

## Patient Delay in Leprosy Treatment in Jhapa District Nepal

*Choulagai BP<sup>a</sup>, Onta SR<sup>b</sup> and Bhattarai PC<sup>c</sup>*

### ABSTRACT

**Introduction** Leprosy remains a public health problem in Nepal with prevalence rate of 3.04 per 10,000 population. Jhapa district has the highest case detection rate of 8.27 per 10,000 as compared to other districts of Nepal. For achieving the elimination of leprosy and reducing the impact on society, early case detection is of utmost priority. Understanding the magnitude of patient delay and factors associated with such delay can provide evidence for making policies and designing programmes aimed at reducing delay.

**Objectives** The objectives of the study were to measure magnitude of patient delay in leprosy treatment and to establish a link of the delay with other variables so that appropriate intervention measures could be taken.

**Methods** The design of the study was cross-sectional, a field survey with a detailed questionnaire for 78 patients and in-depth interview with 7 patients. Structured questionnaire and guidelines were used to obtain quantitative data and for in-depth interviews.

**Results** After adjusting with education, knowledge, perception and type of contact, patient delay in leprosy treatment was found significantly associated with travel time to the diagnostic facilities ( $p=0.03$ ). The information obtained through questionnaire interview and in-depth interview reveal that patients perceive the disease as curable through medication. Findings suggest that there is still an appreciable level of stigma attached to the disease thus hindering the prompt treatment seeking and social integration.

**Conclusion** Majority of patients are delayed by more than 180 days for seeking care of leprosy. The factors playing significant role in making delayed health seeking are knowledge, accessibility to diagnostic health facility, level of education and perception of patients towards the symptoms of the disease.

**Key words** Leprosy, Patient delay, Stigma, Nepal.

### Introduction

Leprosy is a public health problem owing to a permanent disability it causes as well as its social consequences such as discrimination and stigma. Misconceptions and myths about the disease and the stigma that goes with it not only cause untold misery to the patient but to his/her family as well.

Leprosy may present with a variety of skin lesions and nerve damage that is only apparent on careful examination. For patients it is important that the diagnosis of leprosy should be made as early as possible so that effective antibacterial treatment can be started and steps taken to prevent nerve damage.

In 1985, leprosy was endemic in 122 countries. Among them,

108 countries have now reached the goal of elimination at the country level. Today, 90 percent of cases are found in India, Brazil, Nepal, Madagascar, Mozambique and Myanmar (in order of importance)<sup>2</sup>.

Leprosy has existed in Nepal since time immemorial and was recognized as a public health problem as early as 1950. Khokana Leprosarium near Kathmandu was established in 1857 AD and Malunga Leprosarium, Syanja was established in 1939 AD to provide services to the leprosy patients<sup>1</sup>.

Leprosy remains a public health problem in Nepal. The prevalence rate (PR) of leprosy in Nepal is 3.04 per 10,000. There are four districts in Nepal where the PR is over 5/10000 and Jhapa is one of them (7.23/10000)<sup>1</sup>. Likewise the

**Corresponding Author:** Bishnu P Chaulagai, **Email:** bishnuc@gmail.com <sup>a</sup>Research Coordinator; Kathmandu Abortion Morbidity Hospital Study, Kupondole, Lalitpur, Nepal, **Ph:** 00977 1 5552637, <sup>b</sup>Institute of Medicine, Tribhuvan University, Kathmandu Nepal, <sup>c</sup>Nepal Institute of Health Sciences, Purbanchal University, Kathmandu, Nepal.

disability grade II rate of Nepal is 3.95 percent, and that of Eastern Region is 5.65 percent<sup>3</sup>. The high disability grade II statistics implies that there is longer delay between onset of symptoms and start of therapy. At the start of 2004, Nepal has 7549 registered cases of leprosy that is only third to India and Brazil<sup>4</sup>.

For achieving the elimination of leprosy and reducing the impact on society, early case detection is of utmost priority. Little is known about the prevalence of delay in seeking care among leprosy patients in Nepal. Understanding the magnitude of delay and its contextual factors associated with such delay can provide evidence for making policies and programmes aimed at reducing delay by guiding where it really needs to focus in designing such programmes. Such programmes help to increase early case detection, which will be of vital importance to achieving the WHO target of leprosy elimination from Nepal. It also helps to reduce the high rate of disability grade II – which is a consequence of delayed treatment – in leprosy.

The objectives of the study were to measure the magnitude of patient delay in leprosy treatment and to describe the factors associated with longer patient delay.

## Methods

The study was cross-sectional and descriptive. The study used quantitative methods supported by some qualitative data.

