Lepr Rev (2006) **77,** 41–47

Delay in the diagnosis of leprosy in the Metropolitan Region of Vitória, Brazil

PATRICIA D. DEPS*, BRUNO V. S. GUEDES*, JANDER BUCKER FILHO*, MATHEUS K. ANDREATTA*, RAFAEL S. MARCARI* & LAURA C. RODRIGUES**
**Federal University of Espírito Santo, Vitória-ES, Brazil*
***London School of Hygiene & Tropical Medicine, London, UK*

Accepted for publication 16 December 2005

Summary This paper reports on the time between the onset of the first lesion and diagnosis, defined as delay, and is based on results obtained by interviewers from a survey carried out amongst 450 leprosy patients in a leprosy endemic area in the Metropolitan Region of Vitória (MRV), state of Espírito Santo, Brazil. The mean age at diagnosis in all cases was 41·47 years and the median was 42·5 years. The mean age at diagnosis in MB (42·9 years) was greater than in PB (38·5 years). The mean of the delay in all cases was 25·25 months, median 12 months and range 0–360 months. The mean of the delay in MB (27·2 months) was greater than in PB (21·3 months). The results of this study suggest that although the delay in leprosy diagnosis in this region of Brazil was not too long when it was compared with other studies in endemic countries, it is still a problem: 65·4% of patients were diagnosed after a delay of 6 months. The Leprosy Control Programme in this state needs more effective health education in order to reduce the current period of delay before diagnosis.

Introduction

The annual number of new leprosy cases diagnosed worldwide is on the increase;[1] and 49,206 new cases were diagnosed in Brazil in 2003.[2,3,4] In order to 'eliminate' leprosy from all countries by the end of 2005, the World Health Organisation (WHO) formulated 'the final push',[5] a strategy based on the early case detection and treatment with multi-drug therapy (MDT). Leprosy can be a difficult disease to diagnose, sometimes presenting with a variety of skin lesions and nerve damage that can be apparent only on careful testing.[6] For patients, it is important that the diagnosis of leprosy should be made as early as possible so that effective antibacterial treatment can begin and steps taken to prevent nerve damage[6,7] and disability.[8,9] Therefore early detection of cases is necessary not only to reduce the transmission of *Mycobacterium leprae* but also to reduce leprosy-attributable disability,[8,9] and to avoid

Correspondence to: P. D. Deps, Avenida Marechal Campos 1468, Maruípe, Centro Biomédico, Departamento de Medicina Social-UFES Vitória-ES, Brasil CEP 29040-090 (Tel: +55 27 33357210; + 55 27 99620067; pdeps@ndi.ufes.br/pdeps@uol.com.br)

complications resulting from chronic infectious diseases.[3] Measurement of the delay of leprosy case detection by health authorities should be a useful and highly relevant indicator of the quality of any leprosy control programme.[10]

Much has been published on delays in leprosy diagnosis, that is, the time from appearance of the first lesion to the start of treatment, from no leprosy endemic countries[6,8,9,10–15,23] and endemic countries.[16–20]

The leprosy detection rate in Espírito Santo in Brazil in 2003 was 5·50/10,000 and prevalence rate 6·02/10,000, and 17·4% of all patients who were diagnosed in 2004 in the Metropolitan Region of Vitória (MRV) presented WHO grade 1 or 2.[21] From these data, it is clear that leprosy will still be endemic by the end of 2005. The aim of the present study is to quantify the delays in diagnosing leprosy in the MRV, state of Espírito Santo, and to compare this with delays in other endemic countries and in non-endemic countries.

