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Community Perspectives: Qualitative Analysis of Factors Impacting Community-Directed Treatment with Ivermectin (CDTI) Success in Rural South-West Cameroon

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Abstract

Background: The African Programme for Onchocerciasis Control was launched in 24 African countries in 1995. However, despite over a decade of yearly mass treatment with ivermectin distributed under community-led directives (CDTI), a high prevalence of onchocerciasis is still being observed in the Meme river basin of South-West Cameroon (Wanji, 2015).

Purpose: The purpose of this study was (1) to identify attitudinal, behavioral, and organizational aspects in the Kombone Health Area (KHA) of the Meme river basin which may have an impact on CDTI success and (2) elaborate a set of recommendations for community-oriented action to improve effectiveness of onchocerciasis control.

Methods: Using a qualitative, semi-inductive approach, 17 interviews with community members and 4 focus groups (FGDs) with community ivermectin distributors (CDDs) were conducted. Exact transcriptions of interviews were analyzed for content by research theme, condensed into categories and analyzed to understand underlying significance in terms of attitudes, knowledge, experience, and behaviors. Validated FGD results were analyzed by research theme in order to identify and understand the reality of CDTI in KHA.

Results: CDTI was described as being conducted via a top-down, non-participatory approach, negatively impacting the success of the program. Negative attitudes towards CDTI, ivermectin, and CDDs as well as CDTI-impeding behaviors in the community were driven by fear, mistrust, misunderstanding, and a lack of knowledge of the program and its related elements. Organizational issues were also identified as roadblocks to CDTI success.

Conclusion: This research has identified a number factors affecting CDTI success in KHA and offered corresponding recommendations. Those working in similar contexts can use these results and recommendations as a foundation to improve their own programs and increase community participation.

Key words: onchocerciasis, neglected diseases, ivermectin supply and distribution, public participation, international health problems, national health programs

Résumé

Contexte : le Programme Africain de Lutte contre l'Onchocercose a été lancé dans 24 pays africains en 1995. Néanmoins, malgré plus d'une décennie de traitements de masse annuels par l'ivermectine sur directives communautaires (CDTI), une prévalence élevée d'onchocercose persiste dans le bassin de la rivière Mémé du Sud-Ouest du Cameroun (Wanji, 2015).

Objectifs : les objectifs de cette étude étaient d'une part d'identifier les aspects d'attitude, de comportement et d'organisation dans la Zone de Santé de Kombone (KHA) du bassin de la rivière Mémé qui pourraient avoir un impact sur la réussite du CDTI. D'autre part, cette étude cherchait à élaborer une série de recommandations pour l'action, orientée vers la communauté, visant à améliorer le contrôle de l'onchocercose.

Méthodes : au moyen d'une approche qualitative et semi-inductive, 17 entretiens avec des membres de la communauté et 4 focus groups (FGDs) avec des distributeurs communautaires d'ivermectine (CDDs) ont été menés à la KHA. Les retranscriptions des entretiens ont été analysés dans leur contenu avec des thèmes de recherche, condensés ensuite en catégories, et enfin analysés afin de comprendre la signification sous-jacente des informations récoltées par rapport aux attitudes, connaissances, expériences et comportements. Les résultats des FGDs ont été validés et puis analysés par thème de recherche afin d'identifier et comprendre la réalité du CDTI à la KHA.

Résultats : le CDTI peut être décrit comme étant dirigé via une approche "top-down" et non-participative, ce qui a un impact négatif sur le succès du programme. Des attitudes négatives vis-à-vis du CDTI, de l'ivermectine et des CDDs, ainsi que des comportements gênants du CDTI étaient conduits par la peur, la méfiance, un manque de confiance, l'incompréhension et un manque de connaissances du programme. Des problèmes d'organisation ont également été identifiés comme étant des freins au succès du CDTI.

Conclusion : cette recherche a identifié plusieurs facteurs qui affectent le succès du CDTI à la KHA et a présenté des recommandations appropriées. Les personnes travaillant dans des contextes similaires peuvent utiliser ces résultats et ces recommandations comme une base de travail permettant d'améliorer leurs propres programmes mais aussi d'augmenter la participation du public.

Mots clés : onchocercose, maladies négligées, distribution d'ivermectine, participation du public, problèmes internationaux de santé, programmes nationaux de santé

Contents

List of Abbreviations

Acronym	**Definition**
APOC	African Programme for Onchocerciasis Control
CDD	Community-Directed Distributor
CDTI	Community-Directed Treatment with Ivermectin
FGD	Focus Group Discussion
KHA	Kombone Health Area
UB	University of Buea
UCL	*Université Catholique de Louvain*
ULB	*Université Libre de Bruxelles*
WHO	World Health Organization

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Introduction

Onchocerciasis is a neglected tropical illness for which nearly 125 million people are at risk and 37 million people are infected in Africa, Latin, and Central America and Yemen (Albano, 2016; WHO, 2016B). The disease is caused by *Onchocerca volvulus*, a filarial worm which is transmitted in its larval state to humans via the bites of infected *Simulium* flies, or black flies. In the human body, adult worms form nodules and breed. An adult female worm can release nearly 1,000 microfilariae a day into the body. When these microfilariae die, they cause intense inflammatory responses leading to severe itching, rashes, lesions, depigmentation of skin, and, in severe cases, blindness (WHO, 2016B).

In addition to its health effects, the social and economic consequences of onchocerciasis are many. Onchocerciasis-related blindness has been associated with an inability to travel and work as well as higher rates of divorce and lower rates of marriage than in the general population (Evans, 1995). High levels of stigmatization and isolation of infected persons, especially among children, have also been reported in affected communities (Tchounkeu, 2012). Students with onchocerciasis are more likely to drop out of school or have poor academic results due to loss of sleep and distracting itching (Ubachukwu, 2006).

APOC and CDTI

Ninety-nine percent of people infected with onchocerciasis live in thirty-one countries in Sub-Saharan Africa (WHO, 2016B). The public health consequences of the disease in this region have prompted urgent action and in 1995, the African Programme for Onchocerciasis Control (APOC) was launched (APOC, 2007). The goal of this program is to eliminate onchocerciasis as a public health threat and is currently active in 24 African countries. The program's main strategy is yearly mass chemotherapy with ivermectin (name brand: Mectizan™), a drug which kills the microfilariae in the body. Mectizan™ does not however kill the adult *O. volvulus* worm which continues to live and reproduce inside the human for 12-14 years. Because of this, ivermectin must be taken once annually by the majority of the population for at least 14 years to reduce transmission rates and eradicate the disease (APOC, 2007). In order to achieve effective control of the parasite, 65% of the population must be treated with Mectizan™ yearly (APOC, 2013).

To ensure a sustainable administration of this drug in affected communities, the concept of Community-Directed Treatment with Ivermectin (CDTI) was developed. A sustainable and cost-effective way to bring onchocerciasis treatment to communities (the APOC program spent only $112 million on its interventions in 16 countries between 1995-2007 (APOC, 2010)), CDTI

empowers communities to strengthen their own health systems while working towards the elimination of a public health threat.

The concept of CDTI operation is as follows: A health worker proposes the CDTI program to the community's chief and population, who then democratically choose community members who will serve as Mectizan™ distributors (Community-Directed Distributors, or CDDs). Following this, the community chooses a date for the training of distributors who will after conduct a census of the community. After the community as a whole chooses dates for distribution of ivermectin, CDDs distribute the drugs and monitor for side effects. CDDs are trained to treat minor reactions and refer more severe cases to the health center. The distributors also keep records of distribution of the drug which are monitored by health workers (APOC, 2007; APOC, 2010).

The APOC and its CDTI program have been largely successful. By 2013, ivermectin coverage had reached a population of 99.4 million eligible individuals in participating countries, up from just 1.5 million in 1997. This has resulted in a therapeutic coverage of 76.4%. All but three of the twenty-four APOC countries have reached control-level therapeutic coverage rates of at least 65% (APOC, 2010; APOC, 2013).

Problems in the Meme River Basin

CDTI has not however been successful across the board. In 2015, Wanji reported a continued hyper-endemic prevalence of microfilariae in the Meme river basin area of South-West Cameroon (52.7%). High ongoing transmission rates were also observed despite annual CDTI treatment of over a decade (Wanji *et al.*, 2015). A prevalence of this severity is puzzling in light of APOC reports of a therapeutic coverage rate of 80.3% (or elimination-level coverage) in Cameroon (APOC, 2013).

Inconsistencies in statistics raise a number of questions that demand answers. Is CDTI truly effective to eliminate onchocerciasis in the Meme river basin area, and why or why not? Is this program being implemented correctly, how and at what levels? What contextual factors in the Meme river basin area have an impact on onchocerciasis control? Are the APOC, Wanji, or both statistics inaccurate?

Wanji and colleagues have already answered some of these questions. In their cross-sectional study comparing the Meme river basin to two other river basin areas in South-West Cameroon, they discovered that the Meme had the highest entomological indices with a 4.6% infective and 10.6% infection rate of black flies. This was compounded by a number of third-

stage *O. volvulus* larvae found in the heads of female *Similium* flies ranging from 51-542 times the expected level for a CDTI participant community. Wanji attributed such results to the long rainy season (8 months) in the Meme river basin, as well as the hilly terrain which promotes the rapid flow rate of rivers and long periods of *Similium* breeding. Together, these result in the continued transmission of onchocerciasis (Wanji *et al.*, 2015).

Wanji also noted that that the *Similium* flies in the Meme river basin are of the *S. damnosum s.s.* and *S. squamosum A* and *C* varieties--species which have exhibited the "limitation" phenomenon. This phenomenon describes the restriction of the quantity of microfilariae ingested by vectors, thereby ensuring a greater probability of vector survival and transmission of the parasite to humans. The research team suggested that this phenomenon may undermine the effectiveness of CDTI or require an onchocerciasis-control strategy that incorporates more elements than mass ivermectin therapy alone (Wanji *et al.*, 2015).

Finally, the Wanji study noted that the Meme area has no pipe-borne water, and communities are built near rivers. This obligates Meme habitants to spend more time by fast-flowing rivers during daily activities. Wanji suggested that the proximity to and time spent around the Meme encourages a greater exposure to black flies and onchocerciasis infection (Wanji *et al.*, 2015).

The Present Study

Despite Wanji's analysis of environmental, parasitological, and entomological factors affecting onchocerciasis levels in the Meme river basin, questions remain. Specifically, given the large gap between reported overall CDTI performance in Cameroon and these recent prevalence findings in the Meme river basin, the need to concretely understand the CDTI situation and related contextual elements is clear. The present study thus seeks an answer to the following question: what factors exist in the Meme river basin which may hinder onchocerciasis control in the context of CDTI?

For this study, the Kombone Health Area (KHA) within the Meme river basin area was chosen for analysis. This choice was an extension of a micro-project conducted in KHA by six Master students coming from the *Université Libre de Bruxelles* (ULB, Belgium) and University of Buea (UB, Cameroon) which sought to explore, among other themes, whether or not the population in this area was participating in CDTI and why or why not. This micro-project was elaborated within the "Strengthening the Onchocerciasis Elimination Programme in Cameroon" research-for-development project conducted by ULB, UB, and the *Université Catholique de Louvain* (UCL, Belgium).

The micro-project focused specifically on KHA as the area had already been participating in onchocerciasis-specific research conducted by UB. KHA is the largest health area in the Mbonge health district and contains 14 rural villages for a population of 35,962 habitants. The area is co-endemic with loiasis (*Loa loa*) with an estimated prevalence of 60% (Wanji *et al.*, 2015). CDTI has been taking place in the health area since 1995.

Currently, no study exists which explores the contextual community and/or organizational elements which impact CDTI success in the Meme river basin area. Furthermore, there are no guidelines which seek to help Meme communities combat factors which may impede onchocerciasis control.

The objectives of this study are thus as follows:

1. Identify attitudinal, behavioral, and organizational aspects in the Kombone Health Area of the Meme river basin which may have an impact on CDTI success
2. Elaborate a set of recommendations for community-oriented action to improve effectiveness of onchocerciasis control

Hypotheses

1. CDTI in KHA is not implemented according to APOC norms
2. Negative side effects of Mectizan™ deters the population from taking ivermectin within the context of CDTI
3. The KHA community has a set of behaviors which impedes CDTI effectiveness
4. The KHA community has a set of attitudes which impedes CDTI effectiveness
5. There is insufficient knowledge about onchocerciasis, Mectizan™ and CDTI which impedes the CDTI effectiveness

Materials and Methods

Study Design

In order to explore the contextual factors which may hinder CDTI effectiveness in the Meme river basin area, a semi-inductive approach was used.

Data was collected in two ways. The first was via unstructured interviews with the population in KHA. Secondly, focus groups with CDDs were conducted. The interviews and focus groups sought to understand the reality of onchocerciasis control efforts from the perspective of local habitants.

Study Site

All interviews and focus groups took place in KHA, discussed above.

Interviews

Interviews comprised of 6 broad questions were administered to assess attitudes, knowledge experiences, and behavior surrounding onchocerciasis and CDTI.

Interviewees were either onchocerciasis-positive "independent secondary school students" or adult family members of onchocerciasis-positive "dependent secondary school students". "Independent secondary school students" were defined as students in KHA aged from 10-20 who make their own healthcare decisions. "Dependent secondary school students", also aged 10-20, rely on adult family members to make their healthcare decisions for them. This selection method of participants was a function of convenience, as another branch of the micro-project in which this study was completed sought to determine the prevalence of onchocerciasis among secondary school students in KHA. The dependent/independent student classification was employed in order to assure that all interviewees were capable of responding to questions.

