

EMPIRICAL STUDIES

Drawing and interpreting data: Children's impressions of onchocerciasis and community-directed treatment with ivermectin (CDTI) in four onchocerciasis endemic countries in Africa

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Abstract

Although the depiction of a child leading a blind man is the most enduring image of onchocerciasis in Africa, research activities have hardly involved children. This paper aims at giving voice to children through drawings and their interpretation. The study was conducted in 2009 in Cameroon, Democratic Republic of Congo (DRC), Nigeria and Uganda. Children aged 6–16 years were asked to draw their perceptions of onchocerciasis and community-directed treatment with ivermectin (CDTI) in their communities. A total of 50 drawings were generated. The drawings depicted four main aspects of onchocerciasis: (1) the disease symptoms, (2) the negative consequences of onchocerciasis among children and in the community generally, (3) the ivermectin distribution process, and (4) the benefits or effects of taking ivermectin. Out of the 50 drawings, 30 were on symptoms, 7 on effects of the disease on children, 8 on distribution process, and 5 represented multiple perceptions on symptoms, drug distribution processes, benefits, and effects of treatment. The lack of clarity when treatment with ivermectin can be stopped in endemic areas requires working with children to ensure continued compliance with treatment into the future. Children's drawings should be incorporated into health education interventions.

Key words: *Onchocerciasis, community-directed treatment, ivermectin, children, drawings, Africa*

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The African Programme for Onchocerciasis Control (APOC) was launched in 1995 as an expansion of the ivermectin strategy implemented by the Onchocerciasis Control Programme (OCP), using long-term distribution of ivermectin to eliminate the disease and to limit transmission by reducing the parasite reservoir in humans (Benton, Bump, Seketeli & Liese, 2002). Community-directed treatment with ivermectin (CDTI), the main strategy for APOC, has enabled the programme to reach, empower, and bring relief to remote and underserved onchocerciasis-endemic communities. Today,

APOC covers 19 countries including post-war and countries in conflict zones such as Democratic Republic of Congo (DRC), Liberia, Chad, and Angola. Treatment coverage rates are monitored regularly to promptly identify communities with poor or insufficient coverage in order to institute timely and appropriate interventions to improve coverage.

There is evidence that ivermectin treatment has become part of the culture of people in the endemic communities and they are willing to continue with treatment for as long as it is offered through their

governments (Amazigo et al., 2007). Anecdotal evidence from APOC funded participatory independent monitoring of CDTI projects, as well as mission visits by experts, indicate that the therapeutic coverage has increased significantly in all implementing countries. However, while monitoring and evaluation reports illustrate the effectiveness of the CDTI strategy in the delivery of ivermectin to communities and people in need of it, no concrete efforts have been made to ascertain and document the social benefits of CDTI among the beneficiaries. Yet, there is a relationship between perceived benefits and taking actions necessary for continued enjoyment of the benefits (Rosenstock, 1974).

A major gap in CDTI data collection exercises has been the inadequate involvement of children. This is despite the fact that the most enduring image of onchocerciasis is a child leading a blind man.¹ Onchocerciasis has been reported to disrupt children's education, some children are distracted in school by maddening and unrelenting itching; their childhood is stolen as they are forced to look after older relatives blinded by the disease; and marriage prospects of many young women are ruined where beauty and healthy skin are critical assets (Amazigo, 1994; Amazigo & Obikeze, 1991; Brieger, Oshiname & Ososanya, 1998; Clemmons et al., 2002). It is notable that in countries where CDTI has been implemented for the last 15 years, many children are socialised to seeing people with measuring sticks distributing drugs. In many cases, some have waited for about 4 years to start swallowing the drugs on account of age (which at their tender age seems like a long wait).

