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Community perception of epilepsy and its treatment in onchocerciasis-endemic villages of Maridi county, western equatoria state, South Sudan

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ABSTRACT

Objective: To assess the community's perception of epilepsy and its treatment in onchocerciasis-endemic villages of Maridi County, Western Equatoria State, South Sudan. The study was conducted prior to the setting up of a community-based intervention to manage the important disease burden caused by onchocerciasis-associated epilepsy in these villages.
Method: Five focus group discussions (FGD) were conducted with community leaders and with persons with epilepsy (PWE) and their families between November and December 2019.
Results: Villages close to the Maridi dam were considered to be most affected by epilepsy. Misconceptions about the cause and treatment of epilepsy were identified. Most people believed that epilepsy is caused by bad spirits and is contagious, transmitted through saliva, air, and contact with PWE. Very few participants were aware of the link between onchocerciasis and epilepsy. Persons with epilepsy are restricted in their day-to-day activities and children with epilepsy are often denied going to school. Persons with epilepsy are stigmatized and seen as unfit for marriage. Most participants considered both traditional and medical treatment as ineffective. Uninterrupted anti-seizure treatment continuously was unaffordable for most families with one or more PWE.
Conclusion: There is a need to establish a comprehensive epilepsy treatment program which addresses misconceptions about epilepsy and reduces epilepsy-related stigma. Explaining the link between onchocerciasis and epilepsy could lead to a reduction in epilepsy-related stigma.

1. Introduction

Epilepsy is a major public health concern in sub-Saharan Africa, particularly in rural villages where persons with epilepsy (PWE) are often confronted with a wide treatment gap [1] and frequent stigma [2,3]. Epilepsy prevalence is particularly high in onchocerciasis-endemic regions with high ongoing onchocerciasis transmission [4].

Onchocerciasis endemicity in South Sudan is among the highest in Africa, with the disease being prevalent in approximately half of the country with more than 7.5 million people at risk [5]. Civil war and insecurity have led to many years of interruption of the national community-directed treatment with ivermectin (CDTI) program resulting in a major public health crisis in onchocerciasis-endemic regions where onchocerciasis-associated morbidities are prevalent.

In May 2018, in a door-to-door survey involving 2511 households in Maridi County, Western Equatoria State, an epilepsy prevalence of 4.4% was documented [6]. In November 2019, an entomological assessment in Maridi revealed that the Maridi dam spillway was the only blackfly breeding site along the Maridi River (Fig. 3) [7]. In Kazana 2, the village closest to the dam, an epilepsy prevalence of 11.9% was documented. The seroprevalence of onchocerciasis antibodies to the Ov16 antigen among children aged 7–9 years was 66.7% suggesting high ongoing *Onchocerca volvulus* transmission [7].

A variety of seizure types were reported in Maridi: 69% of PWE presented with generalized tonic-clonic seizures and in 45.5% there was a history of nodding seizures [8]. The median age of onset for all seizure types was 10 years, and eight years for nod-

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ding seizures. The diagnostic criteria for onchocerciasis-associated epilepsy (OAE) were met by 85.2% of the PWE [8]. Among the PWE who were skin snipped, 84.9% had detectable *O. volvulus* microfilariae; higher microfilarial densities were observed in persons with nodding seizures compared with persons with other forms of OAE [9]. Nodding seizures were also associated with more severe cognitive impairment than other forms of OAE [9]; therefore, nodding syndrome needs to be considered as a more severe form of OAE. Only 51.4% of PWE were taking antiepileptic medicines [8].

Lack of knowledge and misconceptions about epilepsy may affect health seeking behaviors of PWE and their families [2,3]. In 2019, a research project was started in three onchocerciasis endemic areas in Western Equatoria State in South Sudan: Maridi, Mundri and Mvolo Counties, under the title "Evaluation of a comprehensive community-based epilepsy prevention and treatment program in onchocerciasis-endemic villages of South Sudan" funded by Research for Health in Humanitarian Crisis (R2HC) [10]. To facilitate this community-based intervention in Maridi County, we conducted qualitative research to assess the communities' perceptions of epilepsy and its treatment.

