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Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives in northern Bangladesh and in West Bengal, India

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Summary The objective of our research was to identify factors contributing to delay in diagnosis and start of treatment in leprosy, focussing on patients' narratives of help-seeking behaviour. Our research took place in Purulia, West Bengal, India and in Nilphamari, northern Bangladesh. Between January and August 2000, we conducted semi-structured interviews with 104 patients that explored each individual's narrative of help-seeking behaviour and the context of beliefs and attitudes towards leprosy. Subsequently we surveyed 356 patients currently receiving treatment for leprosy and recorded specific aspects of each help-seeking action and their reports of local beliefs and attitudes towards leprosy. Delay was estimated from time of first symptoms through to start of effective treatment (mean 18 months, median 9 months in Purulia and mean 20 months, median 12 months in Nilphamari). The number of help-seeking actions ranged from 1 to 7. Time committed to first actions contributed 86% (Nilphamari) and 79% (Purulia) to total delay. The most important contributor to delay in the first action occurred when people simply monitored or ignored first symptoms, 80% in Nilphamari and 67% in Purulia. With delay longer than 12 months as outcome, logistic regression analyses identified age over 35 years, multiple visits to practitioners in traditional medicine and multiple visits to health service practitioners as predictive of delay. Attending a nearby clinic and exposure to health education materials were predictive of early presentation reduced delay.

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Introduction

Delay in diagnosis and start of treatment is defined as the time taken from first becoming aware of the symptoms of disease through to the start of effective treatment.[1] This includes periods of inaction when the affected person simply monitors or ignores symptoms, the time allocated to ineffective traditional or popular cures and the time taken by private or general health service practitioners to reach a correct diagnosis and start effective treatment. In leprosy, delay is a recognized risk factor for nerve function impairment.[2]

Every community exhibits a unique mix of cultural attitudes and knowledge that associate simple symptoms of disease with recognized help-seeking actions.[3,4] Since leprosy results in a great variety of symptoms and carries an implicit threat of stigmatization,[3,5] especially for women,[6,7] it also results in a great diversity of routes by which individuals eliminate preferred or alternative sources of help before they finally commit themselves to the health services, receive a correct diagnosis and start treatment.[8,9] Published research in Nepal found an association between delay and difficulty in accessing a distant clinic or choosing the anonymity of a distant clinic.[10]

The World Health Organization (WHO) recognizes the importance of early detection and effective treatment as the keys to breaking the chain of transmission and eliminating leprosy.[11] However, in contrast to the promotion of multi-drug therapy (MDT) as the effective treatment for leprosy, relatively little has been written about promoting early decisions to seek the appropriate treatment. Promoting effective help-seeking is dependent on an understanding of normal help-seeking behaviour. The primary objective of our research was therefore to develop an understanding of help-seeking behaviour and identify specific actions, knowledge or attitudes towards leprosy directly or indirectly associated with delay in the local context.

Materials and methods

Two areas with long established leprosy control programmes participated in this study, the leprosy control areas of Purulia, West Bengal, India and the Danish Bangladesh Leprosy Mission (DBLM) in Nilphamari, northern Bangladesh. The areas were selected because they share the same Bengali language but have different cultures: Nilphamari has a mix of Hindu and Muslim communities, while Purulia is predominantly Hindu. The two areas are some 500 km apart. Each includes both rural and urban populations.

There were 56 new cases during 2000/2001 in the town clinic and 684 in the leprosy hospital, many of whom travelled from neighbouring towns and districts. The rural control work covered the 320,000 population of 345 villages in the area around Jhalda, 45 km to the west of Purulia where 958 new cases were diagnosed in 2000/2001. Prevalence rates at the end of 2000/2001 were 2·21 in Nilphamari, 13·9 in Jhalda and 5·1 in Purulia.[12]. The project in Nilphamari has developed over 35 years and includes some 60 outpatient clinics serving three northern districts of Bangladesh. The area is largely rural but includes the larger centres of Saidpur and Rangpur. Population at the time of fieldwork was in excess of 6 million. There were 2293 new cases in 2000/2001. Government health services in the area include local hospitals and health centres with referral and specialist services in Rangpur. There are also private clinics.