The exclusion of children from previous assessments has been influenced by the restriction of data collection to adults who can express themselves in words during interviews or who can complete self-administered questionnaires. Children who cannot use speech or writing, as modes of communication are particularly excluded (Morris, 1998, 2003). This is despite the fact that literature points to a whole range of communication strengths and a great willingness and ability on the part of young people to communicate their feelings and experiences and to be involved in a process of change (Morris, 1999; Rabiee, Sloper & Beresford, 2005). These children are reported to be imbued with qualities that give them communication strengths such as perseverance, patience, being able to read other people's communication as well as making graphic representation of their impressions (Disabled People Using Scope Services, 2002).

Moreover, development policies that have evolved since the 1990s have recognised the need to consult children and involve them in the decisions about

their lives. The UN Convention on the Rights of the Child emphasised "children's right to receive information and express their views about matters that affect them" and Article 13 directs "attention to the need for appropriate means of communication to be provided for children" (Rabiee et al., 2005, p. 6)

The involvement of children was, therefore, a key consideration in the multi-country study designed to pilot an *assessment tool* to facilitate the documentation of the social benefits of CDTI on the individuals, households, and communities in onchocerciasis meso and hyperendemic foci where CDTI is being implemented. The pilot study was implemented between November and December 2009 in four countries: Cameroon, DRC, Nigeria, and Uganda. This paper documents the children's impressions and perceptions of CDTI as captured through their own drawings and descriptions.

The involvement of children in this study was based on the recognition that they are active participants in the management of onchocerciasis in endemic communities and that they are important to the future of health activities. The fact that they take the medicine and participate in the community activities requires that they become part and parcel of the monitoring and evaluation activities. The main objective of this paper, therefore, is to present the results of the study with a view to illustrating that children are important to the success of CDTI and that there exist qualitative mechanisms through which they can be actively engaged in data collection and health promotion activities.

Participants and methods

Informed consent was sought from the schools where the study was conducted. The responsible teachers were informed about the objectives of the study before they selected the children to participate in the drawing and interpretation exercise. The children were informed that the data generated were to be held in confidence and would only be used for the purposes of the study. Verbal consent was considered sufficient for the purpose of the study.

The engagement of the children in the study was through a consultative process between the study site coordinators and the teachers in primary schools. One primary school was selected in each study community for this component of the study. In situations where there were more than one primary school, the site coordinators used the following criteria to select one of them for inclusion: the school had classes up to the highest level in primary education, was a public entity, and was in session at the time of the study. The coordinators visited the

selected schools, talked to the administrators (in most cases the head teachers or their deputies), and explained the study to them.

The request made to the administrators was to select two children per class randomly (a boy and a girl) representing the age range 6–12 years (primary 1–6 in Nigeria, 1–7 in Uganda, 1–6 in Cameroon, and 1–7 in DRC). The teachers used the class register to select the two pupils. However, given that the schools were predominantly located in rural areas, the children tended to be older than anticipated, therefore, the study captured those aged 6–16 years. After selecting the children, the research team was given space for the drawing and interpretation exercise. Each child was shown where to sit and was supplied with paper, pencil, and crayons for the exercise. Once the children were seated they were briefed on the objective of the exercise, using the following generic words: “make a drawing showing what you know about onchocerciasis in this community. Draw any aspect of the disease including treatment, the signs, and symptoms or anything that to you represents this disease. Take 30–45 min to draw.” Each of the children was asked for verbal consent before participating in the exercise. After completing the drawing, each child was asked to describe what he/she had drawn. In total 50, drawings were made: Cameroon, 10; DRC, 18; Nigeria, 10; and Uganda, 12. The age distribution is presented in Table I. It should be noted that all the schools were rural based and there was equal distribution of the children according to gender (one-to-one).

Although the data collection process was standardised during a joint planning and training exercise for the research team held in Nairobi prior to fieldwork, there were slight modifications in the implementation of this tool:

- Cameroon: the site coordinator showed the children the drug and a health promotion material on CDTI
- DRC and Nigeria: the children were shown a bottle of ivermectin

Table I. Characteristics of the children involved in the study.

