FACTORS ASSOCIATED WITH NON-COMPLIANCE IN COMMUNITY DIRECTED TREATMENT WITH IVERMECTIN FOR ONCHOCERCIASIS CONTROL IN RUNGWE DISTRICT, SOUTH WEST TANZANIA

BY

LAKWO THOMSON LURONI, BSC.

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR THE REQUIREMENTS OF THE DEGREE OF MASTER OF PUBLIC HEALTH

THE UNIVERSITY OF DAR-ES-SALAAM

2002

MEDICAL LIBRARY DAR ES SALAAM

CERTIFICATION

The undersigned certifies that she has read and hereby recommends for acceptance by the University of Dar-es-Salaam a dissertation entitled: **Factors associated with non-compliance in Community directed treatment with ivermectin for Onchocerciasis control in Rungwe district, South west, Tanzania** in partial fulfillment of the requirements for the degree of Master of Public Health.

Supervisor's Signature.....

DR. D.B. GASARASI (BSC, MSPH, ScD)

Date: 24th September 2002

DECLARATION AND COPYRIGHT

I Thomson Luroni Lakwo, declare that this dissertation is my own original work and that it has not been presented to any other University for a similar or any other degree award.

Signature.....

This dissertation is copyright material protected under the Berne Convention, the Copyright Act 1966 and other international and national enactments, in that behalf, on intellectual property. It may not be reproduced by any means, in full or in part except in short extracts in fair dealing, for research or private study, critical scholarly review or discourse with an acknowledgement, without written permission of the Directorate of Postgraduate studies, on behalf of both the author and the University of Dar-es-Salaam.

ACKNOWLEDGEMENTS

I am grateful to Danish Bilharziasis Laboratory for their financial support, which enabled the successful completion of this course. I am very grateful to my supervisor, Dr. D.B. Gasarasi, for her keen interest in the study and guidance provided right from the initial time of research proposal development up to the final write-up of the dissertation. Without her, this dissertation would have been incomplete. Special thanks also go to Professor E.P.Y Muhondwa for his constructive criticism on the qualitative aspects of the study.

I would like to thank Mr. C.K. Makwaya, Mrs. R. Mpembeni and Mr. F. Mayunga of Epidemiology and Biostatistic department for their valuable assistance in all aspects of statistics related to the study. I am also indebted to Dr. S.B. Katenga, National Eye and Onchocerciasis Coordinator, Ministry of Health for his interest in the study and provision of the relevant national data on onchocerciasis. I wish also to thank Dr. M.H. Ruhiso, Acting District Medical Officer, Rungwe District and all his staff. Their interest, facilitation and commitment made it possible for me to successfully complete my data collection. Special thanks also go to Rungwe district officials for allowing me to conduct the study in their district. Many thanks go to my translator Mr. P. Kilewo, and research assistants: Mr. P. Salafu. Mrs. R.H. Kibasi and Mrs. T.M. Mwakyambiki who were involved in the survey.

Last but not least, I would like to thank the MPH Administrator, Mrs. Adeline Kapella for her support during the course, Mrs. Annastella Rutakyamirwa for the secretarial services, to the Ministry of Health, Uganda for granting me study leave, and all my colleagues for their hospitality during my stay in Tanzania.

DEDICATION

This dissertation is dedicated to my wife Mildred and my parents Mr. Yoswa Bongomin Luroni and Mrs. Ejeriya Arach Luroni.

ABSTRACT

A descriptive cross-sectional study was undertaken in Rungwe district, South West Tanzania during May – June 2002. The main objective was to determine the factors associated with non-compliance in community directed treatment with ivermectin for the control of onchocerciasis in Rungwe district. A total of 212 individuals aged 15-70 years and above were interviewed. Information on factors associated with non-compliance was obtained using a three-step approach involving structured interviews, focus group discussions and in-depth interviews with key informants.

The results showed that the respondents were aware of onchocerciasis (66%) but knowledge on the causes was low (29.3%). Similarly, knowledge on symptoms and signs of onchocerciasis was low. Furthermore, only 35.4% knew the side effects of ivermectin and of those 84% could mention 3-4 related side effects. Awareness of the programme and the drug used was high (75.9% and 88.4% respectively). However, knowledge on other programme activities was generally lacking.

The concern of ivermectin side effects as one of the factors influencing compliance was expressed, however 50% of the respondents did not believe it would affect taking the drug in the next treatment cycle. Other factors identified to be affecting programme implementation and associated with non-compliance were local beliefs and the lifestyle of alcoholism existing within the communities. The findings provide guidance for the National Onchocerciasis Control Programme on the importance of improving health education, strengthening monitoring during treatment, regular sensitization meetings and

improvement of mobilization during treatment. Appropriate recommendations have been made. However, further studies have to be conducted to document local beliefs and test their association with compliance.

TABLE OF CONTENTS

ITEM		PAGE
Certification		ii
Declaration and Copyright		iii
Acknowledgements		iv
Dedication		vi
Abstract		vii
Table of contents		ix
List of tables		xii
List of abbreviations		xiv
Chapter 1:	**Introduction**	**1**
1.1	Statement of the Problem	6
1.2	Rationale	7
1.3	General objective	7
1.4	Specific objectives	7
Chapter 2:	**Review of Literature**	**9**
Chapter 3:	**Methodology**	**19**
3.1.1	Study area	19
3.1.2	Study design	20
3.1.3	Study sample	20
3.1.4	Sample estimation	21
3.1.5	Sampling procedure	21

3.2 Methods of data collection 22

3.2.1 Structured interview..... 22

3.2.2 In-depth interviews..... 23

3.2.3 Focus group discussions..... 23

3.2.4 Recruitment, training and supervision of research assistants 24

3.3 Data management, analysis and presentation 25

3.3.1 Quantitative data..... 25

3.3.2 Qualitative data..... 25

3.3.3 Data presentation..... 26

3.4 Ethical consideration..... 26

3.5 Limitations of the study..... 27

3.6 Definitions of terms..... 27

Chapter 4: Results **29**

4.1 Socio-demographic characteristics of study sample by age and sex.... 29

4.2 Knowledge of onchocerciasis as a disease..... 31

4.2.1 Knowledge of the disease..... 31

4.2.2 Knowledge of symptoms and signs of onchocerciasis 31

4.2.3 Knowledge on ivermectin and treatment effectiveness..... 33

4.2.4 Knowledge on side effects of ivermectin 36

4.2.5 Awareness of Onchocerciasis control programme 39

4.3 Factors affecting implementation of onchocerciasis control programme 42

4.3.1 Effect of side effects of ivermectin on compliance 42

4.3.2 Attitude of community towards the treatment programme 45

4.3.3 Attitude of distributors towards the treatment programme 49

Chapter 5: Discussion **51**

Chapter 6: Conclusion and recommendations **63**

References 65

Appendices 73

Appendix A: Questionnaire English version 73

Appendix B: Questionnaire Swahili version 87

Appendix C: English checklist for focus group discussion and In-depth interviews 101

Appendix D: Swahili checklist for focus group discussion and in-depth interviews..... 102

Appendix E: Guideline for scoring knowledge..... 103

LIST OF TABLES

		PAGE
Table 1a:	Socio-demographic characteristics of study sample by age and sex.....	29
Table 1 b:	Sex distribution of major socio-demographic characteristics	30
Table 2:	Level of knowledge on symptoms and signs of onchocerciasis by sex	32
Table 3:	Level of knowledge on symptoms and signs of onchocerciasis by age group	33
Table 4:	Age and sex distribution of respondents who knew the name of the drug used in Onchocerciasis control programme.....	34
Table 5:	Level of knowledge on ivermectin treatment effectiveness by sex	35
Table 6:	Level of knowledge on side effects of ivermectin by sex.	37
Table 7:	Distribution of respondents reporting side effects by sex.	38
Table 8:	Perception of respondents on ownership of onchocerciasis control programme by sex	41
Table 9:	Willingness to take ivermectin in the next treatment cycle by age and sex	43
Table 10:	Respondents' assessment of the drug distribution system	45

Table 11: Reasons for the popularity of the drug distribution programme 46

Table 12: Respondents' preference of method of ivermectin distribution 47

Table 13: Distribution of respondents' choice for effective information system by age and sex 48

LIST OF ABBREVIATIONS

CDTI	- Community directed treatment with ivermectin
WHO	- World Health Organization
OCP	- Onchocerciais Control Programme
APOC	- African Programme for Onchocerciasis Control
CMFL	- Community Microfilariae Load
DALYs	- Disability Life years.
ATO	- Annual Treatment Objective
STI	- Sexually transmitted infections
MOH	- Ministry of Health
AIDS	- Acquired Immune deficiency syndrome
HIV	- Human immunodeficiency virus
FGDs	- Focus group discussions
ID	- In-depth interviews
TEHIP	- Tanzania Essential Health Intervention Project
IEC	- Information, Education & Communication

CHAPTER 1

1.0 INTRODUCTION

Onchocerciasis is endemic in 34 countries world wide, 26 in the African Region, six in the Americas and two in the Eastern Mediterranean Region. The recent estimates indicate that 17.7 million people are infected, of whom 270,000 are blind and 500,000 are severely visually disabled. In terms of public health, the main problem caused by the disease is blindness, although the importance of severe skin disease has recently been recognized. The disease has declined dramatically in prevalence and in public health importance in the original core area of the Onchocerciasis Control Programme (OCP) in West Africa (WHO, 1995).

Until the late 1980s the only drugs available for treatment of onchocerciasis were Suramin and diethylcarbamazine (WHO, 1987). Although these drugs were used successfully in limited mass treatment, the difficulties associated with their administration, toxicity and severe adverse reactions have limited their usefulness in routine treatment (Greene *et al.*, 1985; Awadzi *et al.*, 1995). The advent of an effective microfilaricide ivermectin (Mectizan®) and its registration in 1987 for treatment of Onchocerciasis were breakthroughs in the control of Onchocerciasis (Remme *et al.*, 1989). The principle challenge that followed was to put in place an effective system of drug delivery and distribution, which can be sustained by the endemic countries. The most compelling reason for this is that distribution of ivermectin (Mectizan®) needs to

be continued for a predictable but long period. In view of this fact, search for an effective strategy with sustainable features were made (Habbema *et al.*, 1990).

Between 1988 and 1997, various strategies for ivermectin distribution were used by the major players to provide over 65 million treatments in 33 of the 34 countries where onchocerciasis is endemic (Anon, 1996a; 1996 b). Passive distribution was the first to be tried. In this approach, drugs were left at fixed health centres or posts and only individuals presenting with onchocerciasis were treated. This was found to be particularly useful in hypo endemic areas where the community microfilariae loads (CMFL) indicate low or no risks of onchocerciasis (WHO, 1991). CMFL is the geometric mean microfilariae load per skin snip among adults above age of 20 years, an index that is theoretically proportional to the local intensity of transmission (Remme *et al.*, 1986). Problems associated with passive treatment included low coverage rates (Akpala *et al.*, 1993), non-availability of ivermectin, and wastage of drug kept beyond its shelf life because many patients did not return for further treatment. This method of distribution also had virtually no effect on transmission of onchocerciasis within a community.

Due to this limitation, large-scale distribution based on mobile teams was established. In this, trained local health professionals organized drug distribution at the central place agreed upon by the community. They were paid for the distribution activities. Although

the approach was successful in achieving high treatment coverage, the cost per person treated was high and the system could not be sustained (Amazigo *et al.*, 1998).

In view of this, the new Community directed treatment with ivermectin (CDTI) promoted by the African Programme for Onchocerciasis Control (APOC) was launched. This approach empowers the community to design and implement a method of distribution that is suitable to its needs (WHO, 2000). Furthermore, it enhances sustainability, ownership and cost savings by health departments (Amazigo *et al.*, 1998).

The application of this strategy in the mass distribution of ivermectin in sub-Saharan African countries through community involvement has made a tremendous impact on the burden of the disease (Benton, 1998). However, in spite of this achievement, problems have been encountered in its field implementation and management. Some of these problems include inadequate health education (Miri, 1998), lack of community support to distributors, the mode of distribution, poor attendance to village meetings, and distributors attrition (Katabarwa *et al.*, 2000; Katabarwa & Richards, 2001). These factors are believed to have a negative impact on compliance in any project.

