

The Impact of Permanent Disability on Rural Households: River Blindness in Guinea

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Introduction

In many parts of sub-Saharan Africa household labour remains the most important input for food or subsistence production. In many of these areas diseases are highly endemic and limit productivity through their debilitating, disabling and mortality effects. There has been general recognition of the tremendous impact of disease, but very few successful attempts to document it objectively. Discussion about the shortcomings of analysis of disease impact suggests the following reasons for the lack of significant findings: 1) analysis has been focused almost exclusively on wage labourers working on plantations; 2) only moderately to lightly infected communities have been studied; 3) analysis has attempted to aggregate impact costs in terms of loss to domestic or national product; and 4) the basic unit of production in subsistence agrarian environments, the household, has been overlooked [Prescott 1979; Andreano and Helminiak 1986].

This article considers the impact of blindness on small households in areas of highly endemic onchocerciasis or river blindness. River blindness is a major cause of irreversible blindness, and its preferred victims are males in the prime of their working life. Although much attention has been paid to this disease and its control, very few attempts have been made to elicit its consequences in its most severe form. A major control effort in West Africa, the Onchocerciasis Control Programme (OCP), was launched in the early 1970s on the basis that river blindness, in addition to being a public health problem, was also a major constraint on economic development [WHO 1973].

In 1987 a field study was undertaken in highly endemic areas of onchocerciasis in Guinea (Conakry) to investigate the impact of river blindness on individuals, households and villages. This article uses preliminary results from that study to describe the interaction of the blinding form of the disease with the household over time. The consequences of the blinding form of the disease in hyperendemic areas are illustrated by identifying five phases in the evolution of the disease within a small developing household over a 15-year period. Within each phase the household is described according to a wide range of welfare indicators pertinent to subsistence

environments.

The model demonstrates how the advent of a permanent disability like blindness leads to impoverishment and destitution in young, developing households. Consideration of disease epidemiology in relation to household stage of development reveals a process of impoverishment that is often overlooked when the unit of analysis is the individual. Describing consequences of permanent disability for the household permits the identification of those at greatest risk of impoverishment arising from permanent disability, for whom preventive and palliative responses are a high priority.

The Disease

Onchocerciasis or river blindness is caused by the development in the human dermis of a long thread-like filarial worm called *Onchocerca volvulus*. The female worms, during their 8-12 year sexually active life, give birth to millions of embryos called microfilariae. These micro-worms are mobile in the subcutaneous layer of skin and can enter the eye. They are responsible for the resulting disease symptoms such as itching, skin lesions and, most importantly, visual impairment and blindness.

The disease is transmitted by a blackfly of the genus *Simulium*. The female *Simulium* ingest microfilariae when they bite an infected human. A few of the ingested micro-worms undergo morphological changes within the fly reaching the stage of infective larvae. The larvae are transmitted to an uninfected human in a subsequent fly bite. They develop into adult worms, *Onchocerca volvulus*, and the cycle repeats itself.

Infection with the parasite does not mean that all persons will lose their vision. Only a small portion of those who are infected actually go blind. However, as the intensity of infection increases, i.e. the average number of parasites per person in a population increases, there is a corresponding increase in the prevalence of blindness and severe visual impairment. Consequently, small communities where the intensity of infection is high are areas where the blinding form of the disease is most concentrated. Blackflies breed in fast moving water, and villages that are situated in close proximity to breeding sites suffer from the most severe effects of the disease. In these communities,

prevalence of blindness often exceeds five per cent of the population.

Areas of hyperendemic river blindness are found in a belt of savanna across Africa roughly between 8° and 12° north of the Equator particularly in West Africa. 'Blind' or 'oncho' villages are most often small, with on average perhaps 200 people, and of marginal accessibility. They employ traditional modes of agriculture with hand cultivation, and are dependent on variable seasonal rainfall; they often have no livestock or animal traction due to trypanosomiasis, which is also endemic in onchocerciasis areas; they are asset poor, have no social infrastructure except a village mosque, and have virtually no contact with any form of development programme.

