

Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: a 1-year cohort of new leprosy cases in north Bangladesh

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Summary The current leprosy elimination strategy focuses almost exclusively on delivery of leprosy diagnostic services and multi-drug treatment (MDT). However, the specific problems of people newly diagnosed with leprosy or cured with MDT primarily relate to impairment of nerve function and social and economic consequences of the diagnosis of leprosy. This study was carried out to investigate the relation between socio-economic factors and the development of nerve impairments and stigma. In addition the relation between socio-economic factors and selection for socio-economic assistance was studied. The study population was a cohort of 2364 newly diagnosed people with leprosy in rural Bangladesh in 1996, including 42.5% women, with an overall mean age of 31.4 years. Three hundred and sixty people (15.2%) had WHO grade 1 or 2 disability identified at diagnosis, and 50 (2.1%) had stigma identified on interview at home visit conducted within one month of diagnosis. One hundred and eighty-eight people (8%) were selected for specific assistance for rehabilitation, primarily interest-free loans for income generating activities or vocational training. Factors independently associated with WHO grade 1 or 2 disability at diagnosis were multibacillary (MB) classification, adult status, and manual occupations. Smear positivity, female sex, and the presence of dependents were associated with an increase in the experience of stigma. The presence of nerve impairments and stigma, as well as several indices of poverty were clearly associated with selection for inclusion in an integrated program for socio-economic assistance. An increased focus by leprosy services on the socio-economic factors associated with poorer physical and social outcomes is recommended. Where adequate finances and trained staff are available, efforts could be made to identify those at higher risk of poor outcomes, and to provide or to mobilize appropriately targeted socio-economic interventions.

Introduction

The widespread implementation of multi-drug therapy (MDT) has clearly been extremely successful in curing and reducing the prevalence of leprosy. However, the socio-economic causes and consequences of leprosy related impairments and disabilities, and of social stigmatization have not been so well addressed by leprosy control programmes. Impairments may evolve into fixed deformities under the pressure of socio-economic realities, where self-care takes second place to daily survival. Leprosy related impairments and stigma may lead rapidly to unemployment, community dislocation and destitution.

A number of recent publications have addressed the issue of stigma in leprosy and its associated factors,¹⁻⁴ and demographic or clinical factors related to impairment and disability.^{5,6} However, the number of published articles on the experience of leprosy programmes in the area of socio-economic assessment and intervention has been limited. Rao *et al.*⁷ have recently reported on the experience of LEPRO India in the large scale application of socio-economic rehabilitation in Andhra Pradesh and Orissa states. A variety of other interventions have been described⁸⁻¹² and a broad multisectoral and community based approach has been advocated by Deepak.¹³

The Danish Bangladesh Leprosy Mission (DBLM) is a leprosy and TB control project based in the northwest of Bangladesh. In collaboration with the Government of Bangladesh, it covers a population of approximately 6.3 million, operates 60 clinics for diagnosis, MDT delivery, reaction and neuritis management and other prevention of disability (POD) activities. The new leprosy case detection rate in recent years has averaged over 4 per 10,000 amounting to over 2000 new leprosy cases annually. Since 1995, every person newly diagnosed with leprosy has undergone routine social assessment. The questionnaire for this assessment is administered by experienced field staff who are trained in its use in order to ensure standardization of the information collected. The assessment is performed at the person's home, generally within 1 month of diagnosis, allowing direct observation of their situation and verification of the information from local sources. On the basis of this information a decision is reached on whether to offer socio-economic assistance in the form of a donation, vocational training, or a loan for income generation. Generally this is a 'one-off' input, though further assistance may be offered, depending on the result of the previous initiative in rehabilitation and on available resources. The objective of any assistance is to restore a person to the socio-economic status and potential enjoyed by them prior to the development of leprosy. According to the classification scheme proposed by Cornielje *et al.*,¹⁴ the social rehabilitation component of the DBLM project is probably best described as 'WLFV' in type, i.e. promoting socio-economic well-being (W) in addition to physical care, offering limited (L) choice to clients, involving and extending assistance to family (F) members where needed, and achieving objectives through a variety (V) of activities.

In order to study better the relationships between type of leprosy, socio-economic factors, the experience of stigma, impairment status and project response in terms of selection for assistance, a retrospective, descriptive study of the collected data on new cases registered in the year of 1996 was carried out. The year of 1996 was chosen because of the large number of new cases, and the greater completeness in recording and computerization compared with other years, as well as providing the opportunity to subsequently review the longer-term impact of intervention.