In an initial round of fieldwork we used qualitative methods to collect information on local help-seeking behaviour and identify factors contributing to delay. We then used this

information to design a survey questionnaire to collect structured data to quantify risk factors for delay using logistic regression analysis.

For the qualitative fieldwork, the primary source was patients attending an outpatient clinic and currently receiving multi-drug therapy for leprosy. We used semi-structured interviews to explore each individual's narrative of help-seeking behaviour and asked questions about local attitudes and beliefs towards leprosy. Young children were included only if we could interview an accompanying adult. Excluded were patients not willing to give informed verbal consent and those newly diagnosed. We required all participants to have had at least one month to reflect on the leprosy diagnosis. In each centre, we trained local interviewers selected from project staff. We completed a total of 50 interviews in Nilphamari and 54 in Purulia. All the interviews were carried out in private rooms in outpatient clinics using the local Bengali language. For validation we interviewed local staff at senior and junior levels in each centre and worked with groups of in-patients. In both Nilphamari and Purulia a visiting post-graduate student provided supervision.

Applying the findings from the analysis of the interviews and group work, we designed and piloted a survey questionnaire that would allow us to describe help-seeking behaviour and local beliefs and attitudes associated with delay in diagnosis and start of treatment. The staff who had participated as interviewers in the earlier fieldwork administered the questionnaire survey, working under the supervision of senior project staff. Inclusion and exclusion criteria and arrangements for interviews were the same as those for the earlier round of fieldwork. For purposes of data collection and analysis we develop a system of coding to summarize eight aspects of each help-seeking action. We defined a single action as an individual's response to some change in symptoms or in awareness. Each action was then coded in terms of the reported symptom, the individual's assessment of symptom significance, the people involved in decision-making, the resulting action (or period of inaction), the resulting diagnosis (whether leprosy was suspected or diagnosed), the resulting referral or treatment, the time committed to each action and the cost incurred. We defined the time committed to each action as the period until a subsequent change in symptoms or awareness forced a further action. For each individual, the total time committed to successive help-seeking actions provided an estimate of delay. We planned to survey a total of 400 individuals, 200 in each centre, setting quotas by age and sex.

Data were entered onto computer using EPI-INFO procedures. We used STATA procedures to produce tabulations and for standard chi-squared tests. We tested differences in delay using the Kruskal–Wallis non-parametric test. For logistic regression analyses we defined a dependent variable as delay up to or in excess of 12 months as outcome, this threshold approximating to the median delay in each centre. In a series of analyses, we quantified risks associated with demographic variables, variables describing awareness or exposure to leprosy, variables describing attitudes and beliefs within the community and variables describing aspects of help-seeing behaviour. Univariate and multivariate analyses were used to assess the predictive value of individual variables within each group. Finally, stepwise logistic regression was used to identify a reduced predictive model, one in which all the variables contribute significantly to the regression.

Results

SURVEY COHORT AND DELAY IN DIAGNOSIS AND START OF TREATMENT

The total number of people surveyed was 356, 175 in Nilphamari and 181 in Purulia. Mean and median delays in Nilphamari were 19·9 months and 12 months, respectively and in Purulia 18 months and 9 months. This difference between centres did not reach statistical significance at the 5% level. Table 1 provides a demographic breakdown of the individuals surveyed in each centre and their mean and median delays. We note a tendency for longer delays among older people in Nilphamari ($P < 0{\cdot}05$) and among women in Purulia (P=0·055). In Nilphamari there were 111 multibacillary (MB) cases and 64 paucibacillary (PB) cases Delays were significantly longer among MB cases (23·9 and 16·8 months, $P < 0{\cdot}05$). 21 individuals with WHO grade 2 disability (12%) had a mean delay of 37·0 months. In Purulia there were 105 MB cases and 76 PB cases. We found no evidence of an association between diagnostic grouping or WHO grade and delay.

HELP-SEEKING ACTIONS, TRIGGERS TO PRESENTATION AND RELATED DELAY

In Nilphamari, the number of help-seeking actions totalled 455 and ranged from 2 to 7. In Purulia the total was 500 with a range from 1 to 7. In both centres there was the expected association between high numbers of actions and prolonged delay ($P < 0{\cdot}05$) (Table 2). The number of reported actions was higher among MB patients ($P < 0{\cdot}05$).

