

Psycho-social and economic evaluation of onchocerciasis: a literature review.

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Abstract

Background: Onchocerciasis or river blindness is a chronic parasitic disease caused by the filarial nematode *Onchocerca volvulus*. It occurs in 38 countries in the world, including Africa, Latin America and the Arabian Peninsula. The infection predominantly causes visual impairment, blindness and skin disease.

Objectives: The aim of this project is to review the literature on the psycho-social and economic consequences of onchocerciasis in endemic areas. Economic evaluation studies of onchocerciasis and its control programmes were also reviewed.

Methods: Electronic searches of PUBMED and Google were made. In addition, the Cochrane Library and WHO website were searched. Different types of economic analysis were reviewed to quantify the relationship between the programme costs and impacts.

Results: Eighty papers were identified from different sources, most of which are quantitative studies or literature reviews, and only two were clinical trials.

Onchocerciasis has severe socio-economic and psychological consequences. The stigma associated with the disease may reduce marital prospects among affected individuals, disrupt social relationships, and cause loss of self-confidence. Also among agricultural workers onchocerciasis has been associated with increased time away from work and reduced productivity, leading to lower income.

Discussion: Most of the papers analysed were cross-sectional studies based on data collection through questionnaires. Although there is an increasing number of published papers about the importance of the psycho-social and economic perspective of onchocerciasis, further research is still necessary to quantify and control its consequences.

Conclusion: Onchocerciasis is still a serious problem in poor countries. Infected people face physical disability and social stigma that can dramatically reduce the quality of life and land productivity. Control programmes, though costly, have been very successful and cost-effective. Priority should be given to the development of new tools to support control programmes and to enable eradication of the disease.

Key words: onchocerciasis, onchocerciasis and psycho-social consequences, onchocerciasis and economic evaluation, onchocerciasis and cost-effectiveness analysis, onchocerciasis and cost-benefit analysis.

1. Introduction.

1.1. Definition.

Onchocerciasis or “river blindness” is a chronic parasitic disease caused by the filarial nematode *Onchocerca volvulus* which is transmitted by blood-sucking *Simulium* blackflies. The infection affects multiple organ systems, but the greatest morbidity is due to cutaneous and ophthalmologic

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complications.⁽¹⁾ Blindness tend to predominate in the African savannah and skin disease in rainforest areas.⁽²⁾ Onchocerciasis is the fourth most common cause of blindness in the world and ocular damage is the most serious complication of the disease.

River blindness is essentially a rural disease, affecting only the poorest and most remote communities, populations with the fewest resources and the least access to health services.⁽³⁾ It is now recognized by the World Health Organization as one of the world's major public health problems and it has been included as a target disease within WHO's Special Programme for Research and Training in Tropical Diseases.⁽⁴⁾

1.2. Epidemiology.

Onchocerciasis is endemic in tropical Africa, where the vast majority (over 96%) of the global disease burden is found. Small foci also exist in the Arabian Peninsula (Yemen and Arabia Saudi) and in parts of Central and Southern America such as Mexico, Guatemala, Ecuador, Colombia, Venezuela, and Brazil. (Figure 1)

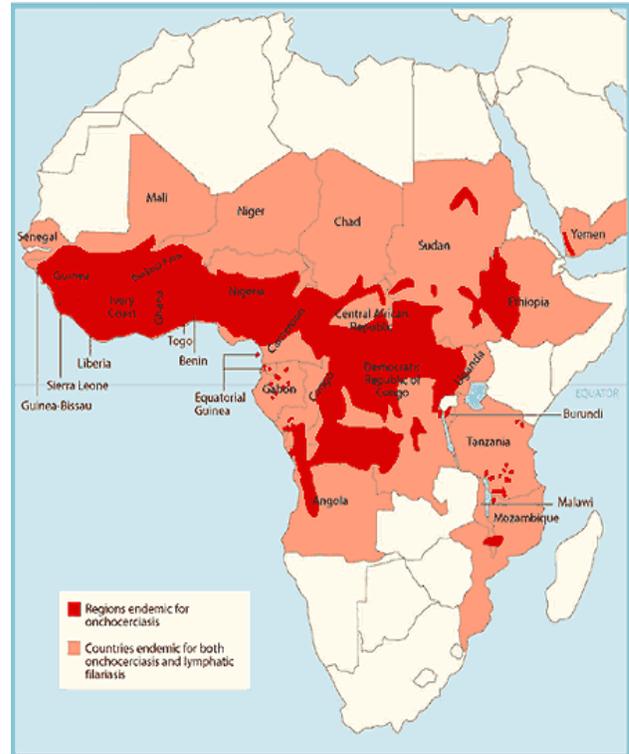
Previous estimates have placed the total number of people infected at 18 million, of whom 99% live in Africa.⁽⁴⁾ Since then, the true extent of the disease has been estimated by Rapid Epidemiological Mapping of Onchocerciasis (REMO). By 2005, more than 22,000 villages in Africa (outside the Onchocerciasis Control Programme area) had been surveyed, allowing the identification of many new foci. Presently, it is estimated that 37 million people are carrying *O. volvulus*, with 90 million at risk in Africa.⁽⁵⁾

Onchocerciasis is the second most common cause of preventable blindness in sub-Saharan Africa.⁽⁶⁾ Globally, approximately 270,000 people are blind and 500,000 have significant visual loss directly as a consequence of onchocerciasis. To these figures is added each year an estimated number of 40,000 new blind.

There are marked geographical variations in the prevalence and clinical manifestations of onchocerciasis and these have a direct bearing on estimates of the burden of the disease in different parts of the world.⁽⁷⁾ There are two fairly broad but distinct clinico-pathological patterns of onchocerciasis, particularly in West-Africa, based on the disease's two predominant and major clinical complications: blindness and skin disease. In West-Africa, blindness rates are significantly higher in hyperendemic communities in the savannah than in

communities with similar levels of infection in the rainforest.⁽⁸⁾ DNA probes have confirmed that these different patterns are the result of different parasite strains.⁽⁹⁾

Figure 1. World distribution of onchocerciasis



1.3. Pathogenesis.

Adult *O. volvulus* worms lie coiled up in subcutaneous nodules, surrounded by a fibrous capsule. The nodules *per se* are relatively asymptomatic but newly formed microfilariae migrate out of the nodules and concentrate in the dermis of the skin, the eye and lymph nodes, where host inflammatory reactions to dead and dying microfilariae result in inflammation and pathology.⁽¹⁰⁾

Until recently filarial products themselves were thought to be the major stimulus for the underlying inflammatory response. However, recent research indicates that endotoxin-like molecules from *Wolbachia* (bacterial symbionts of the major human Filarias, including *O. volvulus*) have a role in the pathogenesis of the disease and in adverse reactions after treatment. *Wolbachia* seem to be essential for nematode fertility and have emerged as a target for chemotherapy that fulfils the priority research objective of long term sterilising activity.⁽⁶⁾

1.4. Clinical features.

Onchocerciasis has a broad clinical spectrum, which is thought to reflect different host immune responses to the microfilarial stage of *O. volvulus*.

The main manifestations of the disease are predominantly seen in the eyes and in the skin. Pruritus is commonly the first clinical symptom of the disease, and may occur on its own or in association with onchocercal skin disease.

Eye disease:

Microfilariae can be seen in all ocular tissues. Dead microfilariae in the cornea cause opacities known as punctate keratitis, which may resolve spontaneously. The more serious and potentially blinding ocular lesions of onchocerciasis are sclerosing keratitis, iridocyclitis, choroido-retinitis, choroido-retinal atrophy, optic neuritis, and optic atrophy.⁽¹¹⁾

Skin disease:

A classification of the cutaneous changes in onchocerciasis has been developed.⁽¹²⁾ This defines the following five main categories of onchocercal skin disease (OSD) which may co-exist: acute papular onchodermatitis (APOD), chronic papular onchodermatitis (CPOD), lichenified onchodermatitis (LOD), atrophy and depigmentation

(DPM). APOD, CPOD, and LOD may be grouped together under the general term “reactive” onchocercal skin disease. Onchocercal nodules are mainly found over bony prominences.