Materials and methods

Information from the socio-economic questionnaires of all new leprosy patients registered from January to December 1996 was routinely entered into an EPIINFO (version 6.0) database. The main social indices examined by the questionnaire were gender, age, religion, occupation, level of education, daily income, type of house, number of family members, number of people depending on the patient's daily income, membership of an NGO group and source of water. In addition, several dimensions of stigma were explored, including lack of support by family members, lack of community cooperation, or a 'social change' due to leprosy, e.g. divorce, losing a job, being denied access to school or mosque. For the purpose of analysis, some recoding of variables and values was performed. People whose occupation was day-labourer or beggar were grouped as the 'poorest' in terms of occupation, being a landless group, with generally very few assets. People working as farmers, day-labourers or rickshaw-pullers were grouped as manual labourers, to assess relationship with impairment status in particular. The three stigma dimensions were also grouped such that if any were positive then stigma was deemed to be present. Regarding financial dependants and educational status, subjects were grouped as either having none or any. This information was further compared in relation to the project main leprosy database (FoxPro version 2.6.) by means of the unique registration number in order to further understand relationships between these socio-economic indices and details on type and group of leprosy, nerve function impairments, and disability status. Cross tabulation analysis was done using SPSS Version 6.1.2. Logistic regression analysis was performed using a generalized linear model with a binomial error distribution¹⁵ under GenStat 5 Release 4.2. The independence of explanatory terms was assessed using a stepwise logistic regression analysis that adds the most significant term to the model, one at a time, until no further significant terms are left.

In 1996, a total of 3159 new cases of leprosy were diagnosed by the control programme and commenced MDT treatment. 630 (19.9%) of these, including 380 men and 250 women had no rehabilitation reports available and were excluded from the analysis. A further 150 (4.7%) were excluded as their rehabilitation data was collected after the date of completion of treatment. Eleven were excluded because of concurrent tuberculosis, since the project also specifically addresses tuberculosis in terms of treatment services and socio-economic assistance. Four cases were found to have duplicate records. There was no significant difference between those with available reports and those without, in regard to WHO impairment grade (393/2529 versus 95/630 with any impairment; $\chi^2 = 0.08$, $P = 0.77$), proportion of women (1078/2529 versus 250/630; $\chi^2 = 1.8$; $P = 0.18$), or mean age (31.53 versus 30.94; $F = 0.64$, $P = 0.42$) at the time of registration.

Results

Of the 2364 new cases, 1004 (42.5%) were women and 1360 (57.5%) were men. The mean age was 31.4 years (range 2-90). Age distribution of cases is shown in Figure 1. A total of 467 cases (19.7%) were multibacillary (MB) and 1897 (80.3%) cases were paucibacillary (PB). Women were significantly more likely to be PB than men (865/1004 versus 1032/1360; $\chi^2 = 38.5$; $P < 0.00001$). 546 cases (23%) were children (<16 years). The majority of cases were Muslim (81%), the remainder Hindu (18%) and Christian (1%). A total of 1444 (61.1%) had no formal education, and only 282 (11.9%) had studied beyond class 5. Women were

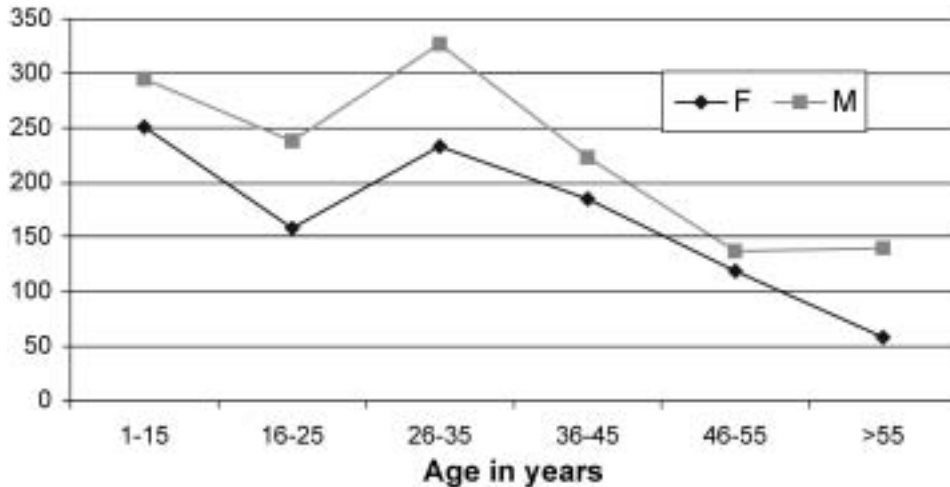


Figure 1. Number of cases by age and sex.

