing PWE and their family using a questionnaire that was used prior to the implementation of the CBETP [6]. Direct costs due to epilepsy included medical consultations and hospitalization cost, transportation cost to the health center/hospital, and the cost of traditional medicine. All expenses in USH were changed to United States Dollars (USD) using the following conversion factor: 1 USD = 3600 USH. Indirect cost due to epilepsy consisted of time (in days) lost by the PWE and/or the caretaker due to seizures, converted to monetary value by assuming that a day’s wage is worth 1/365th of the annual Gross Domestic Product (GDP) per capita in the DRC [17]. More specifically, the number of workdays lost was multiplied with GDP per capita per day. Considering GDP of DRC in 2019 of 48.994 billion USD and a total population of 86,791,000 [18], the GDP per capita is equal to 564.5 USD and GDP per capita per day is equivalent to 1.56 USD. SAS 9.4, (SAS Institute Inc.) was used in the analysis.

2.6. Ethical considerations

The study protocol was approved by the ethics committee of the Antwerp University Hospital/University of Antwerp (May 2017, B300201733011) and of the School of Public Health of the University of Kinshasa (January 2017, ESP/CE/006/2017). All participants provided a signed or verbal informed consent to participate in the study.

3. Results

3.1. Participants’ characteristics

Overall, 9 FGDs (3–9 persons per FGD) and 14 SSIs were conducted, for a total of 67 study participants. The following study procedures were conducted at each participating health center: three FGDs (at least one for teachers, one for PWE or/and their families, and one for RECO and community members not affected by epilepsy) and four SSIs (one with a nurse or head of nurses, two with PWE, and one or two with traditional healers) (Table 2).

### Table 1: Characteristics of the participants in the focus group discussions (FGDs) and semi-structured interviews (SSIs).

| Categories | Inclusion criteria |
|------------|--------------------|
| RECO, teachers and Community members not related to the PWE | - RECO (community health workers) or teachers in the study village  
- Served at least one year as a RECO or teacher  
- Participated in the introduction of the current CBETP  
- Resident in the study villages with no direct relationship with the PWE |
| PWE/PWE’s family members | - Having epilepsy or living in the same household with a PWE  
- Resident of the study village  
- Participating in the current CBETP |
| Traditional healers | - Resident of the health zone  
- Known in the community as traditional healer |
| Nurses | - Being a nurse from the health zone  
- Having participated in the CBETP |

PWE: person with epilepsy; RECO: relais communautaires; CBETP: Community-based epilepsy treatment program.

Fig. 1. Research questions with the framework analysis themes. RECO: (Rélais communautaire); CBETP: Community-based epilepsy treatment program; PWE: Persons with epilepsy.
Moreover, 74 PWE participated in the epilepsy cost follow-up study.

3.2. Qualitative research findings

Five main themes emerged from the analysis of FGDs and SSIs data; the findings for each target group are summarized in Table 3.

3.2.1. Epilepsy-related misconceptions

False beliefs related to epilepsy partially disappeared in the Logo community. Most people do not believe anymore that epilepsy is contagious or is a “hereditary disease”.

‘Following the sensitization, PWE and their family and the communities where they live changed their mentality. PWE now participate in various activities, they participate in church activities, children who have epilepsy go to play with other children…’ (P1, male nurse at local health centre, SSI)

‘…because of the information from the current project, the communities have understood that epilepsy is a disease that is not contagious and not caused by evil spirits, rather it is a brain disturbance which can be treated by appropriate anti-epileptic medication’ (P10, male RECO, FGD).

Although the negative attitudes toward the PWE and the community mentality have positively changed, a large proportion of the affected communities remains uninformed resulting in the false belief that epilepsy may be contagious.

‘Those who don’t have it (people without epilepsy) in their families misjudge us as evil, and they say that we are the ones who bring and cause it (epilepsy), and we too are left with it, and nobody likes suffering because everyone likes happiness…’ (P1, male nurse at local health centre, SSI)

3.2.2. Epilepsy-related stigma

One year following the implementation of the CBETP, both epilepsy knowledge and epilepsy attitudes improved and there was a notable reduction of epilepsy-related stigma in the affected communities.

‘In my village, they (PWEs) are no more stigmatized like before, they are working normally, the community is no longer seeing them as people who can infect them…’ (P3, male teacher at local primary school, FGD).

