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NON-ADHERENCE TO COMMUNITY DIRECTED TREATMENT WITH IVERMECTIN FOR ONCHOCERCIASIS CONTROL IN RUNGWE DISTRICT, SOUTHWEST TANZANIA
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NON-ADHERENCE TO COMMUNITY DIRECTED TREATMENT WITH IVERMECTIN FOR ONCHOCERCIASIS CONTROL IN RUNGWE DISTRICT, SOUTHWEST TANZANIA

T.L. LAKWO and D.B. GASARASI

ABSTRACT

Background: **Community directed treatment with ivermectin (CDTI) for onchocerciasis control was developed as a strategy for achieving sustained high coverage in endemic communities. This strategy for over a short period of time has radically altered the consequences of infection with *Onchocerca volvulus*. The present challenge is maintaining the high therapeutic coverage especially in some of the impoverished endemic countries. One of these challenges is non-adherence to ivermectin treatment and this provides compelling reason for data collection at community level.**
Objective: **To describe the factors associated with non-adherence to CDTI.**
Design: **Cross-sectional descriptive study.**
Setting: **Communities participating in CDTI activities in Ndubi village, Rungwe district, southwest Tanzania.**
Results: **A high proportion (66%) of respondents were aware of onchocerciasis, and this was more significant in males than females ($X^2 = 9.17$; $p < 0.002$). Knowledge on causes of the disease was low, only 29.3% associated it with the bite of *Simulium* fly, 17% associated it with mosquitoes, 17.1% to houseflies, and 30% had completely no idea. Knowledge on signs and symptoms of onchocerciasis was also observed to be equally low (20.4%) among the respondents. Similarly, only 35.4% of the respondents knew itching, swelling of the body, diarrhoea and vomiting as associated side effects of ivermectin. There was, however, no sex difference in knowledge levels ($X^2 = 0.01$; $p > 0.939$). Low knowledge levels on causes of the disease, signs and symptoms and side effects of ivermectin were attributed to inadequate health education in the communities. However, some other factors associated with non-adherence were local beliefs and the lifestyle of alcoholism.**
Conclusions: **Factors identified to affect programme implementation and associated with non-adherence were inadequate knowledge on causes of the disease and sign/symptoms, side effects of ivermectin, local beliefs and lifestyle of alcoholism in the communities.**

INTRODUCTION

The community directed treatment with ivermectin (CDTI) adopted by the African Programme for Onchocerciasis Control (APOC) was initiated to improve on ivermectin distribution in endemic communities. A new chapter in onchocerciasis control was opened following the registration of ivermectin in 1987. This drug has a potent, rapid action against skin microfilariae. Massive reductions in microfilariae counts occur during the first few days. This is attributed to the fact that ivermectin has a marked effect in adult worms by blocking the release of stretched microfilariae from the uterus

followed by microfilariae degeneration. These effects last for more than six months and are mainly responsible for the prolonged suppression of skin and ocular microfilarial counts (1). This eventually has impact on both the prevalence and intensity of *Onchocerca volvulus* microfilariadermia (2). The mass distributions of ivermectin in communities from different geographical zones have registered significant impact on the transmission of the disease (3,4). This treatment strategy also empowers the community to design a method of distribution that is suitable to its needs and has been a major innovation for mass treatment (5), thus enhancing sustainability, ownership and cost savings by health departments (6).

