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PREDICTORS FOR COMPLIANCE WITH COMMUNITY DIRECTED IVERMECTIN TREATMENT IN BUSHENYI DISTRICT OF UGANDA: QUALITATIVE RESULTS

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ABSTRACT

Objective: To understand and elicit the factors influencing compliance with mass treatment with ivermectin for onchocerciasis control with a view of suggesting remedial measures.

Design: Qualitative methods using focus group discussion and individual key informant interviews.

Setting: Bushenyi district, Uganda.

Participants: Fifty key informants who were local council chairpersons and community directed drug distributors (CDDs) for ivermectin. Five focus group discussions with community members.

Main outcome measures: Explored knowledge about onchocerciasis and its treatment, consequences, benefits and perceived dangers of treatment with ivermectin. In addition the FGDs elicited information regarding social influence towards ivermectin treatment and who the source of social influences are. Perceived barriers and supports towards ivermectin treatment were also explored. The key informant interviews mainly elicited the problems they face in ivermectin distribution and their suggestions for improvement.

Results: Factors that could possibly influence mass treatment with ivermectin that were elicited include consequences of treatment, programme organization, charging for ivermectin distribution and programme/community support to the ivermectin drug distributors.

Conclusions: These results are helpful in redirecting community education and in helping to design further quantitative research.

INTRODUCTION

Globally out of 120 million people who are at risk of onchocerciasis, 96% are in Africa. A total of 18 million people are infected with the disease of whom 99% are in Africa resulting into a serious health hazard and impending economic development(1). The parasite causing onchocerciasis is transmitted from person to person by the bites of female simulium fly *Simulium damnosum* and *Simulium neavei*, which breed in fast-flowing rivers and streams. In Uganda's Bantu languages, the simulium fly is locally called *Mbwa flies* (*mbwa* means dog). This is because of the voracious bites the fly inflicts.

In Uganda onchocerciasis is endemic in 18 out of 56 districts with about 1.45 million people infected and about 1.8 million people in the country at risk of infection(2). Bushenyi district located in South Western Uganda has got three forests and several fast running streams/rivers that provide appropriate conditions for the simulium fly breeding. Out of the total Bushenyi district population of 738,355 people 33% live in onchocerciasis infested areas.

Control of onchocerciasis: In the 1960's, the only safe method for control of onchocerciasis was through larviciding to reduce the vectors (by dosing of rivers). Therapeutic drugs like suramin and diethyl carbamazine are very toxic and produce severe adverse reactions. However, the discovery of Mectizan (ivermectin, MSD) that is relatively non-toxic has changed the control of onchocerciasis making mass chemotherapy of infested communities an alternative, safe and cost-effective approach for the control of the disease(1). Mass treatment with ivermectin started in Uganda (Bushenyi district inclusive) in 1992 and will continue for 10-15 years if onchocerciasis is to be eliminated as a disease of public health importance(3).

Compliance with ivermectin treatment in Bushenyi ranges from 20-74%. Yet for elimination of onchocerciasis there is need to attain and maintain a high Annual Treatment Objective (ATO) of at least 90%(4). Moreover, reasons for this persistent low coverage are not well established. Therefore, there is need for operational research to elucidate reasons for low treatment coverage with a view of suggesting

measures for reaching and maintaining a high enough ATO necessary for elimination of onchocerciasis in the district. The objective of this study is to understand and elicit the factors that could be influencing compliance with ivermectin treatment in Bushenyi district with a view of suggesting remedial measures.

MATERIALS AND METHODS

Design: Qualitative research methods were used for data collection using two approaches (focus group discussions and key informant interviews). The data was collected from January to March 2003, two months after the 2002 ivermectin distribution. The focus group discussions (FGDs) were held with community members (a total of five FGDs with community members where onchocerciasis is endemic). The FGDs elicited and explored knowledge about onchocerciasis, its transmission and its treatment. Attitudinal beliefs towards ivermectin treatment, the consequences, benefits and dangers of ivermectin treatment were also explored. Additional information was elicited on social influence regarding ivermectin treatment, who the source of social influences are and on perceived barriers and supports towards ivermectin treatment. The key informant interviews mainly elicited the problems people in the programme face in ivermectin distribution and their suggestions for improvement.