The PWE still experience divorce which might be the result of concealing epilepsy status before marriage, and once it is discovered resulted in divorce.

‘Once my family in-law was informed of my health status (that I have epilepsy), this created something else… I am married and this disease (epilepsy) found me in the marriage and once epilepsy was detected, I was forced to leave the marriage and until now I live with my parents and suffering from epilepsy alone…’ (P4, female PWE, SSI)

3.2.3. Traditional healers’ perspectives

The influence of the traditional healers in the community was still present.

‘There is still a huge influence of traditional healers in the villages. PWE’s families are disrupted with the beliefs that epilepsy is caused by evil spirits, witchcraft, maledictions, sorceries and so on, mostly spread in the community by the traditional healers’ (P5, male RECO, FGD).

Some traditional healers still believe that the cause of epilepsy is the evil spirit.

‘…epilepsy is caused by the evil spirit and the convulsion’ (P6, female traditional healer, SSI).

‘We are capable to detect epilepsy with our powerful spirit that we have, that powerful spirit shows us the PWE and tells us what plant to administer’ (P7, male traditional healer, SSI).

‘Our powerful mind sends us to take the right plant to treat the evil spirit in the people (PWE). The same mind guides the way we

Table 3
Summary of the main findings by themes and by target group.

| Themes                                    | PWE and their family | Traditional healers | RECO/teachers | Nurses |
|-------------------------------------------|----------------------|---------------------|---------------|--------|
| Epilepsy related misconceptions           | Less misconceptions  | Persistence of misconceptions | Less misconceptions |
| Stigma related to epilepsy                | Less epilepsy-related stigma | Persistence of stigma | Less epilepsy-related stigma |
| Traditional practices for diagnosing and treating epilepsy | The healthcare system is preferred as first point of care | Need for dialog and cooperation with health professional to eliminate epilepsy | Positive change to choose the health system as first point of care |
| Perception and benefit of the epilepsy treatment program | Very satisfied with the program and the care received | Improved health status | Very satisfied with the program and the care offered |
| Experience and prospect of epilepsy treatment program | Concerns about the program sustainability | | Very satisfied with the program |

PWE: person with epilepsy; RECO: relais communautaires.
administer this plant. There are medicines to chew and others to drink’ (P6, female traditional healer, SSI).

The RECO proposed a collaboration between the trained health professionals and the traditional healers to cope with epilepsy.

‘As the traditional healers mostly spread wrong beliefs about the causes and treatment of epilepsy, we need to work together to cope with this disease (epilepsy). All we need to do is to ask them if a PWE visit them for care, they have to refer that PWE to the nearest health centre’ (P5, male RECO, FGD).

The traditional healers showed a growing willingness to collaborate with trained health professionals and local healthcare workers (RECO) in coping with epilepsy.

‘The collaboration with trained health professionals is possible, we can work together to serve our people to eliminate this bad evil. By the way, during the era of MOBUTU (former president of DRC from 1965 to 1997), we were given documents to work together with trained health professionals, but nothing has happened’ (P8, male traditional healer, SSI).

‘...I would say, when patients (PWE) come to us (traditional healers), we can re-direct them to the nearest health centre’ (P9, male traditional healer, SSI).

‘The best thing would be, when the patient come to our home for epilepsy and we can write their names and give the names to the head of health centre in our area’ (P6, female traditional healers, SSI).

3.2.4. Perception of the community-based epilepsy treatment program

PWE enrolled in treatment program and their families expressed their level of satisfaction.

‘These people (PWE) are satisfied because they had not had enough medication before. In the past, there was always a shortage of anti-epileptic drugs in the stock and in the pharmacy. ... But now on, the medication is available, PWE and their families are satisfied’ (P10, female RECO, FGD).

‘We had a child in our school from the village which is not far from here (village of Djupamamba), so this child was suffering a lot from the epilepsy and his father embarrassed himself and did everything to get his child back to normal, unfortunately it did not work out. when this program arrived here at Thedeja health area, this child was enrolled to the program, after this care he feels very well. His father is satisfied because the life of his child returned to normal’ (P11, male teacher at local school, FGD).

Families of PWE reported a remarkable improvement of the health status of the PWE enrolled in the program.

