

Socioeconomic consequences of blinding onchocerciasis in West Africa

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Onchocerciasis or river blindness, a major cause of irreversible blindness among adults, has been the focus of international disease control efforts for over 20 years in West Africa. This paper employs the international classification of impairment, disability and handicap (ICIDH) to interpret results from a field study to assess the socioeconomic consequences of onchocerciasis in Guinea in 1987. In a sample of 136 blind, 94 visually impaired and 89 well-sighted persons, decreasing visual acuity is strongly associated with mobility, occupational and marital handicaps. Individual, household and disease correlates were explored. The implications of these findings for the ICIDH concept of handicap are discussed with particular emphasis on the need to extend analysis beyond the individual when assessing the socioeconomic consequences of disabling disease.

Introduction

This article considers the impact of decreased visual acuity, including irreversible blindness on individuals in areas of highly endemic onchocerciasis or river blindness. In the early 1970s, river blindness gained widespread attention as the likely cause of abandoned villages in the fertile river valleys of West Africa. As the disease was a significant constraint to economic development and also a public health problem, it became the focus of a massive control effort through the Onchocerciasis Control Programme (OCP).^a

Although much attention was given to controlling the disease few attempts were made to discover the socioeconomic consequences for the blinded or visually impaired individuals. Young children guiding frail, blind men is the popular image portrayed by the media, often accompanied by anecdotal references to "the living dead"^b or the burden of supporting blind men who are unable to cultivate (1).^{c,d} However, some studies indicate that the blind are

able to cultivate albeit at reduced productivity (2),^e while in a sociological investigation of 17 blind persons in Burkina Faso, one man was quoted as saying that nothing had changed since becoming blind except for not seeing anymore.^f As in so much of the socioeconomic research on tropical diseases, the absence of a framework with which to assess the disease impact has inhibited the development of an understanding of what it means to be blind in West Africa. Missing from the literature are studies which describe the socioeconomic profile of the blind population, e.g., the proportion of the blind who are engaged in agriculture, compared with a sighted population.^g

In the last 15 years a number of models have been proposed to describe the consequences of chronic disabling conditions. Rosenfield and colleagues (3), influenced greatly by the then recently published international classification of impairment, disability and handicap (ICIDH) (4), proposed that the impact of tropical disease could be viewed in terms of a sequence of impairment, disability, and the social and economic consequences of disability or handicap. More recent developments of the

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^a *Onchocerciasis in the Volta River Basin Area. Report prepared for the governments of Dahomey, Ghana, Ivory Coast, Mali, Niger, Togo and Upper Volta.* Unpublished WHO document, WHO/OCP/73.1, 1973.

^b *Série F. Social and economic importance of onchocerciasis.* Unpublished WHO document, ONCHO/WP/75.1, 1975.

^c *Asafu-Adajaye JBB. Some comments by the delegation of Ghana on the report by the OCP Economic Review Mission.* Unpublished paper presented at a meeting of the Economic Review Mission in Ouagadougou, 7-8 September 1978.

^d *Pairault C, Kientz AK. Bemakaha (Pays Senoufo de Côte d'Ivoire): un village de colonisation spontanée en zone onchocercarienne, approche sociologique.* Unpublished paper prepared for the OCP, Ouagadougou, OCP/EPI/76.10, 1976.

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^e *Bradley AK. The effects of disease on rural economy, social structure and settlement: a case study of onchocerciasis on the Hawal Valley, Nigeria.* PhD thesis, University of Liverpool, 1975.

^f *André F. Le statut économique et social des aveugles de Wayen, village Mossi.* Etudes et documents provisoires, Centre d'Economie et de Recherche pour le Développement international, Clermont Ferrand, 1980.

^g A number of studies in the USA have attempted to develop a socioeconomic profile of the visually impaired and blind (see *Kirchner C. Data on blindness and visual impairment in the US.* New York, American Foundation for the Blind, 1985), and the disabled in general (*Nagi SZ. An epidemiology of disability among adults in the United States. Milbank quarterly, 1976, 54: 439-467*), or more recently in *Laplante MP. The demographics of disability. Milbank quarterly, 1991, 69: 55-77.*

ICIDH model have suggested that it is the interaction between the “disabled person on the one hand and the community or the environment on the other which gives rise to handicap” (5, 6), handicap being defined as “the disruption of an individual’s performance of life habits... resulting on the one hand from impairments and disabilities, and on the other from obstacles attributable to environment factors” (Fig. 1) (7).^h

Following a description of onchocerciasis and the field study undertaken in areas of highly endemic onchocerciasis in Guinea, West Africa, this article identifies the handicaps arising from decreased visual acuity, and describes key factors associated with variations in handicap for the affected individuals. These findings are discussed with particular emphasis on the concept of handicap and the implications for the ICIDH model.