Onchocerciasis is also a systemic disease that is associated with musculoskeletal pain, reduced body mass index, and decreased work productivity. Many aspects of the systemic manifestations of onchocerciasis are not fully known. Microfilariae of *O. volvulus* have been found in diverse organs and body fluids and tissues.⁽⁷⁾ Heavy microfilarial infection is also suspected in the onset of epilepsy. A quantitative meta-analysis of all available data has suggested a degree of association between onchocerciasis and epilepsy.⁽¹³⁾

1.5. Diagnosis.

The main diagnostic procedure for onchocerciasis is the skin snip. Other parasitological forms of diagnosis are detection of intra-ocular microfilariae using a slit-lamp and examination of nodules after collagenase digestion. The Mazzoti test can be used in patients with negative skin snips when a diagnosis of onchocerciasis is still suspected.⁽¹⁴⁾

1.6. Treatment.

Prior to 1987, diethyl-carbamazine was the only microfilaricide available for treatment of onchocerciasis but severe Mazzoti reactions and secondary optic neuritis limited its use. Since the microfilaricidal drug ivermectin (Mectizan) was introduced for human use in 1987, the treatment of onchocerciasis has been revolutionized. It has minimal side-effects and it has become feasible to conduct mass treatment of endemic communities. A large placebo-controlled trial in Northern Nigeria showed that ivermectin does not precipitate optic neuritis or posterior segment disease.⁽¹⁵⁾ Ivermectin also blocks the release of microfilariae from the uteri of adult female worms, but the gradual build-up of microfilariae in the dermis of the skin is not fully prevented so ivermectin must be re-administered every 6-12 months throughout the life-span of the adult worm which is about 12 years. A multicountry placebo-controlled study examined the effects of 3-monthly, 6-monthly and annual doses of ivermectin on itching and OSD.⁽¹⁶⁾ An important reduction in the prevalence of itching and the severity of reactive skin lesions was seen in the groups receiving ivermectin compared to placebo.

There was no difference among the various ivermectin regimens.

Several recent studies show that the principle of targeting *Wolbachia* in combination with ivermectin is highly effective and offers the potential of interrupting transmission. A study in Ghana in which patients were treated either with ivermectin or ivermectin plus doxycycline 100 milligrams daily for six weeks (or 200 milligrams daily for four weeks) lead to an interruption of embryogenesis that lasted for 18 months or more.⁽¹⁷⁾

The single annual combined-drug regimen of albendazole and ivermectin is currently being used to control lymphatic filariasis and onchocerciasis in areas of coendemicity.⁽¹⁸⁾

Finally, pre-clinical studies have shown Moxidectin to fulfil many of the criteria for a potential macrofilaricide.⁽¹¹⁾

1.7. *Burden of disease.*

The true burden of onchocerciasis has largely been underestimated. Although the burden of onchocerciasis is relatively small at the global level, at the local level it can be the most important health problem for endemic communities and in some situations it may threaten the survival of the community itself.⁽¹⁹⁾ Excess mortality of the blind, particularly among males, may be considerable. Even in sighted individuals, high microfilarial load can negatively affect a host's life expectancy.⁽²⁰⁾

The lack of information on the importance of OSD initially resulted in a low priority being set for onchocerciasis control in areas with little onchocerciasis blindness. In response to that need, a multi-centre study was undertaken in seven rainforest areas of sub-Saharan Africa with presumed low level of onchocercal blindness.⁽²¹⁾ It was shown that pruritus was a major complaint in the hyper-endemic communities. Also a very strong and statistically significant correlation was found between the prevalence of itching and onchocercal skin disease, and the level of endemicity. This study resulted in a fundamental re-assessment of the burden of onchocerciasis.⁽¹⁹⁾

Onchocerciasis has been estimated to be responsible for the loss of an estimated 1 million DALYs annually globally, with visual impairment and blindness accounting for 40% of this figure, and severe itching 60% i.e. the estimated burden of itching alone was greater than the burden caused by onchocercal eye disease.⁽¹⁹⁾

The current DALY estimates do not yet take the impact of ivermectin treatment into account. It is likely that the burden of disease has already been reduced by some 25-30% during the last five years.⁽²²⁾ Taking into account the effectiveness of control programmes by country, it is suggested that, compared to the global burden of disease 1990 estimate, the burden from onchocerciasis approximately halved by 2000.⁽²³⁾

1.8. *Control programmes.*

The mainstay of onchocerciasis control is through antivectorial and antiparasitic measures (mass administration of ivermectin).

Three Regional Programmes have been established to co-ordinate onchocerciasis control:

The Onchocerciasis Control Programme (OCP): 1974-2002.

This was the first major control programme aimed to eliminate the vector blackfly by regular aerial larviciding of river areas with known high rates of onchocercal blindness. The project started with seven member countries in West Africa (Burkina Faso, Niger, Benin, Ivory Coast, Ghana, eastern Mali, and Togo) and in 1986 the programme was extended to include parts of Guinea, Guinea Bissau, western Mali, Senegal, and Sierra Leone.⁽²⁴⁾

Until the late 1980s, OCP was based exclusively on the strategy of vector control. The decision of Merck Sharpe and Dohme Ltd (Merck) in 1987 to make ivermectin (Mectizan) available free of charge through the Mectizan Donation Programme (MDP) was an important addition to the OCP control strategy.⁽²⁵⁾

The Onchocerciasis Elimination Programme in the Americas (OEPA): 1991-2007.

The Onchocerciasis Elimination Programme in the Americas includes six countries: Brazil, Columbia, Ecuador, Guatemala, Mexico, and Venezuela, with 93% of Latin American cases in the last three countries.⁽²⁶⁾ Its aim was the reduction of morbidity and interruption of transmission by semi-annual mass chemotherapy with ivermectin in all endemic areas. In Latin America it was realized that effective Mectizan distribution might even eliminate the disease forever, as there are less efficient vector flies in the western hemisphere.

OEPA is on the verge of successful elimination of onchocerciasis from Latin America.

African Programme for Onchocerciasis Control (APOC): 1995-2010.

The objective of this most recent programme was to establish within 12 years sustainable Community-Directed Ivermectin Distribution (CDTI) systems in the 19 countries outside the OCP where onchocerciasis still is a public health problem (Angola, Burundi, Cameroon, Chad, the Central African Republic, the Congo, the Democratic Republic of the Congo, Ethiopia, Equatorial-Guinea, Gabon, Kenya, Liberia, Malawi, Mozambique, Nigeria, Rwanda, Uganda, Sudan, and Tanzania). In these countries it is estimated that 6.4 million heavily-infected people live in areas where the parasite strains cause high rates of blindness and some 6 million heavily-infected people live in areas where the parasite strains produce severe itching and skin disease.⁽²⁾

1.9. Current situation on onchocerciasis.

In the OCP area of operation, vector control combined with mass distribution of ivermectin have been so effective that onchocerciasis has been virtually eliminated as a public health problem in the original seven countries of the programme. (Figure 2) In the remaining four, control activities were so advanced that OCP officially closed down in 2002, and all control and surveillance activities transferred to member states.⁽²⁷⁾ It is been a hugely successful programme, which has protected approximately 11 million children against onchocerciasis and around 500,000 people have been saved from blindness. 1.25 million people are rid of their onchocercal infection and, in addition, there has been tremendous socio-economic gain in the resettlements of new communities in the previously infested areas; some 250,000 km² of “new land” has been resettled and is now being cultivated.

