

Involvement of women in community-directed treatment with ivermectin for the control of onchocerciasis in Rukungiri district, Uganda: a knowledge, attitude and practice study

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Received 3 April 2001, Revised 21 May 2001,

Accepted 22 May 2001

A study of knowledge, attitudes and practice was carried out in the Rukungiri district of Uganda, in order to investigate the involvement of women in community-directed treatment with ivermectin (CDTI), for the control of onchocerciasis. The data analysed came from interviews with 260 adult women (one from each of 260 randomly-selected households in 20 onchocerciasis-endemic communities), community informants, and participatory evaluation meetings (PEM) in eight communities.

The women who had been treated with ivermectin in 1999 generally had more knowledge of the benefits of taking ivermectin, were more likely to have attended the relevant health-education sessions and were more involved in community decisions on the method of ivermectin distribution than the women who had not received ivermectin in that year. There were fewer female community-directed health workers (CDHW) than male CDHW in the communities investigated.

The reasons for not attending health-education sessions, not participating in community meetings concerning the CDTI, and the reluctance of some women to serve as CDHW were investigated. The most common reasons given were domestic chores, a reluctance to express their views in meetings outside their own kinship group, suspicions that other women might take advantage of them, and a lack of interest.

Most of the women interviewed (as well as other community members) felt that there were relatively few women CDHW. The women attributed this to a lack of interaction and trust amongst themselves, which resulted in more men than women being selected as CDHW. The rest of the community members were not against women working as CDHW.

It is recommended that communities be encouraged to select women to serve as CDHW in the CDTI, and that the performances of male and female CDHW be compared.

In 1987 the drug ivermectin (manufactured by Merck & Co. Inc, under the trade name of Mectizan®), a microfilaricide and temporary

microfilarial suppressant, was approved for the mass treatment of humans who lived in communities exposed to onchocerciasis. A single annual dose of 150 µg/kg is sufficient to halt the progression of the disease manifestations

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in an infected person. However, such annual treatment has to be continued for at least 10–15 years in order to cover the life-span of the adult worms, which are not killed by the drug (Taylor *et al.*, 1990). Merck & Co. Inc., through its Mectizan Donation Program (MDP), has agreed to provide the drug free-of-charge, for as long as necessary, to all governments and organizations involved in onchocerciasis control (WHO, 1995).

National onchocerciasis control programmes (NOCP), based on chemotherapeutic control with ivermectin, have now been established in almost all affected countries, by consortia formed between the national Ministries of Health and various non-governmental development organizations. The aim of the NOCP is to treat, once a year over a period not exceeding 3 months, all those who are eligible to take ivermectin (i.e. excluding those who are < 5 years of age, weigh < 15 kg, and/or are < 90 cm in height, pregnant, mothers in the first week of lactation and/or the very sick) and are living in communities where $\geq 20\%$ of the population has onchocerciasis. Success is measured by the achievement of a treatment coverage of at least 90% of the annual treatment objective, which is itself equivalent to the whole population that is eligible to take ivermectin (Anon., 1996). This level of coverage is considered necessary if onchocerciasis is to be eliminated as a disease of public-health importance within a period of 10–15 years.

Since 1997, many NOCP have been receiving some financial assistance from the FAO/UNDP/World Bank/WHO African Programme for Onchocerciasis Control (APOC). Programmes involving community-directed treatment with ivermectin (CDTI) were recommended to, and adopted by, all APOC-supported projects, including those in Ugandan communities where onchocerciasis is endemic. During the implementation of the CDTI in Uganda, it was observed that an insignificant number of women had been selected, by their communities, as the community-directed health workers (CDHW). Although the women in traditional Ugandan communities act as healthcare providers for

their families and communities (Katahweire, 1989), their participation in the planning and decision-making processes in most 'modern' healthcare programmes has been minimal. They were assumed to be heavily under-represented in all CDTI activities, from the initial decision-making to the final distribution of the ivermectin. This under-representation is possibly the combined result of cultural beliefs, customs and taboos (including the resistance of men to accepting women as distributors of ivermectin), a general lack of health education, the women's domestic workload, their relatively low levels of education, and the often considerable distances between homes and the centres where community meetings are held.