The application of this strategy in the mass distribution of ivermectin in sub-Saharan African countries through the community involvement has made a tremendous impact on the burden of the disease and has marked an important milestone in the continuing effort to control its adverse consequences (7,8). The APOC was formed in December 1995, with funding from the World Bank and other donors (9). The goal of APOC is to establish, within a period of 12-15 years, effective and self-sustainable community-directed ivermectin treatment in the endemic areas of the 19 countries outside the Onchocerciasis Control Programme (OCP) of West Africa. Within these 19 countries, 85% of the world's onchocerciasis is present. The APOC objective is to establish country programmes that provide yearly treatment to areas meso- and hyperendemic for onchocerciasis (>20% nodule prevalence). It was estimated through a simulation model that by achieving an overall treatment for 65% of the population, the public health consequences of onchocerciasis would be eliminated within 20 years of treatment (10). However, in spite of achievements made through CDTI strategy, problems have been encountered in its field implementation and management. Some of these problems include inadequate health education (11), lack of community support to distributors, poor attendance at village meetings and distributors' attrition (12,13). These factors are believed to have negative impact on adherence to any onchocerciasis control project. These emerging problems need to be addressed if projects are to achieve their control objectives. For instance, cases of refusals and absenteeism during drug treatment have been cited. Oyibo & Fagbenro (14) encountered refusal levels of 2.8% and absenteeism of 38% in Kwara State, Nigeria. Refusals and absenteeism have negative impact because the untreated population can still maintain a significant intensity of transmission in the community. It also contributes to low treatment coverage of the target population.

Tanzania like any other APOC participating countries has not been free of these problems. One of the problems that have emerged is non-adherence associated with refusals and absenteeism reported in two of the five CDTI projects. For instance in 2002, in Tukuyu focus, of the 63,001 eligible populations for ivermectin treatment, 8,211 and 3,200 constituted absentees and refusals, respectively. While in Mahenge focus in Morogoro region, refusals and absenteeism constituted 7.6% and 6.7%, respectively (15,16). Low treatment coverage and systematic non-adherence to treatment can maintain some level of transmission in the population. This paper reports on the factors associated with non-adherence to mass ivermectin treatment in Rungwe District, south west Tanzania. These findings offer some insights into how CDTI implementation could be improved in order to sustain it for the minimum of 15-year period recommended for onchocerciasis control (11).

MATERIALS AND METHODS

Study area: This study was conducted in Ndubi village situated in Tukuyu onchocerciasis focus in Rungwe district, south West Tanzania. This focus is located at the northern end of Lake Malawi between 9° 5′ S to 9° 45′ S and 33° 20′ E covering approximately 3000km^2 (17). The district is endemic for onchocerciasis and 36 villages out of the 142 villages in the district are affected and the total population estimated to be at risk is 69,740 (18). The Ministry of Health initiated community directed treatment with ivermectin (CDTI) in 1999. This replaced the vertical distribution programme that was supported by the River Blindness Foundation (RBF) from mid 1994 to mid-1997 and Sight Savers International in 1998. The therapeutic coverage before introduction of CDTI in 1998 was 89.4%; and post-CDTI coverages were 74.2%, 60.7%, 61.2% and 66.5% in 1999, 2000, 2001 and 2002, respectively (14,17). The Non-Governmental organisation currently working in partnership with Ministry of Health in the control of onchocerciasis in this area is Inter-Church Mission Association (IMA).

The Tukuyu onchocerciasis focus lies at an altitude of 2265 m above sea level. It receives the highest rainfall recorded in Tanzania, with annual mean above 2700 mm. The dry season is from June to October and rainy season from November to May. The vegetation ranges from upland grassland and rainforest on the large volcanoes and escarpment to woodland in the main part of the area. Due to the high fertility of the woodland soil, it is intensively cultivated and the population is the highest (69.4/ km^2) in Mbeya region (17). There are three main river systems in Tukuyu valley, the Kiwira, Mbaka and Lufilyo; all have their source at the slopes of Rungwe Mountains. These rivers have been known to be the main breeding sites for onchocerciasis vector, *Simulium damnosum* complex cytotype *S. kilibanum* (17,19).