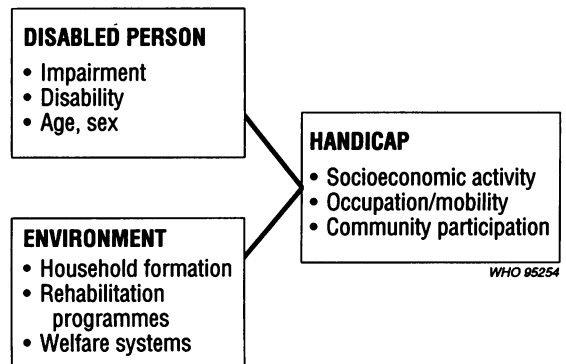
The disease

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 females ingesting the 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. These develop into adult worms, and the cycle is repeated.

Infection with the parasite does not mean that all persons will lose their vision. Only a small proportion 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 pop-

Fig. 1. The interaction of disabled persons and the environment to explain handicap.



ulation 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 the areas where the blinding form of the disease is most concentrated. Blackflies breed in fast-moving water, and villages situated close to breeding sites suffer from the most severe effects of the disease. In these hyperendemic communities, the large majority of the population are heavily infected and the prevalence of blindness often exceeds five per cent of the population. Areas of hyperendemic onchocerciasis are found in a belt of savannah across Africa, roughly between 8 and 12 degrees north of the Equator, particularly in West Africa.

Methods

In 1987, a comparative study of the socioeconomic impact of ocular onchocerciasis was undertaken in Mali, where the Onchocerciasis Control Programme (OCP) had been in operation since 1976, and in Guinea where OCP had not yet begun. This article deals with results from a cross-sectional survey of blind, visually impaired and well-sighted individuals in highly endemic parts of north-east Guinea. The survey consisted of a detailed household census and inventory, and semi-structured interviews with blind and visually impaired individuals within these households. Sighted household members capable of responding to questions about the blind or visually impaired person and his/her impact on the household were also interviewed as a control group.

In 1985 and 1986, OCP conducted epidemiological surveys in well-known foci (8) of onchocerciasis in north-east Guinea, assessing onchocercal infection

^h The appropriateness of the ICIDH conceptual framework and the term “handicap” for research into the consequences of chronic disease is a subject of ongoing debate (see **Bury MR**. The ICIDH: a review of research and prospects. *International disabilities studies*, 1987, 9: 118-121 and **Verbrugge LM**. Disability. *Rheumatic disease clinics of North America*, 1990, 16: 741–761), with alternative classifications of the impact of chronic diseases employed elsewhere (see **Verbrugge LM**, *ibid.* and **Nagi SZ**. *A comparison of conceptual frameworks of disability*. Paper prepared for the Committee on Secondary Prevention of Disability, Institute of Medicine, Washington DC, 1989).

and visual acuity. The results express the prevalence of infection as well as the community mean microfilarial load (CMFL), which represents the geometric mean intensity of infection for a standardized population (9). Sjogren's hand test, an accurate and reliable method for visual screening in illiterate populations (10), was used to assess visual acuity. Blindness was defined as the inability to identify the direction of a large hand at 3 metres in the better eye ($<3/60$), while visual impairment indicated the ability to see the direction of a large hand, but not a small hand, at 6 metres in the better eye ($\geq 3/60$, and $<6/18$).

Measures of infection, intensity of infection, and prevalence of blindness have been used to identify the level of endemicity in areas of onchocerciasis transmission. Although there is no single definition of hyperendemicity, it is generally agreed that villages with a prevalence of infection of $\geq 60\%$, or a CMFL of $\geq 30\text{mf/skin snip}$, or a prevalence of blindness of $>3\%$ are "hyperendemic" (11). A strong positive association exists between the intensity of infection expressed by CMFL and the prevalence of blindness (12, 13). From the OCP epidemiological survey, 14 villages in Guinea were selected from the "hyperendemic" foci of onchocerciasis. Demographic and epidemiological characteristics of the sample villages are presented in Table 1. The foci straddle the Guinean and Sudanic climatic zones, the rainfall in Guinea varying between 800 and 1400 mm per annum, concentrated in a single rainy season from May to October. The actual length of the season and the amount and distribution of rainfall vary enormously from one year to the next.

Semi-subsistence farming is the primary productive activity in the sample population. Using traditional agricultural methods, the wetland cultivation of rice and the dryland cultivation of millet, maize, manioc and fonio¹ are common throughout the area. Swamp rice is the principal crop sold for cash needs, while millet and manioc are reserved for home consumption. Livestock including cattle, sheep and goats are relatively scarce owing to the inhospitable conditions in many of the riverine villages. A variety of activities such as fishing, hunting, illicit gold mining, and dry season migration to the neighbouring Côte d'Ivoire represent important non-farming productive opportunities, which help to bridge shortfalls in domestic food production and help young men

Table 1: Demographic and epidemiological characteristics of 14 study villages in Guinea

Characteristic	Mean number
Population per village	198
Households per village	33
Persons per household	7
Prevalence of onchocerciasis	65%
Community mean microfilarial load	37
Blind persons per village	11
Prevalence of blindness	6.5%
Visually impaired persons per village	9
Prevalence of visual impairment	4.9%

amass sufficient funds for the bride price and other expenses associated with marriage.