2. Methods

2.1. Study setting

The study was conducted in villages of the Maridi county in South Sudan, between November and December 2019. Maridi is a post-conflict county in Western Equatoria State of South Sudan with a very weak health system. The following villages in Maridi County were included in the study: Kazana 1, Kazana 2, Hai Matara, Hai Gabat, and Hai Tarawa. Most residents depend on subsistence farming and local Arabic is the dominant language. Ethical approval was obtained from the ethics committee of the Ministry of Health of South Sudan (January 2018, MOH/ERB 3/2018). The study aims and procedures were explained to all participants and a signed or thumb-printed informed consent was obtained from all of them before the start of the study.

2.2. Study design

Five focus group discussions (FGD) were conducted, one in each study village. Overall, 64 participants were recruited including fifteen (15) community leaders and 49 PWE/family members. Participants were purposively selected using community mobilizers with the assistance of community leaders. In total 41 males and 23 females participated in the FGD. Each FGD consisted of 8–10 participants. Before the FGDs, the selected villages were visited by the study team to sensitize the community about the purpose of the study with the help of the villages leaders. Moreover; the selection of FGD participants was discussed with the villages leaders. In each village the FGD was conducted in a quiet location preselected by the village leaders. The FGD participants were contacted by mobilizers from the selected villages one day before the FGD to confirm the time and place of the meeting. The FGDs were conducted separately with community leaders, and with PWE and/or their family members. The social scientist (MST) from the Amref Health Africa project, who is fluent in local Arabic, acted as the moderator. The discussions were audio-recorded, and the moderator also took written notes. At the end of each FGD, a debriefing was organized with the research team to identify the main themes that emerged during the FGD.

2.3. Data analysis

Data from the FGD were transcribed by a trained field staff verbatim from the local language to English. Framework analysis was then conducted as described by Gale et al. [11]. The data were coded and analyzed according to the five stages of this method: familiarization, identification of a thematic framework, indexing, charting, mapping, and interpretation. During the familiarization stage, the researcher became familiar with the data by reading through the transcripts several times. Identification of a thematic framework was done by coding the first two transcripts for each FGD before applying the codes to the rest of the transcript and constructing an initial coding framework for each transcript (Fig. 1).

For indexing the data, the thematic framework was applied systematically to all the transcripts using a qualitative data analysis tool built in Microsoft Excel. Codes were provided to classify the opinions expressed during the different FGD in relation to the research question. An Excel tool was created to chart the data for each theme by summarizing and charting data for each code within that theme. To map and interpret the data, thematic analysis was carried out on each dataset by reviewing the matrices and making connections within and between codes. This process was