One-on-one interviews were conducted with onchocerciasis-positive independent students at their schools. Group interviews were conducted with available adult family members living in the same home as non-independent students at their homes. Given African social dynamics (De Bloganqueaux & Sagbo, 2012), group interviews were conducted out of contextual necessity.

Interview guide. A non-structured interview guide was developed based on elements found in relevant literature (see "Annex 3"). In order to elaborate the guide, Cible+, Google Scholar, and PubMed database searches were conducted during November 2015. The aim here was to collect articles exploring factors which may have an impact on CDTI quality in contexts similar to the study area.

The inclusion criteria used was that articles treated a mass drug distribution program in an African country and were published within the past five years. Search terms included "onchocerciasis", "attitude", "evaluation", "behavior", "belief", "health system", and "CDTI". Journal articles were retrieved from diverse fields including anthropology, sociology, and public health. Each article's bibliography was studied in order to identify additional sources.

All articles were read in full and evaluated for pertinence. In total, 5 relevant articles were kept (Brieger *et al.,* 2012; Okeibunor *et al.,* 2011; SSemanda *et al*., 2012; Yirga *et al*., 2010 ; York *et al.*, 2015). The main findings of each article were recorded in a table and used to structure interviews. Components contained in the final interview guide included perceptions of and experiences with onchocerciasis, its causes and consequences, CDTI, CDDs, social pressures related to CDTI participation, and Mectizan™ use.

This interview guide was validated by a Cameroonian medical doctor pursuing research in ivermectin distribution, a Cameroonian anthropologist, and an expert in public health sociology conducting research to strengthen the APOC in Cameroon.

Sampling. During the prevalence portion of the micro-project, participants filled out a questionnaire form that was used for sampling purposes. The form was designed to assess age, socio-economic status of the student's family, (in)dependent status in terms of health decisions and lifetime number of Mectizan™ doses. Other elements considered in sampling were onchocerciasis status and microfilarial load per skin snip--both determined during the prevalence branch of the micro-project.

To be included in the potential interviewee pool, students must have had a positive onchocerciasis result and a Mectizan™ dosage history less than age minus 5 years. This dosage rate was determined based on the age for which children are eligible to begin taking ivermectin within CDTI (5 years) (APOC, 2012) and thus reflected a lack of adherence to the program. Of the 598 students screened during the prevalence study, 336 were eligible to be considered for interviewing.

Of those who met inclusion criteria, 30 students were chosen to be contacted for interviews via consensus by a team consisting of a Cameroonian anthropologist (UB), a Cameroonian medical doctor who works in CDTI research (ULB), and two public health graduate students (ULB). Considerations for this selection included socioeconomic status, age of affected child, size of family, level of adherence to CDTI, geographic location, number of microfilaria counted per skin snip, and the presence of contradictory questionnaire responses. The thirty interviewees were selected in order to be both representative of the sample and to highlight particularly interesting cases.

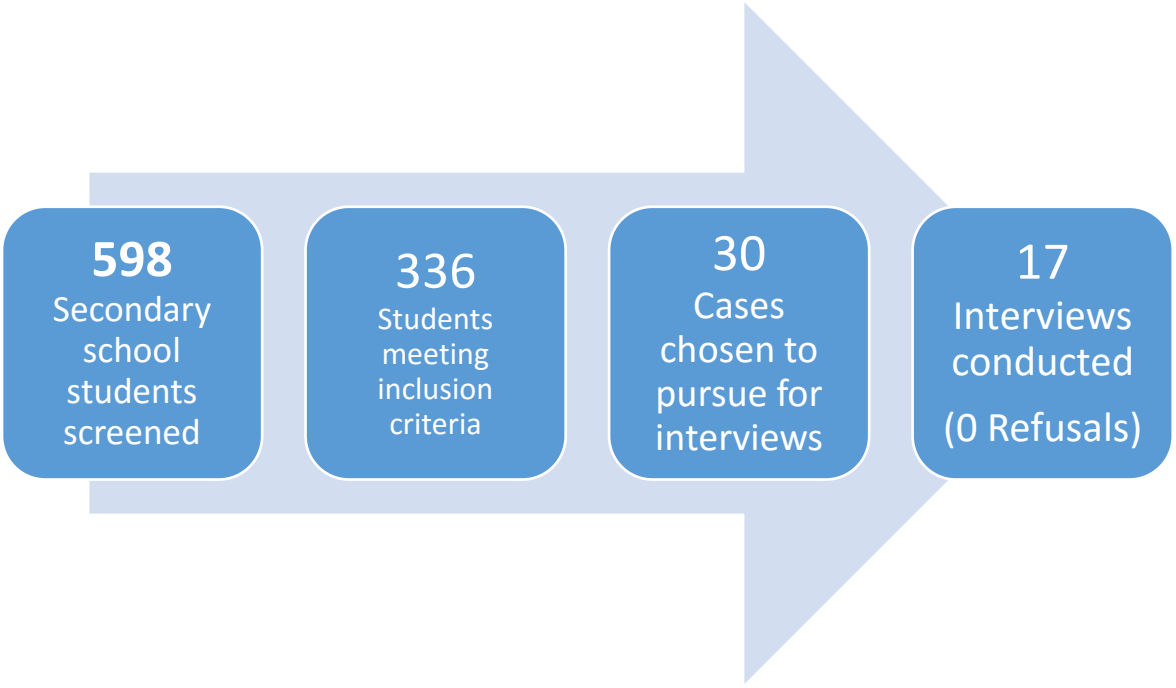

Figure 1. Visualization of the selection process for interviews.

Execution of interviews. Interviews were conducted on 2-4 March 2016 in 'Pidgin English', the local language of interviewees. Special attention was given to interviewers' body language and formulation of questions to assure neutrality and avoid the suggestion of responses to participants.

In total, 17 interviews were conducted before the research team agreed that it had reached saturation of data. No requests for interviews were denied.

Analysis of interviews. As interviews were conducted in Pidgin English, all interviews were transcribed word-for-word and then translated into English in preparation for thematic analysis. Interviews were analyzed for content by research theme (attitude, behavior, and organization) and then classified by hypothesis. After, all information was organized into a table, condensed by concept ("category"), and analyzed to understand its underlying meaning. Interpretations of interviews were validated by two additional researchers.

Focus Groups

Guided focus group discussions (FGDs) were conducted with community distributors of ivermectin to understand the reality of the CDTI program in Kombone Health Area. These discussions were held at the KHA health center in groups of five participants at a time.

FGD structure. The focus groups were administered as a collective exercise. With the guidance of an animator, CDDs participated in the elaboration of a model of a patient's journey through

the CDTI program (a qualitative adaptation of the Piot model (Piot, 1967)) and identification of roadblocks at each step during this journey.

The Piot model was developed in 1967 as a method to analyze the journey that a patient must take through a health program to receive effective treatment and determine the statistical probability that he will successfully complete all requisite steps. This model is useful to identify dysfunctions in a health program and understand the gaps between its theoretical implementation and reality. FGDs specifically drew inspiration from Dujardin's qualitative adaptation of the Piot model which identifies roadblocks to patients reaching effective treatment of tuberculosis (Dujardin *et al.*, 1997). The present study's approach remains novel in that such a model has never been used to qualitatively evaluate a disease control program via stakeholder perceptions.

The output of FGDs was a poster board which was developed via participant consensus to reflect the key steps and roadblocks identified during the conversation. In order to assure that saturation would be reached, the number of FGDs was not established *a priori*.

Materials. A focus group guide based on the same review of literature described for interviews plus the CDTI norms outlined in APOC documents (APOC, 2010) served as a reference to structure FGDs (see "Annex 4"). Elements debated during discussions were: the real CDTI process in KHA versus the normative one prescribed by the APOC, the ideal population journey to reach onchocerciasis control, and difficulties encountered at each phase by the population and CDDs.

Participants were also provided with a short, one-page primer on the Piot model, which included the work of Mumba on malaria (Mumba, 2003) to help them understand the focus group activity (see "Annex 5").

Like the interview guide, the focus group guide and Piot primer were validated by a Cameroonian anthropologist, a Cameroonian medical doctor conducting research in CDTI, and an expert in public health sociology conducting research to strengthen the APOC in Cameroon.

Participants. Inclusion criteria to be admitted into FGDs was having been an active CDD for more than one CDTI cycle. A convenience sampling was used to recruit participants.

Execution of focus groups. FGDs were held on 2-4 March, 2016 in Pidgin English. A total of four FGDs with five CDDs each were held (20 overall participants). In addition to the animator guiding the group activity and discussion, a moderator and two observers were present to assure that each participant had an equal voice and that all nuances were perceived. Focus

group discussions continued until participants felt that saturation had been reached for the session.

Of the four groups, the first one served as a "pilot" group which allowed the research team to adjust subsequent discussions for clarity. The outputs (posters) of groups two and three were combined into a single document which was presented to group four. Group four served to validate the outputs of groups two and three and added further dimension to the model patient journey and roadblocks elaborated during the earlier discussions.

After the fourth "validation" focus group, the team agreed that saturation of information had been reached.

Analysis of focus groups. For this study, the focus group outputs (poster boards) were analyzed. The common elements between the outputs of groups 2-4 were reworked into a single patient journey and set of roadblocks (see "Annex 6"), which was validated by KHA's head nurse. This final output was evaluated and organized into a table by hypothesis.

Ethical Considerations

The interviews and focus groups were held as a sub-branch of the "Strengthening the Onchocerciasis Control Program in Cameroon" project. This program received ethical clearance from the *Comité d'Ethique Hospitalo-Facultaire* of UCL, the *Comité National d'Ethique de la Recherche pour la Santé Humaine* (Cameroon), the *Ministére de la Santé Publique* (Cameroon), and the Regional Delegation of Public Health for the South-West (Cameroon) (see "Annex 1").

Prior to interviews and focus groups, the nature of the study was explained to all participants. Major participants gave explicit verbal consent to be recorded. Minor participants gave explicit oral consent, and written consent was also sought from their guardians (see "Annex 2"). All participation was strictly voluntary.

Interview transcriptions were completely anonymized for analysis within the framework of the present study.

Results

The following results are presented in function of the major themes identified during analysis.

Side Effects

Analysis of interviews revealed two main categories related to ivermectin side effects: fear of adverse reactions and the high economic and academic risk of these effects.

The fear of severe side effects had an effect on both attitudes and behaviors concerning participation in CDTI for respondents. Notably, interviewees who were afraid of such reactions did not want to take Mectizan™:

> *"People will take this [Mectizan™]. And after some days, it makes their bodies to be swollen, and they are rushed to the hospital. That is why so many people are afraid to take Mectizan™."* - Grandmother, Interview 3

It should be noted that one interviewee described suffering from a severe reaction, but said she would nonetheless take the drug again due to its beneficial effects.

Participants also listed financial, academic, and work-related disruptions from Mectizan™ reactions as reasons for not participating in CDTI. Healthcare costs and lost school or work days were deemed too big a sacrifice to take the medication:

> *"During the farming season, [farmers] cannot take [Mectizan™] because it might disturb their work. They may not have the strength to work."* – Uncle, Interview 7

FGDs confirmed that the prospect of hospitalization due to severe reactions to ivermectin can deter community members from taking the drug.

Community Attitudes

Concerning attitudes, data evaluation identified specific labels for community attitudes surrounding Mectizan™, CDTI, and CDDs.

Mectizan™. Four overall categories were identified concerning Mectizan™ attitudes during interviews: positive regard of the medication, perception that it is effective, fear of the medicine, and social network regard. During FGDs, CDDs independently shed further light on these categories.

Mectizan™ was so largely considered a "good" drug which is effective to treat onchocerciasis (or "filaria" as it is called by the community) symptoms during interviews that only one participant doubted its effectiveness:

> *"Mectizan™. It's the best treatment. […] It's because when you drink it, there are some people who have the filaria in the blood. So like Mectizan™ will help remove it physically."* – Mother, Interview 1

In addition to onchocerciasis, many interviewees discussed perceptions that ivermectin is effective for treating *all* illnesses, a faulty idea which was claimed to be propagated by CDDs:

> *"The Mectizan™ expels every illness found in the body when it is drunk. It removes any illness found in the individual."* -- Mother, Interview 2

Although the general perception was that ivermectin is a good and effective medicine, CDDs reported that many community members believe that they should not be made to pay 100 Cameroonian Francs (€0.15) for the drug. CDDs also mentioned that certain habitants of KHA do not feel it necessary to take Mectizan™ without specifically suffering from onchocerciasis symptoms.

Another prevalent attitude during interviews was fear surrounding Mectizan™. Community members reported fear of participation in CDTI without guidance from a doctor, of the drug's side effects, and of ingesting the medicine. These fears were apparently fueled by "horror stories" circulating in the community of people suffering severe side effects (e.g.: eyes nearly popping out of head), permanent damage, or death after ingesting Mectizan™:

> *"There was a man here who had problems with his eyes, and they were told that when you drink Mectizan™, it will make the eyes and the sight to be clearer. Instead of making his eyes to be clearer, it instead made him to be blind. So this man does not see again. This has made many people shy away from Mectizan™, because they see the symptoms that comes out of the body of the individuals in the community."* – Grandmother, Interview 3

During FGDs, CDDs suggested that even a single adverse experience in a village could negatively impact the entire community's perception of the onchocerciasis drug and inspire fear.