The Study

In 1987, a two part investigation into the socio-economic impact of the disease was undertaken in Guinea. The first part of the study was a cross-sectional survey of blind, visually impaired and sighted households in highly endemic areas of onchocerciasis in Guinea. The objective of the survey was to develop a broad base of information on which to generalise about the relative impact of blindness and visual impairment. A single village was chosen for a longitudinal follow-up during the 'peak agricultural season', i.e. the months of highest agricultural labour input to subsistence production [Norman *et al.* 1981]. The aim was to assess the relative importance of onchocerciasis-related constraints to subsistence agricultural production and household well-being.

The Developing Household Model

Impact of disease at the household level is a function of the size and structure of the household. Blindness of a 70-year old woman may not be expected to have very dramatic consequences for a household in which there are plenty of young and healthy producers, whereas for a 40-year old man, onset of blindness may have devastating effects for a household where he is the single producer and has many young children. In areas of high onchocerciasis endemicity the average age of onset of blindness is between 35 and 45 years of age, and occurs in males more often than females [Prost and Prescott 1984; Evans and Murray 1987]. It has been estimated that 45 per cent of males aged 15 in hyperendemic villages will become blind before they die [Prost 1986]. The households of men in this 'high risk' group may be described as young and developing. They are characterised by a large number of dependents or non-active members and very few active or producing members. The impact of blindness in households at this stage of development, therefore, is likely to be quite considerable.

Data from Guinea were used to develop an epidemiological profile of the disease determining such things as average age of the blind, severely visually impaired and visually impaired, the average age of onset, and average duration of decreased visual acuity for both males and females, e.g. of 136 blind persons interviewed, 76 per cent were male and the average age of onset of blindness was 41 years. The resulting profile of progression of the disease in the individual has been integrated into the probable size and structure of the household of the diseased individual. Based on results from the large cross-sectional survey in Guinea the typical household may be described as nuclear, monogamous, composed of a husband aged between 35 and 45, a wife and a number of young children. For example, of 103 blind men 60 per cent were household heads and average household size was five persons. Five phases in the progression of the disease within the household over a 15-year period have been identified: phase 1, the young sighted household; phase 2, onset of visual impairment; phase 3, severe visual impairment; phase 4, onset of blindness; and phase 5, household destitution (see Table 1).

This typical household is hypothetical in the sense that no observations were carried out over a 15-year period. However, it reflects the situation of study households which currently find themselves at some point in the progression of the disease i.e. visually impaired, recently blind, etc. About 40 to 50 per cent of households in hyperendemic villages find themselves somewhere in this process, of which 40 per cent would be 'sighted', 20 per cent visually impaired and 40 per cent blind or destitute. For each phase in the evolution of the disease, typical household circumstances are described using data from the cross-sectional and longitudinal surveys undertaken in Guinea. These profiles contain household information on 1) composition, health and nutrition; 2) the labour force; 3) food production and ability to cope with food shortage; and 4) ability to meet subsistence needs and to participate in the village welfare system.

Although this is only one of many possible scenarios to consider, it is the most likely given the epidemiology of river blindness, and it is also the most crippling as concerns its effect on the ability of the household to sustain its viability.

Phase 1: The Young Sighted Family

Composition, Health, and Nutrition

The young sighted family contains five members: the household head aged 35, his pregnant wife age 26, and three young children, making up 3.6 consumption units. Nutritional indicators for household members are generally good: measures of adult BMI and child weight for height are similar to those found in the