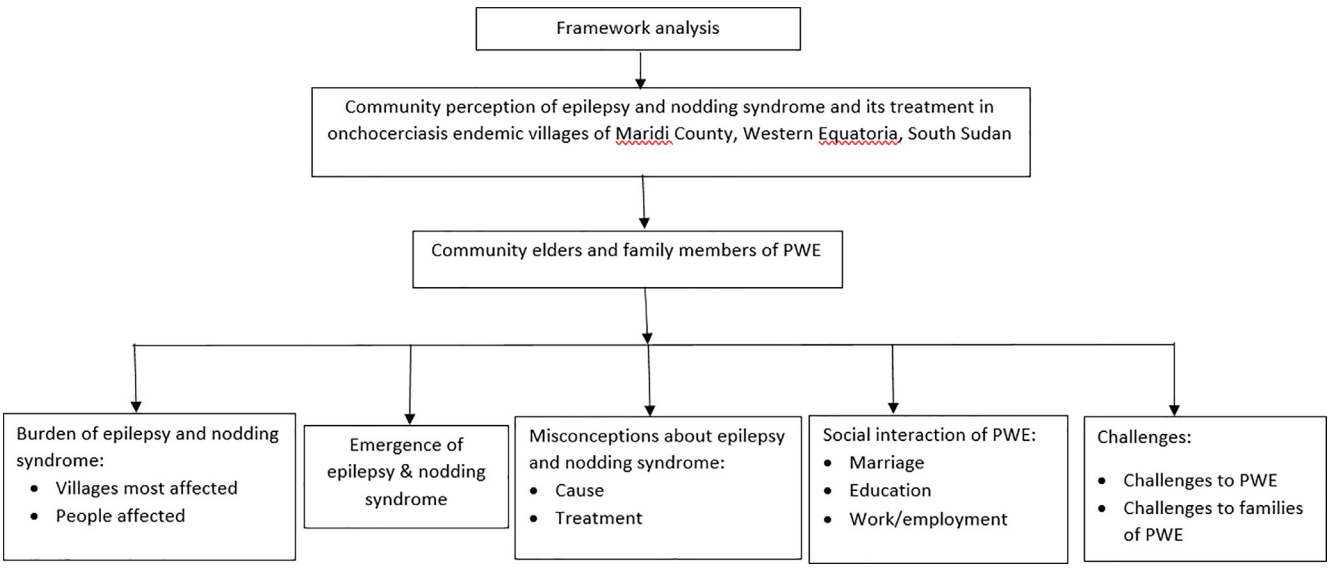

Fig. 1. Framework analysis themes.

influenced by the original research questions as well as concepts generated from the data inductively as described by Pope et al. [12].

3. Results

3.1. Epilepsy and nodding syndrome disease burden

Epilepsy is locally referred to as "jurujurur" (meaning body shaking while nodding syndrome is referred to locally as "duggu ras" (meaning head beating). Epilepsy and nodding syndrome were reported to occur in all villages, but Kazana 1 and Kazana 2, located around the Maridi dam, were cited as the most affected. Epilepsy and nodding syndrome were also reported in the village of Matara, which borders the Kazana villages, and in Araka, Modubai, Napere, Lalama villages as well as many others. A resident of a Kazana village confirmed that there are many cases of epilepsy and nodding syndrome among boys and girls in most households in Kazana:

"*In Kazana here there are many boys and girls that are affected by the disease, the stretches (seizures) and that one that cause the head to nod when food is served (nodding); in Kazana here they are many, there are few households that do not have*". A 26-year-old male family member of a PWE.

Majority of epilepsy and nodding syndrome cases are centered around the Maridi Dam (Kazana 1, and Kazana 2 villages) and as one moves away from the Maridi dam, the number of epilepsy and nodding syndrome cases drop gradually. One participant from Tarawa village said there were few cases in Tarawa, a village located about three miles south east of the Maridi dam.

" *in our area it is few, most of disease is in the area of kazana till that road to Embe going down to the other side of the stream, some of these people are now moving out of their place there to different sites here in Maridi*." A 29-year-old male family member of a PWE.

Another participant said that the disease is not common within Maridi town, but if people move outside the town, you will notice that the number of PWE increases, for example, in the villages of Araka, Mudubai, and Napere:

"What I am seeing is that in the town it's not common but when you move out then you will see it is increasing, for example starting from Araka to the site of Mudubai then down to Napere it's common, and the site of Kazana; kazana in general not kazana 1 or kazana 2. There generally the disease is very common.", A 55-year-old village leader.

The participants mentioned epilepsy and nodding syndrome cases are clustered in households in the villages; in a household, you may find about five or more children suffering from epilepsy, nodding syndrome or both, in some cases the parents of such children are also affected:

"*In some houses you will find 5 to 6 children affceted, me who is taking I have 7 children with nodding and epilepsy all are present in the house. They are my brother's children and two are mine so this disease is common in Maridi. If you go to someone's house you will find 5 to 6 children and that person all his children are spoiled.*". A 37-year-old mother of PWE in Maridi town.

"Mr K (Name) has buried about ten children because of this jurujuru (epilepsy), the one who died recently is also because of jurujuru (epilepsy), and for the one staying in the room, people are waiting for him to also die because of this Jurujuru (epilepsy)". A 40-year-old female, resident of Kazana 1 village.