Although the sample villages were an average of 15 km from a principal road, only 40% of them were accessible throughout the year. The villagers used an intricate network of footpaths to reach distant fields, markets and neighbouring villages as other forms of transport were scarce. None of the 14 villages surveyed possessed any agricultural extension services, health facilities, or rehabilitation programmes for the blind or for any other victims of disabling diseases. Two of the villages (both on main roads) had primary schools and three others held weekly markets. Water from traditional wells, seasonal rivers and springs was available in all the villages year-round.

In each of the 14 villages, all the blind and visually impaired persons were interviewed, unless absent or deceased. A cohort of sighted persons from households with no members suffering from decreased visual acuity was selected as a control for the blind and visually impaired. The control characteristics were age, sex, and household size. A total of 136 blind, 94 visually impaired and 89 sighted persons were interviewed. Information gathered through the semi-structured interview included (1) demographic and disease status; (2) visual acuity history, self-perceived health status and mobility; (3) occupational and agricultural activities; and (4) household food security. In addition, 158 sighted persons, 93 from blind households and 65 from visually impaired households, were interviewed. Having observed the onset of blindness or visual impairment, these individuals, whether a spouse, parent or sibling, responded to questions about the blind/visually impaired person and his/her impact on the household.

The definition and values of the variables according to visual acuity are presented in Table 2. Three dependent variables were chosen to represent

¹ Fonio (*Digitaria exilis*), otherwise known as acha or hungry rice, is an early ripening cereal crop, generally consumed during the "soudure" or hungry season before the main millet or rice harvest (see Jardin C. *List of foods used in Africa*. 2nd ed. revised (FAO Nutrition Information Document Series). Rome, FAO, 1970).

Table 2: Variables and their values according to visual acuity

Variable	Visual acuity			P-value ^a
	Sighted (n=89)	Impaired (n=94)	Blind (n=136)	
Age (years)	51	53	55	NS
Age of onset (years)	NA	47	41	*
Sex (male:female)	62:38	78:22	74:26	
Health ^b				
No complaints	39%	34%	46%	NS
Ill	53%	54%	45%	
Other	8%	10%	12%	
Migration ^c				
Yes	28%	21%	14%	NS
No	72%	79%	86%	
Village role ^d				
Yes	37%	25%	20%	*
No	63%	75%	80%	
Household responsibility ^e				
Head	56%	57%	47%	***
Wife of head	32%	20%	12%	
Other kin	11%	18%	32%	
Non-kin	1%	4%	11%	
Size of household (persons)	7	7	7	NS
Household food insecurity ^f				
Seasonal	83%	85%	76%	NS
Chronic	17%	15%	24%	
Mobility				
Constrained:	13%	49%	83%	***
— to compound	5%	7%	15%	
— to village	8%	42%	68%	
Not constrained	87%	51%	17%	
Occupational status				
Active	98%	62%	21%	***
— agriculture	92%	54%	10%	
— other	6%	8%	11%	
Inactive	2%	38%	79%	
Marital status				
Married	90%	79%	57%	***
Not married:	10%	22%	43%	
— single	7%	11%	14%	
— widowed	3%	11%	17%	
— divorced/inherited	—	—	12%	

^a * $P < 0.05$, ** $P < 0.01$; *** $P < 0.001$; NS = not significant.

^b "Health" refers to self-reported morbidity: "ill" aggregates acute and chronic morbidity regardless of severity; "other" groups all the permanent impairments including the deaf, mute, and physically and mentally disabled, but excluding the blind or the visually impaired.

^c "Migration" has been defined as any departure from the village for a period greater than two weeks in duration. This includes absence for reasons of medical treatment, family visits and begging as well as more traditional migratory activities such as farm labour and petty commerce.

^d "Village role" refers to administrative, religious, cultural and other official positions of responsibility within the village.

^e "Household responsibility" describes the relationship of household members to the household head — the head and his wife or wives forming the group with household responsibility, and other kin and non-kin comprising the group without such responsibility.