The most challenging experiences in most projects is the emerging problems associated with the implementation of the mass treatment in the communities, and this needs 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-

Beyiku (1998) in their study in Nigeria encountered cases of refusal levels of 2.8% and absenteeism of 38%. Refusals and absenteeism have negative impact because the untreated population can contaminate those who have been treated. It also contributes to low coverage of the target population.

In Tanzania, Fischer revealed the existence of onchocerciasis through a case at Rungwe in 1932 (Pedersen & Kolstrup, 1986). Subsequent to Fischer's report, no further work on the disease was undertaken in Mbeya Region until Granbacka (1973) described onchocerciasis cases from Itete (Tukuyu) focus. However, the disease is known to be endemic in 14 of the 114 districts (MOH, 1997). These are largely limited to the chain of isolated block mountains running in an arc from northern Malawi to northeast Tanzania, the so-called Tanganyika-Nyassa montane chain (Maegga, 1991). The area is estimated to cover 32,000 Km^2 (Borg, 1976) and some 650,000 inhabitants persons are already infected with *Onchocerca volvulus* (WHO, 1995). Although the intensity of infection varies widely from area to area, it is believed that currently over four million people are at risk of getting infection (MOH, 1997). This figure may not fully reflect the importance of the disease and its implications on the affected communities

The first attempt to control onchocerciasis in Tanzania was through the use of insecticides. Trials were made in Mahenge and Tukuyu foci using DDT and temephos, respectively. This approach could not be continued due to problems of vector re-invasion and lack of logistical support (Hauserman, 1969; MOH, 1997). However,

in 1992, chemotherapeutic control using ivermectin was initiated in Ruvuma Region, and it was later extended to Mbeya and Morogoro Regions. However, like any other vertical programmes in a developing country it faced the issue of sustainability since it was donor supported.

The transition of this vertical distribution to CDTI in these foci was a step forward in support of the Primary Health care and the current advocated Health sector reform. The National Onchocerciasis Control Programme objective is to establish within a period of 12 years an effective and self sustainable community directed treatment throughout the endemic areas of Tanzania, and where possible to eliminate the vector(s) of onchocerciasis by using environmentally safe methods in selected foci. Its principal strategy is community directed treatment with ivermectin in all areas of Tanzania where onchocerciaisis is of public health importance (MOH, 1997).

However, the implementation and management of this approach has not been free of problems. One of the problems that have emerged is non- compliance associated with refusals and absenteeism reported in two of the five CDTI projects (MOH, 2000). Enyong, *et al.* (1999) during their evaluation encountered refusal and absenteeism levels of 3.1% and 13.1%, respectively in Mahenge focus, Morogoro region. And the most recent report was in Tukuyu focus, where a non-compliance rate of 21.9% was reported in the first CDTI treatment cycle (MOH, 2000). The importance of compliance with annual ivermectin treatment towards the achievement of control objectives is a very

crucial issue for any control programme. However, low treatment coverage and systematic non-compliance can result into the building up of a reservoir population, yet the effectiveness of the drug depends on the long-term therapy. The need to investigate the factors associated with refusals and absenteeism during drug treatment in Tukuyu focus, Rungwe district becomes a matter of priority if the programme is to achieve its goal of eliminating onchocerciasis in this area.

1.1 STATEMENT OF THE PROBLEM

The registration of ivermectin in 1987 and the subsequent adoption of Community directed treatment in its delivery opened a new chapter in onchocerciasis control (WHO, 1995). Distribution using this strategy has made a tremendous impact on the burden of the disease in most endemic countries. However, in spite of this achievement, problems have been encountered in field implementation thus influencing compliance. Some of the problems cited include inadequate health education, lack of community support to distributors, mode of distribution, poor attendance of meetings and attrition of distributors. Available data from Tanzania reveal that problems of non-compliance associated with refusal and absenteeism during treatment has emerged in two of the five CDTI projects. Non-compliance, a behaviour parameter, remains a major cause of poor utilization of available services resulting into low treatment coverage. There are so far limited studies that have addressed this issue in Tanzania. This study was designed to look into factors that affect compliance with ivermectin treatment in Tukuyu focus, Rungwe district.

1.2 RATIONALE

The importance of achieving and maintaining high annual treatment coverage (>90%) in any ivermectin treatment project cannot be overemphasized. The gradual interruption in transmission and reduction in community microfilariae load can only be achieved if the affected communities comply with annual treatment. Non-compliance in the community can only be minimized if the influencing factors are known and rectified. Such factors could be attitudes of the community towards the programme, poor performance of distributors, inadequate knowledge on treatment, side effects of the drug, health education and lack of community support to the distributors. Previous studies have not given sufficient information, to address this problem. The National Onchocerciasis Control Programme, Ministry of Health needs such information to improve the implementation of CDTI projects.

1.3 GENERAL OBJECTIVE

To determine the factors associated with non-compliance in community directed treatment with ivermectin for the control of onchocerciasis in Rungwe district.

1.4 SPECIFIC OBJECTIVES

1. To determine the level of knowledge on signs and symptoms of onchocerciasis.
2. To determine the level of knowledge on the side effects of ivermectin treatment.
3. To assess community awareness on the existence of the onchocerciasis control programme.

4. To determine the effect of ivermectin side effects on treatment compliance.
5. To determine the attitudes of the community towards ivermectin treatment.
6. To determine the attitudes of the distributors towards ivermectin treatment programme.

CHAPTER 2

2.0 LITERATURE REVIEW:

Onchocerciasis, caused by the nematode *Onchocerca volvulus*, is a serious public health problem in much of sub-Saharan Africa where nearly 17.7 million are infected. The World Health Organization (WHO) estimates that 123 million people are at risk of infection in the 34 countries in Africa, Yemen, and the Americas; more than 99% of the population at risk resides in Africa (WHO, 1995). The African onchocercal belt, most of which is north of the Equator, lies mainly between the latitudes of 15^0 N and 14^0 S and extends from Senegal in the West to Ethiopia in the east. Onchocerciasis also occurs, to a much lesser extent and degree, in six Central and South American countries. There are also small foci in two districts of Yemen in the Arabian Peninsula (WHO, 1976).

The epidemiological pattern of the disease shows considerable variations between and within geographical zones. For instance, in West Africa, the disease is characterized as blinding type, whereas in the East African Highlands extending from Ethiopia to Malawi, the disease is less blinding (Anon, 1996a). These patterns have direct bearing on the estimates of the burden of the disease in different parts of the world. However, according to the available data, the total burden of human onchocerciasis in Africa is about 884,000 Disability Life years (DALY) lost annually. On comparative basis, the DALY lost per year because of itching is greater (522,427) than that from all ocular manifestations of the disease (Kale, 1998). It is further believed that individuals with severe skin manifestations which are common cases in sub-Saharan African countries, spend almost USD $ 20 per annum on health related expenditures than uninfected

individual (Benton, 1998). In Tanzania, the known onchocerciasis foci are in fertile hill slopes and plains with adequate rainfall conducive to optimal agricultural productivity (Borg, 1976). Most of these areas have high population densities, simply because of their greater carrying capacity. With current population growth rate, the demand for food and cash crop production requires that such areas remain highly productive. The socio-economic importance and the health of communities resident in onchocerciasis areas are of national priority, in order to increase food and cash crop production (MOH, 1997).

2.1 VECTORS OF ONCHOCERCIASIS

In Africa and Southern Arabian Peninsula, Onchocerciasis is associated mainly with *S. damnosum* complex and to a lesser extent with *S. neavei* group (WHO, 1987). *S.damnosum*, which is by far the most important vector, occurs in a wide variety of permanent and temporary streams and rivers in areas ranging from the rainforest savannah to woodland. The larvae and pupae of most *S. neavei* complex species are found in phoretic association with fresh water crabs in permanent streams and small rivers. In Tanzania, *S. damnosum* is the main vector with the exception of the Usambara and Nguru mountains, where the vector is *S.neavei* complex, *S. woodi* de Meillon. *Simulium woodi* has been noted to be particularly responsible for transmission in both eastern and western Usambaras (Hauserman, 1969). Pedersen & Maegga (1985) also cited *S. damnosum* to be the main vector species in the Tukuyu focus in southwestern part of the country.

2.2 BIOLOGY OF THE PARASITE

The importance of the biology of *O. volvulus* cannot be overemphasized, as it is the basis upon which most chemotherapeutic control strategies have been designed. Fundamental studies on the biology both of adult parasite and microfilariae are essential if new and improved methods are to be developed. This applies in particular to the reproductive biology of the worms in relation to certain drug targets and the impact of chemotherapy on microfilariae hence on transmission (WHO, 1995). It is known that the adult worms live in fibrous nodules, some of which are sub-cutaneous and palpable while others lie deep in connective and muscular tissues. They have a life span of 9-14 years. The females produce abundant microfilariae, which migrate from the nodules to invade the skin, eyes and some other organs. They cause most of the disease manifestations of onchocerciasis. Those ingested from the skin by blood feeding *Simulium* develops over 6-12 days, without multiplication, to form infective larvae, which can be inoculated into new host when the fly feeds subsequently (Nelson, 1991). The most notable effect of *O. volvulus* is the pathological changes that are manifested in various forms on the skin and eye.

2.3 THE DISEASE

Available data reveal that the most common manifestations of onchocerciasis are predominantly dermal, lymphatic and ocular in character (WHO, 1987). All serious complications of onchocerciasis are due to heavy infections persisting for long periods and there is evidence suggesting that the disease can even progress in the absence of

continued transmission (Nelson, 1991). The clinical features of onchocerciasis may comprise of pruritic skin rashes, depigmentation, atrophy, nodules, hanging groins and eye lesions, which eventually culminate into blindness (WHO, 1995). But in some cases, it can also be associated with non-filial dwarfism, the so-called Nakalanga syndrome, in hyper endemic parts of Uganda (Ovuga *et al.*, 1992) as well as weight loss. Knowledge on the clinical manifestations of onchocerciasis have been reported extensively in most endemic areas (Sande, 1992; Johnston *et al.*, 1994; Oyibo & Fagberno-Beyiku, 1998)

Troublesome itching and scratching is an important early manifestation of onchocercal dermatitis usually associated with individuals having high levels of infections (Kale, 1998). Workneh *et al.* (1993) in their study observed that the itching may be mild and intermittent, or severe and continuous that may have a negative impact on work productivity. Similarly, Amazigo (1994) also cited that severe itching reduce the period of lactating mothers breast feed their babies, a serious implications on infant health. In Tanzania, Wagesa (1970) reported pruritis, skin depigmentation, atrophy of skin, nodules, hanging groins and hydrocoeles as common manifestations among the affected communities especially among the males. Ocular complications have not been studied extensively except in Amani and Bwikara where cataract and corneal opacity were detected (MOH, 1997). This is an indication of the public health importance of the disease and the need for greater attention to its control.

2.4 CONTROL OF ONCHOCERCIASIS

2.4.1 Vector control

In the past, control of onchocerciasis relied largely on vector control. Experiences in East and West Africa have shown that larviciding can be very effective in achieving interruption of transmission and eventual elimination of parasite reservoir (WHO, 1995). However, vector control proved to be so expensive beyond the means of most endemic countries and was abandoned except on limited scale where the focus is isolated. Besides cost, vector reinvasion and development of insecticide resistance were some of the major obstacles that frustrated most control efforts (Habbema et *al.*, 1990).

In Tanzania, an attempt of experimental larviciding against *S.woodi* in Lukugwi stream in eastern Usambaras showed very slow larval recolonization of treated habitats. And in 1981, further trials in the three main rivers in Tukuyu focus using Temephos and Chlorphoxim revealed that *S. damnosum* was highly susceptible to temephos. Another trial by Hauserman (1969) in Mahenge focus using DDT along a 20 km stretch of stream was frustrated by vector re-invasion. Control could not continue due to lack of general logistic support (MOH, 1997).

