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Knowledge, Attitudes and Practices (KAP) among adults above 18 years of age towards onchocerciasis elimination in foci that have completed Post Treatment Surveillance (PTS) in Uganda

By

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MSc

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Master of science

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Thesis Committee Chair: Deborah McFarland, PHD

An abstract of

A thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

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Abstract

Knowledge, Attitudes and Practices (KAP) among adults above 18 years of age towards onchocerciasis elimination in foci that have completed Post Treatment Surveillance (PTS) in Uganda

By: **Oumer Shafi Abdurahman**

Purpose: Since the launch of the onchocerciasis elimination policy by the government in 2007, Uganda had successfully achieved elimination in 11 of the 17 disease transmission zones, also known as foci. Based on historical and scientific evidence, annual and bi-annual treatment strategies sometimes complimented by vector control have been implemented. Available data points to the successful elimination of onchocerciasis after the three-year post treatment surveillance period. However, do communities believe that onchocerciasis has been eliminated? This study assesses community beliefs towards the elimination of the disease and examines whether the different intervention strategies in different foci have affected community beliefs towards elimination differently.

Methods: Data was collected between May – July 2016 in three foci of Uganda: namely, Imaramagambo, Mt. Elgon, and Kashoya-kitomi foci where elimination is achieved. Districts from each focus, sub-counties, and perishes were selected purposively based on their proximity to former vector breeding sites and river systems. Households were randomly selected after updating the list of households in the community. confidence in elimination was compared between foci and districts using chi-square tests. Multivariate logistic regression was used to identify variables associated with community belief in elimination.

Results: Forty-eight percent (48%) of the respondents knew that mass drug administration had been stopped because the disease was no longer in their community. However, when pressed about their belief about elimination ("Do you believe river blindness is eliminated from your community?"), 43.8% of the respondents were skeptical. Mt. Elgon focus (in which vector elimination and 13 years of annual treatment followed by 5-years of bi-annual treatment had been implemented), exhibited the highest confidence in elimination at 68% ($p<0.0001$). The likelihood of believing that elimination had been achieved was 8.269 times higher for community members who were informed about what to do next when treatment was stopped when compared to those who were not informed, after controlling for treatment place, having ever seeing someone with the disease, and sources of knowledge about the disease.

Discussion: Despite the successes of elimination efforts, communities are still asking for the continuation of treatment with Ivermectin. Co-endemicity of soil transmitted diseases and fear of recurrence of onchocerciasis has contributed to the continued demand for the drug.

Recommendation: A proper exit strategy is needed before halting treatment as we approach elimination. The end game for one disease should consider other diseases that are co-endemic in the area. WHO, in collaboration with onchocerciasis-endemic countries, should come up with guidelines that focus on strengthening public health interventions to help cut the transmission cycle of soil transmitted diseases and which incorporate treatment with Albendazole or Mebendazole in places where onchocerciasis and lymphatic filariasis are eliminated.

Key words: Belief, confidence, Ivermectin, Mectizan, Community, CDTI, CDD, post treatment surveillance, health education, Disease transmission zone, post treatment surveillance, KAP.

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Chapter one: Introduction

Overview of onchocerciasis program

Onchocerciasis, also known as "river blindness," is a parasitic disease that is caused by an infection from filarial nematode (roundworm), called Onchocerca volvulus. It transmits from person to person by different species of blackflies. Blackflies breed in fast flowing rivers and feed on human blood for the fertilization of their eggs, during which they deposit infective larvae of the parasite into human. Then the larvae migrate to other parts of the human body from where they are encapsulated into a fibrous and palpable nodule, and develop into mature male and female worms. Nodules are usually found on bony parts of the human body such as the iliac crest, rib cage and the head. The female worm produces thousands of larvae that migrate to other parts of the body including the eyes and under the skin where they are picked by other female black fly. When the released embryos called microfilariae die, the immune system recognizes them as foreign bodies and attacks them. This immune reaction triggers off a reaction that results in itchiness. The more efficient the immune system, the more likely that the individual will experience severe itching and scratching. When the skin is damaged, it opens up the individual for other secondary infections resulting in loss of skin elasticity and skin disfiguration and visual impairment that may result in permanent blindness (WHO, 2016). According to the World Health Organization (WHO), 17.7 million people were infected in 1995, of whom about 270,000 were blind and about 500,000 had suffered visual impairment.

Uganda is one of the countries affected by the onchocerciasis. The vectors responsible for the transmission of the disease in Uganda are Simulium damnosum and Simulium neavei (T. L. Lakwo, Ndyomugyenyi, Onapa, & Twebaze, 2006). Onchocerciasis control commenced in the early 1950s in Uganda with vector control with Dichlorodiphenyltrichloroethane (DDT) and in some foci along with diethyl carbamazine citrate (DEC) that was used to treat affected individual in the community (Prentice, 1974). While elimination was achieved in the largest focus, Victoria Nile with DDT application, in other foci, success was short lived (Ndyomugyenyi, 1998). This was mainly due to limited understanding of the transmission areas, and later political upheavals of the 1970s. By 1977, all intervention for onchocerciasis control had been abandoned.

With the discovery of Ivermectin (Mectizan^{R}) and its donation by Merck Co. in 1987, onchocerciasis control received a new life, and in the early 1990s, Uganda government launched a new control program based on annual mass treatment with Ivermectin. This was preceded by mapping the distribution onchocerciasis nationwide (Ngoumou P, Walsh JF, Mace JM, 1994; Katabarwa M, Onapa AW, Nakileza B, 1999). Mapping in Uganda was carried out from 1992 to 1996 in order to launch annual treatment with Ivermectin country wide.

Thirty-seven (37) districts (now 44 due to the split of the districts) with 2.5 million persons found to be at risk of the disease of which around 1.4 million were infected. Uganda had also studied transmission sites of the disease following river prospects and divided it into zones called foci.

The annual Ivermectin distribution through community-directed treatment with Ivermectin(CDTI) by itself was successfully implemented and consistently reached more that 70% coverage (Ndyomugyenyi, Lakwo, Habomugisha, & Male, 2007). Yet, the high coverage did not interrupt transmission (Ndyomugyenyi et al., 2007). Uganda piloted bi-annual treatment in Wadelai focus of northwestern Uganda, and proved that communities can successfully distribute Ivermectin twice a year. A study by Cupp et al.(2011), had demonstrated that bi-annual treatment with Ivermectin could interrupt transmission within 6.5 years(Cupp, Sauerbrey, & Richards, 2011). Based on these studies and the experience from the Americas, Uganda government launched a nationwide onchocerciasis elimination policy in 2007 using bi-annual treatment and vector elimination starting with 15 districts and then expanding to all the districts by 2015 instead of only annual Community directed treatment with Ivermectin (CDTI)(M. N. Katabarwa et al., 2012).

Uganda is one of the first countries in Sub-Saharan Africa that has its own national onchocerciasis elimination guideline to implement the elimination policy, which is based on the 2001 World Health Organization guideline. Ethiopia followed in 2012, and later Nigeria, and as of now, there are no other countries that have developed own national guidelines for onchocerciasis elimination. This guideline provides determination of criteria for verification of elimination, provides an institutional framework for a technical advisory committee to guide the elimination program, and advises the Ministry of Health on the recommendations regarding stopping interventions and follow up during the Post Treatment Surveillance period. When all foci are eliminated, the country will produce a dossier for submission to WHO for verification of elimination. In total, the country had 17 onchocerciasis foci (Annex 1). The Victoria Nile focus was eliminated in 1977, and by 2007, transmission was still ongoing in 16 foci. The foci were categorized under different colors of the “Oncho flag”, that is adjusted and foci periodically placed in categories based on the status of disease transmission. The status of transmission is based on the epidemiological and entomological results from the surveys carried out following the thresholds given under the epidemiological and entomological criteria in the national guidelines studies.

The Ugandan national guideline for onchocerciasis elimination

Certification criteria for elimination in Uganda were set based on the guideline based on I) elimination of morbidity ii) interruption of transmission. To assess elimination of morbidity, the prevalence of microfilariae in skin snips was used as a proxy indicator for eye lesions and skin, and the threshold for elimination was set to less than 5% in all sampled communities and less than 1% in 90% of sampled communities. Presence of less 1% of microfilaria in anterior chamber or in cornea was also considered in an area with ocular diseases. To assess interruption of transmission, both epidemiological (serological and parasitological) and entomological criteria were considered. For epidemiological decision, absence of detectable infection in children aged less than 10 years using a cumulative five-year finger prick immunological blood test was considered. A five-year cumulative incidence of less that **1 new case** per 1000 was considered acceptable. For entomological decision, criteria were set based on the disease vector in each foci since Uganda has two vectors responsible for the transmission of onchocerciasis. In Simulium neavei infested foci, the lack of positive crabs for larvae/pupae of s.neavei species over a period of three years was considered as an indicator for interruption of transmission. For s. damnosum infested foci, infection rates of the vector after dissection and detection by PCR was considered, and infection rate 0.05% in a sample of 10,000 flies per focus was considered as interruption of transmission.

There is a rigorous process for stopping Ivermectin treatment. The Ugandan onchocerciasis elimination expert advisory committee (UOEEAC) reviews all data related the specific foci. If the criteria mentioned above are met, UOEEAC will advise the government to halt treatment. The advice from UOEEAC will be reviewed by an independent national certification committee established by the ministry of health. If agreement is made to stop treatment, health education will be given to the community prior to halting treatment and the program will maintain Ivermectin tablets for clinical treatment of cases as needed. A three-year surveillance (also known as post treatment surveillance or PTS) is established to check for any recrudescence. During the PTS period, no vector Simulium flies or positive crabs should be caught, no infected vector flies with larval stages from L1 to L3 should be detected and at the end of the third year, it should be checked for any documentation of recent transmission before the declaration of elimination.

To date, from the seventeen (17) foci, the disease has been eliminated in six (6) foci (16 districts), Transmission is interrupted in five (5) foci (5 districts), interruption is suspected in four (4) foci (11 districts), and there is an ongoing transmission in only two foci (Annex 1, Uganda Onchocerciasis flag). Three of the foci, our study sites, where Simulium neavei was the responsible vector for disease transmission completed post treatment surveillance period in 2016 (Kashoya-kitomi, Imaramagambo, and Mt. Elgon).

Overview of the three foci of our study sites

Kashoya-Kitomi is a focus found in the western Uganda with a population of 49,223 in 4 districts which had undergone 13 years of annual treatment with Ivermectin followed by 6 years of bi-annual treatment with Ivermectin and 3 years of larviciding with Abate chemical to eliminate the vector Simulium neavei. Epidemiological and entomological data were assessed based on the national guideline. Skin snip microfilaria prevalence decreased from 85% in 1991 to 62% in 2004 and to 0.5% in 2013. Blood samples from children under the age of 10 showed 5 children out 3246 children to be positive which gives point prevalence of 0.15%. Four of the 5 five children who tested positive proved to be negative upon confirmation study using PCR. No vector fly has been caught since 2009. Hence elimination was declared after three years of PTS

(T. Lakwo et al., 2016). Kashoya-Kitomi focus was left with few months of the 3- year period for PTS.

Mt Elgon focus is found in eastern Uganda with a population of 83,547 in 4 districts which had undergone 13 years of annual treatment with Ivermectin and twice per year treatment for 5 years. It followed the exact same steps as mentioned above. Entomological results showed Simulium neavei population and the associated biting to be zero. Microfilaria rates dropped to 0.05%, and blood spots from children showed 0.03% (1/3051) positive. After three years of PTS, Microfilaria from skin snips and from children stayed zero. Hence elimination was declared (M. Katabarwa et al., 2014). Mt. Elgon focus completed the 3-year PTS period in 2014.