Study setting and population: Bushenyi district in southwestern Uganda has a land area of 3949 square kilometers of which 370 square kilometers are wetlands and 396 Square kilometers are covered by water. The altitude is 910-2500 metres above sea level and average annual rainfall about 1500 mm. The district has a population of 738,355 people (2002 census) and is administratively divided into five counties, 28 sub-counties, 166 parishes and 2049 villages. Of these four counties, 10 sub-counties, 33 parishes and 420 villages with about 33 % of the total district population are infested with onchocerciasis. The communities affected by onchocerciasis in Bushenyi district are mainly in highlands around the fringes of the district where access to other health facilities is low. The research was carried out in 4 out of 5 counties afflicted and affected by onchocerciasis in the district. The prevalence of onchocerciasis infection is within the 30-70% range in many of these communities. The people mainly live in rural areas whose main occupation is subsistence agriculture. The political leadership is hierarchical based on the Local Councils and Committees (LCs). The LCs are labeled (I) to (V) depending on the level. Villages are LCI, parishes LCII, sub-counties LCIII, counties LCIV and the district LCV. The leadership includes a LC chairperson who heads the corresponding committee comprising of nine elected members. An LCI executive for example heads the village council and LCII executive heads the parish council and so on. The LCs chairpersons and the local committees are responsible for general administration and decision-making. At least one third of members of the LC executive must be women. In addition there are parallel women councils and committees based on the same system as LCs but which are directly responsible for women affairs.

Ivermectin distribution in Bushenyi district: Community Directed Treatment with ivermectin (CDTI) started in Bushenyi in 1998 with the support of Ministry of Health (MoH) and African Programme for onchocerciasis control (APOC). Since then this has been the method of onchocerciasis control

in Bushenyi. The total number of communities in hyper and meso-endemic areas in Bushenyi district is 418 (these are LCIs). The drug is provided free of charge by Merck drug company to the onchocerciasis control programme of the Ugandan ministry of health. Distribution usually start after an initial mobilization and health education about onchocerciasis and its treatment with ivermectin. Education includes the benefit of ivermectin, as an effective drug against river blindness with possible side effects e.g. itching, dizziness, headache, nausea and swollen limbs which disappear after a while. Communities are supposed to select their own community drug distributors (CDDs) who are then trained by staff of the district headed by the District Onchocerciasis Coordinator (DOC). The DOC is also responsible for distributing the drug to CDDs who then distribute the tablets to community members using the mode of distribution agreed on by the community. The records of treatment are made at the community level and then sent to district health office whose staff are responsible for monitoring and supervision of the implementation process. During the November/December 2002 distribution, 26 Trainers of Trainees (ToTs) were trained and these trained about 1236 CDDs. The first census of affected communities was done in 1998 and the registers were supposed to be updated by the CDDs and LCIs every year before treatment commences. Updating registers included modifying for births, deaths and migrations. However, the updating is sometimes not done due to lack of resources.

Sample size and sampling: In this qualitative aspect of the study, the sample size was determined purposefully and strategically. Five FGDs and 50 key informant interviews were conducted in parishes selected purposefully to reflect variations in ivermectin treatment coverage. The sampling for the FGDs was based on the treatment coverage results of the year 2002. A total of five focus groups were selected considering the variations in performance of the affected parishes. The parishes were categorized according to their performance. Of the five FGDs, two were conducted in areas of high treatment coverage (>70%), two in areas of low treatment coverage (<50%) and one in an area of medium treatment coverage (50-70%). In all cases the focus groups consisted of 8-9 participants with 2 or 3 of them being females.

The key informants were CDDs and LCI chairpersons that were selected from the parishes where the focus group discussions were held. The CDDs and LCs were considered to be key players in onchocerciasis control in their communities and therefore deemed to have vital information.

Data collection tools: A discussion guide was used to conduct FGDs. The FGDs were conducted by three people. One moderator (male), one assistant (female) and one of the principal investigators (JO). The moderator guided the discussion whereas the assistant took notes and also noted the non-verbal communications. The investigator took care of the audio equipment recording the discussions. For the key informant interviews, pre-designed, pre tested interview schedules were used. Both the FGDs and KIs were conducted in the local language of Runyankole.

