



On the March in the Campaign against Onchocerciasis

By Peace Habomugisha

Julie Gipwola, from Uganda's Directorate of Information, recently caught up with Peace Habomugisha. The former wanted to know what, to date, were the major influences upon the latter's work since her appointment as Country Representative of The Carter Center Global 2000 in Uganda. One such influence was a unique assembly that Habomugisha recently attended. It was convened, in the West African metropolis of Ouagadougou, Burkina Faso, by the African Programme for Onchocerciasis Control (APOC). Sustainability of Community Directed Treatment with Ivermectin (CDTI) was its focus. Below we have a summary report, by Habomugisha, including some its benefits to her.

Special Workshop on the Sustainability of Community-Directed Treatment with Ivermectin

Early February, from the 2nd to the 5th, 2004, was the time of the event. Against general assumption that Burkina Faso is very hot, Ouagadougou was exceptionally cool and windy those days – a not so inhospitable background to the workshop.

Key Players

Over thirty delegates – health care specialists and others – converged for the special workshop. African participants came from such countries as Nigeria, Uganda, Ethiopia, Tanzania, Sudan, Cameroon,



Julie Gipwola talking to Peace at the Carter Center Office in Kampala

Chad, Burkina Faso, Congo Brazzaville and South Africa. The World Bank and producers of Mectizan (USA) were also represented. Peace Habomugisha was part of Uganda's three-person delegation to the workshop.

Objectives

The workshop was called to re-examine CDTI sustainability to date – its programs and non-monetary means of action; such of its traits as its successes, failures and weaknesses; methods of tracking and assessing it; its financial

as well as other support mechanisms made possible by African and foreign institutions; and suchlike – with a view to realizing better future results, particularly regarding survival of CDTI, in the governmental and community health frameworks, when APOC funding stops.

Presentations and Procedures

Keynote and other papers came from some of the specialists. Participants, sometimes, split into teams charged

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Published by: Global 2000
River Blindness Program
and Vector Control Division,
Ministry of Health,
Plot 15 Bombo Road
Typeset by: Global 2000,
River Blindness Program;
P. O. Box 12027, Kampala
Tel: 256-41-251025
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with revisiting certain vital matters to make necessary recommendations. Views from the different teams, other times, would come to a common floor for debate, with each such team's deliberations and suggestions first summarized by one of its members.

Benefits

The workshop, in many ways, was highly informative as well as uplifting. Achievements and challenges, in Africa, of the effort to check onchocerciasis tended to come more into one's view. Many were the factors to which this state was due – in particular the assembly's deliberations in the light of APOC's intended or already implemented moves to withdraw its financial support from certain crucial aspects of this drive.

Government-employed health workers, in many areas of Africa, realized the present writer, are either less interested in, or too busy to attend to, community-based medical care. A major alternative to this predicament, she was convinced, is to mobilize and train some elite members of individual communities to serve their own people. Against this background, this author returned to Uganda determined to focus more on health education and advocacy for district leaders, politicians among them, to promote community-centred disease control. Achievement of high coverage as well as encouragement of communities to select as many Community Directed Distributors (CDDs) as possible (in excess of APOC's recommendation of 1 CDD per 20 households) and at least two supervisors per community became my prime goal.

Scheduled interactions with other workshop participants apart, this writer had informal encounters with many important individuals. These included APOC's Director Dr. Azodoga Seketelli, Dr. Uche Amazigo (Head of APOC's Sustainable Drug Distribution Unit), South African health scientist Professor Dr. Detlef R.

Prozesky as well as representatives of the World Bank and the USA makers and donors of Mectizan. Issues discussed with them included whether APOC is fully satisfied that participating national and district governments will sustain the onchocerciasis eradication program after the organization has withdrawn its funding; weaknesses and other challenges faced by APOC evaluators and whether the evaluators' tools and judgements portray what is on the ground. Habomugisha also raised the issue of using kinship zones in CDTI. This was supported by Prozesky and many others who agreed that where kinship exists, it can be exploited by CDTI strategy such as in being used to integrate the element of CDT into the control of community-based diseases other than onchocerciasis. Those and many more enriching experiences were to result in the strategies that were finally recommended by the extraordinary assembly, and to these we now will attend.

