Women, Onchocerciasis and Ivermectin in Sierra Leone

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ABSTRACT

This longitudinal study examines the extent to which rural women in Sierra Leone who were excluded from treatment with Ivermectin because of pregnancy or breast-feeding obtained treatment at a later stage, and if they did not, why. The most important reason for women not seeking treatment was that they were waiting for the next mass treatment campaign. However, some of those who waited were again pregnant or lactating during the next mass treatment visit to their village. The author points out that in areas of high fertility such as Sierra Leone, such women may be continually excluded because they spend a large time of their child-bearing years either pregnant or lactating.

The study also investigates whether pregnant women in the area were treated inadvertently with Ivermectin and whether any side-effects were reported. The research shows that a large proportion of women remain untreated for long periods well beyond the requirements of the exclusion criteria. Moreover, over one quarter of pregnant women interviewed had received Ivermectin treatment (during the first trimester) with no adverse effects.
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The Gender and Tropical Diseases Resource Papers appear as part of a series of unedited final reports resulting from projects supported by the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR). These reports are submitted to the TDR Task Force on Gender and Tropical Diseases for review and evaluation upon completion of a project. Project reports included in this series have not been published in their entirety elsewhere.

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Authors alone are responsible for the views expressed in the Gender and Tropical Diseases Resource Papers and for the presentation of the material contained therein.
Foreword

The UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) is a globally coordinated effort to bring the resources of modern science to bear on the control of major tropical diseases. The Programme has two interdependent objectives:

- To develop new methods of preventing, diagnosing and treating selected tropical diseases, methods that would be applicable, acceptable and affordable by developing countries, require minimal skills or supervision and be readily integrated into the health services of these countries;

- To strengthen - through training in biomedical and social sciences and through support to institutions - the capability of developing countries to undertake the research required to develop these new disease control technologies.

Research is conducted on a global basis by multidisciplinary teams of researchers on the six diseases selected for special attention: malaria, schistosomiasis, filariasis (including onchocerciasis), the trypanosomiases (both African sleeping sickness and the American form, Chagas disease), the leishmaniases and leprosy, and “trans-diseases” areas, including Applied Field Research. The Gender and Tropical Diseases Task Force is one of the initiatives of the Applied Field Research Steering Committee.

The Gender and Tropical Diseases Resource Papers series represents a new communication venture undertaken by TDR’s Gender and Tropical Diseases Task Force. This series has been launched to facilitate and increase communication among social and health scientists, and others interested in gender issues in health, and to disseminate findings from TDR studies to disease control personnel and government officials concerned with improving the effectiveness of tropical disease control.

Resource papers published in this series are final reports of projects funded by TDR and usually include more material than ordinarily published in peer review journal articles. TDR considers this material to be valuable, especially for researchers and disease control personnel in tropical disease endemic countries who require more complete information on a topic than is generally provided in shorter journal articles.

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[Signature]

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Director
Special Programme for Research and Training in Tropical Diseases (TDR)
Acknowledgements

I am grateful to the Special Programme for Research and Training in Tropical Diseases (TDR) - Social and Economic Research - for providing technical and financial support as a re-entry grant of this project.

My gratitude goes to the Ministry of Health; Lunsar Eye Hospital; the Medical Research Council (MRC); Dr Boakye Boatin, epidemiologist; OCP in Burkina Faso; and Dr Njelesani, WHO Representative Sierra Leone, for their assistance in planning and implementing this project.

I am greatly indebted to the research team and respondents who gave their time and provided information.
Preface

The Gender and Tropical Diseases Task Force was established in 1994 in order to develop and implement measures to improve the health of women in countries where tropical diseases are endemic. As part of the preparation for the Task Force, research for the present paper was undertaken with the support of the Australian International Development Assistance Bureau (AIDAB), now known as AusAID. It is therefore appropriate that this paper is the first of the new Gender and Tropical Diseases Resource Paper series.

This paper reviews Australian projects concerned with women’s health, with special attention to those undertaken by non-governmental organizations (NGOs). It draws upon information from interviews with representatives of Australian NGOs, as well as a review of unpublished reports and documentation provided by these organizations.

While the projects all focus on aspects of women’s health, an important underlying goal is the empowerment of women with a participatory approach involving women in the determination of needs and priorities to be addressed. This has become a central approach in the activities supported by the Gender and Tropical Diseases Task Force.

Gender inequities were addressed in nearly all case studies presented in this paper in recognition of the fact that women’s participation in decision-making and their control over resources is key to sustaining the health benefits realized. The importance of gaining the support of men for women-centred interventions is also pointed out, especially with reference to one project where men felt slighted by their exclusion from project activities.

TDR has had a long and consistently positive relationship with the Tropical Health Program, Australian Centre for International and Tropical Health and Nutrition, and the principal author of this paper, Professor Lenore Manderson, has made important theoretical and practical contributions to TDR’s field research and training activities. It is therefore seemly that Prof Manderson and her team inaugurate this new Resource Paper series, based on the significant achievements of Australia’s international assistance programmes.

