

Article

Community knowledge, attitudes and practices regarding onchocerciasis in rural villages with a high epilepsy prevalence in Mahenge, Tanzania: A qualitative study.

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Abstract: Despite of over 20 years of community directed treatment with ivermectin (CDTI), a high prevalence of onchocerciasis and onchocerciasis-associated epilepsy were observed in rural villages in Mahenge, Tanzania. Therefore, we assessed the knowledge, attitude and practice about onchocerciasis in four rural villages in the Mahenge area. This was a qualitative study conducted between June and July 2019. Eleven focus group discussions were organized with persons with epilepsy and their caretakers, community resource persons, and community drug distributors (CDDs), and two in-depth interviews with district programme coordinators of neglected tropical diseases (NTD). Most participants were aware about symptoms of onchocerciasis using local terminologies such as “ukurutu/rough dry skin” and “kuwashwa/itching”. A small proportion of people did not take ivermectin during CDTI for fear of adverse reactions such as itching and swelling. Some men believed that ivermectin may decrease libido. Challenges for high CDTI coverage included, long walking distance by CDDs to deliver drugs to households, persons being away for farming, low awareness of the disease and limited supervision by the NTD coordinators. In conclusion, ivermectin uptake in Mahenge should be optimised by continuous advocacy about the importance of taking ivermectin to prevent onchocerciasis-associated morbidity and by improving supervision during CDTI.

Keywords: onchocerciasis; community directed treatment with ivermectin; elimination; epilepsy; focus group discussions; misconceptions

1. Introduction

Onchocerciasis, commonly known as river blindness, is a neglected tropical disease (NTD) caused by the nematode worm *Onchocerca volvulus* transmitted through a bite of an infective black fly of the genus *Simulium* [1,2]. Onchocerciasis is known to affect the skin and to cause blindness if left untreated. An estimated 20.9 million people are infected globally, of whom 99% reside in sub-Saharan Africa [1].

The World Health Organization (WHO) targeted onchocerciasis for elimination by 2030 using a community-directed treatment with ivermectin (CDTI) strategy (3). For more than 20 years, CDTI has been the global cornerstone strategy for onchocerciasis control and elimination [1]. Due to the former Onchocerciasis Control Programme in West Africa (OCP), the African Programme for Onchocerciasis Control (APOC), and the current Expanded Special Project for Elimination of NTD (ESPEN), onchocerciasis is no longer a public health problem in many onchocerciasis endemic areas in Africa [1,3-5].

In Tanzania, the disease is endemic in Mahenge, in the Ulanga district of the Morogoro region, particularly in rural villages [2,6-8] where a high prevalence of epilepsy, including nodding syndrome, has been reported [9-12]. House-to-house surveys in these rural villages showed that 77.9% of persons with epilepsy met the criteria of onchocerciasis-associated epilepsy [11].

Growing epidemiological evidence suggests a strong association between onchocerciasis and epilepsy, including nodding syndrome [13-16]. In January 2017, the prevalence

2.3. Data collection methods

Focus group discussions and IDIs were conducted to provide in-depth insights into the barriers to onchocerciasis elimination despite over 20 years of CDTI in the Mahenge area. Eleven FGDs were conducted in the four villages which involved the following groups: 1) PWE; 2) parents/guardians of PWE; 3) CDDs; and 4) CORPs (Table 1). As the villages Mdindo and Msogezi are located in the same geographical area, they were merged and one FGD was conducted by each of PWE, CDDs and CORPs. In Msogezi village the PWE group mixed males and females. Each group comprised of 8 - 12 participants, with male and female participants in separate or mixed. The venues for the FGDs were chosen with the local village leaders in each village. Prior to the discussion, the importance of participating in the study was explained. The FGDs were conducted by experienced moderators in a 'round table' manner with numbering of participants in chronological order. The FGDs lasted for 45 to 60 minutes. Each IDI took 30 to 45 minutes and was conducted in a convenient setting for the NTD programme coordinators. Interview guides with open-ended questions were used to collect data. Interviews were conducted in Kiswahili language, the most widely spoken language in Tanzania and audio-recorded in addition to taking notes with permission from the participant(s).

Data collected in FGDs and IDIs included the knowledge, perceptions and beliefs about: 1) onchocerciasis; 2) cause and prevention of the onchocerciasis; 3) association between onchocerciasis and epilepsy; 4) awareness about the role of CDTI for onchocerciasis elimination; and 5) challenges during the mass distribution of ivermectin.