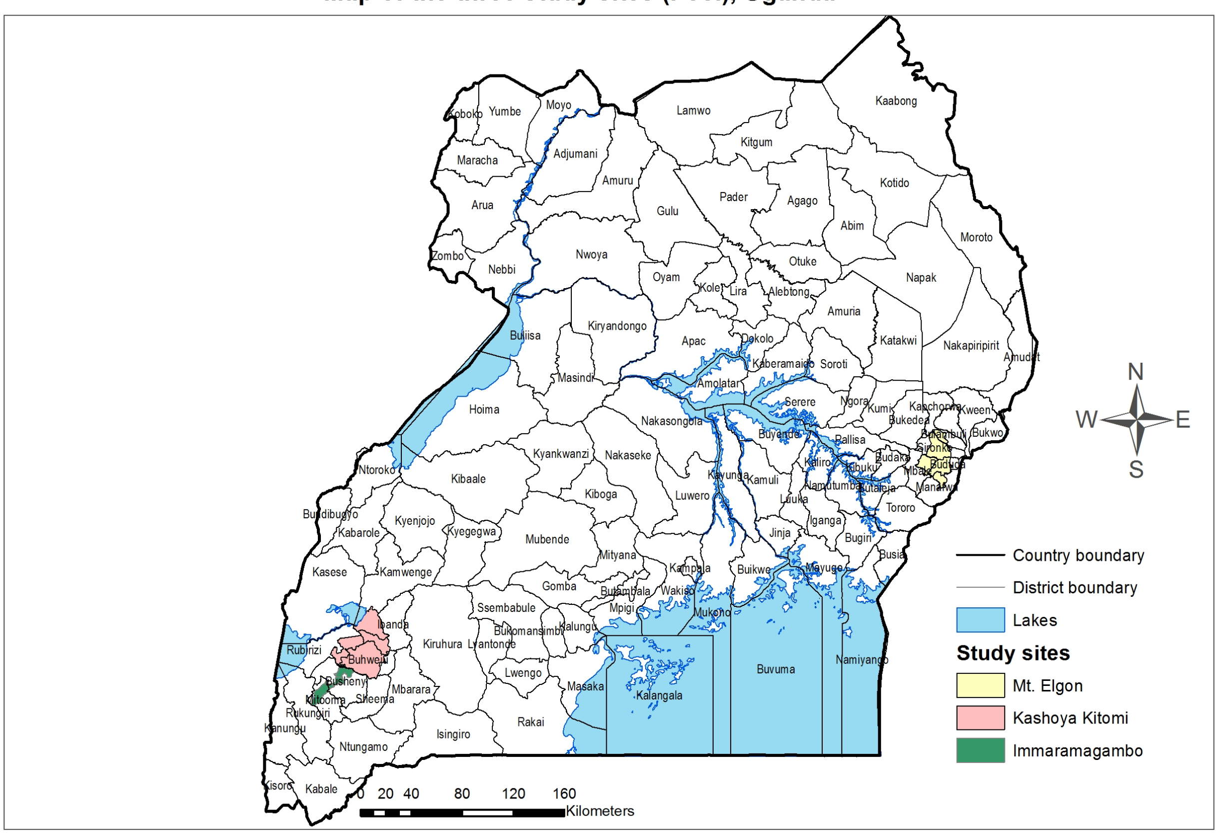
Imaramagambo focus is found in south-western Uganda with a population of 27,540 in 2 districts which had undergone only annual treatment. Treatment data were available for the period 1993-2009. Data were missing between 2009 and 2012. The entomological and epidemiological assessments made in 2012 and subsequent years in this focus indicated the interruption of transmission(Katabarwa et al., 2016). Hence in 2012, the UOEEAC declared the interruption of transmission and recommended three years of PTS. The elimination in this focus attributed to the disappearance of the vector Simulium neavei for unknown reason.

In all the foci where the disease is eliminated, health education about the elimination of the disease was given to the community. The same was done in the Americas after elimination of the disease. However, recent evidence from Guatemala, where onchocerciasis has been eliminated, suggests that more than half of the community did not believe onchocerciasis had been eliminated and recommended the need for Ministry of Health outreach services to address community concerns (Richards et al., 2016). It is important to note that vector elimination was not a strategy used in the Americas, and the communities might be bitten by the uninfected vector which might lead to the belief contrary to the evidence which confirmed the elimination. In Uganda, in the foci investigated in this study, although interruption of transmission is had been attained, including vector elimination, there is no evidence of disease recrudescence. However, it is not clear whether communities believe that onchocerciasis has been eliminated.

If the situation in Uganda is the same with the Americas, it presents challenges for community trust and ongoing treatment for other NTDs in Uganda. This thesis reports on a study of the knowledge, attitude and practice of communities in post treatment surveillance onchocerciasis transmission zones (foci) in Uganda.

Figure 1. Map showing the status of the Ugandan elimination program and our study sites

Map of the three study sites (Foci), Uganda



Steps taken to stop onchocerciasis treatment in Uganda

It would be necessary to study the situation of health education and how the onchocerciasis program stopped treatment for onchocerciasis before we study communities' knowledge about the elimination.

According to the National Coordinator for onchocerciasis elimination program, Mr Lakwo Tom, all the necessary steps mentioned on the elimination guideline had been followed before stopping treatment. After the decision from the Uganda onchocerciasis Elimination Advisory Committee(UOEEAC), the National Certification Committee (NCC) visited the districts, and foci to verify. The NCC found what UOEEAC said to be correct, then they wrote a letter to the Permanent Secretary describing the status of the foci. Then the director general sent letters to the districts. All of the districts in each foci got a letter stating that the data has been reviewed by both committees (expert committee and certification committee). After the letter is written, teams from the national onchocerciasis program moved to the districts for advocacy. The team communicated with all of the district health officials, telling them what is expected of them. From there, the health officials are expected to cascade the advocacy and sensitization to lower levels and then to the community. The national team also supervised that process. The health workers are trained, to monitor the disease from health facilities. They are taught what to do if they see suspected cases. The structure from district to perishes are expected to mobilize the community. District onchocerciasis coordinators, sub-county supervisors and parish supervisors are the ones expected to mobilize, sensitize and teach the community with the help of local council chair persons.

However, there were variations between districts, foci, and villages. For instance, we found a high level of community involvement in Mt. Elgon foci compared to Imaramagambo and Kashoya-Kitomi foci's. It depends on how the district sets their health delivery system. We have prepared health education material for onchocerciasis post-treatment.

Study questions/Objectives/Hypotheses

General Objective:

To determine believes of communities about the elimination of onchocerciasis in Post Treatment Surveillance onchocerciasis transmission zones (foci) in Uganda.

Specific Objectives:

Objectives 1: To investigate whether community members believe that river blindness was eliminated in their communities.

Objectives 2: To find out if there is a difference in belief of community members in foci where vector elimination was applied and where it was not.

Objectives 3: To find out if there is a difference in belief of community members where annual treatment is implemented vs where both annual and bi-annual treatment elimination was applied and where it was not.

Objectives 4: To find out factors influencing the belief of the community about the elimination of onchocerciasis in their communities.

Hypotheses 1

H_O = Community members who had been treated for onchocerciasis for more than 10 years do not believe onchocerciasis was eliminated

H_1 = Community members who had been treated for onchocerciasis for more than 10 years believe onchocerciasis was eliminated treatment.

Hypothesis 2

H_O = There is no difference in knowledge between foci where vector elimination is implemented and not implemented

H_1= There is difference in knowledge between foci where vector elimination is implemented and not implemented.

Hypothesis 3

H_O = There is no difference in community belief between areas where annual treatment was implemented and bi-annual treatment was implemented.

H_1= There is a difference in community belief between areas where annual treatment was implemented and bi-annual treatment was implemented.

Hypothesis 4

H_O **=** Treatment place, Information on what to do next, ever seeing someone with signs and symptoms of onchocerciasis and source of knowledge about onchocerciasis has no significant influence on the belief of the community about the elimination of the disease from their community.

H_1 = Either Treatment place, or Information on what to do next, or ever seeing someone with signs and symptoms of onchocerciasis, or source of knowledge about onchocerciasis has significant influence on the belief of the community about the elimination of the disease from their community.

Significance of the study

Uganda is the country in Sub-Saharan Africa that demonstrated that focal elimination of onchocerciasis is possible. Community engagement in onchocerciasis elimination process is imperative since every activity in the community is implemented by the communities themselves. The Ugandan guidelines for onchocerciasis elimination state that, “If the decision is to stop Ivermectin, health education (information, education, communication) and consultation will take place in communities prior to halting treatment”(Ministry of Health, 2011). Sharing the appropriate scientific evidence with the same community after elimination has occurred will benefit them in many ways. First, they will direct their attention to the next public health problem with the energy and encouragement from the first success while keeping an eye for the eliminated diseases not to come back, through increased surveillance. Informing the community about the stopping of treatment with Ivermectin will also enable the community to strengthen other prevention activities against non-targeted diseases which were suppressed or reduced because of the high effect of the drug Ivermectin, since drug Ivermectin has demonstrated that it has an effect on Strongyloides, scabies and other intestinal parasites (Anselmi et al., 2015).

Acronyms

CDTI = Community directed treatment with Ivermectin

CDD=Community drug distributors

CBIT=Community based Ivermectin treatment

NTDs=Neglected Tropical diseases

MOH=Ministry of Health

CDC= Center for Disease Control

WHO=World Health Organization

DALYS=disability adjusted life years

APOC=African Program for Onchocerciasis Control

PTS=Post treatment surveillance

Important terms

Focus = This term is used to mean the transmission zone in which the vector for Onchocerciasis thrives.

Post treatment surveillance = A three-year period set between the suspected interruption of transmission and confirmation by the world health organization

CHAPTER TWO: Literature review

Neglected tropical diseases

Neglected tropical diseases (NTDs) are a diverse group of parasitic and bacterial diseases that prevail in tropical and subtropical conditions in 149 countries and affect more than one billion people, costing developing economies billions of dollars every year (WHO, 2016). They are called neglected because they have been largely eliminated from developed parts of the world and persist only in the poorest, most marginalized communities and conflict areas (CDC, 2016). Seventeen (17) diseases have been identified by WHO as neglected tropical diseases with the potential inclusion of additional diseases as more evidence emerges. These diseases usually overlap geographically and create multiple burdens on the same community suffering from them. While it is a challenge to the community suffering from the diseases, from a public health intervention perspective, the overlap creates an opportunity to integrate the common interventions for both prevention and treatment. Neglected tropical diseases identified by WHO are: Bruli ulcer, Chagas disease, Dengue and chikungunya, Guinea worm, Echinococcosis, Foodborne trematodiases, Human African trypanosomiasis, Leishmaniasis, Leprosy, Onchocerciasis, Rabies, soil-transmitted helminthiasis, Taeniasis, Trachoma, and Yaws. Two the 17 NTDs, guinea worm and yaws, are targeted for eradication while the rest are targeted for elimination or control.

Countries endemic for these diseases also bare the largest burden of other infectious diseases which forces them to prioritize channeling the resources needed to fight all these diseases. The fact that many of the NTDs are not killer diseases, and economic impact studies (Economic burden studies, intervention cost effectiveness studies, and return-on-investment studies) were not well understood coupled with the scarcity of the tools needed to fight these diseases seems to be the reasons for countries and donors to neglect them. Objective, quantifiable evidence connecting these diseases and their direct impact on the development and economic growth was sought to gain political commitment from endemic countries. A lot has been done over the years to solve these problems. A study on the global burden of NTDs by Mathers et al., (2007) estimated 177,000 deaths worldwide in 2002, mostly in Sub-Saharan Africa, and about 20 million disability adjusted life years (DALYS) or 1.3% of the global burden of diseases and injuries was attributable to NTDs (Mathers, Ezzati, & Lopez, 2007). In a systematic review of global burden of disease burden, Lozano et al., (2012) estimated NTDs result in 152,000 deaths or 2.2 per 100,000 persons (Lozano et al., 2012). Individuals affected by these do not only lose their health, , the diseases also reduced the ability to work. A systematic review by Lenk et al., 2016, describes productivity loss related to Neglected tropical diseases, and presents productivity loss due to lymphatic filariasis as 70-100% if lymphedema is presented, productivity loss of 20% due to onchocerciasis, up to 23% due to schistosomiasis, up to 35% for Soil transmitted helminthiasis, 60-100% due to blindness, and 24.5% from visual impairment due to Trachoma (Lenk, Redekop, Luyendijk, Rijnsburger, & Severens, 2016).