Carol Vlassoff
Manager, Gender & Tropical Diseases Task Force
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BACKGROUND AND RATIONALE FOR THE STUDY

In the countryside in Sierra Leone onchocerciasis is an endemic disease. Statistics for 1989 revealed that over 1 million people are at risk of infection in endemic areas, 300,000 are infected and 10,000 cases of blindness are attributable to the infection (OCP, 1990a). Recent studies done in Bo District in Southern Province by Whitworth et al. (1988) and Sesay & Trpis (1992) in Northern Province confirm that the disease is hyperendemic. In the Bo District study, a combined prevalence of 65% for both sexes and a community microfilariae load (CMFL) of 6.70 mf/mg of skin for those aged 20 and older were confirmed before treatment.

Consequently, Sierra Leone was included in the third phase (1966-1991) of the Onchocerciasis Control Programme (OCP) in West Africa. The programme involved a combination of vector control and the distribution of ivermectin through passive means as well as via treatment on a mass scale. Three mass campaigns have already taken place. The first campaign, which involved treatment of the inhabitants of the Taia and Gbangbaia river basins, achieved a coverage of 70.5% among a population of 39,045, the highest ever in the OCP (OCP, 1990b). The second and third campaigns were retreatment campaigns that achieved coverages that achieved coverages of 68.2% and 67.7%, respectively (OCP, 1991).

Non-governmental organizations (NGOs) were also involved in both mass and passive distribution campaigns. The most prominent NGOs are the Medical Research Council, located in Bo District in Southern Province and the Lutheran Mission Eye Hospital, located in Port Loko District in Northern Province. The records show that between 1988 and 1991 inclusive, the hospital treated 145,678 patients and distributed 202,138 tablets. Of the total number of patients treated, 12,479 were treated at the hospital, 15,757 by mobile clinics and 117,442 through mass campaigns.

These treatment campaigns were carried out in vertical programmes. The programme design did not include research on the knowledge, attitudes or practices of the populations concerned regarding the prevalence and transmission of the disease or on views regarding the criteria for administering treatment.

The present study thus examines knowledge, attitudes and practices regarding onchocerciasis among Sierra Leoneans, with a focus on the perceptions of women. This was done for two main reasons. First, the Special Programme for Research and Training in Tropical Diseases (TDR) was particularly interested in gender issues in relation to tropical diseases. The results of this study will provide information on how women in Sierra Leone recognize and perceive onchocerciasis, their attitudes to and use of medication, and socioeconomic determinants influencing knowledge and treatment practices.

Second, two of the exclusion criteria stipulated by Merck & Co., the pharmaceutical company that developed ivermectin, are specifically directed at women. The company recommends that pregnant women and mothers breast-feeding newborn babies should be excluded from treatment. Perhaps the majority of the 30% of women who were not treated during the first round of treatment in the Gbangbaia and Taia river basins by the national OCP may have been women in this category. If such women are infected but repeatedly excluded from treatment because of pregnancy, or because they are breast-feeding a child, they will form a reservoir for transmitting the disease.

It is therefore important that the views of pregnant and breast-feeding mothers concerning the exclusion criteria and the impact of these criteria on women's treatment prospects be sought.
OBJECTIVES

The aim of the study was to examine women’s perceptions of onchocerciasis in areas receiving mass treatment with ivermectin.

The specific objectives were:

• to study the knowledge, attitudes and practices of women in relation to onchocerciasis prevalence, transmission and treatment with ivermectin;

• to compare the general perceptions of women about onchocerciasis with those of opinion leaders and other community members;

• to investigate the views of pregnant and breast-feeding mothers denied treatment with ivermectin on the basis of the exclusion criteria;

• to assess whether any initiative was taken by pregnant and breast-feeding mothers to seek treatment after the specified period of exclusion;

• to describe the socio-cultural context of women’s lives in order to identify factors influencing health-seeking behaviour;

• to estimate the number of pregnant women treated unintentionally with ivermectin.

RESEARCH METHODOLOGY

Study Design and Selection of Study Villages

We designed a longitudinal study that involved two visits each to a number of villages. Villages along the Gbangbaia and Taia river basins in Southern Province and the Rokel river basin in Northern Province were selected for the study. These villages were chosen because they had been surveyed to assess the level of prevalence and intensity of infection by the OCP during an epidemiological surveillance. The populations of all three river basins subsequently received mass treatment of ivermectin.

Transmission and treatment are known to be different in the vegetational zones of Southern and Northern Provinces. Northern Province has a savanna type of vegetation and is mainly inhabited by the Temne ethnic group, while Southern Province is mainly forest with Mendes being the majority tribe. Separate sampling frames were used to bring out differences in knowledge, attitudes and practices between the two ethnic groups that derived from the varying transmission and clinical patterns of onchocerciasis in the different vegetational zones.

Within each sampling frame, the villages were stratified into high, medium and low levels of infection based on the CMFL. Between 8 and 10 villages were selected in each stratum to yield a total of 53 villages (28 from Gbangbaia and Taia river basins, and 25 from the Rokel river basin).
Data Collection Procedures

Quantitative Study

The main method for obtaining information on knowledge, attitudes and practices in relation to onchocerciasis prevalence, transmission and treatment with ivermectin and women's health-seeking behaviour was through interviews of the target population using predesigned and pre-coded questionnaires. The use of questionnaires had two limitations.