2.4. Data processing and analysis

Interviews were conducted in Kiswahili language. The audio-recorded interviews, with permission from the participant(s), were verbatim transcribed by the research team and then translated into English for analysis. Data were analysed manually using content analysis. Classification and analysis of the data were independently done by the two moderators to enhance the credibility of the categorisation, deepen insights and ensure that findings reflected the research context. Coding was developed based on the predefined objectives of the study and elaborated by a preliminary review of the data to understand the narratives portrayed by participants. Inductive coding was used to identify sub-themes within each of the key themes.

3. Results

3.1. Demographic characteristics of FGDs and IDIs participants

A total of 96 individuals (94 in FGDs) participated in this study, which involved 13 interviews: 11 FGDs and two IDIs (Table 1).

Table 1. Socio-demographic characteristics of FGDs and IDs participants

Type of Interview	Participants	No. of discussion/ interviews	No. of Participants	No. of females (%)	Median age (Range)	Farming (%)
FGDs	CDDs	3	23	7 (30.4)	37 (22-64)	22 (95.6)
	PWE	3	27	10 (37.0)	26.5 (18-50)	25 (92.6)
	PWE caretakers	2	15	9 (60)	34 (21-66)	15 (100)
	CORPs	3	29	8 (27.6)	43 (22-66)	14 (48.3)
IDs	NTD coordinators	2	2	0 (0)	55.5 (55-56)	0 (0)
Total/Average*		13	96	34 (35.4)	35 (18-66)*	76 (79.2)

* CDD = community drug distributor; CORPs = community resource persons; FGD = focus group discussion; IDI = in depth interview; NTD = neglected tropical diseases; PWE= persons with epilepsy.

Most PWE were younger than participants of other groups, and their overall median age was 26.5 years (IQR: 18-50). The majority (79.2%) of study participants were involved in farming activities, with CORPs having the lowest proportion (48.3%) of individuals involved in farming. Other categories in the CORPs group included traditional healers (13.8%), public employees (13.8%) and religious leaders 10.3%. Females represented 35.4% of all discussants. Most PWE had schooling up to or below standard three, while other groups mainly had attained standard seven or above (Figure 1).

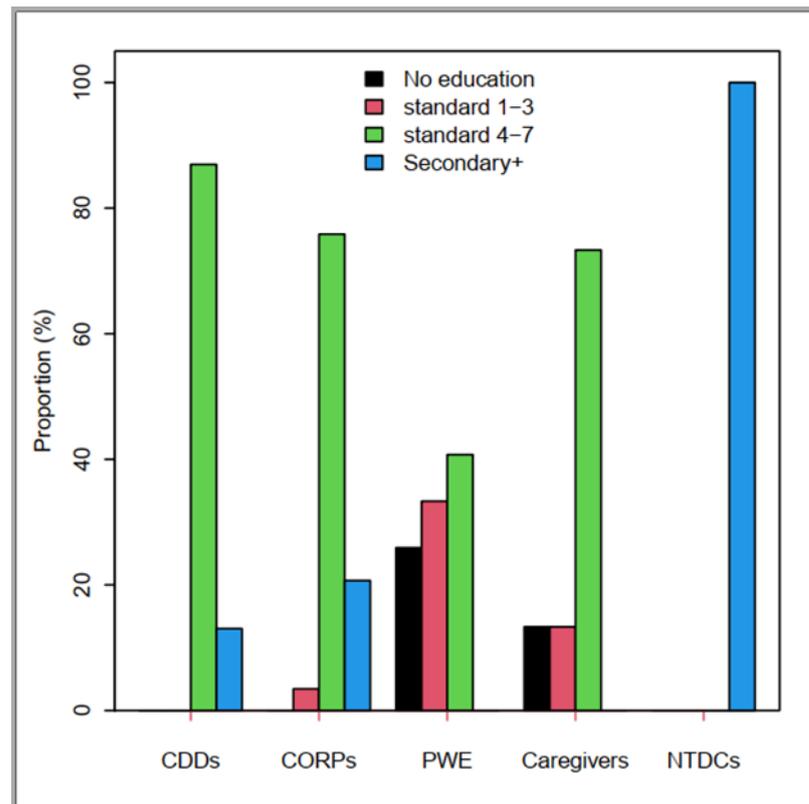


Figure 1: Education levels of different FGDs and IDIs participants. CDDs = community drug distributors; CORPs = community resource persons; NTDCs = NTD coordinators; PWE= persons with epilepsy.