From Table 3, it is apparent that inaction in response to first symptom was by far the most important contributor to initial delay in both centres. Inaction accounted for 80% of time committed to first action in Nilphamari and 67% in Purulia. First actions accounted for 86% of overall delay in Nilphamari and 79% in Purulia.

We extended this analysis to examine all help-seeking actions. Active help-seeking accounted for 26% of total delay in Nilphamari, of which 10% was committed to popular medicine, 8% to health services and doctors and 6% to traditional or alternative medicine. 2% of total delay related to individuals who were not diagnosed or failed to comply with a referral after leprosy had been suspected by case-finding or contact survey teams. In Purulia, 33% of

Table 1. Overall delay and breakdown by age and sex

Age and sex grouping	No. patients	Delay
Nilphamari		
Women over 35 years	19 (11%)	Mean 35·5 months, median 18 months
Women up to 35years	35 (20%)	Mean 16·1 months, median 12 months
Men over 35 years	40 (23%)	Mean 24·2 months, median 12 months
Men over 35 years	81 (46%)	Mean 18·8 months, median 12 months
All individuals surveyed	175	Mean 19·9 months, median 12 months
Purulia		
Women aged over 35 years	20 (11%)	Mean 23 months, median 13 months
Women aged up to 35 years	29 (20%)	Mean 25 months, median 12 months
Men aged over 35 years	42 (23%)	Mean 18 months, median 12 months
Men aged up to 35 years	86 (46%)	Mean 15 months, median 6 months
All individuals surveyed	181	Mean 18 months, median 9 months

Note: four cases of unknown age.

Table 2. Number of actions and delay in presentation

Number of actions	1	2	3	4	5+
Nilphamari					
Number of individuals		107 (61%)	44 (25%)	16 (9%)	8 (5%)
Mean delay (months)		17·9	22·4	21·8	59·7
Median delay (months)		12	12	9·5	39
Purulia					
Number of individuals	5 (3%)	87 (48%)	57 (31%)	18 (10%)	14 (8%)
Mean delay (months)	0·2	14·9	19·5	20·0	40·2
Median delay (months)	0	6	10	12	23

Table 3. Time committed to first action in response to first symptom

First action type	First actions by each individual	Associated months delay (mean, median, range) and percent contribution to initial delay
Nilphamari		
Inaction	139 actions (80%)	Mean 19·1 months, median 12 months, range 1–48 months, 79·9% of initial delay
Found by survey	1 (<1%)	12 months delay to start of treatment
Used popular medicine	16 (9%)	Mean 16·8, median 6, range 1–120, 7·8% of initial delay
Presented to doctors or health services	9 (5%)	Mean 15·8, median 12, range 1–48, 5·6% of initial delay
Use traditional or alternative medicines	10 (6%)	Mean 13·2 months, median 5 months, range 1–60 months, 6·3% of initial delay
Purulia		
Inaction	115 (64%)	Mean 17·2, median 8, range <1–240, 66·8% of initial delay
Found by survey	9 (5%)	Mean 8·7, median 0, range 0–60, 2·6% of initial delay
Used popular medicine	31 (17%)	Mean 6·2, median 3, range 1–6, 9·4% of initial delay
Presented to doctors or health services	19 (10%)	Mean 12·1, median 1 month, <1–2, 10·8% of initial delay
Use traditional or alternative medicines	7 (4%)	Mean 25·1, 4, <1–132, 8·3% of initial delay

total delay was accumulated through time committed to popular medicine (9%), to health services or doctors (14%) or to traditional or alternative medicines (7%). The remaining delay arose when individuals were not diagnosed or failed to comply with referrals by case-finding or contact survey teams.

In a total of 40 visits to practitioners in traditional or alternative medicines there were no cases where leprosy was suspected or a referral made. In contrast, pharmacies and village doctors proved relatively effective at recognizing the possibility of leprosy and making referrals (nine in 41 visits in Nilphamari, six in 52 visits in Purulia).