On a more community-oriented scale, there seemed to be a mix of positive and negative perceptions. Interviewees reported both their social networks encouraging them to take Mectizan™ or having received or witnessed judgement and ridicule for taking the medicine:

> *"My friends and family say [Mectizan™] is a good tablet."* – 20-year-old male, Interview 17

> *"The community said many negative things about her, and I went and asked her. She told me that is because she took Mectizan™, and this is what the people were saying."* -- 18-year-old female, Interview 13

CDTI. Categories identified concerning attitudes towards CDTI included positive regard of CDTI and negative regard of CDTI. Interviewee attitudes were more or less equally split between the two. Here, CDDs also highlighted community attitudinal elements which detract from the program's success.

Among those with positive attitudes towards CDTI, it should be noted that there was very little demonstration of understanding the long-term and community benefits of CDTI; positive attitudes were mostly based on individual and immediate benefits, with little to no mention of wider benefits:

> *"When I take Mectizan™, the filaria will get finish and it will not itch again."* – 10-year-old male, Interview 6

Negative feelings and wariness towards CDTI were rooted in the desire to consult with a doctor before taking Mectizan™ from CDDs, a lack of resources available for the program (i.e.: anti-inflammatories available in case of side effects), and an overall distrust of the program:

> *"When the community sees the CDTI personnel distributing the drug they say that it is not real drugs. They say that until they go to the hospital they will not believe in it. You also have to understand that the world of today is evil and people are afraid that distributors carry wrong drugs. So it has made the people skeptical… So they prefer to go to the hospital and collect."* – 18-year-old female, Interview 13

CDDs confirmed this general culture of mistrust, mentioning also that some community members think that census information will be used for political purposes.

CDDs. Similar to CDTI-related attitudes, categories for CDD-related attitudes were positive regard for CDDs and lack of trust of CDDs. Results contained both widespread positive attitudes towards the volunteers and a suspicion of their competence or character.

Positive attitudes towards the CDDs were rooted in perceptions that they were kind, support doctors, work well, help the community, and help to eradicate onchocerciasis from the locality:

> *"[The CDDs] do a great job. They are fine! They help to eradicate filaria and stop those who have it already."* – 17-year-old male, Interview 12

Two participants expressed their trust for CDDs based on the fact that they are sent by the government:

> *"[The CDDs] know how. The government knows how to do the sharing. The government knows its work. If they know that these boys they are sending to give us Mectizan™ are capable of doing it, we will take from [them]."*
> – Father, Interview 8

For the six participants who demonstrated a lack of trust in CDDs, they mainly citied their preference for doctors to distribute Mectizan™ to the community. Doctors were seen as more trustworthy and better able and equipped to handle complicated situations and side effects. Some participants said they would or did participate in CDTI after the approval of a doctor. For two participants, information given by CDDs was not enough to be confident to take Mectizan™ during CDTI:

> *"[The CDDs] don't sensitize us about the reactions. […] When I tried to ask, he told me that Mectizan™ is the kind of drug that has the power to kill you, but that he had never thought of it. If you cannot sensitize me about Mectizan™, I cannot take it from you. […] I will take Mectizan™ from a doctor. […] I prefer to take it from a doctor who will sensitize me about the drug. Then I can take it. But if they are unable to instruct me on how to take it, then I will not take it."* – Older brother, Interview 6

It did not seem that CDDs were sensitive to these community perceptions during FGDs.

During FGDs, it was brought to light that pre-existing conflicts between tribes may drive negative attitudes towards CDDs originating from certain ethnic groups.

CDTI-Impacting Behaviors

Three categories of behaviors impeding the effectiveness of CDTI became evident during interviews: forbidding or discouraging others from participating in CDTI, applying Mectizan™ topically, and not participating in the program. FGDs confirmed these behaviors and listed additional potentially problematic behaviors in the community.

All problematic behaviors regarding CDTI did not however stem from the community itself; both FGDs and interviews identified CDTI-undermining behaviors also coming from CDDs. Interview categories for CDD behaviors included: failure to give satisfactory information, not reaching every home, and failure to provide follow-up treatment.

Community behaviors. For behaviors originating from the community, cases of parents discouraging or forbidding their children from CDTI participation were found for both secondary school students whose parents make their healthcare decisions for them and for those who make their own healthcare decisions:

> *"It is because when I want to drink [Mectizan™], my grandmother refuses that I should not take it."* – 14-year-old female, Interview 1

Reasons for some community members not ingesting Mectizan™ but applying it topically to reduce dermal symptoms included a belief that this is effective to treat severe onchocerciasis and a fear of ingesting the drug:

> *"They are afraid to drink [Mectizan™]. So they prefer to grind it and put it inside the oil. The filaria that is on the skin, it scatters it."* – Uncle, Interview 14

During interviews, community members listed many specific reasons for not participating in CDTI. These included: witnessing others' negative experiences, fear of or having experienced severe negative side effects, economic and academic consequences of side effects, a lack of information from CDDs, not trusting CDDs, not feeling the need to take Mectizan™ (i.e.: not being sick), not being told by a doctor to participate in the program, and preferences to receive Mectizan™ from a doctor:

> *"As for me, I took [Mectizan™] once. When I took it, I suffered the effects for one week and then I went to the hospital. I was given a cooler which helped me. Since then, I have not taken it again."* – Uncle, Interview 07

> *"I will only like to take [Mectizan™] during holidays and not school hours."* – 20-year-old male, Interview 17

> *"No, [I have never drunk Mectizan™], because I was not sick."* – 15-year-old male, Interview 11

> *"[Mectizan™] will disturb [my granddaughter]! I will not have the money to take her to the hospital. Because the body gets swollen and it cracks and she has wounds. Wounds all over her. When or if you don't have money in such a case, it will be a big problem."* – Grandmother, Interview 1

FGDs complemented this information by explaining that one person's negative Mectizan™ experience could deter an entire community from participating in CDTI. CDD discussions also confirmed that the prospect of time lost from work or school was enough to discourage many from taking ivermectin during distribution periods.

Further community CDTI-impeding behaviors identified during focus groups included refusal to pay 100 Cameroonian Francs to CDDs for treatment, accept Mectizan™ from a CDD originating from a conflicting tribe, participate in (or give wrong information during) censuses, or follow protocol (ex: not consuming alcohol after taking ivermectin to avoid adverse effects).

It should be noted that some of these community behaviors branch from the disruptive side effects discussed above. This is explored further in the "Discussion" section of this paper.

CDD behaviors. During FGDs, CDDs mentioned their failure to follow norms during censuses, distribution, and follow-up of CDTI. Participants attributed this in part to program activities taking place during the rainy season thus creating traveling difficulties on muddy roads and damaging paper-and-ink records. CDDs further explained, however, that their lack of following protocol was mostly due to time constraints caused by a combination of personal work responsibilities (namely tending to farms during the peak cacao season) and large populations of responsibility. These behaviors were confirmed by interviewees who claimed that unsatisfactory or no information was given to them by distributors concerning CDTI and Mectizan™, that CDDs did not reach every home, and that follow-up treatment by CDDs was not available as guaranteed by CDTI protocol:

> *"When I was taking [Mectizan™], they did not explain. They just give and went. I didn't know where I could see [the CDDs after a negative reaction to Mectizan™]. The people were just moving."* – 14-year-old male, Interview 10

> *"[The CDDs] give. They are passing, but I don't see them. I only hear about them."* – Grandmother, Interview 1

A further potentially CDTI-impeding behavior identified during FGDs was failure to distribute Mectizan™ to members of conflicting tribes.

APOC Norms

While some interview participants reported CDTI experiences that correspond with APOC norms (announcements of campaign periods, CDDs move door-to-door measuring and

distributing Mectizan™, and the community workers educate the community on Mectizan™), a significant number of normative problems were identified during data collection—as already discussed in the behavioral analysis above. These issues, however, encompass more than just behavior and extend into the realm of the program's organization. Norm-breaking categories identified during interviews were: not reaching all members of the community, problems with program communication, problems with education by CDDs, and problems with the "community-directed" aspect of CDTI. FGDs confirmed a number of these problems and offered organizational explanations for them.

For interviewees, reasons for exclusion from CDTI efforts spanned from knowing nothing about the Mectizan™ campaigns to having CDDs skip over their homes during distribution (five interviewees reported that CDDs had *never* come to their homes):

> *"I have never seen [a CDD] in my house. The only people I know are those who walk for Polio. […] I used to see the CDTI personnel, but they have never come to my house."* – Mother, Interview 4

CDDs attributed the omission of some households to not having enough time to reach the whole community and the layout of villages making it difficult to concisely define areas of responsibility. It should also be noted that one interviewee reported that follow-up care was not available to her after suffering an adverse effect from Mectizan™.

As far as CDTI-related communications, one interview responder reported that in Bombele village of KHA, there is no longer a person responsible for notifying the community about the start of CDTI:

> *"There are people [distributing Mectizan™]. It's just that our former youth president is no more the youth president when he used to be. He would alert the community about the distribution."* – Uncle, Interview 7

CDDs explained during focus groups that they feel that many community members receive little, no, or unsatisfactory information due to no fliers being distributed to the community and a reliance on town criers to spread information about CDTI.

Several interviewees also reported the community workers giving them unsatisfactory, insufficient or wrong information regarding CDTI. While two responders explained a distribution scenario void of any explanations or education, another two reported wrong information being given to them by CDDs pertaining to the uses and ingestion of Mectizan™:

"[CDDs] explain to us that this campaign… When you take it that you take this drug because it is not only for filaria, but for all diseases that could be in the stomach." – Grandfather, Interview 14

Responses by participants in both the interviews and focus groups suggested that CDTI in KHA is run by a more "top-down" approach than prescribed by the APOC:

"We only hear from the health minister who passes the order that these particular people will come around and distribute the drugs." – Great uncle, Interview 14

There were no mentions of the CDDs being elected democratically during interviews or focus groups, and the government-mandated timing of the campaign during the rainy farming season reportedly poses academic, financial, climatic, and logistical constraints for the community. Both CDDs and community members reported inconvenience at having to take time off of work during peak season to run CDTI or deal with Mectizan™ side effects.

One further finding concerning the implementation of CDTI according to norms was unveiled during FGDs: CDDs simply do not have enough time to supervise the ingestion of Mectizan™ of each community member. The time issue was a recurring element in CDDs failing to follow prescribed CDTI norms.

Knowledge Surrounding Onchocerciasis, Mectizan™ and CDTI

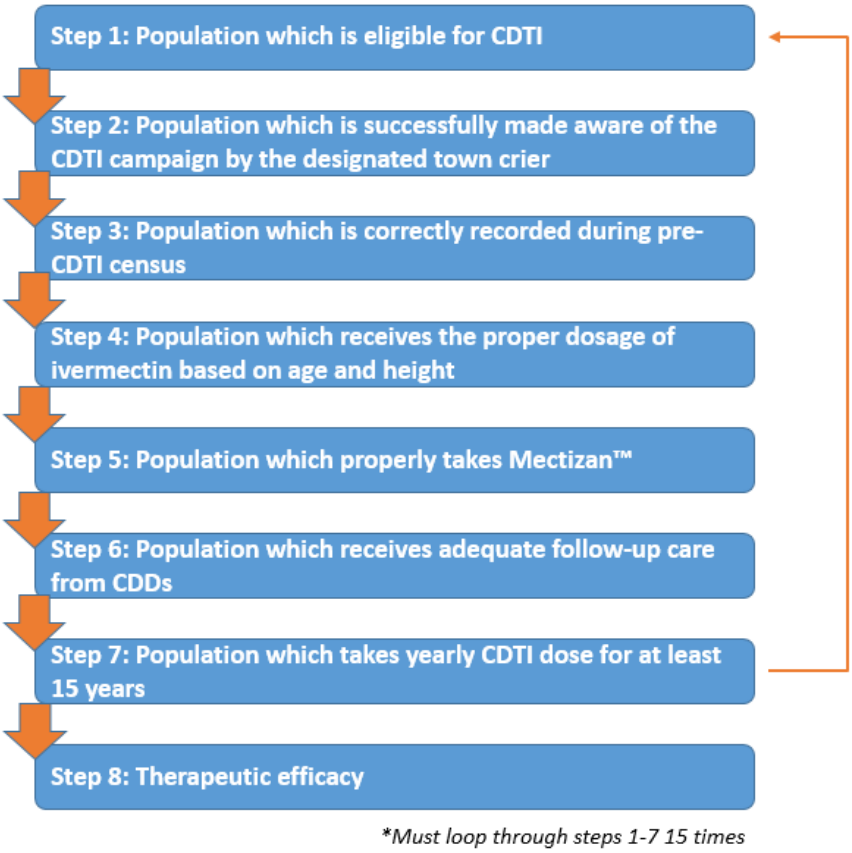

Figure 2. The patient journey model elaborated during focus group discussions.

FGDs revealed that CDDs had exceptional knowledge about onchocerciasis, Mectizan™, and CDTI. When asked to elaborate a model patient journey through the program, each group was capable of outlining an inclusive 8-step process and detailing the necessary items to conform to APOC norms. The specifics of CDD responsibilities (including education and communication), CDTI and the mechanism by which it works as well as Mectizan™ and its side effects were clear to the FGD participants. Despite this, widespread insufficient knowledge was observed among community members during interviews concerning onchocerciasis, Mectizan™, and CDTI.

Community knowledge.

