

## Help-Seeking habits of untreated leprosy patients reporting to a referral hospital in Uttar Pradesh, India

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In a potentially disabling disease like leprosy, the need for prompt diagnosis and start of treatment cannot be over-emphasized. With the advent of massive Information, Education and Communication (IEC) strategies and easy accessibility of free multi drug therapy (MDT), delay in treatment is more dependent on patient initiative and subsequent health seeking habits. To study the factors contributing to delay, a random sample of 86 new untreated leprosy patients presenting to The Leprosy Mission Community Hospital, Naini, Allahabad during 2011 were interviewed in depth with the help of a check list. 61% of patients had disability at first presentation. The most common first symptom was a hypopigmented patch. Mean delay was found to be 25.9 months. Reasons for delay varied from ignorance about the symptoms and signs of the disease, monitoring of symptoms in the hope that they would disappear by themselves and lack of vigilance among local medical practitioners in the lower levels of the health system. The authors discuss the typical sequence of events that contributed to delay at each stage before finally presenting at a referral hospital. It is necessary to outline recommendations to address delay in terms of intense health education campaigns, mass communication strategies and developing a high index of suspicion among primary health care givers.

**Key words :** Help-seeking habit, Leprosy

### Introduction

Help-seeking habits play a critical role in early diagnosis and effective treatment for many diseases (Paananen et al 2011, Smith et al 2005, Cheung 1987). The factors determining the health behaviour are complex and multifaceted; it includes physical, socio-economic, cultural and political aspects (Arnault 2009, Karasz and Dempsey 2008, Harju et al 2006, de Nooijer et al 2003). The utilization of a health care system depends on socio-demographic factors, social

structures, level of education, cultural beliefs and practices, gender discrimination, status of women, economic and political systems, environmental conditions, disease pattern and health care system itself (Shaikh and Hatcher 2005). Misdiagnosis and ineffective treatment results in more severe and disabling forms of disease. In the case of leprosy, such behaviour leads to progression of the disease, irreversible disabilities and further compounds the transmission of infection in the community (van Brakel et al 2004, Nicholls et al 2003a).

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Several published articles have documented the delay in seeking treatment of leprosy, and the possible reasons for such delay (Nicholls et al 2003b, Zhang et al 2009) and this scenario has not changed in recent times, in this era of elimination. It is more than 5 years since Leprosy was eliminated as a public health problem in India and nearly a decade of integration of leprosy services into the general health system in many parts of India (Joshi et al 2007). Referral hospitals such as those run by the Leprosy Mission, have seen increasing number of untreated leprosy patients reporting late (TLM Annual Report 2009). If this trend continues, the hopes of eradication of leprosy will gradually fade, and further, leprosy will tend to increase and become endemic with ensuing consequences.

In the light of massive health education and IEC campaigns, recent studies show that knowledge and attitudes to leprosy are far from effective (Barkataki et al 2006). It is therefore most urgent to address the issues of delay, and describe the usual help-seeking habits, and mount a massive health education programme. In this paper, we present a brief report on a project done in 2010 on the health seeking habits of the newly diagnosed, untreated leprosy patients attending a referral hospital in Naini, Allahabad district in Uttar Pradesh, India.

### **Materials and Methods**

The research used an epidemiological, descriptive cross-sectional study design, using a specially developed and tested Interview guide and checklist.

Representative random samples of newly diagnosed, untreated leprosy patients reporting to the outpatient department of the The Leprosy Mission Hospital, Naini, Allahabad were interviewed by the authors using an interview checklist from September to December 2010. Apart from the socio-demographic details extracted from the hospital charts, each patient

was interviewed after obtaining consent and a rapport built to explain the purposes of the interview and seeking reliable information. Each interview lasted for about 20 minutes and ascertained details on the first symptom, first action taken, the sequence of events that lead to effective therapy and finally their motivation to come to this hospital. Most of the questions were repeated in different ways and verified with family members to obtain an accurate record of their help-seeking habits. Relevant data were transferred to SPSS data entry format and analysed for various descriptive statistics, and the associations tested by chi-square test or ANOVA.