2.4.2 Chemotherapy

Since 1987, chemotherapy with ivermectin has proved to be a practical alternative to vector control (WHO, 1995). Ivermectin (Mectizan) is a potent, oral, microfilarial drug

with markedly improved safety profile compared with that of diethylcarbamazine (Greene *et al.*, 1985). Researchers noted its non-lethal effect on adult *O. volvulus* parasites, but when given as a single dose at least annually it keeps levels of microfilariae in the body low enough to prevent skin and eye disease from developing in those who are infected (Mabey *et al.*, 1996). The resulting implication is the lowered number of microfilariae to be taken by blackflies following ivermectin treatment. It has been further observed that this reduction in the availability of transmittable microfilariae in the skin results in a significant decrease in transmission (Chavasse *et al.*, 1995). This can only be achieved if the affected communities generally comply with treatment so as to avoid building up pockets of reservoir population. And the effectiveness of treatment can be recognized by the changes in skin texture and reduced itching as has been previously reported (Brieger *et al.*, 1998; Hagan, 1998).

Cases of adverse side effects have been reported in a number of areas in the endemic countries (Whitworth *et al.*, 1991; Burnham, 1993). In Tanzania, Mwetta & Hills (1994) in their study in eastern Usambara focus reported very high (91.8%) cases of adverse reactions following ivermectin treatment. They noted that in some serious reactions people failed to do their normal work although it needed no hospital admission or emergency resuscitation. It is not very clear whether this has any influence on treatment compliance in Tanzania. However, recent studies by Brieger *et al.*, (2002) and Chijioke (2000) from Nigeria, noted that fear of ivermectin side effects was one of the reasons for refusals of treatment among the onchocerciasis endemic communities. But these side

effects usually subside with the increasing round of ivermectin treatment if there is annual compliance (Pacque *et al.*, 1989). Despite the adverse reactions of ivermectin, its extra benefits in expelling intestinal parasites especially *Ascaris* has been recognized (Whitworth *et al.*, 1991; Johnston *et al.*, 1994; Akogun *et al.*, 2000). This opportunity can be exploited to promote treatment programme.

2.4.3 Drug distribution methods

The challenge key players in onchocerciasis control faced at the beginning was to put in place an effective system of drug delivery and distribution that could be sustained by the endemic countries. Some distribution methods had to be abandoned because of the high cost per person being treated and their inability to be sustained (Amazigo *et al.*, 1998). For instance, the first method of passive or clinic-based could not be extensively used because it was only applicable in hypo endemic areas and not sustainable (WHO, 1991). Similarly, when large-scale distribution using mobile teams was introduced, high treatment coverage was achieved in most endemic countries but later this was unsustainable due to its logistical and financial implications. Hopkins (1998) from Central African Republic had a classical example where this system failed after three years because it could not be sustained, especially the payment of village distributors. In Tanzania, this approach was initiated in 1992 in Ruvuma region where a total of 7,830 people were treated. This was later extended to Tukuyu in Mbeya region and Kilombero and Ulanga districts in Morogoro region. However, the success of this approach was not evaluated when CDTI was introduced in these areas (MOH, 1997).

The introduction of Community directed treatment with ivermectin (CDTI) was observed to be a very timely event since this has the features of sustainability necessary for endemic countries (Habbema *et al.*, 1990). Of recent, donor organizations and Ministries of Health throughout the developing countries have shown increasing commitment to health delivery programmes that are sustainable, cost-effective and integrated horizontally within the overall health care system (WHO, 1995). In CDTI, various levels of health care delivery system have their role to play. For instance, at the national level, the Ministry of Health of the participating country is responsible for the procurement of ivermectin and support supervision.

Similarly, at the district level, the authorities responsibilities would be to:

- Transport ivermectin to rural health centres or other delivery centres within 5 km of each endemic community.
- Provide health education to members of the community.
- Train the community directed distributors (CDDs).
- Initiate the annual mobilisation of communities.
- Provide advice and support in the management of adverse reactions.
- Collect reports on treatment from the distributors.

Once the community has obtained the knowledge and necessary guidance from the district technical staff, the members would then be expected to:

- Select distributors of their own choice.

- Identify convenient treatment centres within the community.
- Register all community members.
- Collect ivermectin from a health delivery point not more than 5 km.
- Provide the necessary support to the selected distributors in carrying out their work.

The success of the community setting up a good distribution system usually have a lot of in-put from the respective village heads or leaders as reported earlier (Akogun *et al.*, 2001).

All those who are eligible to take ivermectin (i.e. excluding children aged <5 years, those below 15 kg in weight or <90 cm in height, women in first week of lactation, and those very ill), and are living in communities where more than 30% of the population have onchocerciasis are treated once a year over a period not exceeding three months (Katabarwa *et al.*, 2000). A recognizable success is measured by the achievement of a treatment coverage of 90% of the annual treatment objective (ATO), itself equivalent to the whole population that is eligible to take ivermectin (Anon, 1996a). This level of coverage, which may be difficult to achieve and to maintain, is considered necessary if onchocerciasis is to be eliminated as a disease of public health importance within a reasonable period of 10 – 15 years. During the course of implementation and management of CDTI, some communities succeed in providing treatment at the desired level while others fail. Some of the reasons for the failure have of late emerged in some projects and this has been the kind of challenges earlier cited (Dadzie, 1998). Available

reports do indicate that some of the factors are associated with poor compliance with treatment. Brieger *et al.* (2002), in their study in Oyo state, Nigeria recorded an absenteeism level of 34.9%, refusals of 13.7% and those not informed about treatment contributed 3.7%. They observed that absenteeism pattern was common among age group 15-24 years. Further similar study from Nigeria by Oyibo & Fagberno-Beyiku (1998) also noted that inadequate health education and mobilization, adverse side effect of treatment and improved skin conditions due to treatment were some of the key factors responsible for non-compliance.

However, in the East African region, studies from CDTI projects in Uganda revealed that selection of distributors, mode of distribution, poor attendance of health education sessions, lack of support to distributors and distributors' attrition had a lot of influence on compliance (Katabarwa *et al.*, 2000). Apparently the issue of non-compliance seems to be a major problem also in the control of other communicable diseases. For instance, studies in Nigeria have shown that morbidity and mortality of tuberculosis have been blamed on neglect of human dimension of tuberculosis control. One of such factors is non-compliance that has led to multi-drug resistant tuberculosis and poor treatment outcome in directly observed treatment (Erharbor *et al.*, 2000). Tanzania like any other endemic countries is no exception; non-compliance has been reported in two of the five CDTI projects (MOH, 2000; 2002). If the National Onchocerciaisis Control Programme is to achieve its control objective, this issue has to be addressed at the earliest opportunity time.

CHAPTER 3

3.0 METHODOLOGY

3.1.1 Study area

The study was conducted in Ndubi village situated in Tukuyu onchocerciasis focus in Rungwe district, Southwest, Tanzania. This was selected because it is one of the Onchocerciasis foci in Tanzania where the problem of non-compliance with ivermectin drug had been reported. This focus is located at the northern end of Lake Malawi between 9^0 5'S to 9^0 45'S and 33^0 20'E to 34^0 20'E covering approximately 3,000 Km^2 (Pedersen & Maegga, 1985). 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 (MOH, 1997). The highest microfilarial densities and prevalence in this focus was reported from Kilugu (62.6%) and Kisegesi (51.9%) villages along River Lufilyo (Maegga, 1991). Community directed treatment with ivermectin (CDTI) was initiated in this focus in 1999 replacing the vertical programme that started in 1994. However, the district total population according to projection from 1988 census is 326,480 and growth rate of 1.4%. The district has an established network of health facilities, including three hospitals, three health centers and 44 dispensaries. These facilities provide both preventive and curative services in the district.

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. The main economic activity of the area is subsistence farming. Food crops include maize, beans, bananas, fruits and vegetables such as tomatoes and cabbages. 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 (Pedersen & Maegga, 1985). There are three main river systems in Tukuyu valley, the Kiwira, Mbaka and Lufilyo, all starting at the slopes of Rungwe Mountains. These rivers have been known to be the main breeding sites for onchocerciasis vector, *Simulium damnosum* in this valley (Pedersen & Maegga, 1985).

3.1.2 Study design

This was a cross sectional study conducted in Ndubi, one of the onchocerciasis endemic villages in Rungwe district. Both quantitative and qualitative methods (including focus group discussions-FGDs and in-depth interviews –ID) were used in the data collection.

3.1.3 Study sample

The samples for the administration of structured interviews were drawn from individuals who were 15 years and above. For the focus group discussions and in-depth interviews, the sample was from the same community excluding those who participated in the structured interviews.

3.1.4 Sample Estimation

In the estimation of sample size, the formula for estimation of proportions described by Kazaura *et al.* (1997) was used:

$$N = 4p\,(100\text{-}p)\,/E^2$$

Whereby: N= the desired sample size.

p = Estimated proportion of the population that comply with treatment = 68.6% (MOH, 2002).

E^2 = Maximum likely error between proportions set at 8%.

Using this formula the estimated sample size was 135 individuals.

N= 4x 68.6 (100 – 68.6)/64 =135. This was multiplied by 1.5 as design effect since the final sample size was obtained by multistage cluster sampling. 135 x 1.5 = 202 ~ 212. Inclusion of 5% of the minimum sample size gave the final sample size of 212 individuals.

3.1.5 Sampling procedure

Multistage cluster sampling technique was adopted to obtain a representative study sample. A list of the eight-onchocerciasis endemic wards in the district was obtained from the District onchocerciasis control Programme office. In the first stage, one ward (Kisondela) was randomly selected from the list of eight endemic wards. A ward has about 4 to 5 villages. In the second stage, a list of villages in Kisondela ward was made from where one village (Ndubi) was randomly selected for the study. A village has

about 2-20 village units (Vitongoji). But for the case of Ndubi it has three village units (vitongoji). In the third stage, one village unit (kitongoji) was randomly selected from the list of three. From the selected village unit (kitongoji), all the accessible households were randomly visited and individuals 15 years and above were interviewed until the required sample was obtained. Discussants for the focus group were obtained from the same community. However, for the in-depth interviews, because there were only six distributors in Ndubi village, two more distributors were obtained from the neighbouring village of Bugoba. Purposive sampling method was used to obtain individuals for FGDs and in-depth interviews.

3.2.0 METHODS OF DATA COLLECTION

3.2.1 Structured interview

Interview schedule was used to collect information, and individuals aged 15 years and above were interviewed. The schedule consisted of 40 closed and 4 open-ended questions. The major themes of the questionnaire focused on socio-demographic characteristics of the community, knowledge on signs and symptoms of onchocerciasis, side effects of ivermectin, their awareness on the control programme, effect of side effects on compliance, and attitudes of the community to the treatment programme (Appendix A). Data collection was on daily basis except on Sundays. Each interview took between 30-35 minutes. For knowledge, there were a total of four multiple response questions, two measured knowledge on symptoms and signs of onchocerciaisis while two were for measuring knowledge on side effects of the drug. For each item the

respondents mentioned, a score of one point was given. The maximum scores that a respondent could get in any of the four questions were six points. Each of the questions was scored separately. Details of categorization of knowledge level are shown in Appendix E.

3.2.2 In-depth interviews

In-depth interview was conducted to explore information on ivermectin treatment and problems associated with CDTI implementation specifically geared to compliance. The theme for the interview is attached in Appendix C, Part II. Six ivermectin distributors from Ndubi village and two from Bugoba 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 tape recording for all the eight interviews were done in the field. Summary of notes were done immediately so as to control quality of data. Expanded notes were done later. Prior to interview, each of the key informants was informed about the use of tape recorder and consent was obtained. The researcher later transcribed the interviews with the help of the translator.

