

Delay in presentation and start of treatment in leprosy: experience in an out-patient clinic in Nepal

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Summary Delayed presentation is a recognized risk factor for disability in leprosy but is the result of complex interactions between physical, social, economic and psychological factors. The present study is a response to the situation in an outpatient clinic in Nepal where the wide variation in delay in presentation was a cause for concern. A purpose-written questionnaire was used to collect information on 166 consecutive outpatient admissions. The data included demographics, the first symptom of leprosy, first actions, initial help-seeking behaviour, the reasons for finally seeking treatment and experience with professional health services. Initial analysis found a relationship between delay in presentation and age, rural environment, leprosy classification, walking time, housing not shared with another person affected by leprosy, and an inappropriate first action. The relationship with lack of education and total travel time just failed to reach significance. Further analysis identified that for the study population initial lack of awareness of leprosy and an inappropriate first action were the primary contributors to delay. Extensive and effective health education is needed to address this situation.

Introduction

In order to prevent disability amongst people affected by leprosy much emphasis is placed on encouraging early presentation and a prompt start of treatment. However, published statistics for 1998–1999¹ show a global grade 2 disability rate of 9% with wide variation between countries. Identifying the causes of local variation in delay in presentation remains a matter of concern. The present study was conceived as a response to such a situation in Nepal. The study describes the experience of consecutive new patients newly presenting at an outpatient clinic and seeks to identify the risk factors for delay in presentation.

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In their study in Ethiopia, Bekri *et al.*² identify wrong beliefs about leprosy, low awareness of modern treatment, stigma and the influence of traditional healers or community leaders as important factors associated with delay. Awofeso³ identifies a gap between the true number of people affected by leprosy and the number of cases actually registered. This is made up of people who may be aware of leprosy but delay in presenting, and those who are ignorant of leprosy. While knowledge is an important factor, there are social and cultural pressures that have an impact on decision making and contribute to delay. Even in situations where social pressures are minimal the individual's own perception of the risks involved in diagnosis are a further pressure on decision making. Scambler⁴ distinguished between enacted and felt stigma, the latter referring to fear of discrimination rather than to actual stigma. As a result of perceived stigma, people may adopt a first-choice strategy of non-disclosure and concealment. Scambler's conclusion, though expressed in the context of epilepsy, is very relevant in leprosy, namely that successful concealment resulting from felt stigma may prove more disruptive of people's lives than enacted stigma.

In their study in Tanzania, van der Broek *et al.*⁵ set out to assess the effectiveness of health education activities in changing knowledge, attitudes and behaviour towards leprosy. The authors found that while health education activities had some impact on the knowledge and attitude of school children there was no clear impact on knowledge and attitudes amongst the population at large. Croft and Croft⁶ found that health education programmes in northern Bangladesh had been effective in changing knowledge and attitudes towards leprosy and tuberculosis, though attitudes lagged behind knowledge. Similarly, Raju and Kopparty⁷ found that education programmes had been successful in increasing knowledge about leprosy but stigmatizing attitudes still remained.

It is clear that in describing the reasons for delay in presentation wide ranging medical, social, economic and psychological factors must be considered and their relative importance assessed. The present study seeks to identify the relationship between some such factors and delay in presentation in one location in Nepal.

Materials and methods

The study was carried out at the leprosy referral clinic of Anandaban Leprosy Hospital, which is held weekly in Patan City, Lalitpur, in the Central Region of Nepal. Patients are referred from hospitals within Kathmandu and elsewhere in Nepal. Some patients are referred from Government health posts, others by existing or former patients or family members, often travelling from remote parts of the country. During the period from October 1993 to March 1995, 166 consecutive newly registered patients were studied using a structured interview conducted in Nepali or with a translator if the patient was not Nepali-speaking. In the case of children an accompanying relative was interviewed.

The questionnaire was piloted in the clinic situation. In addition to demographic information, questions were asked about the patient's response to the first symptom of leprosy, their initial help-seeking behaviour, the reasons for finally seeking treatment and their experience with professional health services. Replies to standard questions were coded and entered into computer records for analysis using EPI-INFO and SPSS. A small amount of narrative information was also recorded.