First, the majority of questions required pre-coded answers from which respondents could choose. This restricted exploration of views beyond the answers provided. Second, some of the questions reflected a biomedical view of the disease or illness, and questions pertaining to treatment with the drug also utilized the trade names of the drug.

Qualitative Study

Prior to the interviews, a qualitative study was carried out to address some of the above limitations. The qualitative study was done in two villages which were not selected for the actual study. The first was in Giema, in Bo District in Southern Province, and the other was in Karen, in Port Loko District in Northern Province. The aim of the qualitative study was twofold. First, it provided the opportunity to identify the names of onchocerciasis, blackfly and ivermectin in Mende and Temne, the local languages of the study sites, and also gave an indication of the general perceptions of both communities about the aetiology and treatment of the disease. Second, it helped in pre-coding answers to questions in the pre-coded questionnaire.

Focus group discussions were used for collecting the qualitative data. The group discussions were set up in both villages for adult males, adult females and children between 8 and 14 years. The discussions were led by trained focus group researchers speaking in Mende and Temne. The details of the discussions were recorded by one note taker with the assistance of a tape recorder.

The guidelines prepared for the qualitative study and the questionnaires used in both quantitative studies (baseline and follow-up) were pretested before final use.

Interviews with the Study Population

The interviews were conducted during two separate field visits in 1993 and 1994. During the first visit, four trained interviewers collected information from the target population in the villages located in each of the two provinces using the pre-coded questionnaires.

All females in the reproductive age group (15-49 years) provided information on knowledge, attitudes and practices in relation to onchocerciasis prevalence, transmission and treatment with ivermectin. Pregnant and breast-feeding mothers who had been excluded from treatment during the last OCP treatment campaign prior to the interview, and a few women who received treatment with ivermectin, were asked specific questions about their views regarding the exclusion criteria.

Data were also collected on demographic, social and economic characteristics of the participants' households, as well as daily activities and child-care responsibilities. This information facilitated the exploration of issues and themes which helped in understanding women's perceptions and behaviour.
Community leaders and elders, local healers, drug peddlers, pharmacists and health workers who were usually regarded as opinion leaders in the community provided similar information using the same questionnaires as those used for the women. Another target group was children between the ages of 8 and 14 years living in the same study villages. The fieldwork lasted for approximately one month in each of the two provinces.

The second field visit was carried out after a year's interval in 1994 in the study villages located along the Rokel river basin in Northern Province. The planned follow-up visit to villages along the Gbangbaia and Taia river basins in Southern Province was not done because of threatened rebel attacks in the area during the period scheduled for the visit.

During the follow-up visit to villages along the Rokel river basin, the pregnant and breast-feeding mothers who were identified during the first visit as having been excluded from treatment were reinterviewed. The purpose of this visit was to assess whether they had received treatment with ivermectin from the nearest health centre as a result of the information provided by the survey team during the first visit, or whether they had relied on the half-yearly visit of the Lunsar Eye Hospital team.

Data Management and Analysis

Questionnaires were reviewed for completeness and logical consistency. The coded data from both surveys were entered into a computer using dBASE, and analysed using Epi Info version 5.0.

Harvard Graphics was used for the graphical presentation of data. For the analysis of the qualitative data, written notes from the group discussions were synthesized with information from the recordings and analysed with reference to broad categories.

RESULTS

Coverage Achieved during the Fieldwork

Table 1 provides a summary of the study population for villages and eligible women. All 53 targeted villages (25 in the Rokel river basin and 28 in the Gbangbaia and Taia river basins) were visited to collect the required data. Of the 2637 women estimated to be within the reproductive age group (15-49 years) in the selected villages, based on the 1985 census projection (Govt. Of Sierra Leone, 1989), 2458 were successfully interviewed, producing a response rate of 93%.

During the first field visit, 265 women in the Rokel river basin study area were identified as not having received treatment during the mass treatment campaign carried out prior to the visit because they were either pregnant or breast-feeding. Contacts were made with all 265 women during the follow-up visit carried out after an interval of one year.
Table 1

Summary of the study population at both study locations

<table>
<thead>
<tr>
<th></th>
<th>No. targeted</th>
<th>No. actually contacted/interviewed</th>
<th>% response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study villages</td>
<td>53</td>
<td>53</td>
<td>100</td>
</tr>
<tr>
<td>Women 15-49</td>
<td>2637</td>
<td>2458</td>
<td>93.2</td>
</tr>
<tr>
<td>Women excluded from treatment (Rokel river basin only)</td>
<td>265</td>
<td>265</td>
<td>100</td>
</tr>
</tbody>
</table>

Characteristics of the Study Population

General Characteristics

Table 2 summarizes the general breakdown of the study population by location. The table shows that a total of 2678 respondents were interviewed in the 53 villages in both study locations (1249 respondents in villages along the Rokel river basin and 1429 in villages along the Gbangbaia and Taia river basins).

The respondents were classified into nine categories in the questionnaire. Three of these categories targeted women in the reproductive age group: pregnant women, nursing mothers and other females 15-49 years. The other six categories were children 8-14 years, traditional elders and leaders, health workers, local healers, drug peddlers and adult males. Women in the reproductive age group constituted 93.6% of the study population in the Rokel river basin and 91.3% in the Gbangbaia and Taia river basins.