There is a learning and implementation cycle in these programs. Evidence about implementation feed the learning about the programs which in turn informs the implementation. For authorities to decide whether to implement these programs or not, they had to understand the economic benefits from these programs either somewhere where the programs were implemented or they have to implement and generate the information from their own countries. Many disease specific economic benefits of the interventions (return on investment) have been presented by the scientific community from the programs which were implemented for years. A study by Chu et al., 2010 on the economic benefits of the 8 years (2000-2007) implementation of the Global program for elimination of lymphatic filariasis estimated $21.8 billion direct economic benefits over the life time 31.4 million individuals have been gained(Chu, Hooper, Bradley, McFarland, & Ottesen, 2010). The contribution of onchocerciasis program was described as beyond the health and well-being of individuals. Dunn et al., (2015) described the contribution it had to the Millennium development goals (MDG) 1-6 and MDG goal 8 (Dunn et al., 2015).

Above all the evidence presented in different fronts, the commitment to fight these diseases has grown dramatically following the London Declaration on Neglected Tropical Diseases which was launched on 30 January 2012 (WHO 2017). In this declaration, countries, donors and drug donating companies agreed to work together to control or eliminate at least 10 of the NTDs by 2020. This declaration was inspired by the WHO 2020 road map on NTDs.

Onchocerciasis

Onchocerciasis, also known as River Blindness, is an eye and skin disease caused by a filarial parasite Onchocerca Volvulus (WHO, 2016). It is the second blinding infectious disease globally next to trachoma (Etya'ale, 2008). It's called river blindness because the vector harboring the parasite, blackflies, breed in fast flowing rivers and streams. The female vectors repeated biting during human blood meal gets the parasite from infected person to uninfected person. In the human body the adult parasite Onchocerca Volvulus produces larvae called microfilariae that migrates to the skin, eyes and other organs. Symptoms, specially itching, is caused by the microfilariae moving in the subcutaneous tissue and then inducing inflammatory responses when they die.

Worldwide, more than 123 million people are at risk of contracting the disease, 37 million people are already infected, and millions are suffering from debilitating skin disease, terrible itching, impaired vision and blindness(APOC, 2011).

Africa endures 99% of the global burden of onchocerciasis (CDC, June 2011). It is mainly prevalent in west and central Tropical Africa. Thirty-two (32) African countries, Yemen in Middle East, and Brazil, Ecuador, Guatemala, Mexico, Venezuela, and Colombia in Latin America are endemic for the disease.

Onchocerciasis and poverty:

Onchocerciasis, together with other NTDs, is "both the result of and a contributor to the poverty"(Hopkins, Richards, Ruiz-Tiben, Emerson, & Withers, 2008). Onchocerciasis usually affects economically marginalized communities with low political voices. The situation is often described by the saying - "Where the road ends, onchocerciasis starts", showing the lack of infrastructure where these communities live. In the 1970s, when the first surveys were done in west Africa, "more than 60% of the savannah population carried the parasite;10% of the adult population and 50% of males over 40 years of age were blind" (Amazigo U, 2006) In African countries, land farming is strongly associated with the wellbeing the same which was affected by onchocerciasis in 1970s. When this large, productive population goes blind or is unable to spend much of their time with farming activities, there will be substantial decrease in productivity. Another aspect of the high prevalence of the disease is that people usually tend to move to highlands where the disease transmitting vector does not have the environment to reproduce, and transmit the disease from person to person. This means people had to leave the fertile low land and live in the overcrowded highlands which directly decreases productivity. A study done on the effect of onchocerciasis skin disease on health labor productivity of workers at a coffee plantation in southwestern Ethiopia showed permanent workers at the coffee plantation without onchocerciasis earned, on average, \$5.32 ($p < 0.05$) more than workers with the disease(Waters, Rehwinkel, & Burnham, 2004).

Onchocerciasis and stigma

The social stigma and discrimination associated with skin diseases have been documented for many years. Whether they are infectious or not, skin diseases have been a major source of stigma (Brieger, Oshiname, & Ososanya, 1998). One particular example is leprosy where people infected with the disease are disabled which in turn excluded them from social participation. Van Brake et al., (2012) studied the role of leprosy-related impairment, activity, social participation, stigma and discrimination in Indonesia, said that around 60% of affected people reported activity limitations and participation restriction and 36% anticipated stigma (van Brakel et al., 2012). The situation with onchocerciasis is no different. Brieger et al., (1998) studied stigma associated with onchocerciasis skin disease in western Nigeria on a 13-item, 39- point stigma scale and found a mean score of 16.8, the highest ranking was associated self-esteem such as being embarrassed, feeling of being pitied, thinking less of oneself, feeling that scratching annoys others, and feeling avoided(Brieger et al., 1998). Although all genders are affected by the stigma in the community, the level and category of the stigma they face varies. A study by Vlassoff et al., (2000) on gender and the stigma of Onchocerca skin disease in four countries of Africa (Cameroon, Ghana, Nigeria and Uganda) showed that men were more concerned about the effect of the disease on their sexual performance and economic prospects whereas women were more concern about physical appearance and marriage(Vlassoff et al., 2000). However, due to continuous treatment over the years, there is a change in attitude mainly because the skin conditions have improved. Tchounkeu et al., (2012) studied the changes in the same countries studied by Vlassoff et al.,

(2000) after over seven (7) years of treatment with Ivermectin, and found avoidance of people with onchocerciasis skin disease decreased from 32.7% to 4.3%(Tchounkeu et al., 2012).

Onchocerciasis Control/elimination programs:

The control and elimination of onchocerciasis has gone through different phases and challenges. The largest bearer of the scourge, Africa, has gone through different strategies to fight this disease. Formed in 1974, the West African Program to Control Onchocerciasis (OCP) implemented a successful implementation of weekly aerial spraying of insecticide over fast-flowing rivers and streams, the breeding sites of the blackflies. By doing that, it was possible to massively reduce the fly density and hence reduce transmission. OCP then evolved to a new entity called African Programme for Control of Onchocerciasis (APOC) in 1995 with the objective “to eliminate onchocerciasis as a disease of public health importance in Africa” (WHO/APOC 2017). This new transformation was needed to expand the control effort to all the endemic countries in the continent with the introduction of new tools and better partnership into the program. “In 1987, Ivermectin is registered for human use and the manufacturers – Merck & Co., Inc. – pledge to donate Ivermectin free of charge for as long as it is needed “(APOC, 2016). After 2 years of community based Ivermectin treatment (CBIT) approach, APOC introduced a new drug distribution strategy called Community directed treatment by Ivermectin (CDTI) which strives to empower the members of the community to lead and own the distribution of the freely donated drugs. This change in strategy was driven by the results of a large, multi-country study which showed CDTI as a feasible and effective way of ensuring that the drug reached endemic communities.

The key element of CDTI is that the villagers who live in meso- or hyper-endemic communities decide themselves who should become community drug distributors , and plan the period, dates, locations, and modes of distribution (Amazigo et al., 2002). With the introduction of CDTI as a strategy, treatment coverage increased from 1.5 million in 1997 to 75.8 million in 2010 and to 100.79 million in 2013 (Fobi et al., 2015).

APOC classified intervention areas into four levels of endemicity based on nodule prevalence in the communities during the pre-control era. Nodule prevalence of less than 5% was classified as non-endemic, nodule prevalence between 5% to 20% was considered as hypo-endemic, nodule prevalence from 20%-40% was classified as meso-endemic, and nodule prevalence greater than 40% was classified as hyper-endemic. According to APOC's guideline, communities with meso-endemic and hyper-endemic prevalence were subject to annual treatment with Ivermectin, although the guidelines were revised to include hypo-endemic areas in 2014 (WHO/APOC 2004).

Through its innovative community directed treatment with Ivermectin, APOC had helped onchocerciasis endemic countries to treat from 1.5 million in 1997 to over 112 million people in 2014 (Afework H. Tekle et al., 2016). Due to APOC's contribution from 1995-2010 the prevalence of infection declined from 45% in 1995 to 31% in 2010, and to 18% in 2015. Similarly, the prevalence of troublesome itch was reduced from 14% to 6% to 2%, and prevalence of visual impairment was reduced from 1.2% to 0.8% to 0.6%(Coffeng et al., 2013).

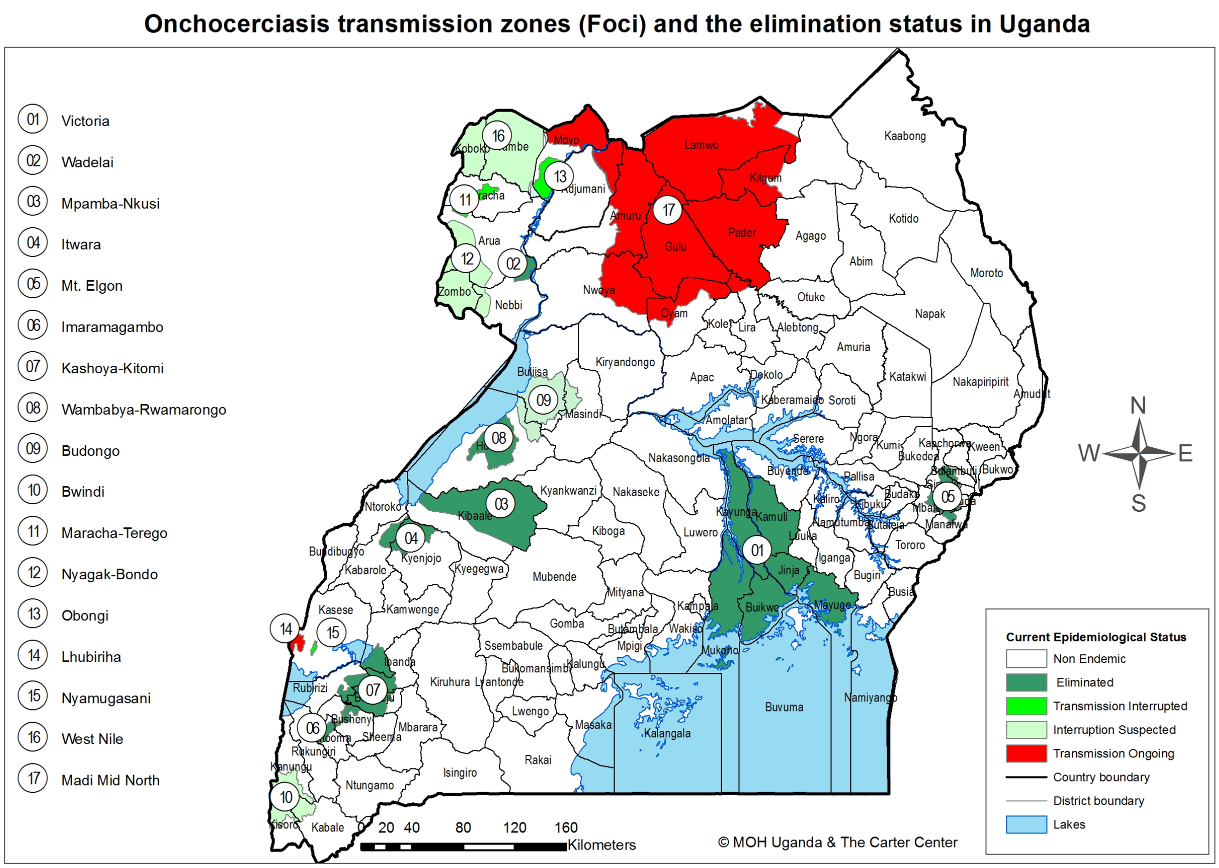
It was in APOC's core strategy that annual treatment with Ivermectin can interrupt transmission. However, in its report of the 2015 Joint Action Forum (the forum for ministers of endemic countries with the APOC's secretariat), APOC came up with the idea of using an alternative strategy without mentioning twice per treatment explicitly (WHO/APOC 2015). Although OCP had implemented 14 years of vector control by spraying of insecticides over fast-flowing rivers and streams, except in four areas of Uganda, the united republic of Tanzania, and Equatorial Guinea, where vector control was coupled with annual treatment with Ivermectin, APOC considered vector control to be not feasible and cost-effective if not implemented in selected foci.