Table 1. Study cohort profile

Sex	48 females (29%), 118 males (71%)
Age	Age range 6–72 years, mean 35.9 years, SD 15.6 years, median 35 years
Education	95 had no education (57%), 33 had 1–5 years schooling (20%), 28 had 6–10 years, 9 had more than 10 years (1 not known)
Occupation	84 farmers (51%), 18 housewives (11%), 11 factory workers (7%), 14 children of school age and 5 students. 9 occupations recorded as professional, clerical or teaching and 19 others included drivers, priests, beggars, fishermen, labourers, milkmen, wholesaler, cook, carpenter, postmen or tailor. Four individuals were retired (2 not known)
Home district, environment	Cases came from 32 of Nepal's 75 Districts. Seventeen (10%) cases were from India. Forty-seven (28%) came from a city or town and 118 (71%) from a rural environment (1 not known)
Distance travelled and cost	Total travel time to clinic: mean 13.4 h, SD 27.4 h, median 7 h Walking time: mean 6.2 h, SD 24.7 h, median 1 h Cost of travel: mean Rs 213, median Rs 60 but 37 cases reported expenditure of Rs 300 or more. For those working on a basic daily wage this represents the equivalent of several days' earnings

Results

The profile of the study cohort is summarized in Table 1. Details of leprosy classification, disability and overall delay to time of presentation are summarized in Table 2. The grade 2 disability rate of 42% reflects the concerns underlying the present study.

DESCRIPTION OF PRESENTATION AND DIAGNOSIS

Patients were asked about the first sign or symptom of leprosy. The most common signs were: patches (86), tingling (28), anaesthesia (28), ulcer (12) and swelling (7). The remaining five cases exhibited muscle weakness (foot drop), auricular nerve enlargement, dry skin, pain and fever.

Patients were asked what their first action was after discovering their first symptom. The largest group (42 cases, 25%) had done nothing until coming to the clinic, 36 (22%) had gone to visit the jankri or traditional faith healer, 35 (21%) had visited a private doctor, 15 (9%) had attended a hospital, 14 (8%) had attended their local health post, 13 (8%) had gone to a medicine shop and seven had used ointments from a variety of sources.

Patients were asked how long ago they first became aware of the possibility of leprosy. Eighty-three individuals (50%) said that they had only just realized the possibility, 55 (33%) said they did not know at the point of interview that they had leprosy, 28 (17%) had thought

Table 2. Leprosy classification, WHO Disability Grade, and Delay in Presentation

Classification	22 cases (13%) tuberculoid, 101 (61%) borderline (BT, BB and BL combined), 16 (10%) lepromatous. 5 (3%) indeterminate, 22 PN (13%)
WHO Disability Grade— (165 cases graded)	48 cases had grade I disability (29%), 48 (29%) had grade 2, 69 (42%) grade 3
Delay from first symptom to presentation for treatment	Range from within the past month to 35 years previously, mean 37.6 months, SD 58.9 months, median 18 months

they might have leprosy more than 6 months previously and of these only 7 (4%) thought they might have leprosy more than 4 years previously.

The most common reasons for not seeking treatment earlier was failure to recognize the possibility of leprosy (87 cases, 52%). Seventeen cases (10%) gave reasons relating to practical difficulties, the distance and actual or perceived cost of travel, a heavy workload or lost earning opportunity, seven cases (4%) did not know of the availability of treatment or of clinics, five cases (3%) reported reasons of fear and social consequences while five others spoke in terms of not having anyone to help them, suggesting at least a measure of isolation, 11 cases (7%) had attended health posts or bought drugs at local pharmacies and 26 (16%) were judged not to have delayed.

The most common single means of referral was by another person affected by leprosy (35 cases, 21%). Referrals by relatives, friends, neighbours or other individuals totalled 53 (32%), referrals from various health service providers totalled 66 (40%) and eight cases living locally referred themselves. Of 94 individuals reporting earlier contact with professional health services 38 said that a leprosy diagnosis had not been confirmed (40%).

Forty-two cases (25%) had family members affected by leprosy, 21 of which lived in the same house (two cases not recorded).