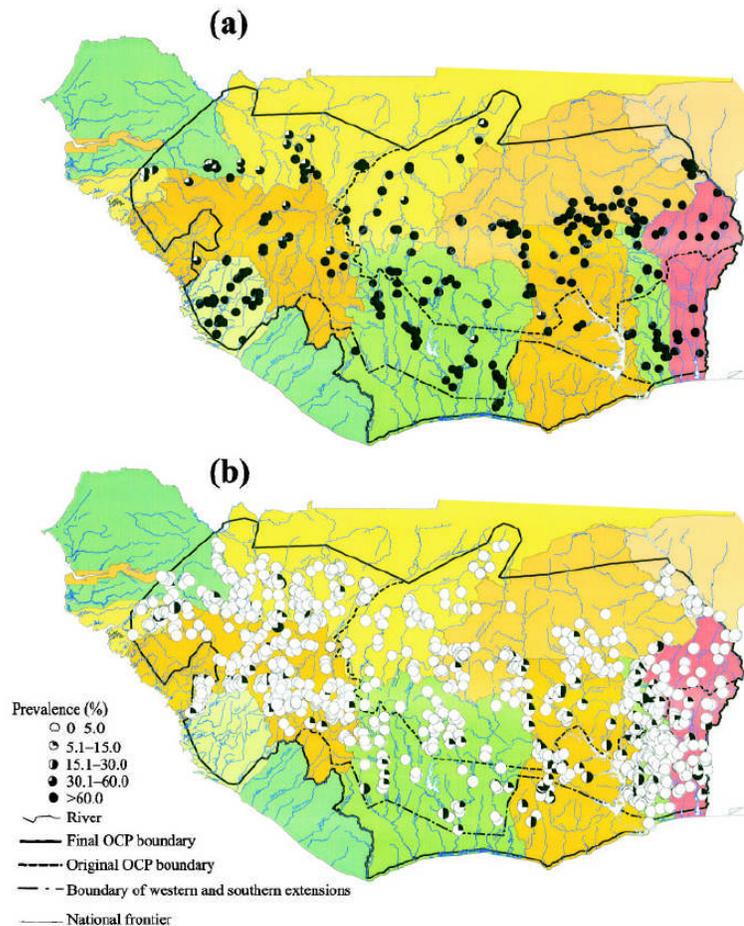


Figure 2. Maps showing the efficacy of the interventions by OCP in West Africa. a) Prevalence of onchocerciasis in 1970, before the interventions. b) Prevalence of onchocerciasis by 2000-2001⁽²⁸⁾

Since it was initiated, APOC has implemented, with great success, the modality of community-directed treatment with ivermectin (CDTI), by which communities themselves appoint accountable local distributors. By the end of 2005, 400 million treatments had been supplied by Mectizan Donation Programme, with an estimated 40 million people living in 90,000 African villages being treated by nearly 30,000 community distributors throughout APOC projects. By 2010, when APOC is due to be phased out, 50 million persons are expected to be receiving annual treatment, 65% of the total project area population.⁽²⁵⁾

2. Objectives.

The two main objectives of the present literature review were as follows:

- i) to determine the social, psychological and economic consequences of onchocerciasis.
- ii) to review the available economic evaluation studies on onchocerciasis control programmes.

More specific objectives included:

- iii) to critically appraise the quality of the available literature.
- iv) to consider how knowledge of the social, psychological and economic impact of onchocerciasis can assist in design of further intervention strategies.
- v) to make recommendations for further research in this area.

3. Methods.

The main datasets used for the literature review were PUBMED, Cochrane Library, and Google. Web search was based on the following agencies: WHO and World Bank.

Different key words were used in varying combinations to identify primary and secondary studies (reviews).

Key words used were:

- Onchocerciasis
- Onchocerciasis and psycho-social consequences.
- Onchocerciasis and psycho-social impact.
- Onchocerciasis and economic evaluation.
- Onchocerciasis and cost-effectiveness analysis.
- Onchocerciasis and cost-benefit analysis.

Inclusion criteria: quantitative or qualitative studies related to the topic of interest, published between 1975 and 2007; Full text in English (not just the abstract) to allow a proper evaluation of the papers.

Exclusion criteria: papers which did not exactly match the search criteria and those in a language other than English were excluded.

Psycho-social and economic studies.

The literature was assessed in a systematic manner and the findings tabulated, (Tables 1.1 and 1.2 in Appendix 1) The author, year of publication and location of the study were noted. Also the type of study, sample size, methods, and summary of the results were recorded.

Economic evaluation studies.

The literature was assessed as above, in a systematic manner and the findings tabulated. (Table 2 and 3 in Appendix 2)

The economic evaluation studies of onchocerciasis and its control programmes were considered using three main types of analysis:

- Burden of Disease studies: calculating costs of disease (costs include lost wages, costs of treating, etc...).
- Cost-benefit analysis (CBA): provides information on both the costs of the intervention and the benefits, expressed in monetary terms. Results are generally expressed as *Net Present Value (NPV)* or the *Economic Rate of Return (ERR)*.
- Cost-effectiveness analysis (CEA): provides information on the cost of the intervention and its effectiveness, where effectiveness is not expressed in monetary terms but rather by a defined metric. When results are expressed in terms of Quality Adjusted Life-Years (QALYs) or Disability Adjusted Life-Years (DALYs), this approach is referred to as Cost-Utility analysis.

4. Results.

Eighty articles in total were identified and analysed from the above sources, including those used for the background/introduction. Two of them were clinical trials.

Twenty-eight articles related to the main aims of the review were identified.

4.1. *Psycho-social and economic impact of onchocerciasis.*

4.1.1. *Summary of the results.*

Twenty-three articles were related to our first objective: eighteen linked to the psycho-social aspects of onchocerciasis and four related to its economic consequences.

Quantitative studies: fourteen. Four of these also included a qualitative analysis about the psycho-social perceptions and stigma of affected individuals.

Qualitative studies: three.

Literature reviews: three.

Reports: three.

4.1.2. *Socio-demographic consequences of onchocerciasis.*

It has been estimated that in areas of high onchocerciasis endemicity the average age of onset of blindness is between 35 and 45 years of age. A mean reduction in life expectancy of 13 years for 40% of the adult population is a major direct demographic consequence of the blindness caused by onchocerciasis. According to research studies in White and Red Volta south area, in severely affected villages (blindness rates of 5% or more and fewer than 200 inhabitants), population growth was less than 1.8% per annum compared with the national average of 2.7%. A blindness prevalence of 4-5% seems to be the threshold beyond which the same demographic consequences are always seen, i.e. emigration by young people, low marriage rate and production, aging of the population, drop in production, economic stagnation, and inexorable social disintegration. The final stage is the abandonment of the village or the death of its last inhabitants, almost all of them blind.⁽²⁹⁾

4.1.3. *Cultural beliefs.*

Cultural beliefs about the disease affect different aspects of onchocerciasis. Knowledge of the disease, including its name, the method of transmission, and the complex of signs and symptoms is poor in endemic communities in Africa and the Americas.⁽⁴⁾ Attitudes and practices

regarding onchocerciasis also vary between different areas.⁽³⁰⁾

According to the results of a study to examine the beliefs of rural women in an endemic Nigerian community, it was found that most women believe that the different forms of onchocerciasis are caused by different aetiological agents.⁽³¹⁾ Eighty per cent of women believe that onchocerciasis is transmissible from mother to child during pregnancy and 73% believe treatment should begin in adolescence.

In some areas of Western Nigeria, onchocerciasis (also called “*nárun*”) is attributed to the “ubiquitous worms inside the body” which are believed to be harboured by everyone and to be necessary to stimulate fertility. Skin manifestations and itching are thought to be brought on by eating certain vegetables, especially if these are not well cooked. Other reported causes, such as exposure to sun, not bathing enough, mosquito bites, fever, or too much work imply that *nárun* is a temporary reaction to another problem. The term *nárun* is thought to be derived from the phrase *iná òdòrín* (fire from the heavens). Although people believe everyone needs some *nárun* to make him/her potent/fertile too much is thought to cause impotence and infertility.⁽³²⁾ Furthermore, according to the results from this group, Youruba women in rural Nigeria believed that onchocerciasis affected menstruation.

The beliefs linking onchocerciasis and infertility/impotence are perhaps the most damaging aspects of stigma as borne out by individual case histories. Research evidence indicates that people affected with OSD think that it affects reproductive capacity and birth outcomes, leading to infertility, abortion, and stillbirth among women and impotence among men.⁽³³⁾

It is clear that most women are much more concerned about the effect of the disease on reproductive health and the risk of transmission to offspring than they are about skin lesions or even blindness.⁽³¹⁾

4.1.4. *Onchocerciasis and gender.*

The available literature suggests that gender is an important factor in the experience of stigma.

Some studies have tried to highlight possible gender differences in the impact of onchocerciasis.