Materials and methods

This paper reports the results of a descriptive study of delay in diagnosis among leprosy patients. The study was conducted in the MRV, state of Espírito Santo, Southern region of Brazil, between June 2003 and August 2004. Five hundred and six patients were invited and recruited amongst leprosy patients at the beginning of treatment in four health units. They were consulted by interview in the units, and none of them came from the unit by active case finding. We accepted the diagnosis made by the physician of the Leprosy Control Programme (according to WHO recommendations).[22]

Four hundred and fifty leprosy patients accepted were interviewed at the health unit by a team of six (four medical students, one physician and one nurse) using a standard questionnaire on demographic characteristics (age, sex, place of birth and of current residence). The interviewers used months as the measuring unit and took care not to interfere with the patients' recall. Each interviewer spent about 10–30 min according to the necessity of each patient. A calendar was offered and provided to the patients, just in case this was needed. Information on the operational classification of leprosy (multibacillary or paucibacillary) was collected from the Programme. The patients were grouped into four age categories: under 15 years old, 15–40 years old, 41–60 years old and over 60 years old. All patients were asked when they noticed their first symptoms of the leprosy skin lesion. The data supplied by the patients was checked against their clinical records held at the health unit they were attending. The delay can include time spent in the consultation and referral process where either no diagnosis or a misdiagnosis was made. In our study, the delay in diagnosis was defined as being the time (in months) of awareness of the first symptom to the start of treatment.

Ethical approval was granted by the Ethical Committee in Research of the Biomedical Centre from the Federal University of Espírito Santo, Vitória, Brazil. Informed consent was given verbally.

For statistical analysis, a chi-squared test was used to determine the significance of differences between categorized data and of trends. A P-value of $< 0{\cdot}05$ was considered to be statistically significant. Each analysis was carried out using commercial statistical software, SPSS version 9.0 for Windows.

Papers for comparing our results were selected by searches of PubMed with search 'leprosy' or/and 'diagnosis' or/and 'delay' between 1990 and 2004, and with similar methodology.

Results

Four hundred and fifty patients out of 506 was able to state when they become aware of their first symptom and when they started treatment (this defines the parameters of 'delay'): 302 (67·1%) of those were MB and 148 (32·9%) were PB. The delay was up to 12 months in 257 (57·1%) patients, from 12 to 36 months in 116 (25·8%), from 37 to 144 months in 68 (15·1%) and more than 144 months in nine (2%). The mean of delay was 25·25 (SD 41·4) months, the median 12 months, and ranged from 0 to 360 months. Table 1 shows the mean, median and range of the age at diagnosis and of the delay in diagnosis for all cases, and in both the MB forms and PB forms separately. The mean and median of the age at diagnosis were higher in MB than in PB patients, and this difference was statistically significant ($P < 0{\cdot}05$). Mean and median delay in diagnosis were higher in MB than PB patients ($P = 0{\cdot}157$).

Table 2 shows the delay in diagnosis by age of the patients. Most cases in the younger patients had short delays and most long delays were amongst older patients, but the differences were not statistically significant. 106 (34·6%) patients had delays shorter than 6 months.

Table 3 shows the delay in diagnosis related with the type of leprosy, MB or PB. The MB patients experienced longer delays than PB patients. The differences were not very marked but they were statistically significant ($P = 0{\cdot}015$).

Table 1. Timing of leprosy symptoms and diagnosis (in months)

	Mean (SD)	Median	Range
Age at diagnosis	In years	In years*	In years
All cases	41·47 (17·45)	42·5	04–87
MB	42·9 (17·2)	44	
PB	38·5 (17·6)	38	
Delay in diagnosis	In months	In months**	In months
All cases	25·25 (41·4)	12	0–360
MB	27·2 (39·8)	12	
PB	21·3 (44·3)	6	

*$P = 0{\cdot}013$; **$P = 0{\cdot}157$.