3.2.3 Focus Group discussions

Focus group discussions (FGDs) were held with four categories of the community: health workers, men, women and schoolchildren resident in Ndubi village. A focus group consisted of 6-8 people. Two groups (boys and girls) consisted of schoolchildren of age range 14-19 years. The other five groups consisted of adults, two groups of adults

less than 30 years old and three groups of adults 30 years and above. The village chairman assisted to identify and assembled the group members, but for the schoolchildren, the Headmaster of Kisah Primary School was responsible. The moderator of the focus groups was the translator. He had extensive experience in qualitative data collection methods acquired when he was working with the Tanzania Essential Health Intervention Project (TEHIP) and Lymphatic Filariasis Project. The note taker was a Senior Nurse from Tukuyu hospital, and she had done this kind of work with the Sexually Transmitted Infections (STI) project of the district. All focus group discussion procedures followed what had been described earlier (Bernard, 2000). Seven group discussions were conducted following the designed theme (Appendix C, Part 1).

3.2.4 Recruitment, training and supervision of research assistants.

Three research assistants and a translator was recruited to assist in interviewing. They were trained after a brief overview of the purpose of the study. Training was on how to conduct the interview after requesting consent from the interviewee. The research assistants were responsible for conducting interviews with individuals in households under supervision of the researcher. The translator assisted the researcher during in-depth interviews, focus group discussions and daily crosschecking of the questionnaires. To observe and maintain quality of data, the researcher assisted by the translator closely supervised the process of data collection in Ndubi village. Each research assistant wrote his/her name on the questionnaire for ease of monitoring the quality of performance of each assistant. The structured questionnaire, topic check lists for both FGD and in-depth

interviews were pre-tested in Lugombo village unit (kitongoji), Kitundulu village in Ilima ward before they were administered in Ndubi village.

3.3 Data management, analysis and presentation.

3.3.1 Quantitative data

The data from the structured interviews were thoroughly crosschecked, and codes were assigned to variables. Opened –ended questions were coded based on the responses from randomly selected scripts. Data were entered using Epi-Info Soft ware that was also used for analysis. Data cleaning was done before analysis. Knowledge was classified into levels according to a score guide designed by the author. The scoring system takes into consideration of individual awareness on signs and symptoms of onchocerciasis, how to judge the effectiveness of treatment on the signs, knowledge on side effects and how to handle it. Two categories of scoring were used; in category one where the maximum score was six points, 0 – classified as no knowledge, 1-2 points was classified as low level, 3-4 points moderate and 5 points and above highly knowledgeable. In category two with maximum score of four points, 0 was classified as no knowledge, 1 point was low level of knowledge, and 2-3 points was moderate while 4 points was highly knowledgeable (Appendix E).

3.3.2 Qualitative data

Non-computerized analysis was used to analyze the qualitative data. Summary made from field notes and audiotape transcriptions from FGDs and in-depth interviews were

used in the process of analysis. The scripts were translated from Swahili to English and back to Swahili for checking of possible inconsistencies due to language differences. Looking at the pattern in responses and formulating ideas that could account for those similarities and differences. The method mainly used was analyzing information based on the theme of the interview (content analysis). Consideration was also given to the actual words used by participants or use of quotes.

3.3.3 Data presentation

Frequency distribution tables and cross tabulation have been used to present most of the data. Chi-square tests have been used where required.

3.4 Ethical Consideration

The Muhimbili University College of Health Sciences Ethical Committee cleared the proposal. Permission to conduct the study in the district was obtained from Rungwe municipality. For each of the respondent or those who were involved in focus group discussions and in-depth interviews, the aim of the study was explained. They were informed of the voluntary participation and only those who provided informed verbal consent were recruited in the study. They were assured of the confidentiality and anonymity.

3.5 Limitations of the study

The study design was subject to recall bias. To minimize this bias, information collected strictly referred to the last ivermectin treatment cycle that was from October – December 2001. Finding people at home during normal working hours was a problem. Repeat visits were made and some were interviewed in their nearby gardens. The researcher has poor background of Swahili to adequately grasp what the respondents said. A translator was recruited and briefed in detail the objectives of the study and methods of data collection. All interviews were recorded and later verified by an independent Swahili speaker to compare the consistencies in translation made by the translator.

3.6 Definition of terms

Non-compliance- Not acting in accordance with the required treatment protocol.

Community - A group of people living together and sharing common interest.

Community directed treatment with ivermectin - A control approach in onchocerciasis Control Programme where the community itself designs and implements a method for drug delivery that is most suitable to its needs.

Ivermectin -

An oral drug that was registered (Mectizan®) and approved for the mass treatment of humans who live in communities exposed to onchocerciasis.

Onchocerciasis -

Is a parasitic disease caused by a thin filarial worm, *Onchocerca volvulus,* and transmitted by blackflies of the genus *Simulium.*

Attitude -

An individual point of view towards the drug treatment programme. A person has a positive attitude when he/she approves of activities that promote ivermectin distribution. But when one disapproves or believes in rumours, local or religious beliefs on the treatment programme he/she has a negative attitude.

Awareness -

A person is taken to be aware of onchocerciasis control programme if he/she knows its activities, who owns it and the drug used in the programme.

Knowledge -

As used in this study was recall of facts on symptoms and signs of onchocerciasis, effectiveness of treatment, side effects of ivermectin and how to handle it.

CHAPTER 4

RESULTS

4.1 Socio-demographic characteristics of study sample by age and sex:

The results of socio-demographic characteristics are summarized in Table 1 (a & b). A total of 212 individuals 15 years and above were interviewed, 54.7% were males and 45.3% were females. Most of the respondents were aged 20-29 years and majority of the respondents were married. Majority (72.6%) of the respondents had Primary level education. Few went to secondary level and Post-secondary levels. There were more female respondents with no formal education compared to male respondents. Most of the respondents (84.4%) had been resident in this village for more than 10 years. The main economic activity that involves a sizeable proportion of the respondents is farming. Other occupations noted were fishing, business, civil servants and students (Table 1 b).

Table 1 (a): Socio-demographic characteristics of study sample by age and sex.

Age	Male (%)	Female (%)	Total (%)
Less than 20 years	8 (6.9)	13 (13.5)	21 (9.9)
20 – 29	29 (25.0)	16 (16.7)	45 (21.2)
30 – 39	19 (16.4)	18 (18.8)	37 (17.4)
40 – 49	14 (12.1)	12 (12.5)	26 (12.3)
50 – 59	16 (13.8)	13 (13.5)	29 (13.7)
60 – 69	20 (17.2)	13 (13.5)	33 (15.6)
More than 70 years	10 (8.6)	11 (11.5)	21 (9.9)
Total	**116 (100)**	**96 (100)**	**212 (100)**

Table 1 (b): Sex distribution of major socio-demographic characteristics.

Social status	Male (%)	Female (%)	Total (%)
Marital status			
Single	31 (26.7)	15 (15.6)	46 (21.7)
Married	75 (64.7)	55 (57.3)	130 (61.3)
Cohabitation	1 (0.9)	0 (0.0)	1 (0.5)
Widowed	4 (3.4)	19 (19.8)	23 (10.8)
Divorced	5 (4.3)	7 (7.3)	12 (5.7)
Total	**116 (100)**	**96 (100)**	**212 (100)**
Education			
Primary	91 (78.4)	62 (64.6)	154 (72.6)
Secondary	11 (9.5)	5 (5.2)	16 (7.5)
Tertiary	2 (1.7)	1 (1.0)	3 (1.4)
Never went to school	12 (10.3)	27 (28.1)	39 (18.4)
Total	**116 (100)**	**96 (100)**	**212 (100)**
Duration of residence			
Less than 5 years	10 (8.6)	4 (4.2)	14 (6.6)
5 – 10 years	9 (7.8)	9 (9.4)	18 (8.5)
More than 10 years	97 (83.6)	83 (86.4)	180 (84.9)
Total	**116 (100)**	**96 (100)**	**212 (100)**
Occupation			
Farming	109 (94.0)	88 (91.7)	197 (92.9)
Fishing	1 (0.9)	1 (1.0)	2 (0.9)
Business	0 (0.0)	2 (2.1)	2 (0.9)
Civil servant	4 (3.4)	2 (2.1)	6 (2.8)
Student	2 (1.7)	3 (3.1)	5 (2.5)
Total	**116 (100)**	**96 (100)**	**212 (100)**

4.2 Knowledge of onchocerciasis as a disease.

4.2.1 Knowledge of the disease.

Respondents were first asked if they had ever heard of onchocerciasis. It was found that 66% (140/212) of the respondents had heard of onchocerciasis as opposed to 34% (72/212) that had never heard. The males seem to be more aware of the disease than the females. This finding was statistically significant ($X^2 = 9.17$, $p = 0.002$). Similarly, of the respondents who heard of onchocerciasis, 52.9% (74/140) correctly knew the local name of the disease compared to 30% (42/140) who had no idea. Other respondents 17.1% (24/140) knew it as "imbwele" (local name for houseflies). Onchocerciasis is locally known as "Tusunia" in Kinyakyusa language. "Tusunia" is a local name for the *Simulium* fly, a vector for onchocerciasis. The respondents who knew the local name were able to associate the vector fly that transmits the disease and the existing skin itching problems. On the causes of onchocerciasis, only 29.3% (41/140) correctly knew that the disease was associated with the bite of *Simulium* fly while 30% (42/140) had no idea regarding the cause of this disease. Some of the respondents associated the cause with mosquitoes 17.9% (25/140) while 22.8% (32/140) perceived its cause as a water insect without specifying the name.

4.2.2 Knowledge of symptoms and signs of onchocerciasis.

A symptom checklist was used to assess the respondents' level of knowledge. These included; itching, skin rash, skin colouring, wrinkled skin, presence of nodules and blindness. As described in the methodology the respondents were categorized as having

no knowledge, *low*, *medium* or *high* knowledge depending on the number of items mentioned. The results show that the majority of the respondents had low knowledge of the symptoms and signs of onchocerciasis followed by those with no knowledge levels. Only a few people knew more than four symptoms or signs from the checklist. Males seemed to know more of the symptoms compared to females. However, there was no significant difference between knowledge levels for males and females ($p > 0.05$, Table 2).

Table 2: Level of knowledge on symptoms and signs of onchocerciasis by sex.

Sex	Knowledge level n=140		
	No knowledge	Low	Moderate
Male	35 (39.8)	35 (39.8)	18 (20.4)
Female	20 (38.5)	26 (50.0)	6 (11.5)
Total	**55 (39.3)**	**61 (43.6)**	**24 (17.1)**

$X^2 = 2.31$, df =2, $p = 0.314$

In addition to that, there seemed to be no difference in levels of knowledge with respect to age except in the moderate levels. However, no statistical difference was demonstrated ($X^2 = 2.29$, $p = 0.317$, Table 3).

Table 3: Level of knowledge on symptoms and signs of onchocerciasis by age group.

	Knowledge level		
Age group	No knowledge	Low	Moderate
10 – 39	27 (39.1)	27 (39.1)	15 (21.7)
40^{+}	28 (39.4)	34 (47.9)	9 (12.7)
Total	**55 (39.3)**	**61 (43.6)**	**24 (17.1)**

$X^2 = 2.29$, p =0.317

4.2.3 Knowledge on ivermectin and treatment effectiveness.

Majority of the respondents (88.4%) knew the name of the drug used in the control programme. However, a few of the respondents mistook it to be Asprin tablets while others did not know. There was a slight difference in awareness on ivermectin among males and females but this was not statistically significant ($X^2 = 0.67$, $p = 0.715$). Level of knowledge of the drug seemed to be low among the older age group of 70 years and above (Table 4).

Table 4: Age and sex distribution of respondents who knew the name of the drug used in onchocerciasis control programme.

Name of drug	MALE				FEMALE				Total
	10-39	40-69	70^{+}	Total	10-39	40-69	70^{+}	Total	
Aspirin	2 (33.3)	4 (66.7)	0 (0.0)	6 (5.5)	2 (40.0)	3 (60.0)	0 (0.0)	5 (5.6)	11(5.5)
Ivermectin	47 (49.0)	40 (41.6)	9 (9.4)	96 (87.8)	42 (52.5)	28 (35.0)	10 (12.5)	80(89.9)	176 (88.4)
Don't know	4 (50)	3 (37.5)	1(12.5)	8 (7.2)	1(25.0)	2 (50.0)	1 (25.0)	4 (4.5)	12 (6.0)
Total	**53 (48.2)**	**47 (42.7)**	**10 (9.1)**	**110(100)**	**45 (50.6)**	**33 (37.0)**	**11 (12.4)**	**89 (100)**	**199 (100)**

The respondents were asked whether they had ever taken ivermectin, and the data revealed that 93.4% (198/212) had at one time taken this drug. Only 6.6% (14/212) had not taken it. Some of the reasons for not taking it were that, they never heard of the drug while others reported that they disliked the drug distributors. Some of the respondents had other reasons such as pregnancy, sickness and travel. There was no sex difference in the number of respondents who never heard about the drug.