TABLE 1
HOUSEHOLD IMPACT OF RIVER BLINDNESS OVER A 15-YEAR PERIOD

PHASE	HH COMPOSITION	CONS UNITS	AGRIC LABOUR FORCE	ACTIVE UNITS	DEPEND RATIO	FOOD PROD SUFF	OTHER FOOD PROCURING ACTIVITIES				HOUSEHOLD VIABILITY			CHARITY	
							months	hunt/ fish	dry season mgrtn	sale of labour	wild food gath	Food	Clothing		Shelter
PHASE 1 Fully sighted	<p>35 + 26 + 9 + 7 + 5 pregnant</p>	3.6	<p>35 26</p>	1.8	2.0	9	<p>35</p>	<p>35</p>	<p>35</p>	<p>26</p>	+	+	+	+ net giver	
PHASE 2 Visually Impaired	<p>37 + 28 + 11 + 9 + 2 pregnant</p>	4.3	<p>37 28</p>	1.8	2.5	9	<p>37 fish only</p>	<p>37</p>	<p>37</p>	<p>26 11</p>	+	+	+	+ net giver	
PHASE 3 Severely Visually Impaired	<p>40 + 31 + 14 + 12 + 10 + 5 TB, dead measles</p>	4.7	<p>40 31 12</p>	1.0	4.7	6	—	—	<p>31 12</p>	<p>31 14</p>	—	—	—	—	
PHASE 4 Blindness Onset	<p>42 + 33 + 16 + 14 + 12 + 7 TB, marriage</p>	3.6	<p>33 14</p>	0.6	6.0	5	—	<p>14</p>	<p>33 14</p>	<p>33 12</p>	—	+	—	—	
PHASE 5 Destitute	<p>50 + 41 + 22 + 20 + 15 dead perm TB, mgrtn pregnant</p>	2.2	<p>15</p>	0.3	7.3	3	—	<p>15</p>	<p>15</p>	—	—	—	—	—	—

population at large. Health in this household is good, although in a larger sample of sighted households 35 per cent of respondents claimed to suffer from chronic illness such as arthritis, hernia or TB. Both the household head and his wife are likely to be heavily infected with the onchocerciasis parasites which was shown to be positively correlated with reported morbidity.

Agricultural Labour Force

The household agricultural labour force is dependent on the household head and his wife. The household head spends about 70 per cent of his days during the peak agricultural season farming, while his wife spends about 35 per cent of her time performing traditional women's tasks such as weeding. The most important constraint to agricultural work is time spent in immediate food procuring activities such as fishing or hunting, or working as daily labour in others' fields. The husband is likely to participate in an age group labour exchange system. The system operates by gathering members of an age group for particular agricultural tasks such as clearing and seeding of rice. The advantage of the group is that working collectively is thought to increase productivity and decrease the monotony of working alone and the tediousness of certain tasks. Participation in this system is dependent on being able to feed the members of the group when they come to your field. In severely endemic onchocerciasis villages the system runs on a very limited and small scale due to general poverty: most households cannot feed an additional contingent of workers, and there is a shortage of surplus labour. The equivalent active units for the household are between 1.5 and 2. The household dependency ratio ranges from 1.8 to 2.4. The household will cultivate an area of 0.6 hectares of crops almost exclusively for subsistence needs, including labour intensive swamp rice. The area cultivated per consumption unit is 0.17 hectares and per equivalent active unit is between 0.3 and 0.4 hectares.

Food Sufficiency

The harvest from the domestic field feeds the household for about nine months, such that 80 per cent of sighted households experience food shortage lasting between one and three months. This food shortage is not normally severe: most households manage at least two meals per day during the food shortage period, which corresponds with the peak agricultural season. To procure food during shortage households undertake a number of activities, the majority of which are labour dependent in this asset-poor village. The household head may have migrated during the dry season and returned with some money to purchase food. Fishing, hunting, daily contract work, collection of wild foods, and market gardens provide hungry season sources of food and/or income to purchase food.

Viability

Seasonal food shortage exists, but can be overcome by a combination of the coping strategies mentioned above. Income earned during dry season migration enables the purchase of clothes for the family. The structures of the compound are maintained by the household head. The household participates in the muslim tradition known as 'djaga', whereby 10 per cent of the harvest is put aside for elderly and disabled households. They are also likely to prepare meals and make 'gestures' to members of the extended family. These 'gestures' can be considered strategic in the long term, in the sense that they strengthen the basis for extended family support if and when the household finds itself in need of assistance.