In much of Africa marriage and fertility are closely associated with respect, happiness, and security in old age. An important study by Amazigo and Obikeze (1991) in east Nigeria showed that girls appeared to be more disadvantaged than boys because of their greater dependence on physical appearance for social acceptance, marriage and well-being. In contrast, the women in Nebbi District (Uganda) expressed less worries than men over their chances of getting married.⁽³⁴⁾

Furthermore, according to the results from a multi-country study about gender and stigma in Africa by Vlassoff (2000), it was found that half the affected respondents of both sexes denied any negative effect of OSD on marriage prospects (perhaps suggesting problems in facing the issue), on the quality of ongoing marriage, sexual functioning, or marriage of family members. By contrast, unaffected respondents showed significantly greater concern about the impact of OSD on ability to marry than the affected group, both for men and for women. When men did admit that OSD had caused marriage problems, they typically referred to issues of gender roles and identity, such as their ability to work, support their families, and perform sexually. In all study sites, more men than women reported worry over the impact of OSD on sexuality.⁽³⁵⁾

Amazigo (1994) also documented the social impact of OSD on women in eastern Nigeria. Those affected appear to marry at a later age and wean their children sooner than those without skin lesions. During in-depth interviews and focus group discussions, restlessness while breast-feeding, joint pain, backache, and fatigue due to incessant itching from lesions were the predominantly mentioned reasons which motivated an infected mother to discontinue breast-feeding.⁽³⁶⁾

4.1.5 Onchocercal eye disease.

Onchocercal blindness is irreversible and is the most serious clinical manifestation of onchocerciasis in Africa. In some communities, where blindness may exceed 10% of the adult population,

the prevalence of impaired vision may reach 50%.⁽³⁷⁾

Since river blindness gained attention in the early 1970's, several studies have proposed that the impact of the disease could be viewed in terms of a sequence of impairment, disability, and the social and economic consequences of disability or handicap (disruption of an individual's performance of life habits). According to the results of a study in West Africa in 1995, a higher prevalence of constrained mobility, "inactive" occupational status, and "non-married" status are representative of a handicap associated with blindness and decreased visual acuity. Among the blind, 68% claimed they were unable to walk beyond the village, compared to 42% and 8% among the visually impaired and sighted individuals. Only 10% of the blind compared to 54% of visually impaired and 92% of the sighted described their occupation as farmer. Also blindness and, to a lesser extent visual impairment were associated with high rates of celibacy, widowhood, divorce, and low rates of marriage.⁽³⁸⁾

4.1.6 Onchocercal skin disease.

It is appreciated that there are harmful stigmatising and other psychosocial effects from onchocercal skin disease.⁽³⁴⁾ In addition, recent studies in Ethiopia, Nigeria, and Sudan have shown that OSD is responsible for poor school performance and a higher school dropout rate among infected children. In addition, low productivity, low income, and higher health related costs are seen among affected adults.

a) Stigma and OSD.

Social stigma has been defined as a physical, mental, or social attribute of an individual or group that elicits an aversive or discriminatory response from others.⁽³⁹⁾ Stigmatised persons thus suffer from psychological problems such as self-hate, self-derogation, and lack of social acceptance.

Recent studies indicate that onchocercal skin disease poses a more serious social problem than previously appreciated. The presence of onchocercal skin lesions affects the ability of the afflicted to interact with their peers. Their health

condition causes them great unhappiness, and damages their ego and self-confidence. As a result, they tend to withdraw and isolate themselves from society. Embarrassment, sleeplessness, and reduced concentration have also been associated with onchocerciasis.⁽⁴⁰⁾

In a formal attempt to document the stigmatising effect of OSD, the Pan-African Study Group on Onchocercal Skin Disease (1995) of the UNDP/World Bank/WHO Special Programme of Research and Training in Tropical Diseases (TDR), conducted a multi-country study at eight sites. They developed, validated, and used a 10-item stigma scale constructed around the following indicators: disclosure, esteem, leadership, heterosexual relationships, pity, avoidance, shame, marriage, and sexual functioning. The study group found that persons with reactive skin disease (i.e. APOD, CPOD, or LOD) had higher levels of stigma than those with non-reactive lesions such as depigmentation and atrophy of the skin. Approximately one-third of those with OSD reported low self-esteem and difficulties in attaining marriage. It was also shown that some affected persons thought less of themselves or thought they were worthless, and 1-2% considered suicide. The level of stigmatisation increased with the level of education of study subjects.⁽⁴¹⁾

b) Stigmatisation among individuals not affected by OSD.

The attitude of the non-affected towards the affected in the community is suspicious and partially discriminatory⁽⁴²⁾, as Brieger et al. and the Pan-African Study have reported (WHO,1995). The attitude of partial avoidance of the affected by the non-affected amounts to fear based on ignorance on the mode of transmission.⁽⁴⁰⁾

Ovugas et al's results from the study on the psycho-social aspects of OSD in Uganda revealed that people stigmatise, fear, and avoid affected subjects, though selectively, depending on the nature of relationships.⁽³⁴⁾ The affected individual tended to be considered dull, weak, dirty, dangerous, and emotionally cold. People would not elect them for positions of leadership. The stigmatised individual was naturally made to keep

out of the mainstream of group social activities to avoid being shamed or embarrassed. Furthermore, non-affected persons (65%) perceived onchocercal skin disease as a problem that would make it impossible for anyone to get married. By contrast, affected individuals had mixed reactions about the effects of onchocercal disease on marriage and sexual functions.

c) Help-seeking and coping mechanisms.

The Pan-African Study Group on Onchocercal Skin Disease (1995) found that about half of affected individuals perceived onchocerciasis as a very serious matter. However, there was hope among the people who took part in this study that there was a cure for them.

In terms of types of help used, nine out of every ten people in the study said that modern medicine is more effective for both reactive lesions and non-reactive skin lesions. However, the lack and cost of drugs in hospitals and dispensaries frustrated the patients and they had to rely on help at home and help from friends. (see Table 4, page 17). Therefore, despite the value attached to modern medical service, cost is still considered a very important barrier for its use. Although more information would be useful, it appears that the condition imposes considerable financial burden on the affected individuals.⁽⁴¹⁾

According to a study in endemic communities of southwestern Ghana, affected people coped with onchocercal skin disease in various ways. Their behaviour could be categorised loosely into negative, passive, and positive strategies. Those who coped negatively kept others from knowing that they had the condition. Negative coping strategies often reflected the perception of stigma due to lesions. They included attempts to classify or label an onchocercal skin disease as non-disease (for instance, attributing depigmentation to old age or APOD/CPOD to heat rashes). Those who coped passively no longer wished to seek treatment for the condition and adopted fatalistic attitudes. This might have resulted from failure in the past to secure effective treatment. At the other end of the spectrum were those who coped positively by seeking some form of treatment.⁽⁴³⁾

Table 4. Types of help used by respondents (The Pan-African Study, WHO, 1995)

Types of help	Reactive skin lesions (%)	Depigmentation (%)	All subjects (%)
Self care	53.8	46.7	51.1
Help at home	31.7	33.1	32.2
Friends/Relatives	18.4	18.1	18.3
Chemist/Pharmacy	36.7	31	34.5
Modern Doctor/Hospital	42.7	39.7	41.6
Traditional Healer	25.3	27.5	26.1
Faith healer/pray house	8.1	13.3	10
Other	2.5	26.8	22.6
None (142 cases)	20.1	26.8	22.6

4.1.7 Economic productivity.

The economic loss due to effects of onchocerciasis can be difficult to estimate as a result of the mainly subsistence economy of the region. However, findings obtained from Ovuga's research group (1995), showed that, as a result of general weakness, body pains, joint pains, and headache associated with itching, the personal productivity of 67% of onchocerciasis-affected individuals was reduced.⁽³⁴⁾ Furthermore, the debilitating effects of dermal and ocular onchocerciasis led to considerable loss of working time due to attendance at hospitals and clinics for treatment. Thus, working efficiency is reduced both directly and indirectly.⁽²⁹⁾

According to the results of a study about farm land size and onchocercal skin disease in Nigeria, farmers with OSD had an overall lower standard of living, as indicated by fewer personal wealth indicators such as owning motorcycles, radios, iron roofing and cement-plastered houses. Furthermore these farmers did not seem to have developed alternative cropping strategies such as diversification or choice of less demanding crops. One could therefore conclude that individuals with OSD had reduced holdings under cultivation and demonstrated a real inability to work as strenuously as people without obvious signs of the disease.⁽⁴⁴⁾

4.2. Economic evaluation studies on onchocerciasis.

4.2.1 Summary of the results:

A total of five economic evaluation studies from different sources were identified and analysed. One of them was a burden of disease study, two were cost-benefit analyses, and one a cost-effectiveness analysis. The last paper was an overview of the economic evaluation studies of APOC.