^f Household food insecurity: "seasonal insecurity" refers to household food shortage of up to 4 months duration; "chronic insecurity" refers to food shortage of >4 months.

various dimensions of the handicap associated with decreased visual acuity: mobility, occupation, and marital status. All subjects were asked if they walked outside their compounds, and if so, if there were areas where they were not able to do this. Responses on mobility were coded as "constrained", i.e., unable to walk beyond the confines of the village, and "not constrained". The indicator of economic consequences was the occupational status, the responses being categorized as "active", i.e., having an occupation, or "inactive" with no occupation. Marital status referred to whether married or not married, i.e., single, widowed or "other". This last category includes divorce and the practice of wife inheritance. In Mande culture, recently widowed women are inherited by their deceased husband's oldest surviving brother or, in some cases, given to destitute men who are frequently victims of leprosy, poliomyelitis or blindness.

Initially the data were analysed using contingency tables and chi-squared tests. To control for interactions, i.e., the degree to which one independent variable is a proxy for another, and to identify the smallest group of variables which account for the greatest proportion of variance in the dependent variable, stepwise logistic regression models were derived for each dependent variable. Logistic regression is a multiple regression technique for nominal data whereby the dependent variable is transformed by a logistic function. In this analysis the independent variables were introduced into the model in a stepwise fashion, entering the independent or explanatory variables into the model in ascending order of their ability to account for variance. Variables were assessed at each step to determine whether or not their contribution remained significant, given the effect of other variables in the equation (14).

Results

The results are presented in two stages: (1) the handicap of decreased visual acuity and its determinants; and (2) the variation in socioeconomic consequences within both the blind and the visually impaired populations. The first stage involves comparing the visually impaired and blind populations with a sighted cohort for three specific social and economic indicators: mobility, occupation, and marital status. Any significant deviations from the behavioural norm of the sighted cohort may imply the existence of a handicap due to ocular impairment. Since visual acuity is not likely to be the single variable explaining variation in these indicators, its importance relative to other independent factors such as age and sex was assessed.

Among the blind, 68% claimed they were unable to walk beyond the village, compared to 42% and

8% among the visually impaired and sighted samples, respectively (see "Mobility", Table 2). Only 10% of the blind compared to 54% of the visually impaired and 92% of the sighted described their occupation as farmer (see "Occupational status", Table 2). Also blindness and, to a lesser extent, visual impairment were associated with high rates of celibacy, widowhood, divorce and wife inheritance, and low rates of marriage (see "Marital status", Table 2). Fig. 2 demonstrates graphically the strong association between decreasing visual acuity and increasing frequencies of having a mobility constraint and no occupation, and being unmarried.

A wide variety of other independent variables were associated with each of the socioeconomic consequences. For example, younger age, marriage, migratory activity, and household food insecurity, in addition to better visual acuity, were all significantly correlated with unconstrained mobility and occupational activity (see Table 3). Upon stepwise logistic regression, visual status was selected as an independent predictor of each of the three dependent variables, mobility, occupation and marital status.

The second stage of analysis involved comparing the determinants of socioeconomic function specific to each visual status group. Among the blind, the step 0 likelihood ratio chi-square for mobility (Table 4) indicated a number of significant associations. Unconstrained mobility among the blind was correlated with younger age, and age of onset of blindness, migration activity, occupation, household responsibility, village role, and severe or

Fig. 2. Percentage of the population affected by handicap, according to level of visual acuity. Adapted from M. Chamie. Survey design strategies for the study of disability. *World health statistics quarterly*, 1989, 42: 122-140.

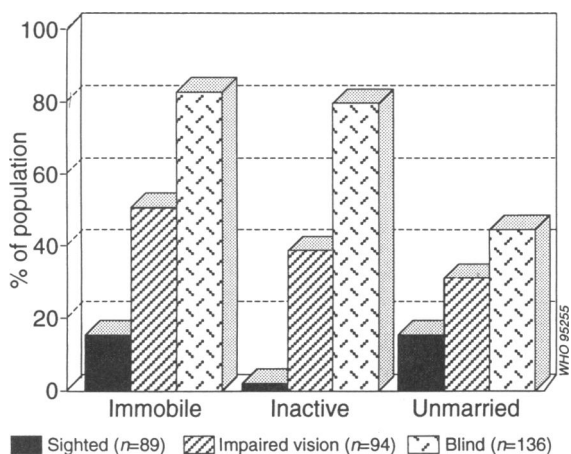


Table 3: Step 0 likelihood ratio chi-squared and summary of stepwise logistic regression of mobility, occupation, and marital status

Explanatory variable	Mobility ^a (approx. F-to-enter) ^b	Occupation ^a (approx. F-to-enter) ^b	Marital status ^a (approx. F-to-enter) ^b
Visual acuity	62.4***	102.1***	17.2***
Sex	0.6	0.2	0.2
Age	31.2***	35.5***	0.0
HHRESP (Household responsibility)	7.8**	6.0*	21.1***
Household size	0.6	0.9	0.2
Health	0.1	2.6	0.8
Migration	27.8***	23.7***	0.0
Household food insecurity	4.2*	12.1**	0.3
Village role	—	—	5.6*
Mobility	—	—	15.3***
Occupational status	202.1***	—	19.1***
Marital status	15.7***	19.1***	—