Lay referral (referral by family or community members, self referral or referral by a person previously affected by leprosy) was by far the most common trigger to presentation (Nilphamari 82 (47%) and Purulia 97 (54%)). Referrals from doctors were 17 (10%) in Nilphamari and 26 (14%) in Purulia. Referrals from pharmacies and village doctors were

8 (5%) in Nilphamari and 3 (2%) in Purulia. In both locations, case-finding or contact surveys had been the trigger to presentation, 67 (38%) in Nilphamari and 55 (30%) in Purulia. However, while each of these triggers effectively ended the period of delay, none was found to be associated with reduced delay.

Three individuals in Nilphamari each reported early contacts with case-finding or contact survey teams that had not led to diagnosis or start of treatment. In two of these leprosy was not suspected and no referral made, in the other leprosy was suspected but the individual did not seek treatment. Two other individuals reported that they had been found by survey teams and had begun but then discontinued treatment. Fourteen individuals in Purulia reported similar contacts with survey teams. Three individuals reported a total of seven occasions when a survey team suspected leprosy but they did not seek treatment. Four other individuals presented to leprosy clinics but the diagnosis was not confirmed. In all other contacts with survey teams leprosy had not been suspected.

DEMOGRAPHIC VARIABLES AND THEIR ASSOCIATION WITH DELAY

Table 4 presents the results of univariate and multivariate logistic regression analyses assessing the association between demographic variables and delay. We found evidence that age over 35 years is associated with increased delay while attending the nearest clinic is associated with reduced delay. Living in a rural area approaches statistical significance as a further variable predicting reduced delay.

In a separate analysis of data from each centre, we found that Purulia had the higher proportion of individuals who were married or widowed (81·2% compared with 64·7%, $P < 0{\cdot}01$) and a higher rate for 6+ years education (40·9% compared with 22·3%, $P < 0{\cdot}001$), with related differences in literacy rates. The Nilphamari patients had a higher rate for rural residence (94·3% compared with Purulia 65·2%, $P < 0{\cdot}001$) but distances travelled to clinics were greater, reflecting the larger geographical control area. There was no difference in the choice of clinic, 94% overall choosing to attend the clinic closest to home. With these points in mind we repeated the logistic regression analysis for each centre independently. In both centres, age over 35 years was identified as the strongest risk factor for delay. In Purulia, literacy was associated with reduced delay and limited schooling with increased delay.

AWARENESS AND ATTITUDES TOWARDS LEPROSY AND THEIR ASSOCIATION WITH DELAY

Variables listed in Table 5 described beliefs, awareness and attitudes to leprosy in the community. Univariate and multivariate logistic regression analyses identified only one, exposure to educational leaflets, to be associated with reduced delay (odds ratio 0·55, $P < 0{\cdot}05$, 95% confidence interval 0·34–0·91). Informing friends or neighbours of the leprosy diagnosis approached statistical significance as a predictor of reduced delay.

Comparing these variables between centres, we found that in Nilphamari 82% individuals reported that neighbours were aware of their leprosy, while in Purulia the rate was 48%. The rates of reporting fear of physical and health consequences and of consequences for family, marriage and ability to work were all higher in Nilphamari. Logistic regression analyses of data from Nilphamari found belief in other causes of leprosy including food, water and bad hygiene to be associated with delay. We found that informing friends or neighbours of the leprosy diagnosis to be associated with reduced delay. Analysis of data from Purulia

Table 4. Demographic risk factors for delay in diagnosis and start of treatment in excess of 12 months

	Univariate analysis			Multivariate analysis			Stepwise multivariate analysis		
	Odds ratios	Probability levels	95% CI	Odds ratios	Probability levels	95% CI	Odds ratios	Probability levels	95% CI
Male sex	0·82	NS	0·51–1·30	0·77	NS	0·46–1·30			
Age 36+ years	1·77	$P < 0·05$	1·13–2·78	1·63	NS	0·96–2·76	1·79	$P < 0·05$	1·12–2·86
1–5 yrs education	1·06	NS	0·60–1·85	2·93	NS	0·77–11·08			
6+ years education	0·77	NS	0·47–1·27	2·12	NS	0·48–9·40			
Married or widowed	0·70	NS	0·42–1·16	0·98	NS	0·54–1·78			
Rural resident	0·68	NS	0·41–1·15	0·65	NS	0·35–1·21	0·59	$P < 0·10$	0·34–1·02
Literate	0·78	NS	0·51–1·20	0·39	NS	0·10–1·54			
Travel >5 km	0·84	NS	0·54–1·30	0·81	NS	0·47–1·42			
Attend nearest clinic	0·35	$P < 0·05$	0·14–0·87	0·23	$P < 0·01$	0·08–0·64	0·27	$P < 0·01$	0·10–0·70
Used public transport	1·19	NS	0·68–2·07	0·94	NS	0·48–1·84			
WHO grade 1				1·03	NS	0·53–1·98			
WHO grade 2				1·74	NS	0·80–3·79	1·93	$P < 0·10$	0·94–3·98
BL or LL leprosy				1·59	NS	0·88–2·88	1·82	$P < 0·05$	1·07–3·09
MB leprosy				1·43	NS	0·84–2·48			
				R^2=0·0645			R^2=0·0497		