The majority of economic evaluation studies were based on previously made economic assumptions. Three of the studies identified within a review by Waters et al. (2004) were unpublished and not available on the reviewed datasets (Cost-benefit analysis by Haddix 1997, Cost-benefit analysis by McFarland and Murray 1994, and Cost-effectiveness analysis by McFarland and Murray 1994).

4.2.2. Burden of Disease studies.

Kim (1997) studied the effects of onchocerciasis on health and labour productivity among 425 workers at the Teppi coffee plantation in southwest Ethiopia. The results of the study showed that permanent employees with severe OSD earned on average almost 30 Birr (\$5.32) less per month

and worked almost 2 fewer days per month when compared with non-OSD workers in the same employment category. Severely-affected OSD permanent employees earned lower monthly wages not only because they worked fewer days, but also because they were less productive on the days they did work. It was found that the presence of severe-OSD decreased the daily wage of workers by approximately 16%.

On the other hand, severe-OSD did not appear to affect the average income or productivity of temporary workers.

Analysis of these data from plantation records indicated that the economic impact of OSD was a function of various factors including type of employment, age, and gender. Relatively older (>35), permanent, male employees have the biggest OSD-related loss in economic productivity in terms of diminished earnings and OSD adversely-impacted labour supply.⁽⁴⁵⁾

The World Bank (1997) conducted a multi-country study of the economic impact of OSD. The four sites included two in Nigeria and one in both Sudan and Ethiopia. Costs of health-related expenditures at the individual and community levels, productivity, transportation, non-cash exchanges, and time spent in seeking health care and accompanying patients were included. More specifically, the study's objectives included assessing the impact of OSD on children's education and the direct costs and indirect costs (i.e. diminished income-generating capacity). On average, persons suffering from OSD were found to spend an additional \$8.10 over a 6-month period in comparison with their non-OSD counterparts from the same community, and to spend an additional 6.75 hours seeking health care over the same 6-month period.

With regards to the impact on children's education, the risk of becoming non-attenders was twice as high if the head of their household had OSD than if the head was unaffected. Severe OSD in heads of households was more likely to have a detrimental impact on the attendance at school of female children than of male. Furthermore, OSD was seen to be associated with diminished time allocated to household activities, those with OSD spending relatively more time in activities classified under sickness and fatigue.

4.2.3. Cost-benefit analyses.

Several studies have used cost-benefit analysis to calculate the Net Present Value (NPV) and the Economic Rate of Return (ERR). A positive NPV is an indicator of a successful investment. An ERR of 10% is considered by the World Bank and others as a standard for successful public health programmes.⁽⁴⁶⁾

Benton and Skinner (1990) estimated costs and benefits of the OCP over the life of the programme and beyond. Costs and labour-related benefits of OCP over a 50 year period were estimated to be \$231 at a discount rate of 5%, and \$140 at a discount rate of 10%. The average cost per person protected in the "at risk" population of 17 million was estimated to be approximately \$0.45 per annum in constant dollars over a 50-year period, 1974 - 2023. It was calculated that OCP had a considerable internal rate of return of between 7% and 11%. Once the land-related benefits had been factored in, OCP had a minimum internal rate of return of between 11% and 13%.⁽⁴⁷⁾

It was concluded that the largest economic benefit would be achieved by improved access to underused land. The estimated "new land" to be available by onchocerciasis control was 25 million hectares or 250,000 km².

McFarland and Murray (1994) project costs for OCP over 10 years were estimated at \$195 million. The assumptions were that the programme served 18.6 million persons, that 500,000 cases were prevented annually and that the subsistence income level was \$150 (1985 dollars), resulting in economic benefits of \$75 million per annum. Additionally, land-related benefits for the OCP were estimated at \$205 million over a 50 year project horizon (1974-2023) with a 5% discount rate, resulting in a net present value of \$85 million over a 10 year project time period.⁽⁵⁰⁾

Kim and Benton's (1995) cost-benefit analysis of the OCP is the most extensive economic analysis carried out since the programme was initiated. This study takes into consideration the sum of expenditures incurred from 1974 to 1993 and projected expenditures from 1994 to 2002 (year when OCP concluded). The costs included all donor and government programme costs – including those for the vector control programmes – but not Merck's costs in production and distribution.⁽⁴⁶⁾

The total expenditures (actual as well as projected) for the two time periods, 1974-2002 and

1974-2012, were \$571 million in 1987 constant dollars.

The benefits gained due to onchocerciasis control tend to accumulate in the later stage of the project cycle and are expected to continue for at least another 10 years, even if no further action were taken. These benefits are represented by additional agricultural output produced as a result of the extra productive labour force and agricultural land made available through the control of onchocerciasis ("new land").

Limited and over-cultivated farm land was a major constraint to agricultural production before OCP began operations and was also a casual factor for out-migration. Total agricultural land had been slowly decreasing over years in OCP countries. In most cases, the onchocerciasis-freed land provides better farming opportunities than land utilized in areas which were lightly or non-infected before the programme began.

The estimated total size of the "new land" was about 25 million hectares. New land began to be utilized in 1983 when the first year of land-related benefits materialized.

This study showed that the NPV of labour and land-related benefits together (assuming 85% labour participation and land utilization over a 39 year project horizon 1974-2012) ranged between \$3.729 million and \$485 million in 1987 constant dollars at discount rates of 3% and 10% respectively. The estimated ERR under the same assumptions was of 20%. Using a shorter project horizon of 29 years yielded an ERR of about 18%. The cost of protecting each person in the 11 country area was \$0.57 per annum in 1987 constant dollars.

Furthermore, since one case of blindness prevented adds another 20 years of productive life to the individual, the extra labour supply due to OCP is estimated by calculating a moving sum of lives saved over the previous 20 years.

This cost-benefit analysis confirms the considerable economic benefits of the programme in addition to its major contribution towards alleviating poverty of the rural poor throughout a major sub-region of West-Africa. The analysis suggests that land-related benefits are greater than labour-related benefits in net present value terms.

In 1997, an economic impact analysis of APOC with benefits accruing from reductions in onchocercal blindness was led by Benton (1997).

He estimated APOC programme's costs over the time period 1996-2007 to be \$161 million in

nominal dollars and \$131.2 million in 1996 constant dollars, using an annual deflator of 4%. These figures include all costs incurred by the donors, the beneficiary governments, and NGOs, but exclude the costs incurred by Merck, vector control costs, and benefits from increased value of land.

Based upon epidemiological information, there were an estimated 46,000 new cases of blindness resulting from onchocerciasis in APOC countries in 1996. In the absence of APOC, the incidence of new cases of blindness was projected to grow at 2.5%. Benton's (1997) analysis calculated the value of preventing blindness as an increase of 20 productive healthy life-years discounted at 3%.

A disability weight of 1 for blindness is assumed (i.e. 1 year of blindness is economically equivalent to 1 year of premature death).

APOC activities are expected to result in almost 10 million discounted healthy life-years being added in the time horizon 1996-2017, which roughly represents 27 healthy life-days added/\$ invested in the APOC. For the shorter project horizon (1996-2009), about 13 healthy life-days/\$ will be added as a result of the programme.⁽⁴⁸⁾

Assuming that each case of blindness prevented augments the productive labour force and yields additional agricultural output, Benton (1997) estimated an NPV of \$15.5 million and ERR of 6% at a 10% discount rate for 1996-2009 project horizon, while for the 1996-2017 project horizon the NPV was \$53.7 million and the ERR was 17%. These results depend almost entirely upon whether the APOC achieves its primary goal of long-term, sustainable treatment of onchocerciasis.