Step No.	Term entered	Improvement χ^2	P-value ^a	Goodness of fit χ^2	P-value
Mobility:					
0				413.9	0.000
1	Occupational status	130.9	***	282.9	0.712
2	Visual acuity	16.2	***	266.8	0.880
3	Migration	10.6	**	256.2	0.946
4	Age	7.9	**	248.2	0.973
5	Household responsibility	6.9	**	240.8	0.987
6	Household size	6.9	**	233.9	0.994
Occupational status:					
0				417.6	0.000
1	Visual acuity	144.0	***	273.9	0.817
2	Age	20.6	***	253.3	0.962
3	Migration	19.7	***	233.6	0.996
4	Household responsibility	10.8	**	222.7	0.999
Marital status:					
0				350.5	0.018
1	Visual acuity	32.5	***	318.5	0.166
2	Household responsibility	16.8	***	302.7	0.351
3	Sex	9.5	**	293.2	0.486
4	Food insecurity	4.1	*	289.1	0.537

^a * $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

^b At step 0 the F-to-enter for a variable corresponds to the F statistic computed from a one-way analysis of variance (ANOVA) of that variable for the groups used in the analysis.

“chronic” household food insecurity. Occupation and migration were the strongest independent predictors accounting for about 34% of the variance in mobility. Village role, age and household responsibility were also selected in the stepwise model, and accounted for another 30% of the variance.

A similar set of associations was found among the blind for the analysis of occupational status. Older age and later age of onset of blindness, no household responsibility, immobility, and seasonal household food insecurity were all significantly correlated with inactivity among the blind (Table 4). Household food insecurity, mobility and age were

selected as independent predictors of occupation, accounting for 37%, 20% and 5% of the variance, respectively. Only household responsibility and late age of onset of blindness were significantly associated with “married” marital status at step 0 (Table 4). However, once household responsibility was entered in the stepwise model, females and small household size became significant predictors of “married” status.

Among the visually impaired who were immobile, there were associations with no occupation and migration activity and older age (Table 5). Occupation was the most powerful predictor of mobility ($P = 0.429$); while age and migration were signifi-

Table 4: Step 0 likelihood ratio chi-squared and summary of stepwise logistic regression of mobility, occupation, and marital status among the blind

Explanatory variable	Mobility ^a (approx. F-to-enter) ^b	Occupation ^a (approx. F-to-enter) ^b	Marital status ^a (approx. F-to-enter) ^b
Age of onset	5.1*	8.8**	4.6*
Sex	1.7	0.2	0.2
Age	7.3**	8.5**	0.3
Household responsibility	7.1**	4.2*	10.9**
Household size	0.1	1.2	0.7
Health	0.1	2.9	1.5
Migration	18.6	—	1.7
Household food insecurity	5.4*	22.1***	0.1
Village role	5.2*	—	—
Mobility	—	18.1***	1.72
Occupational status	19.4***	—	0.00
Marital status	0.01	—	—

Step No.	Term entered	Improvement χ^2	P-value ^a	Goodness of fit χ^2	P-value
Mobility:					
0				157.1	0.005
1	Occupational status	15.8	***	141.2	0.200
2	Migration	8.4	**	132.8	0.344
3	Village role	4.7	*	128.1	0.431
4	Age	6.1	*	122.0	0.558
5	Household responsibility	4.0	*	118.0	0.635
Occupational status:					
0				139.0	0.279
1	Food insecurity	16.7	***	122.3	0.649
2	Mobility	10.9	**	111.3	0.853
3	Age	4.6	*	106.8	0.903
Marital status:					
0				179.3	0.003
1	Household responsibility	10.4	**	168.9	0.012
2	Sex	5.8	*	163.0	0.023
3	Household size	4.5	*	158.6	0.034
4	Age of onset	4.0	*	154.6	0.048

^a * $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

^b See footnote *b* in Table 3.

cant but relatively weak predictors of mobility ($P = 0.098$ and 0.079 respectively). Constrained mobility, older age and older age of onset of visual impairment, and poor health were significantly correlated with no current occupation. Mobility was the most powerful predictor ($P = 0.341$), and when entered in the model both age and age of onset lost their significance, thereby leaving health as the only other significant predictor of occupation ($P = 0.122$). At step 0, only household responsibility was significantly associated with "married" status among the visually impaired (Table 5). Once household responsibility was entered in the stepwise model, seasonal household food insecurity and later age of onset of visual impairment were identified as significant predictors of marital status.