In 2015, endemic countries and their partners agreed to transform APOC to focus on an integrated, broader spectrum of neglected tropical diseases elimination. Hence, in May 2016, another entity called Expanded Special Project for Elimination of Neglected Tropical Diseases (ESPEN) launched by WHO (WHO, 2015). With the paradigm shift from control to elimination, and with the increased support from the global community, many endemic countries had demonstrated better commitment by including more endemic communities under treatment, and even twice per year treatment when needed.

Success stories in onchocerciasis elimination:

There are many success stories in the control and elimination of onchocerciasis in both Africa and Latin America. In Africa, many of the success stories have not yet been achieved at national level. Tekle et al., (2012) reported that it was possible to eliminate the disease in Kaduna state of Nigeria after long-term treatment of onchocerciasis with Ivermectin (A. H. Tekle et al., 2012). A longitudinal study done by Traore et al., (2012), demonstrated the possibility of elimination in some specific foci in Mali and Senegal. Repeated success reports from Uganda had been published; Lakwo et al., (2016) reported interruption of the transmission of Onchocerca volvulus in the Kashoya-Kitomi focus of western Uganda by reducing microfilarial prevalence from 85% in 1991 to 62% in 2004; and to only 0.5% in 2013 using combination of annual and bi-annual treatment, and larviciding of the vector Simulium neavei (T. Lakwo et al., 2017). Katabarwa et al., (2016) reported interruption of transmission from Imaramagambo focus of Uganda (Katabarwa et al., 2016). Katabarwa also reported interruption of transmission from Mt.Elgon of eastern Uganda (Moses Katabarwa et al., 2014). Lakwo et al., (2013) also reported disappearance of the disease from Uganda's Itwara focus (T. L. Lakwo et al., 2013). Katabarwa reported the interruption of transmission in Wadelai Focus of northwestern Uganda (Moses N. Katabarwa et al., 2012). Uganda also had reported 11 foci suspected interruption of transmission (unpublished).

Figure 2. Map showing all the foci of onchocerciasis in Uganda



Sudan has also reported successful elimination of the disease in a few of its endemic foci. Zarroug IM et al., (2016) reported confirmed elimination of onchocerciasis from Abu Hamad foci of the Sudan (Zarroug et al., 2016).

While the challenges are not exactly the same as the African situation, the achievements in Latin America are country-wide elimination of the disease. In July 2015, Mexico became the third country in the world after Colombia in 2013 and Ecuador in 2014 to be declared free of onchocerciasis after successfully implementing elimination activities for decades (WHO, 2016). These Latin American countries used treatment strategies twice and even four times per year as opposed to the once per year treatment strategy used in many countries of Africa. In Mexico, for example, all 559 endemic communities have undergone semi-annual mass treatment with Ivermectin since 1998. In 50 communities of this focus, Ivermectin frequency shifted from twice to four times a year in 2003; an additional 113 communities were added to the quarterly treatment regimen in 2009 to achieve a rapid suppression of transmission (Rodr et al., 2013). Other countries in Latin America are also on the verge of declaring elimination of onchocerciasis. In Venezuela, for example, by following a mix of bi-annual and tri-annual treatment strategies, transmission was suppressed in Yanomami communities in its southern part of the country after 15 years of 6-monthly and 5 years of 3-monthly mass Ivermectin treatment (Botto et al., 2016).

Exit strategy of onchocerciasis programs after elimination:

All these global efforts needed full community engagement to succeed and collaboration between stakeholders; drug companies, implementing NGDOs, countries and the affected community. While we should celebrate stopping any public health program when it is not needed any more, further precaution needs to be taken to convince the community that the program to be halted is not needed any longer.

It's understood by both the scientific and the affected communities that the impact of onchocerciasis program is beyond the single disease- due to the wide spectrum benefit from the drug Ivermectin on soil-transmitted helminthiases (STH; Ascariasis, Trichuriasis, Hookworm, and Strongyloides), Lymphatic filariasis (LF), and Scabies. Krotneva et al., (2015), estimated that STH infections, Strongyloidiasis, and scabies would have caused a cumulative burden of 1.7 million disability-adjusted life year (DALYs) lost between 1995 and 2010 in individuals who would otherwise have been treated with Ivermectin"(Krotneva et al., 2015).

The WHO guideline for verification of elimination describes every step that must be taken to verify elimination. But it doesn't mention the exit strategy needed to be followed to inform the community. African countries who have elimination guideline (Uganda and Ethiopia) described the health education procedures which needs to be taken into account in their documents. Communities might continue to demand the treatment either due to the misconception about the disease elimination from their community or the continued demand on Ivermectin to treat other diseases. Hence, it is important to evaluate the community's perception and fill the gap, if need be.

CHAPTER THREE: Methods

Questionnaire formulation

A structured, close ended questionnaire was prepared based on the local knowledge of the experts and from other similar study which was conducted by the Carter Center in Guatemala. However, major modifications were to it made since we did not expect the two communities to think similar way. Pre-testing of the questionnaire also helped us confirm our thoughts. The questionnaire prepared was then administered to the households in the sample by a trained interviewer, focused on specific aspects of knowledge, attitude and practice in PTS areas of previously onchocerciasis endemic areas. We also compared the responses from individual household level questionnaires with the beliefs from the community representatives by holding community meetings.

Questionnaire was developed between March- April 2016. Pre-testing was done in Wambabya-Rwamarongo foci in April 2016. Following the pre-testing, adjustment to the questionnaire was done in early May, and data collection was done between May to July, 2016.

Main focus areas of the questionnaire were a) knowledge and experience of onchocerciasis; b) treatment- Ivermectin and vector elimination efforts (Knowledge and participation;c) PTS and key health education messages (Effectiveness of PTS education);d) the presence or absence of flies or crabs (Confidence or skepticism about elimination); e) other benefits of Ivermectin beyond onchocerciasis elimination (its influence in spite of good knowledge of onchocerciasis elimination);and f) knowledge of onchocerciasis in any areas beyond the focus in question

Pre-testing the questionnaire

After preparing our questionnaire, we piloted it in in Hoima district, Wambabya-Rwamariongo focus, an isolated focus which had recently achieved elimination. Comments from the piloting were included.

Below are lists of comments we got from the pilot test of the first draft questionnaire (Annex 2. Survey questionnaire). Additionally, during our exercise we learned by only changing the order of the questions, respondents found it easier to answer or give consistent answers.

Study Areas

The study was conducted in three previously onchocerciasis endemic foci of Uganda. Mt Elgon foci which is found in the eastern part, Imaramagambo foci which is found to the west surrounded by Imaramagambo forest, and Kashoya-Kitomi foci, surrounded by the Kashoya-Kitomi forest, also found in western Uganda (Map1).

Sampling

Multi-stage, random and purposive sampling

A multi-stage, and a mix of both purposive and random sampling was used at each government structure. Before we started any sampling, we defined our sampling frame as all the 10 districts in the three foci of Mt. Elgon (Mbale, Sironko, Bududa, Manafwa), Kashoya-Kitomi (Buhweju, Ibanda, Rubirizi, and Kamwenge) , and Imaramagambo (Bushenyi and Mitoma).

After projecting district populations of our study districts (our sampling frame/10 districts) for 2016, we researched actual population numbers to determine the population at risk, excluding areas which are non-endemic within a district. From population data we estimated the number of households in each district. This estimation was informed by the Uganda Bureau of Statistics 2014 national census data that reported the average household number of Uganda of 4.7. From these household estimates, we were able to calculate the number of households in the entire study area, about 160,310 households (Table 1). Sample size calculation was done based on the sampling of the 10 districts in the study.

The next step was to decide the districts in which the survey would be conducted and providing the sample size we calculated based of the sampling frame to the districts selected in each foci.

For Mt. Elgon foci, we made a decision to take two of the four districts since we didn't expect much diversity between the four districts. The two districts were selected randomly. In Kashoya-Kitomi focus, we used a mix of purposive and random sampling. We first grouped the districts into two groups based on their homogeneity (districts which split after 2013 assuming that they are homogenous). We then selected one district from each group randomly. We included all the two districts from Imaramagambo focus. Since the six districts selected have different populations, household proportion was calculated for these 6 districts based on their population to give an equal chance to every household to be selected.

We used purposive sampling for both sub-county and parish levels. At both levels, we went to the areas which are closer to the river and were previously onchocerciasis endemic. Because sub-counties and parishes do not have equal number of villages or communities, we chose the villages proportionally based on the parishes. We then used random sampling of villages from the sub-county and parishes which were selected purposively. At village level we took 15-20 households.

To avoid convenient sampling at village level, with the help of village chair persons (also called Local councilor/ LC chair persons) and parish supervisors, we updated lists of household heads from the community registers that were being used during treatment (last update was in 2011). Households to be visited were randomly selected using systematic sampling where the first household was randomly selected and thereafter we used skip method with a computed interval.

$$\text{Sampling interval} = \frac{\text{Number of households in the village}}{\text{Total number of HHs needed from that village}}$$

Sample size calculation, Confidence level and Minimizing error

With 95% level of confidence and with a margin error of 0.025, from 160,310 households, we determined the sample size needed as 1,522 households. We added 5% non-responsive rate which makes our sample size 1602.

Sample size $\boldsymbol{n} = \mathbf{[DEFF*Np(1\text{-}p)]/\ [(d^2/Z^2{}_{1\text{-}\alpha/2}*(N\text{-}1)+p*(1\text{-}p)]}$

$$\text{Final sample size with 5\% non} - \text{response rate} = \frac{\text{calculated sample size}}{(1-0.05)}$$

Where

n = required sample size

d = design effect/Margin of error (de = 0.025);

p = estimated baseline prevalence of knowledge (0.5,)

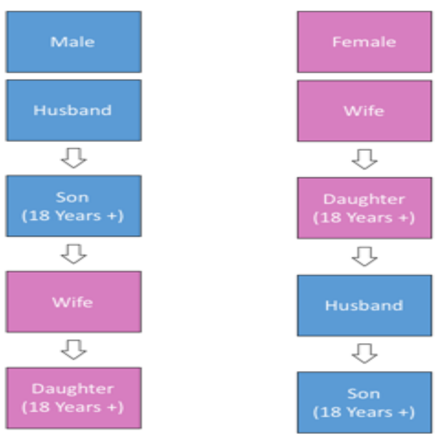
Z = the z-score corresponding to the desired confidence level (we used

$Z_{0.95}$ = 1.96)

Avoiding gender bias

Based on previous survey experiences, our team was concerned about male domination in responding to questions and the gender bias. To avoid gender bias, we randomly started with one gender and then alternatively followed our sampling pattern. In situations where men were selected and the husband was not there, the survey team looked for the eldest son (>18 years old), and if that was not possible, the survey team interviewed a woman. The same procedure was done where a woman from the household was selected. If the woman from that household is not present, the eldest daughter (>18 years old) were interviewed, and if that is not possible, the team interviewed a man (husband) (Figure 3).