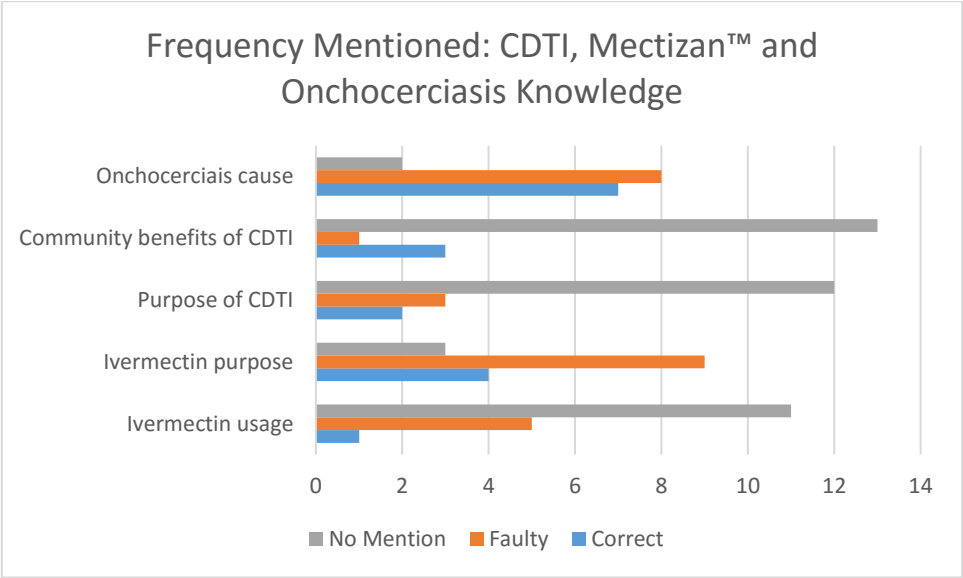

Figure 3. Distribution of faulty, correct or no knowledge of CDTI-related elements during interviews.

Onchocerciasis. The two categories identified during interviews for insufficient knowledge pertaining to onchocerciasis were: cause and consequence.

While participants demonstrated a general good understanding that insects cause filaria (although they were less able to identify specifically which insect) and that the vector is present by streams and in places of work, play, and study, several interviewees revealed a faulty understanding of the exact mechanism which causes onchocerciasis:

> *"The female mosquito lands on the excrement and then it bites you. Later, you scratch the place. By doing so, it penetrates the substances that it has deposited there and then you now contact the filaria."* – Older brother, Interview 6

> *"When standing on the water, the mosquito lays eggs on it. When he drops the eggs in it, he has filaria. He gives filaria by sucking the blood."* – 14-year-old male, Interview 10

Only one participant was able to explain the link between onchocerciasis-positive humans infecting black flies during blood meals who then transmit the disease to other humans.

It is of note that two interviewees guessed that food causes filaria, and three interviewees (one parent and two secondary school children) admitted that they had "no idea" what causes the disease:

"That filaria… I can't really tell you what causes it. I don't know what causes it. I don't know whether or what or… Whether it is mosquito or is what or… I can't tell!" – Mother, Interview 3

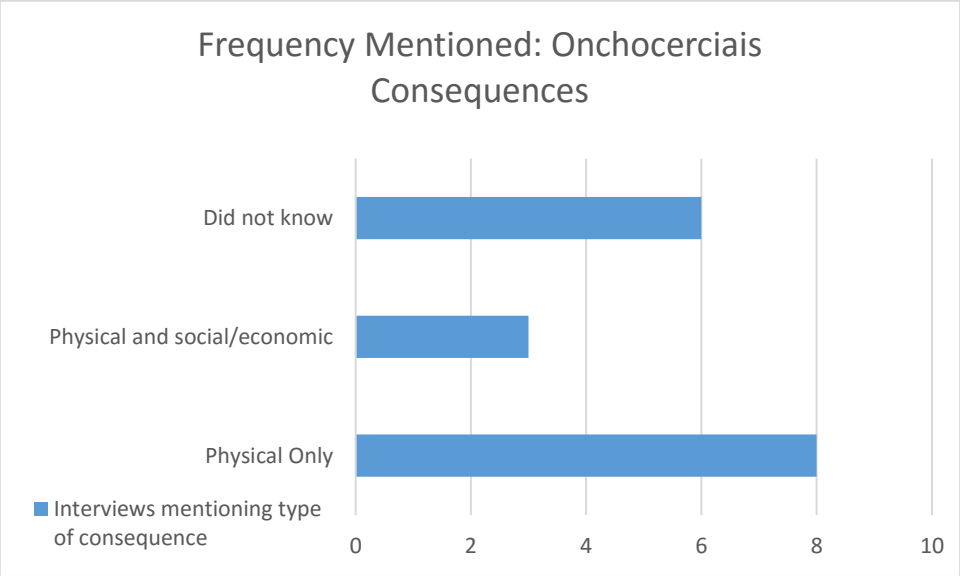

Figure 4. Knowledge of onchocerciasis consequences among the community.

In terms of consequences of the disease, interview participants demonstrated a limited knowledge. Although itching and rashes were often cited, respondents did not frequently list eye problems or blindness:

"We see it on the body. As a child begins to constantly itch the body, the body becomes black. I don't know how to go further." – Grandmother, Interview 3

Furthermore, there was nearly no demonstrated conception of non-physical consequences of the disease; only three interview participants mentioned academic or social impacts:

"It makes the students to be slow thinkers. He or she does not pick up fast. It also makes some of the students who have excess of this filaria to have itching eyes and watery eyes. This, it makes the child not to sight the board well." – Older Brother, Interview 3

"Nowadays, men mostly love ladies who are clean and neat physically. They look at the outer appearance and not at the inner appearance. Then they look at your body who has many rashes, black spots… Some of them will refuse getting married to you." – 18-year-old female, Interview 13

Mectizan™. Categories pertaining to insufficient knowledge of Mectizan™ were defined as follows: (contra)indications, side effects, and purpose.

For (contra)indications of the medicine, two participants thought that Mectizan™ was "not for children". Of these two cases, one cited children under 12 as ineligible for taking Mectizan™, and the other, who was aged 17, believed the drug was not appropriate for him due to his age. Additionally, contradicting and faulty information pertaining to in which situations Mectizan™ is helpful was apparent; one participant claimed that Mectizan™ will "disturb" someone who takes it without having filaria, while another claimed that taking the drug while having visible filaria symptoms is "not good".

Typical Mectizan™ side effects (swelling, itching and rashes) were generally well-known in the community, but circulating rumors and misinformation were also grouped in here. Respondents also believed that ivermectin can cause permanent swelling, death, and blindness.

Pertaining to the purpose of Mectizan™, there was a prevalent belief that the medicine cures all illnesses:

> *"When they give you [Mectizan™] and you have any kind or type of illness including filaria, it will remove it on the body."* – Grandfather, Interview 3

This belief has been reportedly promoted by some CDDs, although FGDs did not confirm this. Only one participant claimed to have "no idea" what Mectizan™ was used for.

CDTI. The categories identified treating insufficient CDTI knowledge were: functioning of CDTI, purpose of CDTI, community benefits of CDTI, and CDDs.

During interviews, participants did not know or did not mention the mechanism by which CDTI works or why Mectizan™ distribution occurs once yearly:

> *"I don't know [why the distributors come once a year]."* – 16-year-old female, Interview 15

Only two participants were able to mention that CDTI reduces the rate of and eradicates filaria from the community. Interviewees otherwise tended to only list the personal and short-term benefits of CDTI:

> *"[CDTI] helps because when you drink the Mectizan™ and you have filaria, your body will swell and then after some four days' time, it comes back to*

its normal shape. Sometimes, your eyes will be swollen and itches, but after, it will not be itching again." – Great aunt, Interview 14

The interviewees seemed to lack understanding that CDDs are equal members of their community. CDDs were not once explained as democratically elected members of the community, and one participant thought they were doctors.

Discussion

The above results revealed several factors which stand to impact the efficacy of CDTI in KHA. The following discussion puts these findings into perspective with relevant existing research and public health theory before elaborating a set of recommendations to improve overall adherence, community ownership, and success of this program.

Ivermectin Side Effects

The study population indicated several Mectizan™-related side effects including: swelling bodies, pain, itching, gastrointestinal disturbances, and death. Save gastrointestinal disturbances—which could be due to a number of factors related to living in rural South-West Cameroon--these side effects are consistent to those listed in the literature (Oyibo & Fagbenro-Beyioku, 2003; Rothova *et al*., 1989). Participants evoked these side effects as reasons for not wanting to continue or for not participating in CDTI. These attitudes are consistent with the work of Njomo and colleagues who showed that the experience of adverse effects from Mectizan™ were associated with low compliance to CDTI programs ($p \leq 0.001$) (Njomo *et al*., 2012). Side effects in the community were also seen to breed rumors and horror stories, which have been shown to play a role in community reluctance or refusal to participate in CDTI (Haselow *et al*., 2003).

Adverse reactions to Mectizan™ are probably caused by an acceleration of normal processes which occur upon the death of microfilariae in the body (Burnham, 1993). At death, microfilariae release inflammatory compounds into the bloodstream of the host (Oyibo & Fagbenro-Beyioku, 2003). When large numbers of the parasite simultaneously die—such as after the ingestion of ivermectin—the high levels of inflammatory compounds cause adverse reactions in the patient. It should be noted, however, that Rothova *et al.* (1989) found that side effects tend to subside with continued treatment, hypothesizing that as the parasitic load decreases, so do adverse effects. This fact can be stressed in order to help reduce population anxiety around ingesting Mectizan™.

The APOC program treats ivermectin-related side effects up to three days after distribution. However, Burnham (1993) found that adverse effects can occur up to 14 days after ingestion of Mectizan™, bringing into question the appropriateness of this treatment window. It is also reasonable to assume that some ivermectin recipients in KHA delay the ingestion of the drug as interviews and FGDs explained that (1) Mectizan™ distribution takes place during economically and academically inconvenient periods and that (2) CDDs do not observe every resident taking their dose at the time of reception. A delay in ingestion further minimizes the window in which CDTI participants can seek care for side effects. It is therefore possible that those suffering side effects are unable to receive appropriate care, which may further deter community members from participating in the future.

Loa loa. Focus group discussions and interviews also described severe side effects in the community after taking Mectizan™ that were consistent with co-infection with *Loa loa* (including severe functional impairment and death). It should, however, be noted that while *Loa loa*-like reactions were reported, it is impossible to confirm their presence as no biological or clinical work was conducted during reactions for this study. In any case, these particular side effects in the community also promote rumors and fear surrounding ivermectin and CDTI.

There are a number of considerations to take into account concerning CDTI in *Loa loa*-endemic areas. WHO guidelines recommend not conducting mass treatment with Mectizan™ when population infection levels are above 20% (WHO, 2016A). This is because ivermectin ingestion with a *Loa loa* co-infection has been associated with severe impairment of mobility, encephalitis, severe hepatitis, and death (Boussinesq *et al.*, 1998; Gardon *et al.,* 1997; Veit *et al.*, 2006). While the exact prevalence of the disease for KHA is not available, the prevalence for the general Meme river basin area is estimated at 60% (Wanji *et. al*, 2015). This is three times higher than the WHO guideline and raises questions about the appropriateness of conducting CDTI in KHA.

Additionally, the elevated dangers of taking Mectizan™ while co-infected with *Loa loa* are well-documented. Gardon *et al.* studied the relative risk of developing moderate and severe side effects between *Loa loa*-infected and non-infected individuals in Cameroon. The team found that that the odds to have any reaction from Mectizan™ when *Loa loa* is present in the body is higher by a ratio of 1:20 (Gardon *et al.*, 1997). Especially considering the Wanji (2015) statistics, distributing Mectizan™ *en masse* to the population of KHA without having sufficient information on *Loa loa* prevalence and distribution could be considered inappropriate.

Finally, as previously mentioned, the APOC's CDTI program only takes responsibility for side effects up to three days after the date of distribution. However, Gardon *et al.* (1997) also found that *Loa loa*-related side effects may begin to manifest as late as seven days after the ingestion of Mectizan™, further calling into question the appropriateness of the 3-day treatment window.

Attitudes

The results above describe a general perception among respondents that Mectizan™ is effective to treat onchocerciasis. Positive attitudes towards the efficacy of ivermectin have been positively associated with high compliance during CDTI (Brieger, *et al*., 2012; Ndyomugyenyi *et al*., 2009). However, despite these encouraging perceptions, dissatisfaction, fear, mistrust, and a lack of valuing CDTI are prevalent attitudes in the community. All four of these elements have been shown to significantly decrease compliance in CDTI or other mass drug distribution programs (Njomo *et al*., 2012; Nuwaha *et al*., 2005; Rilkoff *et al*., 2013; York, *et al*., 2014). Future interventions should thus focus on improving attitudes in these areas to improve compliance (see "Recommendations").

In KHA, identified negative attitudes were shown to stem from not understanding aspects of the CDTI program including: to what purpose does CDTI serve, who exactly are CDDs, how dosages are determined, what the side effects of Mectizan™ are, why a doctor does not distribute the ivermectin, and for what information collected during the census is used. It is important to note that lower levels of knowledge surrounding mass drug distribution programs have been significantly associated with lower rates of compliance (Njomo *et al*., 2012; York, *et al*., 2014), highlighting the importance of sufficient information available to the public which responds to their needs and preoccupations.

The prevalent lack of understanding CDTI and its related elements in KHA raises questions about whether APOC norms (which include communicative and educational guidelines) are being sufficiently relayed to regional and local workers or if these norms can be realistically implemented. The CDDs' ability to create an inclusive patient journey model during FGDs suggests that the norms are properly communicated to CDDs. However, it is possible that contextual factors may interfere with their ability to properly communicate with and educate the community or that CDDs simply do not have the skills to effectively share their knowledge to program beneficiaries. This element is further explored in the "Norms" section of this discussion.