Study design and sampling procedure: This was a cross-sectional study conducted in Ndubi village, one of the onchocerciasis endemic villages where CDTI is being implemented in Rungwe district. Ndubi village has a total population of 734, with 320 male and 414 female. In the estimation of sample size, the formula ($N = 4p\ (100-p)/Ý^2$) for estimation of proportions described by Kazaura *et al* (20) was used. The estimated sample size was multiplied by 1.5 as design effect since final sample size was obtained by multistage cluster sampling. A list of eight onchocerciasis endemic wards in Rungwe district was obtained from the District Onchocerciasis Control Programme office. One of the wards was randomly selected from the eight. A ward has four to five villages. In the second stage, a list of villages in the selected ward (Kasondela) was made from where one village (Ndubi) was randomly selected. A village consists of two to twenty village units. And in the third stage, Ndubi village has three village units (Kililia, Ndubi, Lusungo) and one village unit (Ndubi) was randomly selected for the study. The selection of the household started from the centre of the village unit and every fifth household was selected from each direction of the village unit until the sample size was obtained. The research assistants administered the questionnaires to members of households above 14 years participating in the CDTI programme.

Structured interviews: Structured questionnaire was used for data collection among respondents aged 14 years and above. The main theme of the questionnaire focused on knowledge on the disease, signs and symptoms, side effects of ivermectin, effects of side effects of the drug on adherence and attitudes of the distributors on CDTI programme. Each interview conducted in local language (Swahili) took between 30-35 minutes.

In-depth interviews: In-depth interviews with the distributors were to explore information on ivermectin treatment and problems associated with CDTI implementation specifically geared to adherence to treatment. Key informants were purposively selected based on their experiences and knowledge on the subject (21). Fifteen distributors from this village were interviewed. The interviews were conducted in one of the offices of the village chairman, agreed by the key informants as convenient and centrally placed. Note taking and audiotape recording for all the interviews were done. Summary of notes were done immediately so as to control quality of data. Consent for using tape recorder during interviews was obtained from the key informants.

Focus Group Discussions (FGDs): A total of seven FGDs following a prepared theme were conducted. This consisted of five groups among adults and two for the schoolchildren. The health workers also constituted one of the groups for the FGD in this village. A focus group consisted of six to eight people. Common factors among these groups included being in the same village of study and their participation in the CDTI activities.

The planning, organising and conducting all the focus group discussions in this village followed procedures that had been earlier described (21).

Data analysis: Non-computerised analysis was used for qualitative data. Summary from field notes and audiotape transcriptions from FGDs and in-depth interviews were used in the process of analysis. Two readers processed the transcripts, whereby potential themes from the scripts were identified, pulled out and categorised based on the research objectives under consideration. The final results of the analysis were presented using quotes from the discussions. The method mainly used was based on content analysis (21). Intergenerational analysis was not done since there was no prior set objective or

hypothesis for it. For quantitative data, the questionnaires were coded and entered in Epi Info 6 software for analysis. The key variables included in the statistical analysis were sex, awareness of onchocerciasis, knowledge, side effects; and sign and symptoms. Chi-square test was used where required. The level of significance was $p<0.05$.

Ethical consideration: Ethical approval for the study was obtained from Muhimbili University College of Health Sciences Ethical Committee. The respondents were informed of the voluntary participation and only those who provided informed verbal consent were recruited in the study.

RESULTS

Study population: The number of individuals who participated in the study is shown in Table 1.

Table 1

Showing individuals who participated in the study in Ndubi village, Rungwe district southwestern Tanzania

Study category	Number of individuals (n = 283)
Structured interviews	212
Focus Group Discussions	56
In-depth Interviews	15
Total	283

Structured interviews: Overall, 221 people were interviewed in the survey and among these 66% of the respondents had heard of onchocerciasis as opposed to 34% that had never heard. The males seem to be more aware of the disease than the females ($X^2 = 9.17$, $p<0.002$). Majority (52.9%) knew the local name of the disease as "Tusunia" in a Kinyakyusa language. "Tusunia" is a local name for *Simulium*, the vector for onchocerciasis. On the causes of the disease, only 29.3% (41/140) knew that the disease was associated with the bite of the *Simulium* fly while 30% (42/140) had no idea of the cause. Some of the respondents associated the cause with mosquitoes 17.9%; 17.1% (24/140) attributed it to houseflies and 12.9% (18/140) perceived the cause as a water insect without specifying the name. On knowledge regarding signs and symptoms of onchocerciasis, majority of the respondents had low knowledge on this subject. However, the most common signs and symptoms known by the few were body itching and skin rashes. No significant difference between knowledge levels on signs and symptoms was observed for males and females ($X^2 = 2.31$, $df = 2$; $p>0.314$).