Figure 3. Decision flow chart for an interview at household level



Selection of interviewees

Table 1. showing the current status in the study foci

Focus	District	Sub counties	Parishes	Communities	Population (2016)	Number of Households (2016)
Kashoya Kitomi	Buhweju	4	18	97	66,220	14,089
	Kamwengye	4	10	58	51,563	10,971
	Ibanda	2	6	60	29,097	6,191
	Rubirizi	6	27	170	84,467	17,972
Sub total		16	61	385	231,347	49,223
Elgon	Mbale	5	8	131	60,172	12,803
	Sironko	6	26	179	91,196	19,403
	Bududa	6	40	412	194,406	41,363
	Manafwa	3	12	36	46,898	9,978
Sub total		20	86	758	392,672	83,547
Imaramagambo	Bushenyi	3	9	44	61,162	13,013
	Mitooma	4	19	166	68,277	14,527
Sub total		7	19	166	129,439	27,540
Total		43	166	1309	753,458	160,310

Table 2. showing sample size of each district

Focus	District	Sub counties	Parishes	Communities	Population (2016)	Number of Households	Proportion	Number of Households interviewed
Kashoya Kitomi	Rubirizi	6	27	170	84,467	17,972	0.22	355
	Ibanda	2	6	60	29,097	6,191	0.08	122
Sub total		8	33	230	113564	24163	0.3	477
Elgon	Sironko	6	26	179	91,196	19,403	0.24	383
	Manafwa	3	12	36	46,898	9,978	0.12	197
Sub total		9	38	215	138094	29381	0.36	580
Imaramagambo	Bushenyi	3	9	44	61,162	13,013	0.16	257
	Mitooma	4	19	166	68,277	14,527	0.18	287
Sub total		7	28	210	129,439	27,540	0.34	544
Total		**24**	**99**	**655**	**381,097**	**81,084**	**1**	**1601**

Table 3. showing the targeted interviews and actual interviews conducted by district

Focus	District	Sub counties	Parishes	Communities	Population (2016)	Number of Households	Proportion	No. of Targeted Respondents	Actual No. interviewed
Kashoya Kitomi	Rubirizi	3	8	18	84,467	17,972	0.22	355	342
	Ibanda	2	3	8	29,097	6,191	0.08	122	119
Sub total		5	11	26	113,564	24,163	0.3	477	461
Elgon	Sironko	3	7	19	91,196	19,403	0.24	383	371
	Manafwa	2	4	14	46,898	9,978	0.12	197	203
Sub total		5	11	33	138,094	29,381	0.36	580	574
Imaramagambo	Bushenyi	2	4	13	61,162	13,013	0.16	257	254
	Mitooma	3	9	15	68,277	14,527	0.18	287	288
Sub total		5	13	28	129,439	27,540	0.34	544	542
Total		**15**	**35**	**87**	**381,097**	**81,084**	**1**	**1601**	**1577**

Community Meetings

One community meeting in each selected district was planned to be held to compare data from household interviews using structured community discussion guide (Annex 3). However, due to logistic constraints, we were able to conduct 5/6 community meetings. Such meetings were helpful to deeply understand the emic perspective of the topic under study. For example, the meeting was used to determine if the community is educated about stopping treatment amid the knowledge of elimination of the disease. We were interested if the community wanted to continue the treatment because of the benefits from Ivermectin which is beyond onchocerciasis. To eliminate the influence of community meetings on household level interviews, we did the community meetings at the conclusion of the household surveys. At the end of the community meetings, health education was given, especially in communities that insisted on Mectizan continuation.

Composition, selection and training of data collectors

Two data collectors from each village were selected by the district onchocerciasis coordinator. Former CDD's were excluded from data collection for data quality purposes since they were involved in the process of halting treatment. Hired by the district health office, district onchocerciasis coordinators are focal points in all the districts. They had helped in entomological, parasitological and treatment activities during elimination efforts. Data collectors were selected by their ability to read and write English as well as speak the local language. Above all, as described by the district onchocerciasis program coordinator, they were called "people of integrity," meaning trusted and responsible. We went to the districts one by one. Training was done at sub-county level. Data collectors, village chair persons and parish supervisors were called at sub-county level. Overall, 6 district onchocerciasis coordinators, 35 parish supervisors and 174 data collectors were trained and used for data collection. The purpose of the study was explained to them. Then training on the questionnaire was given to the data collectors while village chair persons and parish supervisors were asked to update the list of households in a parallel session. Particular attention was given to data quality. Each question was discussed one by one to make sure data collectors understood all the questions. Participants were asked to read the question and then repeat it in their local language. Other participants were asked to confirm if the translation to the local language was correct. They were asked how they would ask that question in their local language. In a situation where we were not comfortable with their reading and interpretation, they were substituted by another person who could read and translate properly.

Whenever we felt the data collectors were incompetent we substituted data collectors who had demonstrated better performance. Questions asked in one group were discussed in all the groups in spite of whether it was asked in the specific group or not.

Role-play was conducted to check how much they understood the questionnaire. Some technical advice was also given to the data collectors. We discussed skip patterns, technical terms, multiple answer versus single answer situations. A simple example used by the trainer to explain skip pattern was “did you eat dinner last night? if no then there is no need to ask what they eat last night!”.

How the interview was conducted?

Data collectors were advised not to use the questionnaire in an investigate manner to enquire about the participants' knowledge. Instead we emphasized engaging the participant in a conversational-like discussion. Cultural sensitivities and norms were respected. Data collectors were also advised not to record their own answer or prompt others answers with their opinions. When we got contradictory answers on the survey (example they said they don't know the disease in the previous responses and then they know the transmission), we sent the survey team back to the respondents to confirm again, instead of guessing the response ourselves.

Special situations during data collection and how we dealt with them

Polygamous Families

If a compound/polygamous family contains more than 1 household, each HH was included separately in the list for household selection. This information was communicated when the list of households was constructed with the village leader.

Absent Household

In case of absent households, the teams went back twice. If they were not available on the second round, or if the survey team learned that those households would not be available in the two survey days, they visited the next selected household according to the sampling procedure that was used, without replacing this household because it was accounted for in the planning stage by inflating the sample size with the non-response rate.

Abandoned Household

Empty households which were not occupied for a long time were not included in the list of households used for household selection at the preparatory steps.

Non- Respondent reasons

1. Absent households (majority)

2. Religion/Beliefs: Three households in Zesui sub-county of Sironko district refused for religious reason. These communities, also known as "Triple 6," are known to resist receiving all the health services.

Special occasion: people with disability

One situation encountered by the data collectors where the selected household had a respondent with hearing and speaking disability.

Data management

Every paper based data was transferred to a SPSS software. Data was entered by trained Students from University of the South, USA as part of their summer practicum. Data cleaning was done right after each entry. Paper copy of the data was stored at The Carter Center, Uganda. For analysis, SAS software version 9.4 (2002-2012 by SAS Institute Inc., Cary, NC, USA. Licensed to EMORY UNIVERSITY ROLLINS SCHOOL OF PUBLIC HEALTH T&R) was used.

Data analysis

Univariate and multi-variate analysis were used to see basic statistics and the relationship between variables. To test our hypothesis about the community's belief of elimination regardless of years of treatment, chi-square statistic was used. Additionally, chi-square analysis was used to test the hypothesis which compares foci based on vector control, and annual and bi-annual treatment. After identifying variables which had statistically significant relationship with the belief of the community about the elimination of the disease, logistic regression was used to assess variables contributing to the believes of the community regarding the elimination of the disease.

Logistic regression (**PROC LOGISTIC**) was used to build the best fit model. Receiver operating characteristics (**ROC**) curves were used to evaluate our model using the SAS code **PLOTS(ONLY)=ROC.** Multicollinearity, which may be defined as a phenomenon in which two or more predictor variables in a multiple regression model are highly correlated, were checked by using a SAS code "**/VIF**" and no variable showed **VIF** result of greater than 10. Forward, backward and step-wise model selection steps were used in SAS to choose the best predicting variables/effect. Odds ratios and the confidence intervals in which the calculated odds ratio falls was used for interpretation of the model.

Results from community meetings and open ended questions were analyzed qualitatively. Issues raised by the community and through an open ended questions were categorized by themes and presented as description.

Planning and execution of activities

Logistic plan

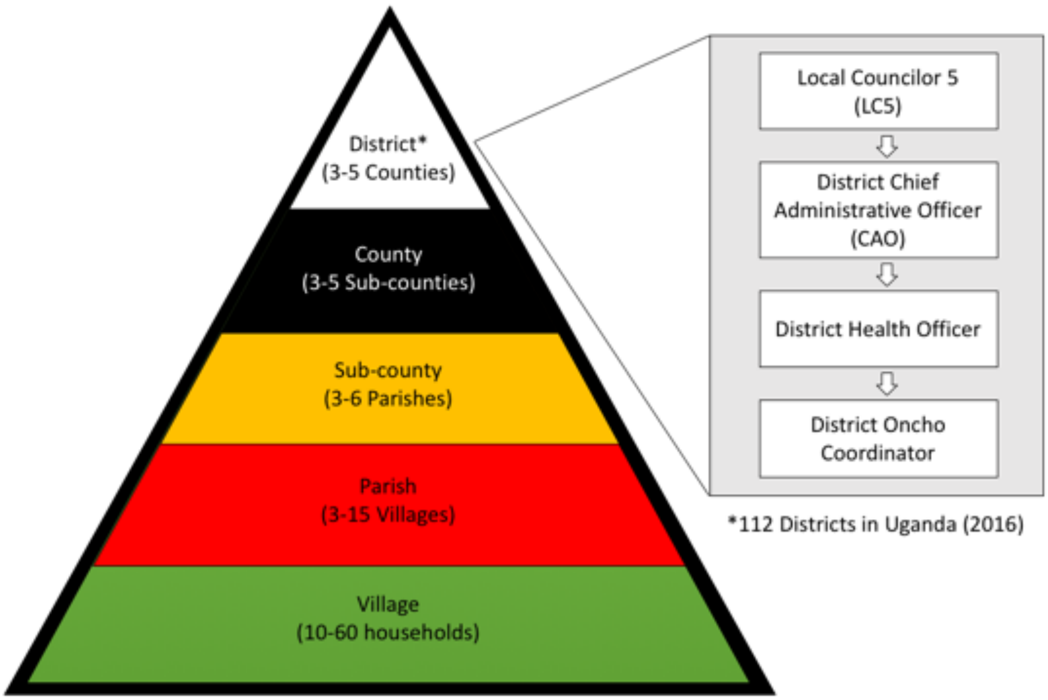
A clear logistical plan was put in place as to not waste time getting the team going each morning. A car, a driver, where the team was going each day, who was in each car, departure times and so forth were clearly planned before going to the field. Supplies for each district included: Printed questionnaire, community meeting guide, list of selected villages, pens, reams of paper, masking tape, black polyethylene bags, stapling machine, payment forms, random number tables, calculator, and phone numbers of each district onchocerciasis coordinators(DOCs). Proper communication was done between the central team and DOCs.

Government Procedures

It is very important to follow government structure throughout all the districts for political support of the project. For our survey, we first visited district onchocerciasis coordinators (DOC's) to explain the purpose of our study. The DOC then accompanied us as we repeated our purpose to each member of the chain of command: District Health Officers (DHO), Chief Administrative Officer (CAO). The CAOs are appointed by LC5s.

LC5s are elected chairs of the district. After meeting with the CAOs, we received official permission to visit sub-counties and perform our survey. It was mandatory to register our names, dates, and purpose, at each government structure (Figure 4).

Figure 4. Uganda government structure at district level



Ethical approval

The protocol for this study deemed non-research (evaluation of a public health program) by the Institutional Review Boards of Emory University (Annex 4).

Limitations of the study

The first limitation of the study is the recall bias of the community. For example, in Mt. Elgon focus, although post treatment surveillance had been recently established, the elimination of the disease and its vectors had been achieved more than five years prior to our study. It was difficult to assess if the community actually remembered the accurate level of health education given and the details in the health education messages, (e.g. where they heard the information from, when, and who gave them the information).

Another limitation is the community's "love" for the drug Ivermectin. Given the multiple benefits of Ivermectin and the community's experience with taking the drug for over 15 years, it was difficult to know whether survey respondents were speaking from a perspective of still wanting the drug or real knowledge of disease elimination. This introduced bias to our study.

A third limitation was the comprehension level and commitment of data collectors. It is demanding to expect the same level of understanding from 174 data collectors. Although the team maintained consistent supervision throughout the study areas, supervisors were unable to be present during all interviews, and had to trust that data was recorded accurately.