‘...my big sister was often rude. Since the start of the treatment in this program there has been a remarkable change, she now smiles with people, it is like a miracle in our family. Before the program, she often had a seizure almost every day but now she has not experienced any seizure attack over a long period’ (P12, female PWE’s family member, FGD).

‘In the past, I usually used the traditional medicines, these medicines have already disappointed me. From the beginning of my illness (epilepsy), I have used all kinds of traditional medicine with no success, I changed many times the traditional healers without any success, and I have even changed my religion to find the solution of my illness, and no success, since the start of this project, almost a year I had only 2 seizures, I would say the treatment from the program has helped me considerably, it relieved my suffering; no more seizure disruption as in the past’ (P13, male PWE, SSI).

PWE and their families gained crucial experience in managing PWE during seizure attacks.

‘In case of seizure attack, we firstly have to take him (PWE) straight to the nearest health centre. In the past, we feared them (PWE), but with the knowledge we gained from the training during the program we should not be afraid of them (PWEs)’ (P14, PWE’s family member, SSI).

Nurses and doctors at the health center reported increased work satisfaction as they observed day-to-day improvement of their patients.

‘Because of the services and AEDs that PWE are receiving, we have observed an enormous improvement in their health status, these positive improvements of the PWE give a good feeling to the nurses that their work has an impact to the society’ (P15, female nurse at local health centre, SSI).

PWE and their family changed their attitudes toward the local healthcare services. Healthcare providers experienced a meaningful collaboration with PWE and their families. Participants advocated that the epilepsy problem in the area could end if the CBETP continues.

‘Nowadays, there is a good collaboration between the nurses at the local health centre and PWE and their families, because they are happy and they are satisfied with the services they get here at the health centre and they experience the amelioration of their health status (P16, male nurse at local health centre, FGD).

This project has made PWE and their families, health professionals and the RECOs to work together as one and everyone feel satisfied because we are all in the same community, in the same family no one is happy when other is feeling the pain (P17, male RECO, FGD).

3.2.5. Experience and prospects of the epilepsy treatment program

PWE and their families reported a positive feeling concerning the way they are treated in the community. One year after starting the treatment program, some PWE returned to their normal activities (mainly farming) and students returned to school, and ladies have married.

‘...I observed the patients (PWE) that I was following who were inactive, now they play football very well, some could not cultivate or trade, but now they cultivate and trade’ (P10, female RECO, FGD).

‘...among my patients, there is one who returned to school and another who was always bothered with seizures, after starting the program, it has been already 10 months without any seizure attack’ (P17, male RECO, FGD).

‘...One of my patients did not even walk to the health centre - he always needs a motorbike to come to the health centre, but now he comes to the health centre himself by feet, he does his own laundry, takes a bath himself’ (P15, female nurse at local health centre, SSI).

I also (health care provider) have a patient now started to do business, another who got re-married (P18, male nurse at local health centre, SSI).

The practice to first seek care with traditional healers has changed.

‘Nowadays, we receive a few patients (PWE), because a lot of people do not accept the traditional care, they qualify it as wrong treatment, more people go to seek care in the hospitals. This could be the reason why my patients are no more looking for care at my house...’ (P8, male traditional healer, SSI).

Nurses and RECO were concerned about the sustainability of the program. They felt ending the program will lead to poor adherence with AED treatment, thereby increasing the frequency and severity of seizures.
Our main concern is to abandon our patients in the coming days, we would like to help these people so that they continue and finish their treatment, because if we abandon them like that, their life will not be like others, they will suffer with stigmatization, and discrimination in the society as they were before. (P15, female nurse at local health centre, SSI).

We would need the time to inform them (PWE) that the AEDs is no more free... to reassure that they will continue to get the AEDs for small amount and the medication will always be available every day’ (P19, male RECO at local health centre, FGD).

3.3. Cost related to epilepsy

A total of 74 PWE and their family completed the questionnaire to assess the direct and indirect epilepsy costs for the family, one year after the implementation of the CBETP. Of these, 40 (54%) were female, and 71 (96%) were taking AEDs regularly. The median age was 22.5 years (IQR: 18–31), and the median duration of epilepsy among the PWE was 8.5 years (IQR: 3–17).

The weighted mean direct cost per month due to epilepsy was reduced from 10.5 USD/per month to 0.5 USD per month after one year of CBETP. PWE spent about 38% of the total cost on transportation from or to the health center. Within a year, the expenses on traditional medicine had reduced from 68% to 5% of the direct epilepsy cost (Table 4).