3.2. Most affected age group

Epilepsy and nodding syndrome affect people of all ages; however, it mainly affects children and adolescents. Epilepsy starts as early as three years of age with most cases affecting children between 5 and 20 years.

"*This is what is there; most of it is to the children but few is for the big (adult) people*". A 40-year-old female and a family member of a PWE.

"Let me say this, I see that the age mostly affected by this disease is 3 years and above up to 15 years is the maximum this disease can affect. If a child becomes an adult, I see that it is not affecting them much". A 53-year-old Male, Kazana 2 resident

3.3. Evolution of epilepsy and nodding syndrome in the area

Participants admit epilepsy is present in the area years ago, but the rate of increase in numbers and the appearance of the new type of the disease (nodding syndrome) was a new phenomenon.

"It looks like the old disease during the time we were growing up, during the time of our grandfathers, is that one which cause a child to convulse... That was in the old days., but now when the food is served, the child will start to sleep; I think in old Sudan this one was not there." 56 years old male, resident of Kazana 1 village.

"It started in 2005 or 2006, it is the time it became common... It is just in 2000s when it started to increase seriously, the old one (form of epilepsy) affects one child and it continues only with that child. But the [new form of epilepsy] one which increases seriously started in 2006, 2007 and it is increasing till now." 47 years old Man, resident of Kazana 1village.

3.4. Misconceptions about the cause of epilepsy

During the FGDs, majority of the participants expressed the belief that epilepsy is a contagious disease transmitted through, saliva, sweat, air, and direct contact with the person living with epilepsy.

"We know it transmits from child to child, if there is this disease at a home you will see so many children at that home will be affected and then from that home it will move to the neighbor's home and from neighbor to another neighbor and like that" A female 40 years old, resident of Kazana village.

"Someone told me, if someone with the disease has fallen down, you should not hold his legs or touch his saliva... That is the thing that I heard, it can be transmitted always". A 30-year-old male community resident.

"We believe that these people should not sit with other people and play together, because like we have said previously the disease is present in the breath, saliva, sweat, blood. This will cause the disease to spread, even their feces...You have to protect you self from that feces, handle it with care, thraw it in the latrine, then wash your hand with soap. That is the way to do it. Things like cups, plates, place to sleep to be separate". A 56-year-old, Man, village leader

"Things like blood, sweat, air, and saliva that is the way that the disease is transmitted" A 40-year-old male, community resident

Some participants believed that epilepsy is caused by the war that displaced a number of people who converged in a particular village. Consequently those who might have had epilepsy and nodding syndrome transmitted them to those who did not have the disease.

"Really this war gathered many people in one place, people that you didn't live with them before, came among you with the sickness... That is why the sickness is much..." A 30-year-old female family member of a PWE.

Health facility staff seem to have encouraged parents of PWE to serve PWE food separately. One participant said:

"... you will find out yourself if you take him/her to the hospital and the doctor will be the one to tell you that his or her cup should be separate ...". A 33-year-old male family member of a PWE.

Some believed that the presence of blackflies at the Maridi dam might have caused epilepsy and nodding syndrome:

"I see the kazana flies (blackflies) are the problem, they have breed a lot there, if we sit till evening here you will see them like ngongo (Local Name of certain flies)... I think it's these flies which affect people, we realized when they started to increase the disease increased also, previously they were not there and the disease was not there even the Dam itself was not there". A 66-year-old male village leader.

3.5. Epilepsy treatment

Antiepileptic medicines and traditional medicines were used to treat epilepsy; however, majority of the participants were not convinced about the effectiveness of these treatment options

"*The medicine is not found for it, the medicine from the hospital is given but it is not enough, and the traditional medicine also is not doing anything* ". A 38-year-old male member of a family with PWE.