3.2. Knowledge, perceptions and beliefs about onchocerciasis

3.2.1. General knowledge and disease burden

Onchocerciasis was known by all participants of the FGDs but described using different local terminologies. The disease was referred to mainly by its skin manifestations. All the participants used the term “*filaria*”, the name used to describe the disease during CDTI campaigns. Other terminologies mentioned were itching skin, dry skin and spotted pigmentation of the skin, especially of the legs. Such terminologies were locally referred to as “*ukurutu/mkita*” (itching and dry skin) “*lung’ang’a*” (leopard skin, the chronic skin pigmentation caused by onchocerciasis). These conditions were mentioned by almost all groups in the discussions.

Participants had different views regarding onchocerciasis as a public health problem in their communities. Most participants considered onchocerciasis a serious health problem; however, epilepsy was perceived as the most afflicting disease. One CORP described epilepsy as the most burdensome condition in Msogezi village:

“In Msogezi, we are troubled with diseases like Malaria, onchocerciasis and other diseases, especially epilepsy which is the most devastating disease” [Msogezi, CORP].

Out of four CORPs from Sali village, two indicated epilepsy as the most important public health problem in their villages, while the other two considered malaria followed by epilepsy as the most important diseases. One ranked onchocerciasis in third position after epilepsy. Parent/caregivers from Sali and CORPs from Msogezi, mentioned epilepsy and malaria as the diseases most affecting their community.

Regarding onchocerciasis, a CDD from Sali stated that some participants considered the disease a trivial treatable condition:

“This is just a normal disease, and we all use drugs (ivermectin) which are distributed every year” [Sali, CDD].

It was common understanding for most communities that ivermectin alleviate the clinical manifestations caused by onchocerciasis. However, this notion might have a negative impact on the uptake of ivermectin by people who do not feel sick. As a CDD exemplified:

“People who are supposed to swallow the drugs would ask you: Who told you that I am sick so that I swallow the drug?” should [Sali, CDD].

A similar situation was portrayed by the NTD coordinators, in which some villagers stopped taking ivermectin once symptoms disappeared:

“As a result of long-term use ivermectin, some people do not swallow the drugs (ivermectin) because they no longer suffer from clinical conditions such as itching and rashes which were prevalent in previous years” [NTD Coordinator].

Most community members recognised that the burden of onchocerciasis decreased since the inception of CDTI over twenty years back. One of the IDIs explained that the prevalence of onchocerciasis dermatological manifestations decreased, but that it was still present in some people:

“A big problem was skin itching and hard, dry skin, which are less pronounced nowadays, although still few present skin itching” [NTD Coordinator].

3.2.2. Perceived causes and transmission of onchocerciasis

Study participants in all FGD knew that onchocerciasis is transmitted by a black fly, locally known as *“vifuna”* (plural) and *“kifuna”* (singular). Most discussants understood that black flies pick parasites from an infected person and inject it into another person, who can then acquire the disease as quoted in one of the groups:

“Many community members know that black flies are the agent that transmits onchocerciasis in their area”. [Mzelezi; CDD].

Another participant said:

“Not every black fly carries the filarial parasite, only if the fly has bitten somebody with the infection, then the fly could transmit onchocerciasis to another person” [Mzelezi, CDDs], while a PWE caregiver said: “Blangck flies bite people and leave them with this disease which causes rashes and itchi” [Sali PWE Caretakers].

Several participants were aware that black flies breed in fast-flowing waters. A participant from Sali said:

“It was also reported to have a rapid flowing river close by with falls where black flies breed and bite people” [Sali, PWE caregiver]

However, one of the NTD programme coordinators explained that some of the local communities related black flies to a major spring water course:

“They (local community of Chirombola village) link the breeding sites of the “vifuna” (black flies) to ground/spring water flowing from the mountains in Kitope sub-village; This is the area with many people with epilepsy”. [NTD coordinator].