Table 5. Awareness and contact with leprosy as risk factors for delay in diagnosis and start of treatment in excess of 12 months

Variables describing reported awareness of leprosy in the community	Variables describing reported attitudes to leprosy in the community
Confidence in cure	Fear of physical consequences
Seen leaflet	Fear for impact on general health
Seen TV	Fear for impact on marriage
Learned at school or in other way	Fear for impact on family
Belief that the cause was a spirit or ghost	Fear for impact on relationship with neighbours
Belief that the cause was judgement or God's will	Fear for impact on ability to work
Belief that leprosy was a result of food, water or hygiene	Told family members (i.e. not concealed from family members)
Belief that leprosy was inherited	Told friends or neighbours (i.e. not concealed from friends or neighbours in the community)
Not know cause	
Belief that leprosy was caused by a germ or by contact	
Family member affected	
Friend or community member affected	

identified seeing a leaflet and learning about leprosy from some other source, e.g. in school, to be associated with reduced delay. Informing neighbours of the leprosy diagnosis approached statistical significance as a risk factor for reduced delay. Having a family member already affected by leprosy was associated with increased delay. In this case it appears that awareness of the symptoms of the disease gave rise to caution rather than to an early start of treatment.

ASPECTS OF FIRST SYMPTOMS, HELP-SEEKING BEHAVIOUR AND DELAY

Variables summarizing response to first symptom and aspects of help-seeking behaviour proved to be the most effective predictors of delay (Table 6). We identified having a first symptom that was more than a single skin patch was associated with reduced delay. Repeated use of popular medicines or repeated use of traditional or alternative medicines was associated with delay as was making multiple visits to health service practitioners and failing to comply with referral from case-finding or contact survey teams who suspected leprosy. Separate analyses of data from the two centres showed the same combination of risk factors. In Purulia, initial inaction was also associated with delay.

BEST PREDICTIVE MODEL ARISING FROM ANALYSIS OF ALL VARIABLES

Table 7 presents the results of multivariate and stepwise analyses of all the assessed variables. The stepwise analysis identifies six primary risk factors for delay:

- Repeated periods of inaction – failure to recognize the significance of symptoms and take some action.
- Repeated contacts with health service practitioners.

Table 6. Aspects of help-seeking behaviour as risk factors for delay in diagnosis and start of treatment in excess of 12 months

	Univariate analysis			Multivariate analysis			Stepwise multivariate analysis		
	Odds ratios	Probability levels	95% CI	Odds ratios	Probability levels	95% CI	Odds ratios	Probability levels	95% CI
First symptom more than a single skin patch	0·93	NS	0·60–1·41	0·56	$P < 0·05$	0·33–0·95	0·60	$P < 0·05$	0·37–1·00
Assess first symptom as unimportant	0·95	NS	0·60–1·51	0·78	NS	0·32–1·86			
Involve others in decision-making	1·00	NS	0·65–1·53	1·23	NS	0·76–1·99			
No action in response to first symptoms	1·10	NS	0·69–1·78	1·75	NS	0·51–5·98	2·98	$P < 0·01$	1·52–5·86
No. periods of inaction	1·28	NS	0·88–1·87	1·66	NS	0·84–3·27			
Times used popular medicine	1·17	NS	0·78–1·76	1·78	$P < 0·05$	1·07–2·99	1·64	$P < 0·10$	0·99–2·70
Times used traditional medicine	2·43	$P < 0·01$	1·29–4·56	4·16	$P < 0·01$	1·83–9·47	3·72	$P < 0·01$	1·69–8·17
Times presented to general health services	1·67	$P < 0·01$	1·24–2·25	2·10	$P < 0·001$	1·43–3·09	2·10	$P < 0·001$	1·46–3·00
Times found by survey	2·58	$P < 0·05$	1·12–5·94	3·34	$P < 0·05$	1·27–8·78			
WHO Grade 1				1·03	$P < 0·10$	0·52–2·03			
WHO Grade 2				1·91	NS	0·83–4·40			
BL or LL leprosy				1·46	NS	0·79–2·73			
MB leprosy				1·42	NS	0·80–2·54	1·84	$P < 0·05$	1·10–3·06
				R^2=0·1129			R^2=0·0828		