"*The traditional medicine is not working, the only medicine is the one bought from the pharmacies, it is bought 30 in number and when he will swallow all of them, the disease will continue. The real medicine for it is not there.*" 46-year-old male, Family member of PWE in Kazana 1

"The issue of the medicine bought from the pharmacies, you keep buying even for 25 years till the child dies, there is no cure for it." A 37-year-old family member of PWE in Kazana 2

Participants were convinced the anti-seizure medication from the hospital or bought from private clinics needs to be taken continuously to reduce frequency of the seizures. However, they believed it is not the treatment to cure the disease.

"The medicine of the hospital, people are tired taking it but it is not able to cure the disease. We believe the real medicine to kill this disease is not yet discovered". A 55-year-old male family member of PWE in Gabat area.

"*There is medicine, when you go and buy it they will tell you it is not going to finish the disease; it will just reduce the power (severity) of the disease.*" A 35-year-old female family member of a PWE.

"The medicine bought is not to cure this disease, it's just to reduce the severity of the disease and to prevent the body to pain. There is no real medicine for it." 40-year-old male, community leader in Kazana 1

Unknown traditional surgical procedures performed by traditional doctors were also tried by PWE and their families to cure the disease but it failed.

"One person said he studied about opening people's brain to see what disease is there; that is the thing he has studied, he is the doctor of brain. He took the child of my uncle here in Maridi for operation inside and we stayed out there Then he came out with something I think it's a skin cut from this area (pointed to her head) because there was a wound and plaster on the place, and gave it to us saying that he cut it (the disease) out. We stayed there for days and he told us to go home and come for removal of stitches and it did not take long when the wound healed. As I am now saying here in front of you, the convulsions started again and till now she (the child) is still convulsing." A 45-year-old female family member of a PWE in Tarawa village.

3.6. Social interaction of PWE

Since most people believe that epilepsy is transmissible from person to person, PWE were restricted in their social interactions within and outside the family. At family level, most children with epilepsy are not allowed to share food in the same plate with their siblings without epilepsy; they are not allowed to mix freely with healthy children and to share a bed. They are prohibited from sitting near a healthy sibling while eating food and will be given a chair at a distance of about one meter from the rest of the siblings. Persons with epilepsy also do not share cups for drinking. Their belongings like cups and plates are kept separately from those of other family members. Some of the participants said:

"I have seen this with my eye, there is woman, a mother of these children (children with nodding syndrome), she had proper care, chair like that one is for sick child, nobody else is allowed to sit on this chair. For this boy, his plate is separate there, his table is there, and his cup is there. The other 3 children or more at home are not allowed to go to him and he is not allowed to come to them." A 41-year-old female resident of Kazana 1

PWE may interfere with social and cultural gatherings like funerals and playing football, and some parents of PWE may not allow their children with epilepsy to share a mat or chair.

"When you bring a mat at a funeral, and her boy comes to sit on it, she will say, no, no don't sit on this person's mat, this person has children at home, so as not to transmit the disease to them." A 55-year-old male community leader.

3.7. Marriage

Participants had mixed reactions toward marriage of PWE. Some argued that PWE should not be allowed to marry since they would not be able to take care of their children and at the same time marriage will act as a medium of transmission of epilepsy from one family line to another, Others believed that PWE have the right to marry since it is their biological right and that they said that PWE should be supported by both parents in managing their family affairs.

"If a boy has the disease (epilepsy), for the daughter of somebody to accept to marry a boy with this thing which causes convulsion is a problem, because this disease doesn't want people to meet as one (sexual intimacy). If the girl does not have the disease and they stayed with the boy as one, with the breath of the boy on her body, surely the girl will get this disease also. So people are afraid to give your daughter to a boy who is convulsing, and the same way the boy will not go and show himself with a girl who has the disease which causes convulsion." A 55-year-old female and family member of PWE.

"The boy and the girl have the feeling of nature in their bodies, so if it comes to the issue of marriage, let us allow them to marry and the unaffected people at home to take care of them. But in the community here people refuse them to marry. If the girl got pregnant from a good (non-epileptic) person, the in-laws will say we don't want your daughter because she is sick ... In my opinion that is

nature; a person can be married and the people in that family can take care of them." A 42-year-old female village member.