significantly less likely than men to have any formal education (707/1004 versus 737/1360; $\chi^2 = 71.7$; $P < 0.00001$); however, this difference in educational status was absent in children. Of 753 adult women, 667 (88.6%) stated their occupation as housewife, while 528 (49.6%) out of 1065 adult men described themselves as farmers, and a further 267 (25.1%) as day-labourers. Twenty-four (1.0%) of all new cases, including two children, were beggars, twice as many of whom were female (F = 16 versus M = 6; $\chi^2 = 5.8$; $P = 0.016$). The 'poorest' (defined as beggars and day-labourers combined) made up 368 (15.6%) of the total. 48 (8.8%) of all children were included in this group. Manual workers (defined as day-labourers, farmers or rickshaw-pullers) made up 933 (39.5%) of the total, including 827 (65%) males, and 70 (12.8%) children.

Daily income was less than US\$0.50 in 1156 (66.4%) of 1740 adults with recorded incomes. This included 633 (92.4%) of 685 women, and 523 (49.6%) of 1055 men. Only 69 (4.0%) reported a daily income of more than US\$1 per day. The average number of family members was 5.2, and the mean number of dependents 1.8 (range 0–12). 23% had family members with leprosy, though only 216 (9.1%) were detected on active contact survey. One hundred and forty-two (6.0%) were members of NGO credit groups, and 1839 (77.8%) had access to safe drinking water via a tube well, either their own or a neighbour's. In all, 2196 (92.9%) lived in houses made of mud clay or bamboo, while only 129 (5.5%) lived in a house made with permanent materials.

A total of 360 (15.2%) cases had WHO disability grade 1 ($n = 208$) or grade 2 ($n = 152$) at registration. The percentage of new cases with any nerve function impairment (i.e. WHO Grade > 0) by age and sex is shown in Figure 2. Analysis of risk factors for any impairment is shown in Table 1. Analysis by grade 2 disability alone yielded the same significant factors as in Table 1 with the exception of the absence of education, which had a P value of 0.06. Logistic regression analysis resulted in three independent predictive factors for disability, namely leprosy group (MB 42.6% versus PB 7.5%), manual work (18.2% versus 11.9%), and adult status (16.3% versus 8.3%), all with independent P values of < 0.001 . After allowing for treatment group, manual work and adult status, no other factors had any significant association with nerve impairments.

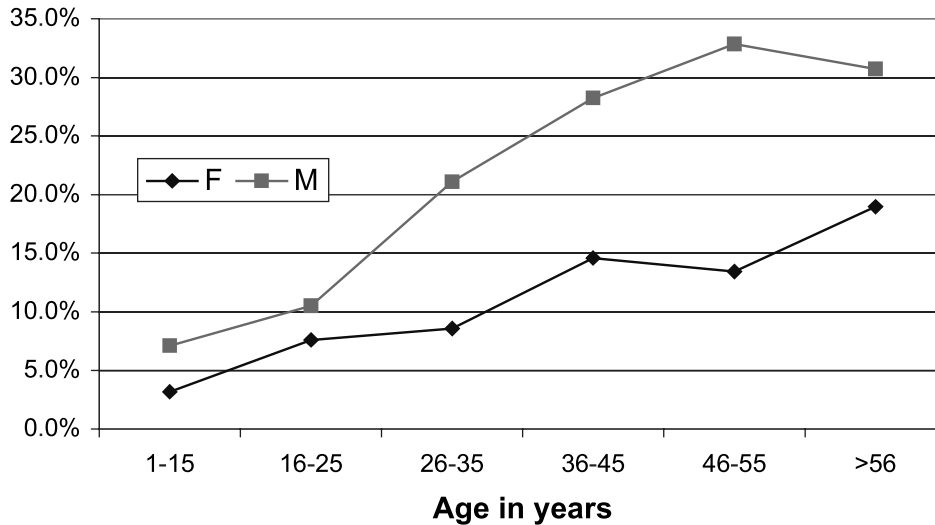


Figure 2. Percentage of new cases with WHO grade >0 by age and sex.

Thirteen (0.6%) people reported deterioration in family behaviour towards them as a result of a diagnosis of leprosy. Twenty-nine (1.1%) reported deterioration in local community cooperation. Twenty-seven (1.1%) reported a specific change in social status due to the diagnosis, such as loss of job, or lack of access to religious or educational or medical facilities. Fifty (2.1%) individuals in total reported at least one of these aspects of social stigma. Breakdown of percentage by age and sex is shown in Figure 3. Socio-economic factors related to stigma are summarized in Table 2. Logistic regression analysis yielded three independent predictive factors for stigma namely skin smear positivity (positive 8.4% versus negative 2.0%; $P=0.001$), female sex (female 4.2% versus male 1.1%; $P<0.001$), and presence of dependents (any 3.6% versus none 1.1%; $P=0.003$).