On side effects, majority of the respondents (64.4%) did not know the side effects of ivermectin and only a small proportion (35.4%) indicated that they knew the problems like itching of the body, body swelling, diarrhoea, headache and vomiting associated with this drug. There was however no sex difference in knowledge regarding side effects of ivermectin ($X^2 = 0.01$; $p>0.939$). The results further indicated that a small proportion of the respondents (15.5%) reported to have experienced ivermectin-associated side effects mainly body swelling and itching. The majority (84.5%) did not experience any problems. Slightly more males (56.7%) than females (43.3%) reported to have experienced side effects. However, this difference was not statistically significant ($X^2 = 0.07$; $p>0.0786$).

Focus Group Discussions: The qualitative information from FGDs among adults aged less than 30 years confirmed that inadequate knowledge on the disease and side effects of ivermectin do exist. Lack of appropriate knowledge about the disease does compromise the willingness among communities to take ivermectin tablets. One of the discussant was quoted:

> "We do not exactly know the cause of this disease, yet they tell us to swallow these tiny tablets. (Male, 27 years, Ndubi village)"

Similarly, the occurrence of side effects in the absence of appropriate health education allows misconceptions to persist in the community. One of the discussants expressed:

> "The community thought the drug could bring fever and flu. People feared this was a kind of test in their body (Male, 29 years, Ndubi village)"

They believe if people knew more about the problem, they would be able to differentiate how this disease presents and hence the value of the current treatment programme. Due to inadequate knowledge,

onchocerciasis signs and symptoms are associated with HIV/AIDS disease. One male adult said:

> "The sign of this disease is relating to HIV/AIDS and people thought this was a way of giving out HIV. Others thought this is an experiment for HIV/AIDS (Male, 42 years, Ndubi village)"

The influence of ivermectin side effects on adherence revealed that most males constituted more of the refusals and absenteeism. Qualitative studies provided additional information on the influence of side effects on treatment adherence. It was noted that the respondents had a uniform belief that side effects have a lot of influence on community decision to take ivermectin drug. One health worker said:

> "Other people when they took this drug they got side effect such as swelling of the neck. And even myself when I took this drug my neck got swollen, and I am afraid of the drug (Female health worker, 50 years, Kisah Health Centre,"

In-depth interviews: On attitudes of distributors towards CDTI programme, it was observed that they had a positive attitude despite the problems encountered in the implementation of programme activities. They reported that some cases of refusals of the drug are associated with the lifestyle of the communities. One distributor said:

> "The main problem I faced was that some people were refusing to take the drug because they may not have time for drinking alcohol. Even in the central place for drug distribution some people absented themselves (Male distributor, 42 years, Ndubi village)"

They further observed that besides side effects of the drug and alcoholism, local beliefs have some significant impact on adherence. They noted that some religious beliefs have detrimental effect on their treatment effort. For instance, followers of certain religious sect (Assembly of God) believe that the power of the Lord Jesus Christ will cure all the diseases they have including onchocerciasis, therefore there is no need for swallowing ivermectin. One distributor said:

> "They believe through regular prayers the power of the Lord will protect them from any disease (Female distributor, 30 years, Ndubi village)"

These misconceptions are also shared by some sections of the communities who are linked to the religious sect.