A PWE caretaker stated that Mzelezi village had a high burden of onchocerciasis with intensive black flies biting rates, which could be why many people are affected by epilepsy:

“The Kitope area is terribly affected, it has plenty of black flies, there you can find about two to three people in one household having epilepsy because of onchocerciasis” [Mzelezi, PWE caretaker]

3.2.3. Prevention of onchocerciasis

Participants had different views on the onchocerciasis prevention approaches. The majority believed the disease is preventable through taking ivermectin. One participant explained to have noticed that the burden of onchocerciasis decreased since ivermectin began to be distributed:

“Since we started taking the medicine (ivermectin), there have been big changes when it comes to (onchocerciasis) transmission where people are no longer presenting with symptoms as it used to be” [Mzelezi, CORP]

Another added to be aware that ivermectin prevented onchocerciasis:

“According to my understanding, filaria is caused by small flies, and its prevention is through taking (ivermectin) pills; apart from that, I know nothing” [Sali, PWE caretaker].

Conversely, other participants did not believe onchocerciasis is preventable since bites from black flies are unavoidable and abundant in their communities:

“Onchocerciasis cannot be prevented since black flies are too many around here” [Sali, PWE and caretakers], while another participant said: *“Eventually, we will all get onchocerciasis because, when we go outside to sweep or wash dishes, the flies bite us; now what are we preventing”* [Sali, PWE and caretakers], a third person stated: *“There is no prevention for onchocerciasis”* [Mzelezi, CORP].

Ivermectin has been in use for so long in these communities that few people currently present clinical manifestations besides onchocerciasis-associated epilepsy. This changed the habits and perceptions of people towards using ivermectin. One of the NTD programme coordinators described that some community members were taking ivermectin intermittently, which can perpetuate transmission, as the adult worms do not die with ivermectin:

“Individuals presenting with clinical conditions of the disease are very few nowadays due to prolonged use of ivermectin, so people think (ivermectin) drugs are no longer required. But we provide education that if we take the drug annually, it will kill the microfilariae and adult worms, which are not killed by the drug and have a lifespan of about 15 years, will be sterilised from releasing microfilariae. This will stop transmission. Unfortunately, this misconception that people are no longer sick and that there is no need to take drugs has been why some people refused to take the drug” [IDI, NTD coordinator].

3.2.4. Knowledge of the association between onchocerciasis and epilepsy

Knowledge about the association between onchocerciasis and epilepsy was limited. Only a few participants were aware of this association, especially CDDs involved in the

distribution of ivermectin or community health workers involved in the surveillance of epilepsy. As a CDD explained, the knowledge of onchocerciasis and epilepsy association was recently acquired following awareness sessions implemented in the study villages and facilitated the CDTI:

“The community at some point did not understand that onchocerciasis can cause epilepsy, but after we (CDD) had been educated, we explained to the community that it could cause epilepsy. So, now over 70% of people understand it, which has made the distribution of ivermectin easy as most people are now coming for the drug instead of waiting at home” [Sali: CDD].

Another CDD from Sali village reiterated the awareness of the association that community health workers were communicating to the village:

“... Community health workers were providing education that if you do not take ivermectin, you will get epilepsy. So now they (Sali community) know the association and understand why it is important to take the drug (ivermectin)” [Sali; CDD].

The community's recent awareness of the association between onchocerciasis and epilepsy is also supported by one of the IDIs. The NTD programme coordinator confirmed that the local knowledge of the association was low since the training only recently included sessions on the association between epilepsy and onchocerciasis. He further described that the local belief that epilepsy is hereditary or the result of intermarriage had increased community resistance to changing perceptions of the cause of epilepsy, despite Mahenge being known to be endemic for both onchocerciasis and epilepsy:

“I can say, the knowledge on association is very limited (minimal), since there are so many thoughts, and everyone has their own knowledge and perceptions. Others think it is a hereditary disease, while others think it is due to intermarriage and bi-witching, ..., but due to recent training on the association between the two diseases, the knowledge seems to increase (on epilepsy being associated with onchocerciasis)”.

Nonetheless, groups not directly engaged in activities related to NTD or epilepsy control shared personal awareness of the association. A resource person admitted to being aware of the association and noticed a decrease in epilepsy incidence since CDTI was introduced:

“To my knowledge, it is possible that onchocerciasis is a major cause of this disease (epilepsy); experience from the past when ivermectin was introduced shows that the epilepsy cases have been declining, and even the skin rashes have disappeared nowadays. My belief is that the parasite goes directly into the human brain and then causes epilepsy” [Sali: CORP].