3.8. Education

Most participants reported that children with epilepsy are not allowed to attend to school due to the belief that epilepsy is contagious and suggest a separate schools should be established for children having epilepsy and nodding syndrome.

"They don't go to school, if they go to school they will be chased from there because they are going there to affect other children." A 40-year-old male family member of PWE.
"*These children with the disease, their school needs to be separate and all who are sick will go and study there.*" A 47-year-old male community elder in Kazana 2.

3.9. Work and employment

Participants agreed some PWE can carry out some minor work at home, church, and farm, but they expressed caution about working together with other healthy siblings and peers.

"This disease is difficult for the boys. . . they cannot be left to do a work with their other brothers in my house. . . if left together there is no guarantee because this disease is transmitting seriously. If they are left together with others then tomorrow the child of somebody got affected, the blame will be put on me. People will say if you know your child has the disease, why you allow him to mix with others?". A 38-year-old male family member of PWE.

3.10. Daily life challenges

PWE face challenges related to social exclusion, premature death, and injuries from fits. Persons with epilepsy experience injuries that occur during seizures. They may fall into a fire or on any sharp object or stone that might injure them.

"When the disease starts, it causes them to fall on the ground sometimes they sustain injuries, some may fall on fire and get burned, that is the challenges that they face". A 41-year-old female family member of a PWE.
"*most of them die from water, for example in the stream if there is no one near, they just fell into the water and die, they always day because of water, sometimes in the river when he goes alone to bath, when this thing causes him to convulse there that is the end*" A36 years old female, Family member of PWE.

Some PWE are chained by their parents to not get lost when the parent or guardian is away. A female participant told the story of a child with epilepsy who was roaming whenever the parents were away and due to the parents' fear of losing the child, they decided to chain the child.

"Yesterday when I was returning from the farm, there was one there. . . Sometimes he moves out of the home to the town looking for money and comes back (wanders). His people saw that he makes them suffer a lot, so they tied him down with a chain". A 41-year-old female village member

Some PWE face negligence from their families and caregivers, and they have been seen as useless. Most families do not take great care of their children with epilepsy allowing the children to roam within the community and risking their lives.

"Parents are neglecting these children, saying that they are not helping them anymore and they are useless. They leave them alone, so awareness needs to done to the people so they will know these children are also important". A 37-year-old female caretaker of a PWE.

PWE are stigmatized by the community and within the family; in marriage couples, once epilepsy is discovered this may lead to separation or divorce.

"Government to build a compound and they are all to be collected from all villages and put in that compound, and they will be looked after there ". A 50-year-old Male community leader.
"We found a girl and we married her, the in-laws were not frank to us, they did not tell us that the girl has the disease (epilepsy). We took that girl to our house we stayed for some time. Finally when she got pregnant the disease appeared, she when to the well to bring water and fell there and convulsed. Then the report come that this lady is sick. Since she was under our responsibility, when she delivered the baby, the in-laws came and took the girl back and the baby was left with us and was breastfed by another woman." 62-year-old Male community Leader

3.11. Challenges for families of PWE

Most of the participants expressed financial challenges facing families with PWE, as they often have insufficient money to buy anti-seizure medication continuously to treat seizures.

". . .for some families this disease is a burden, it puts you under pressure to find money from nowhere to buy the medicine, always to buy the medicine; and this medicine cost money, and that is another problem to the household head". A 39-year-old father of PWE.

People with epilepsy are having difficulties accessing anti-seizure medicines from public facilities, many participants reported buying anti-siezure medicines from private clinics.

"*The medicine is brought to the hospital here in Maridi, but if you go there they will not give you, so this will force you to go and buy from the clinic and it is very expensive in the clinic. For you to manage buying it for 4 or 5 children, it will not last for long period and it will finish soon, and for you to find another money to buy again. This is a problem because you have to feed the children and do other things*". A 59-year-old male family member of a PWE.

Many parents of PWE are stressed when they leave their children with epilepsy alone at home.

"*There are many things that can arise, for instance he (the parent) is not happy, during journeys he is not happy because he will be thinking of the child left . . .*" A 34-year-old male family member of a PWE.