A total of 188 people, or 8% of the total, were offered some form of socio-economic rehabilitation assistance. The forms of assistance given are shown in Figure 4. Logistic regression analysis of factors associated with selection for assistance yielded six significant independently associated factors namely: presence of any WHO disability grade (14.3% with disability grade versus 5.6% without), poorest forms of occupation (14.5% beggars and day-labourers helped versus 5.3% other occupations), poor housing (9.5% versus 0%), presence of dependents (9.0% with any dependents helped versus 4.6% without), presence of stigma (21.4% with stigma helped versus 6.7% without), and MB treatment group (10.5% MB helped versus 6.1% PB) (Table 3).

Discussion

An assessment of socio-economic factors, and attention to socio-economic rehabilitation is seen by the authors as an important accompaniment to leprosy control services. Unfortunately the need to focus on socio-economic issues is usually inversely proportional to the resources available for this. Bangladesh was estimated to have a national GDP per capita in 1996 of

Table 1. Factors associated with WHO impairment grade 1 or 2

Variable	Subgroup	<i>n</i>	<i>df</i>	Impaired	Percent	χ^2	<i>P</i>
Sex	Male	1360	1	266	19.6	46.5	
	Female	1004	–	94	9.4	–	<0.00001
Adult (>15 years)*	Adult	1818	1	331	18.2	54.1	<0.00001
	Child	546	–	29	5.3	–	–
Dependants	Any	915	2**	201	22.0	60.9	<0.00001
	None	1013	93	–	9.2	–	–
WHO grade disability*	Any	360	1	–	–	–	–
	None	2004	–	–	–	–	–
WHO grade 2	Yes	152	1	–	–	–	–
	None	2212	–	–	–	–	–
Education	Nil	1444	2**	249	17.2	14.9	0.0006
	Any	911	–	108	11.9	–	–
Treatment classification*	MB	467	1	219	46.9	452.1	<0.00001
	PB	1897	–	141	7.4	–	–
Leprosy affected family members	Any	537	2**	72	13.4	1.8	0.4
	None	1669	–	264	15.8	–	–
Income	0–\$0.50	1624	2**	235	14.5	10.4	0.006
	>\$0.50	613	–	114	18.6	–	–
Manual occupation*	Yes	933	2**	213	22.8	69	<0.00001
	None	1397	–	143	10.2	–	–
Member of credit group	Yes	142	1	17	12.0	1.2	0.26
	No	2222	–	343	15.4	–	–
Type of house	Non-permanent	2196	3**	336	15.3	4.2	0.23
	Permanent	129	–	15	11.6	–	–
	Nil/rented	21	–	6	28.6	–	–
Beggar/day-labourer	Yes	368	2**	92	25.0	32.3	<0.00001
	No	1962	–	264	13.5	–	–
Reaction at diagnosis	Yes	344	1	176	51.2	402.7	<0.00001
	No	2020	–	184	9.1	–	–
Religion	Muslim	1909	2	286	15.0	2.3	0.32
	Hindu	432	–	68	15.7	–	–
	Christian	23	–	6	26.1	–	–
Smear positivity	Positive	152	1	66	43.4	100	<0.00001
	Negative	2212	–	294	13.3	–	–
Stigma	Yes	50	1	14	28.0	6.5	0.01
	No	2314	–	346	15.0	–	–
Source of water	Tube well	1839	3	280	15.2	1.7	0.63
	Other well	280	–	40	14.3	–	–
	Pond/other	30	–	7	23.3	–	–
	Tap	215	–	33	15.3	–	–
Total		2364	–	360	15.2	–	–

* Significant independent risk factors for disability on logistic regression analysis.

** Missing values were included in the analysis.

Tk 11,288 per annum¹⁶ or approximately US\$0.53 per day. The average personal daily income among subjects in this study was estimated at US 30 cents. Two-thirds of adults reported an income of less than US 50 cents per day, and only 4% of adults reported a daily income of more than \$1 per day. Though the current analysis does not specifically include land ownership, an attempt was made to include the value of crops gained from owned land as part of the daily income. Forty-eight percent of adult women as opposed to 7% of adult men reported no daily income, reflecting the financial dependence and hence vulnerable status of women in rural Bangladesh. The lack of formal education in 61% of all subjects, including