CHAPTER FOUR: Results

Demographic information

The mean age of the respondents was 43.7 with the range of 18 – 99. An almost equal number of men and women were interviewed; 796 (50.48%) were men and 781(49.52%) were women. 1286 (81.6%) have lived in the community for more than 10 years.

Knowledge about onchocerciasis

With respect to knowledge of onchocerciasis, 91.43% (1440) of the respondents said they know the disease. However, there was a wide range of diversity in the source of their knowledge. 23.47% (337) said they learned of it through community health education, while 44.85% (644) said they learned from village chair persons' meetings and 20.06% (288) said they learned by seeing people who are affected by the disease. Only 8.36% (120) said they learned about onchocerciasis from radio programs. Seventy percent (70%) of the respondents had actually seen someone who had the disease. When asked if they know anyone who is currently suffering from the disease, 15.72% (226) said yes. The vast majority (93.7%) know that there had been treatments in their community and 97.93% know the drug Ivermectin. House to house treatment was mentioned as the main strategy used during the treatment time. 55.7% of the respondents said they received the treatments house to house while 15.5% said they were treated at the community centers. Treatment at the community drug distributor's home was also mentioned as the other strategy used with 18.77% (254) of respondents citing it. When asked if they had been treated for onchocerciasis themselves, 91.79% (1320) of them said that they had. When asked why they are no longer undergoing treatment, 38.65% (557) were unaware. Only 27.84% (438) said they were told what to do next after treatment was stopped. Only 43.8% of the respondents believe the disease is eliminated while the rest either did not believe it had been or did not know and 83.29% (1311) of them wanted the treatment to continue.

Table 4. Comparing knowledge about river blindness among the three foci.

Knowledge variables	Elgon %(no.)	Imaramagambo %(no.)	Kashoya-Kitomi %(no.)	Significance level (95% CI)
Do you know river blindness (YES, n=1440)	32.89% (518)	32.62%(498)	26.92%(424)	P=0.4401
Have you ever seen people with sign and symptoms of river blindness (YES= 1012)	21.81%(314)	24.58%(354)	23.89%(344)	P<0.0001
Are you aware of anyone in your community who is currently suffering from river blindness (YES, N=226)	6.12%(88)	5.08%(73)	4.52%(65)	p=0.5904
Have the people in your community ever been treated for river blindness (YES,N=989)	34.58%(498)	31.11%(448)	27.99%(403)	p=0.0001
Have you ever been treated with Ivermectin (YES, N= 1320)	34.98%(503)	28.65%(412)	28.16%(405)	P<0.0001
Are the people in your community still been treated with Ivermectin (YES, N=48)	0.57%(9)	1.33%(21)	1.14 (18)	p=0.0355
When treatment was stopped, were you told what to do next (NO, N=1035)	19.01%(199)	26.06%(410)	27.08%(426)	P<0.0001
Besides treatment with Ivermectin, was there any other intervention that were used to fight river blindness (No, NO=1350)	26.97%(424)	28.5%(448)	30.41%(478)	P<0.0001

Factors associated with belief in elimination

Only 45.8% of respondents who know the disease onchocerciasis/river blindness believe the disease is eliminated (P= 0.0001). Of the respondents who said they did not know anyone currently suffering from the disease, 47.8% believe that it is eliminated. Others (52.3%) believed the disease is either not eliminated or do not know about the situation (P-Value = 0.001). There was no significant difference between men and women in belief about elimination (P-Value = 0.1792). Of the respondents who knew the drug Ivermectin, only 46.5% said the disease is eliminated. However, this association was not significant (P-value = 0.5716). While the main source of knowledge about onchocerciasis was found to be from village chairpersons' community meetings, only 55% of the respondents who said they got their knowledge from these meetings believed the disease is eliminated (P<0.001). Marital status of the respondents had no effect on the belief of the respondents about elimination (P= 0.7058), nor did gender (P = 0.1792). Only 45.2% of respondents who had been in the community for more than 10 years believed the disease is eliminated (P = 0.021). Respondents age was positively correlated with the belief that onchocerciasis had been eliminated (Pearson correlation coefficient =0.01846). About forty-two percent (41.8%) of respondents who mentioned the treatment site/strategy as house-to-house believed the disease is eliminated (P=0.0001).

Table 5. Association between knowledge and belief in elimination of onchocerciasis

	Belief in elimination of the disease %(no.)	Significance level (95% CI)
Do you know river blindness (yes, N=1438)	41.92%(659)	P<0.0001
Have you ever seen people with sign and symptoms of river blindness (yes, N=1011)	29.83%(429)	p<0.0001
Are you aware of anyone in your community who is currently suffering from river blindness (yes, N=1210)	40.25% (578)	P=0.0001
Have the people in your community ever been treated for river blindness (YES, N=1348)	43.60%(627)	p=0.0695
Have you ever been treated with Ivermectin (yes, n=1318)	42.83%(615)	p=0.0328
Are the people in your community still been treated with Ivermectin (No, N=1525)	42.78%(673)	p=0.1376
When treatment was stopped, were you told what to do next (No, N=1135)	21.45%(337)	P<0.0001
Lived for more than 10 years (yes, N=1284)	54.83% (704)	P=0.021

Impact of elimination strategies in the six districts on belief in elimination

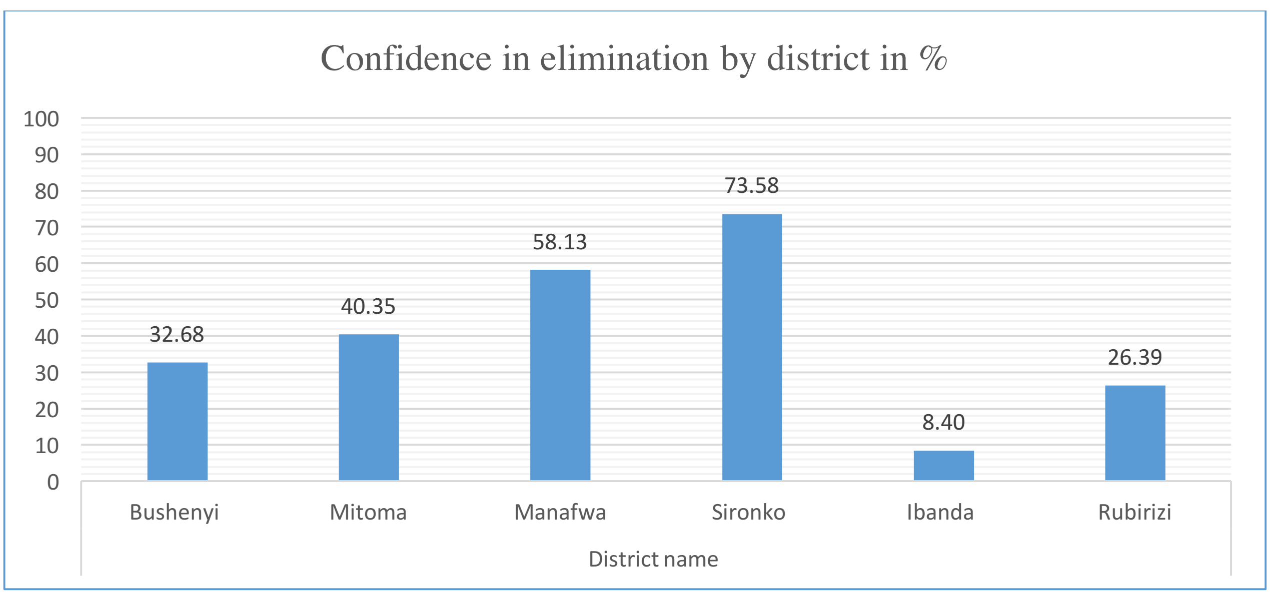
There was a significant difference between respondents who believe the disease is eliminated vs respondents who do not belief in the elimination of the disease, when compared across the three foci using bi-annual treatment vs annual treatment and where vector elimination is implemented vs where vector elimination is not implemented.

Table 6. comparison between foci by vector elimination and treatment rounds Vs respondents' belief in elimination of onchocerciasis.

Focus name	Vector elimination strategy implemented	Annual Vs Bi-Annual treatment	Belief about whether the disease had been eliminated from the community		
			Yes	No	I don't know
Imaramagambo	No	Annual	36.73%	32.28%	30.98%
Kashoya-Kitomi	Yes	13 years of annual followed by 5 years of bi-annual treatment	21.74%	44.13%	34.13%
Mt. Elgon	Yes	13 years of annual followed by 5 years of bi-annual treatment	68.12%	15.85%	16.03%

Further analysis by district puts Sironko district in the Mt. Elgon focus with the most respondents who believe that elimination has been achieved. (Figure 5).

Figure 5. Confidence in elimination among respondents of study districts



There was a mismatch between the belief that the disease had been eliminated and the need for a treatment with Ivermectin.

Table 7. Respondents belief of elimination Vs the interest for the treatment to continue and confidence of going to previous sources of vectors

	Belief about whether the disease had been eliminated from their community	significance level
If you believe river blindness is eliminated, are you confident to continue going to river or forest areas previously associated with the disease? (YES)	84.72%(582)	N/A
Should treatment with Ivermectin continue(YES)	30.24%(475)	P< 0.0001

As can be seen from table 7, there is a continued interest to take Ivermectin even when they believe the disease is no longer a treat. We held community meetings to understand the emic perspective of the community and open-ended questions gave us similar results. Communities needed the continuity of the treatment despite their belief that the disease had been eliminated (Photograph 1). Responses were categorized into themes.

Theme one: fear of the recurrence of the disease: Community members gave different responses related to fear. Many of them said, “We still live near the forest area where black flies come from”. Others said, “Black flies are still biting us” or “Black flies may come back” or “Disease might come back”. Others indicated that continuity of the treatment puts them to the safer side, using the idiom “better safe than sorry!”.

Theme two: lack of knowledge about the disease: Many of the respondents said that if young children or newborns were not treated for onchocerciasis, they are not “immunized” against the disease. Few said, “we do not know how long Ivermectin dosage lasts in our body”. Some also doubted the elimination of the vector by saying, “medicine they sprayed may have expired from the forest areas”.

Theme three: other benefits of Ivermectin: Communities know other implications or benefits of using Ivermectin. It’s not exaggeration if we say they are addicted to this drug. The very consistent response from majority of the community members was “Ivermectin helps us to eradicate other infections”.

Theme four: relating other skin or eye diseases to onchocerciasis: Many respondents thought any eye disease they experience is related to river blindness, mentioning that their vision had gone bad since the treatment is stopped. Other skin diseases were also mentioned as onchocerciasis.

Factors associated with belief of onchocerciasis elimination

Analysis of maximum likelihood towards the belief of onchocerciasis elimination

After running logistic regression with all the variables, we finally fit a logistic regression model relating the likelihood of the community to believe that the disease had been eliminated to the place where treatment was given, receipt of the information on what to do next after treatment was stopped whether or not they have ever seen anyone with the disease, and knowledge source.

Table 8. Likelihood estimate table

Parameter	**DF**	**Estimate**	**Standard Error**	**Wald Chi-Square**	**Pr > ChiSq**
Intercept	1	-0.3254	0.1363	5.6986	0.0170
Treatment place	1	0.2497	0.1262	3.9165	0.0478
Informed what to do next when treatment was stopped	1	2.1125	0.1457	210.12	<.0001
Have ever seen people with signs and symptoms of onchocerciasis	1	-0.4303	0.1395	9.5120	0.0020
Knowledge source	1	-0.4057	0.1275	10.1202	0.0015

The overall model equation

ln ($p^{\wedge}/1-p^{\wedge}$)= **-0.3257+0.2497***(Treatment place=house to house)+**2.1125*(**informed what to do next=yes)-**0.4303***(ever seen signs=yes)-**0.4057***(knowledge source= Village health team and LC1 chairpersons community meetings).

Fitness of the model

The area under the curve from the ROC curve for the model shows ROC=0.7505 which is very good fit as it is close to 1. Further diagnosis of the model shows that the Likelihood ratio $\chi 2$ test which assesses the overall model significance shows $\chi 2$ <0.0001. Variance of Inflation (HIF) also shows that there is no issue with multi-collinearity among independent variables.