Demographic characteristics	Cameroon	DRC	Nigeria	Uganda
Sex				
Male	5	9	5	6
Female	5	9	5	6
Age				
6–9 years	4	8	4	3
10–12 year	4	6	4	3
>12 years	2	4	2	6

- Uganda: the site coordinator provided a description of the programme but no materials were displayed

The variations in the approach have implications on the results as discussed further below.

Interpretation of the drawings

At the end of each session, the researcher sat with each child and asked him/her to describe what he/she had drawn. The researcher then noted the description as presented by the child. Clarification was sought from the child and numbers used in case of complex drawings to illustrate the items referred to by the child. No meaning other than that stated by the child was added on to the drawings in an effort to retain the children's views on onchocerciasis and the control programme.

Results

The children's drawings tended to focus on four main themes: (1) the disease symptoms, (2) the negative consequences of onchocerciasis among children and in the community in general, (3) the ivermectin distribution process, and (4) the benefits or effects of taking ivermectin as summarised in the Table II. The selection of pictures presented in this paper was based on those that were clear after scanning and those that presented the different aspects of CDTI. Efforts have been made to showcase pictures from the four study sites. The results show that the children were able to relate the correct external symptoms to onchocerciasis as illustrated in some of the drawings shown in the sub-sections below.

Negative consequences of onchocerciasis

The most common signs of onchocerciasis identified by the children were rashes all over the body (some could even be seen through clothing), nodules, and blindness. As shown in Figure 1 above, the patient had rashes all over the body while Figure 2 depicts children who have scabies and seem to be experiencing some discomfort. Both figures, drawn by children in DRC, illustrate that the children are aware of the signs and symptoms of onchocerciasis as defined in their communities.

In Nigeria, the drawings focused on swellings and rashes as captured in Figure 3. The children, through the drawings, explicitly illustrated nodules and swellings of different parts of the body. For this child (Figure 3), he magnified the swellings on the

Table II. Distribution of children’s drawings according to country and perceptions.

Description	Cameroon	DRC	Nigeria	Uganda	Total
Drug distribution process	5	2	–	1	8
Negative effects of the disease on children and community in general	–	7	–	–	7
Symptoms of the disease (rashes, swellings, epilepsy, etc.)	1	8	10	11	30
Mixture of symptoms, benefits and effects of treatment	4	1	–	–	5
Total	10	18	10	12	50

side of his drawing to provide a clear illustration of the swollen parts.

In Uganda and Nigeria, children depicted swellings as the key manifestations of onchocerciasis as illustrated in Figures 4 and 5. One of the children

alluded to the psychological impacts of onchocerciasis and talked about an epilepsy linkage to the disease.

Four children in DRC drew children leading adults, typical of what used to be common in onchocerciasis literature, as illustrated in Figures 6 and 7. What is insightful about these drawings is the expression by one of the pupils that the “boy leading his blind father is out of school in order to provide care.”

The interpretation provided by the children shows that they understand that if they take ivermectin they will be protected against the consequences of the disease including blindness that robs them of their childhood. This could be the main motivation for their annual consumption of ivermectin.