The respondents were further asked to respond to questions related to alleviation of symptoms and signs of onchocerciasis following treatment with ivermectin. Respondents were categorized into different levels of knowledge depending on the score of mentioned items. The majority had no knowledge of the expected changes in symptoms and signs of onchocerciasis including; alleviation of itching, no skin rash,

change in skin texture or other benefits such as de-worming. There seemed to be a sex difference in levels of knowledge ($X^2 = 6.32$, $p = 0.042$, Table 5).

Table 5: Level of knowledge on ivermectin treatment effectiveness by sex.

Sex	Knowledge level n =140		
	No knowledge	Low	Moderate
Male	43 (48.3)	14 (15.7)	32 (36.0)
Female	22 (43.1)	17 (33.3)	12 (23.5)
Total	**65 (46.4)**	**31 (22.1)**	**44 (31.4)**

$X^2 = 6.32$, $p = 0.042$

With respect to age, the majority (46.4%) in the age groups 10-39 and 40 years and above had no knowledge. The age difference in knowledge was observed in the low and moderate knowledge categories; however, this was not statistically significant ($X^2 = 2.90$, $p = 0.234$).

The information on this subject was further supplemented by qualitative data, which revealed some inadequate knowledge on the disease and the drug used. Some discussants were not aware of the specific function of ivermectin drug. The discussants in most of the groups agreed on the importance of educating the community both on the disease and about the drug. They believed that 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 symptoms

and signs are linked to other diseases like HIV/AIDS. One male adult said: *"The sign of this disease is relating to HIV/AIDS and people thought this was a way of spreading HIV. Others thought this is an experiment for HIV/AIDS" (Male adult, 42 years, Ndubi village).* Similarly, the key informants also mentioned the wrong belief of associating this drug to HIV/AIDS: One distributor said: *"People refuse to take the drug because they believe the drug kills. Swelling of the body is one of the reasons. Other people also believe that the drug transmits HIV/AIDS" (Female distributor, 18 years, Ndubi village).*

4.2.4 Knowledge on side effects of ivermectin.

Knowledge on side effects of ivermectin was assessed using a side effects checklist including; itching of the body, swelling, diarrhea, headache, vomiting and fever. The respondents were categorized; into *no* knowledge, *low*, *moderate* and *high* levels of knowledge as described in the methodology depending on the number of items mentioned. Generally, the majority of the respondents 64.6% (137/212) did not know the side effects of ivermectin and only a small proportion 35.4% (75/212) indicated that they knew the problems associated with the drug.

The respondents who reported to be informed about the side effects were further assessed for knowledge. The results indicate that majority were in *moderate* level of knowledge category therefore capable of mentioning three or four side effects of ivermectin. Only a few were in the low knowledge scale, and there was no respondent in

high level category. There was no sex difference in knowledge regarding side effects of ivermectin (X^2 = 0.01, p = 0.939, Table 6). Similarly, among the age groups of 10-39 and 40 years and above, relatively no knowledge difference was observed.

Table 6: Level of knowledge on side effects of ivermectin by sex.

Sex	Knowledge level n = 75	
	Low	Moderate
Male	7 (16.3)	36 (83.7)
Female	5 (15.6)	27 (84.4)
Total	**12 (16.0)**	**63 (84.0)**

X^2 = 0.01, p = 0.939

Further inquiry was made to find out whether respondents experienced ivermectin related side effects, and the level of severity. The results indicated that a small proportion of the respondents 15.5% (30/193) experienced ivermectin associated side effects. However, the majority 84.5% (163/193) did not experience any problems. Side effects were slightly more among the males 56.7% (17/30) than females 43.3% (13/30), but this difference was not statistically significant (X^2 = 0.07, p = 0.0786). Of the respondents who reported to have experienced some of the side effects related to ivermectin, the majority seem to have experienced itching and body swelling (Table 7). Most of the respondents experienced these side effects for more than 5 days 53.3% (16/30). But some had it for 1-3 days 46.7% (14/30).

Table 7: Distribution of respondents reporting side effects by sex.

Side effects	Male	Female	Total
	N = 30		
Itching	4 (50.0)	4 (50.0)	8 (26.7)
Headache	0 (0.0)	2 (100)	2 (6.7)
Muscle pain	2 (50.0)	2 (50.0)	4 (13.3)
Joint pain	1 (33.3)	2 (66.7)	3 (10.0)
Vomiting	1 (100)	0 (0.0)	1 (3.3)
Diarrhea	0 (0.0)	2 (100)	2 (6.7)
Swelling of body	4 (57.1)	3 (42.9)	7 (23.3)
*Others	2 (66.7)	1 (33.3)	3 (10.0)
Total	**14 (46.7)**	**16 (53.3)**	**30 (100.0)**

* Reduce sexual power/poor vision/problem in hearing.

In addition to assessing knowledge of side effects, an assessment was made of knowledge on ways of handling side effects including; consulting health workers, reporting side effects to distributors and taking Asprin or Panadol. Results showed that the level of knowledge in handling side effects is lacking. The majority of the respondents mentioned only one measure they would take when they experience side effects.

Commonly reported measures among those respondents were consulting health workers 42.3% (58/137) and reporting side effects to the distributors 19.7% (27/137).

The qualitative information from FGDs confirmed that, inadequate knowledge on the side effects of ivermectin and how to handle them do exist. This was expressed in all the groups as a contributing factor to refusals and absenteeism. They believed that the occurrence of side effects in the absence of appropriate health education allows wrong beliefs to persist in the community. This was expressed by one of the discussants:*" The community thought the drug could bring fever and flue. People also feared this was a kind of test in their body" (Male adult, 29 years, Ndubi village).*

Similarly, the distributors had the same view that the side effects of ivermectin remain an issue of concern in their treatment programme. They believed the best way of handling this was for the affected persons to consult the nearest health facility. Others mentioned that what happens in reality was that the names of those who suffered were just recorded down. One distributor said: *"The names of those who suffered from side effects were written down but they were given nothing" (Female distributor, 35 years, Bugoba village).*

4.2.5 Awareness of Onchocerciasis control programme.

The respondents' knowledge on the extent to which they are aware of the onchocerciasis control programme and its associated activities in the village was further assessed.

The findings suggest that awareness of onchocerciasis control programme is high 75.9% (161/212). Some of the respondents had no idea of the existence of the programme 24.1% (51/212). It was further observed that the males were more aware of the programme than the females and this was demonstrated to be statistically significant ($X^2 = 3.63$, $p < 0.05$). The level of awareness on programme activities was high (89.8%) with respect to drug distribution. But, regarding other activities, awareness was relatively low, for instance; discussion about onchocerciasis 6.3% (10/160), community information 12.5% (20/160), and selection of distributors had the lowest level of awareness 2.5% (4/160).

With respect to programme ownership a small proportion (8.1%) of the respondents believed that the programme belongs to the community. The majority believed that the programme belongs to the central government and associated it with donors. Yet a high proportion of the respondents were completely ignorant (Table 8).

Table 8: Perception of respondents on ownership of onchocerciasis control programme by sex.

Perceived ownership	**Male**	**Female**	Total
Community	8 (61.5)	5 (38.5)	13 (8.1)
Distributors	3 (60.0)	2 (40.0)	5 (3.2)
Government	39 (50.0)	39 (50.0)	78 (48.4)
Health workers	15 (88.2)	2 (17.8)	17 (10.6)
Don't know	18 (50.0)	18 (50.0)	36 (26.1)
Donors	4 (80.0)	1 (20.0)	5 (33.3)

Information emanating from the FGDs revealed that one of the reasons for lack of awareness on programme activities has been attributed to inadequate education on the disease and treatment programme. Views expressed by the seven groups pointed out that in order for the programme concept to be promoted, there should be adequate knowledge about it. One health worker said: *"Drug distributors should be well educated about the programme so that they can educate the community. Also we the health workers have to be educated so that we are able to explain to those who get side effects" (Female health worker, 50 years, Kisah Health Centre).* The distributors also had a strong belief that to minimize problems encountered during ivermectin treatment, the communities should be properly educated about the drug used in the programme. This will enable them to make positive decision on treatment. One distributor said: *" My suggestion is to educate the*

people about the drug through meetings. Those who refuse should be punished" (Male distributor, 42 years, Ndubi village).

4.3 Factors affecting implementation of onchocerciasis control programme.

Other factors affecting the implementation of CDTI were assessed. The major issues examined were concerning side effects of ivermectin and attitudes of community and distributors to the treatment programme.

4.3.1 Effect of side effects of ivermectin on compliance.

On categorization of the side effects into levels of severity, 40% (12/30) of the respondents experienced mild, 23.3% (7/30) moderate and 36.7% (11/30) severe side effects. Among those who experienced the side effects, 46.7%(14/30) had their normal work affected, while 53.3% (16/30) were not affected. The activity mainly affected was going to the field 84.6% (11/13). However, a few were also not able to fetch water and do normal housework. It was further observed that males were more affected than females with percentages of 84.6% (11/13) and 15.4% (2/13), respectively.

To assess whether ivermectin side effects have any influence on the respondents' compliance, an inquiry was made with respect to willingness to participate in the next treatment cycle. The results indicate that 97.6% were still willing to take ivermectin drug in the next treatment cycle. Only a small proportion of the male respondents were unwilling to take ivermectin in the next treatment cycle. It was further observed that

compliance was high among age group 20-29 years for males and for females it was high in young age groups <20 years of age. The main reason expressed by all the respondents not willing to take the drug was associated with the side effects of the drug (Table 9).

Table 9: Willingness to take ivermectin in the next treatment cycle by age and sex.

Age group	Male			Female			Total
	Yes (%)	No (%)	Total	Yes (%)	No (%)	Total	
< 20	8 (38.1)	0 (0.0)	8 (6.9)	13 (61.0)	0 (0.0)	13 (61.0)	21 (9.9)
20 – 29	28 (62.2)	1 (2.2)	29 (25.0)	16 (35.6)	0 (0.0)	16 (35.6)	45 (21.2)
30 – 39	19 (51.4)	0 (0.0)	19 (16.4)	18 (48.6)	0 (0.0)	18 (48.6)	37 (17.5)
40 – 49	14 (53.8)	0 (0.0)	14 (12.1)	12 (46.2)	0 (0.0)	12 (46.2)	26 (12.3)
50 – 59	15 (51.7)	1 (3.5)	16 (13.8)	13 (44.8)	0 (0.0)	13 (44.8)	29 (13.6)
60 – 69	18 (54.5)	2 (6.1)	20 (17.2)	13 (39.4)	0 (0.0)	13 (39.4)	33 (15.6)
70^{+}	9 (42.8)	1 (4.8)	10 (8.6)	11 (52.4)	0 (0.0)	11 (52.4)	21 (9.9)
Total	**111 (52.3)**	**5 (5.4)**	**116 (100)**	**96 (45.3)**	**0 (0.0)**	**96 (45.3)**	**212 (100)**

The qualitative arm of the study provided additional information on the influence of side effects on treatment compliance. The issue of side effects was expressed in all the focus groups. They had a uniform belief that side effects have a lot of influence on community decision to take ivermectin. One health worker said: *" Other people when they took this drug they got side effect such as swelling of the face. 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). One of the male discussants narrated his experience. He 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 male sexual power. So even next time I will not take it again" (Male adult, 35 years, Ndubi village).*

Among the schoolchildren, they shared similar view that side effects are one of the reasons associated with refusals and absenteeism during treatment. They believed that people who got side effects negatively influence others not to take the drug. The fear of side effect also seems to be a problem in the community. A school girl said: *"The community is fearful of side effect of the drug, therefore they are afraid of taking it again because they can get swelling of the body, rashes etc" (School girl, 16 years, Kisah Primary School).*

To confirm whether side effects of ivermectin are a major issue in relation to refusals, assessment of the respondents' attitude was made using an attitude statement (*"Most people refuse to take ivermectin tablets because of its side effects")* whereby they were to agree or disagree on it. The results indicated that 50% of the respondents disagreed to this statement as opposed to 36.8% who agreed to the statement. There was however, no sex difference observed in both cases ($X^2 = 0.57$, $p = 0.752$).