Other participants refused to accept the association because they considered epilepsy a hereditary disease and onchocerciasis an infectious disease::

“What I know is that epilepsy is hereditary and not an infectious disease. So, I cannot say onchocerciasis can cause epilepsy” [Msogezi, CORP]

3.2.5. Community acceptance of the CDTI programme

Study participants were aware of the CDTI strategy. According to some participants, not everybody took ivermectin during the distribution period due to various claims, such as the drug causing itching and swelling of the body. One of the CORPs confessed never to have taken ivermectin since the CDTI started:

“I had never taken them since when the distribution started” [Mzelezi, CORP]

Another participant added the uncertainty that some people might receive the ivermectin tablet from the CDD but decide not to take it afterwards:

“There is a possibility that people receive the tablets and say that they will take them tomorrow/thereafter but end up throwing them away” [Mzelezi, PWE and caretakers]

3.2.6. Perceived reasons for not taking ivermectin

Different reasons for not to take ivermectin were reported. Some men were afraid that the drug could cause infertility or the inability to participate fully in sexual intercourse:

“The drug (ivermectin) causes infertility and reduces sexual drive (loss of libido) in men” [Msogezi, CDD],

Another participant said:

“Men do not want to take the medicine (ivermectin) because they do not want to reduce their libido” [Sali, female PWE caretaker].

Another portrayed the perceptions referred by some community members as follows:

“We cannot swallow these medications since they reduce sexual drive in men and at the end we will not be able to reproduce, ..., You cannot find these medications in town even white people do not use them” [Sali: CORP].

However, an NTD coordinator stated that now people understood the benefits of taking ivermectin, while in the past, they confused the symptoms of onchocerciasis with the side effects of the treatment:

“Such misconceptions of ivermectin causing sexual performance existed in the past, but nowadays, people understand the benefits and need of the medicine (ivermectin). In the past, people were so affected with oncho; that is why they had less libido. They used to scratch themselves so much that they could not sleep or perform any economic activities, but after using these medicines, they sleep and work peacefully” [IDI, NTD coordinator].

3.2.7. Perceived challenges during mass drug administration

Reported challenges by FGDs participants included poor geographical coverage, lack of incentives, absence of prophylactic medications for ivermectin side effects and transport, refusal of the community members to take the drug, and negligence by CDDs and village leaders to adhere to the stipulated guidelines. A community health worker mentioned the latter problem:

“Drug distribution was very poor because they were aiming at reaching the required (CDTI) coverage without even taking measurements (height of children to determine the number of ivermectin tablets to give), only using registers to administer drugs. Currently, this problem has been less compared to the initial days.” [Msogezi, CORP].

Some areas are hard to reach due to the topographical layout of Mahenge terrain. Therefore, a CDD acknowledged that some CDDs could not reach all households in the hard-to-reach and large areas due to the limited number of days (two weeks) to carry out the CDTI:

“Some households are located too far from the village, and it is difficult to reach them repeatedly, especially when distributing ivermectin; you can go around even three times without finding residents” [Mzelezi, CDD].

Low compensations for CDDs participating in distribution of ivermectin was also pointed as another challenge that affects the distribution. The CDDs suggested increasing the allowance to improve CDDs productivity:

“The allowance we receive is too low. In order to reduce complaints from the CDDs and improve efficiency, we suggest increasing the allowance” [Mzelezi, CDD].

Supervision during CDTI is very important to ensure that CDDs are performing their work according to the guidelines which include how to dispense the drug according to height and directly observed. The supervision should involve programme coordinators, persons incharge of health facilities and community leaders.

One the CDD pointed out how some of the villages leaders fails to play their supervision role:

“Village chairpersons consider themselves as bosses, therefore, do not supervise drug distribution activity, they only concentrate on other business, and during the day they send false information to the authority although they did not follow up” [Msogezi, CDD].

Wrong timing for distribution was also another challenge that was affecting the CDTI programme.

To increase the CDTI coverage, a participant suggested switching the time of the year to carry out the CDTI:

“The activity should not be carried out in the months of June or July, which is the farming season in the area.” [Mzelezi, CORP].