The coverage and sustainability of CDTI would probably be improved if more women were actively involved, since women tend to stay within their communities throughout the year whereas the men move about more, in search of jobs (Rutabajuuka, 1994). Selection of CDHW is generally by show of hands in community meetings and one might expect the women present at such meetings to support the selection of other capable women in their community as CDHW. Unfortunately, this does not happen very often. The main aim of the present study was to investigate the reasons why so few women are CDHW, so that strategies for increasing the involvement of women in the CDTI can be formulated. As Ugandan women feel more comfortable and capable of community activity when among their own kinship or in kinships into which they have married, the organization of CDTI in endemic communities along kinship lines, for example, may increase female involvement (Katabarwa *et al.*, 2000a). The specific objectives of the present investigation were to: assess the attitudes of women towards the CDTI strategy; determine the levels of involvement of women in the design and implementation of CDTI; identify the constraints impeding (or factors in the existing health services which might promote) the involvement of women in the mass treatments; and devise appropriate ways of integrating CDTI into the women's other activities.

SUBJECTS AND METHODS

Study Area

The present study of knowledge, attitude and practice (KAP) was carried out in the Rukungiri district in south-western Uganda, in August–September 2000. At the time of the study, this district had a population of about 39 000, living in 12 onchocerciasis-endemic parishes where ivermectin is actively distributed. Two of these parishes—Masya (with nine communities and a total population of 3155) and Karangara (with 11 communities and a total population of 3082)—separated by a distance of at least 20 km, were selected for investigation.

Face-to-face Interviews with Women

One adult female respondent (aged >18 years) was chosen, for face-to-face interview, from each of 260 households (i.e. 13 from each of the 20 communities in the two study parishes). The first household investigated in each community was selected with the assistance of a random-number table (Kuzma, 1992), and then every second household following the first in the community-household register was selected until all 13 study households had been identified. Each interviewee was questioned on her knowledge of onchocerciasis, on her attendance at health-education sessions, on her knowledge of women's involvement in ivermectin distribution; and about the attitudes of women towards being distributors.

Participatory Evaluation Meetings (PEM)

While the face-to-face interviews of women in selected households were being carried out, PEM were also taking place in each of eight of the study communities: Kashenyi, Butare, Nyakabungo and Ngororero in Masya parish, and Nyamabare, Nsangyi, Kagoma and Rutare in Karangara parish. The selected communities were informed about the PEM and were involved in setting the day, time and place of the meetings (Katarbarwa *et al.*, 2000*b*). At least 35 adults (similar numbers of women and men) attended each PEM. The main issues

considered in these meetings, before arriving at a consensus, were the knowledge and attitudes on women's involvement, the involvement of women in the decision-making process, and the socio-cultural structures and processes that enhance or hinder women's involvement in CDTI. A few female 'key informants' were also used, especially where the study team sensed that some information was deliberately being 'left out' during a PEM.

Data Analysis

All the quantitative data collected, once checked, were coded, recorded on a computer and analysed using the Epi-Info software package (Centers for Disease Control and Prevention, Atlanta, GA). For most analyses, the women interviewed face-to-face were divided into those who had received ivermectin in the previous treatment round (in 1999) and those who had not. The data for these two groups were then compared, using χ^2 tests with Yates' correction.

RESULTS AND DISCUSSION

The valid responses of the interviewed women to the eight questions that could be answered simply 'yes' or 'no' are summarized in Table 1. For three of these eight questions, the percentage of the women who answered 'yes' differed significantly between those who had been treated in 1999 and those who had not. These differences indicated that, compared with the untreated women, the women who had been treated were more likely to claim that they knew the benefits of taking ivermectin, that they had attended health-education sessions, and that they had taken part in deciding on the method of distribution ($P < 0.05$ for each).

The numbers of respondents who said they had not attended health-education sessions, not attended community meetings to select CDHW, and/or had not attended community meetings to select the method to be used for distributing the ivermectin are given in Table 2, with the reasons for the non-attendances.

TABLE 1
The responses to the interview questions that could be answered 'yes' or 'no'

Question	No. and (%) of the women treated in 1999		No. and (%) of the women not treated in 1999		P
	Giving valid answer	Answering 'yes' / Answering 'no'	Giving valid answer	Answering 'yes' / Answering 'no'	
KNOWLEDGE OF ONCHOCERIASIS					
Do you know about onchocerciasis and its control?	200	200 (100)	0 (0)	60 (100)	> 0.05
Do you know the benefits of taking ivermectin?	200	198 (99)	2 (1)	50 (88)	< 0.001
Do you know the exclusion criteria for taking ivermectin?	200	198 (99)	2 (1)	58 (97)	> 0.05
Do you know people with onchocerciasis?	200	151 (76)	49 (25)	38 (63)	> 0.05
HEALTH EDUCATION					
Do you attend the health-education sessions on the ivermectin treatments?	200	168 (84)	32 (16)	34 (58)	< 0.001
COMMUNITY DECISION-MAKING					
Did you take part in the selection of CDHW?	200	135 (68)	65 (33)	36 (62)	> 0.05
Did you take part in the decision on the method of distribution?	200	131 (65)	69 (35)	30 (52)	< 0.05
Would you be willing to be a CDHW if selected?	200	155 (78)	45 (23)	46 (79)	> 0.05

CDHW, Community-directed health worker.