Discussion

As seen in Fig. 2 and the Step 0 associations in Table 3, visual status appears to stratify the sample for each of the three measures of socioeconomic function. The selection of visual status as an independent predictor indicates that decreasing visual acuity is not simply a proxy for increasing age or poor health status, but rather explains a large part of the difference in social and economic functioning of the population. Therefore, the higher prevalence of constrained mobility, "inactive" occupational status, and "non-married" status are representative of a handicap associated with decreased visual acuity. Visual status, however, is not an exclusive or absolute predictor of handicap. Although less powerful as predic-

Table 5: Step 0 likelihood ratio chi-squared and summary of stepwise logistic regression of mobility, occupation, and marital status among the visually impaired

Explanatory variable	Mobility ^a (approx. F-to-enter) ^b	Occupation ^a (approx. F-to-enter) ^b	Marital status ^a (approx. F-to-enter) ^b
Age of onset	9.9**	8.5**	0.2*
Sex	0.1	—	0.0
Age	11.2**	9.7**	0.2
Household responsibility	0.0	0.2	6.2*
Household size	0.3	0.4	1.5
Health	0.7	5.4*	0.1
Migration	5.1*	—	1.3
Household food insecurity	0.3	0.0	2.2
Village role	0.1	—	—
Mobility	—	24.1***	0.7
Occupational status	34.1***	—	1.2
Marital status	0.7	—	—

Step No.	Term entered	Improvement χ^2	P-value ^a	Goodness of fit χ^2	P-value
Mobility:					
0				104.4	0.035
1	Occupational status	24.9	***	79.5	0.464
2	Age	4.1	*	75.4	0.562
3	Migration	3.4	*	72.0	0.641
Occupational status:					
0				107.8	0.021
1	Mobility	25.0	***	82.8	0.362
2	Health	4.3	*	77.8	0.484
Marital status:					
0				80.5	0.463
1	Household responsibility	5.8	*	74.7	0.617
2	Food insecurity	4.4	*	70.3	0.721
3	Age of onset	4.3	*	66.0	0.782

^a * $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

^b See footnote b in Table 3.

tors, other variables such as age, sex, household responsibility, and household size do meet the entry criteria or explain the variance in economic and social functioning in the population.

With the different degrees of handicap identified among the blind and visually impaired, it is interesting to consider how and why the levels of handicap differ within these groups. The step 0 associations for mobility and occupation among the blind (Table 4) reveal a very similar cluster of variables: early age of onset of blindness, younger age, household responsibility, and household food insecurity are linked with unconstrained mobility and occupational activity. These associations might suggest that the handicap of blindness is partly a function of age and age of onset of blindness, i.e., the younger the blind and the younger their age of onset of blindness, the greater their ability to adapt to physical impairment and to remain mobile and active. These variables, however, are either not selected or explain only a

small portion of the variance in handicap upon entry in the stepwise model. The selection of (and the large P -values attributed to) household food insecurity (change in $P=0.37$, Table 4) and occupation and migration for the models of occupation and mobility, respectively, suggest that a second hypothesis of economic necessity may have more power in explaining the activity and mobility of the blind.

In Mande culture, the household and village-level social networks function to support the elderly and disabled,^j thereby alleviating the need to remain mobile and active among the older blind. Furthermore, in focus group discussions the importance of the family in supporting the blind was universally stressed; the household does everything possible to

^j Adams A. *Seasonal food insecurity in the Sahel: nutritional, social and economic risk among Bamana agriculturalists in Mali*. PhD thesis, University of London, 1992.

ensure there is no need for blind persons to continue working. Blindness is viewed as an impairment which entitles the individual to a life of dependency on others. It is recognized, however, that there are situations where village charity and the reduced productive strength of the household are not sufficient to support a blind individual. In these cases, the blind individual's productive input, diminished as it may be, cannot be spared by the household. Hence, young blind individuals in positions of household responsibility may find that, in a less secure household situation, they remain economically active and mobile despite their disability. This concurs with Carroll's analysis of the blind in which he states "only the strongest motivations of terrible need will cause the blind person to move" (15).

Although their disability is not as severe as the blind, it appears that young age, young age of onset of visual impairment, occupation, migratory activity and mobility define the less handicapped visually impaired. The absence of a significant association with household food insecurity may indicate that the handicap of the visually impaired is generally not severe enough to influence the food security of the household, although the activity of the young visually impaired suggests that households rely on their productive input. Furthermore, self-reported ill-health is significantly correlated with inactivity for the visually impaired but had no association with the activity of the blind. Thus, sickness appears to be linked to the economic imperative, i.e., blind persons will work whether or not they consider themselves ill, if their labour input is needed.