Workshop Recommendations

After four days of exchange and discussion of a wide spectrum of experiences, ideas and visions, recommendations, for best performance in the war on onchocerciasis, were made. Minor editorial changes aside, the following are the resolutions from the workshop in verbal as well as material terms. The editing was necessitated by the need to make clearer, than previously, certain points or simply to cut out things that are not that relevant to the present report.

Health Service at State, Regional and Provincial Levels

- The level should devolve planning, financial and material inputs to the District/Local Government health service, including fund management.
- The weak link of Frontline Health Facility (FLHF), at the sub-district level, in the CDTI implementation chain should receive attention by the National Onchocerciasis Task

Forces (NOTFs).

- The NOTFs should ensure the implementation of recommendations of project evaluations and subsequent sustainability work plans should be developed.

District/LGA Health Service

- Integration of CDTI activities into other related services at this level (District/LGA) should continue. Where such integration has occurred, it should be implemented.
- Operational research should be carried out to test the positive effect of decentralized health systems on the sustainability of CDTI.

Sub-District/Frontline Health Facility

- There is urgent need to improve the capability of FLHF level personnel on record keeping, monitoring and supervision, training of CDDs as well as health education, sensitization, advocacy and mobilization (HSAM).
- The NOTFs should strengthen the FLHF to up-scale community self-monitoring.
- The quality of HSAM and training of community members and CDDs should be improved.
- Up-to-date information should be provided to communities to select as many CDDs as they require to achieve a ratio of 1 per 20 households.

Community Level

- APOC may consider developing a rapid sustainability evaluation tool that limits evaluation to the FLHF and communities.

- Communities should be able to decide how to disburse the funds from cost sharing.
- Documentation of costs contributed by communities, health personnel and districts should be subject of operation research in selected areas using a well-designed protocol.
- APOC should support research in CDTI management in urban communities and add on interventions.

Integration

- Ministries of health (MOH) should carry out organized high-level assessment of the integration of health services. Remedial action in response to the issues raised above might include issuance of guidelines on the role and active involvement of FLHF in planning local and district agendas. It may also involve organising district health management and Primary Health Care (PHC) teams on functional rather than profession lines.

APOC

- APOC should encourage countries to integrate activities such as training and training content.

Grading Projects Sustainability – Critical Elements

- Both qualitative and quantitative approaches should be used in judging the sustainability of projects.
- Qualitative data should be incorporated in future evaluations to enrich reports.
- Relevance or appropriateness of indicators for each level should be evaluated.
- To be able to use available baseline data in monitoring project performance the same groups of indicators

should be maintained.

Review of the Guidelines for Developing Sustainability Plans

- All partners supporting CDTI activities in a given area should be involved in the development of sustainability plans.
- During the development of sustainability plans, information on the background and performance of a project as well as the REMO map should be available.
- The role of each participating partner should be clearly defined in the sustainability plan.
- Development of the sustainability plan should critically address the issues raised in evaluation reports for different levels.
- CDTI activities should be an integral part of the health plan at the national, regional and district levels.
- The developed sustainability plan should conform to the set conditions for further support by APOC.
- The developed sustainability plans once ready should be signed by the responsible district authorities and Non-governmental Developmental Organisations (NGDOs) representatives prior to forwarding them to APOC.
- There should be a clear documentation, awareness and accountability on the contribution and flow of monies for CDTI activities by the District authorities.
- District authorities should attend discussions to plan CDTI sustainability as well as feedback meetings to have insight of project performance.
- District sustainability plans should be reorganized to reduce cost.
- CDTI projects should liaise with other health programs to make it possible to include gov-

ernment-employed and other health staff in routine training of CDTI implementers.