Table 7. Results of multivariable and stepwise logistic regression on all available variables

	Multivariate analysis			Stepwise multivariate analysis		
	Odds ratios	Probability levels	95% CI	Odds ratios	Probability levels	95% CI
Age 36+ years	2·07	$P < 0·05$	1·11–3·87	2·03	$P < 0·01$	1·21–3·41
1–5 yrs education	3·90	$P < 0·10$	0·89–17·19			
Nearest clinic	0·18	$P < 0·01$	0·05–0·58	0·24	$P < 0·01$	0·87–0·67
Seen leaflet	0·57	NS	0·29–1·12	0·61	$P < 0·10$	0·35–1·08
Not know cause	1·52	NS	0·62–3·71	1·89	$P < 0·05$	1·10–3·24
Caused by spirit, curse etc.	0·27	$P < 0·10$	0·06–1·19	0·28	$P < 0·05$	0·08–0·97
Caused by food, water, poor hygiene	1·70	NS	0·62–4·68	2·13	$P < 0·10$	0·89–5·06
First symptom more than a single skin patch	0·53	$P < 0·05$	0·28–0·99	0·61	$P < 0·10$	0·36–1·03
No. periods of inaction	1·84	NS	0·85–4·00	2·53	$P < 0·001$	1·54–4·16
Times used popular medicine	1·88	$P < 0·05$	1·04–3·41	1·56	$P < 0·10$	0·95–2·57
Times used traditional medicine	6·04	$P < 0·001$	2·27–16·09	4·51	$P < 0·001$	1·97–10·34
Times presented to general health services	2·46	$P < 0·001$	1·56–3·86	2·05	$P < 0·001$	1·42–2·97
Times found by survey	4·13	$P < 0·05$	1·39–12·28	3·56	$P < 0·05$	1·32–9·66
BL or LL leprosy	1·67	NS	0·83–3·37	1·82	$P < 0·10$	0·98–3·33
	R^2=0·1980			R^2=0·1517		

Note: variables failing to reach statistical significance have been omitted.

- Repeated contacts with practitioners in traditional or alternative medicines.
- Failure to comply with referral by survey teams.
- Age more than 35 years.
- Not knowing the cause of leprosy

In addition to these, being affected by lepromatous (LL) or borderline lepromatous (BL) leprosy, repeated use of popular medicines and belief that leprosy was caused by water, food or hygiene each approached statistical significance as a risk factor for delay. Variables associated with reduced delay were as follows:

- Attending the clinic nearest to home.
- Belief that leprosy was caused by a curse, a spirit or a ghost.

Having a first symptom in the form of multiple skin patches or reaction, i.e. more than a single skin patch, and seeing an educational leaflet each approached statistical significance at predictors of reduced delay.

Discussion

As reported in Nigeria,[8] in Thailand[9] and in Sudan,[13] we heard of local beliefs that attributed leprosy to food or water or poor hygiene. There were also attributions to divine intervention, to supernatural causes and to inheritance. While the numbers concerned are small, our results contrast the effect of different traditional beliefs about the cause of leprosy. While belief in alternative natural causes (food, water or hygiene) and admission of ignorance of cause was associated with increased delay, belief in forms of supernatural cause (curse, spirit, or ghost) was associated with reduced delay. It may be that individuals living in rural areas where there is a tendency to shorter delays consider themselves to be in control of their food and water supplies and hygiene arrangements. Recognizing the possibility of leprosy, they perhaps take early decisions to seek help in order to gain control over a disease traditionally associated with supernatural causes. In contrast, those living in urban areas, where delays tend to be longer, appear more likely to reject beliefs relating to supernatural causes and attribute their disease to environmental factors relating to arrangements for drinking water, food supply and hygiene that are not entirely within their control. This analysis raises new questions for research that might inform future health education activities. Our finding may also reflect more effective case-finding and educational activities in rural areas.