Also to consider is that the literature shows that perceived vulnerability to onchocerciasis plays a significant role in adhesion to CDTI (Ndyomugyenyi *et al*., 2009; Nuwaha *et al*., 2005; Yirga, *et al.*, 2010). This is consistent with the Health Belief Model (Strecher & Rosenstock, 1997) and studies on patient perceptions in compliance (Becker *et al*., 1979) which list perceived vulnerability to a disease as an important factor in adopting a health behavior. As this study did not explore perceived risk to onchocerciasis among the community, future research could focus on this to help evaluate whether perceived susceptibility is an appropriate area for intervention.

Behaviors

Similar to attitudes, two major factors seem to drive the identified CDTI-impeding behaviors of refusing to participate, discouraging others from participating, and applying Mectizan™ topically among community members. These factors are fear and mistrust of elements of CDTI (CDDs and Mectizan™) and a lack of understanding of the mechanism by which CDTI works—both already discussed in "Attitudes". This observed lack of understanding which drives fear and mistrust in the community and further reduces participation rates (Haselow *et al*., 2003) reflects a fundamental problem with providing pertinent, comprehensible information which responds to the needs of the community in KHA.

It should be noted that the cause of some non-participations in KHA also lies in organizational and community ownership issues. Many interviewees discussed being unavailable, absent or unable to take Mectizan™ on distribution dates due to work and school responsibilities or an inability to take time away from responsibilities to deal with side effects. The democratic election of distribution dates to accommodate the work and academic lives of community residents could serve to increase participation rates. Mistrust of CDDs could also be in part remedied by their democratic election.

It should also be stressed that the public consequences for individual non-participatory behaviors are of particular importance to CDTI success. If a part of the population remains infected with microfilariae due to non-treatment during distribution periods, transmission may continue in the entire community--thus undermining success for everyone (Brieger *et al*., 2012).

Of particular note is the finding that some community members are discouraging their families or social networks from participation in CDTI. Family members are the primary building block of social support networks and are the foremost providers of information (ex: encouragement, advice, and affirmation) (Sandstrom, 1998; Simich *et* al., 2003). They can thus have a profound

influence on health behaviors and decisions. In fact, Nuwaha *et al*. (2005), Rilkoff *et al*. (2013), and Yirga, *et al.* (2010) all found that those who received encouragement from their family to take Mectizan™ during CDTI are significantly more likely to be high compliers. Correspondingly, Brieger, *et al*. (2012) reported that low compliers were significantly more likely to report that they received discouragement from participating in CDTI.

The wider social network has also been shown to impact CDTI compliance. Other research has found that those who receive encouragement from religious leaders are more likely to comply to CDTI (Nuwaha *et al*., 2005), and high CDTI compliers are significantly more likely to have received encouragement to participate from their social network (Nuwaha *et al*., 2005; Rilkoff *et al*., 2013). Ensuring that positive attitudes towards CDTI is prevalent among families and social networks is fundamental its success.

Furthermore, community ownership of Mectizan™ campaigns has been heavily linked to higher participation rates in the literature (Amazigo *et al*., 2007; Wanji *et al.*, 2015; Yirga, *et al.*, 2010). It is thus important to mention that on multiple occasions, community members explained that Mectizan™ distribution takes place during highly inconvenient times for them (i.e.: the school year or the farming season), and zero interviewees or FGD participants mentioned a democratic election of CDDs. This brings into question just how "community-directed" CDTI in KHA is and lends to the argument that organizational issues of CDTI in KHA are undermining its success (here, by negatively impacting community behaviors).

Concerning CDDs, this study has determined that many behavioral issues (not reaching every house for census and distribution or educating community members) also in part stem from a non-community-elected distribution period. An apparent lack of community ownership here creates contextual difficulties in the way of environmental and economic conditions. As a simple matter of practicality, CDDs are unable to fulfil their duties in rainy conditions or when they must tend to their farms.

Especially in light of CDDs' demonstrated knowledge of the CDTI program, these identified organizational issues suggest that the root cause of CDTI-impeding behaviors is, in fact, organizational. However, it should also be considered that CDDs may not have adequate communication skills to respond to the community's needs and concerns--as evidenced by the community's dissatisfaction with information provided and lack of knowledge. This could also have a negative impact on CDTI-related behaviors. Future research should thus focus on establishing the limits of CDDs' communications skills to establish whether an intervention is necessary.

Norms

Community participation. As already discussed in part above, CDTI in KHA has been met with a number of organizational issues causing norms to not be respected.

In theory, there is supposed to be a high level of citizen participation and community ownership of CDTI programs with local citizens actively participating in most decisions. The APOC-prescribed level of participation for CDTI is consistent with rung seven of the Wheel of Participation (Arnstein, 1969). This is the "delegated power" level in which citizens obtain the majority of decision-making power (time, place, method of distribution, choice of CDDs). The benefit of this high level of community ownership is that the legitimacy of decisions and efforts made by powerholders is increased; local citizens are better able to realize their capacities to generate positive change and control their personal health outcomes—or to become empowered; and programs are more effective as target populations can offer a specialized expertise of the context, terrain, feasibility, and effects of a given program (Massé, 2005). However, this study's results show that in practice, KHA is currently at the third rung in the Arnstein model—the "informing" level. In KHA, community members have the option to be heard in theory, but the reality of the situation offers no real assurance that their views or needs will be taken into account in decision-making. Information provided at this level is offered too late to allow citizens to have a real impact on the planning, implementation, or evaluation of CDTI in their community (Arnstein, 1969). This reflects a "top-down" approach to CDTI and poses several demonstrated obstacles to the program's success.

Because Yaoundé (the administrative capital of Cameroon) mandates distribution according to its own schedule, census and distribution periods fall during the rainy farming season in KHA. This renders CDTI activities logistically and environmentally difficult for CDDs and community members—as already discussed in "Behaviors". The delegation (*not* community election) of CDDs may also fuel the distrust of distributors and their qualifications in the community and/or the apparent preference for doctors.

Besides failing to meet APOC norms, the top-down approach of the Cameroonian government may be undermining the program's ability to reach the largest population possible with treatment. The literature shows that when communities have higher levels of participation in CDTI—such as via the implication in the selection of CDDs and distribution dates—the program has greater compliance rates, success, and sustainability (Amazigo *et al*., 2007; Wanji *et al.*, 2015; Yirga, *et al.*, 2010). The WHO also affirms that community ownership of CDTI programs is

fundamental to their sustainability (WHO, 2000). Serious efforts should therefore be made to increase community ownership of CDTI in KHA.

Information – communication and education. Quality information to the public is a prerequisite for any meaningful public participation in health programs (Davidson, 1998; Massé, 2005). Reflecting this, APOC norms make provisions to assure that community members understand CDTI and its related elements and are adequately informed to maximize participation in all aspects. It is clear from interviews, however, that there is a gap between actual CDTI education and communication in KHA and APOC standards. This is problematic because without proper education and communication, community members do not see the importance of participating in CDTI, may maintain suspicions and propagate horror stories, and may not know how or when to participate in CDTI. This, in turn, undermines participation in and success of the program (Brieger *et al*., 2002; Brieger *et al*., 2012; Lakwo & Gasarasi, 2006; Njomo *et al*., 2012; Nuwaha *et al*., 2005; York *et al*., 2014).

Quality communication and education which respond to community members' needs and concerns would thus serve to make the CDTI program more transparent, quell fears, and assure that all community members are aware of census and distribution periods. This would, in turn, also serve to address other attitude and behavior problems identified in this paper and should thus be considered a priority. It must also be noted here that a simple one-way flow of information to community members is not sufficient. In order to truly promote a level of understanding which fosters participation in CDTI and health empowerment, information to the community must be presented in such a way as to foster critical thought, debate, and action (Bourhis *et al.*, 2005). For more on this, see "Recommendations".

Monitoring doses. Finally for norms, CDDs confirmed that time constraints make it impossible for them to monitor every community member taking Mectizan™ during CDTI. This raises numerous questions about the reliability of participation statistics coming from CDD registries. Are all those who receive Mectizan™ actually taking it? What, then, is the true proportion of KHA compliance for CDTI? When (if at all) are community members taking their doses of Mectizan™? Are levels of reported side effects truly accurate given the 3-days-after-distribution treatment timeframe? Further research should investigate these questions to better understand the situation in KHA.

Knowledge

Much misunderstanding among the community was reported in this study concerning the mechanism of onchocerciasis infection, appropriate use of Mectizan™, the mechanism by which CDTI works and its community benefits, and who CDDs and their specific competences are. This discussion has already explored possible causes for this including: community members not being present for communications and CDDs not having sufficient time or skills to educate program beneficiaries.

The consequences of insufficient knowledge surrounding CDTI and its elements, including a perpetuation of fears and rumors, lower levels of compliance, and the continuation of CDTI-impeding behaviors have already been discussed above. The role of sufficient knowledge in fostering positive attitudes towards and participation in CDTI was also already explored.

It is of primordial importance that the KHA community understands the basic etiology of onchocerciasis infection, the uses of Mectizan™, the expected side effects of Mectizan™, and the interest of participating annually in CDTI even if they feel well. This will help increase perceived vulnerability and have a positive impact on attitudes and behaviors (Brieger *et al*., 2012; Ndyomugyenyi *et al*., 2009). These factors therefore must be incorporated into future interventions.

Recommendations

As per the issues identified during FGDs and interviews--and in function of the implications present in the relevant literature--a set of recommendations specific to this study area has been elaborated below.

Empower the community. The entire concept of CDTI revolves around community ownership of the program. As discussed above, this has been shown to contribute to successful CDTI outcomes (Amazigo *et al*., 2007; Wanji *et al.*, 2015; WHO, 2000; Yirga, *et al.*, 2010). True community ownership of a health program is contingent upon the genuine participation of the public (Arstein, 1969; Davidson, 1998). Davidson illustrates what this entails in his Wheel of Participation:

- the program solves problems in partnership with the community during all phases;
- the community is allowed to make their own decisions on certain issues;
- the community is actively involved in the discussion of issues and action to take prior to decisions being made;

- community perceptions and opinions of existing services are genuinely considered during all phases of the program's conception, planning, implementation, and evaluation;
- and clear information the community needs or wants is available at all phases of the program (Davidson, 1998).

Communities are not simply able to assume these active consultative roles in the public sphere—they must be deliberately equipped and empowered to do so. The following section thus contains practical and relevant recommendations to empower the KHA community to take ownership of its CDTI program with the aim of improving its outcomes.

***High-quality information*.** Practical, high-quality information which addresses the concerns, needs and wants of the public while equipping them to engage in debate, critical thought, and action is a precursor to any meaningful public participation (Bourhis *et al.,* 2011). One way to transmit participation-promoting information is via educational initiatives, which are thus a recommended route for action.

Although simple, static education is not enough to empower citizens to assume responsibility for their own health outcomes, CDTI education designed to respond to the expressed fears, uncertainty, and rumors circulating in the community *can* offer a multifaceted opportunity for empowerment. The first facet here is the prospect of CDTI education to serve as an enabling tool to augment community participation. Secondly is its capacity to increase trust in the program and its elements while positively influencing community attitudes. Thirdly, tailored education can help community members better understand the various elements of CDTI. Finally, an added value of CDTI education is that it can augment perceived vulnerability to onchocerciasis—an important factor in CDTI compliance already discussed above.

This study's findings also identified a number of information topics which should be stressed in KHA. Education should focus on the CDTI purpose, process, and benefits, proper ivermectin use and expected side effects, and onchocerciasis cause and consequences. In terms of side effects, it may be useful to stress that adverse reactions gradually subside with each successive Mectizan™ treatment, disturbing the recipient less each time (Oyibo & Fagbenro-Beyioku, 2003). This can help to avoid program drop-out from those who experience adverse effects. Additionally, teaching families to be aware of early warning signs can also dispel fear from the community and help those who suffer negative effects receive proper treatment as soon as possible. This plays an additional role of bestowing responsibility onto community members, thus further implicating them in their own health outcomes.

Although other studies have suggested that CDDs can do CDTI-related education while making house-to-house visits (York, *et al*., 2014), it should be noted that the time constraints revealed in this study's context make this solution highly unrealistic for KHA. Other avenues for education should therefore be exploited.

In addition to education, communication also plays a large role in the dissemination of high-quality information. This study highlighted a number of communications issues which impede overall CDTI success in CDTI. To help improve CDTI-related communications in KHA, the dissemination of information should take place in function of the work schedules of local habitants. As seen in this study, conducting community activities during peak work seasons can prevent many residents from being implicated in important public health events. It may also be practical to provide high-quality, tailored information in schools and churches where large groups of residents are regularly present. As per the recommendations of CDDs during FGDs, messages could be reinforced and more uniformly disseminated via the circulation of flyers.

Additionally, CDTI-related communications should come from trusted members of the community (chiefs, head nurses, religious leaders). Results showed a community preference for these people, and research confirms that encouragement from community leaders can lead to improved CDTI adherence rates (Nuwaha *et al*., 2005). In response to the expressed concerns of the community, communications should clearly explain CDTI, important dates, what census information is used for, and the competences of CDDs as well as seek to increase trust in CDTI and CDDs.

Increase community direction. This study's results identified major problems with the "community-directed" aspect of CDTI in KHA. The program's reality, which does not respond at all to Davidson's (1998) description of genuine public participation, has led to apparent issues in its implementation.

Efforts should be made to ensure that the ivermectin distribution period is democratically elected by the beneficiary community. This will principally help to solve issues like being absent from distribution dates due to work and school and increase community ownership of the program. CDDs should also be chosen by means of democratic election. This will promote trust, grant legitimacy, and increase community ownership of the program. Seeking to run a CDTI initiative that specifically responds to APOC norms at the national, regional, and local levels will also help remedy the identified community-direction issues.