### Study setting and population

The study was conducted in Jhapa district where there is highest new case detection rate (8.27 per 10000) of leprosy as compared to other districts of Nepal and disability grade II 5.65 percent<sup>3</sup>. The choice of Village Development Committees (VDCs) was made based on leprosy prevalence data from the District Public Health Office (DPHO). All the leprosy patients receiving service from Gauradah HP, Rajgadh HP, and Damak Sub Health Post (SHP) were taken as study subjects.

### Sampling

There were 93 cases of leprosy found registered in the three health institutions during the study period. Out of this, only 78 cases were included in this study. Among the others, eight patients were included in pre-testing of the tools, three were excluded because of their age below 15 years, one unwilling to participate, and three patients could not be traced.

### Data collection and analysis

Before interviewing the patients, number of eligible study subjects by each treatment centres was recorded by consulting DPHO Jhapa and reviewing the leprosy registers at the health institutions. In coordination with the respective health institution, the eligible patients were traced to their residence for interview. Research assistants having the qualification of Community Medicine Auxiliary (CMA) were oriented and employed for data collection. Information like name of health institution, patients' registration number, last name of patient, date of diagnosis and type of leprosy were recorded from leprosy registers.

Patient delay was estimated from the date of onset of symptoms until the patients first see health care providers. For this, some fundamental symptoms namely hypo pigmented patches with definite loss of sensation, and weakness of muscles of hands, feet and face were considered.

For the collection of qualitative data researcher himself was involved in in-depth interview.

The data were entered in the database created in SPSS 11.5 for Windows. Summary output tables of percentage distributions and median were produced. In univariate analysis, chi square test was done for comparing the categorical variables. Logistic regression analysis model was used to obtain estimated odds ratios (EOR) with 95 percent confidence intervals (95% CI).

Information collected through in-depth interview was also incorporated in the quantitative findings.

## Results

A total of 78 patients were interviewed. Table 1 shows some of the general characteristics of the respondents.

**Table 1:** General characteristics of study population

| Characteristics     |                            | Frequency | Percent |
|---------------------|----------------------------|-----------|---------|
| Age (years)         | 15-24                      | 35        | 44.9    |
|                     | 25-34                      | 10        | 12.8    |
|                     | 35-44                      | 12        | 15.4    |
|                     | 45 and above               | 21        | 26.9    |
| Gender              | Male                       | 50        | 64.1    |
|                     | Female                     | 28        | 35.9    |
| Ethnicity           | Brahmin, Chhetri           | 25        | 32      |
|                     | Rai, Limbu, Gurung, Magar  |           |         |
|                     | Tamang                     | 13        | 16.7    |
|                     | Damai, Karki, Sarki, Majhi | 6         | 7.7     |
|                     | Terai Castes               | 28        | 35.9    |
| Marital status      | Muslim                     | 6         | 7.7     |
|                     | Unmarried                  | 35        | 44.9    |
|                     | Married                    | 42        | 53.8    |
| Education           | Widow                      | 1         | 1.3     |
|                     | Illiterate                 | 28        | 35.9    |
|                     | Literate, primary          | 22        | 28.2    |
|                     | Lower secondary, secondary | 21        | 26.9    |
| Permanent residence | Higher secondary and above | 7         | 9       |
|                     | Local                      | 69        | 88.5    |
| Type of leprosy     | Non-local                  | 9         | 11.5    |
|                     | Multi bacillary            | 47        | 60.3    |
|                     | Pauci bacillary            | 31        | 39.7    |

### Recognition of onset of symptoms

The date of onset of symptoms was estimated from ensuring the recognition of at least one of the two symptoms namely hypo-pigmented patches with loss of sensation and weakness of the muscles of hands, feet or face. Almost four

in every five cases (78.2%) had first recognized the symptom of leprosy as hypo-pigmented patches with loss of sensation. Rest had noticed the first symptom as the weakness of muscles of hands, feet or face (Table 2).

**Table 2:** Recognition of onset of symptoms

| Symptoms                                      | Frequency | Percent |
|---|-----------|---------|
| Hypo pigmented patches with loss of sensation | 61        | 78.2    |
| Muscle weakness of hands feet or face         | 17        | 21.8    |
| Total   | 78        | 100     |

### Patient delay

From the understanding of other researches and consultation with experts of related field, and considering the contextual socio-economic status and health care delivery mechanism in the country, a period of 180 days was chosen as maximum 'acceptable delay', and defined as a cut-off point for longer patient delay. The patient delay comprises of the delays made by the traditional healers from where the proper diagnosis of leprosy cases could not happen.