Researchers in Sudan[13] found that lack of knowledge affects routes to diagnosis and start of treatment. Our research draws attention to extended periods of inaction as the primary contributor to delay. Failure to seek help or take advantage of the knowledge available meant that referral by friends, neighbours or other lay persons did not result in an early start to treatment. Our findings suggest that, at the time of our research, levels of knowledge and awareness in the community had not reached a sufficient level to ensure that people responded quickly to the early signs of leprosy by making appropriate decisions to seek help.

We identified routes to presentation involving popular, folk and professional health services similar to those reported from Nigeria.[8] We heard of no practitioners in traditional or alternative medicine suspecting leprosy or making a referral, but providers of popular medicines – pharmacists or village doctors – were relatively successful in suspecting leprosy

and making referrals. This draws attention to individuals and occupations within the community that might be a focus for dissemination of health education materials or with potential as a source of referrals.

The number of individuals reporting any contact with health services or private medical practitioners was 45 (25·7%) in Nilphamari and 37 (20·4%) in Purulia. Time committed to these contacts amounted to 12·3% of total delay, 21·1% in Purulia and 6·0% in Nilphamari. This compares with 15% reported from Ethiopia.[1]

While health service practitioners were relatively effective in recognizing the possibility of leprosy and making appropriate referrals, the logistic regression analysis found repeated contacts with health services to be associated with delay. A number of points need to be considered in interpreting this finding. First, some patients reported being prescribed tests and treatments that included X-rays, injections, vitamins and miscellaneous drugs, treatments that suggest that leprosy was not suspected. However, at least some of these may have been appropriate responses to concurrent infections or other conditions. Eliminating routine skin conditions in order to identify persistent lesions associated with leprosy is a legitimate approach to treatment. It would therefore be inappropriate to label all of these as occasions when doctors failed to diagnose leprosy. Second, some individuals claimed they did not know their doctor's diagnosis, while others admitted they had not complied with referrals. Third, we heard evidence that many individuals did not make good use of the health services, tending to move on from one doctor to another, either seeking a second opinion or an alternative, acceptable diagnosis. Fourth, it was apparent that the cost of consultations and prescribed treatments was a deterrent to seeking further help, especially so when initial treatment had proved ineffective and travel costs and lost earnings were taken into account.

It follows that repeated contacts with health service practitioners is a complex indicator reflecting a number of factors that may contribute to delay. Our findings echo those of Neylan from his work in Thailand,[9] who found that contacts with the health services and resulting treatments were started and discontinued in accordance with each patient's assessment of short-term gains and losses. The outcome of these contacts depended on decisions taken by the patient, on the knowledge of the medical practitioner and on the ability of the practitioner to respond in an appropriate way to their patient's interpretation of leprosy.

With integration of leprosy services into general health services, the results presented here provide a baseline to assess future progress towards achieving early detection and start of treatment for people affected by leprosy. Integration of leprosy services is expected to improve access to health services. Our finding that attendance at the nearest clinic is associated with reduced delay suggests that integrated services may prove effective in reducing delays. Much will depend on levels of awareness of leprosy, effective arrangements for referral and sensitivity to the impact of leprosy on those affected.

Conclusion

The objective of our research was to understand help-seeking behaviour and identify factors that contribute to delay. In the communities covered by our research we identified those at risk as individuals aged over 35 years and those continuing to rely on traditional or alternative treatments. To achieve early lay referrals will require more effective communication and increased awareness of the early signs of disease so that those affected are persuaded to take early and appropriate decisions to seek help. To avoid delays within the health service will

require adequate levels of awareness among practitioners and clear referral routes as well as increased sensitivity to the broad impact of leprosy so that people are persuaded to start treatment. Further research might explore circumstances and events that trigger decisions to seek help and identify interventions that promote early detection and start of treatment.

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