Table 2. Delay in diagnosis and stratified age

	Delay in diagnosis (months)				
	< 12 (%)	12–36 (%)	37–144 (%)	> 144 (%)	Total
Stratified age (years)					
< 15	16 (3·6)	2 (0·4)			18 (4)
15–40	106 (23·6)	47 (10·4)	23 (5·1)	4 (0·9)	180 (40)
41–60	94 (20·9)	51 (11·3)	34 (7·6)	2 (0·4)	181 (40·2)
> 60	41 (9·1)	16 (3·6)	11 (2·4)	3 (0·7)	71 (15·8)
Total	257 (57·2)	116 (25·7)	68 (15·1)	9 (2)	450 (100)

$P = 0{\cdot}115$.

Table 3. Delay in diagnosis and type of leprosy

	Delay in diagnosis (months)				
	<12 (%)	12–36 (%)	37–144 (%)	>144 (%)	Total (%)
Type of disease					
MB	158 (35·1)	86 (19·1)	53 (11·8)	5 (1·1)	302
PB	99 (22·1)	30 (6·6)	15 (3·3)	4 (0·9)	148
Total	257 (57·2)	116 (25·7)	68 (15·1)	9 (2)	450 (100)

$P = 0{\cdot}015$.

Discussion

Our results provided evidence that in MRV 89% out of 506 leprosy patients were able to state the time of onset of their skin lesions of leprosy. The mean age at the time of diagnosis was 41 years old. The mean of delay in diagnosis was just over 2 years, with half the patients being diagnosed and starting treatment within 1 year of onset. The delay in MB patients was on average 6 months longer than in PB patients with age at diagnosis being 43 years old in MB patients and 38·5 years old in PB cases.

In non-endemic countries such as Cuba, for example, a study of 87 leprosy patients, established that the average time of the delay in diagnosis was 16·6 months in one town and 10·7 months in another;[11] in Kuwait 121 patients were interviewed and a study there established that the mean delay was 10·5 months;[12] in the United Kingdom, a study of 28 patients established that the mean delay was 3·1 years and the median 1·8 years[6] and in Paraguay, a study of 36 leprosy patients established that the mean delay 47 months and the median delay 24 months: the mean of age of patients at diagnosis was 47 years.[13] Wu *et al.*[14] published an epidemiological analysis of approximately 1 805 leprosy patients in China showing the average age at onset was 34·19 years old and the average delay of diagnosis 3·24 years (39 months). Also in China, Chen *et al.*[10] studied the delay in the detection of leprosy cases among 27 928 patients. The delay was up to 2 years for 55·1% of the new patients and more than 10 years for 7·0%, with a median value of 22 months. In Guadeloupe, 25% of the cases studied showed a diagnosis delay of more than 6 months.[15] In Ethiopia, data from 692 newly detected patients showed a mean of delay of 2·4 years (28·8 months) for males and of 2·3 years (27·6 months) for females.[8]

Studies from leprosy endemic countries have showed different results. In a Brazilian study with 87 patients 71·1% of them the delay in diagnosis was longer than 6 months.[16] In another study in Brazil, the diagnosis was made 1 year after the awareness of signs/appearance of symptoms in 55% of the 40 leprosy patients interviewed.[17] Pimentel *et al.*,[18] also in Brazil, reported that after interviewing 100 multibacillary patients, 29% of them had experienced a delay of up to 6 months and 71% had experienced a delay of 7 months or more. In India, out of 560 new cases asked about the delay in leprosy diagnosis, only 17·7% were diagnosed within 1 year of the onset of first signs or appearance of symptoms.[19] In addition, another study carried out on 166 leprosy patients from Nepal found the mean of the delay in diagnosis to be 37·6 months (SD58·9) and median of 18 months.[20]

In addition, comparatively, the data from our study show that the median delay among PB cases (6 months) was shorter than MB (20 months) and this agreed with the cases reported by Becx-Bleumink[23] in Ethiopia and Chen *et al.*[10] in China. However, Schreuder[9] in Thailand obtained different results, 27·5 among PB and 22·4 months among MB cases.