Generally the respondents were young. The mean age of all females in the reproductive age group in both study locations was 28.0 years (27.9 years in the villages in the Rokel river basin, and 28 years in villages in the Gbangbaia and Taia river basins).

Education levels were relatively low. Over 75% had no formal education. The level of education was nevertheless significantly higher ($P < 0.0001$) among respondents located in Southern Province compared with those in Northern Province. In Southern Province, 14.6 and 5.9% of respondents had primary and secondary levels of education, respectively. Only two persons resident in the study villages located in Southern Province had progressed beyond secondary education (Table 3).
Table 2
Percentage distribution of the study population by age

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Rokel (N = 1249)</th>
<th>Gbangbaia and Taia (N = 1429)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcategory</td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>Pregnant female</td>
<td>148 (11.8%)</td>
<td>124 (8.7%)</td>
</tr>
<tr>
<td>Breast-feeding mother</td>
<td>515 (41.2%)</td>
<td>380 (26.6%)</td>
</tr>
<tr>
<td>Other female 15-49 years</td>
<td>499 (39.9%)</td>
<td>801 (56.0%)</td>
</tr>
<tr>
<td>Traditional elders</td>
<td>42 (3.4%)</td>
<td>71 (5.0%)</td>
</tr>
<tr>
<td>Other adult males</td>
<td>5 (0.4%)</td>
<td>15 (1.0%)</td>
</tr>
<tr>
<td>Health worker/local healer</td>
<td>9 (0.7%)</td>
<td>5 (0.3%)</td>
</tr>
<tr>
<td>Children 8-14 years</td>
<td>31 (2.5%)</td>
<td>33 (2.3%)</td>
</tr>
</tbody>
</table>

**Socioeconomic Profile**

At least 45% of respondents were indigenous to the area in which they lived, with 20% having lived in that location since birth and 25% for 10 or more years. The ethnic pattern observed was therefore as expected. The Mendes were the predominant group in Southern Province (82.4%), and the Temnes in Northern Province (99%).

Household sizes were relatively large. At least 74% of respondents belonged to households of between seven and nine or more persons. The housing facilities, with an average of four rooms per house, reflected the rural location of the study area.

Eighty percent of respondents located in villages along the Rokel river basin in Northern Province used pit latrines for toilet facilities, while about half (54%) of the residents in the study villages in Southern Province used the bush. Also, 72% of respondents in Northern Province depended on streams or rivers as their major sources of water, while those in Southern Province, depended almost equally on wells (41%) and streams or rivers (59.2%) as their sources of water.
Table 3
Educational status of respondents

<table>
<thead>
<tr>
<th>Educational Status</th>
<th>Rokel (N = 1237)</th>
<th>Gbangbaia and Taia (N = 1429)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>None</td>
<td>1083</td>
<td>87.6</td>
</tr>
<tr>
<td>Primary 1-3 years</td>
<td>37</td>
<td>3.0</td>
</tr>
<tr>
<td>Primary 4-7 years</td>
<td>52</td>
<td>4.2</td>
</tr>
<tr>
<td>Secondary</td>
<td>34</td>
<td>2.8</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Arabic</td>
<td>31</td>
<td>2.5</td>
</tr>
<tr>
<td>Other(s)</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Knowledge, Attitudes and Practices regarding Onchocerciasis Prevalence, Transmission and Treatment with Ivermectin for the Entire Population and for Women in the Reproductive Age Group

Local Terminologies for Onchocerciasis, Blackfly and Ivermectin

The local terminologies for onchocerciasis, blackfly and ivermectin and their literal translations among the Mende and Temne communities living in the two study locations are described in Table 4 below.

Two local names are used to identify onchocerciasis among the Mende community. One is linked to blindness (pumui heigbei) and the other (mayangay) to its skin-itching characteristics. Among the Temne community the two local names used to describe the disease are both associated with itching. *Mara* specifically means "skin itching sickness". The alternative name *roto* describes the itching symptom as "little frogs in the skin".

In both communities the itching symptoms were linked to the blackfly as the causative agent. The blackfly was known as *morwei* among the Mendes and *mapug* among the Temnes. The Mendes used two terms to identify ivermectin. One, *morwei halei*, associates the drug with treatment of the disease caused by the blackfly (*morwei*). The other, "oncho pills" is also used among the Temne community (but referred to as "oncho"). The term "oncho" is derived from an abbreviation of the biomedical term "onchocerciasis", and the word "pill" is the alternative English term for tablets.
Table 4
Local terminologies for onchocerciasis, blackfly and ivermectin

<table>
<thead>
<tr>
<th>Name</th>
<th>Mende</th>
<th>Temne</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Local terminology</td>
<td>Meaning</td>
</tr>
<tr>
<td>Onchocerciasis</td>
<td><em>pumu heigbe</em></td>
<td>blind sickness</td>
</tr>
<tr>
<td></td>
<td><em>mayangay</em></td>
<td>skin itching</td>
</tr>
<tr>
<td>Blackfly</td>
<td><em>morwei</em></td>
<td></td>
</tr>
<tr>
<td>Ivermectin</td>
<td><em>morwei halei</em></td>
<td>blackfly medicine</td>
</tr>
<tr>
<td></td>
<td><em>oncho pills</em></td>
<td>tablets for onchocerciasis</td>
</tr>
</tbody>
</table>

Disease Causation and Mode of Transmission

Respondents' perceptions of the cause of known symptoms of onchocerciasis and the mode of transmission of the disease were investigated in both the qualitative and quantitative studies. Participants in the focus group interviews discussed the causes of itching and blindness, while in the quantitative study the questions focused on knowledge about microfilaria, its mode of transmission and consequences of infection.