On average PWE lost 7.1 days of work per month, while the caretaker lost 3.7 days of work per month before the CBETP. The average weighted indirect cost due to epilepsy for PWE was reduced from 11.1 USD/month to 1.09 USD after 1 year. Indirect cost incurred by the caretaker/family members of PWE also reduced from 5.8 USD to 0.6 USD per month (Table 5).

| Table 4 | Impact of community-based epilepsy treatment program on direct epilepsy-related cost for the family. |
|---------|--------------------------------------------------------------------------------------------------|
| Direct cost related to: | Before implementation of the CBETP | One year after the implementation of the CBETP |
| Number of PWE | Average cost | Weighted average cost (USD) | Weighted average cost (%) | Number of PWE | Average cost | Weighted average cost (USD) | Weighted average cost (%) |
| Antiepileptic drugs spending on this item | 163/258 | 3.4 (5.6) | 2.1 | 20 | 0 | 0 | 0 | 0 |
| Medical consultation | 48/258 | 3.0 (5.2) | 0.6 | 6 | 5/74 | 1.5 (2.4) | 0.10 | 20 |
| Hospitalization | 11/258 | 9.1 (11.6) | 0.4 | 4 | 1/74 | 14.3 | 0.19 | 38 |
| Transportation | 30/258 | 2.8 (5.0) | 0.3 | 3 | 6/74 | 2.4 (1.8) | 0.19 | 38 |
| Traditional medicine | 126/258 | 14.6 (24.5) | 7.1 | 68 | 2/74 | 0.9 (0.8) | 0.02 | 5 |
| Total direct cost | | 10.5 | 100 | 0.5 | 100 |

CBETP: community-based epilepsy treatment program; USD: United states dollar.

| Table 5 | Estimated impact of the community-based epilepsy treatment program on indirect epilepsy-related cost for the family. |
|---------|--------------------------------------------------------------------------------------------------|
| Indirect cost related to: | Before the implementation of the CBETP | One year after the implementation of the CBETP |
| Number of persons concerned | Average number of work days lost (SD) (days/month) | Total work days lost due to epilepsy (days/month) | Average cost (USD) | Weighted average cost (USD) | Number of persons concerned | Average number of work days lost (SD) (days/month) | Total work days/month lost | Average cost (USD) | Weighted average cost (USD) |
| PWE | 199/258 | 1824 | 8.9 | 6.8 | 23/74 | 0.7 (1.4) | 51 | 0.9 | 0.3 |
| Family of PWE | 138/244 | 965 | 4.6 | 2.6 | 9/70 | 0.4 (1.0) | 21 | 0.5 | 0.1 |
| Total | 2789.9 | 9.4 | 72 | 0.4 |

CBETP: community-based epilepsy treatment program; USD: United states dollar.

Epilepsy costs had reduced by over 95% compared to the cost before CBETP (Table 6).

4. Discussion

Our study shows that the CBETP had a very positive impact in the Logo community. One year after the introduction of the program, epilepsy misconceptions had positively changed, and most people did not believe anymore that PWE are infectious as was previously reported [10]. A similar effect was observed in a comparable program in Tanzania [19]. The CBETP changed the health seeking behavior in the study area. PWE now prefer to first seek care at a health center instead of consulting traditional healers.

However, despite epilepsy sensitization efforts, traditional healers in the Logo health zone still believe that epilepsy is contagious and is caused by evil spirits, and witchcraft, as was also observed in several other sub-Saharan Africa studies [20–25]. Because of the influence of traditional healers and past cultural beliefs [10], some individuals in the Logo community still prefer to consult traditional healers and the churches alongside trained healthcare providers.

The program contributed to the reduction of epilepsy-related stigma and increased adherence to AEDs as was reported in other studies [16,26,27]. Traditional healers in the zone experienced an important reduction of PWE people seeking their services. A similar experience was observed in Kenya, where misconception about epilepsy, cultural treatment, and negative stereotypes positively changed after a community-based educational intervention [27].