TABLE 2

Reasons given by the treated and untreated women for their non-attendance at health-education sessions, at community meetings to select community-directed health workers (CDHW), or at community meetings to decide on the method of ivermectin distribution

	<i>No. and (%) of the respondents who:</i>	
	<i>Had been treated in 1999</i>	<i>Had not been treated in 1999</i>
HEALTH-EDUCATION SESSIONS		
Reason given for non-attendance:		
I was not informed of the session	6 (19)	3 (12)
I had too much work	6 (19)	2 (8)
I was sick	4 (12)	3 (12)
The session was based too far away	8 (25)	3 (12)
I was too lazy	8 (25)	3 (12)
None	0 (0)	11 (44)
No. not attending	32	25
MEETINGS FOR SELECTION OF CDHW		
Reason given for non-attendance:		
I was not informed of the meeting	26 (40)	2 (9)
I was sick	25 (39)	9 (41)
I was busy in my garden	7 (11)	3 (14)
I was pregnant	2 (3)	6 (27)
I thought it was only for educated people	1 (2)	0 (0)
I was unable to walk the long distance	1 (2)	0 (0)
My husband attended and selected for me	3 (5)	0 (0)
None	0 (0)	2 (9)
No. not attending	65	22
MEETINGS TO CHOOSE DISTRIBUTION METHOD		
Reason given for non-attendance:		
I was not informed of the meeting	35 (51)	10 (36)
I was informed but failed to attend	23 (33)	6 (21)
I was sick	2 (3)	6 (21)
My husband prevented me	4 (6)	2 (7)
I was not interested	5 (7)	4 (14)
No. not attending	69	28

Fifty-seven of the respondents said they would be unwilling to become CDHW if asked to do so by their community (Table 3). Most (251) of the women interviewed were willing to say if they thought men, women or neither made better CDHW (for the purposes of ivermectin distribution); in this respect, there was no statistically significant difference between the answers of the treated and untreated women, or between the percentages who thought men made better CDHW and those who thought women made better CDHW (Table 4). All but two of the women

interviewed responded to a question on how they perceived the performances of women and men as CDHW: 98 (38%) said that women were more likely to be patient and tolerant than men, 73 (28%) thought that men were more active than women but more impatient, 82 (32%) said that women were more committed than men, and five (2%) said that men were rude.

Further analysis revealed that those who said that they had attended the health-education sessions were more likely to have been involved (or, at least, to claim they had

TABLE 3

The reasons why 57 of the women respondents (45 of the treated and 12 of the untreated) said they would not become community-directed health workers (CDHW) if selected

<i>Reason given</i>	<i>No. and (%) of the respondents who:</i>	
	<i>Had been treated in 1999</i>	<i>Had not been treated in 1999</i>
I could not manage the task	25 (56)	7 (58)
I have too many other responsibilities	12 (27)	3 (25)
This is educated work and I am illiterate	5 (11)	1 (8)
This work is for men only	3 (7)	1 (8)

TABLE 4

The performance of men and women as community-directed health workers (CDHW) distributing ivermectin, as perceived by 251 of the women respondents (196 treated and 55 untreated)

<i>Respondent's view</i>	<i>No. and (%) of the respondents who:</i>	
	<i>Had been treated in 1999</i>	<i>Had not been treated in 1999</i>
As CDHW, men are better than women	78 (40)	20 (36)
As CDHW, women are better than men	55 (28)	18 (33)
As CDHW, men and women are equally good (provided they are trained and willing)	63 (32)	17 (31)

been involved) in the selection of CDHW, the choice of the method of drug distribution, and the decision-making on the time of distribution ($P < 0.001$ for each) than those who said they had not been to the education sessions.

There were no significant differences between the two parishes investigated (data not shown). A large proportion (at least 70%) of the women interviewed in each parish claimed to have been involved in the decisions on the method of distribution, the location of treatment venues and/or the timing of the distribution. Similarly, >70% of the respondents in each parish said they would be willing to distribute ivermectin (within their kinship zones) if selected as CDHW.