The information in the quantitative study was obtained by asking questions related to the following four areas: awareness that skin snipping was done in the village, reason for skin snipping, mode of transmission of microfilaria and consequences of bite from blackfly and microfilaria in the skin.

However, since the main aim of the study was to obtain women's perceptions of the disease, the results described in the following subsections focused on the perceptions of women in the reproductive age group.

Mode of Transmission of Onchocerciasis

Ninety-six percent of the women interviewed in the study villages along the Rokel river basin recalled the procedure of skin snipping of some individuals in their villages as compared with 77% of those in the Gbangbaia and Taia villages. The difference in recall was significant ($P < 0.0001$).

Similarly, 82.6% of women in the Rokel study villages attributed the procedure to the detection of microfilaria in the skin. The corresponding proportion of women in the other study location was 68.2% ($P < 0.0001$). A total of 17% of all women interviewed associated skin snipping with
detection of diseases in general, and 39% acknowledged that they did not know the reason for the procedure. More women in the Gbangbaia and Taia villages contributed to the "looking for disease" and "don't know" categories.

Most female respondents who were aware of the existence of tiny worms in the skin (microfilariae) also knew about the mode of transmission. Knowledge about the existence of blackfly was more widespread than was knowledge about microfilaria. With the exception of 26 women in the reproductive age group in the entire study population, the remaining women knew of the existence of the insect (blackfly). At least 60% of women in the entire study population mentioned blackfly as the agent for transmission.

Rapidly flowing water and farms were the two habitats or areas identified spontaneously by over 70% of women interviewed in the study villages in Southern Province (Gbangbaia and Taia) as likely areas for seeing blackflies. Fifty-six percent of the women in the same study location also mentioned the village. Female respondents in the study villages located in Northern Province (Rokel river basin) mentioned the farm as the site where blackflies are more likely to be found. Interestingly, 28% of those interviewed in Southern Province and 23% of those in Northern Province attributed transmission to mosquitoes.

Table 5
Percentage distribution of women in the reproductive age group by reasons given for skin snipping

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Rokel N = 1153 %</th>
<th>Gbangbaia and Taia N = 1302 %</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking for tiny worms in the skin</td>
<td>82.6</td>
<td>68.2</td>
<td>P &lt; 0.0001</td>
</tr>
<tr>
<td>Looking for diseases</td>
<td>2.4</td>
<td>14.2</td>
<td>P &lt; 0.0001</td>
</tr>
<tr>
<td>Don't Know</td>
<td>12.2</td>
<td>26.3</td>
<td>P &lt; 0.0001</td>
</tr>
<tr>
<td>Taking Blood</td>
<td>1.0</td>
<td>0.9</td>
<td>P &gt; 0.05</td>
</tr>
</tbody>
</table>

Perceptions of the Symptoms of Onchocerciasis

Perceptions of the symptoms and consequences of onchocerciasis were obtained from the focus group discussions and from individual interviews. Perceived symptoms of onchocerciasis include itching, skin diseases, blurred vision and blindness.

*Itching*: Data collected through individual interviews indicate that over 90% of females in the target group associated itching with bites from blackfly and the presence of microfilaria in the skin. This knowledge was even more widespread among women interviewed in the study villages in the Gbangbaia and Taia river basins (96.7%) as compared with women in the Rokel river basin (92.8%).
Skin disease: Some dermatological problems are perceived as due to onchocerciasis infection. Seventy-two percent of the female respondents in the Rokel river basin and 83% of those along the Gbangbaia and Taia river basins attributed “skin diseases” to bites from blackfly or the presence of worms (microfilariae) in the skin.

Blurred vision and blindness: These appear to be the least-known symptoms of onchocerciasis on the basis of responses obtained through individual interviews. The majority of female respondents, over 80%, linked neither microfilaria nor blackfly to blurred vision or blindness. Knowledge of the causative relationship to blindness was nevertheless significantly different ($P < 0.0001$) by study location. More females in the study villages along the Rokel river basin knew of this relationship (19%) than did those in the Gbangbaia and Taia villages (14%).

Perceptions of the Consequences of Onchocerciasis Infection

Participants in the group discussions identified persistent itching, skin sores, nodules, general malaise (headaches, bodily pains), blurred vision and blindness as the major physical consequences of symptoms of onchocerciasis infection. In addition, they reported that those suffering from severe symptoms of itching, skin complications and blindness are exposed to stigmatization. They are usually isolated by the community, and as a result are described as “embarrassed, unhappy, and depressed”. The blind in particular feel insecure, being at risk of environmental hazards.