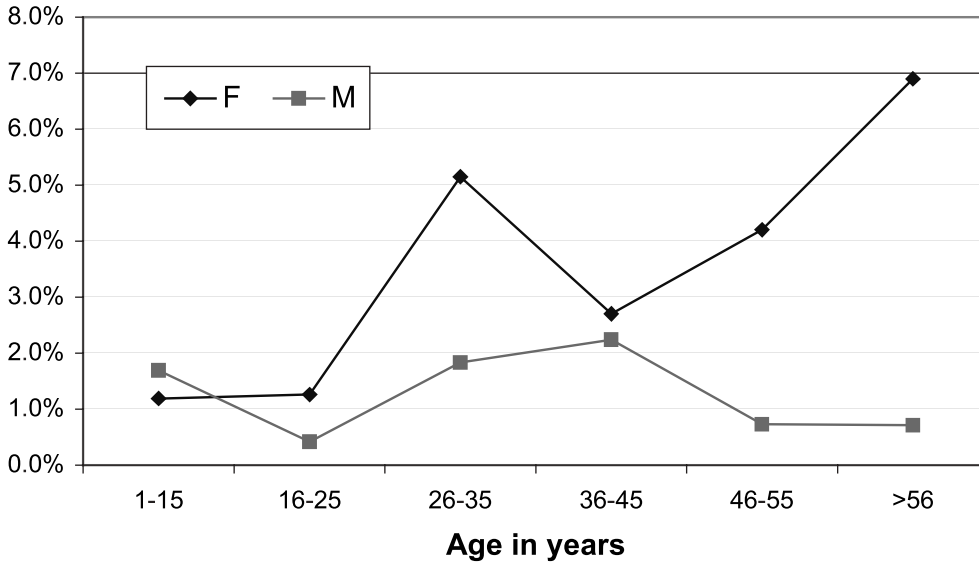


Figure 3. Percentage experiencing stigma by age and gender.

61% of adult men, 84% of adult women, and 29% of children compares unfavourably with the official illiteracy figures of 55% for all, 52% for men, 60% for women, and 18% of children in the Bangladesh population according to official statistics for 1996.¹⁶

NERVE FUNCTION IMPAIRMENT

A large number of factors were found to be associated with nerve function impairment at diagnosis (WHO ‘disability’ grade >0), including adult status, presence of dependents, passive versus active modes of detection, lack of education, male sex, MB treatment group status, higher incomes, manual occupations, status as beggar or day-labourer, reaction at diagnosis, positive skin smear status and stigmatization. Many of these have been noted in previous studies as noted in Gilbody’s review.¹⁷ Delay to diagnosis could not be tested as an independent risk factor for the whole cohort as this data was not routinely collected for all subjects, except for the first 3 months of 1996, as part of another study. For this subset, grade 2 impairment status was significantly more likely in those who had a delay of more than 24 months before commencing treatment (14/146 versus 16/353; $\chi^2 = 4.7$; $P = 0.03$). Only three factors were independently associated with nerve impairments in this study: MB treatment group, manual work, and adult status. Association with MB treatment group has been noted by many, as summarized by van Brakel.¹⁸ Rest is an established treatment for neuritis, and it is therefore not surprising that manual occupations are associated with more nerve impairment. Lower rates in children could conceivably result from earlier case-detection through a focus on children in case-detection activities through school programs and surveys. However, further analysis by age group showed a progressive increase in impairments with age (Figure 2). Early socio-economic intervention in new patients in these high risk groups may help minimize further nerve impairment.