### **Results**

#### **Demographic details, Type of Leprosy and Disability Grade**

A total of 86 newly diagnosed leprosy patients were interviewed; 69 (80.2%) were men, and 12 (14%) were below 15 years of age. Seventy (81.4%) were from the state of Uttar Pradesh, while 16 (18.6%) were from other states (Madhya Pradesh and Bihar). Most of the patients interviewed, 37 (43%) were illiterate, 19 (22.1%) had primary school education, 26 (30.2%) completed high school and only 4 (4.7%) had attended graduate school. Fifty seven patients (66.3%) were manual or unskilled labourers, 11 (12.8%) were skilled workers, 15 (17.4%) were students and 3 (3.5%) were unemployed at the time of interview. Of the 86 patients, 62 (72.1%) were multibacillary (MB) type and 24 (27.9%) were paucibacillary (PB) type. Among the MB patients, 25 (40.3%) were smear positive; 11 (17.7%) upto 2+, 5 (8.1%) were 3 to 4+ and 9 (14%) were more than 4+. More than half of the patients interviewed (60.4%) presented with disability. Thirty four (39.5%) had WHO Grade 1 and 18 (20.9%) had Grade 2 disability. Twenty (23.3%) gave history of household contact with a HD patient.

### Help-seeking habits and Treatment Delay

In table 1, the first symptom as mentioned by the patients is presented.

More than half first perceived an anaesthetic or hypoesthetic patch. Action taken by the patient on noticing the first symptom is given in table 2.

The treatment delay *i.e.* time taken from the first symptom to the start of effective therapy is shown in table 3. The treatment delay ranged from 1 week to more than 15 years. The mean delay was 25.9 months. 39 (45.3%) delayed by more than 1 year. In about 5%, the delay was more than 10 years.

There is no association of delay with sex, education or occupation of the patient, whereas age shows some correlation. Longer delay was seen in older patients. Occupation of the patient shows some association with delay. Skilled

workers and Students tend to present early. No correlation is seen between the type and bacillary index of Leprosy.

The reasons for this delay are displayed in table 4.

More than half (59.3%) of those interviewed cited "Ignorance", which includes delaying seeking help due to painless, non-severe nature of symptom, and assumption that it would resolve itself and a wait and watch policy. Eleven (12.8%) were delayed due to utilization of "Alternative therapy" *i.e.* Homeopathy, Naturopathy (neem and mineral oils were frequently used) and Ayurvedic medication. Socio-economic reasons were cited by 5 (5.8%), this included financial, time and transportation constraints. Eighteen (20.9%) were misguided by the Health service provider (local PHC doctor, private practitioners) in seeking therapy.

**Table 1 : First Symptom**

Symptom	No	Percent
Tingling	18	20.9
Patch	46	53.5
Ulcer	5	5.9
Sensory loss	7	8.1
Deformity	3	3.5
Reaction	7	8.1
Total	86	100.0

**Table 3 : Treatment Delay**

Delay	No	Percent	Cumulative Percent
< 1 year	47	54.7	54.7
1–5 years	29	33.7	88.4
6–10 years	5	5.8	94.2
11–15 years	2	2.3	96.5
>15 years	3	3.5	100.0
Total	86	100.0	

**Table 2 : Action taken based on first symptom**

Action Taken	No	Percent
None	54	62.8
Self medication	3	3.5
Traditional therapies	7	8.1
Government services	8	9.3
Private practitioner	13	15.1
TLM Naini	1	1.2
Total	86	100.0

About 60% did nothing on taking note of the first symptom.

**Table 4 : Reasons for Delay**

Reasons of Delay	No	Percent
Ignorance	51	59.3
Alternative therapy	11	12.8
Socio-economic	5	5.8
Health service delay	18	20.9
No delay	1	1.2
Total	86	100.0

**Table 5 : First Symptom vs Delay**

Symptom	Delay					Total
	<1yr	1-5yrs	6-10yrs	11-15yrs	>15 yrs	
Tingling	7	8	1		2	18
Patch	25	17	3	1		46
Ulcer	3	1	1			5
Anaesthesia	4	2			1	7
Deformity	1	1		1		3
Reaction	7					7
Total	47	29	5	2	3	86

**Table 6 : Reason vs. Delay**

Reason	Delay					Total
	<1yr	1-5yrs	6-10yrs	11-15yrs	>15 yrs	
Ignorance	28	14	2	2	2	48
Alternative	4	8	0	0	1	13
Socio-economic	3	3	1	0	0	7
Health service	12	4	2	0	0	18
Total	47	29	5	2	3	86

**Table 7 : First Action vs. Delay**

Action	Delay					Total
	<1yr	1-5yrs	6-10yrs	11-15yrs	>15 yrs	
None	33	19	0	1	2	55
Self medication	1	2	0	0	0	3
Alternative Rx	3	2	1	1	0	7
Government Services	4	1	2	0	1	8
Private Practitioner	6	5	2	0	0	13
Total	47	30	5	2	3	86

Table 5 shows the association between delay and the first symptom perceived by the patient. They tend to present earlier if the first symptom was an ulcer or anaesthesia. All 7 patients who presented with Leprosy reaction came early for therapy. Patients presenting with "tingling" largely ignored the symptom.