Table 6
Percentage distribution of responses of women in the reproductive age group about mode of transmission of microfilaria

<table>
<thead>
<tr>
<th>Mode of transmission of microfilaria</th>
<th>Rokel ($N = 1128$) %</th>
<th>Gbangbaia and Taia ($N = 913$) %</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bitten by blackfly</td>
<td>58.2</td>
<td>41.8</td>
<td>$P &lt; 0.0005$</td>
</tr>
<tr>
<td>Bitten by mosquito</td>
<td>23.5</td>
<td>28.1</td>
<td>$P &lt; 0.05$</td>
</tr>
<tr>
<td>Eating/drinking contaminated food/water</td>
<td>14.6</td>
<td>10.6</td>
<td>$P &gt; 0.05$</td>
</tr>
<tr>
<td>Contact with an infected person</td>
<td>2.7</td>
<td>1.2</td>
<td>$P &lt; 0.05$</td>
</tr>
<tr>
<td>Don't know</td>
<td>22.9</td>
<td>29.3</td>
<td>$P &lt; 0.001$</td>
</tr>
</tbody>
</table>

Personal Experience of Onchocerciasis and Treatment Practices

Forty-three percent of the females in the target age group interviewed claim to have personally experienced symptoms of onchocerciasis in the past. Significantly more women (62%) in the study villages along the Gbangbaia and Taia river basins had apparently experienced symptoms of
onchocerciasis compared with women residing in the study villages in the Rokel river basin ($P < 0.0001$). The prevalence rate among women in the latter study villages according to their own perception is 23%.

Among those who experienced the infection, symptoms mentioned in both study locations include itching (89%), nodules (40%), skin disease (42%), blurred vision (10%) and blindness (0.4%). Only four women (one from the Rokel river basin and three from the Gbangbaia and Taia river basins) claim to have become blind as a result of onchocercal infection.

The most widely known means of treatment was the use of the drug ivermectin, as mentioned by 88% of the respondents. The national Onchocerciasis Control Programme (OCP) and Lunsar Eye Hospital provided treatment during mass treatment campaigns to 78% of the women who claimed to have suffered from symptoms of the disease. All but 9% of women admitted to improvement of the severity of the symptoms following treatment. However, 62% were still experiencing one or more of the symptoms. The proportion still suffering from the symptoms was significantly higher (69%, $P < 0.0001$) among women in the villages along the Gbangbaia and Taia river basins than in the Rokel villages. Figure 1 illustrates the decrease in the proportion of women in the target age group suffering from each symptom after treatment for each location.

**Fig. 1**: Proportion of women experiencing symptoms of Onchocerciasis (past / present)

![Bar chart showing proportion of women experiencing symptoms](image)

Even though ivermectin is distributed on a mass scale, 80% of the 1114 women who responded to the question on the exclusion criteria accurately identified small children, pregnant women, mothers
breast-feeding babies under one month old and the sick as groups excluded from treatment. Another 16% knew only of pregnant and breast-feeding mothers as groups excluded from treatment.

The frequency of treatment was recognized as biannual by 66% of the respondents. The women living in the Ghangbaia and Taia villages were more aware of the frequency of mass treatment with ivermectin than were their counterparts in the other study location (74% as compared with 57%). The difference was significant ($P < 0.0001$).

Ninety-seven percent of total female respondents knew that ivermectin is distributed at no cost to the individual. The distribution of the number of times the female respondents in the target age group have been treated by study location reveals that about half of those in the reproductive age group (54%) have received two or more treatments with the drug during mass treatment campaigns. Nearly one-third (30%) of those interviewed in the Rokel villages have never received treatment with ivermectin. The corresponding proportion of women in the Ghangbaia and Taia villages who had never received treatment with the drug was 14.1% ($P < 0.0001$).

As many as 51% of women in the target age group had not received treatment during the treatment campaign prior to the interview. The coverage achieved for the study villages in the Ghangbaia and Taia and Rokel river basins was 70 and 30%, respectively ($P < 0.0001$).

The most frequently mentioned reasons for non-treatment during the last campaign are presented in Table 7.

**Table 7**
Reasons given by women in target age group (15-49) for non-treatment during treatment campaign prior to interview, both locations combined ($N = 1163$)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living elsewhere</td>
<td>313</td>
<td>26.9</td>
</tr>
<tr>
<td>Absent on the day of treatment</td>
<td>245</td>
<td>21.1</td>
</tr>
<tr>
<td>Pregnant or suckling baby</td>
<td>534</td>
<td>45.9</td>
</tr>
<tr>
<td>Ill</td>
<td>22</td>
<td>1.9</td>
</tr>
<tr>
<td>Did not want treatment</td>
<td>49</td>
<td>4.2</td>
</tr>
</tbody>
</table>

The mass treatment campaigns have been relatively successful because of the positive perception of the effects of the drug. Besides relieving symptoms of onchocerciasis, women claim that the drug expels all other worms, resulting in improvement of general health. Respondents nevertheless identified oedema of the face, hands and feet, temporary increase in itching, dizziness, palpitation and insomnia as some of the side-effects experienced after taking the drug.
Overall Results Relating to Knowledge of Transmission and Treatment of the Disease

The level of overall scientific knowledge about the transmission of onchocerciasis and preferred treatment practices was, on the whole, higher for the respondents in the Gbangbaia and Taia study villages compared with those in the Rokel study villages.