3. Discussion

Our study aimed to identify factors explaining the persistence of onchocerciasis transmission and the high prevalence of epilepsy in rural villages in Mahenge despite more than 20 years of CDTI. In 2018, a research project was initiated in the area to reduce the incidence of onchocerciasis-associated epilepsy. Within this project, a bi-annual CDTI programme was initiated in 2019 based on the successful impact of such intervention in Northern Uganda on reducing the incidence of epilepsy and nodding syndrome [19].

All study participants had a basic knowledge about onchocerciasis and used local names to describe the clinical manifestations of the disease. Similar to observations in 2018 in Mahenge, in the villages of Isongo and Uponera, most participants associated the transmission of onchocerciasis with black flies (*“vifuna”*) [20]. Some participants further described that black flies carrying larvae obtained during a blood meal infect other humans during a subsequent bite. Furthermore, there was a consensus among the NTD programme coordinators and some FGD participants that the burden of skin itching caused by onchocerciasis had decreased due to CDTI.

Similar to previous studies in Mahenge [20], Nigeria [21] and Ethiopia [22,23], witchcraft, and supernatural powers were not mentioned as causes of onchocerciasis. This is in contrast with persistent misconceptions about epilepsy in the Mahenge area[24]. The fact that there were no misconceptions about onchocerciasis most likely is the consequence of the over 20 years of CDTI. Before each CDTI round, training sessions are organised by the NTD programme to orient the CDDs on how to approach the communities and raise community awareness on why ivermectin is important. However such programmes were rarely implemented. National campaigns through radio and other media have been the cornerstone to educate communities. However, only a small proportion of people in rural areas listen to the radio and watch TV. A nationwide media survey in Pakistan indicated that in rural settings only 18% watched TV regularly and only 14% listened to the radio [25]. This indicates that community meetings should be used to complement radio and TV programmes.

The knowledge about the association between onchocerciasis and epilepsy was recently acquired as a consequence of the ongoing research project in the area [9-12,24]. The fact that onchocerciasis is associated with epilepsy has shown to increase the adherence to CDTI and coverage in areas with high epilepsy and onchocerciasis prevalence [18].

Most study participants were aware of the CDTI strategy. This awareness is crucial for attaining high geographical coverage and reaching the last miles of onchocerciasis elimination. However, some community members refused to take ivermectin due to fear of adverse events. Particularly men were afraid of reduced libido. This was also reported in another study in Tanzania[26]. Such fear is not justified as there is no evidence that ivermectin at the therapeutic dose given during CDTI will not affect the persons libido [27]. Similarly to a previous study, the acceptability of the CDTI was high among the respondents [20] and the onchocerciasis disease burden was described to have decreased in Mahenge since the implementation of CDTI.

Reported challenges for the CDTI programme included poor geographical CDTI coverage, lack of incentives for CDDs, lack of prophylactic medications for ivermectin side effects, refusal of the community members to take the drug and negligence of CDDs and village leaders to adhere to WHO stipulated guidelines to administer the ivermectin dose to children based on height. Similar challenges were reported in other studies [28,29]. Poor programme management with lack of supervision and monitoring of CDDs were also reported. Because of long-distance walking without transport in a mountainous area, CDDs often failed to distribute the ivermectin in a directly observed way. Moreover, in Mahenge, only one CDD per 250 people was considered to be insufficient for distributing ivermectin in two weeks. Advocacy from the CDTI programme leadership was mentioned to be important to increase the uptake of ivermectin; however, such support was reported to be lacking. Respondents felt that there is a need to assign more and better salaries for CDDs to engage more people. It was advised not to distribute ivermectin in June or July because it is the farming season, and villagers move away from their homes to their farms.

A limitation of our study is that the villages included in our study were villages with a high prevalence of onchocerciasis-associated epilepsy that had been targeted with interventions to increase the CDTI coverage. As such, misconception about onchocerciasis and ivermectin may have been even more prominent in other endemic villages of Mahenge.

5. Conclusions

Continuous advocacy about the importance of taking ivermectin bi-annually and regular supervision during CDTI by district and national coordinators are crucial to attain the onchocerciasis elimination goal. District coordinators and CDDs must ensure drugs are available at the health facility before the distribution days, and advocacy campaigns should associate ivermectin uptake as prophylactic treatment for onchocerciasis and associated epilepsy. There is also the need to motivate CDDs with more incentives and increase the number of days assigned to CDTI. Additionally, it was suggested to distribute ivermectin during the months that farming is not taking place to maximise CDTI coverage.

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