The association between treatment delay and

the reason for not seeking treatment is shown in table 6.

Patients seem to present earlier if they ignored their first symptom (28/48, 58.3%) or if they did not take any action following awareness of the first symptom (33/47, 70.2%). Table 7 shows the association between first action taken and the treatment delay.

## **Discussion**

In a study on health-seeking behaviour in two cultural groups for ambiguous symptoms, Karasz and Dempsey (2008) conclude that the relationship between conceptual models of cause and cure depends on the 'match' of both to broader, unarticulated cultural models of health and disease. Harju et al (2006) report that both implicit and explicit attitudes play a key role in deciding when and where to seek medical care. Leprosy continues to be associated with significant stigma among communities translating into delay in seeking appropriate treatment and adversely affecting their care seeking habits (Nicholls et al 2003a). Knowledge and attitudes relating to leprosy continue to be deficient even in the light of health education and IEC campaigns. (Barkataki et al 2006).

Typically in our study, we have seen that most patients ignore early leprosy symptoms due to their painless, quiescent nature and seek help only with the onset of visible or bothersome complaints. As the majority of our study population was from rural districts of UP, Bihar and Madhya Pradesh, adopting native/traditional forms of therapy was a common first action. Application of neem leaf oils, bandages, mineral oils and other modes of home remedies and alternative medicine (homoeopathy, ayurveda) were implemented. It is interesting to note that 53.5% reported a patch as the first symptom. Other study populations have noticed tingling sensation/numbness preceding the patch and this may be regarded as an early symptom of Leprosy (Zhang et al 2009). First contact with the health service was usually a local medical professional (quacks, PHC medical officers, private GP/dermatologist). An alarming finding was the considerable number of misdiagnoses/delays in suspecting leprosy among the local

medical practitioners that proved to be a determining factor in keeping the patient from start of effective treatment and hence preventing disability. We saw that patients have been referred to our hospital by their local doctors only on developing ulcers or visible physical deformities. Finally, a considerable portion of the study population presented at our referral hospital only when advised by neighbours/relatives, a fact which emphasizes the role of word-of-mouth as a means of mass communication.

It is important to note that Bacillary index and disability grade at presentation are objective indicators of delay (van Brakel et al 2004). Data suggests that delay longer than 6 months is detrimental to the clinical outcome (Nicholls et al 2003b, WHO 1998). Percentage of disability was 61% in our study, of which 20.9% was grade 2 as compared to the national rate of grade 2 disability which is 3.08 (WHO 2010). This could be due to the knowledge that reconstructive services are available at our centre.

The mean delay in this study was 25.9 months, median was 12 months. This is longer when compared to other studies – 13 months in a tertiary hospital in South India, 18 months in Purulia, West Bengal, 20 months in Nilphamari, Bangladesh (Renita et al 2010, Nicholls et al 2003a).

The reasons for this delay as found in this study can be categorised under medical (painless and insidious initial symptoms), cognitive (ignorance, lack of awareness, inadequate knowledge about treatment availability, lack of motivation), socio economic (work constraints, reluctance to lose daily wages due to hospital visits, gender bias in health seeking), psychological (stigma and denial) and also time spent in pursuit of ineffective forms of treatment or doctor shopping. Worth high-

lighting is that local medical practitioners as found in this study tend to maintain a low index of suspicion for leprosy even in endemic regions.

Addressing this delay in diagnosis and transmission is essential if leprosy has to be eradicated. Although knowledge about leprosy has increased as a response to IEC strategies, it is evident that there is still scope for improvement in attitudes and actions. There is a need for educational interventions to highlight the disabling and hence further stigmatising sequelae of untreated leprosy. Mass media tools need to be adequately utilised. Better training of personnel at grassroot levels of the health system to maintain a high index of suspicion is recommended. The potential role of Anganwadi workers and ASHAs for diagnosis of leprosy among women which may otherwise go unreported or unnoticed because of their low social status and limited mobility is noteworthy.

The break in the chain of infection and transmission of this terrible disease and its ultimate eradication is possible only with targeted efforts to reduce delay in its diagnosis and treatment.

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