From the qualitative information (FGD,s) the majority were of the opinion that side effects of ivermectin have a negative influence on community decision to take

ivermectin hence resulting in refusals and causing fear. *"Those who were afraid of the drug on observing people who have taken and experienced side effects, refused totally to take this drug" (Male adult, 42 years, Ndubi village).*

4.3.2 Attitude of community towards drug treatment.

In exploring further the problems associated with programme implementation, community attitude was assessed with respect to community directed treatment, on issues related to; attitude to the distribution system, preference of ivermectin distribution method, and choice of effective information system. With respect to the drug distribution system, the majority of the respondents (93.9%) indicated that they like the distribution system. There was no significant difference between male and female opinion on the system ($X^2 = 2.88$, $p = 0.596$, Table 10). Similarly, 90.6% (192/212) of the respondents considered this distribution system popular and liked by many people. Only 9.4% (20/212) considered it unpopular.

Table 10: Respondents' assessment of the drug distribution system.

Assessment	Male	Female	Total
Good	109 (54.8)	90 (45.2)	199 (93.9)
Not good	1 (33.3)	2 (66.7)	3 (1.4)
No opinion	6 (60.6)	4 (40.0)	10 (4.7)
Total	**116 (54.7)**	**96 (45.3)**	**212(100)**

$X^2 = 2.88$, $df = 3$, $p = 0.596$

Assessment was further made among respondents who consider drug distribution popular. It was observed that the main reason for the popularity among the respondents was because ivermectin alleviates the symptoms and signs of onchocerciasis. Besides, it acts as a cure for many diseases and was considered to be accessible (Table 11).

Table 11: Reasons for the popularity of the drug distribution programme.

	Number of respondents	
Reasons	**n =192**	**Proportion (%)**
Accessible	45	23.4
Distributors are friendly	9	4.7
Medicine taken only once a year	16	8.3
Medicine alleviates symptoms	60	31.3
Cures many diseases	48	25.0

On the qualitative aspect, the discussants had mixed opinion on the programme, especially the provision of free drug to the community. In three of the FGDs, the rationale for provision of the free drug was questioned especially in this era of cost sharing. One of the female youth said: *"The community don't want free drugs like that of onchocerciasis because they are used to buying drugs" (Female youth, 25 years, Ndubi village).* Another discussant from the adult women group had this to say: *"Because this drug is brought free of charge some people have their own decision to take it" (Adult woman, 40 years, Ndubi village).* Some health workers also shared the

same opinion on the distribution of this drug in the affected villages. One female health worker said: *"When you give the drug to the society when they are not sick, they usually refuse to take the drug because they know drugs are for some one who is sick. They first have to find themselves with the disease before taking the drug" (Female Health worker, 40 years, Kisah, Health Centre).*

Further assessment was made on the respondents' preferences for the method of distribution in the village. The results indicate that most of the respondents are in favour of central place distribution 87.5% as opposed to house-to-house distribution. However, there was no sex difference observed in the choice for the method of distribution ($X^2 = 0.26$, $p = 0.878$, Table 12).

Table 12: Respondents' preference of method of ivermectin distribution.

Method	Male	Female	Total
	n = 212		
House to house	13 (59.1)	9 (40.9)	22 (10.4)
Central place	100 (54.1)	85 (45.9)	185 (87.3)
I don't know	3 (60.0)	2 (40.0)	5 (2.3)
Total	**116 (54.7)**	**96 (45.3)**	**212 (100)**

$X^2 = 0.26$, df =2, $p = 0.878$

The respondents' choice for effective information system was also assessed to find out whether this has any influence in the implementation of the programme. The results

indicated that majority of the respondents preferred village leaders as an effective information dissemination medium compared to other forms of information dissemination. Furthermore, health workers seem to be preferred by age groups below 70 years of age in both sexes (Table 13).

Table 13: Distribution of respondents' choice for effective information system by age and sex.

MEDIA	MALE				FEMALE				TOTAL
	10-39	40-49	70+	Total	10-39	40-49	70+	Total	
Radio	12(52.2)	10(43.5)	1(4.3)	23(17.8)	5(83.3)	1(16.7)	0(0.0)	6(6.5)	29 (13.1)
Village leaders	30(42.9)	25(35.7)	15(21.4)	70(54.3)	32(53.3)	19(31.7)	9(15.0)	60(65.2)	130 (58.8)
Health workers	12(40.0)	16(53.3)	2(6.7)	30(23.3)	8(42.1)	10(52.6)	1(5.3)	19(20.7)	49 (22.2)
Church	3(50)	2(33.3)	1(16.7)	6(4.6)	4(57.1)	2(28.6)	1(14.3)	7(7.6)	13 (5.9)

To confirm the respondents' choice in effective communication system, views were gathered in the FGDs. The discussants had a uniform opinion that when village leaders are used as entry points in the community; it can be easier to effectively mobilize for the treatment programme. Further views expressed were that the village leaders rally very big support among the community and have the capacity to organize village meetings. A schoolboy said: *"It is a good system because all communities can be informed at the same time. It is easy also for every one to understand" (Schoolboy, 16 years, Kisah Primary school).*

Further inquiry was made to find out the steps taken if a member of the community does not comply with the programme activity. Some of the respondents (29.2%) indicated that the distributors do nothing regarding those who refuse to take the drug. Others had the opinion that the distributors should follow them up (27.4%). A low proportion opted for reporting them to village leaders and punishment. Suggestions from the FGDs on handling problems of drug refusals seem to focus on village leaders. It is believed that village leaders have a crucial role to play in this issue given their status in the community. One schoolboy said: *" Village chairman should go house to house to ensure that all the people have taken the drug. Those who refuse to take the drug should be punished" (Schoolboy, 16 years, Kisah Primary School).*

4.3.3 Attitude of distributors towards the treatment programme.

Since distributors are the key persons behind the success of all ivermectin treatment programmes, an inquiry was made to find out whether they were in support of the treatment programme in this village. In-depth interviews were conducted on various aspects of the programme as described in the methodology. Eight community directed distributors, five males and three females, whose age ranged from 18 to 44 years (mean 33.8 years) participated in the interview. All the participants were indigenous Wanyakyusa tribe from Ndubi and Bugoba villages in Rungwe district. The findings for males and females were similar; therefore they have been presented in an integrated manner. The general findings suggest that the distributors have a positive attitude towards the programme despite the problems they encounter in their operations.

The distributors also reported some cases of refusals of the drug by members of the community. This was mentioned by four of the informants. They believed this behaviour has frustrated their effort to achieve the desired treatment coverage. One distributor said: *"The main problem I faced was that some people were refusing to take the drug because they will not have time for taking alcohol. Even in the central place for drug distribution some people absented themselves" (Male distributor, 42 years, Ndubi village).* Other problems were side effects of the drug and local beliefs existing in the community. In order for the community to comply appropriately they have to be informed usually during distribution. The distributors had a strong opinion that the best way could be through village meetings. They believed this facilitate information dissemination. One distributor said: *"The communities were informed about treatment through village meetings. A meeting was also held at a local bar. I believe these were successful" (Male distributor, 22 years, Ndubi village).* Besides side effects of the drug, the distributors believe alcoholism and local beliefs have some significant impact on compliance. One distributor said: *" I think they cared much about alcohol and this is the main reason why people refuse to take it" (Female distributor, 30 years, Bugoba village).*

The distributors had strong opinion that the reasons for the refusal of drug were similar to those of absenteeism since all are attributed to the same drug. They also observed that some religious beliefs have a detrimental effect on their treatment effort. Some followers of certain religious sect have a disbelief in orthodox medicine.

CHAPTER 5

DISCUSSION

Community directed treatment with ivermectin (CDTI) has been adopted as the main strategy for onchocerciasis control in most endemic areas. However, since its inception in 1995, a number of projects have experienced some challenges in its field of implementation in an attempt to maintain high treatment coverage (Miri, 1998). The main objective of this study was to determine the factors associated with non-compliance with ivermectin in community directed treatment for the control of onchocerciasis.

The results of this study have shown that onchocerciasis is a disease known by the community in Ndubi village and 66% of the respondents reported to have heard of the disease. However, this proportion is much lower than those previously reported in Mahenge focus, Ulanga district (Sande, 1992) and Nigeria (Oyibo & Fagberno-Beyiku, 1998). This variation is probably associated with the extent to which a particular community has been exposed to information about the disease. A significant difference in awareness was observed among the males and females ($p<0.05$). This difference could be attributable to lifestyle differences. Males are known to move from place to place and in the process may meet more onchocerciasis patients than females. Since the disease is most common in males (Wagesa, 1970), they are likely to know more about their colleagues than females, accounting for the difference in disease awareness.

Similarly, a relatively high proportion (52.9%) knew the local name of onchocerciasis, referred to as "Tusunia". This is an indication that respondents are able to differentiate

onchocerciasis from other endemic diseases prevailing in the village. When people live with an endemic disease they generally get to know the local name used for the condition. However, in Thyolo focus in Malawi, Johnston *et al.* (1994) reported a much higher proportion of respondents (97%) knowledgeable about the local name of onchocerciasis. The respondents were even able to recognize the vector of onchocerciaisis and the biting time.

Contrary to a relatively high proportion of awareness of the disease in Ndubi village, a very low proportion (29.3%) of the respondents knew the cause of onchocerciasis and associated it with Simulium (locally known as "Tusunia"). However, this proportion is much higher than 11.8% previously reported in Mahenge focus (Sande, 1992). 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 (63.3%) was reported (Oyibo & Fagberno-Beyiku, 1998). Health education provides the necessary information, education and communication for change of beliefs, change of attitudes and change of behaviour. It is possible that the Health education in the Nigerian site could have been more effective. 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 symptoms and signs of onchocerciasis may be an important aspect of knowledge that is very crucial for the endemic communities if the effort to control onchocerciasis is to be achieved. The clinical classifications of the symptoms and signs has permitted

meaningful comparisons to be made of survey results from different geographical areas and helped in assessment of effects of mass treatment (Hagan, 1998). However, the current data revealed that knowledge on the symptoms and signs of onchocerciasis seemed generally low among the respondents (Table 2). This could probably reflect the background of the programme initiation in the village and the effectiveness of the health education strategy being used. However, this situation is different from Mahenge focus where a high proportion (99%) of the community knew at least four main clinical manifestations of the disease (Sande, 1992).

Low levels of knowledge coupled with the existence of local beliefs were reflected in the focus group discussions. For instance, the symptoms and signs of onchocerciasis were associated with other diseases like HIV/AIDS and one male adult said: *"The sign of this disease is relating to HIV/AIDS and people thought this was a way of spreading HIV. Others thought this is an experiment for HIV/AIDS"* Associating the symptoms and signs of onchocerciasis to HIV/AIDS should draw some concern given the fact that this is currently a sensitive issue among most communities. Knowledge on symptoms and signs of a disease may influence the decision to seek health care and judging effectiveness of treatment following alleviation of relevant symptoms. In the present study, 31.4% of the respondents were able to indicate changes in known symptoms and signs following treatment (Table 5). The reported recognizable changes were reduced itching and skin improvement. However, majority of the respondents had no knowledge of the symptoms and signs of onchocerciasis (Table 3). Given this low knowledge levels

background, the level of appreciation of the treatment programme may be limited (Mabey *et al.*, 1996;Brieger *et al.*, 1998). It is hypothesized that low knowledge on clinical manifestations of the disease may negatively influence judgment on effectiveness of the drug and could be one of the contributory factors to non-compliance. Contrary to the findings from this study, the findings from Thyolo focus in Malawi indicated that due to high level of knowledge of clinical symptoms and signs of onchocerciasis, the communities were much aware of treatment effectiveness of ivermectin (Johnston *et al.*, 1994).