In order foster CDTI democracy, efforts should be made to mobilize and encourage citizens to participate in CDTI organization at all steps. This can be accomplished via establishing citizen

panels, community discussion groups, citizen representation at planning meetings, multi-stakeholder situation analyses, and regular socio-anthropological questionnaires and interviews (Bourhis *et al.*, 2011).

Here, special attention should be paid to including representatives of minority groups in committees. This will aid the community in finding solutions for effective drug distribution despite possible inter-tribal conflicts and assuring the representation of all residents' interests.

Manage side effects. Better managing ivermectin-related side effects would serve to decrease concerns around taking the medication in the community, increase confidence in the program and CDDs, and promote higher levels of continued adherence to CDTI. A number of practical steps can be taken to achieve this.

The practice of treating side effects for free only up to three days after ivermectin administration should be reevaluated. This is scientifically supported, as the studies of Gardon *et al.* (1997) and Ndyomugyenyi *et al*. (2009) showed Mectizan™-related side effects to appear as late as 14 days after ingestion. An enlarged free treatment window would also respond to and help reduce expressed anxieties around taking the medication in the KHA community.

CDDs should be equipped with a basic drug kit which contains analgesics and antihistamines so that they can treat minor reactions (Brieger *et al.*, 2012). This can help increase the community's confidence in the program as they will know that treatment is available in the case of possible side effects.

Additionally, CDDs and community health professionals should be trained to recognize the early signs of adverse effects and establish a community-designed action plan in case of severe adverse effects. Families should also be educated to distinguish between expected side effects and serious side effects in order to ensure that those suffering from severe effects are treated as soon as possible. They should also be educated on post-treatment alcohol consumption in order to avoid negative side effects (Haselow *et al*., 2003). Educational efforts of this variety would respond directly to the expressed concerns and fears of the community (i.e.: side effects) and is therefore consistent with the community-empowerment recommendations discussed above.

Special consideration should be given for those who have been previously confirmed to have severe cases of onchocerciasis (skin snip of more than 50 mf/ml). These people should be medically supervised when taking ivermectin due to the increased likelihood of adverse effects (Rothova *et al*., 1989).

Finally, CDTI beneficiaries should take Mectizan™ in front of CDDs. Distributors should under no circumstances leave doses behind for absentees as the date of ingestion (and thus window of free treatment) cannot be confirmed in this case. Furthermore, CDDs should take pain to write down the exact date and time of ivermectin ingestion for each recipient. Not only will this help better manage side effects, but it will also aid monitoring, evaluation, and research efforts in the future.

Loa loa. The WHO does not recommend conducting CDTI in areas where the prevalence of *Loa loa* is above 20%. As per the Wanji (2015) estimate of 60% infection rate in the Meme river basin area, KHA should ensure that *Loa loa* rates are within acceptable limits before continuing further with CDTI. Once it is assured that *Loa loa* prevalence is at an acceptable level, KHA can use methods such as RAPILO (WHO, 2016A) to identify infected community members with and disqualify them from that year's CDTI.

Efforts to reduce the rate of *Loa loa* infections would have far-reaching public health benefits. In terms specific to onchocerciasis control via CDTI, KHA community members would experience milder side effects and a lower incidence of severe reactions to Mectizan™ (Gardon *et al.*, 1997). This, in turn, could increase confidence in CDTI, decrease rumor-propagating horror stories and possibly encourage more people to "risk" taking Mectizan™.

As the exact prevalence in KHA is not available, future research should focus on establishing the *Loa loa* rate in each community in order to determine whether CDTI is appropriate. Further action can be planned from there.

Relieve CDDs' burden. This study revealed that CDDs are simply unable to reach every community member's home during CDTI given the size of populations to cover and work-related time constraints. To relieve the workload of CDDs, ivermectin could be provided at a central pickup station in each village every year. This form of distribution could turn CDTI into a special community event with villagers mobilizing and encouraging each other to participate and has been associated with higher coverage rates (Brieger *et al*., 2002). More CDDs could also be trained in order to lessen their proportional workload. The literature shows that higher CDD-to-habitant ratios are associated with an increased CDTI treatment rate (Amazigo *et al*., 2007).

Although Ndyomugyenyi & Kabali (2010) found no significant difference in coverage rates between communities where CDDs were paid and communities where CDDs were not paid, the economic realities of asking distributors to take significant time away from income-generating activities may necessitate monetary compensation. This further raises the question

of who should be responsible to compensate CDDs. It is important to consider that in other resource-challenged settings, even a small out-of-pocket cost for health services have been shown to dramatically limit access for the public (Kipp *et al.*, 2001; Kivumbi & Kintu, 2002; Nuwaha *et al*., 2005). It therefore stands to reason that CDD payment should come from the APOC program or the government and not as an obligation of those who accept the treatment.

Maintain and enhance CDDs' skills. CDDs play an essential role in the success of CDTI. It must thus be assured that their work both meets the needs of the community and encourages individual participation in the program. Although CDDs demonstrated that they are sufficiently educated about CDTI and its related elements, knowledge is not sufficient to meet these objectives. This was evidenced by the community's apparent lack of CDTI-related knowledge during interviews. Distributors should thus also be trained in communication techniques in order to effectively relay pertinent information to their assigned residents. Improved communications skills will make CDDs a channel for high-quality, empowering information to the public. Better communicators can also serve to both improve community knowledge levels (and indirectly, compliance rates (Lakwo & Gasarasi, 2006; Yirga, *et al.*, 2010)) and attitudes towards CDDs, CDTI, and Mectizan™. To ensure that CDDs are best providing the information that the KHA community needs, yearly refresher courses designed in function of expressed concerns (perhaps through a yearly community evaluation) can be held.

Equip CDDs. CDDs explained during FGDs that rains during CDTI activities cause difficulties in traveling house-to-house and damage census registers. The community also expressed dissatisfaction with the CDDs not having medications on hand in case of adverse effects to Mectizan™. Supplying CDDs with rain boots, rain coats, a simple medication kit, and register-protecting supplies (e.g.: waterproof bags) would be a significant contribution towards better achieving norms, improving community attitudes, relieving the CDD burden, and generally improving the quality of CDTI in KHA.

Study limitations. While this study is highly informative, it is not without its limits. First of all, this is a qualitative study which has no statistical work or biological confirmations to back up findings. Data collected thus reflects the perceptions and perspectives of community members and not objective realities.

Additionally, focus groups and interviews, although conducted in the native language of responders by trained Cameroonian researchers, were conducted in the presence of one or more Caucasian researchers. This could have caused respondents to give information they

deemed the “foreigners” would want to hear. The possible presence of a desirability bias is thus a factor which cannot be discounted when interpreting these results.

This study was conducted in a unique entomological, organizational, cultural, and epidemiological context. These factors make the results highly-specific to this community and may not be generalizable to other CDTI or mass drug distribution programs.

Finally, focus groups were designed via a convenience sampling, which may have led to an unknown selection bias or information that is not completely representative of the KHA reality. Furthermore, there was no demographic data available on KHA CDDs to help researchers understand to what extent the FGD participants were representative of their peers.

Future research. Although this discussion has already mentioned a number of pertinent paths for future research, a few more should be mentioned. First, quantitative research focusing on the themes identified here should be conducted to complement, quantify, and confirm findings.

Future studies should also seek to identify at-risk groups and their CDTI roadblocks in order to better tailor interventions to community needs. Focusing on these groups will help to reduce inequalities in terms of access, power-holding, understanding, and outcomes of CDTI, thus creating a healthier, more empowered community. “At risk” groups can be identified in terms of: non-participation in CDTI (decision-making and ingestion of ivermectin), reception and/or comprehension of CDTI-related information, and perceived vulnerability to onchocerciasis infection.

This study’s findings give good reason to doubt the reliability of CDD registers. Research should be conducted to establish real patterns of CDTI adherence and side effects in KHA. Information here could be used to evaluate the accuracy of CDD register books and whether further training or material support is necessary.

Finally, research should be undertaken to understand community attitudes towards the value and interest of participation in CDTI conception, planning, implementation, and evaluation. This can help identify intervention points to create a more pro-participation environment surrounding CDTI in KHA.

Conclusion

This study sought to identify the attitudinal, behavioral, and organizational aspects in KHA which may impact the success of CDTI and elaborate a relevant set of recommendations to

improve effectiveness of the program. Five hypotheses were used to structure qualitative research and analysis.

A number of important findings emerged: Possibly of most note is that this research revealed that CDTI in KHA seems to be run by a top-down approach, which is against the main participative philosophy of the program. This was shown to cause a number of logistical, environmental, and economic difficulties for the community and CDDs—negatively impacting the success of CDTI. Secondly, the KHA population expressed fear of ivermectin side effects which may bring discomfort, costly hospital bills, or a loss of work or study time as a reason for not participating in CDTI.

Knowledge surrounding CDTI and its related aspects was identified as a significant problem. Despite good CDD knowledge on these subjects, results showed an obvious lack of comprehension among KHA community members. Misunderstandings and misinformation were often cited as reasons for not participating in CDTI. Analysis also revealed negative attitudes in the community--including a lack of valuing CDTI, mistrust, and dissatisfaction—as a root cause of non-participation in CDTI.

CDTI-impeding behaviors in the community were identified to be driven by fear, mistrust, and misunderstanding of CDTI and its elements. However, it was also discovered that some of these behaviors are the results of organizational issues.

The exploration of these organizational, behavioral, and attitudinal aspects succeeded in bringing to light a number of important considerations which need to be pursued with further research. In the future, quantitative work in KHA can complement this study by focusing on: detecting at-risk groups for exclusion from CDTI, establishing the rate of participation at all steps in the program, and identifying the concerns, needs, and wants of KHA residents as patients and owners of their local CDTI program.

Context-specific recommendations elaborated here placed special emphasis on the participative aspects of CDTI, as local participation is one of the main pillars of the APOC initiative. In KHA, these recommendations should be evaluated and discussed by all relevant stakeholders—with a special emphasis on the community's participation—in order to identify paths for action that are the most relevant, pressing, and feasible. Professionals working in CDTI or mass drug distribution programs in other contexts can use these results and recommendations as a base to develop improve their own programs and increase community participation.

References

African Programme for Onchocerciasis Control. (2007). *Revitalising health care delivery in sub-Saharan Africa: The potential of community-directed interventions to strengthen health systems.* Ouagadougu: African Programme for Onchocerciasis Control - World Health Organization.

African Programme for Onchocerciasis Control. (2010). *Report of the external mid-term evaluation of the African Programme for Onchoceriasis Control.* Ouagadougou: African Programme for Onchocerciasis Control - World Health Organization.

African Programme for Onchocerciasis Control. (2012). *Curriculum and training on the community-directed intervention (CDI) strategy for faculties of medicine and health sciences.* Ouagadougou: African Programme for Onchocerciasis Control – World Health Organization.

African Programme for Onchocerciais Control. (2013). *The World Health Organization Year 2013 Progress Report.* Ouagadougou: African Programme for Onchocerciais Control - World Health Organization.

Albano, P., Barbell P., Bengraine, K., Brown, N., Dimar, A., Eckert, K., ..., & Prendki, G. (2010). *Lion's onchocerciasis control efforts in Cameroon.* Lions Club International Foundation.

Amazigo, U., Okeibunor, J., Matovu, V., Zouré, H., Bump, J., & Seketeli, A. (2007). Performance of predictors: Evaluating sustainability in commmunity-directed treatment projects in the African Programme for Onchocerciais Control. *Social Science & Medicine, 64*, 2070-2082.

Arnstein, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224.

Becker, M., Maiman, L., Kirscht, J., Haefner, D., Drachman, R., & Taylor, D. (1979). Patient perceptions and compliance: Recent studies of the Health Belief Model. In R. T. Haynes (Ed.), *Compliace in Health Care* (8th ed., pp. 78-109). Baltimore: Johns Hopkins University Press.

Bernard, R. (2011). *Research methods in anthropology: Qualitative and quantitative approaches.* (5th ed.). Lanham: Rowman Altamira.

Bourhis, C., Chantriane, A., Ferron, C., Vétel, L., Landuren, M., Briand, A., ..., & Sourimant, M. (2011). *Quand la promotion de la santé parle de la participation.* Bretagne: IREPS Bretagne.

Boussinesq, M., Gardon, J., Gardon-Wendel, N., Kamgno, J., Ngoumou, P., & Chippaux, J. (1998). Three probable cases of *Loa loa* encephalopathy following ivermectin treatment for onchocerciasis. *American Journal of Tropical Medicine and Hygiene, 58*(4), 461-469.

Brieger, W., Otusanya, S., Oke, G, Oshiname, F., & Adeniyi, J. (2002). Factors associated with coverage in community-directed treatment with ivermectin for onchocerciasis control in Oyo State, Nigeria. *Tropical Medicine and International Health, 7*(1), 11-18.

Brieger, W., Okeibunor, J., Abiose, A., Ndyomugyenyi, R., Wanji, S., Elhassan, E. & Amazigo, U. (2012). Characteristics of persons who complied with and failed to comply with annual ivermectin treatment. *Tropical Medicine and International Health, 17*(7), 920-930.

Burnham, G. (1993). Adverse reactions to ivermectin treatment for onchocerciaisis. Results of a placebo-controlled, double-blind trial in Malawi. *Transactions of the Royal Society of Tropical Medicine and Hygiene, 87*(3), 313-317.

Davidson, S. (1998). Spinning the wheel of empowerment. *Planning*, *1262*, 14-15.

Davila, A. & Dominguez, M. (2010). Formats des groupes et types de discussion dans la recherche sociale qualitative. *Recherches Qualitatives, 29*(1), 50-68.