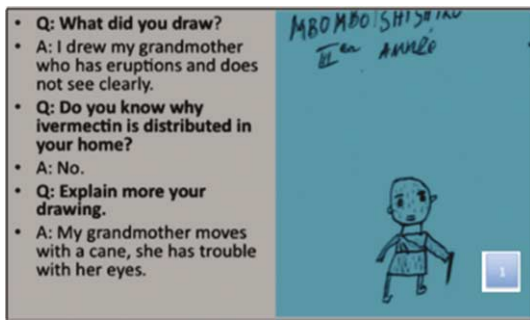


Figure 1. A patient with rashes all over the body

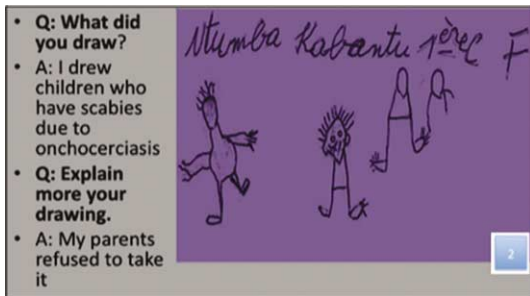


Figure 2. Children with skin problems

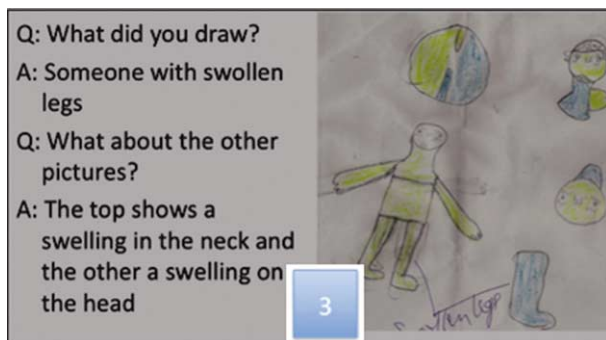


Figure 3. Swellings due to onchocerciasis



Figure 4. Someone with swollen legs

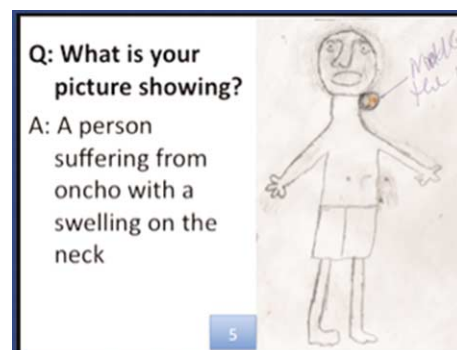


Figure 5. Someone with a nodule on the neck

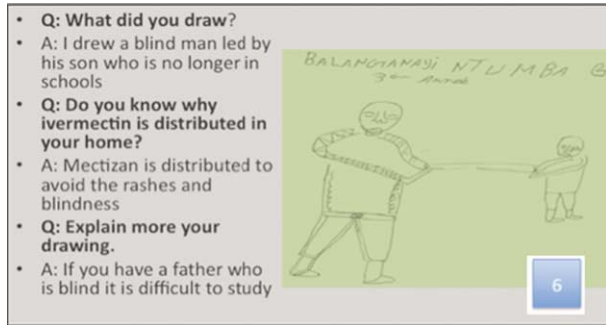


Figure 6. A boy child leading a blind man

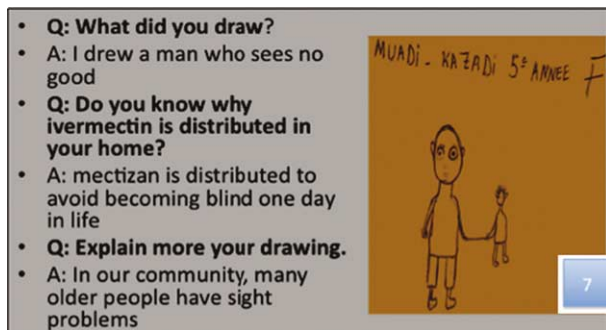


Figure 7. A girl child leading a blind man

In Uganda, one pupil's illustration (in Figure 8) showed a child being taken to the hospital as a result of an epileptic fit. This figure is in line with the close link between epilepsy and onchocerciasis in Ugandan onchocerciasis literature as will be discussed further below.

There were, however, some subtle differences in the drawings—children in DRC had more drawings of children leading the blind and missing out on schooling opportunities. Those in Cameroon tended to show the consequences of itching while those in Nigeria were more inclined towards swellings/nodules.