Most of the women attending the PEM—111 (55%) of those in Masya parish and 99 (87%) of those in Karangara—appeared to know the symptoms of onchocerciasis, how the causative agent was transmitted, and how

the disease might be controlled (with ivermectin). Most of the women who attended the PEM—173 (87%) of those in Masya and 89 (78%) of those in Karangara parish—had also been treated during 1999. These results were generally similar to those of the face-to-face interviews.

The women who had not been treated in 1999 claimed they had not taken ivermectin because they were pregnant or very sick (and therefore ineligible) or newly married (and coming from communities where onchocerciasis was not endemic), because the treatment centres were too far away, or because of sheer laziness.

The PEM and discussions with key-informants indicated that basing ivermectin distributions on kinship zones rather than whole communities led to relatively short distances between homesteads and distribution or health-education centres, relatively quick but effective distributions, and better support and

increased appreciation of both female and male CDHW. There was a marked tendency among the inhabitants of both of the parishes investigated to attend only those community-information or health-education meetings that were held in their own kinships/zones, and long distances between home and the place of the meeting were definitely a deterrent to attendance. The men were clearly not opposed to women distributing ivermectin; in fact, several men stated that they would be pleased and proud to see their wives taking on this task. However, even among the study communities that had used a distribution system based on their kinship zones, there were still far fewer female CDHW than male. Seven (28%) of the total of 25 CDHW in the eight communities where PEM took place were female. Just nine (39%) of the 23 CDHW distributing ivermectin in Masya parish during 1999, and seven (29%) of the 24 CDHW in Karangara parish at the same time were female. (The corresponding values during the PEM were 31% of 13 in Masya and 25% of 12 in Karangara.)

Information from a number of female informants indicated that, although female CDHW would work effectively in their own kinship zones, many of them had married into other kinship zones and were therefore not closely related to those to whom they were giving ivermectin. Such CDHW were therefore not particularly trusted by their female neighbours, particularly by those belonging to the predominant kinship. This may explain, to some extent, why most women said they preferred male CDHW to female CDHW.

The present results indicate that a high percentage of the women in the study communities were knowledgeable about onchocerciasis, and of its control with an annual dose of ivermectin. The general view was that women were at least as capable of distributing ivermectin as men. It became apparent, during the discussions in the PEM, that the men in the study communities had no objection to the selection of female CDHW. Attendance at community-information or health-education meetings was better if such gatherings were arranged within a kinship or

kinship zone, close to the homes of the target population. Similarly, the members of a community were not keen to receive ivermectin from CDHW selected from outside their own kinship or zone. Indeed, CDHW selected from another zone are not well supported and cannot expect to receive the full co-operation of the target zone during ivermectin distribution (Katarbarwa, and Richards, 2001). Likewise, women appointed by community leaders (rather than being selected by community members) to function as CDHW (in areas inside and/or outside their own kinship zone) would suffer the same difficulties as males so appointed, and would be unlikely to continue the work for more than 1 year (Katarbarwa *et al.*, 2000a; Katarbarwa and Richards, 2001).

In analysing tribal communities, one has to make sense of kinship to make sense of everything else. Kinship is still a very important part of the social structure in most rural communities of Uganda. The competition for economic advantage and political power between these communities can be explained in terms of kinship. Kinship serves as a model for relationships to non-relatives and often to deities. Obligations between relatives are viewed as morally binding and their fulfilment ranks high among the 'paramount virtues' (Keesing and Strathern, 1998). Kinship replaces individual needs with collective goals, and self-gratification with social obligation. Many aspects of life become organized in terms of lineages, households, and networks of obligations which are defined by kinship and marriage. Each kinship in Uganda occupies a specific area of land which is either collectively owned (as commonly observed in the east and north of the country) or split into smaller pieces each of which is owned by an individual (as in central and western Uganda).

Ugandan kinships are patrilineal in nature, marriage requiring the bride to leave her parent's home and join her husband and his kinsmen. The children born through this marriage belong to the husband's lineage. Although women who marry into another kinship are integrated into that kinship, and still have a recognized place, roles and rights

within it, they are at a disadvantage when it comes to issues of inheritance and intra-kinship matters. Their access to resources, to social legal support and to respect and trust during community service are not guaranteed, and this drastically limits most of their functions within their husbands' kinship groups. Ignorance of, or bias against, this traditional structure and its legal system, by the promoters of modern health programmes, can be highly detrimental to the programmes' success (Katarbarwa *et al.*, 2000a). If the clan/kinship system is employed in the implementation of CDTI, then the distances to be covered by CDHW during their work are reduced, the number of individuals treated/week is increased, time is saved, ivermectin coverage is rapid and thorough, and the kinsmen are supportive not only of the CDHW but also of the programme.