Phase 2: Onset of Visual Impairment

Composition, Health and Nutrition

The household head, aged 37, is now visually impaired, revealed by his inability to identify the direction that a small hand is pointing from a distance of six metres (and ability to identify the direction of a large hand at the same distance). This degree of visual impairment is not perceived by 30 per cent of those afflicted, most of whom (70 per cent) are women. Likewise, 40 per cent of the families are not aware of the subject's decreased visual acuity. Health of household members remains reasonably good, and reported morbidity increases but has no effect on activity. The youngest child's low weight for height suggests he is undernourished, which may be related to the mother's large workload and sixth pregnancy. The household contains six members, or 4.3 consumption units.

Agricultural Labour Force

Agricultural work by the household head continues unhindered by the visual impairment, as is the case with the majority of visually impaired under 60 years of age. His wife continues to participate in household agricultural work. Together the input to household fields is between 1.5 and 2 equivalent active units. The household head continues to participate in labour exchange in a small way. The dependency ratio of the household is between 2.2 and 2.8 — a slight increase from two years earlier. The area cultivated remains constant at about 0.6 hectares. The area cultivated per consumer unit decreases to 0.14 hectares, but the area cultivated per active unit doesn't change.

Food Sufficiency

The household harvest continues to provide food for about nine months, and the food gap is successfully bridged by a variety of coping mechanisms. Hunting, however, is sensitive to this degree of visual impairment, and is likely to be abandoned — in fact this is the first sign for many men that they are losing

their sight.

Viability

The household head will seek low-cost traditional treatment for his diminishing sight, as do 83 per cent of those who are aware of it. He may also spend some of his dry season migration earnings on eye creams or drops found in migration areas. The household is not compromised by this expenditure, and retains its viability.

Phase 3: Severe Visual Impairment

Composition, Health and Nutrition

Three years later, the household head, aged 40, is severely visually impaired (SVI); he is unable to identify the direction a large hand is pointing at six metres, but can do this at three metres. The health of the household head is not affected, although 27 per cent of SVI experience increased morbidity described primarily as headaches and fatigue. The health of his wife has deteriorated; she complains of chest pains, a persistent cough and weakness symptomatic of tuberculosis. Their youngest child dies from measles. The nutritional status of the household declines; BMI of adults falls below the village mean, while children have low weight for height. The household size is six members or 4.7 consumption units.

Agricultural Labour Force

The large majority (70 per cent) of SVI cease to work. However, family circumstances in this case do not permit the household head to do so. He continues to work, albeit in a limited capacity — having to be led to and from the field, and with greatly reduced working capacity. He is no longer capable of participating in an age group work association. His wife, despite her poor health and significant household work, assumes responsibility for the household field, aided by her youngest son, now 12 years old. Labour intensive swamp rice gives way to more easily tended but nutritionally inferior crops, such as manioc. In some cases attempts are made to use swamp-lands for a second year, due to insufficient labour to clear a new swamp area. The continued efforts of father, wife and son amount to about 1.0 equivalent active units. The area cultivated may increase if there is a shift from wet-land to dry land cultivation or remain the same if cultivation continues in the same swamp rice field. The dependency ratio increases to 4.7 consumption units per active unit.

Food Sufficiency

Food production sufficiency decreases to about six months, due to the weakened labour force and long period of maturation required for manioc. If swamp rice is retained its yield will be drastically reduced, due to problems with weeds. The range of household

coping strategies is also severely limited. The household head will abandon all of his activities due to SVI, including dry season migration, which is an important source of cash and clothing. His wife and eldest son take whatever daily work they can find. The worst period of food shortage is during the peak agricultural season, during which the household consumes two meals per day maximum and only one meal at times when labour contracts are hard to find and food in the village is scarce and expensive.

Viability

Household viability is precarious: it cannot cope with increased food shortage; it has lost its primary source of cash income and clothes; and no longer has anyone capable of maintaining the living quarters of the compound. The harvest of the household is too small to allow it to contribute to the village welfare system, and it actually becomes a net receiver. Receipts are minimal; because of the young age of the household head most villagers do not consider the family worthy of assistance. Most aid will come from the extended family, provided it is in a position to offer this.