FACTORS ASSOCIATED WITH DELAY IN PRESENTATION

We assessed relationships between delay in presentation and the factors described above. We found the expected pattern of delay relating to leprosy classification with longer delays in lepromatous patients. There was a strong relationship between delay and the WHO Disability Grade, with 28% of cases delaying up to 2 years having grade 2 disability.

There was no association between sex and delay in presentation but there was a relationship between age and delay, younger people tending to present earlier. The association between delay in presentation and education was not statistically significant.

Where an individual shared a house with another person affected by leprosy, delay in seeking treatment was reduced compared to those who did not. The development of ulcers were the most commonly reported reason for final presentation. Only five individuals volunteered that social stigma delayed their presentation for treatment. Cases who took help from traditional healers or took no action at all had longer delays in presentation. Of 94 cases attending local health posts or local doctors, 38 (40%) had not had a leprosy diagnosis confirmed.

We found that living in a rural area was a significant indicator for delay. Walking time showed a very significant relationship with delayed presentation.

UNDERLYING RISK FACTORS

A number of variables (six) described above were found to be related to delay in presentation: age, delay to first action, urban/rural, walking time, classification and shared house. In order to ascertain their relative importance the six variables showing a statistically significant association together with educational level and travel time were subjected to a logistic regression. The results are presented in Table 3.

The multivariable regression provides an insight into the contribution of individual variables after adjusting for the effect of others. The two variables that are as statistically significant both relate to awareness of leprosy—a first action not directed towards

Table 3. Results of univariate and multivariate regression

	Single variable (univariate) regression analysis		Multivariate regression analysis	
	Exp(B)	Sig. Level	Exp(B)	Sig. Level
Age (± 35)	0.44	$P < 0.01$	0.65	NS
Education	2.12	$P = 0.057$	2.71	0.090
Rural/urban	0.47	$P < 0.05$	0.81	NS
Travel time	0.55	$P = 0.055$	0.58	NS
Walking time	0.43	$P < 0.05$	0.82	NS
Classification	0.39	$P < 0.05$	0.45	NS
Shared house	3.25	$P < 0.05$	4.23	$P < 0.05$
First action	0.43	$P < 0.05$	0.33	$P < 0.05$

professional health service providers and not sharing a house with another person affected by leprosy.

Discussion

Where individuals recognize increasing signs of disease, continuing delay in presentation is the result of an on-going process in which physical impact is only one of several factors affecting decision-making. Each change is assessed in the context of changes in knowledge and awareness of leprosy and the perceived or actual social or economic costs involved in being diagnosed and treated. Only when these processes are understood can we achieve earlier presentation and a reduced disability rate.

It is apparent that progress across these three continua of development of physical disease, increased awareness and a series of actions will be highly individualistic. For some individuals the learning process may be slow, for others there may be partial prior knowledge. The beliefs and attitudes of the wider community provide the context for assessing the risks involved in being diagnosed and recognized as a person affected by leprosy. There can therefore be no simple ordering of events or imposition of a standard time frame. Van de Weg *et al.*⁸ in their study of explanatory models and help-seeking behaviour in Nigeria found that differences in understandings of sickness and treatments resulted in widely varying choices and outcomes.

In conclusion, 50% of the study cohort delayed presentation for more than 18 months from time of first symptom (mean 37.6 months). For the cases included in the present study the most significant single factor causing delay in presentation and start of conventional treatment was ignorance of the disease. Amongst those who went to professional health services 40% did not receive a definite leprosy diagnosis. Fear of social consequences was not identified as a primary factor in delay though there is anecdotal evidence to suggest that some individuals were successful in concealing the disease from close relatives.

The present study has explored the relationship between selected clinical, knowledge, social and health service factors and delayed presentation. Future studies may address these factors in greater detail, using qualitative as well as quantitative methods and exploring knowledge, attitudes and practice in the community at large and amongst health service

professionals as well as amongst those directly affected by leprosy. Where groups are found with high levels of disability the concern must be to build an understanding of the full range of contributing factors and to address these through improved targeting and more effective programme activities.

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