CDTI principles require that the community receive education from distributors as well as health personnel regarding annual treatment for many years, benefits of treatment, handling side effects and their responsibilities in the programme (Habbema *et al.*, 1990). The current data revealed that, the majority (64.6%) of the respondents were not informed about the side effects associated with ivermectin. However, the low proportion informed were able to mention at least three or four side effects, which was relatively good for a community like that of Ndubi (Table 6). Lack of information on side effects can be detrimental to the future of the programme. Even though the programme seemed to be popular, information from focus group discussions indicated that, generally the community is fearful of ivermectin side effects. This state of affairs may negatively influence participation in future treatment cycles. As one discussants put it: *"Those who were afraid of the drug on observing people who have taken and experienced side effects, refused totally to take this drug"* Similarly, this was cited in one of the projects in Nigeria where communities were not informed of the expected associated side effects

of ivermectin and this resulted in low treatment coverage (Oyibo & Fagberno-Beyiku, 1998).

The most commonly mentioned side effects were itching and swelling, consistent with findings from other ivermectin treatment programmes. Itching and swelling of the face or limbs were the most common adverse reactions reported in the first five-ivermectin treatment trials in Sierra-Leone (Whitworth *et al.*, 1991). The communities however, need to be given assurance that the likelihood of reactions is small after repeat treatment if compliance is to be maintained. The need for prior information on side effects as a pre-requisite for maintaining high treatment coverage was reported in Tanga region, northeast Tanzania (Mwetta & Hills, 1994).

Similarly, knowledge on handling side effects plays a very important role in the achievement of good treatment coverage (Whitworth *et al.*, 1991). In the present study it was observed that knowledge on handling side effects was generally low. The most common measure known to the respondents was consulting health workers and reporting cases to the distributors. Although these are among the acceptable measures to be taken, the communities may not easily appreciate it since they may need immediate help to alleviate their problem. Burnham (1993) reported that establishment of a routine referral system for adverse cases of side effects was quite effective in maintaining good treatment coverage in Malawi. However, in the present study, although this referral system was reported to exist during treatment, the cost implication due to user fee may be one of the obstacles encountered by the community. Some of the discussants

complained of the cost implications involved while treating side effects of ivermectin and wanted the programme to meet the cost. But in Mahenge focus, Enyong *et al.* (1999) noted that the distributors were not recording cases of side effects contrary to what has been observed in the current study. They further noted that there was no emphasis put on reporting side effects. In the present study, the situation is much better since record keeping is in place. One of the distributors said: "*The names of those who suffered from side effects were written down but they were given nothing*"

However, in the absence of any post-treatment counseling, most of the respondents may be de-motivated from taking treatment since they would have lost confidence invested in the distribution system. The communities should be given assurance and confidence about the tolerable nature of side effects of ivermectin if non-compliance is to be minimized. Appropriate ways of handling side effects and its management by medical auxiliaries or community volunteers have been emphasized as a measure of minimizing non-compliance (Burnham, 1993;WHO, 1995).

Despite the problems of side effects, the present data on compliance suggest high support for taking ivermectin in the next round (Table 9). However, the high compliance observed among age group 20-29 years could be associated with their better understanding of the benefits of the programme. The current non-compliance level of 5.4% is lower than the 14.8% reported in the last treatment cycle in the same village (MOH, 2002). This difference could be attributed to the fact that the communities are

becoming more enlightened about the programme and realizing its benefits. It is notable however, that non-compliance was reported among males only (Table 9). This could probably be associated with their lifestyle linked to alcoholism and fear of side effects as expressed in the FGDs and in-depth interviews with 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 expressed influence of side effects on compliance, the community has misconceptions about the drug and its use. Information from FGDs revealed that, fears about ivermectin are linked to the community belief that the drug is being tested for its efficacy against HIV, while other sectors, think it is some kind of contraceptive being indirectly tested in the community. This was the perception linked to complaints from some male respondents that the drug affects sexual power. A similar kind of local belief associated with ivermectin treatment was 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 (Hopkins, 1998). Miri (1998), in Nigeria encountered this similar kind of misconception in a treatment programme where one of the religious sects decided to refuse ivermectin because it was thought to be a contraceptive.

Generally, despite the existing misconception about the drug, the results showed high awareness of the programme among the community. This is likely to be attributed to the

fact that ivermectin distribution was initiated in this focus as a vertical programme since 1994 (MOH, 1997). At least most of the respondents might have been exposed to information related to the programme. However, it was noted that the general awareness of the communities about responsibilities in the programme was restricted to taking the drug every time it is distributed. Awareness on activities outside drug distribution was relatively low. This lack of information on other programme activities may be an indication of information gap on the programme. These finding are consistent with what was observed among the communities in Mahenge focus who were aware of the drug distribution as the only activity of the programme (Enyong *et al.*, 1999). This is an indication that sustainability of the programme may be a problem in future since the communities are not aware of other activities they are supposed to support.

It has been noted that for an effective implementation of CDTI and its sustainability, community participation and programme ownership is very important (WHO, 1995). The results of this study suggest that the understanding of these concepts is still lacking, only a small proportion knew that the programme is for the community, whereas a high proportion associated it with the central government and donors (Table 8). This is an indication that the old ideologies that delivery of health care services should be the sole responsibility of the government still exist. Similarly, in Mahenge focus the communities believed the programme belongs to the government (Enyong *et al.*, 1999). These findings suggest that the communities may not have had adequate health education to enable them understand the major activities of the programme. The

importance of education was again alluded to in FGDs and one of the health worker said: *"Drug distributors should be well educated about the programme so that they educate the community. Also we the health workers have to be educated so that we are able to explain to those who get side effects"* Miri (1998) noted that to empower communities, decentralize cost and promote sustainability of the programme, a proper understanding of its concept is very important. Unless the community is made to clearly understand the fundamental concept that the programme belongs to them, they may not understand the need for ensuring that each and every one should take ivermectin annually.

The assessment of the drug distribution system revealed that the community has a positive attitude towards the programme. This positive attitude has been promoted by the accessibility of the drug, its capacity to alleviate symptoms of the disease and because it cures many diseases (Table 11). The extra benefits of ivermectin including de-worming were previously reported (Whitworth *et al.*, 1991; Akogun *et al.*, 2000; Brieger *et al.*, 2002).

One of the programme related factors that has been reported to influence treatment coverage and compliance is the drug distribution system (Katabarwa *et al.*, 2000).

The choice for the distribution method is usually the responsibility of the community. In Ndubi village, the respondents' choice for central point distribution as opposed to movement from house-to-house (Table 13) is in line with the CDTI principles

(WHO, 1995; Akogun, *et al.*, 2001). This method is popular among communities in most endemic areas since it conforms to most African cultural norms where social interaction is very much valued as a means of strengthening cultural bond (Akogun *et al.*, 2001). However, the disadvantages associated with it could be difficulty in following up defaulters and the distance from distribution points for some respondents. The old age group and disabled may find problems of accessing the treatment points. In Uganda, Katabarwa *et al.* (1999) noted that the use of the compound of distributors as fixed centers for ivermectin distribution was associated with success, whereas use of the community centre for distribution was associated with failure.

Information dissemination is an important component in any programme implementation. The respondents' preference for village leaders as media for disseminating information about treatment is in line with the advocated CDTI principles (WHO, 1995; Akogun *et al.*, 2001). Both quantitative and qualitative information do support that village leaders rally very big support among the community and have the capacity to organize meetings. In Nigeria, the roles of village leaders have been reported in the promotion of CDTI projects (Akogun *et al.*, 2001). In eastern Sudan, very high ivermectin acceptance levels were achieved when community leaders were involved as well as initiated other beneficial programmes in the community (Baraka *et al.*, 1995). The existing administrative set up in the villages can further be utilized to set up a system of following up defaulters during treatment. Available data revealed that the defaulters are usually left at large without any close follow up either by the distributors

or the community. For effective treatment coverage there is need for close follow up during treatment. However, for this to be effective, the role of village leaders with the support of the community would be very crucial.

One of the pillars of the CDTI success at the community level rests on the distributors (WHO, 1995) and they are responsible for ensuring that ivermectin is taken by the community. In the current study the results have shown that distributors had positive attitudes towards the treatment programme. This is a good indication for the programme and rules out their negative contribution to the existing level of non-compliance. Similarly, their selection conformed to the APOC guidelines. Previous studies pointed out that selection of distributors by community members at a meeting was associated with success, whereas their selection by community leaders, health personnel, or self-appointment was associated with failure of the programme (Katabarwa *et al.*, 2000). However, the informants noted with concern some of the obstacles frustrating their effort in the treatment programme besides side effects to be associated with the lifestyle of alcoholism and some religious beliefs. For instance, one distributor said: "*The main problem I faced was that some people were refusing to take the drug because they will have no time for taking alcohol. Even in the central place for drug distribution some people absented themselves.*" This could partly explain why non-compliance to ivermectin treatment was only noted among the males. This kind of behaviour has been noted to have some influence on the low treatment coverage (MOH, 2000).

Similarly, the influence of some religious sect appears to be detrimental to the treatment effort as they sway some of its followers from taking the drug because of their disbelief in orthodox medicine. According to the FGDs these sects believed that God is there to protect them against all kinds of diseases so no need to take this drug.

However, the distributors believed, educating the community would be a long lasting solution. This would give the appropriate background for making positive decision regarding the treatment programme. Katabarwa *et al.* (1999) noted in their study that health education had increased the respondents' knowledge on onchocerciasis and its control in Uganda. It also gave the communities the confidence in deciding on the method of ivermectin distribution, the location of distribution site, and mobilizing other community members for treatment. There is a strong belief among the distributors that refusals and absenteeism during treatment have very much to do with side effects, inadequate education, alcoholism and local beliefs in the community. These were confirmed in focus group discussions and some other earlier studies (MOH, 2000). If the issue of non-compliance is to be minimized there is need to address these issues using appropriate strategies.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS.

The study has shown that the community in Ndubi village is aware of onchocerciasis disease, but the knowledge on its causes was observed to be low. Inadequate health education seems to have contributed to low knowledge levels on symptoms and signs of onchocerciaisis and other programme activities. Although the attitude of both the community and distributors was observed to be positive, other community related factors identified to affect implementation of the programme were side effects of ivermectin, alcoholism and local beliefs.

RECOMMENDATIONS

1. **Bridge knowledge gap:** As a programme seeking to improve treatment coverage and sustainability, there is a gap between knowledge and practice. What people should know about onchocerciasis and do during treatment has not reached all the community adequately. Re-education campaign should be tailored to health workers, village leaders and community at large, using appropriate IEC materials about onchocerciasis and ivermectin (Mectizan). Onchocerciasis films should be shown to the communities if feasible in order to sensitize and create clear understanding of the disease.

2. Community education on key issues like programme ownership, community responsibility, reporting side effects and handling should be emphasized.

3. There is need to improve on post-treatment counseling by the distributors and health workers to create positive thinking and confidence about the drug.

4. Re-training of health workers as resource persons to support the treatment programme. Their roles will be in educating the community and handling of the side effects of the drug during treatment.

RESEARCH:

Some of the qualitative data indicated that there are some local and religious beliefs against orthodox medicine and concerns about side effects that are important to consider. Research may be needed to document beliefs and test their association with coverage.

REFERENCES:

Akogun, O.B., Akogun, M.K. and Audu, Z. (2000). Community perceived benefits of ivermectin in northeastern Nigeria. *Soc. Sci. Med.* **50**: 1451-6.

Akogun, O. B., Audu, Z., Weiss, M.G., Adelakun, A.O., Akoh, J.I., Akogun, M.K., Remme, H., Kale, O.O. (2001). Community directed treatment of onchocerciasis with ivermectin in Takum, Nigeria. *Trop. Med. Int. Health* **3**:232-243.