- District authorities should sign final sustainability plans as a clear indication of their full participation, understanding and commitment to CDTI activities.
- APOC takes the responsibility of preparing budget forms and sending them to NOTF offices of the participating governments. NOTF offices are to be responsible for sending these forms to their respective projects.
- Well before the time of feedback and workshops for drawing up sustainability plans, districts should receive copies of necessary guidelines to scrutinize them.
- All projects should be evaluated in their 3rd year and only those found problematic in sustainability terms should be re-evaluated in their 5th year.
- Evaluated projects, during their 3rd year, should take advantage of taking account of evaluators' recommendations.
- International and national experts should be involved in both evaluations.

A Critical Outlook and Concluding Words

APOC's pull out from districts, where it has been carried out or is yet to be executed, is one thing about which this writer is sceptical despite the viewpoint that it has a great potential to sustain CDTI. Most especially in Uganda, APOC did not give to onchocerciasis-infested districts all the funding they were supposed to get from it. Individual districts were thus constrained by this, and were, consequently, not able to do and accomplish all that they hoped

to achieve. In the short term, at least, the pull out will likely jeopardize the districts' ability to create strong CDTI systems as they cannot be self-reliant enough overnight.

APOC's February assembly has, no doubt, brought a significant perspective to the current writer's work in the campaign against onchocerciasis. One great idea, however, is that such extraordinary workshops could be held, on a rotational basis, in different African countries to benefit larger numbers of officers, high and low, pitted against river blindness. This is one high-profile way by which we can wrest the campaign from the hands of the top few officials to the many who wage the onslaught.

End

Onchocerciasis in Kisoro District: One Man's Perspective

By Peace Habomugisha
in collaboration with
Stella Agunyo

Kisoro is at the extremity of southwestern Uganda, just next door to Rwanda and the Democratic Republic of Congo. Here, in the village of Bitare, lives Mzee Petero Ndyabarutsya – the man who shares with us how he sees and has seen what we know as onchocerciasis. An opinion leader, in the elderly stage as shown by the title *Mzee*, he has seen tens of decades come and go in his homeland about which he knows quite a lot.

It was Habomugisha's original plan to interview Ndyabarutsya and others of his ilk herself. An impact assessment of river-blindness activities in Uganda's Bushenyi District, under the supervision of the African Program for Onchocerciasis Control (APOC) and in which she was allo-

cated an important role, barred her from heading for Kisoro for the appointed time. This prompted the district's Onchocerciasis Co-ordinator (DOC), Christopher Ruzaza, to step in at the last minute and interview Ndyabarutsya using questions earlier organized by Habomugisha and others. All that, happily, took place under the keen eye of Stella Agunyo, of Uganda's national office of The Carter Center Global 2000, who was in the region for a monitoring exercise on the ongoing treatment and health education activities there. Below are the excerpts of the interview, which took place on 16th March 2004, followed finally by a wrap-up from Habomugisha. Every one of the questions is put to Ndyabarutsya who does



Mzee Petero Ndyabarutsya

all the answering.

Question: Please tell us about yourself.

Answer: I am called Mzee Petero Ndyabarutsya, of Bitare village. I am 72 years old, was a *Mutongole* (parish) chief till the National Resistance Movement (NRM) government came to power in Uganda. This was about the mid-1980s and that was when I retired. At the moment I am an opinion leader in my village. I am a peasant and that is

my source of survival; but because I am quite old and weak I hire labour occasionally.

Question: Do you know about the disease onchocerciasis?

Answer: Yes, I first heard about it in 1993 when my village was involved in skin snipping and rapid assessment. Although I had seen cases of onchocerciasis I did not know what kind of disease it was or what its cause was. Gradually, I got to know more about it through education by such health workers as community supervisors and drug distributors.

Question: Tell us more about it.

Answer: I know that it is treated using small white tablets that are given once every year. A dose is mainly determined according to one's height using a calibrated stick but there are also instances when age has been used to determine dosage. The signs and symptoms of the disease are rough skin, scars on the body, nodules, blindness, and elephantiasis of the private parts. Victims of onchocerciasis or its potential casualties, who are

not eligible to receive treatment, are pregnant mothers, children less than 5 years and people suffering from heart attack.