Odds ratio estimates and their interpretations

Table 9. Likelihood odds ratios

Odds Ratio Estimates			
Effect	**Point Estimate**	**95% Wald Confidence Limits**	
Treatment place (house to house vs other strategies)	1.284	1.002	1.644
Informed what to do next when treatment was stopped (Yes vs No)	8.269	6.214	11.002
Have ever seen people with signs and symptoms of onchocerciasis (Yes vs No)	0.650	0.495	0.855
Knowledge source (community meetings vs other platforms)	0.666	0.519	0.856

Interpretation

- The likelihood of belief in the elimination onchocerciasis had been eliminated for the community members who were treated at their home is 1.284 times that of those who were treated at places other than their home, controlling for knowledge source, information on what to do next after elimination, and ever seeing someone with the signs and symptoms of the disease.
- The likelihood of belief in the elimination of onchocerciasis for community members who were informed what to do next when treatment was stopped was 8.269 times that of those who were not informed, controlling for treatment place, ever seeing someone with the disease and their source of knowledge about the disease.
- The likelihood of belief in the elimination of onchocerciasis for community members who had ever seen people with signs and symptoms of onchocerciasis is 0.65 times that of those who had never seen people with the signs and symptoms, controlling for treatment place, information on what to do next and their source of knowledge about the disease. In another words, respondents who had seen people with onchocerciasis were less likely to believe.
- The likelihood of belief in elimination of onchocerciasis for community members who got their knowledge from community meetings is 0.666 times that of those who got their knowledge from other sources (radio, etc.), controlling for treatment place, information on what to do next when treatment was stopped, and seeing people with the sign and symptoms.

CHAPTER FIVE: Discussion

Uganda has exhibited impressive results in terms of reaching out to communities suffering from onchocerciasis. It is the first African country to achieve elimination by implementing flexible annual and biannual treatment strategies. The vector control division at the Ministry of Health was instrumental in identifying the types of vectors responsible for the transmission of onchocerciasis to be targeted for either control or elimination. Communities that received annual treatments for more than 15 years demonstrated high knowledge about onchocerciasis. 1444 of 1577 (91.4%) respondents correctly identified the transmission mechanism and described the signs and symptoms of the disease and 1530 (97%) of respondents confirmed awareness of the drug Ivermectin.

Respondents from the Mt. Elgon focus were more likely than the other two foci to believe that elimination has been achieved. This result is concurrent with the description from the program manager for Onchocerciasis elimination in Uganda, Mr. Tom Lakwo, stating that Mt. Elgon is the focus with the highest levels of community mobilization (Chapter One). A significant difference was found in the belief that elimination had been achieved between areas of biannual treatment and annual treatment, especially between Mt. Elgon (5 years of biannual treatment and vector control/elimination) and Imaramagambo (only annual treatment). Unexpectedly, Imaramagambo, with only annual treatment, had higher confidence in elimination than Kashoya-Kitomi, which had 5 years of biannual treatment and vector control/elimination similar to Mt. Elgon. However, districts south west of Uganda including Kashoya-Kitomi focus have the highest prevalence of soil-transmitted helminthiasis ranging from 20% to 50% (Global Atlas of Helminth Infection, 2017). The epidemiology of soil transmitted helminths in Kashoya-Kitomi focus may have played a role in depleting community's confidence. However, the less confidence in Kashoya-Kitomi might also be because of inconsistency in health education in the foci. It is also important to note that repeated treatment doesn't necessarily equate with repeated rounds of health education.

Almost half (48%) of the respondents knew that mass drug administration was stopped due to the disease no longer being present in their community. However, when pressed about their belief in elimination ("Do you believe river blindness is eliminated from your community?"), 43.8% were skeptical. This is lower than a similar study in Guatemala by Frank Richards and colleagues (2016), in which 53% of the community reported that they remained skeptical. Onchocerciasis elimination in Guatemala was a very focused, intensive program with strong health education and communication components. Elimination of the disease was celebrated in many of the communities (The Carter Center Annual Review Meeting, 2017). Although it is difficult to understand, having more doubters in Guatemala could have been due to over sensitization of the community to report every case. It is also important to note the difference between communities. The social structure, culture, and psychology of communities in Uganda, an African nation, may not be similar to those of the communities of Guatemala, a Latin American nation.

In Uganda, despite participants' strong belief in elimination, the number of respondents who wanted the treatment to continue (83%) is staggering. This contrasts with the phenomenon seen in the developed world, where communities contest public health interventions once a disease is no longer considered a threat. This is illustrated by the 94% reduction of Tetanus in the United States and Europe which was followed by increase in resistance to all vaccinations (Omer, Orenstein, & Koplan, 2013). Omer and colleagues (2013) explained resistance to vaccination using the health belief model, according to which, "the uptake of a health intervention is associated with perceived susceptibility to and severity of the relevant disease and the intervention's safety and efficacy." Therefore, according to the health belief model to help explain resistance to stopping Ivermectin treatment, we would expect that the community would no longer desire Ivermectin because there is no longer a perceived susceptibility to onchocerciasis. However, because risk still exists from several other parasitic diseases in the community, and Ivermectin is effective against these pathogens as well, the health belief model is still valid due to the perceived susceptibility to other diseases and the additional benefits of Ivermectin.

Since house to house treatment was the main strategy used to control and eliminate onchocerciasis, communities who were treated at household level exhibited higher likelihood in confidence (OR=1.28) compared to those who were treated at community centers. Community center treatment strategies are complimentary strategies used when there is low coverage of treatment in the community. When public health programs are withdrawn, informing the community what should be done if community members see any case with the signs and symptoms, plays a major role in community confidence about elimination of the disease (OR=8.29). This information assures the community members that they can still get treatment if there is recrudescence of the disease This was also strengthened by the idea that many of the doubters of elimination were community members who had ever seen someone with the signs and symptoms of the disease (OR=0.65). Thus those who had seen the disease in individuals were more likely to be skeptical that onchocerciasis had been eliminated.

Further study is needed to understand the independent contribution of each of the concerns raised by the community. From the open ended questions, the main themes identified as reasons why the community might deny that elimination was achieved were; 1) lack of knowledge about the disease and its transmission; 2) fear about recurrence of the disease; 3) the presence of other skin or eye diseases in the community; and 4) the many additional benefits of Ivermectin.

As long as other parasitic diseases persist in the community, the demand for Ivermectin will continue. So the question becomes: will the community stop asking for Ivermectin if other deworming programs are strengthened? Ivermectin is effective against onchocerciasis. The same drug is used to treat lymphatic filariasis in combination with Albendazole. Albendazole is also used against soil transmitted helminthiasis. After onchocerciasis and lymphatic filariasis elimination, the most beneficial usage of Ivermectin is against the *Strongyloides* parasite. Drugs used in deworming programs (Albendazole and Mebendazole) are more effective against soil-transmitted helminthiasis ((roundworms (*Ascaris lumbricoides*), whipworms (*Trichuris trichiura*) and hookworms (*Necator americanus* and *Ancylostoma duodenale*)) than *Strongyloides* (Muennig, Pallin, Challah, & Khan, 2004). If treatment with Ivermectin is discontinued, deworming programs with Albendazole and Mebendazole alone are not likely to be the strategy to change community perceptions about stopping Ivermectin treatment. Hence, focusing on cutting the transmission cycle of *Strongyloides* by strengthening health education and bolstering treatments with Albendazole or Mebendazole for soil transmitted diseases should be the future direction when treatment is stopped.

Conclusion and Recommendations

This study has shown that 43% of the respondents were skeptical about the elimination of the onchocerciasis from their community and 83% of the respondents continued to demand Ivermectin regardless of their confidence in elimination. The study from Guatemala showed a greater percentage (50%) of the communities were skeptical about elimination. As more onchocerciasis endemic countries approach the end game for onchocerciasis elimination, global guidelines are needed to prepare communities for the day when treatment will no longer be available. As the global focal point for NTD guidance to member countries, WHO should consider recommendations that address the following scenarios.

Scenario One

If the area where onchocerciasis was eliminated is endemic for lymphatic filariasis, strongyloides and other soil transmitted diseases, treatment with Ivermectin and Albendazole should continue. However, it is still important to strengthen house to house health education programs by giving special emphasis on the community members who have never seen the signs and symptoms of onchocerciasis as they are the most likely to doubt elimination.

Scenario Two

If the area where onchocerciasis was eliminated is not endemic for lymphatic filariasis, but still endemic for Strongyloides and other soil transmitted diseases, treatment with Ivermectin will stop. Thus the oncho/LF platform for community directed treatment will no longer continue. In addition to all the activities in scenario one, we need to work on how we can bolster community's confidence about elimination of the disease. Ensuring that primary health care unit are supplied to treat if individual suspected cases come to health care providers can be a method to use. More focused health education on controlling the transmission of strongyloides, and treatment with Albendazole or Mebendazole for STH should continue.

Scenario Three

If the area where onchocerciasis was eliminated is not endemic for lymphatic filariasis and strongyloides, but endemic for soil transmitted helminthiasis, halting treatment with Ivermectin is not a challenge. However, strengthening STH programs is needed. Treatment with Albendazole or Mebendazole and hygiene and sanitation prevention activities should also be strengthened.

Further study is required to evaluate how ending one health program impacts community trust and what implications this has for other ongoing public health interventions. In a country like Uganda, where there are many community-based public health interventions, it is expected that the reputation of one program could have a spillover effect. This will allow programs to achieve elimination of other diseases with the trust and support of the community. In many communities in onchocerciasis endemic countries, the ability and presence of NTD programs to reach those at the end of the road has increased trust in the health system that must not be underestimated or squandered.

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Annex A. Uganda Onchocerciasis elimination flag

						Total # of Treatments stopped next year						0	
	Light Green = Transmission Interrupted					Total Pop treatments not stopping due to LF						215,933	
	Greyish Green = Interruption Suspected					Total Pop of Interrupted Suspected						1,344,717	
	Red = Transmission Ongoing												
UOEEAC RECOMMENDED PLAN - AUG 2016													
ID No.	Focus	Vector	District	# MDA annual rounds	# of MDA semi-annual rounds	Total Pop 2016	Planned Annual Txs 2016	Planned Semi Annual Txs 2016	Status of Transmission	Yr of elimination	Plan for MDA treatment	Larviciding (years)	LF Status
1	Victoria	S. damnosum	Jinja	N/A	N/A	539,498			Eliminated	1973	None	Vec elim (??-??)	
			Mukono	N/A	N/A	595,236			Eliminated	1973	None	Vec elim (??-??)	
			Kamuli	N/A	N/A	542,173			Eliminated	1973	None	Vec elim (??-??)	
			Mayuge	N/A	N/A	502,881			Eliminated	1973	None	Vec elim (??-??)	
			Kayunga	N/A	N/A	370,254			Eliminated	1973	None	Vec elim (??-??)	
3	Mpamba-Nkusi	S. neavei	Kibale	17	8	216,275			Eliminated (2016)	2016	PTS	Vector Elimination	
4	Itwara	S. neavei	Kabarole	20	2	37,361			Eliminated (2016)	2016	PTS	Vector Elimination	
			Kyenjojo	20	2	77,731			Eliminated (2016)	2016	PTS	Vector Elimination	
5	Mt. Elgon	S.neavei	Manafwa	15	8	46,145			Eliminated (2016)	2016	PTS	Vector Elimination	
			Mbale	15	8	57,111			Eliminated (2016)	2016	PTS	Vector Elimination	
			Sironko	15	8	86,797			Eliminated (2016)	2016	PTS	Vector Elimination	
			Bududa	15	8	183,686			Eliminated (2016)	2016	PTS	Vector Elimination	
6	Imaramagambo	S.neavei	Bushenyi	18	0	116,124			Eliminated (2016)	2016	PTS	Not done	
2	Wadelai	S.neavei	Nebbi	15	8	22,351			Interrupted (2010)		LF treatment	Not done	LF
7	Kashoya-Kitomi	S.neavei	Buhweju	16	13	63,925			Interrupted (2013)		PTS	Vector Elimination	