Yet trends in knowledge were remarkably similar between the two study locations. Women in the older age group (40+) were more knowledgeable than those aged 15-39 in both study locations. Opinion leaders demonstrated greater knowledge of the transmission process and preferred treatment practices than did women in the reproductive age group and children between the ages of 8 and 14.

Knowledge of the transmission and treatment of onchocerciasis seem to increase with the level of intensity of infection. In both study locations, respondents in villages categorized as having high levels of infection were more knowledgeable than were their counterparts from areas with medium and low infection levels.

The Exclusion Criteria

Women's Views on the Exclusion Criteria

A total of 1114 women belonging to two separate categories expressed views on the exclusion criteria. The two groups included all pregnant women and women breast-feeding under one month who were excluded from taking ivermectin (569), and other women who had received treatment during the last treatment campaign (545).

Almost all of the women interviewed on this issue (97%) were aware of the reason for the non-treatment of some women in the reproductive age group during treatment campaigns. The majority (92%) approved of the exclusion criteria, irrespective of whether they had received treatment.

The distribution by reasons given for this positive view was significantly different for the two groups of women interviewed. Sixty percent of women who received treatment supported the exclusion criteria because of their respect for the views of medical authorities, whereas over 70% of the women who were excluded favoured the decision because of the view that it is for the safety of either the baby and the mother (Table 8). Sixty-nine of the women who approved of the exclusion criteria did not provide any reasons for supporting the exclusion.

However, 89 women (8%) interviewed favoured treatment for all women. The majority (76%) in support of the idea were women from the Rokel villages. Furthermore, out of the 89 women who felt treatment should be given to all women, 54 (61%) were women who had not received treatment during the last treatment campaign. Treatment was preferred because some women were personally experiencing symptoms of onchocerciasis while others disagreed with the reasons on which the exclusion criteria were based.
Table 8
Reasons for supporting the exclusion criteria (both locations combined)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Received treatment ($N = 452$) %</th>
<th>Did not receive treatment ($N = 504$) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect for medical views</td>
<td>60.8</td>
<td>24.2</td>
</tr>
<tr>
<td>Safety of baby</td>
<td>17.3</td>
<td>20.8</td>
</tr>
<tr>
<td>Safety of mother</td>
<td>19.7</td>
<td>52.8</td>
</tr>
<tr>
<td>Safety of mother and baby</td>
<td>2.2</td>
<td>2.2</td>
</tr>
</tbody>
</table>

Women Treated Inadvertently with Ivermectin

The possibility of inadvertent treatment with ivermectin during pregnancy was explored by establishing the pregnancy state at the time of the last treatment of those women found pregnant at the time of interview who had also received treatment during the last campaign.

Of the 100 pregnant women interviewed, it was found that 27 were treated inadvertently during pregnancy. Of those 27 women, 8 were between 15 and 19 years, another 8 were aged 20-29 and the remaining 11 were 30 years old or older. All such treatment took place during the first trimester of pregnancy.

Women's Health-Seeking Behaviour

Since a small amount of the drug is excreted in breast milk, and neonates do not have an intact blood-brain barrier, the World Health Organization (WHO) recommends an interval of at least one week after delivery before use of the drug by breast-feeding mothers. The study therefore also assessed whether breast-feeding mothers who were excluded sought treatment out of personal motivation by the time the baby was at least one month old.

Health-Seeking Behaviour of Breast-Feeding Mothers after the Exclusion Period

A total of 534 women (265 from villages in the Rokel river basin, and 269 from villages in the Obangbaia and Taia river basins) did not receive treatment, because they were either pregnant or breast-feeding. Out of these, 427 (80%) responded to the question on health-seeking behaviour. Only 5 (1.2%) of these women obtained treatment with ivermectin at either the Lunsar Eye Hospital or by the OCP after the stipulated exclusion period of one month. The remaining 422 women had not received treatment at the time of the interview. Half said they did not know where to get treatment. For 28%, the high cost of transportation was the obstacle to seeking health care, while 15% relied on the half-yearly visit of the Lunsar Eye Hospital or the OCP team for treatment (see Table 9).
Table 9
Reasons given by women for not seeking treatment after exclusion (both locations combined)

<table>
<thead>
<tr>
<th>Reason</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not know where to get treatment</td>
<td>221</td>
<td>52.3</td>
</tr>
<tr>
<td>Did not appreciate the need for treatment</td>
<td>9</td>
<td>2.1</td>
</tr>
<tr>
<td>Could not afford transportation costs</td>
<td>118</td>
<td>27.9</td>
</tr>
<tr>
<td>Waiting for the Lunsar Hospital or OCP team</td>
<td>65</td>
<td>15.4</td>
</tr>
<tr>
<td>Not stated</td>
<td>9</td>
<td>2.1</td>
</tr>
<tr>
<td>Total</td>
<td>422</td>
<td>100</td>
</tr>
</tbody>
</table>

Health Seeking Behaviour after One-Year Interval

In March 1994, a follow-up visit was made to the study villages in the Rokel river basin. This visit was carried out exactly one year after the first visit. The plan to make a similar follow-up visit to the study villages in the Gbangbaia and Taia river basins had to be abandoned because of security threats in the area.