Haddix (1997) also evaluated the APOC programme using the same cost values as Benton (1997) and also excluding the costs of Merck. He estimated APOC programme's costs to be \$108.5 million in nominal dollars (4% discount rate). Haddix (1997) estimated the long-term NPV using a 3% societal discount rate to be \$307 million, for an ERR of 24%, and a corresponding NPV of \$87.6 million with a 10% discount rate.⁽⁵⁰⁾

4.2.4. Cost-effectiveness analyses.

Very few analyses evaluating the cost-effectiveness of onchocerciasis control have been conducted to date. DALYs have been calculated for onchocerciasis by several authors.

Prost and Prescott (1984) used four different effectiveness measures for the analysis, namely,

years of healthy life added, productive years of healthy life added, discounted years of healthy life added, and discounted productive years of healthy life added.

The essence of the procedure for estimating the cost-effectiveness of onchocerciasis control is to discount the costs and effectiveness over the life of the control project, assumed here to run for 20 years from 1975 to 1994.

It was estimated previously that the cost of OCP which should be attributed to onchocerciasis control in Upper Volta was \$2.6 million per year in 1977 prices. Assuming a 10% discount rate, the sum of the discounted value of these costs over 20 years was \$22.1 million.

It was calculated that the activities of the OCP in seven West African countries could add 1.1 million healthy life-years added over 20 years, at a cost of \$20 per healthy life-year added. They assumed that one case of blindness resulted in 23 healthy life years lost.⁽⁴⁹⁾

McFarland and Murray (1994) analysed the period from 1994-2004. Costs included donors, governments, and NGO's, but not Merck's. Costs from vector control activities and increased value of land availability over 50 years were not included. They estimated \$195.5 million total costs programs for 10 years for the whole continent.

McFarland and Murray calculated that on an annual basis in Africa onchocerciasis accounts for 640,000 Disability-Adjusted Life-Years (DALYs). This represents 0.22% of the total disease burden for the region. They estimate that a programme to properly address onchocerciasis on the continent would cost \$19.5 million annually, which would result in a cost per DALY of \$30.47 if all onchocerciasis DALYs were eliminated.⁽⁵⁰⁾

Benton (1997) calculated that APOC's activities, with a cost of \$53.7 million dollars, would result in 10 million discounted healthy life-years being added in the time horizon 1996-2017, equal to a programme cost of \$13.52 per DALY prevented (1996 US dollars).

5. Discussion.

5.1. Limitations of the studies.

Some important limitations of the data are related to the location of the studies: most of them are developed in Nigeria or other West African countries, and are not representative of the whole global endemic area affected by onchocerciasis.

One study which was more representative geographically of the entire (non-OCP) African region was the one conducted by the Pan African Study Group (WHO 1995), as this spanned a total of eight study sites across West, Central, and East Africa.

Sample sizes tended to be small in many of the studies, and selection/observation bias was not taken into account properly. Therefore, it is mandatory to be cautious with generalizing the results.

For instance, Amazigo's (1993) study to report the effect of onchocerciasis on reproductive health and the risk of transmission to off-spring was based on relatively small sample size of 75 infected women with OSD and 70 non-infected controls without skin lesions.

Similarly, Amazigo's (1994) report about the detrimental effect of OSD on marriage and breast-feeding utilised this same small group of individuals.

Selection bias can arise in different forms. To analyse the stigma associated with OSD, Brieger et. al. (1998) used the following inclusion criteria: adults aged 20 or older, employed, not pregnant and not having a serious illness. Bearing in mind that individuals with severe OSD have a higher rate of absenteeism from work, it is easy to realise that the results may be biased. Besides, the more stigmatised individuals are less likely to participate in the study as they may feel embarrassed. Another example of selection bias is found in Oladepo's study (1997) to assess the association between farm land size and onchocerciasis status in a Yoruba community of Nigeria. The initial screening of subjects was based on individuals' availability. Again those who are less affected and those who are more aware and conscious about the disease are more likely to take part in the study and their answers may not be representative of the whole population.

No studies about the psycho-social and economic impact of onchocerciasis in Latin America were found. This may have been because papers not written in English were excluded.

5.2. Analysis and quality of the literature.

Most of the papers (e.g. Evans 1995, Vlassoff 2000, Workneh 1993) analysed in the present review were well-designed prevalence or quantitative studies (cross-sectional studies) based on data collection through questionnaires or skin

snips and skin examinations. The prevalence of different forms of onchocerciasis and its association with certain attitudes and behaviours of the affected individuals were properly analysed. Some of these studies also included a brief qualitative evaluation of the disease using different score systems. However, only a few studies approach the psychosocial perspective of the disease with a purely qualitative methodology, which is the most suitable one to assess the subjective perceptions and stigma among individuals.

Studies on the stigmatising effect of OSD were few (Ovuga 1995, Brieger 1998, Vlassoff 2000, Wagbatsoma 2004). The psycho-social explanatory models and stigma score systems used to evaluate the results vary among different studies and were not always validated. The Pan-African Study Group (WHO 1995) used large samples of randomly selected individuals and applied an Explanatory Method Interview Catalogue to study the experience and the meaning of OSD among affected individuals.

This model had previously been used in studies of leprosy and other psychiatric disorders.

Vlassoff 2000 used a standard protocol which included cross-sectional psycho-social, parasitological and dermatological surveys in the study. Questionnaires were also adapted from the Explanatory Model Interview Catalogue, previously used by the Pan-African Study (WHO 1995).

With regards to gender and stigma different studies showed contradictory results. Girls appeared to be more disadvantaged than boys because of their greater dependence on physical appearance for social acceptance, marriage and well-being. However, while most of the research conducted in Nigeria indicated that adolescent girls had less chances of getting married if their onchocerciasis lesions were known by others (Amazigo and Obikeze 1991), the women in Nebbi District, Uganda expressed less worries than men over their chances of getting married (Ovuga EBL et al, 1995). It is not clear if the lack of worry among the Ugandan women had anything to do with probable cultural practices and social attitudes towards women, or attempts by women to hide skin lesions from prospective suitors.

Review of the literature indicates that stigma seems to be an important aspect in onchocerciasis. What remains to be explored is how stigma associated with OSD influences people's economic

and social decisions and how treatment might influence these.

Moreover, the findings on help-seeking behaviour revealed that onchocercal skin disease triggers its own peculiar help-seeking and coping strategies which need to be studied in their own right and against the background of the poor rural communities where it is endemic.

The economic consequences of onchocerciasis include lost economic productivity, diminished earnings, adverse effects on supply of labour, and reduced agricultural output due to exodus from arable land. The socio-economic consequences of onchocerciasis are most marked in the hyperendemic belt that extends across sub-Saharan Africa.

Most of the reviewed studies evaluating the economic consequences of onchocerciasis were based on surveys taking into account variables such as farmland under cultivation, incomes per person per month and/or days of absenteeism from work among affected individuals compared with non-affected.

Several economic evaluation studies on onchocerciasis and its control have been conducted in recent years. Burden of disease studies, Cost-benefit analysis and Cost-effectiveness analyses have been used to quantify the relationship between the programmes' costs and impacts.

The majority of the reviewed economic evaluation studies were based on previously made economic assumptions. Cost-benefit studies were the most common and conducted an assessment of the costs of the control programmes as well as their health and land benefits.

In spite of the economic benefits demonstrated by the different economic evaluation studies, cost-benefit analyses of APOC (Benton 1997, Haddix 1997) significantly understated the net benefits from APOC activities since they only considered reduction in onchocercal blindness as the most important economic benefit resulting from APOC, although OSD also causes an evident burden on those infected and on society in general.

The studies on the economic impact of onchocerciasis control have shown that, in addition to blindness reduction, there are probably substantial benefits resulting from the reduction of skin-related symptoms through Mectizan treatment. The difference in the costs of the OCP and APOC control programmes can be partially attributed to the longer horizon for the OCP and to the cost of

vector control included in the OCP programme. However, APOC's activities would also likely need to be sustained for at least 20 years to have a substantial permanent impact.