De Bloganqueaux, S. & Sagbo, J. (2012). De l'usage des outils de la recherche qualitative en milieu rural ivoirien: Une analyse de l'influence du groupe social sur la strucutre de l'entretien. *Recherches Qualitatives, 31*(1), 6-28.

Dujardin, B., Kegels, G., Buvé, A, & Mercenier, P. (1997). Tuberculosis control: Did the programme fail or did we fail the programme? *Tropical Medicine and International Health, 2*(8), 715-718.

Evans, T. (1995). Socioeconomic consequences of blinding onchocerciasis in West Africa. *Bulletin of the World Health Organization, 73*(4), 495-506.

Gardon, J. Gardon-Wendel, N., Demanga-Ngangue, Kamgno, J., Chippaux, J., & Boussinesq, M. (1997). Serious reactions after mass treatment of onchocerciasis with ivermectin in an area endemic for *Loa loa* infection. *The Lancet, 350*(9070), 18-22.

Haselow, N., Akame, J., Evini, C., & Akongo, S. (2003). Programmatic and communication issues in relation to serious adverse events following ivermectin treatment in areas co-endemic for onchocerciais and *Loa loa*. *Filaria Journal, 2*(Suppl 1), S10.

Kipp, W., Kamugisha, J., Jacobs, P., Burnham, G., & Rubaale, T. (2001). User fees, health staff incentives, and service utilization in Kabarole District, Uganda. *Bulletin of the World Health Organization*, *95*, 502-503.

Kivumbi, G. & Kintu, F. (2002). Exemptions and waivers from cost sharing: Ineffective safety nets in decentralized districts in Uganda. *Health Policy and Planning*, *17(*Suppl), 64-71.

Lakwo, T. & Gasarasi, D. (2006). Non-adherence to community directed treatment with ivermection for onchocerciasis control in Rungwe district, southwest Tanzania. *East African Medical Journal, 83*(6), 326-332.

Liesse, A. Lafontaine, C., & Vandoorne, C. (2000). Participation, santé communautaire, partenariat, participation communautaire: Des concepts identiques? *Education Santé, 153*, 4-5.

Massé, R. (2005). Les fondements éthiques et anthropologiques d'une participation du public en santé publique. *Ethique Politique, 7*(2), 107-124.

Moreau, A., Dedianne, M., Letrilliart, L., Le Goaziou, M., Labarère, J., & Terra, J. (2004). S'approprier la méthode du focus group. *La Revue du Practicien, 18*(645), 382-384.

Mumba, M., Visschedijk, J, van Cleeff, M., & Hausman, B. (2003). A piot model to analyse case management in malaria control programmes. *Tropical Medicine and International Health, 8*(6), 544-551.

Ndyomugyenyi, R., Byamungu, A., & Korugyendo, R. (2009). Perceptions on onchocerciasis and ivermectin treatment in rural communities in Uganda: Implications for long-term compliance. *International Health, 1*(2), 163-168.

Ndyomugyenyi, R., & Kabali, A. (2010). Community-directed interventions for integrated delivery of a health package against major health problems in rural Uganda: Perceptions on the strategy and its effectiveness. *International health*, *2*(3), 197-205.

Njomo, D., Amuyunzo-Nyamongo, M., Magambo, J., & Njenga, S. (2012). The role of personal opinions and experiences in compliance with mass drug administration for lympatic filariasis in Kenya. *PLOS One, 7*(12), e48395.

Nuwaha, F., Okware, J., & Ndyomugyenyi, R. (2005). Predictors of compliance with community-directed ivermectin treatment in Uganda: Quantitative results. *Tropical Medicine and International Health, 10*(7), 659-667.

Okeibunor, J., Amuyunzu-Nyamongo, M., Onyeneho, N., Tchounkeu, Y., Maniaga, C., Kabali, A., & Leak, S. (2011). Where would I be without ivermectin? Capturing the benefits of community-directed treatment with ivermetin in Africa. *Tropical Medicine and International Health, 16*(5), 608-621.

Oyibo, W. & Fagbenro-Beyioku, A. (2003). Adverse reactions following annual ivermectin treatment of onchocerciais in Nigeria. *International Journal of Infectious Diseases, 7*, 156-159.

Piot, M. (1967). *A simulation model of case finding and treatment in tuberculosis control programmes.* Geneva: World Health Organization.

Rilkoff, H., Tukahebwa, E., Fleming, F., Leslie, J., & Cole, D. (2013). Exploring gender dimensions of treatment programmes for neglected tropical diseases in Uganda. *PLOS Neglected Tropical Diseases, 7*(7), e2312.

Romelaer, P. (2005). Chapitre 4 : L'entretien de recherche. In P. &. Roussel, *Management des ressources humaines: Méthodes de recherche en sciences humaines et sociales* (pp. 101-137). Bruxelles: De Boeck Supérieur.

Rothova, A., Van Der Lelij, A., Stilma, J., Wilson, W., & Barbe, R. (1989). Side-effects of ivermectin in treatment of onchocerciasis. *The Lancet, 333*(8652), 1439-1441.

Sandstrom, K. (1996). Searching for information, understanding, and self-value: The utilization of peer support groups by gay men with HIV/AIDS. *Social Work in Health Care, 23*(4), 51-74.

Simich, L., Beiser, M., & Mawani, F. (2003). Social support and the significance of of shared experience in refugee migration and resettlement. *Western Journal of Nursing Research, 25*(7), 872-891.

Slokum, N., Elliott, J., Heesterbeek, S. & Lukensmeyer, C. (2006). *Méthodes participatives. Un guide pour l'utilisateur.* Brussels: Fondation Roi Baudouin.

Sombié, I., Amendah, D., & Soubeiga, K. (2015). Les perceptions locales de la participation communautaire à la santé au Burkina Faso. *Santé Publique, 27*(4), 557-564.

Ssemanda, E., Levens, J., Mkocha, H., Munoz, B., & West, S.K. (2012). Azithromycin mass treatment for trachoma control: Risk factors for non-participation of children in two treatment rounds. *Neglected Tropical Diseases, 6*(3).

Strecher, V. J., & Rosenstock, I. M. (1997). The health belief model. *Cambridge handbook of psychology, health and medicine*, 113-117.

Tchounkeu, Y., Onyeneho, N., Wanji, S., Kabali, A., Manianga, C., Amazigo, U. V., & Amuyunzu-Nyamongo, M. (2012). Changes in stigma and discrimination of onchocerciais in Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene, 106*(6), 340-347.

Touré, E. (2010). Réflexion épistémoligique sur l'usage des focus groups : Fondements scientifiques et problèmes de scientificité. *Recherches Qualitatives, 29*(1), 5-27.

Ubachukwu, P. (2006). Socio-economic impact of onchocerciasis with particular preference to females and children: A review. *Animal Research International, 3*, 494-504.

Veit, O., Beck, B., Steurwalk, M., & Hatz, C. (2006). First case of ivermectin-induced severe hepatitis. *Transactions of the Royal Society of Tropical Medicine and Hygiene, 100*(8), 795-797.

Wanji S., Kengne-Ouafo, J., Esum, M., Chounna, P., Tendongfor, N., Adzemye, B., ..., & Taylor, D. (2015). Situation analysis of parasitological and entomological indices of onchocerciasis transmission in three drainage basins of the rainforest of South West Cameroon after a decade of ivermectin treatment. *Parasites & Vectors, 8(202)*.

Wanji, S., Tendongfor, N., Nji, T., Esum, M., Che, J., Nkwescheu, A., ..., & Taylor, D. (2009). Community-directed delivery of doxycycline for the treatment of onchocerciasis in areas of co-endemicity with loiasis in Cameroon. *Parasites and Vectors, 2*(39).

World Health Organization. (2000). *Report of the mid-term (Phase 1) external evaluation of APOC.* Geneva: World Health Organization.

World Health Organization. (2016A, May 15). *African Programme for Onchocerciasis Control (APOC): mappinng co-infection with* Loa loa *(RAPLOA)*. Retrieved from http://www.who.int/apoc/cdti/raploa/en/

World Health Organization. (2016B, May 05). *Geographical distribution of onchocerciasis*. Retrieved from http://www.who.int/onchocerciasis/distribution/en/

Yirga, D., Deribe, K., Woldemichael, K., Wondafrash, M., & Kassahun, W. (2010). Factors associated with compliance with community directed treatment with ivermectin for onchocerciais control in Southwestern Ethiopia. *Parasites & Vectors, 3*(48).

York, K., Kabole, I., Mrisho, M., Berry, D. & Schmidt, E. (2014). Factors affecting community participation in the CDTI program in Morogoro, Tanzania. *Journal of Nursing Scholarship, 47*(1), 96-104

Annexes

Annex 1: Ethical Clearances

Université Catholique de Louvain
Faculté de médecine

Bruxelles, ce 05 janvier 2015

Comité d'Éthique
Hospitalo-Facultaire

Professeur Annie ROBERT
IREC-EPID
UCL

Concerne : Protocole ARES-CCD - Cameroun

Chère Collègue,

Nous avons bien reçu votre protocole et les annexes en rapport avec le projet ARES-CCD.

Le Comité d'Ethique donne un avis favorable à ce projet.

Nous vous prions d'agréer, cher Collègue, l'expression de nos sentiments les meilleurs.

Pharm. P. de PIERPONT
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COMITE NATIONAL D'ETHIQUE DE LA RECHERCHE POUR LA SANTE HUMAINE

Arrêté N° 0977/A/MINSANTE/SESP/SG/DROS/ du 18 avril 2012 portant création, organisation et fonctionnement des comités d'éthique de la recherche pour la santé humaine au sein des structures relevant du Ministère en charge de la santé publique

N° 2015/01/543/CE/CNERSH/SP

Yaoundé, le 15 janvier 2015

Cnethique_minsante@yahoo.fr

CLAIRANCE ETHIQUE

Le Comité National d'Ethique de la Recherche pour la Santé Humaine (CNERSH), en sa session ordinaire du 15 janvier 2015, a examiné le projet de recherche intitulé : **«Renforcement du programme d'élimination de l'onchocercose au Cameroun»** soumis par le **Docteur MBIGHA GHOGOMU Stephen,** Investigateur Principal, Université de Buea.

Le projet est d'un grand intérêt scientifique et social. La procédure de l'étude est bien documentée et claire. Les risques liés aux prélèvements de biopsies cutanées et de sang sont précisés et seront minimisés par un personnel médical expérimenté. Les prélèvements seront réalisés dans des conditions optimales d'asepsie avec du matériel stérile et à usage unique. La notice d'information et le formulaire de consentement éclairé, en français et en anglais, sont bien élaborés et simples à comprendre. Les mesures prises pour garantir la confidentialité des données collectées sont bien présentes dans le document. Les CVs des Investigateurs les décrivent comme des personnes compétentes, capables de mener à bien cette étude. Pour toutes ces raisons, le Comité National d'Ethique approuve pour une durée d'un an, la mise en œuvre de la présente version du protocole.

Les Investigateurs sont responsables du respect scrupuleux du protocole approuvé et ne devraient y apporter aucun amendement aussi mineur soit-il, sans avis favorable du CNERSH. Les investigateurs sont appelés à collaborer pour toute descente du CNERSH pour le suivi de la mise en œuvre du protocole approuvé. Le rapport final du projet devra être soumis au CNERSH et aux autorités sanitaires du Cameroun.

La présente clairance peut être retirée en cas de non respect de la réglementation en vigueur et des recommandations susmentionnées.

En foi de quoi, la présente clairance éthique est délivrée pour servir et valoir ce que de droit.

Le Président

Pr Lazare KAMGNO

Ampliations

- MINSANTE

N.B : cette clairance éthique ne vous dispense pas de l'autorisation administrative de recherche (AAR) exigée pour mener cette étude sur le territoire camerounais. Cette dernière vous sera délivrée par le Ministère de la Santé Publique.

REPUBLIQUE DU CAMEROUN

Paix – Travail - Patrie

MINISTERE DE LA SANTE PUBLIQUE

SECRETARIAT GENERAL

DIVISION DE LA RECHERCHE OPERATIONNELLE EN SANTE

D30-277
N°_____/L/MINSANTE/SG/DROS/CRSPE/BBM

REPUBLIC OF CAMEROON

Peace – Work - Fatherland

MINISTRY OF PUBLIC HEALTH

SECRETARIAT GENERAL

DIVISION OF HEALTH OPERATIONS RESEARCH

Yaoundé, le 22 AVR 2015

LE MINISTRE

A

Dr. Stephen G. MBIGHA

Email :stephen.ghogomu@ubuea.cm
Tel : 678455646

Objet : Autorisation Administrative de Recherche
N° 631-13-15

Après examen du projet de recherche intitulé : « **Programme de Renforcement de l'Elimination de l'Onchocercose au Cameroun** », introduit en vos noms respectivement, **Dr Stephen MBIGHA GHOGOMU,** Université de Buea, comme Investigateur principal et le Pr Joseph KAMGNO, Directeur du Centre de Recherche sur les Filaires et Autres Maladies Tropicales comme Co-Investigateur,

J'ai l'honneur de vous signifier l'autorisation à démarrer cette recherche. En tant qu'Investigateur principal, vous devez assurer la conduite de cette recherche comme stipulée dans le protocole y relatif. Vous voudrez bien retenir que, la Division de la Recherche Opérationnelle en Santé est chargée du suivi de la conformité aux principes de bioéthique de ce projet et devra être tenue informée de vos activités, ainsi que des conclusions de cette recherche. Le Ministère de la Santé Publique se réserve par ailleurs le droit d'arrêter la mise en œuvre de celle-ci, en cas de non respect du protocole approuvé et pour lequel cette Autorisation Administrative de Recherche est délivrée.