Data management and analysis: After each FGD, the first impressions from the discussion were discussed and written down. Within a few days of collection of raw data, the notes and the tapes were transcribed into a wellorganised set of information. The organized raw data was then ordered in relation to the discussion topics using a manual analysis sheet. The ordered data was then summarised by listing the data that belong together(5,6). Analysis of interviews of key

informants was based on the questions asked during the interview. This involved sorting the interviews by the questions asked and ordering the responses. Then the responses were then grouped together and summarised.

Quality control: Research assistants were trained in conducting FGDs and administering the individual key informant interviews. Interview schedules were translated in the local language (Runyankole) and then back to English to ensure that the meanings are maintained. By comparing data from the two sources (FGDs, key informant interviews), it was possible to collaborate the various sources of data.

Ethical Considerations: The study was approved by the Uganda National Council for Science and Technology. Prior to data collection written permission was sought from the Bushenyi district authorities. Informed verbal consent was obtained from all subjects before interviewing commenced.

RESULTS

Five FGDs and 50 key informant interviews were held during this study. All the FGDs were held in rural areas either under a tree shade or in a quiet room. Each FGD lasted about 1.5 -2 hours. The FGDs consisted of 8-9 people each and included men as well as women. Thirty of the key informants were CDDs whereas 20 were LCI chairpersons. The results from FGDs and KI interviews are presented in an integrated manner. A note is made where the results differ, though in most cases they collaborated and complimented each other.

Perception of onchocerciasis as a health problem: The FGDs and key informant interviews indicated that malaria was the main health problem in their areas. In all the five FGDs conducted for heads of households, malaria was spontaneously mentioned as the number one health problem. This was followed by dirty water and then onchocerciasis (*Obukambi* in local language). About 80 % of the CDDs however ranked onchocerciasis as number two health problem following Malaria and then dirty water as third most common health problem. Others mentioned as health problems in the FGDs included cough, dental diseases, worms and HIV/AIDS.

Cause /transmission of onchocerciasis: The participants in the FGDs and key informant interviews were mostly not able to differentiate between cause and transmission of onchocerciasis. Cause and transmission in most cases were used interchangeably. Most of the participants in the FGDs said that onchocerciasis is caused by drinking or even just coming in contact with dirty water. Such situations the participants said include bathing in the river, collecting water from the river and washing cloths in the river. Others however said onchocerciasis is caused by a small insect (*Akakoko*). Some participants referred to the small insect as "embwa flies" (*Simulium*) and they believe the flies live in the forests and in the game park in company of wild animals. A few participants however thought that the small insect lives in fast running water in the valleys. About 85 % of the CDDs on the other hand said that onchocerciasis is caused by "Embwa" or *Simulium* flies which live in dirty river water.

Knowledge of signs and symptoms of onchocerciasis: The FGDs and KI revealed that the people in these affected communities can easily identify signs of onchocerciasis. They are quite knowledgeable about the manifestations of the disease. Signs and symptoms mentioned by the participants include body swelling, body itching/scratching, scaly skin, hardening of skin, white pale bodies, hanging groins, stunted growth, blindness, watery eyes, blurring of vision and red eyes. The household heads seemed as knowledgeable as the CDDs and LCs with respect to the signs and symptoms of onchocerciasis. The general impression gathered by FGDs and KI interviews was that a person cannot be infected with onchocerciasis and yet be asymptomatic.

Treatment and prevention of onchocerciasis: Most participants in the FGDs and key informant interviews said that onchocerciasis is treatable/preventable and can only be treated/prevented with modern medicine. But a few participants believe that onchocerciasis is not treatable/preventable. Their argument was that if onchocerciasis was treatable why is it that the patients tend to die immediately they are given this tablets. One participant remarked; "In my village three people who had symptoms of the disease died as soon as they took the tablets". This view was mainly held by participants in one of the parishes which performed poorly in the last ivermectin distribution exercise. No mention was made in the FGDs of alternative ways of treatment like traditional medicine.