5.3. *The impact of Mectizan distribution.*

Even with Merck donating Mectizan, within-country distribution can be expensive, particularly because of the limited ability of governments and individuals in most of the affected countries to pay these costs. Distribution strategies for ivermectin have evolved starting with relatively expensive mobile teams, moving to community-based distribution and community-directed systems. Data available from some countries show that community-directed treatment with Ivermectin (CDTI) systems are less costly than vertical systems. Nevertheless, in order to implement a self-financing system, it is important to involve the community from the beginning in designing the appropriate scheme. This implies discovering how much they can pay and how they are willing to pay.⁽⁵¹⁾

A community-directed system has been adopted by APOC for ivermectin distribution because of its high cost-effectiveness. Under this approach, communities have a greater involvement on the programme. According to the results from a study by UNDP/World Bank/WHO (2004), CDTI overwhelmingly exceeds the treatment coverage rates of regular health services in Ghana and Kenya. It produces therapeutic coverage well over the 65% threshold necessary for long-term river blindness elimination.⁽⁵²⁾

The success of CDTI in onchocerciasis control has received attention from other disease control programmes and there have been many attempts to use CDTI system with its Community-Directed Distributors (CDDs) for other health interventions.⁽⁵³⁾ Large number of CDDs are already involved in other health and development activities, e.g. distribution of vitamin A, malaria treatment, polio immunization, nutrition, EPI, water protection, etc. Results from some studies on this topic show that the addition of other activities to CDDs does not imply a threat to onchocerciasis control but rather provides an opportunity to enhance other community-based health care and development programmes.⁽⁵⁴⁾

The key to sustaining CDTI lies in strengthening full community participation and in integrating the process within the formal health

system. This helps to improve the responsiveness of the health sector and gives communities the unique chance to manage their own health priorities.⁽⁵⁵⁾

Nevertheless, the public health impacts of ivermectin distribution may be significantly underestimated by using blindness as the only health-related outcome. The drug can reverse skin disease, weight loss, and musculo-skeletal complaints associated with onchocerciasis. Also, the effects of ivermectin on other parasites causing geohelminth infection, scabies, and lymphatic filariasis represent additional benefits to individuals and populations covered by distribution programmes which may contribute significantly to the acceptability of chemotherapy⁽⁵⁶⁾; benefits that are not captured in the reviewed economic analysis.

5.4. *Future challenges for disease control and implications for future interventions.*

The principal challenge for onchocerciasis control is to deliver ivermectin treatment to all target communities and to sustain high treatment coverage over a very long period.

Other substantial threats to the control of onchocerciasis include the migration of competent, infective black-fly vectors and potential emergence of drug resistance to ivermectin.⁽⁵⁶⁾

Furthermore, severe neurological reactions, including several deaths, have been reported in persons with high intensity of *Loa Loa* infection. This has seriously affected ivermectin programmes in areas potentially co-endemic for *Loa Loa*.

OCP activities ceased in 2002 and APOC is planned to finish in 2010, although the parasite will not have been eliminated. Inter-country collaboration and operational research will be needed to support countries' efforts to prevent recrudescence of the infection and disease during the post APOC/OCP period.

6. **Conclusions.**

6.1. *Conclusions.*

Onchocerciasis or "river blindness" is a disease of poverty. Neglect manifests itself in many guises. The socio-economic consequences of the disease are severe. Infected people face physical disability and social stigma that can dramatically reduce their quality of life. The intense itching and blindness hinder individuals' contributions to their own well-being and undermine the emotional and economic health of the household and community.

Over the last 30 years, onchocerciasis has been eliminated from large parts of the African continent through the efforts of a solid international partnership and a broad disease control programme. In recent years, onchocerciasis control programmes have evolved from a vertical strategy into a bottom-up, integrated approach that couples strong regional coordination with the empowerment of local communities to address not only onchocerciasis but, potentially, many other health problems.

Several economic evaluation studies on onchocerciasis and its control have been conducted. Burden of disease studies, cost-benefit analyses, and cost-effectiveness analyses have been used to quantify the relationship between the programmes costs and impacts.

As one can see from the economic evaluation studies, the economic benefits of onchocerciasis control have largely outweighed its costs. Nevertheless, the stigma associated to the disease and its severe socio-economical consequences still constitute a potential threat for the development of endemic countries in Africa.

In spite of the spectacular success of the onchocerciasis control strategies, further financial and political commitment are required not only to support the control programmes, but also to fund the research necessary to provide the tools to enable parasite elimination.

6.2. Recommendations for future research.

Although there are an increasing number of published papers about the importance of the psycho-social and economic perspectives of onchocerciasis, further research is still necessary to quantify and control its consequences. Explanatory and scores systems to measure stigma and the psychological consequences of the disease need to be validated and more widely adopted.

The beliefs and health related behaviours of local people are often neglected by health professionals. By addressing traditional concepts of the disease and incorporating these ideas into control strategies, it may be possible for control programmes to address the problems of those most in need of health care more effectively.

Further quantitative and qualitative studies with larger sample sizes are needed not only to improve our knowledge about the psycho-social and economic dimension of the disease but also to assist the design of new and more effective intervention strategies.

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Abbreviations

APOC	African Programme for Onchocerciasis Control.
APOD	Acute Papular Onchodermatitis.
CBA	Cost-Benefit Analysis.
CDTI:	Community-Directed Treatment with Ivermectin.
CDD	Community Directed Distributors.
CEA	Cost-Effective Analysis.
CPOD	Chronic Papular Onchodermatitis.
DALYs	Disability Adjusted Life Years.
DPM	Depigmentation.
EPI	Expanded Programme of Immunization.
ERR	Economic Rate of Return.
LOD	Lichenified Onchodermatitis.
MDP	Mectizan Distribution Programme.
MERCK	Merck Sharpe and Dohme Ltd company
NPV	Net Present Value.
OCP	Onchocerciasis Control Programme.
OEPA	Onchocerciasis Elimination Programme in the Americas.
OSD	Onchocercal Skin Disease.
REA	Rapid Epidemiological Assessment.
REMO	Rapid Epidemiological Mapping of Onchocerciasis.
TDR	Research and Training in Tropical Diseases.
\$	American Dollars.
WHO	World Health Organization.

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APPENDICES

Table 1. Summary of psycho–social and economic studies on onchocerciasis.

Table 1.1. Psycho-social studies on onchocerciasis.

AUTHOR	YEAR	LOCATION	TYPE OF STUDY	SAMPLE SIZE	METHODS	RESULTS
Brieger WR et al	1986	Oyo state, Nigeria	Quantitative (cross-sectional)	25 farm hamlets (306 respondents)	Questionnaire and in-depth interviews.	41.8% don't know the cause. Variable responses: poor blood, food, etc...
Evans T	1987	Guinea Conakry	Quantitative (cross-sectional) and qualitative	136 persons interviewed	Cross-sectional survey and follow-up	40%-50% communities affected (20% visually impaired, 40% blind or destitute, with no means of production or reproduction)
Brieger et al	1987	Idere community of Ibaroa, Nigeria	Quantitative (Cross-sectional)	422 women	Questionnaire and skin snips to detect cases.	35.4% had onchocerciasis. 56% and 60% believe it affects menstruation and infertility.
WHO Expert Committee on onchocerciasis	1987		Report			
Nwoke BEB	1990	Nigeria	Review	25 articles reviewed		Loss of productive activity and desertation are consequences of onchocerciasis.
Amazigo U	1993	Etteh, Nigeria	Quantitative (cross-sectional) and qualitative	145 women	Questionnaire, in-depth interviews and focus groups methods.	80% believe in mother-to-child transmission. 83% believe that different forms caused by different agents.
Amazigo U	1994	Etteh, Nigeria	Quantitative (Cross-sectional)	285 women	Skin biopsy to select cases. Questionnaire, in-depth interviews and group discussions.	Mean age at marriage was higher in women with disease (21.1 vs. 19.1). Infected women stop breast-feeding earlier (26% vs. 2%)
Jhonston K et al	1994	Thyolo Highlands, Malawi	Quantitative (Cross-sectional)	20 persons interviewed	Individual interviews.	Itching the most common complaint (61%). No respondents associated <i>S damnosum</i> with onchocerciasis.
The Pan-African study group on onchocercal skin disease, TDR	1995	Multi-country (8 sites): four sites in Nigeria and one each in Tanzania, Uganda, Cameroon, Ghana.	Quantitative (Cross-sectional) and qualitative study	6910 persons has skin examination. 100 affected interviewed per endemic site.	Skin examinations. Explanatory Model Interview Catalogue, focus group, in-depth interviews.	Troublesome itching showed strong correlation with level of endemicity. Affected show concern about ability to work and interact socially. OSD is associated with severe stigma. Higher scores in males than in females.
WHO, Technical Report Series	1995		Report			
Ovuga EBL et al	1995	Uganda	Qualitative	253 persons interviewed	Questionnaire, group discussions	Itching is the most troublesome symptom. OSD leads to self-destructive behaviour. Productivity of 67% of affected was reduced. 47% thought that the condition would kill them.