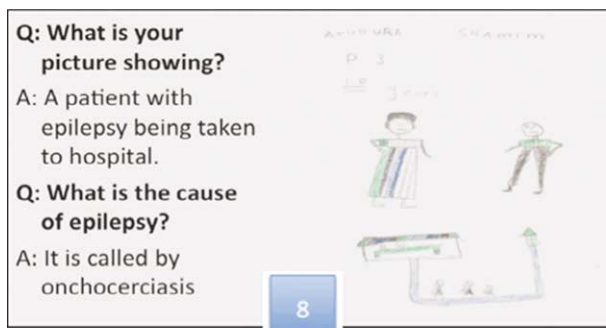


Figure 8. A patient suffering from epilepsy being taken to a health facility

The ivermectin distribution process

A common thread in the children's drawings was the measuring stick to illustrate CDTI (as shown in Figure 9). This could be due to the fact that the measuring stick used by community drug distributors is also used to assess whether the children are old enough to start taking the drugs and to determine dosage. Some of the drawings illustrated the complex process of delivering ivermectin and the care given to those who react to treatment as shown in Figures 10 and 11.

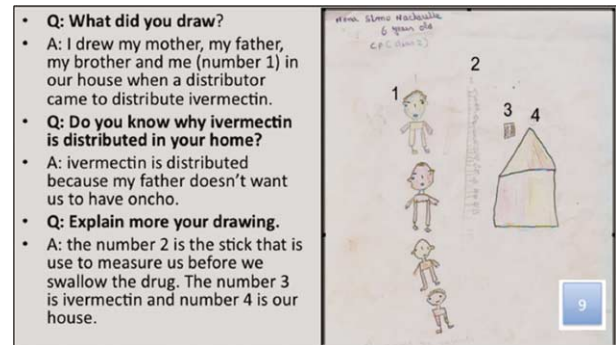


Figure 9. A drawing showing the drug distribution process

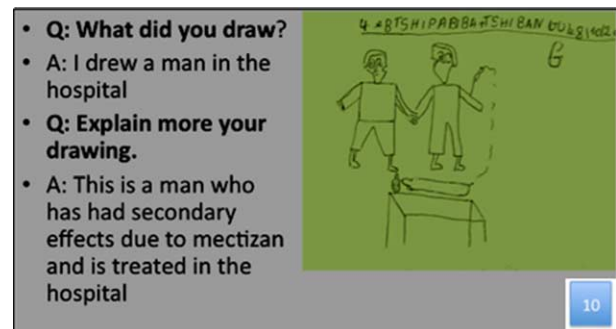


Figure 10. A patient being taken to a health facility after reacting to treatment

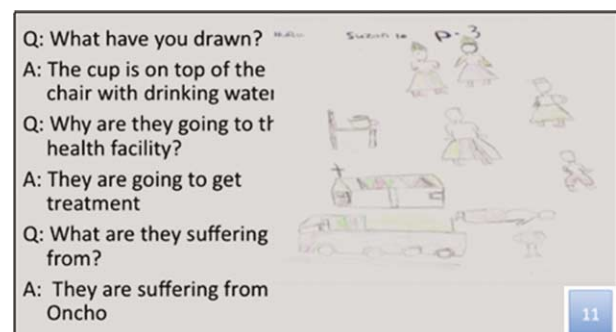


Figure 11. Patients suffering from onchocerciasis seeking for treatment

Figure 10 shows that the child understands what should be done when a person suffers side effects after taking ivermectin, which is to take him/her to the nearest health facility. Furthermore, Figure 11 illustrates an understanding by the child that those with symptoms should seek treatment from health facilities.

Benefits of ivermectin

Several children provided illustrations of the benefits of taking ivermectin as shown in Figure 12 (drawn by a child in Cameroon). What is illustrative in this figure is that the child sees him/herself as a CDD. He also shows both the positive impacts of taking ivermectin and the consequences of not taking the drug. A child in DRC illustrated the preventive nature of taking ivermectin as shown in Figure 13. He noted that his mother had skin eruptions and she was giving him medicine to avoid similar experiences in future.