Patient delay is described in relation to general characteristics of study population, knowledge about symptoms and disease, knowledge of availability of diagnostic facility, perception towards the disease, stigma,

type of first contact made for treatment seeking, accessibility to diagnostic facility etc.

It was found that 53.8 percent of the leprosy cases were delayed by more than 180 days for seeking the care of symptoms they recognized, and thus accessing the appropriate health care facilities where the proper diagnosis could have been made or proceed for the diagnosis (Table 3).

Exactly half of the male patients were found consulting any formal health care providers no later than 180 days whereas for females almost three out of five patients were found to be delayed by 180 days or more.

However, the difference was not statistically significant ( $\chi_{df}^2 = 0.829$ ).

**Table 3:** Patient delay in relation to Gender

| Gender | Patient delay |              |
|--------|---------------|--------------|
|        | Lesser delay  | Longer delay |
| Male   | 25 (50%)      | 25 (50%)     |
| Female | 11 (39.3%)    | 17 (60.7%)   |
| Total  | 36 (46.2%)    | 42 (53.8%)   |

**Patient delay by type of first contact made for treatment seeking**

Patients were asked to recall their history of visiting with different health care providers (public, private or traditional healers) from the very first time until the final diagnosis made as a leprosy case (Table 4). Majority of the leprosy patients (71.8%) were found consulting to public sector for the first time in seeking care of their illness while others consulted to private clinics, private pharmacies, traditional healers, and Ayurvedic care.

**Table 4:** Type of first contact health care provider

| Types of first contact | Patient delay |              |
|------------------------|---------------|--------------|
|                        | Lesser delay  | Longer delay |
| Public sector          | 28 (50%)      | 28 (50%)     |
| Private and others     | 8 (36.4%)     | 14 (63.6%)   |

**Patient delay by accessibility to diagnostic facility**

Patient’s accessibility to diagnostic facility was assessed in terms of time-distance to the facility where they were diagnosed as leprosy case, from their current residence. Accessibility was also measured in kilometres and mode of transportation to the diagnostic facilities (Table 5).

It was found that 44.9 percent of the patients interviewed used bicycle as the means of transportation while visiting

**Table 6:** Predictors of longer patient delay by attributes of patients based on logistic regression model

| Predictors            | P value | Estimated odds ratio (95% CI)                 |
|-----------------------|---------|---|
| Education             | 0.04    | Illiterate and up to primary level<br>1       |
|                       |         | Lower secondary and above<br>0.32 (0.10-0.98) |
| Time distance         | 0.03    | d”20 minutes<br>1                             |
|                       |         | More than 20 minutes<br>3.45 (1.13-10.53)     |
| Perception            | 0.03    | Good<br>1                                     |
|                       |         | Average<br>7.09 (1.10-45.49)                  |
|                       |         | Wrong/poor<br>9.32 (1.22-70.91)               |
| Knowledge             | 0.09    | Good<br>1                                     |
|                       |         | Average<br>3.23 (0.83-12.57)                  |
|                       |         | Poor<br>3.54 (0.69-18.14)                     |
| Type of first contact | 0.38    | Public sector<br>1                            |
|                       |         | Private/other sectors<br>1.70 (0.52-5.51)     |

diagnostic centre followed by on foot 35.9 percent, by bus 16.6 percent and by rikshaw 2.6 percent.

Majority of the patients (53.8%) had traveled between one to five km to reach the diagnostic facility while around one-third (26.9%) had traveled more than 5 km, and around one-fifth (19.3%) had traveled one km or less to reach the diagnostic facility.

In terms of time-distance, two in every five patients (41%) accessed diagnostic centre within 20 minutes whereas the rest (59%) had to travel for more than 20 minutes to reach the diagnostic centre.

**Table 5:** Distance to diagnostic centre (in km and min)

| Distance to diagnostic Centre (one way) | Frequency | Percent    |
|---|-----------|------------|
| In Km                                   | 1         | 15<br>19.2 |
|   | 1 - 5     | 42<br>53.8 |
|   | e”5       | 21<br>26.9 |
| In minutes                              | d”20      | 32<br>41.0 |
|   | >20       | 46<br>59.0 |

**Results of logistic regression analysis**

Logistic regression analysis model was used to obtain adjusted odds ratios with 95 percent confidence intervals (95% CI). The analyses were performed to find the adjusted odds ratios for longer patient delay with variables educational status, time-distance to diagnostic facility, perception, knowledge level and type of first contact health care provider. Adjusted odds ratio showed that patients with wrong perception are at significant risk of delayed health seeking (Table 4). Likewise, a distance of more than 20 minutes to diagnostic health facility increased the risk of patient delay by 3.45 times (p = 0.030) as compared to less than or equal to 20 minutes time-distance to the facility. Educational status was also found to be significantly associated with patient delay as shown in table 6.