			Rubirizi	16	13	81,955			Interrupted (2013)		PTS	Vector Elimination	
			Ibanda	16	13	27,736			Interrupted (2013)		PTS	Vector Elimination	
			Kamwenge	18	13	48,405			Interrupted (2013)		PTS	Vector Elimination	
8	Wambabya-Rwamarongo	S. neavei	Hoima	16	13	80,345			Interrupted (2013)		PTS	Vector Elimination	
11	Maracha-Terego	S.neavei/S.damnosum	Maracha-Terego	19	0	193,582			Interrupted (2012)		LF treatment	Not done	LF
13	Obongi / Moyo	S.neavei/ S. damnosum	Moyo	20	0	39,825			Interrupted (2014)		PTS	Not done	
15	Nyamugasani	S. Sebwe	Kasese	21	0	11,709			Interrupted (2015)		PTS	Not done	
9	Budongo	S.neavei	Masindi	17	19	52,428		85,710	Interruption Suspected		Semi-Annual	Vector Elimination	
			Buliisa	17	19	33,375		57,700	Interruption Suspected		Semi-Annual	Vector Elimination	
			Hoima	17	19	80,115		132,586	Interruption Suspected		Semi-Annual	Vector Elimination	
10	Bwindi	S.neavei/ S. damnosum	Kabale	17	19	32,313		51,456	Interruption Suspected		Semi-Annual	Vector Control	
			Kanungu	17	19	62,297		100,880	Interruption Suspected		Semi-Annual	Vector Control	
			Kisoro	17	19	39,829		64,244	Interruption Suspected		Semi-Annual	Vector Control	
12	Nyagak Bondo	S.neavei	Nebbi	20	9	137,416		224,084	Interruption Suspected		Semi-Annual	Vector Control	LF
			Zombo	20	9	244,755		404,212	Interruption Suspected		Semi-Annual	Vector Control	LF
			Arua	20	9	180,868		307,402	Interruption Suspected		Semi-Annual	Vector Control	LF
17	West Nile	S.neavei/ S. damnosum	Yumbe	22	0	304,070	258,459		Interruption Suspected		Annual	Not done	LF
			Koboko	22	0	177,251	150,663		Interruption Suspected		Annual	Not done	LF
14	Lhubiliha	S. Sebwe & S. kilibanum	Kasese	20	5	131,113		216,618	ongoing		Semi-Annual	Vector Control	
18	Madi Mid North		Pader	6	7	186,756		312,546	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Kitgum	6	7	104,626		175,964	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Lamwo	6	7	142,560		234,988	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Gulu	19	7	332,570		570,640	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Amuru	19	7	231,476		370,880	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Nwoya	19	7	149,467		253,930	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Oyam	19	7	23,147		39,660	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Lira	3	7	75,614		131,240	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Moyo	20	5	88,086		153,794	ongoing		Semi-Annual	Vector Control Feasibility	LF
			Adjumani	20	5	27,756		45,842	ongoing		Semi-Annual	Vector Control Feasibility	LF
	Total			**655**	**329**	**6,778,993**	**409,123**	**3,934,376**					
					N.B: Population figures as per Aug 2016 treatment projections								

Annex B. Survey questionnaire

Knowledge, attitude and practice of people towards Onchocerciasis elimination in Uganda (original)

Introduction

This questionnaire is for face-to-face interview at household level intended to get peoples' knowledge, attitude and practice towards river blindness elimination in Uganda. The study will help to improve river blindness elimination activities in the country and also contribute to the body of knowledge. You have been randomly selected as one of the participants to provide information. Your contribution will be highly appreciated and the information provided will remain confidential. You are free to participate or not in this interview.

Focus: ……………………………..…………… District: ………………………

Sub-county: …………………………………… Parish: ……………………

Community: …………………………………… House head name: …………………

Household No: ……………………………… Household Sample No: ………………

Background information

1. Sex of the respondent

   [1]. Male

   [2]. Female

2. Age of respondent……………………………………………………………………….

3. What is your marital status?

   [1]. Married

   [2]. Single

[3]. Widow

[4]. Widower

[5]. Divorced

4. What activities are you involved in? (Multiple answers allowed)

[1] Teaching

[2] Crop farming or animal rearing

[3] Lumbering

[4] Fishing.

[5] Others

(specify)………………………………………..…………………………………….

5. For how long have you lived in this community?

[1] Less than 2 years

[2] 2 to 5 years

[3] 6 to 10 years

[4] More than 10 years

Knowledge about River blindness signs, Symptoms and treatment

6. Do you know a disease called River blindness?

[1] Yes

[2] No if no, go to number 15)

7. If yes to number 6, how did you come to know about it?

[1] Community health education

[2] VHT and LCI chairperson community meetings

[3] I had seen with some people in our community

[4] Radio program

[5] Others

specify……………………………………………………………………………………

8. What are the signs and symptoms of River blindness? (Multiple answers allowed).

[1] Vomiting

[2] Diarrhea

[3] Rough skin

[4] Swelling around the bone parts of the body

[5] Itching skin

[6] White patches commonly on the legs

[7] High temperatures

[8] Others(specify)…………………………………………………………………………

9. Have you ever seen people with signs and symptoms of River blindness?

[1] Yes

[2] No

10. Are you aware of anyone in your community who is currently suffering from river blindness?

[1] Yes

[2] No.

[3] I don't know

11. Have the people in your community ever been treated for river blindness?

[1] Yes

[2] No (if no, go to question 14)

[3] I don't know

12. If yes to **No. 11,** indicate the medicine used to treat River blindness.

[1] Antimalarial (coartem,fansider,chloroquine)

[2] Praziquantel

[3] Aspirin

[4] Ivermectin (Medicine for Filaria, Mectizan, Medicine for Obukambi etc.)

[5] Other (specify)………………

13. If yes to no 11, where was treatment with Ivermectin given?

[1] At the Community Center within my community

[2] At the CDD's home within my community.

[3] At the local leader's home within my community.

[4] Outside my community.

[5] Others (specify) (house to house)………………………………

14. Have you ever been treated with ivermectin?

[1] Yes

[2] No

15. Are the people in your community still being treated with ivermectin?

[1] Yes (if yes, skip question 16 and go to 18)

[2] No

[3] I do not know

16. If no to **number 15**, why are they no longer under treatment?

[1] We lack medicine for River blindness

[2] Treatment was stopped

[3] I don’t know

[4] Others (specify)…………………………………………………………….

17. If you said that treatment was stopped **(No 16 part 2 above**), give reason(s) why? (multiple answers allowed)

[1] We were informed that there was no more River blindness in our community

[2] The MoH /districts do not have money to buy the drug for River blindness

[3] Black flies disappeared.

[4] Bad skins disappeared from the people.

[5] Itchiness stopped

[6] I don’t know

[7] Other (specify)……………………………………………………………

18. When treatment for River blindness was stopped in your community, were you informed on what to do next?

[1]Yes

[2]No

19. If yes to number 18, what were you told? (Multiple responses allowed)

[1} to report any suspected people with rough skin related to river blindness to the community leader

[2] To report any black fly to the nearest community leader/Village health team member.

[3} To refer suspected persons to the nearest health unit for diagnosis.

[4]. River blindness drugs will be brought back to our community.

[5]. Nothing.

20. If yes **to number 18,** how did you get the information?

[1] Health workers told us

[2] Village Health Team members informed us

[3] We were told by the Community Drug Distributors

[4] Informed by Local Council leader (LCI) Chairman

[5] We heard from the Radio programs

[6] Others (specify)………………………

Transmission of River blindness disease

21. How does a person get River blindness?

[1] Through the bites of mosquitoes

[2] Through the bites of Tsetse flies

[3] Through the bites of Black flies

[4] Through Poor Hygiene

[5] Others (specify)……………………………………

22. From which place(s) do people get river blindness disease?

[1] When one is close to fast running rivers in or out of forests.

[2] I don't know

[3] Others (specify)……………………………………………………………………

23. Besides treatment with ivermectin, was there any other interventions that were used to fight river blindness?

[1] Yes

[2] No (If no, skip question number 24)

24. If yes to **number 23**, which other interventions were used to fight river blindness?

25. Do you believe that river blindness was eliminated in your community?

[1] Yes

[2] No (If no, go to 28)

[3] I don't know (if the answer is I don't know skip and go to question 29.

26. If you feel that river blindness was eliminated, are you confident to continue going to river or forest areas associated with the disease?

[1] Yes

[2] No

27. If yes to **number 26**, give reason(s) for your answer. (Multiple answer allowed)

[1] We were informed that there was no more River blindness in our community

[2] The MoH/districts do not have money to buy the drug for River blindness

[3] Black flies disappeared

[4] Bad skins disappeared from the people

[5] Itchiness stopped

[6] I don't know

[7] Other specify…………………………………………………………….

28. If no to **No 25 above**, give reason(s) for your answer

[1] The river has never dried.

[2] I have begun itching

[3] My sight has gone bad since I stopped taking Ivermectin.

[4] Flies are still biting us

[5] Other specify………………………………………………….

29. Should treatment with Ivermectin continue?

[1]Yes

[2]No

30. If yes, why? …………………………………

31. And if no why?………………………………

Thank you

Annex C. Community meeting Guide

A guide for conducting community meeting

---

1. A community meeting should only take place after the study team has informed community leaders, and a convenient day and time for the meeting fixed.
2. Then all community members should be mobilized to attend.
3. The study team should arrive at the venue in time, and if possible work with the leaders to ensure that the sitting arrangement encourages communication between community members and the animator.
4. When community members have arrived at the venue, community leaders should take the lead to introduce the visitors (study team) and purpose of the meeting. Normally, the purpose is to exchange ideas on programme activities and find solutions for identified challenges.
5. The lead member of the study team should have come with at least two persons to help in recording responses from community members. In order to encourage participation, include 2 local members from the community to be involved in counting.
6. Non-residents or visitors among the community members should be identified and given a special place so that they do not confound the results obtained from residents.

<u>Principles to adhere to are:</u>

1. The meeting should have more than 40 residents of the community.
2. No response is wrong, and therefore each response should be appreciated, recorded, and all persons supporting it.

3. If you don't know the language spoken by community members, the translator should only do his or her job, but not to help participants polish their responses. If he or she can't comply, quickly find another one. All translators should be warned before the meeting begins.

4. the study team should identify at least 2 translators in areas where language is a problem. Health workers should not be among the translators.

5. The animator must be charismatic in his or her approach (should look convincing and interested throughout the meeting). Acknowledge even those responses considered weird. Normally responses considered weird usually spark off heated discussions, thus allowing the truth to come out. This is what you want. At that point some people are laughing while others may be angry. In such a situation take charge and appreciate the respondents, and tactfully ask the community members to clap for everybody who gave his or her contribution. This will make the respondents feel appreciated and provide weirder responses which in most cases, correct information. Quickly, comfort those who are angry, and move on.

Points to consider

1. Ask selected community members to count residents present (male/Female - 15 and above years of age).
2. Do you know the signs and symptoms of River Blindness?
3. How does a person get river blindness?
4. Do you have river blindness in this community?
5. Can you identify a person with river blindness in this community?
6. If no, how come there is no river blindness in your community
7. Do you still take Ivermectin tablets?
8. If no, why?

9. If yes, why?
10. Should Ivermectin treatment be re-established?
11. If yes, why?
12. If no, why?
13. Is there any person who had ever suffered from river blindness present in the meeting? (let the person share his story)
14. Ask whether they know any of other person in their community that had suffered from river blindness
15. How many people present in the community share his/her story (show of hands)
16. Are there persons who worked as CDDs for river blindness present?
17. What are the CDDs doing now?

- Ask the gathering if they have any questions or comments regarding elimination of river blindness.
- Thank them and the leaders for the good work they have done regarding elimination of river blindness
- Let the community leader close the meeting.

Annex D. Photo taken during the discussion with the community

Photo: By Oumer Shafi