AUTHOR	YEAR	LOCATION	TYPE OF STUDY	SAMPLE SIZE	METHODS	RESULTS
Evans TG	1995	Guinea	Quantitative (Cross-sectional)	319 persons interviewed	Semi-structured interviews.	68% blind vs. 85% sighted were unable to walk. 10% blind vs. 92% sighted are farmers. Blindness associated with celibacy and widowhood.
Brieger et al	1998	Western Nigeria	Qualitative and quantitative	1032 persons examined; 500 with skin lesions interviewed.	Skin examinations, questionnaire and in depth-interviews.	Itching was the most common symptom (48.3%). Highest ranking items focused on issues of self-esteem. Perceived stigma among affected less than among non-affected.
Awedoba AK	1998	Ghana	Quantitative (Cross-sectional)	1200 persons interviewed	Skin examination and two semi-structured interviews.	Drugstores are the most used facilities (49.4%). Next in importance is self-help (17.6%).
Vlassoff C et al	2000	Multi-country study: results of 5 sites, two in Nigeria, one each in Cameroon, Ghana, Uganda.	Qualitative	1000 persons interviewed (100 with OSD and 100 unaffected per site).	Skin snips, nodule palpation, cross-sectional and psycho-social surveys. Explanatory Model Interview Catalogue.	Stigma is expressed more openly by unaffected. Men are more concerned about sexual performance and economic prospects. Women express more worries about life chances and marriage.
Wagbatsoma VA, Okojie OH	2004	Apana, Edo state, Nigeria	Quantitative (Cross-sectional)	385 persons interviewed	Skin examination and questionnaire.	Embarrassment (33%), sleeplessness (29.4%), avoiding people (10.9%), isolation (8.1%), difficulty in getting married (0.8%).
Amazigo U et al	2004	Etteh, Nigeria	Case report	2 cases		Ivermectin improves the skin condition and self-esteem of females with onchocerciasis.
Dimomfu BL et al.	2007	Central African Republic, Democratic Republic of Congo.	Qualitative		Semi-structured individual and group discussions	Knowledge, attitudes and practices regarding onchocerciasis vary between foci.

Table 1.2. Economic studies on onchocerciasis.

AUTHOR	YEAR	LOCATION	TYPE OF STUDY	SAMPLE SIZE	METHODS	RESULTS
Evans T, Murray CJL	1987		Critical appraisal of OCP cost- effectiveness analysis by Prost and Prescott.			Depending on discount rate, OCP is 7-40 times more costly as measured by discounted yeas of productive life added than measles immunization.
Dladepo O et al	1997	Oyo state, Nigeria	Quantitative (follow-up study)	200 subjects	Skin examination and personal interviews.	Farmers with OSD had less farmland under cultivation (9117m ²) than those with no OSD (13850m ²). Farmers with OSD have no alternative income strategies and lower personal wealth indicators.
Workneh W et al	1998	Baya Farm, Teppi Coffee plantation, Ethiopia	Quantitative (cross-sectional)	196 subjects	Skin examination, Skin biopsy, Visual acuity with Snellen's "E" chart. Personal interviews.	Prevalence of onchocerciasis was 82.7%. No visual impairment detected. Controls had higher incomes than cases, earning 11.5 Birr more per month (25% over the salary of cases)
Onwujekwe OE et al	2000	Achi, Nike and Toro communities, South Eastern Nigeria	Quantitative (cross-sectional)	404 household heads in Achi, 393 in Nike and 214 in Toro.	Interviewer- administered pre-tested structured questionnaires.	The majority of household heads were willing to pay (around 90%). The amounts range from 20 Niara (\$0.06) to 100 Niara (\$1.25). Fee-for-service preferred in Achi and Nike, pre-payment in Toro.
Waters HR et al	2004		Review	26 articles reviewed		Cost-benefit and cost- effectiveness studies for OCP and APOC reviewed. NPV and benefits of the control programmes analysed.

Table 2. Summary of Cost and Cost-benefit studies
(from evaluation studies and literature review)

SOURCE	TYPE OF STUDY	PROGRAMME/ LOCATION	TIME PERIOD	TOTAL COSTS	ASSUMPTIONS	VALUE OF HEALTH GAINS	NET PRESENT VALUE	ECONOMIC RATE OF RETURN
Kim (1997)	Costs	Coffee plantation in South western Ethiopia	1996	Loss of 1,9 work days and 29,7 birr per month in wages (16% less wage).				
World Bank (1997)	Costs	Multicountry: Nigeria, Ethiopia, Sudan	1997	Average increase of US\$8,10 in medical costs and 6,75h seeking health-care of time over 6-month period.				
Benton and Skinner (1990)	CBA	OCP	1974-2004 (costs) 1974-2023 (benefits)	\$571 million	Blindness results in complete loss of productivity		From \$8 million to \$312 million (10%-5% discount rate)	With land benefits, minimum 11-13%
McFarland and Murray (1994)	CBA	OCP	10 years	\$195 million	Programme serves 16.8 million persons. 500000 cases averted annually. Subsistence level of \$150.	Benefits of \$75 million annually.	\$85 million at discount rate of 5%	Not given.
Kim and Benton (1995)	CBA	OCP	1974-2002	\$571 million	It includes sum of expenditures from 1974-1993; all donors and government costs (not Merck's)	An increase of 20 productive healthy years discounted at 3%	Between \$3729 million and \$485 (3% vs. 10% discount rate);39 horizon period	18% for 3 and 10% discount rates.
Haddix (1997)	CBA	APOC	1996-2007	\$108,5 million (4% discount rate)	The same as Kim and Benton (1995)	Total number of additional years of labour available	\$307,4 million (for 1996-2017 horizon at 3% discount);\$87,6 million at 10% discount	6% for 1996-2007; 24% for 1996-2017.

SOURCE	TYPE OF STUDY	PROGRAMME/ LOCATION	TIME PERIOD	TOTAL COSTS	ASSUMPTIONS	VALUE OF HEALTH GAINS	NET PRESENT VALUE	ECONOMIC RATE OF RETURN
Benton (1997)	CBA	APOC	1996-2017	\$131,2 million	Costs include donors, governments, NGOs but not Merck's or vector control. Benefits from increased value of land not included.	Preventing one case of blindness results in an increase of 20 productive healthy years (1 year of blindness is economically equivalent to 1 year of premature death).	\$53,7 million at 10% discount rate (for 1996-2017)	17% (for 1996-2017).

Table 3. Summary of cost-effectiveness studies.

SOURCE	TYPE OF ANALYSIS	PROGRAMME	TIME PERIOD	TOTAL COSTS	ASSUMPTIONS	VALUE OF HEALTH GAINS	COST-EFFECTIVENESS RATIO
Prost and Prescott (1984)	CEA	OCP	1975-1994	\$22,1 million	One case of blindness resulted in 23 healthy life years lost.	1 million healthy life-years added over 20 years (147294 annually).	\$13.52 per healthy life-year added.
McFarland and Murray (1994)	CEA	OCP	1994-2004	\$195.5 million	Costs included donors, governments, NGO's but not Merck's. Costs from vector control activities and increase value of land availability over 50 years not included. \$150 annual wages and 500000 cases averted.	Labour force increased is \$75 million; 640000 DALYs lost annually	\$30.47 per healthy life-year added.
Benton (1997)	CEA	APOC	1996-2017	\$53,7 million		10 million discounted health life-years added	\$20 per healthy life-year added.



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