Some PWE respond aggressively to anything they think is targeting them from any person including their parents as one participant said:

". . . the sick also have hearts that are hot (aggressive behaviour); if the colleagues abuse them that 'your sick brain' this is another war..". A 35-year-old female village member.

3.12. FGD recommendations

When asked what could be done to reduce the epilepsy disease burden, six participants suggested that there is need for an epilepsy treatment center with enough anti-seizure medication.

". . . let them find a place like a centre, maybe a special centre and if they find a sickness at home he will be referred to that centre

immediately because there is treatment in that centre ...". A 44-year-old female and family member of a PWE.

It was also suggested that more research on epilepsy and nodding syndrome needs to be done to establish its cause.

"*Let it be checked ... take the blood of these children with epilepsy and nodding syndrome, take the stool, saliva, urine and even opening their brain whether it is by operation or any other way; is it in brain or in the stomach or from where...*". A male 57-year-old community leader.

Epilepsy awareness and training should focus on the rights of PWE in relation to food, a decent life, education, and health care.

"*... the first thing that need to be done is awareness to them that these children are like this so that they will show love to these children because others neglect them...*". A 43-year-old female family member of PWE.

Families with a PWE need to be supported because they lack basic needs like clothing or even food to provide for their children with epilepsy.

"*If there is a way of supporting, they will be given maybe money*". A 45-year-old female family member of PWE.

The main findings by themes and target groups are presented in Table 1.

4. Discussion

This paper describes the perceptions of the community about epilepsy in Maridi County, Western Equatoria State. The community in Maridi considered that epilepsy is contagious and most FGD participants believed that epilepsy is caused by bad spirits. Similar beliefs have been reported by studies in other sub-Saharan African countries.

In many communities in sub-Saharan Africa, epilepsy is considered to be caused by spiritual forces that might be associated with greed, sin or demonic possession [13–18]. The fact that in onchocerciasis-endemic regions with high ongoing *O. volvulus* transmission epilepsy is clustered in certain villages and families, is seen by the community as a proof that this condition is contagious and also hereditary [16,19]. FGD participants reported that the villages located close to the dam (Kazana) were the most affected. However, only a few participants mentioned that blackflies biting at the Maridi dam could play a role in causing epilepsy. The Maridi dam spill way has been shown to be the only blackfly breeding site in the area and most likely induced, in the absence of an effective CDTI program, an increase in epilepsy cases after the dam was repaired in the year 2000 [7].

Similar to Maridi, PWE in other sub-Saharan communities are often subjected to social exclusion [13–16,18,20]. Even healthcare workers may show negative attitudes toward epilepsy [21,22]. Saliva, urine, breath, and flatulence of a person with epilepsy are often thought to carry infectious agents [14,21,22]. Therefore people may be reluctant to intervene to prevent injuries when a PWE is having seizures. Moreover, in some communities there may be the belief that by touching a person during a seizure the bad spirit could jump over to the other person [23].

Some FGD participants argued that PWE should not be allowed to marry. A similar opinion has been reported from other communities in sub-Saharan Africa [16,24]. Women with epilepsy frequently remain single [25], but may have children whose fathers deny any association with the mother and the children [16]. Men with epilepsy also may remain single or their wives leave them because they are not able to financially sustain a family [16].

In many parts of sub-Saharan Africa, PWE are socially ostracized, and have reduced life chances in terms of marriage and employment, and this may lead to poor self-esteem, anxiety, and depression [26].

Most FGD participants reported that children with epilepsy are not attending school due to the belief that epilepsy is contagious. In many other places in sub-Saharan Africa, children with epilepsy drop out of school at an early age because of poorly controlled epileptic seizures, cognitive impairments, and stigma [14,15,27]. Moreover, the psychiatric manifestations that the child with epilepsy may present may increase the belief that the child is possessed by an evil spirit. Therefore, most schools are not prepared to receive children with epilepsy and teachers are rarely trained on how to deal with seizures [15,28]. Children with epilepsy who drop out of school become solely dependent on their caregivers [15,29]. It has also been observed that non-affected siblings are sometimes compelled to drop out of school to compensate for the economic burden on the household and/or the caretaking of the affected child [14].