The analysis of marital status among the blind provides further insight into their handicap. Unmarried status was strongly associated with a cluster of variables including no household responsibility, male sex, large household size and early onset of blindness. As was borne out in focus group discussions, the onset of blindness before marriage for men made it very unlikely that they would ever marry or assume positions of responsibility within the household. Instead, they remain within households (usually large) that can support them. Blind women are considered eligible for marriage, but their families receive a much reduced bride price.^k For those blind

and visually impaired with spouses, the large majority (88%) were married before the onset of decreased visual acuity. The advent of blindness was not considered to pose irreconcilable problems, although it was noted that women may leave a blind husband in cases of poverty and extreme hardship.^l The high percentage of blind men who are "widowed" may also be related to this phenomenon of women leaving blind men because of extreme hardship.

The marital handicap of the visually impaired is much less severe than that of the blind, which is partly due to the fact that others may not be aware of their disability. When comparing the marriage profiles of the visually impaired and the sighted population, the evidence of handicap lies in the greater rate of "widowed" persons (11% vs. 3%, Table 2) and to a lesser extent the "single" population (11% vs. 7%, Table 2). The greater rate of widowed status probably represents the fact that the majority of elderly widowed persons in areas of hyperendemic onchocerciasis are likely to have some visual impairment. However, the higher rate of "single" visually impaired, relative to the sighted, is likely to be indicative of severe visual impairment which is socially perceptible and therefore, like the blind, a virtually insurmountable barrier to marriage.

The following brief case studies illustrate some of the patterns of handicap discussed above.

- Djiba is 45 years old and has been blind for 4 years. Together with his eldest son Mory, age 14, he walks to the household field each day, and cultivates until fatigue and hunger overcome his efforts. The household has no food stocks and is dependent on what Djiba's wife can procure by working. With no prospect of extended family support, and five dependent children, Djiba recognizes that despite his disability he must continue to cultivate in an effort to provide for his starving family.

- In contrast, Moriba, 67 years old, ceased to cultivate and walk beyond the village at the onset of his blindness 7 years ago. Unlike Djiba, he has a large extended family to support him. He enjoys food security and busies himself like most other village elders with the religious and political activities of the village.

- Finally, Sekou, just 26 years old, lost his sight 6 years ago. Although he is much respected for his

^k In her analysis of landless agricultural labourers in Tamil Nadu, India, Heyer discusses the low cost of marrying disabled persons (Heyer J. Landless agricultural labourers' asset strategies. *Institute of development studies bulletin*, 1989, 20(2): 33-40). Likewise, in an analysis of the disabled in urban Senegal, Fassin describes disadvantages in marriage transactions for invalid men and women (Fassin D. Handicaps physiques, pratiques économiques et stratégies matrimoniales au Sénégal. *Social science and medicine*, 1991, 32: 267-272).

^l This theme of women leaving blind husbands due to hardship in the household has been popularized in an article on the importance of blindness rehabilitation in Burkina Faso (see Ouattara S. Quel métier pour les aveugles? *Famille et développement*, 1987, 45: 30-37).

agricultural prowess, he has little prospect of marrying and establishing a family. Unlike most men of his age who migrate to the Côte d'Ivoire during the dry season in order to raise the funds necessary for a bride price, Sekou remains a dependent in his father's household, without a wife or a family of his own.

It is useful to consider the implications of the findings of handicaps arising from decreased visual acuity, in the context of the conceptual framework presented in Fig. 1. When viewing the sample population as a whole, decreasing visual acuity is strongly correlated with more severe mobility, occupational and marital handicaps. In addition, other factors such as age, sex, household responsibility, and household size are significantly associated with variance in handicap. This demonstrates that handicap is not a direct consequence of the disability arising from visual impairment, but a product of the interaction between the disability, or the disease process, and other factors. These other factors are explored in some detail when investigating why handicap varies among the blind and the visually impaired. Multivariate models reveal age, sex, health, and age of onset of blindness or visual impairment to be factors specific to the individual which explain the variance in mobility, occupation and marital status among the blind and the visually impaired. Specific factors such as household food security, household responsibility, and household size are also identified as significant predictors of the handicap variables. For example, household food insecurity, the strongest predictor of activity among the blind (Table 4), provides evidence for the hypothesis that in food-insecure households it may be necessary for the blind to work (the case of Djiba), while in food-secure households their productive services may not be required (the case of Moriba). Evidence that factors not specific to the "individual" (in this case the household) can play a significant role in determining the degree of individual handicap emphasizes that handicap cannot be viewed solely as the product of interactions between the individual and the disease process. Rather, larger social organizations such as the household and community must also enter the equation. This corresponds to the concept of handicap (outlined above) as an interaction of the disabled person and the environment (see Fig. 1). Similar findings in the literature on rheumatoid arthritis reveal that social and family factors exert a significant influence on work disability (16, 17).