Question: Did you receive treatment with ivermectin this year?

Answer: Yes.

Question: Are there people in this community who do not take ivermectin?

Answer: Yes, but they constitute a very small percentage of the society.

Question: What are the reasons they give for not using the drug?

Answer: The reasons are many. For some, they do not have worms. The other reason that they give is that they have taken the medicine for quite long, so there is no need to continue. Others say that when they take ivermectin they get side effects. For the *Barokore*, saved Christians, Jesus is

Question: What is the composition of these *Barokore*?

Answer: There are about equal numbers of adult males and females. The leaders of this religious sect tend to target men for new membership because the former know that men have authority over their families. So, usually, when a man joins this group, he takes along his wife and children.

Question: What then is the way forward? Namely, what do you, as com-

Answer: The common practice is that a meeting is convened by the community leaders in a community center. Community members then select people from among themselves by show of hands. These are people in whom the members have confidence.

Question: As an opinion leader in this society, how have you been involved in the Community-Directed Treatment with Ivermectin (CDTI) program?

Answer: My main task is mobilization for mass treatment. People are beginning to wonder whether this treatment will ever end, and if it is to do so, when. I encourage them to go for treatment and I educate them as well about the need for continued treatment for as long as the drug is available.

Question: What are the common diseases in your village?

Answer: The common diseases are malaria, dental problems, worms, measles, backaches, eye ailments, swelling of the legs and ulcers.

Question: Do you have a village health committee?

Answer: No.

Question: What do you think should be the possible solution to your health problems?

Answer: We need an ambulance because the distance from our village to the health centers is quite long. More importantly, there is urgency for health education to advance knowledge and practice of high-level hygiene among community members. Use of safe water needs stressing in a big way. It is also significant that people should be advised to construct latrines.



Christopher Ruzaza (DOC, Kisoro) addressing the religious sect ('Barokore')

their healer; so there is no need to take ivermectin. It is however amazing that among the *Barokore* it is the men who normally refuse to take the medicine. The women usually take the drug secretly without informing their husbands.

Question: Can you tell us more about this religious sect, the *Barokore*, in your society?

Answer: It is very difficult, basing on my own experience, to get information about these people and what exactly they are involved in. This is because they do not interact closely with the rest of the community members.

community members, plan to do to promote the use of modern medicine, among the *Barokore* and others, who are ill-disposed to it, in fighting onchocerciasis?

Answer: Nothing, we will wait for government to come to our help.

Question: Well, let us go back to the matter of the distribution of ivermectin; how is it organized?

Answer: Community leaders and the distributors mobilize people to take the drug after they have been informed about its arrival by the supervisors.

Question: How were your distributors selected?



A traditional ambulance managed by the engozi group

Question: Which is the health center nearest to this community?

Answer: It is Rutaka Health Center which, however, is NGO-funded. It is about 11km from our community. We also have a government health center called Kinanira. This one is about 13km away. Some people go to Kinanira; others to Rutaka.

Question: What is the mode of transport to health facilities in the case of very sick people?

Answer: In such situations, we have the 'traditional ambulance', *engozi*, which is managed by a special group of individuals. This 'ambulance' is a stretcher made of local materials. When need arises, members of the *engozi* group carry the patient to hospitals or other health centers. Otherwise most people walk to health facilities.

Question: What do people do when they fall sick?

Answer: They seek medical treatment. They prefer modern medicine to 'traditional' drugs because they think it is far superior to the latter. Herbs and other 'traditional' medical concoction are, however, used for treatment of some diseases, but usually among the older generations.

Question: Thank you very much *Mzee*. What do you think you people can do, as fellow community members, to eradicate from your midst the affliction of onchocerciasis?