Consistent with other studies, traditional healers in the Logo health zone expressed the willingness to collaborate with trained health professionals in coping with epilepsy [25,28,29]. Given the strong influence of traditional healers and the persistence of epi-
lepsy-related stigma, such collaboration should be considered. Similar initiatives have been tried in the past whereby an agreement was signed, even though there was “little or no follow-up” (traditional healer said). In Tanzania, traditional healers are recognized as pillars of seizure management because of their position as custodians of Tanzanian culture and their ability to counsel PWE with very severe or mild seizures [24]. In South-Africa it has been attempted to establish a collaboration with traditional healers for epilepsy management, but the idea was not approved by South-African health policy makers [25,30]. PWE and their families who participated in our study were very satisfied with the CBETP and reported a considerable improvement in their quality of life thanks to the program. A similar experience was reported in Brazil [31], where after healthcare workers received training in seizure management, the majority of PWE reported health status improvement. Healthcare providers expressed increased satisfaction in their work as they observed day-to-day PWE’s life improvement.

Our results demonstrated that a community-based intervention’s aim to increase the access to AEDs at little or no cost will have a prominent effect on the overall economic cost of epilepsy and will improve the quality of life of PWE in high endemic setting. Following the implementation of a CBETP, epilepsy-related cost for the family reduced by 95%. Our findings concur with previous findings in similar settings where providing epilepsy care at the community level reduced the cost related to epilepsy by 80–90% of the initial cost [32,33].

The results of our study need to be interpreted in light of some limitations. The full impact of the CBETP cannot be evaluated using only a qualitative study. Moreover, the program included only the PWE and their families who participated in the trial to evaluate the effect of ivermectin on the frequency of seizures [8]. Persons not included in the trial who were followed up less strictly may have had different and less positive experiences. The community-based intervention covered only one health zone; therefore, traditional healers from other neighboring health zones may still be actively spreading false knowledge about epilepsy. The reported epilepsy costs are only estimations of the real-life scenario, because we did not quantify intangible costs (cost due to psychosocial pain and suffering), as well as the costs related to lost schooling or employment opportunities because of seizures. Some FGDs had few participants and they cannot be considered representative of all RECO, PWE, healthcare workers, traditional healers, or community members in the health zone. Moreover, during FGDs, certain participants may not express themselves freely and they may influence each other. In addition, it is possible that the presence of a moderator in the group discussion may have affected the views and opinions of the participants.

A lesson learned from this study is that we missed the opportunity to conduct a full evaluation of the CBETP including an estimation of its cost benefit. To do so we should have developed a protocol and data collection tools before the start of the program. Data should have been collected at baseline and prospectively during implementation of the program. Quality of life and epilepsy-related stigma should have been evaluated using validated questionnaires. Moreover, information about epilepsy-related costs, not only for the family but also concerning the implementation of the program should have been collected.

In conclusion, our study shows the benefit of the CBETP in the Logo health zone. The main perceived benefits were the positive changes related to the misconceptions about epilepsy and epilepsy-related stigma. Families with PWE understood the benefit of seeking health care with trained health professionals rather than with traditional healers. The direct and indirect costs for families to take care of a PWE reduced considerably after the program. Further quantitative research with larger and unbiased samples is needed to assess the generalizability of our findings. Moreover, the cost-effectiveness and long-term sustainability of this approach remain to be investigated.

**Competing interests**

The authors declare no conflict of interest. The study sponsors had no role in the design, execution, interpretation, or writing of the study.

**Funding**

This work was supported by the funding from the European Research Council (ERC) grant awarded to R.C (Grant number 671055, Project title: NSETHIO).

**CRediT authorship contribution statement**

**A. Dusabimana:** Conceptualization, Methodology, Software, Formal analysis, Data curation, Writing - original draft, Writing - review & editing, Visualization. **M.N. Mandro:** Validation, Investigation, Data curation, Writing - review & editing, Visualization, Project administration. **J.N. Siewe Fodjo:** Methodology, Validation, Investigation, Data curation, Writing - review & editing, Visualization. **H. Dolo:** Methodology, Software, Formal analysis, Investigation, Data curation, Writing - review & editing, Visualization. **S. Coenen:** Conceptualization, Methodology, Validation, Formal analysis, Data curation, Writing - review & editing, Visualization, Supervision. **R. Colebunders:** Conceptualization, Methodology, Validation, Resources, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration, Funding acquisition.

**Acknowledgements**

We are grateful to all the nurses, community health workers, teachers, and research assistants who participated in the study. We also thank the local authorities and the populations for consenting to participate.

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