There are clearly several factors, noted by the present subjects, which might hinder the involvement of women as CDHW in a CDTI. Whereas women are, in general, free and assertive during community discussions within their own kinship zone, they are often much more reluctant than men to express themselves in public while outside their kinship zone. Women are generally reluctant to attend any community meetings outside their kinship zone.

Although many of the present respondents participated in selection of CDHW, they tended to select male CDHW from their own kinship zone. The men, unlike the women, are likely to be of the same kin as all of the children and other men in the zone. The women themselves admitted that they had a tendency to disagree with their female neighbours over petty issues and to hold long-term grudges as a result. The female key-informants mentioned that a female neighbour, although your potential supporter, is also a potential enemy, as you are likely to disagree with her over petty issues. If you selected her as a CDHW and later you argued, she would have a chance of retaliating by mis-using the ivermectin or the water that CDHW give with the tablets (see Colson, 1966). The fact that a female neighbour appointed as a CDHW is

unlikely to be of your original kinship or even your husband's was seen as a particular problem by the women. At least their male neighbours were probably of the same kinship as their husband's and therefore considered more trustworthy than their female neighbours. Males also appear to have more opportunities of meeting and solving problems among themselves than women, and hence were less likely to keep grudges for long periods. There is no established structure or mechanism for solving any disputes arising between the women, however trivial. The mix of kinships represented by the women in each community makes close interactions among the women difficult.

When female informants were asked whether they would want to distribute ivermectin, it was evident that they valued distribution of ivermectin even if they did not get any monetary benefit out of it. They felt that they would gain something valuable which other women in the community, who did not distribute the drug, would not have. However, many wished to be less conspicuous to curious eyes, to retain their privacy, and be free from the pressure often exerted on the families of female CDHW to support other kinsmen (Haviland, 1997). They simply did not wish to 'stand out from the crowd'; this type of 'levelling' helps to minimise the prominence of any one woman in a community. By progressing, apparently at the expense of other women, a female CDHW would encourage envy and jealousy to develop, with some perhaps disastrous repercussions; such envy and jealousy is well described as the phenomenon of 'limited good' (Salzman, 1999).

Curiously, although these images of the 'limited good' and of 'levelling' appeared to be strong in the study communities, the women interviewed still appeared supportive of the selection of female CDHW. When the female key-informants were asked what could be done to give women the confidence to select their female neighbours as CDHW, they suggested the organization of neighbourhood women's groups. Such groups could take on small projects, to benefit the neighbourhood and to strengthen the bonds between the

members of each group. The groups would create more opportunities for regular discussions between the women, making it easier for the women to resolve their differences and increasing the level of trust between them. During the face-to-face interviews and PEM, several other problems reducing the involvement of women in the CDTI were identified: women having too much work at home; the centre for meetings being too far away; not being informed of meetings; sickness; husbands refusing to let their wives attend meetings; and women thinking that it is only men who can work as CDHW. By consensus, the community members attending the PEM (including many women) agreed that women's involvement would be enhanced if women attended health-education sessions, if meetings were held close to their homes, and if women participated in deciding when and where to meet.

In conclusion, increasing the involvement of women in the CDTI-related decision-making processes and respecting, understanding and making use of the traditional social structures and social legal systems are vital preliminaries to the recruitment of women as CDHW. Although most community members claimed that they were not opposed to the selection of female CDHW, social concerns led many women to vote against female neighbours who could have been nominated as potential CDHW. Dialogue among the women

and indeed all community members, on the recruitment of more women as CDHW, should be encouraged. General discussion and trust between women and the resolution of minor disputes between them should also be encouraged. The performances of community-selected and -trained male and female CDHW, and the extents to which the communities they serve appreciate the services of male and female CDHW, need to be compared.

ACKNOWLEDGEMENTS. This study would not have been accomplished without the combined support from the African Programme of Onchocerciasis Control (APOC), the Ugandan Ministry of Health, and The Carter Center, Global 2000 River Blindness Programme (CC-GRBP). We are also grateful for the logistical support received from J. Ocaka and H. Sengendo of the CCGRBP. We thank Rukungiri-district health services for allowing us to conduct this study in this district. We are indebted to M. Bajjurenda, the onchocerciasis co-ordinator for Rukungiri district, and his supervisors for travelling with us to communities to help in the collection of the data. We also acknowledge the co-operation and valuable information received from the local councils and community members. This study would not have been successful without the generous assistance of the respondents from Masya and Karangara parishes.

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