What these figures illustrate is that the children are cognisant of the impacts of onchocerciasis and understand the need to take ivermectin. They are also able to express their understanding of the side effects that can occur when they take the drugs, an important indicator of the effectiveness of health education in the study sites. There are specific elements identified with CDTI: drug distributor, measuring stick, box of drugs, water for swallowing the tablets, and the presence of community members. The fact that one child considered him/herself a distributor shows that CDDs are role models in onchocerciasis endemic communities.

Comprehensive understanding

The drawings provide comprehensive understanding of children's impression of onchocerciasis, its treatment as well as the benefits of the treatment. For

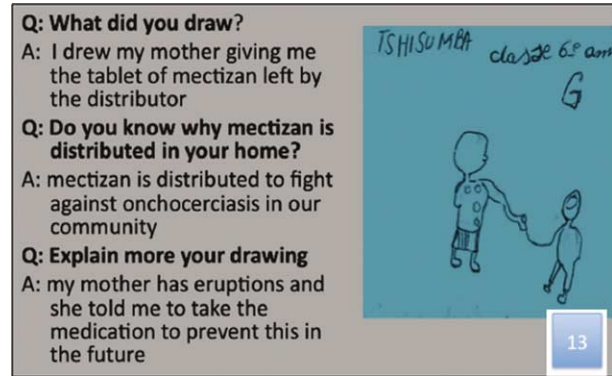


Figure 13. A mother giving her child ivermectin to protect him from infection

instance, the drawings show that the children are aware of onchocerciasis although they seem to be more aware of the aesthetic effects (rashes and nodules). However, some variations were noticed in the different sites and this reflects the preponderance of the cases in the different communities. For instance, while the drawings from DRC emphasised children leading blind adults, Nigeria emphasised nodules and rashes. In Uganda, one of the children's drawings projected epileptic seizures, reflecting the association between onchocerciasis and epilepsy. The children's drawings also captured their awareness of ivermectin for treating onchocerciasis as well as their perception of the benefits. Their awareness of the control programme was captured in the drawing of the measuring stick CDDs use for dosage determination.

Discussion

It is clear from the study that children are aware of the range of conditions that characterise onchocerciasis including severe itching, nodules/swellings, skin rashes, and blindness (Amazigo, 1994; Amazigo & Obikeze, 1991; Brieger et al., 1998). What is

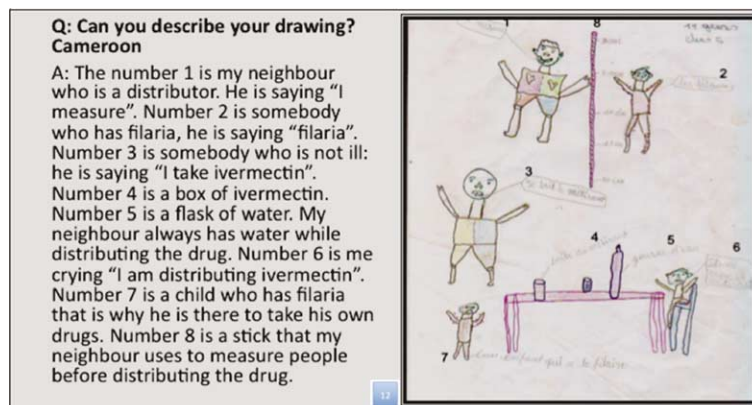


Figure 12. The different people and materials used in ivermectin treatment

insightful from the study was the ability of the children to express some of the local specific knowledge of the signs and symptoms of onchocerciasis. For instance, a child in Uganda alluded to epilepsy as a consequence of onchocerciasis, tackling an issue addressed by other researchers on this phenomenon although not conclusively (Druet-Cabanaca et al., 2004).

The children in DRC were expressive of the blinding aspect of onchocerciasis, which is no longer a big issue in the other countries involved in the study. The fact that they could allude to the “missed opportunities for children who have to lead the blind” calls for the communities to find alternative ways of addressing the needs of visually impaired people without infringing on the children's life prospects.