## Discussion

There are few studies conducted on patient delay in developing countries. Studies<sup>5-7</sup> reveal that longer delays in getting appropriate care of leprosy may lead to adverse effects to patients, their families, society and the leprosy control programme, an understanding of what proportion of symptomatic leprosy patient delay seeking care and the reason for doing so may prove crucial to controlling leprosy.

Among 78 leprosy patients interviewed almost three in every four cases belonged to economically productive age group of 15-44 years. The age group 15-24 years comprised 44.9 percent of the total respondents.

Patient delay was estimated from the date of onset of symptoms until the patients first see the health care providers. The present study revealed that majority (78.2%) of the respondents recognized hypo pigmented patch with loss of sensation as the onset of leprosy. Others recognized muscle weakness as the first symptom of the disease. It is easier to notice the patch in the body. They are easily visible in brown/dark skinned people. Particularly in hot climate area, people do not cover all body parts by the clothes, such patients are noticed earlier. Therefore, it is natural that many people recognized this as first symptom of the disease.

This study found that more than half of the patients (53.8%) were seeking care in Jhapa district only after 180 days of the onset of symptoms. Regarding gender-wise patient delay 50 percent of the males were having longer patient delay; the statistic is higher in females – 60.7 percent Further exploration in this regard may be needed.

In this study, wrong/poor and average perception towards the disease was found significantly associated with delayed care seeking in leprosy. All the times and in most of the societies, stigma has been found as a reason for people with leprosy to keep their disease secret and thus leading to delayed treatment seeking. More than half (55.1%) of the respondents were found less stigmatized whereas the percentage of highly stigmatized patients was 5.1 percent. Although findings of quantitative information do not show significant association of stigma to patient delay the information from in-depth interview reveal that an appreciable level of stigma attached to the disease. Delayed treatment seeking was found higher among highly stigmatized patients. It is deemed useful to conduct a larger scale study using qualitative methods regarding perception and stigma and its relation with patient delay.

Knowledge is an essential component of self care, and so is the growing perspective of need to acquire knowledge concerning the risk of leprosy before they can be successful in achieving program objectives. In this study, significant association was not found between knowledge of symptoms and disease.

It is encouraging that majority of the respondents (71.8%) reported to visit public sector for the first time in seeking care of their illness; whereas remaining portion of them visited to private clinics, private pharmacies, traditional healers, and Ayurvedic care. This could be due to stigma and knowledge about availability of services. Patient delay was found shorter in public sector than private and other sectors. Turning first to health care provider other than public sector was strongly associated with longer patient delay. Educational programs addressing stigma and knowledge are deemed useful for increasing utilization of public sector facilities.

Patient's accessibility to diagnostic health facilities is an issue of equity in patient health right perspective, while it is an issue of leprosy control programme's service coverage indicator in programme perspective. In this study, patient's accessibility was measured in reflecting the physical accessibility in terms of time-distance from their current residence to the diagnostic health facility. Forty one percent of the patients accessed diagnostic centre within 20 minutes whereas the rest (59%) had to travel for more than 20 minutes to reach the diagnostic centre. Logistic regression analysis has shown a significant association of time-distance with longer patient delay after adjusting with education, knowledge, perception and type of contact.

An attempt was made to describe the level of satisfaction among patients with health care providers. It was found through in-depth interview that, in general, patients were satisfied with the service of government health facilities and Non Government Organization (NGO). The patients who sought first the services of private clinics were unsatisfied with the services because the medicines including injections did not work or worsened their conditions. They eventually resorted to public sector health facility. Similarly, seeking help through traditional healers first had also contributed to longer patient delay.

During in-depth interview patients revealed that they could benefit more if there was provision of management of side effects of Multi Drug Therapy (MDT). They also emphasized changing negative attitude towards leprosy patients and the role of family members in helping patients in seeking care and taking medicines properly.

## Conclusion

Majority of the patients are delayed by more than 180 days for seeking care for leprosy. The factors playing significant role in making delayed health seeking are accessibility to diagnostic health facility, level of education and perception towards the symptoms and the disease. Findings from qualitative data collection reveal that stigma attached to the disease is also a contributing factor in concealment and delayed care seeking.

## Acknowledgements

The authors would like to thank Dr Mark R C Macdonald, Ananda Ban Leprosy Hospital, Dr Anand Ballav Joshi, Assoc. Professor TU Institute of Medicine, Dr Rajendra Kumar BC, Chief Research Officer, NHRC and Deepak Kumar Karki for their help and valuable contributions in this study.

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