Phase 4: Onset of Blindness

Composition, Health and Nutrition

At age 42, the household head is blind; unable to determine the direction of a large hand at three metres. He is thin and inactive, but does not complain of other health problems. His wife's health continues to deteriorate under her unmanageable burden. The eldest daughter leaves the household through marriage. The remaining three children are all short and thin; the 14-year old son has a very low BMI and is frequently ill during the peak agricultural season; the 12-year old daughter is thin, weak and visually impaired, although this is not yet noticed; the youngest boy is minus two standard deviations in weight for height. The household consumption units decrease to 3.6 due to the departure of the daughter and the inactivity of the blind household head.

Agricultural Labour Force

The large majority of the blind interviewed in Guinea were inactive, and not a single person had received or was aware of rehabilitation. Deteriorating health of the household head's wife and the demands of immediate food procurement diminish her input to the household field. The eldest son, aged 14, assumes responsibility for household food production. Inexperience, frequent hunger and illness minimise the number of work days and their duration. Equivalent active units of labour for the household decrease to 0.6, and the area cultivated decreases to between 0.3 and 0.4 hectares. The dependency ratio increases to 6 and the hectares cultivated per consumption unit decreases to about 0.1.

Food Sufficiency

Decreased area cultivated, combined with increased ravages of predators due to inadequate labour supply reduce the harvest sufficiency to five months or less. In order to cope, the household continues to take on contract work during the peak agricultural season. During that time one meal a day for extended periods is not uncommon. In fact one of the advantages of contract work is that it includes a meal. Wild foods are gathered by mother and daughter to supplement manioc staple. The eldest son will attempt dry season migration, despite his feeble stature; his absence will mean one less mouth to feed. The eldest daughter's marriage and bride price endow the household with badly needed income and food. However, most of the income is taken by the household head, who believes, like 40 per cent of other blind persons, that regaining his vision is possible provided one has sufficient money. The eldest daughter's marriage also extends the family network, meaning that another source of support is available. However, the prospect of taking on the burden of such a dependent household would have weighed heavily in the agreement of the groom's parents to consent to marriage: the bride price was probably smaller than one might normally expect.

Viability

The household remains unviable: food production ability is very low, and combined with the food received through the dowry will not last more than five months. The migration of the eldest son makes it difficult for repairs to be made to structures, although something may have been negotiated as part of the dowry. The probability that the eldest son will be successful in returning with significant cash or clothing from dry season migration is very low, given his age, strength and lack of working experience. The village welfare system is more likely to recognise the plight of the household now that the household head is blind and no longer going to the field. The household will be largely dependent on formal and informal channels of assistance.

The stress in a household in such difficult conditions must be emphasised. Inadequate food, over-worked and burdened wife and son, a blind person who cannot accept his fate — all these lead to further weakening of the household. The wife will resent the decision by her husband to usurp the money from their daughter's bride price, and the eldest son's decision to migrate may well have been based on personal plans that have little or nothing to do with the well-being of his family. Often fingers will be pointed accusingly at people outside the household as the enemies responsible for their condition. The household becomes a difficult, stressed, unhappy environment, full of suffering.

Phase 5: Household Destitution

Composition, Health and Nutrition

This phase depicts the household eight years after the onset of blindness. The blind household head is left a widower with the death of his wife, a marital status which describes 17 per cent of blind persons and only three per cent of sighted persons. The remaining daughter also becomes blind during this period. Age of onset of blindness for women was found to be earlier than for men, and the transformation of their visual acuity more rapid. There is also evidence that suggests blindness is family linked. Unlike men, blindness before marriage is not associated with celibacy among women. Blind women, however, command no bride price, and can hope for nothing better than to marry someone similarly poor or handicapped. The blind daughter in this household is also pregnant, but without a declared father for the child.

The blind household head is very thin, having a dangerously low BMI of 14, where a figure of 18-20 is normal for men his age. His blind daughter is also below mean BMI for women of her age. The remaining son, in addition to being undernourished, suffers from poor health, particularly during the peak agricultural season. The number of consumption units decreases to 2.2 with the death of the household head's wife and the departure of the eldest son.