Table 2. Factors associated with any stigma

Variable	Subgroup	<i>n</i>	<i>df</i>	Stigma	Percent	χ^2	<i>P</i>
Sex*	Male	1360	1	19	1.4	8.0	0.005
	Female	1004	–	31	3.1	–	–
Adult (>15 years)	Adult	1818	1	42	2.3	1.4	0.23
	Child	546	–	8	1.5	–	–
Dependants*	Any	915	2**	22	2.4	7.5	0.024
	None	1013	–	13	1.3	–	–
WHO grade disability	Any	360	1	14	3.9	11.7	0.003
	None	2004	–	36	1.8	–	–
WHO grade 2	Yes	152	1	9	5.9	11.4	0.0008
	None	2212	–	41	1.9	–	–
Education	Nil	1444	2**	37	2.6	3.7	0.16
	Any	911	–	13	1.4	–	–
Treatment classification	MB	467	1	16	3.4	4.8	0.03
	PB	1897	–	34	1.8	–	–
Leprosy affected family members	Any	537	2**	14	2.6	4.1	0.13
	None	1669	–	36	2.2	–	–
Income	0–\$0.50	1624	2**	31	1.9	1.3	0.52
	>\$0.50	613	–	15	2.4	–	–
Manual occupation	Yes	933	2**	13	1.4	5	0.08
	None	1397	–	37	2.6	–	–
Member of credit group	Yes	142	1	6	4.2	3.2	0.07
	No	2222	–	44	2.0	–	–
Type of house	Non-permanent	2196	3**	46	2.1	16.5	0.001
	Permanent	129	–	1	0.8	–	–
	Nil/rented	21	–	3	14.3	–	–
Beggar/day-labourer	Yes	368	2**	11	3.0	2.2	0.32
	No	1962	–	39	2.0	–	–
Reaction at diagnosis	Yes	344	1	16	4.7	12.5	0.0004
	No	2020	–	34	1.7	–	–
Religion	Muslim	1909	2	36	1.9	3.6	0.16
	Hindu	432	–	14	3.2	–	–
	Christian	23	–	0	0.0	–	–
Smear positivity*	Positive	152	1	10	6.6	15.6	0.00008
	Negative	2212	–	40	1.8	–	–
Stigma	Yes	50	1	–	–	–	–
	No	2314	–	–	–	–	–
Source of water	Tube well	1839	3	34	1.8	10.5	0.015
	Other well	280	–	13	4.6	–	–
	Pond/other	30	–	0	0.0	–	–
	Tap	215	–	3	1.4	–	–
Total		2364	–	50	2.1	–	–

* Significant independent risk factors for disability on logistic regression analysis.

** Missing values were included in the analysis.

STIGMA

Stigmatization of those affected by leprosy is difficult to define and quantify. A distinction can be usefully made between 'felt stigma', which tends to occur at diagnosis, is primarily a fear of discrimination, and may lead to concealment, as opposed to 'enacted stigma', which refers to actual discrimination.¹⁹ The dimensions used in this study focused on enacted stigma experienced soon after diagnosis. The recorded rate of stigma thus defined was low, affecting only 50 individuals, i.e. 2.1% of all new cases. DBLM field workers report that the negative

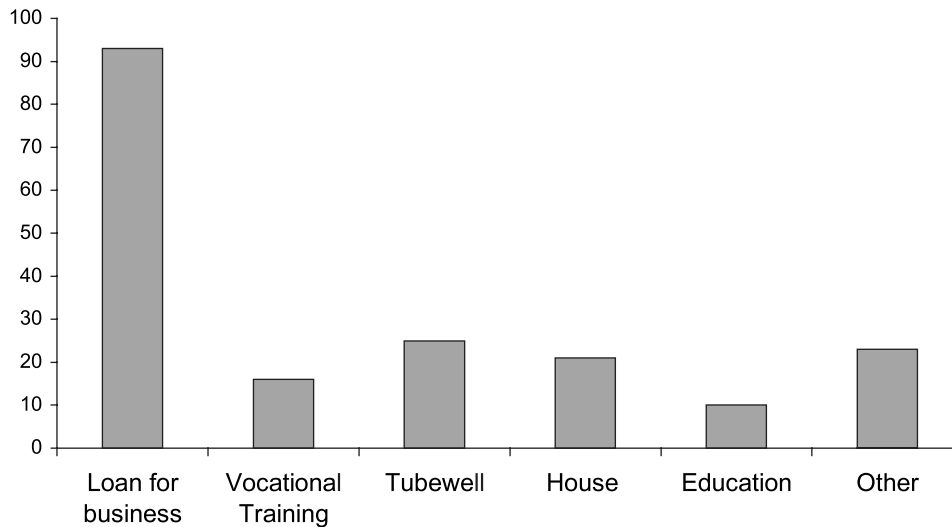


Figure 4. Type of socio-economic assistance ($n = 188$).

social effects of a diagnosis of leprosy have decreased markedly in the region over the last two decades since the program began. A study into knowledge, attitude and practice regarding leprosy in DBLM in 1997²⁰ showed a significant decrease in stigmatizing attitudes and reported practice in the area reached by the awareness program compared with that not reached. Since most assessments in this study were done early after registration, awareness of the new diagnosis of leprosy among neighbours may have been limited, and the number of patients experiencing stigma may be expected to increase over time. Longer term and more subtle stigmatization such as marriage problems for young people from leprosy affected families would be more readily detected in a longitudinal study.