Community mobilization for CDTI and services of CDDs: The majority of the participants in the FGDs and key informants said the drug is usually distributed by the CDDs once a year, and that after the distribution season you cannot find the drug anywhere. However, most of them could not tell when the next distribution will take place.

Selection of CDDs: The FGDs revealed that the local council chairmen usually choose the CDDs. This was in agreement with the finding in the KI where 22 out of the 30 CDDs interviewed said they were selected by the L/C chairman. Choice of the CDDs is therefore not done by the community in the majority of cases. Individual LC chairpersons interviewed said they select people to become CDDs basing the decision on their education and demonstration of cleanness.

Duties of CDDs: Participants in the FGDs pointed out two main duties that are being performed by the CDDs namely distribution of the tablets and keeping treatment records. The LC chairmen also concurred with this observation. However, about 80% of the LCI chairpersons and CDDs complained that keeping of records was more cumbersome than distribution of tablets. They further added that updating of registers and keeping records was too much work to be done on voluntary basis. Most of the LCIs and participants in FGDs also said that other than distributing the drugs the CDDs do not perform their other functions of health

education and sensitization of the community on onchocerciasis treatment. The majority of the participants in the FGDs also said the CDDs are not able to explain to the people all aspects of onchocerciasis. The CDDs blamed this on inadequate training, lack of supervision and lack of facilitation like transport. In the KI with the CDDs it was revealed that the training usually lasts one day, which they said is inadequate. Sixteen out of 30 CDDs (53.3%) said the training lasted only one day and all of them said the training was inadequate.

Eligibility to take ivermectin and dose determination: Generally participants in the FGDs and KI were aware of the categories of people who are not supposed to take ivermectin. They said that children less than five years of age, sick people, pregnant women, and breast feeding mothers are not supposed to take the drug. The heads of households were as knowledgeable as the CDDs on this issue. The criteria for determining how many tablets an individual should take was, however, highly contested. The participants doubted the accuracy of the practice of measuring the heights as a way of determining the dose of ivermectin. They argued that one can be very tall and yet weak so such a person can easily be overdosed. They linked this "error" to cases of instant deaths following ivermectin administration. One participant in FGDs said "you can be short like me but have more strength than a very tall person. So in that case I can withstand a higher dose of that strong drug than a tall person. Tall people are usually weak. There is a man in my place who survived death narrowly. His body is still swollen. These people gave him four tablets because he is tall and he could not manage them. Infact most people don't want to take the tablets because of over dose. They should take body weight not height".

Support and payments to the CDDs: Some of participants in the FGDs and the individual interviews said that the CDDs charge 100 Uganda shillings (about 0.05 US\$) per person for the tablets but that this is not compulsory. The money is meant for lunch for the CDD during the distribution exercise. The CDDs however were divided on this issue. Twenty out of 30 CDDs (66.6%) said they don't charge any fee for the tablets while others (33.3%) said that some community members give them some little money for lunch but not as a fee for the tablets. It was also said that some CDDs are paid in kind by the community (e.g. by giving them food, drinks, chicken, or exempting them from community service).

Beliefs about ivermectin: Participants in the FGDs and the KI interviews mentioned very many reasons why some people in the community hesitate to take ivermectin. The statements made by some of the participants regarding mass treatment are below. "Some people fear side effects of the drug like, swelling of the body, body itching, hardening of the skin, diarrhoea with worms in the stool, headache, dizziness and vomiting" "Some people say they are not sick of

onchocerciasis so they can not take drugs for nothing". "Some people believe that if you take the tablets when you are already infected with HIV you die faster so they don't want to shorten their life". "People whose relatives have died after taking ivermectin don't accept to take the drug for fear of death". "Some people do not take the drug because of the restrictions that accompany it for example you are not allowed to drink, smoke or play sex until after four days". "Some people just refuse to take the drug without any reason". "Some people believe that ivermectin causes infertility". "Some men believe that the drug affects their manhood. Once you take that drug you can not perform in bed" "Some people believe that this is governments plan to reduce fertility in rural areas". "Some people think this is a trick by the white man to kill all black people".