Agricultural Labour Force

With the death of his mother due to TB, the eldest son migrates permanently, realising that he will never find money for a wife as long as he is supporting two blind persons at home. His younger brother, short, thin and sickly, remains the single active person whose time is spent primarily working in exchange for food. The equivalent active units of labour that are directed towards the household field equal about 0.3. The area cultivated decreases to about 0.2 hectares, much of which will be destroyed by predators before the harvest. The dependency ratio increases to 7.3, and the area cultivated per consumption unit decreases to 0.09 hectares.

Food Sufficiency

The harvest from the household field will last three months at best. The youngest son will sell his labour to procure food. The household will eat one meal per day or less for over half the peak agricultural season. The blind daughter will attempt to earn some food by offering her services for household work in other compounds. As a charitable gesture, other compounds will let her pound their rice or fonio (a cereal) and give her the chaff in payment. In the dry season the remaining son will migrate in the direction of his older brother, resentful of his burden and fearful of becoming blind.

Viability

The household is destitute, with no means of production or reproduction. The blind will be taken care of by extended family or others better off, such as the village chief.

The five phase description of the progression of the disease within the young developing household can be summarised as follows:

- increasing dependency ratios;
- decreasing health and nutritional status of all household members and increasing vulnerability to other diseases;
- decreasing labour input measured by equivalent active units;
- decreasing ability to participate in traditional labour exchange systems;
- decreasing area under cultivation;
- decreasing ability of household food production to feed household members;
- increasing duration of food shortage;
- increasing severity of food shortage;
- decreasing ability to undertake food shortage coping strategies;
- increasing expenditure of scarce household resources on health problems, particularly blindness;
- decreasing household viability;
- increasing stress and household disunity;
- increasing reliance on village welfare system and extended family.

There is no simple line of progression through all of these symptoms of household decay; they are all mutually reinforcing, and entrench the process of impoverishment leading to destitution.

The model presents the impact of river blindness by identifying the most probable epidemiological pattern of disease progression in the individual, and integrating it into a typical household to consider its consequences over time. The model is not meant to be exhaustive; individuals do become blind at other ages and in different household circumstances, the impact of which is by no means inconsiderable. Likewise, this model is not only onchocerciasis specific; other households at the same vulnerable stage of development risk impoverishment and destitution due to other disabling diseases, such as tuberculosis.

By considering the impact of disease at the household level rather than the individual level a larger dynamic process of impoverishment and decay has been uncovered. The severity of the household consequences can be extrapolated to the village level to describe a similar process.

Implications for Research

There is much to be learned by considering the interaction of disease over time in relation to household stage of development. The focus of this article has been to describe the most significant impact of disease, with the aim of identifying those in greatest need. Often the needs of the worst-off are not duly considered when the individual is used as the unit of analysis. Disease epidemiology must be considered more carefully when assessing disease impact; the case of onchocerciasis is not unique in the sense that many tropical diseases tend to be concentrated such that relatively small populations are subject to the most severe disease conditions. The socio-economist must make efforts to identify these populations, in order to elicit the most important consequences of disease.

By extending impact analysis to include all of the stages of an individual's illness instead of a single stage, and by considering the household or social environment of the individual throughout instead of focusing exclusively on the individual, a wider dynamic of disease consequences has been revealed. Other disabling diseases with epidemiologies similar to river blindness, for instance, affecting adults in the prime of their working life, could usefully be examined in this way. This could draw attention to a neglected and preventable disease such as tuberculosis, or in the case of AIDS provide some indication of the myriad social and economic externalities we should expect given the spectre of a pandemic.

Implications for Policy

Hyperendemic onchocerciasis is an impoverishing disease whose victims deserve a high priority for palliative and preventive policies. Blindness prevention efforts should concentrate on getting new drugs to the hyperendemic areas in the first instance. Rehabilitation programmes are sorely needed, especially in hyperendemic villages where large numbers of blind persons are concentrated. If the rehabilitation efforts undertaken in Northern Ghana and Burkina Faso are any indication, then much of the devastation arising from blindness could be avoided. In the absence of rehabilitation, women's burdens in those households with blind household heads remain inhuman and life threatening. They most certainly must be considered a very high priority for measures aimed at relieving their work load. Finally, any rural development schemes must be sensitive to the labour constraints and wider impoverishing effects of disease resulting from permanent disability.

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