Three factors were independently associated with stigmatization on regression analysis in this study: skin smear positivity, female sex, and the presence of dependents. Figure 3 shows the relationship between gender and stigma according to age group, highlighting those women between 26 and 35 years, and those greater than 45 years as at highest risk. Others have reported increased stigma affecting women,²⁻⁴ though occasionally the reverse is reported.²¹ The commonly-reported increased rates of disability among men are a potential confounding factor. De Stigter¹ noted the main motive for negative behaviour towards people affected by leprosy in Eastern Nepal to be a fear of infection by germs, in 64% of those expressing negative attitudes. Such a fear may underlie the association of stigma with smear positive status in the present study, though it is unclear how this information would have become known to the new patient's community. It is possible that the meaning of a positive test (or of a presumptive positive test based on the clinical picture at diagnosis) is communicated to patients and their accompanying relations at diagnosis by project staff without satisfactory reassurance about the efficacy of MDT in rapidly stopping infectivity. Alternatively, the cosmetic deformities such as earlobe nodules, which are frequently associated with a positive skin smear, may underlie this observed increase in stigma. The reasons for an increase in negative social consequences in those with dependents compared to those without are not clear. It may be that a perceived increased risk of transmission by

Table 3. Factors associated with selection for socioeconomic assistance

Variable	Subgroup	<i>n</i>	<i>df</i>	Selected	Percent	χ^2	<i>P</i>
Sex	Male	1360	1	131	9.6	12.3	0.0004
	Female	1004	–	57	5.7	–	–
Adult (>15 years)	Adult	1818	1	169	9.3	19.4	<0.00001
	Child	546	–	19	3.5	–	–
Dependants*	Any	915	2	110	12.0	43.2	<0.00001
	None	1013	–	40	3.9	–	–
WHO grade disability*	Any	360	1	82	22.8	127.5	<0.00001
	None	2004	–	106	5.3	–	–
WHO grade 2	Yes	152	1	45	29.6	104.0	<0.00001
	None	2212	–	143	6.5	–	–
Education	Nil	1444	2	131	9.1	6.65	0.04
	Any	911	–	56	6.1	–	–
Treatment classification*	MB	467	1	83	17.8	76.7	<0.00001
	PB	1897	–	105	5.5	–	–
Leprosy affected family members	Any	537	2	39	7.3	0.87	0.65
	None	1669	–	134	8.0	–	–
Income	0–\$0.50	1624	2	125	7.7	1.49	0.47
	>\$0.50	613	–	55	9.0	–	–
Manual occupation*	Yes	933	2	112	12.0	38.8	<0.00001
	None	1397	–	71	5.1	–	–
Member of credit group	Yes	142	1	19	13.4	6.1	0.014
	No	2222	–	169	7.6	–	–
Type of house*	Non-permanent	2196	3	180	8.2	19.9	0.0002
	Permanent	129	–	0	0.0	–	–
	Nil/rented	21	–	4	19.0	–	–
Beggar/day-labourer*	Yes	368	2	75	20.4	95.8	<0.00001
	No	1962	–	108	5.5	–	–
Reaction at diagnosis	Yes	344	1	68	19.8	76.8	<0.00001
	No	2020	–	120	5.9	–	–
Religion	Muslim	1909	2	145	7.6	2.6	0.27
	Hindu	432	–	42	9.7	–	–
	Christian	23	–	1	4.3	–	–
Smear positivity	Positive	152	1	30	19.7	30.8	<0.00001
	Negative	2212	–	158	7.1	–	–
Stigma*	Yes	50	1	15	30.0	33.9	<0.00001
	No	2314	–	173	7.5	–	–
Source of water	Tube well	1839	3	139	7.6	7.9	0.047
	Other well	280	–	21	7.5	–	–
	Pond/other	30	–	6	20.0	–	–
	Tap	215	–	22	10.2	–	–
Total		2364	–	188	8.0	–	–

* Significant independent risk factors for disability on logistic regression analysis.

affected parents to young children underlies this. Since those with dependents are generally married, this may also be a marker for significantly increased stress within marriage following a diagnosis of leprosy.

SELECTION FOR SOCIO-ECONOMIC REHABILITATION (SER)

Selection of candidates for assistance is a difficult task where many needs exist, both within the target group and the surrounding community. In DBLM an interview board, decentralized to district level was responsible for selection. Written guidelines for priority in selection for

SER were developed by the project in 1996. First priority was given to those with physical impairments *and* social stigmatization, followed by either criterion alone. Those with poorer economic status, and women were to be given particular emphasis. In selection for vocational training and for disbursement of loans, age limits were set and the potential to work successfully and to repay the loan were considered. Donations tended to be focused on those requiring assistance but not meeting these criteria. Loans were tied to viable income generating activities including financing of small shops selling small goods or fresh produce, small businesses for rice husking, farming and processing, poultry and livestock, or for rural transport, such as a cycle rickshaw. The form of assistance chosen rested on a joint decision of client, health worker, family and community, out of a prescribed range of options within the DBLM system.