DISCUSSION

The present study reports a survey on the non-adherence to ivermectin treatment in one of the CDTI villages in southwestern Tanzania. The results revealed that women were less aware of the disease than men although the disease is commonly known in the local language as "Tusunia". The existence of the name in the local language is expected to create a better understanding of the disease among the communities. This relatively low level of awareness could be attributed to life style differences. Men are known to move from place to place and in the process may meet more people suffering from onchocerciasis than women. Our study differs from that of Katabarwa *et al* (22) from western part of Uganda where they found that the women were more knowledgeable about the disease and benefits of taking ivermectin. In view of this, their participation in CDTI activities were much better than other endemic areas in the region. These regional variations could probably be due to the level of health education and participation in CDTI activities. And this finding has a possibility of influencing the treatment seeking behaviour of women in this particular study village.

The very low knowledge level on the cause of onchocerciasis in this community could still be linked to the poor health education set up. However, this proportion is much higher than the 11.8% previously reported in Mahenge focus, Morogoro region (16). It is interesting to note that in one of the ivermectin treatment programmes in Nigeria (Kwara state) where health education had been implemented, a higher proportion of respondents knowledgeable about the cause of the disease (63.3%) were reported (14). Health education provides the necessary information for change of beliefs, attitudes and behaviour. The low level of knowledge on the cause of the disease in the study area could be attributable to the level of health education received, and this

might have been inadequate hence the present information gap. The signs and symptoms of onchocerciasis is an important aspect of knowledge that is very crucial for the endemic communities if the effort to control onchocerciaisis is to be achieved. The clinical classifications of the signs and symptoms has permitted meaningful comparisons to be made of survey results from different geographical areas and helped in assessment of effects of mass treatment (23). However, this could probably reflect the background of the programme initiation in the village and health education strategy being used. Information on the disease is disseminated through the national radio station. This is however constrained by the mushrooming radio stations and most people prefer to listen to programmes of their choice. Thus most of the people miss the health education message put on the national radio. Similarly, the coverage of other information dissemination media like posters, use of churches and schools appear to be very poor.

Lack of information on side effects has been observed to be detrimental to the future of the programme even when the programme seemed popular. Information gathered from FGDs confirmed that, generally the community is fearful of ivermectin side effects. This anticipation of adverse reactions was an important deterrent to participation in future treatment cycles. The fear of side effects was also cited in some projects in Nigeria where communities were not informed of the associated side effects of ivermectin and this resulted in refusals and low treatment coverage (14). Among APOC participating countries, fear of adverse events appeared greatest in Cameroon, a country with relatively low ivermectin treatment coverage. This has been associated to potentially serious reactions that have occurred after treatment of persons co-infected with *Loa Loa* (3).

The present data on adherence suggest that non-adherence was reported mostly among the men in this village. This could probably be associated with their social lifestyle and fear of side effects as expressed in FGDs and in-depth interviews with the community directed distributors. One discussant said:

> "I am among the people who experienced problems after taking this drug. I refused to take this drug because the drug brings side effects such as body weakness, skin rashes and reduction in sexual power. So even next time I will not take it again"

Besides, the community has misconceptions about the drug and its use. Information from FGDs revealed that fears about ivermectin are linked to the community beliefs that the drug is being tested for its efficacy against Human Immunodeficiency Virus (HIV). One of such local beliefs associated with ivermectin treatment was also reported in Central African Republic where the community refused to take the drug because it was considered to be a poison from the President who wished to "kill off" the opponents (24). In this present study the various misconceptions encountered needs to be properly understood by programme implementers if they are to understand community perceptions of the disease and the need for the current treatment with ivermectin.

In conclusion, the study revealed high awareness of onchocerciasis disease. But knowledge levels on the causes of the disease, sign and symptoms and side effects of ivermectin were observed to be low. The low knowledge level seems to be attributed to inadequate health education. Key factors identified to affect implementation were side effects of ivermectin, social life style of alcoholism and local beliefs.

RECOMMENDATIONS

To improve treatment coverage there is need to bridge the gap in knowledge and practice. This should focus on mobilisation; re-education campaign tailored to health workers, village leaders and community at large, using appropriate health education materials about onchocerciasis.

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