Furthermore, larger forms of social organization such as the household must not only be viewed in terms of their influence on individual handicap, they must also be considered in the context of the consequences of an individual's disability on the house-

hold. The association between household food insecurity and activity among the blind (Table 4) may represent the degree to which household production capacity is compromised by the less productive blind member: the chronic food insecurity experienced by Djiba's household may be a direct result of his blindness. This emphasizes the necessity to extend the analysis of handicap beyond the individual to the household and community,^m especially in environments where the household, not the individual, is the primary economic unit. Similar concepts have been identified when considering the unremitting burden on the carers and on families resulting from chronic disease (18, 19).

Another issue which emerges from this analysis is how to interpret different measures of individual handicap: does greater handicap mean an individual is worse off than someone with a lesser handicap? From the results in this study, the elderly blind who are inactive and immobile (Moriba) appear more handicapped than those who are younger, active and mobile (Djiba). However, the younger blind are also more likely to belong to food-insecure households (Djiba) and are unlikely to find a spouse (Sekou). It appears therefore that the multiple dimensions of individual handicap do not lend themselves easily to a single aggregate measure. It may be more useful from a policy perspective to view the spectrum and dynamic nature of handicaps arising from a disabling disease as it affects individuals and households at different stages of life.

^m See Evans TG. The impact of permanent disability on rural households: river blindness in Guinea. *Institute of development studies bulletin*, 1989, 20(2): 41-48, and Evans TG. *The socio-economic consequences of human disease on subsistence agriculture: the case of onchocerciasis in West Africa*. Unpublished DPhil thesis, Oxford University, 1989.

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Résumé

Conséquences socio-économiques de l'onchocercose cécitante en Afrique de l'Ouest

L'onchocercose, ou cécité des rivières, est une cause majeure de cécité irréversible chez les adultes au faite de leur vie active, et contribue à l'abandon des villages dans les vallées fluviales de l'Afrique de l'Ouest. Comme cette maladie fait peser de lourdes contraintes sur le développement économique, outre le problème de santé publique qu'elle pose, elle a fait l'objet d'un important effort de lutte, concrétisé par le lancement du Programme de lutte contre l'Onchocercose (OCP) en 1974. Cet article présente des données primaires en provenance de régions de Guinée où l'onchocercose est fortement endémique, et examine le modèle des conséquences de la maladie fourni par la *Classification internationale des handicaps: déficiences, incapacités et désavantages*, pour évaluer les conséquences socio-économiques de la cécité et de la perte de vision dues à cette maladie.

En 1987, une enquête transversale portant sur les personnes et les ménages frappés de cécité ou de déficience visuelle, ou ayant une bonne vue, a été réalisée dans le nord-est de la Guinée. L'échantillon de 136 aveugles, 94 déficients visuels et 89 personnes ayant une bonne vue a été obtenu dans 14 villages d'hyperendémie onchocercarienne identifiés lors d'enquêtes épidémiologiques portant sur l'infection onchocercarienne et l'acuité visuelle réalisées en 1985 et 1986 par l'OCP. Lors d'entretiens avec les sujets de l'échantillon et les personnes faisant partie de leur ménage, des enquêteurs qualifiés ont utilisé des questionnaires portant sur les antécédents d'acuité visuelle, l'état de santé tel qu'il est perçu par l'intéressé, la mobilité, l'activité agricole, la sécurité des approvisionnements alimentaires du ménage, et les données démographiques.

Trois indicateurs socio-économiques spécifiques (mobilité, profession et situation de famille) ont été retenus pour comparer les groupes d'aveugles et de déficients visuels et la cohorte de sujets ayant une bonne vue. Parmi les aveugles, 68% étaient incapables de se déplacer à pied en dehors du village, contre 42% des déficients visuels et 8% des sujets ayant une bonne vue. Seuls 10% des aveugles contre 54% des déficients visuels et 92% des sujets ayant une bonne vue se déclaraient agriculteurs. La cécité, et dans une moindre mesure la déficience visuelle, était associée à des

taux élevés de célibat, de veuvage ou de prise en charge de la veuve d'un frère décédé, et à un faible taux de mariage. Dans une analyse multivariée, l'acuité visuelle a été retenue comme facteur prédictif indépendant pour chacune des trois variables socio-économiques, d'autres facteurs indépendants, comme l'âge, le sexe, la position de l'intéressé au sein du ménage et le nombre de personnes composant le ménage, satisfaisant aussi aux critères de significativité.

La variation du handicap à l'intérieur de chaque groupe d'acuité visuelle a été étudiée au moyen de modèles de régression logistique multiple pour chacune des trois variables socio-économiques. Diverses variables indépendantes ont pu être associées à la variation du handicap, et ont été par la suite interprétées en utilisant des données qualitatives. Ces observations sont discutées dans le cadre du concept de handicap selon la Classification internationale des handicaps, et en soulignant le fait que des facteurs tant individuels que liés au ménage ou à l'environnement jouent un rôle important dans le degré de désavantage associé à une maladie chronique invalidante telle que la cécité.

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