Selection for SER in this study was independently associated with impaired nerve function status, poorest form of occupation, poor housing, presence of dependents, the presence of stigma, and MB treatment status. Personal income was not independently associated, perhaps because it was too blunt a tool to usefully differentiate between levels of poverty in this very poor study group. In a predominantly rural economy as in this study, personal income may also be unrepresentative of actual personal wealth, even where attempts to include crop value have been made as in this study. The other poverty indices employed here may be more useful in practice. Nutritional status was not measured routinely in this study, though it may also provide a useful way to target assistance appropriately as recently advocated.²² The reason for inclusion of MB treatment status is not clear. Staff may have considered the present or potential future status of more impact due to leprosy.

Some 188 individuals (8%) were selected for SER assistance. The variety of interventions selected for these 188 clients is shown in Figure 4. Only 48% of these had either nerve impairments or experienced stigma. By contrast, 77% of those with impairments were not selected for SER, nor were 70% of those experiencing stigma. Though there is evidence for increased vulnerability of women, there is no indication that increased assistance was offered to women as a whole.

Provision of socio-economic rehabilitation assistance is not inexpensive. Adding a socio-economic dimension to leprosy services may undermine already stretched diagnostic and treatment services, whose staff generally do not have the training, time or resources to consider such issues. However the neglect of socio-economic needs ignores issues of fundamental importance to many patients, and has potential increased costs in the longer term through worsened disabilities. To what degree rehabilitation at an earlier stage may offset future expenditure will be a relevant consideration for health managers and planners. Potential benefits include decreasing rates of re-admission to hospital, decrease in recurrent ulceration, and the wider and sometimes intangible benefits of socio-economic development for this very vulnerable group. Analysis of results of systematic, long term follow up of large numbers of clients will be required to see if anticipated benefits in physical and socio-economic status are both significant and sustained. A follow up study to assess the outcome of rehabilitation in clients in this study cohort is currently underway in DBLM.

The approach described, with a socio-economic focus directed so specifically at individuals and at leprosy, will be increasingly difficult to justify in areas of decreased leprosy prevalence, where geographical considerations are less favourable than Bangladesh, and where other needs are more pressing, and resources severely limited. Alternative, or supplementary approaches, with enhanced potential for cost-effectiveness, include projects nearer the 'AECR' end of the spectrum of rehabilitation projects as described by Cornielje,¹⁴

which are more aimed at advocacy (A), empowerment (E) of affected people, targeting or involving the community (C) at large, and operating through referral (R) to other rehabilitation service providers.

CONCLUSIONS AND RECOMMENDATIONS

Most leprosy control programs do not record socio-economic data, and are not involved in the systematic application of socio-economic rehabilitation. Traditionally, many socio-economic interventions have been confined to donations for the destitute and extremely old and disabled. A more logical approach is to also target those at risk of disability and destitution as a preventative measure. This requires adequate funding, staff retraining, and a more developmental approach. Where such funding is not available to leprosy services, the possibility of networking with and referring to other local organizations could be explored.

Where resources are adequate, the early and systematic assessment of key socio-economic indices, and a better understanding of nerve impairment and stigmatization in relation to socio-economic factors, is recommended as an important addition to the provision of early diagnosis and treatment with MDT. Suggested indices include type of occupation, housing status, and number of dependents. Measuring income should be done with care in rural settings and should consider land ownership. Older people with MB disease, and those in manual occupations are at increased risk of nerve impairments and warrant special care, and possibly early SER intervention. The presence or potential for social exclusion through stigma warrants specific consideration and questioning by service providers. Special attention regarding community advocacy and personal counselling needs to be paid to new cases with positive smears, women, and those with children, who appear to be at highest risk of early stigmatization. Further standardization in the measurement of stigma is needed to aid further research, as well as program monitoring.

Ideally, SER programmes should be closely networked with leprosy control programs to allow early and preventative intervention before destitution occurs. Since most leprosy control programs are now integrated into general health services, in these settings SER programs will preferably cater to the broader range of disabilities dealt with by general health services if they are to be cost-effective. Such programs will need the flexibility to address individual socio-economic needs and to monitor response to assistance. They also require systematic methods to ensure that the most needy target groups are reached, and that efforts are coordinated with other potential providers. Alongside such individualized SER programmes, and where such programmes remain but a dream because of resource constraints, broader community based advocacy initiatives can be promoted, aimed at minimizing social exclusion for all people with disabling conditions.

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