Children are engaged in CDTI activities in various ways. They carry the measuring stick, they ferry water for taking the drugs and participate in community meetings where they gather vital information on health and other issues. Those who are able to swallow the drugs participate through complying with the treatment. It is therefore critical for research teams to find mechanisms through which children's participation in generating data, monitoring and evaluating the programme impacts, and health education can be integrated in data collection processes and community sensitisation. Furthermore, the children's drawings and interpretation could be used in developing health education messages relevant to the communities.

Engaging children in CDTI activities is considered critical mainly due to the fact that there is no clear indication when onchocerciasis transmission can be interrupted in order to stop treatment. The current evidence shows that it could take up to 15–17 years of annual mass drug administration of ivermectin for vector transmission to be interrupted (Diawara et al., 2009). Therefore, it is important for children to be sensitised to comply with treatment for sustained success of CDTI.

There were some differences in the expressions of the children through the drawings. We suspect that this could have been influenced by the way the issue was introduced by the study site coordinators. The children in Cameroon and DRC had more detailed drawings denoting a better understanding of the issue compared to those in Uganda and Nigeria. It is important for future research activities to standardise the approach through showing a box of ivermectin without providing detailed descriptions of the exercise. This would then allow the children to present their views without too much or too little prior information.

This study sought to explore the children's perceptions towards CDTI in their communities. The engagement of children was an effort by the study team to give them a voice considering their socialisation that has exposed them to CDTI for several years. The fact that children are engaged in guiding kin blinded by onchocerciasis in some countries provided further impetus for the research team to hear them out. This paper therefore was aimed at exploring the children's views towards the disease and the CDTI process and activities. The use of drawings as a data collection method was to assess if the children would be able to communicate the implications of CDTI through a tool that has been explored in other studies and found convenient for their engagement (Di Leo, 1983; Kitahara & Matsuishi, 2008; Mitchell, 2006; Wright, 2008).

Conclusion

In conclusion, we note that it is possible for children to generate data that could contribute to a better understanding of the impacts of CDTI in the communities. Through drawings and interpretation, children are able to express their views regarding the impacts of the on-going efforts to address the disease and the perceived benefits. Given the long-term nature of treatment with ivermectin, it is essential for children to be part and parcel of data collection activities during baseline, monitoring, and evaluation exercises. Their role in programme implementation should be explored and enhanced, more so in health education.

Study implications

The study results highlight various implications for CDTI activities as briefly presented below.

1. Children in endemic communities are impacted in various ways with onchocerciasis. Apart from suffering some of the signs and symptoms, for some, their future life prospects are interfered with as they are forced to drop out of school to care for blind and sick relatives. The children realise the impact this has on their lives, which calls on communities to devise alternative care strategies that do not infringe on the ability of children to acquire an education and improve their life prospects.
2. We believe that children are critical to the systematic compliance to ivermectin and other drugs. Drawings, stories, and other forms of interaction can contribute to a better and wholesome understanding of CDTI and participation in mass drug administration in different

communities and for varied conditions. The engagement of children in data collection would be important in the co-administration of multiple drugs for the control of neglected tropical diseases (NTDs), especially in communities that are endemic for schistosomiasis, lymphatic filariasis, and onchocerciasis.

3. Children are active participants in CDTI, which implies that they should be actively drawn into the programme activities. It is clear that they gather information through health education and informal discussions in the community; therefore, it is important for programmes to design messages that target their involvement.
4. For sustainable compliance with treatment, it is important for programmes to include children in their implementation activities. It is possible that the current 7-year-olds could be taking the drugs well into their teen years. The success of the control programmes will therefore be determined by how they are sensitised and involved in the activities as they grow older.

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Conflict of interest and funding

The authors have not received any funding or benefits from industry to conduct this study.