CDTI performance according to the population: The majority of the participants said they preferred the current programme compared to the earlier one. A number participants highlighted the fact the current programme is using their own people to distribute the tablets and that these days it is easier to get the tablets. The CDDs however had their own reservations about CDTI programme. One such CDD had this to say. "CDTI is working well but it does not know its workers. They don't care about the welfare of the people who distribute the tablets. Updating registers and keeping records is a lot of work that should not be for free".

Problems faced by the CDDs: The problems mentioned by the CDDs in key informant interviews included lack of transport and facilitation to traverse the whole village in 20 out of 30 CDDs, non-payment of allowances in 18 out of 30 CDDs, resistance by the people to take ivermectin by 10 out of 30 CDDs, lack of carriers for the tablets by 13 out of 30 CDDs and lack of proper storage facilities for the tablets at home mentioned by 7 out of 30 CDDs.

Social support to take ivermectin tablets: In the FGDs it was said that it is mainly a personal/family choice to choose or not to choose ivermectin. However, participants said that some people in the community like health workers, CDDs, local leaders, religious leaders, friends, may actually influence whether one takes ivermectin or not. Information got from radios was also mentioned as influencing taking of ivermectin tablets.

DISCUSSION

This study combined FGDs and individual key informant interviews to understand and elicit factors influencing mass treatment with ivermectin. We have previously found these combined methods useful in explorative research related to health promotion, in identifying determinants for behaviour and to elicit responses for subsequent use in the quantitative phase(7). In this study these two methods of data were complementary and gave the advantage of exploring the depth of the study issues in question and eliciting the

factors that are probably important in influencing compliance. Data from the two sources largely collaborated and enriched each other.

This study revealed that the community is not knowledgeable about the cause of onchocerciasis. As expected the lay people seem to mistake the agents of transmission for the cause. The participants were aware that the "small water insect", and forests play a role in causing/transmitting onchocerciasis but they cannot appreciate how. This knowledge gap is probably due to insufficient health education to the community. This might in turn affect compliance to treatment and prevention methods. The majority of the participants easily mentioned the signs and symptoms of onchocerciasis especially skin and eye changes. Furthermore most participants agreed that onchocerciasis is treatable. They have seen people who have improved after treatment with the modern drug ivermectin. Use of such people to give testimonies like during village meetings may be helpful in encouraging others to take ivermectin.

Most participants were in agreement that some people in the community do not take the medicine for onchocerciasis. The negative attitudinal beliefs identified in this study may explain the reasons for not taking the drugs. A lot of sensitization is thus required to counteract these negative beliefs. However, most participants indicated that people are more willing to take the tablets than before as was indicated in the number of people taking tablets increasing with time. The participants attributed the increasing compliance to the new community directed approach of distribution of ivermectin. They said the CDDs are people from within their communities, are easily available and are trusted by the people. Health education is one the main strategies towards improving treatment, so the role of the CDDs becomes very crucial. Unfortunately, according to the participants the CDDs themselves are not knowledgeable enough on the subject. Most CDDs admitted that they are lacking knowledge and that the training was too short to have equipped them with the necessary knowledge and skills to conduct health education on onchocerciasis. Indeed individual interviews with CDDs revealed that most CDDs were trained for only one day.

The CDDs who participated in the study also cited other problems they encounter in their work. They included among others: non-payment of allowances, and lack of facilities for proper storage and dispensing the tablets. These data also indicate that some CDDs charge a small fee for the tablets. This may deter some people from taking the tablets. Experience from Uganda and elsewhere shows that payment of even a small fee (0.25US\$) for other health services greatly hinder access(8-10).

It is necessary to realize that the results of this study are useful in identifying possible beliefs and barriers that could influence compliance with CDTI. It is not possible with this design to gauge which of these beliefs/barriers differentiates people who comply from those who do not comply. Additional quantitative research is necessary to identify which of these elicited responses are important for compliance with CDTI. The results of this study will be used to design a questionnaire that will be used to collect determinants for compliance with CDTI in a quantitative way. However, these results can help managers of CDTI in tailoring their health education to the needs and beliefs of this population.

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