The belief that epilepsy is caused by evil spirits is one reason why communities affected by epilepsy seek care from traditional healers. As such, there are often delays in seeking treatment from health facilities which detrimentally affects the health of the patient [30]. In Maridi, FGD participants reported the use of traditional, spiritual, and medical ways of treating epilepsy and nodding syndrome, but believed that the treatment is not effective. They reported the lack of anti-seizure medication in the public health facilities in Maridi and said that the lack of money to buy the anti-seizure medication from private pharmacies limited their ability to treat epilepsy.

The epilepsy treatment gap is a major public health problem in sub-Saharan Africa [31,32]. Uninterrupted access to affordable anti-seizure medication is urgently needed to improve people's quality of life and the psycho-social issues linked to the condition. Reducing the epilepsy treatment gap could reduce epilepsy related stigmatization. To decrease this gap decentralization of epilepsy treatment and care services is crucial. In onchocerciasis-endemic areas with high *O. volvulus* transmission in particular, there are many PWE in need of treatment and at the same time the health services in those areas are very weak.

Knowledge in Maridi about the link between onchocerciasis and epilepsy was limited, as in most societies affected by onchocerciasis-associated epilepsy [19]. Increasing the awareness about this association could contribute to reducing stigma toward

Table 1
Summary of main findings by themes and by target group.

Themes	Community leaders	PWE/ Family
High burden of epilepsy and nodding syndrome in the area	✓	✓
High burden of epilepsy and nodding syndrome among young children	✓	✓
Misconceptions concerning the cause of epilepsy and nodding syndrome	✓	✓
Stigma related to epilepsy and nodding syndrome	✓	✓
Epilepsy/nodding syndrome leads to divorce/ separation	✓	✓
AEDs are not available in public facilities		✓
Not convinced about the efficacy of the AEM, and the traditional medicines		✓
Financial barriers to obtain AEM		✓
Limited employment options for PWE	✓	✓
Negative psychosocial impact of epilepsy on PWE/ and Family		✓
Need for specialized treatment center for PWE	✓	✓
Need for awareness about epilepsy	✓	✓
Need for financial support for PWE/and Family		✓

PWE: person with epilepsy, AEM: Antiepileptic medication.

PWE [33]. In an onchocerciasis-endemic region in Ituri, in the Democratic Republic of the Congo, a community-based epilepsy treatment program was able to cause a shift in the community perceptions and attitudes toward epilepsy [34]. Thanks to this program, most community members no longer believe that epilepsy is contagious, and acknowledge that this condition can be treated in local health facilities. As a consequence, PWE and their families experience less epilepsy-related stigma and are less likely to consult traditional healers [34]. Increasing the awareness about OAE is also important to motivate people to take ivermectin and for community-directed distributors of ivermectin to increase their efforts to reach a maximum level of CDTI coverage. Since 2021, because of the high OAE prevalence and incidence, bi-annual CDTI has been implemented in Maridi. It is now extremely important that people and in particular children, take the ivermectin. Since December 2019, a community based "Slash and Clear" vector control intervention has been implemented at the Maridi dam [7]. This has been very successful in reducing blackfly biting rates [35] and should further reduce onchocerciasis transmission.

5. Conclusion

A community-based epilepsy awareness program should be established in Maridi to educate the community about epilepsy. In such a program it should be explained that epilepsy is not contagious and that most of the epilepsy in the area is caused by bites of *O. volvulus* infected blackflies. Nodding syndrome should no longer be called a "mysterious condition" of unknown etiology as such statements lead to misconceptions and result in PWE and their families consulting traditional healers. Healthcare workers also need to be educated on the cause of onchocerciasis-associated epilepsy and nodding syndrome, and trained on its treatment and ways to improve home-based care [36]. All these interventions will contribute to reducing stigma within the community and improve the health seeking behavior of PWE and their families.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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