Answer: We need to continue taking ivermectin for as long as we can get it. It also is important for us to encourage other affected communities to receive the same treatment. What I should mention here, and that is what I should have noted at the beginning of this interview, is that we appreciate this programme and ask that you continue sending us the drugs. We now generally know the need and benefits of taking this drug, which include, among others, de-worming oneself, improvement in one's skin condition and improved eyesight. Thank you so much.

Wrap-Up

This we shall attempt in few words. The dialogue-like interaction between Ndyabarutsya and his interviewer says a lot. For example, it is quite an important window into the nature of some of the facts, misunderstandings, myths and hypocrisies surrounding the offensive, in Kisoro, on onchocerciasis. Ndyabarutsya, for his part, towers as one of a new crop of people ready to venture and experiment with modern therapy despite its real or perceived weaknesses.

End

News Flash

Justin Ochaka (27th January-2nd February, 2004)

Was in Nebbi District, Uganda, where he held a meeting with the District Health Team. They discussed issues pertaining to CDTI sustainability, in the area, as well as those concerning total involvement of the district health staff in the matter. Ochaka also visited the district's sub-counties where onchocerciasis is endemic. This was a follow-up on the pledges they made in support of their community supervisors. He did, too, call upon some of the region's communities to find out the level of their involvement in CDTI activities.

Peace Habomugisha (1st-5th February, 2004)

Participated in a special APOC meeting, in Ouagadougou, Burkina Faso, on the sustainability of CDTI.

Stella Agunyo and Harriet Sengendo (2nd-8th February, 2004)

Were in Kanungu District, Uganda. There they had discussions with some important district leaders regarding the latter's role in and contributions towards CDTI activities. Again, they met certain members of some communities: With them, the duo discussed issues concerning these

Treatment Updates (Jan-Mar 2004)

Name of District	Total Popn	Popn treated during current month	Popn treated cumulative for 2003	Ultimate Tx Goal (UTG) for 2003	Total Popn TX % for 2003	Popn TX % of UTG 2003	No. of Villages treated during the current month	Active villages cumulative for 2003	Active villages UTG for 2003	Active villages % for UTG for 2003
Apac	15,672			12,818					9	
Gulu	204,879			150,660					187	
Kabale	17,475			15,235					48	
Kanungu	46,448			38,873					105	
Kasese	95,717			79,637					131	
Kisoro	21,315	1,890	15,062	17,861	70.7	84.3	32	32	32	100
Mbale	179,749			140,091					580	
Moyo	177,788	13,168	61,880	140,069	34.8	44.2	82	82	189	43.4
Nebbi	283,519	82,144	82,144	232,546	29	35.3	376	376	670	56.1
Sironko	59,789			49,905					191	
TOTAL	1,273,479	131,502	254,400	1,024,258	20	24.8	574	642	2,360	27.2

people's knowledge of onchocerciasis and its control. The people's involvement in CDTI was, as well, a focus of discussion. The two officers also tracked down ivermectin records from the district headquarters down to health centers IV, III and II. Also they had talks with the health workers, at these levels, on matters of integration of onchocerciasis control into their health system.

Peace Habomugisha (27th February 4th March, 2004)

Went to Atlanta, Georgia, USA, on invitation to attend the 'annual programme review' event of The Carter

Center Global 2000.

Stella Agunyo (15th-21st March, 2004)

Travelled in Kisoro, Uganda, to monitor ongoing treatment and health education activities. Mainly she visited some communities that had had a history of low treatment coverage under the onchocerciasis program. Several issues, concerning CDTI, were discussed between her and community members.

Peace Habomugisha (15th-30th March, 2004)

Was in Bushenyi District, Uganda, to take part in 'program impact assessment' un-

der APOC. Other 'assessors' were from such countries as Ghana, Togo, Sudan, Tanzania and Kenya. Habomugisha served in the role of social scientist for the evaluation.

Justin Ochaka (22nd-31st March, 2004)

Worked in Moyo and Adjumani districts to monitor ivermectin distribution and other CDTI activities. He also discussed, with district leaders, issues concerning program sustainability and their commitment to monetary contributions for supporting CDTI work.

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