Out of the 265 women who had been excluded from treatment in the Rokel villages because they were pregnant or breast-feeding, 262 (99%) recalled that they were advised to seek treatment by the survey team. They had also received information on the nearest health facility from which treatment could be obtained. Fifty-seven (22%) adhered to the advice and received treatment with the drug.

Table 10 documents the reasons given by the remaining 208 women for not seeking treatment. From the responses it is evident that there are other competing priorities which influence women's decisions to seek health care. For half of the women, domestic and child-care responsibilities were major contributing factors. Another quarter again cited the high cost of transportation as the main reason for not seeking treatment. However, the majority (76%) were relying on the half-yearly mass campaign for treatment.
Table 10
Reasons given by women for not seeking treatment one year after first visit (Rokel river basin only) (N = 208)

<table>
<thead>
<tr>
<th>Reason</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too busy with domestic activities</td>
<td>70</td>
<td>33.6</td>
</tr>
<tr>
<td>Too busy with child-care responsibilities</td>
<td>40</td>
<td>19.2</td>
</tr>
<tr>
<td>Could not afford transportation cost</td>
<td>52</td>
<td>25.0</td>
</tr>
<tr>
<td>Waiting for the next visit of the Lunsar Eye Hospital team</td>
<td>157</td>
<td>75.5</td>
</tr>
</tbody>
</table>

Despite hoping to receive treatment during the mass campaigns, 31% of the women were once again denied treatment during the subsequent mass treatment carried out in 1993 because they were either pregnant or breast-feeding at the time of the visit. This finding has implications for transmission of onchocerciasis. If such women are infected but repeatedly excluded from treatment because of pregnancy or lactation, then they will form a reservoir for transmitting the infection. They will also suffer from the discomfort caused by the diseases over a longer period than will others.

Socio-cultural Context of Women’s Lives with Possible Influence on Health-Seeking Behaviour

Gender Differences in Daily Activities

In addition to farming, women are also responsible for other domestic activities such as laundry, cooking and child care. Animal husbandry is apparently the only activity in which men predominate.

Marital Status, Reproductive History and Child-Care Responsibilities of Women

In the study area marriage was both universal and stable. By age 29, 95% of women were already married; by age 39 virtually all had been married, and 2% were already widowed. Fertility is high in the area (averaging 4.3 children among women in the study population); almost half of the women in the age group 15-19 had at least one child. The majority of women in the study population were within the reproductive age group and actively involved in child care. Sixty percent were responsible for children below the age of five, while 36% cared for more than one child within this age group. Younger children are breast-fed on demand and require more of their mother’s time.
DISCUSSION & CONCLUSION

In the past, the emphasis in control efforts against tropical diseases, including onchocerciasis, was based on epidemiological factors of disease transmission. In many instances, disease control programmes have not achieved the desired impact because local disease concepts, perceptions and behaviour were not considered in the design and implementation of the control programmes. Recently, however, it has been widely recognized that successful disease control is closely linked to an understanding of community-level factors, including knowledge and treatment-seeking behaviour.

This study demonstrated that despite a high level of knowledge about onchocerciasis, as well as positive attitudes towards mass treatment campaigns, many women remained untreated, especially those who were pregnant or breast-feeding at the time the mass treatment occurred. As many as 30% of the women interviewed in the Rokel river basin and 14% of those in the Gbangba and Taia river basins had never received treatment.

While the majority of respondents agreed with the exclusion criteria, probably because of their confidence in the judgements of medical advisors, those women who were excluded but experiencing symptoms of the disease faced a real dilemma. It was therefore not surprising that over half (61%) of such women disagreed with the reasons on which exclusion was based, and favoured treatment for all women.

Furthermore, the study established that out of 100 women found pregnant at the time of interviews, 27 were inadvertently treated with ivermectin, especially during the first trimester of pregnancy. It is not clear whether these women took the drug accidentally or deliberately denied their pregnancy status because of the discomfort they experienced from the disease. While no immediate negative effects were found, this group nevertheless offers the potential of providing information on side-effects and long-term consequences of the drug (Rathgeber, 1993).

Utilization of health services by women is known to be a complex behavioural phenomenon affected by factors such as availability, cost, distance, quality of care, social structure, health beliefs and the low status of women. The low status among the women studied, characterized by high average parity, full-time child care and domestic responsibilities, no doubt influenced their failure to report for treatment. In addition, men's control over family resources in the community negatively affected women's mobility and treatment-seeking behaviour.

Perhaps the coverage of women routinely excluded from taking ivermectin during mass treatment campaigns could be enhanced by adopting a community-based distribution approach, where community members such as leaders of women's groups, traditional birth attendants (TBAs) and community health workers (CHWs) would participate in the treatment programme. It may also be necessary to integrate ivermectin treatment into maternal and child health care (MCH) activities in order that women who may be excluded can have access to treatment during postnatal care visits. In addition, health workers should ensure that women who frequently utilize health services for immunization and other purposes (for their children), are advised on their own health. These contacts with health facilities present an excellent opportunity for receiving treatment with ivermectin.
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