Toute découverte au cours de cette recherche devra être signalée à l'Administration avant publication et les quatre parties, le **Centre de Recherche sur les Filarioses et Autres Maladies Tropicales (CRFILMT), l'Université Libre de Bruxelles (ULB), l'Université de Buea (UB)** et l'Administration Publique Camerounaise **(APC)** en détiendront les droits de propriété intellectuelle.

De même, toute modification du présent protocole devra également être signalée par écrit à l'Administration après une nouvelle approbation par le Comité d'éthique. Le numéro de votre Autorisation sus référencée, devra être cité dans vos courriers ultérieurs.

Copie :

- *CAB/MSP/SESP*
- *MINRESI*
- *SG/MINSANTE*
- *DLMEP*
- *DROS*
- *INTERESSES*
- *Archives / chrono*

André MAMA FOUDA

REPUBLIQUE DU CAMEROUN
Paix - Travail - Patrie
MINISTERE DE LA SANTE PUBLIQUE
DELEGATION REGIONALE
DU SUD OUEST

REPUBLIC OF CAMEROON
Peace - Work - Fatherland
MINISTRY OF PUBLIC HEALTH
REGIONAL DELEGATION
FOR THE SOUTH WEST

Tel: 233 32 22 10 General office
233 32 22 62 Regional Delegate
233 32 29 43 Drug Programme
Email: contact@swrdph.org

BUEA the, 04th May 2015

THE REGIONAL DELEGATE

Ref: R11 /MINSANTE/SWR/RDPH/PS/ 1041302

TO:

Dr Stephen Mbigha Ghogomu
University of Buea, Cameroon

Subject: An Administrative Authorization to carry out a research study

Your Application to carry out a research on "***Strengthening of the Onchocerciasis Elimination Program in Cameroon***" was received at the South West Regional Delegation of Public Health.

The results of your research will help evaluate the effect of the Community Directed Treatment of river blindness in our region and certainly serve to develop new strategies of combatting the disease in case very little impact has been obtained.

Taking note of the fact that an ethical clearance has already been obtained and considering the importance of your research, ***an Administrative Authorisation has been granted for you to carry out your research in Health Facilities in the South West Region.***

I hereby call on District Medical Officers and all health facilities Authorities in the Region to give you their greatest collaboration.

My best Regards

The Regional Delegate of Public Health

Dr. Mbome Njie Victor

Cc: DMOs SWR

Annex 2: Informed Consent for Minors

Attestation of Sensitization for Skin Snips, Medical Consultations, Blood Collection and Interviews within the Framework of the Multidisciplinary Analysis of Onchocerciasis Management in Kombone Health Area, Cameroon

University of Buea – Université Libre de Bruxelles

Académie de Recherche et d'Enseignement supérieur of Wallonia-Brussels

I, Mpa Fritz Oku INFP, am the Chief of Post of Kombone Health Area (Mbongé, Cameroon). On 10 February, 2016, a research team from the University of Buea (Director: Dr. Stephen Ghogomu) and the Université Libre de Bruxelles (Director, Dr. Jacob Souopgui) contacted me about a study they were conducting on Onchocerciasis in Kombone Health Area. They explained to me the nature of the project and asked if I would facilitate the research in my village which was to include: blood collection, skin snips, medical consultations and interviews.

a) I hereby agree to facilitate the research being conducted by the University of Buea and the Université Libre de Bruxelles in Kombone Health Area
b) I will ensure that the chief of each village and the director of each secondary school:
    a. is sufficiently informed about the research
    b. consents to having his village/school participate in the study
    c. knows the rights of the students involved in the research
    d. will sensitize and seek consent from the parents of secondary school students involved in the study
c) I am aware that this study has been authorized by the Minister of Public Health (Administrative Authorization for Research) and ethically cleared by the National Ethics Committee for Research on Human Health
d) I assure that my facilitation of this research is entirely voluntary

UNIVERSITY OF BUEA FACULTY OF SCIENCES

Signed, Mpa Fritz Oku INFP on 10/02/2016

(Print name) (Date)

REPUBLIC OF CAMEROON MINISTRY OF PUBLIC HEALTH KOMBONE HEALTH CENTER MBONGE MEME DIVISION S.W.P.

X

(Sign name)

Telephone:

Email:

Attestation of Sensitization for Skin Snips, Medical Consultations, Blood Collection and Interviews within the Framework of the Multidisciplinary Analysis of Onchocerciasis Management in Kombone Health Area, Cameroon

University of Buea – Université Libre de Bruxelles

Académie de Recherche et d'Enseignement supérieur of Wallonia-Brussels

I, Mkpa Fritz Oku INFP, am the Chief of Post of Kombone Health Area (Mbongé, Cameroon). On 10 February, 2016, a research team from the University of Buea (Director: Dr. Stephen Ghogomu) and the Université Libre de Bruxelles (Director, Dr. Jacob Souopgui) contacted me about a study they were conducting on Onchocerciasis in Kombone Health Area. They explained to me the nature of the project and asked if I would facilitate the research in my village which was to include: blood collection, skin snips, medical consultations and interviews. I agreed and have done the following on their behalf:

a) I have ensured that the chief of each village and the director of each secondary school:
   a. was sufficiently informed about the research
   b. consented to having his village/school participate in the study
   c. knew the rights of the students involved in the research
   d. sensitized and sought consent from the parents of secondary school students involved in the study
b) I assure once again that my facilitation of this research is entirely voluntary

UNIVERSITY OF BUEA BIOTECHNOLOGY FACULTY OF SCIENCE

Signed Mkpa Fritz Oku INFP on 22/02/16

(Print name) (Date)

X

(Sign name)

REPUBLIC OF CAMEROON MINISTRY OF PUBLIC HEALTH KOMBONE HEALTH CENTRE MBONGE HEALTH DIVISION

Telephone:
Email:

Informed Consent Form for Interviews within the Framework of the Multidisciplinary Analysis of Onchocerciasis Management in Kombone Health Area, Cameroon

University of Buea – Université Libre de Bruxelles

Académie de Recherche et d'Enseignement supérieur of Wallonia-Brussels

I, the undersigned, am the director of GSS Bole, located in Kombone Health Area (Mbongé, Cameroon). On 04 March, 2016, a research team from the University of Buea came to my school and conducted interviews with my students, some of whom were minors.

In my capacity as guardian of minor students registered at my institution during school hours, I consented to the interviews on their behalf.

The team informed me of the rights of the students to anonymity and the right to refuse recording or participation. I understood that interviews would last roughly 30-45 minutes, that there would be no negative repercussions for anything the students discussed in the interview and that the study within which the interviews were taken place had been authorized by the Minister of Public Health (Administrative Authorization for Research) and ethically cleared by the National Ethics Committee for Research on Human Health.

I agreed without solicitation to have my minor students participate in the interviews. The minor students are as follows:

1. MBAKOA Joseph (15 years)
2. ETONGWE John (17 years)
3. TAPIA Julius (14 years)

Signed,

_____ NKOT LOVERT OK on 04 March, 2016

(Print name)

X_____

(Sign name)

PO

Telephone: 677567682

Email:

Informed Consent Form for Interviews within the Framework of the Multidisciplinary Analysis of Onchocerciasis Management in Kombone Health Area, Cameroon

University of Buea – Université Libre de Bruxelles

Académie de Recherche et d'Enseignement supérieur of Wallonia-Brussels

I, the undersigned, am the director of MCHS Kombone Mission, located in Kombone Health Area (Mbongé, Cameroon). On 04 March, 2016, a research team from the University of Buea came to my school and conducted interviews with my students, some of whom were minors.

In my capacity as guardian of minor students registered at my institution during school hours, I consented to the interviews on their behalf.

The team informed me of the rights of the students to anonymity and the right to refuse recording or participation. I understood that interviews would last roughly 30-45 minutes, that there would be no negative repercussions for anything the students discussed in the interview and that the study within which the interviews were taken place had been authorized by the Minister of Public Health (Administrative Authorization for Research) and ethically cleared by the National Ethics Committee for Research on Human Health.

I agreed without solicitation to have my minor students participate in the interviews. The minor students are as follows:

1. MUKETE Modestus (17, male)
2. AMBUFE Silvie (16, female)
3. NGENI Vanic (10, male)

Signed, OK

NKimeh Peter Agah on 04 March, 2016

(Print name)

X

(Sign name)

PRINCIPAL MCHS

Telephone:

Email: 677351195

Informed Consent Form for Interviews within the Framework of the Multidisciplinary Analysis of Onchocerciasis Management in Kombone Health Area, Cameroon

University of Buea – Université Libre de Bruxelles

Académie de Recherche et d'Enseignement supérieur of Wallonia-Brussels

I, the undersigned, am the director of GSS Kombone, located in Kombone Health Area (Mbongé, Cameroon). On 04 March, 2016, a research team from the University of Buea came to my school and conducted interviews with my students, some of whom were minors.

In my capacity as guardian of minor students registered at my institution during school hours, I consented to the interviews on their behalf.

The team informed me of the rights of the students to anonymity and the right to refuse recording or participation. I understood that interviews would last roughly 30-45 minutes, that there would be no negative repercussions for anything the students discussed in the interview and that the study within which the interviews were taken place had been authorized by the Minister of Public Health (Administrative Authorization for Research) and ethically cleared by the National Ethics Committee for Research on Human Health.

I agreed without solicitation to have my minor students participate in the interviews. The minor students are as follows:

1. AKAMA Daniel (16, male)

Signed,

_____ on 04 March, 2016

(Print name)

X_____

(Sign name)

Cell No: 674994028.

Telephone:
Email:

Annex 3: Interview Guide

Leading Question	Justification	Areas to discuss
We first have some questions about who you and your family are:	**Specific objective 3**: describe the attitudes of families which induce a reduction in the adhesion to children of CDTI -To contextualize interview -To 'warm up' conversation	• Size of family • Education • Head of household and occupation • Religion • Sex (to note) • Ethnicity • Family responsibilities (1)
What do you think about 'oncho'? ***To use word used by each community***	**Specific objective 3** -To introduce the theme of the interview -To gauge the knowledge of and attitude towards onchocerciasis	• What is it? • What causes it? (15) ○ Physical, spiritual, environmental • Consequences for SSS (2, 3) • Susceptibility (as adults and as children) (4)
What do you think about the treatment of onchocerciasis with CDTI?	**Specific objective 3** -To understand attitudes towards ivermectin and CDTI of interviewed families and independent students	• Drug used • Effectiveness for SSS (5) • Benefits for SSS (6) • Risks to SSS (7) • Fears for SSS (8) • Motivations to give or take / not give or take the treatment (9)
What do you think about the ivermectin distributors (CDD)?	**Specific objective 3** -To understand attitudes towards CDDs of interviewed families	• Competence (10) • Confidence in distributors (10, 11) • Communication, information (10, 11)
Can you tell us about the experience of your family / your experience with ivermectin treatment taken every year?	**Specific objective 3** -To understand attitudes towards CDTI of interviewed families and independent students	• Motivation to take the treatment (9) • Side effects (12) • Impact of social network (13) • Did it work? (5, 6)

Can you tell us about your experience/ the experience of your child with Mectizan™?	**Specific objective 3**
	
	-To understand attitudes towards CDTI of interviewed families and independent students in the specific context of the infected SSS
		• First dose of ivermectin
		  ○ Motivation (9)
		  ○ Consequences (12)
		• Perceived role of ivermectin in journey (14

Annex 4: Focus Group Guide

Focus Group Guide

Piot Model – CDTI

1. **Please introduce yourself**
2. **How does a new person in the village become involved in the CDTI?**
    - Justification: to detail the steps of the Piot Model
        - How to start the in program
        - How to continue in the program
        - How to successfully complete the program
        - How do we know when the campaign can be stopped?
3. **How is each of the previously detailed steps completed? Can you describe how you perform these steps?**
    - Justification: to understand the steps and identify potential roadblocks to successful completion
4. **What are some possible difficulties involved in each step?**
    - Identify possible roadblocks
        - From patient perspective
        - From CDD perspective
        - From health system perspective
            1. WHO
            2. Health Zone
            3. Fritz

Annex 5: Focus Group Piot Primer

Focus Group Discussion

Piot Model Lesson

1. Piot model definition

The Piot model is a tool which describes the journey of a patient through the health system. It is a model that is built with different steps or 'phases'. Each step is a stage that the patient has to complete to access to the next one. The final goal is to be cured of the condition.

2. Steps

The model usually has 5 to 7 "steps"; the total number of steps depends on the specific program and the complexity of the illness. The first "step" is always that the patient has developed the illness (example: patient with malaria). The last "step" always reflects the goal of the health program (example: patient cured).

3. Illustration

This is an illustration for malaria:

- → **Step 1:** Patient (P.) with malaria
- → **Step 2:** P. is aware of the disease
- → **Step 3:** P. is motivated to ask assistance
- → **Step 4:** P. is correctly diagnosed
- → **Step 5:** P. correctly starts treatment
- → **Step 6:** P. properly adheres to treatment
- → **Step 7:** Medication taken has been effective
- → **Step 8:** P. is cured

4. Why are we using this model?

We are using this model to understand the real-life execution of CDTI and to identify the "steps" where patients may leave this program. This model can be used to improve the CDTI program.

5. Our model

- → **Step 1**: Patient eligible for CDTI (over 5 years old, non-pregnant)
- → **Step 2:** ....

Annex 6: Final Output, Focus Group Discussions