Akpala, C., Okonkwo, P.O., Nwagbo, D. & Nwakoby, B. (1993). Comparison of three strategies for mass distribution of ivermectin in Achi, Nigeria. *Ann. Trop. Med. Parasit.* **87**: 399-402.

Amazigo, U. (1994). Detrimental effects of onchocerciasis on marriage age and breast- feeding. *Trop. Geogr. Med.* **46**: 322-325.

Amazigo, U., Noma, M., Boatin, B.A., Etyaale, D.E., Seketeli, A. & Dadazie, K.Y. (1998). Delivery systems and cost recovery in treatment of Onchocerciasis. *Ann. Trop. Med. Parasit.* **92** (*suppl.*): S23-S31.

Anon, (1996,a). *African Programme for Onchocerciasis Control*. Ouagadougou: Committee of sponsoring agencies of APOC.

Anon, (1996,b). *Donation status Report:* Document 15. Atlanta, GA: Mectizan Donation Programme.

Awadzi, K., Hero, M., Opoku, N.O., Addy, E.T., Buttner, D.W., & Ginger, C.D. (1995). The chemotherapy of onchocerciasis. XVIII. Aspects of treatment with Suramin. *Trop. Med. Parasit.* **46:** 19-26.

Baraka, O. Z., Khier, M.M., Ahmed, K.M., Ali, M.M.M., El-Mardi, A.E., Mahmoud, B.M., Ali, M.H., Homeida, M.M.A. and William, J.F. (1995). Community-based distribution of ivermectin in eastern Sudan: acceptability and early post-treatment reactions. *Tran. Roy. Soc. Trop. Med. Hyg.* **89**: 316-318.

Benton, B. (1998). Economic impact of Onchocerciasis control through the African Programme for Onchocerciasis control: an overview. *Ann. Trop. Med. Parasit.* **92** *(suppl.)*: S33-S39.

Bernard, H. Russel (2000). *Social Research Methods: Qualitative and Quantitative Approaches*. Sage Publications, Inc. London. Pp. 207-211.

Borg, J. (1976). *Onchocerciasis survey in Rungwe, Kyela and Ileje districts, Mbeya Region*. Report to Danida and Ministry of Health, Tanzania.

Brieger, W.R., Awedoba, A.K., Eneanya, C.I., Hagan, M., Ogbuagu, K.F., Okello, D.O., Osasanya, O.O., Ovuga, E.B.L., Kale, O.O., Burnham, G.M. and Remme, J.H.F (1998). The effects of ivermectin on onchocercal skin disease and severe itching: results of multicentre trial. *Trop. Med. Int. Health.* **3**: 951-961.

Brieger, W.R., Otusanya, S.A., Oke, G.A., Oshiname, F.O. and Adeniyi, J.D. (2002). Factors associated with coverage in community directed treatment with ivermectin for onchocerciasis control in Oyo state, Nigeria. *Trop. Med. Int. Hlth.* **7**(1): 11-18.

Burnham, G.M. (1993). Adverse reactions to ivermectin treatment for onchocerciasis. Result of a placebo controlled, double blind trial in Malawi. *Trans. Roy. Soc. Trop. Med. Hyg.* **87**: 313-317.

Chavasse, D.C., Whitworth, J.A.G., Lemoh, P.A., Bennet, S. & Davies, J.B. (1995). Low-level ivermectin coverage and transmission of onchocerciasis. *Trans. Roy. Soc. Trop. Med. Hyg.* **89**: 534-537.

Chijioke, C.P. (2000). Factors affecting adverse event reporting during mass ivermectin treatment for onchocerciasis. *Acta Tropica*, **76** (2): 169-173.

Dadzie, K.Y. (1998). Control of onchocerciasis: challenges for the future. *Ann. Trop. Med. Parasit.* **92**: S61.

Enyong, P., Kirumbi, E., Malley, K.D. & Kisoka, W. (1999). *Report on Independent Monitoring Team (APOC): CDTI process – Mahenge focus project, Morogoro Region, Tanzania.*

Erharbor, G.E., Aghanwe, H.S., Yusuph, M., Adebayo, R.A., Arogundade, F.A. and Omudura, A. (2000). Factors influencing compliance in patients with tuberculosis in directly observed therapy at Ile-ife, Nigeria. *E. Afr. Med. J.* **77**: 235-239.

Fischer, (1932). Studien Zur Pathologie and Epidemiologie Ost-Afrikas Beobachtungen und Untersuchungen im Maudatsgebiet Tanganyika (Deutsch – Ost – Afrika). Bei Z. Schiffs; *Trop. Hyg.* **36**: 1 – 104.

Granbacka, P. (1973). Onchocerciasis in Southern Tanzania. *Tran. Roy. Soc. Trop. Med Hyg.* **67**: 150

Greene, B.M., Taylor, H.R., Cupp, E.W., Murphy, R.P., White, A.T., Aziz, M.A., Schulz-Key, H.D., Anna, S.A., Newland, H.S., Goldschmidt, L.P. (1985). Comparison of ivermectin and diethylcarbamazine in the treatment of onchocerciasis. *N. Eng. J. Med.* **313:** 133-138.

Habbema, J.D.F., Plaiser, A. P., van Oortmarssen, G.J. & Remme, J. (1990). Prospective evaluation of onchocerciasis control strategies. *Acta Leidensia*, **59**: 387-398.

Hagan, M. (1998). Onchocercal dermatitis: clinical impact. *Ann. Trop. Med. Parasit.* **92**: S85-S96 (*Suppl.)*.

Hauserman, W. (1969). On the biology of *Simulium damnosum* Theobald, 1903, the main vector of Onchocerciasis in Mahenge Mountains, Ulanga, Tanzania. *Acta Tropica*, **24**: 29-69.

Hopkins, A.D. (1998). Mectizan delivery systems and cost recovery in Central African Republic. *Ann. Trop. Med. Parasit.* **92** (*suppl.*): S97-S100.

Johnston, K., Courtright, P. and Burnham, G. (1994). Knowledge and attitudes towards onchocerciasis in Thyolo highlands of Malawi. *Trop. Med. Prasit.* **45**: 341-343.

Kale, O. (1998). Onchocerciasis: the burden of disease. *Ann. Trop. Med. Parasit.* **92:** (*suppl.*): S101-S115.

Katabarwa, N. M., Mutabazi, D. and Richards, Jr. (1999). The community-directed, ivermectin-treatment programme for onchocerciasis control in Uganda- an evaluative study (1993-1997). *Ann. Trop. Med. Parasit.* **93**: 727-735.

Katabarwa, N.M., Mutabazi, D. & Richards Jr., F.O. (2000). Controlling Onchocerciasis

by Community directed, ivermectin treatment programmes in Uganda: why some communities succeed and others fail. *Ann. Trop. Med. Parasit.* **94**: 343-352.

Katabarwa, N.M., Richards Jr., F.O. (2001). Community directed health (CDH) workers enhance the performance and sustainability of CDH programmes: experience from ivermectin distribution in Uganda. *Ann. Trop. Med. Parasit.* **95**(3): 275-286

Kazaura, M.R., Makwaya, C.K., Masanja, C.M. & Mpembeni, R.C. (1997). *Lecture notes in Biostatistics.* Department of epidemiology and Biostatistics, Institute of Public Health, Muhimbili University College of Health Sciences (Dar.).

Mabey, D., Whitworth, J.A., Eckstein, M., Gilbert, C., Mande, G., Downham, M. (1996). The effects of multiple doses of ivermectin on ocular onchocerciasis. Six years follow up. *Opthalmology* **103**: 1001-1008.

Maegga, B.T.A. (1991).Onchocerciasis. *In*: *Health and Diseases in Tanzania*. Mwaluko. G.M.P., Kilama, W.L., Mandara, M.P., Murru, M. & Macpherson. Eds. Happer Collins Academic Press. Pp. 177-188.

Ministry of Health, Tanzania.(1997).*National Plan of Action for Onchocerciasis control.*

Ministry of Health, Tanzania. (2000). *Annual report on Tukuyu focus CDTI project.*

Ministry of Health, Tanzania. (2002). *Annual report on Tukuyu focus CDTI project.*

Miri, E.S. (1998). Problems and perspectives of managing an Onchocerciasis Control Programme. *Ann. Trop. Med. Parasit.* **92** (*suppl.*): S121-S128.

Mwetta, E. and Hills, E. (1994). Community treatment with ivermectin for onchocerciasis in the East Usambara Mountains. *E. Afr. Med. J.* **71**: 790-791.

Nelson, G.S. (1991). Human onchocerciasis: notes on the history, the parasite and life

cycle. *Ann. Trop. Med. Parasit.* **85:** 83-95.

Ovuga, E., Kipp, W., Mungherra, M., & Kasoro, S. (1992). Epilepsy and retarded growth in hyperendemic focus of onchocerciasis in rural Western Uganda. *E. Afr. Med. J.* **69**: 554-556.

Oyibo, W.A. & Fagberno-Beyiku, A.F (1998). Evaluation of community compliance with annual ivermectin treatment in Patigi, Nigeria. *E. Afr. Med. J.* **75**: 237-242.

Pacque, M.C., Dukuly, Z., Greene, B.M., Munoz, B., Keyvan-Larijani, E., Williams, P.N., & Taylor, H.R. (1989). Comparative community based treatment of onchocerciasis with ivermectin: acceptability and early adverse reactions. *Bull. Wld. Health Org.* **67**: 721-720.

Pedersen, E.M. & Maegga, B.T.A. (1985). Quantitative studies on the transmission of *Onchocerca volvulus* by *Simulium damnosum* s.l. in the Tukuyu valley, southwest Tanzania. *Trop. Med. Parasit.* **36**: 249-254.

Pedersen, E.M. and Kolstrup, N. (1986). The epidemiology of onchocerciasis in the Tukuyu valley, southwest Tanzania. *Trop. Med. Parasit.* **37**: 35-38.

Remme, J., Ba, O., Dadzie, K.Y., Karam, A. (1986). A force-of-infection model for onchocerciasis and its application in the epidemiological evaluation of the Onchocerciasis Control Programme in Volta river basin area. *Bull. Wld. Hlth. Org.* **64**: 667-681.

Remme, J., Baker, R.H.A., De Sole, G., Dadzie, K.Y., Adams, M.A., Alley, E.S., Avissey, H.S.K., and Walsh, J.F. (1989). A community trails of ivermectin in the onchocerciasis focus of Asubende, Ghana. I. Effect on the microfilariae reservoir and the transmission of *Onchocerca volvulus*. *Trop. Med. Parasit* **40**: 367-374.

Sande, P.D. (1992). Community perception of onchocerciasis in Ulanga district, Tanzania. *M.Sc Thesis, University of Dar-es-Salaam*.

Wagesa, P. (1970). The present status of Onchocerciasis in Tanzania. A review of the distribution and prevalence of the disease. *Trop. Geogr. Med*. **22**: 345-351.

Whitworth, J.A., Morgan, D., Maunde, G.H., Downham, M.D., and Taylor, D.W. (1991). A community trial of ivermectin for onchocerciasis in Sierra-Leone: adverse reactions after the first five treatment rounds. *Trans. Roy. Soc. Trop. Med. Hyg*. **85**: 501-505.

WHO (1976). *Epidemiology of Onchocerciasis.* Report of a WHO Expert Committee. Technical report series, No. 597.

WHO (1987). *WHO Expert Committee on Onchocerciasis*. Third report. Technical report series No. 752.

WHO (1991). *Strategies for ivermectin distribution through Primary Health care systems*. Document. WHO/PBL/91.24. Geneva: WHO.

WHO (1995). *Onchocerciasis and its Control.* Report of a WHO Expert Committee. Technical report series, No. 852.

WHO (2000). *Community Directed treatment of LymphaticFilariasis*. UNDP/World

Bank/WHO special Programme for Research & Training in Tropical Diseases, TDR/IDE/RP/CDTI/00.2.

Workneh, W., Fletcher, M., & Olwit, G. (1993). Onchocerciasis in field workers at Baya farm, Teppi coffee plantation project, southwestern Ethiopia: prevalence and impact on productivity. *Acta Tropica*, **54**: 89-97.