Note

1. This is one of the images that grace the entrance to the World Health Organisation (WHO) headquarters in Geneva, Switzerland.

References

Amazigo, U. V. (1994). Onchocerciasis and women's reproductive health: indigenous and biomedical concepts. *Tropical Doctor*, 23, 149–151.

Amazigo, U. V., & Obikeze, D. S. (1991). *Socio-cultural factors associated with prevalence and intensity of onchocerciasis and*

onchodermatitis among adolescent girls in rural Nigeria. SET/TDR Project Report. Geneva: World Health Organization.

Amazigo, U. V., Okeibunor, J. C., Matovu, V., Zoure, H., Bump, J., & Seketeli, A. (2007). Performance of predictors: Evaluating sustainability in community directed projects of the African Programme for Onchocerciasis Control. *Social Science and Medicine*, 64(10), 2070–2082.

Benton, B., Bump, J., Seketeli, A., & Liese, B. (2002). Partnership and promise: Evolution of the African river-blindness campaigns. *Annals of Tropical Medicine & Parasitology*, 96(Suppl. 1), 5–14.

Brieger, W. R., Oshiname, F. O., & Ososanya, O. O. (1998). Stigma associated with onchocercal skin disease among those affected near the Ofiki and Oyan Rivers in Western Nigeria. *Social Science & Medicine*, 47(7), 841–852.

Clemmons, L., Amazigo, U. V., Bissek, A. C., Noma, M., Oyene, U., Ekpo, U., et al. (2002). Gender issues in the community-directed treatment with ivermectin (CDTI) of the African Programme for Onchocerciasis Control (APOC). *Annals of Tropical Medicine & Parasitology*, 96(Suppl. 1), 59–74.

Diawara, L., Traoré, M., Badji, A., Bissan, Y., Doumbia, K., Goita, S. F., et al. (2009). Feasibility of onchocerciasis elimination with ivermectin treatment in endemic foci in Africa: First evidence from studies in Mali and Senegal. *PLoS*, 3(7), e497.

Di Leo, J. H. (1983). *Interpreting children's drawings*. New York: Brunner/Mazel Publishers.

Disabled People Using Scope Services. (2002). *The good practice guide for support workers and personal assistants working with disabled people with communication impairments*. London: Scope.

Druet-Cabanaca, M., Boussinesq, M., Dongmoc, L., Farnarierd, G., Bouteillea, B., & Preuxa, P. M. (2004). Review of epidemiological studies searching for a relationship between onchocerciasis and epilepsy. *Neuroepidemiology*, 23, 144–149.

Kitahara, R., & Matsuishi, T. (2008). *Research on children's drawings*. Retrieved March 5, 2008, from www.matsuishilab.org/childrenFiguresummary1_E.html

Mitchell, L. M. (2006). Child-centered? Thinking critically about children's drawings as a visual research method. *Visual Anthropology Review*, 22(1), 60–73.

Morris, J. (1998). *Don't leave us out—Involving disabled children and young people with communication impairments*. York: Joseph Rowntree Foundation/York Publishing Services.

Morris, J. (1999). *Space for us: Finding out what disabled children and young people think about their placements*. London: Borough of Newham.

Morris, J. (2003). Including all children: finding out about the experiences of children with communication and/or cognitive impairments. *Children & Society*, 17(5), 337–348.

Rabiee, P., Sloper, P., & Beresford, B. (2005). Desired outcomes for children and young people with complex health care needs, and children who do not use speech for communication. *Health & Social Care in the Community*, 13(5), 478–487.

Rosenstock, I. M. (1974). Historical origin of the health belief model. *Health Education Monograph*, 2(4), 328–335.

Wright, S. (2008). *Young children's meaning-making through drawing and "telling": Analogies to filmic textual features (free full-text available): Last updated Thursday, 09 October 2008*. Retrieved April 21, 2001, from http://www.earlychildhoodaustralia.org.au/index2.php?option=com_content&do_pdf=1&id=996