The mean age at detection was greater in our study, 41 years, than in many other studies.[6,10,14] The mean of age at detection in MB cases was greater than in PB. This was also reported by WU *et al.*,[14] who attributed this to three reasons: PB leprosy may self-cure, so some PB children may have self-cured on reaching adulthood; and also, the MB has a long incubation period.

The main limitation of our study results from patients having been interviewed after diagnosis and therefore being vulnerable to possible recall bias, if differential diagnosis caused misunderstanding by patients about the onset of the leprosy skin lesions. Delay in diagnosis is difficult to measure accurately since interviewees rely on the memory of the patient as to when the disease became symptomatic.[9,24,25] Unfortunately, we did not ask separately about the time from onset to presentation of the disease and from presentation to start of treatment.

Delays in the present study are shown to be shorter than in any other countries, except Cuba,[11] Kuwait[12] and Guadalupe.[15] This is true for other endemic countries like India[19] and Nepal[20] and other studies from Brazil;[8,16–18] in non-endemic countries like Ethiopia,[8,25] UK,[6] China[10,14] and Paraguay,[13] the delays were shorter than in our study.

The delay in diagnosis has been classified into patient-related delay, and physician-related.[11] Arguably, there is also an important delay which is related to difficulty of access. In non-endemic developed countries delays in leprosy diagnosis are common because leprosy is unfamiliar to medical personnel.[6,26] Delays can also result from lack of access to care. In China, cases in non-endemic areas were detected earlier than those in endemic areas, probably reflecting differences in socio-economic development. In general, the endemic areas are less developed and poorer than the non-endemic areas with poorer and less accessible healthcare systems.[10] In a qualitative study many findings linked delay in presentation to traditional beliefs, lack of awareness of early symptoms of leprosy, stigma, seeking help from natural healers, and to lack of interaction with the health services.[13]

There have been no definitions of what constitutes an acceptable delay, but Muller[15] suggests that longer than 6 months is deleterious to the patient and to the economy. In patients with neuritic leprosy, risk of deformities is much higher (15–18 times) with delay in diagnosis of over 5 years.[19] Paralytic deformities were rare (1%) in patients diagnosed early (<1 year) but increased considerably when diagnosed late. However, the increase in deformity with length of delay is less marked among PB patients than in MB patients.[19]

To conclude, the results of this study suggest that although the delay in leprosy diagnosis in this region was the shortest amongst leprosy endemic countries, it is still a problem: 65·4% of the patients were diagnosed after 6 months. It is a pity that we did not investigate how much of this delay was caused by either the patient, accessibility to health services, or physicians. More research is needed to investigate this so that the Leprosy Control Programme can make informed decisions on provision of more health education, training of medical and paramedical staff, and improvement of the delivery of the service at the peripheral level to promote the early diagnosis of leprosy patients.[23]

Acknowledgements

We are grateful to Dr Fausto Lima Pereira and Professor Luis Fernando Schettino for encouraging our work; Dr Rita de Cássia Birschner, Dr Ivan Cleber A. Prates, Ms Maria Célia Sales, Ms Luciana, Dr Dadia and Dr Délio Delmaestro for collaborating with the interviewers; Ms Sofia O. Nasser, Ms Marisa Simon, Ms Patricia B. Guerra, Ms Jane Rosa de Paula for valuable collaboration during the data collect and processing. We thank LEPRA UK for financial supporting during the analysis period for one of the authors (PDD). Also, we would like to thank Mrs Susan Doherty and Mrs Barbara Stacey, from the London School of Hygiene & Tropical Medicine, for helping with the presentation of the manuscript.

References

[1] Meima A, Smith WC, van Oortmarssen GJ, Richardus JH, Habbema JDF. The future incidence of leprosy: a scenario analysis. *Bull WHO*, 2004; **82**: 373–380.
[2] WHO. Global Leprosy Situation, 2004. www.who.int/lep/stat2002/global02_files/lep04.xls (accessed May, 05, 2005).
[3] WHO. Guide to Eliminate Leprosy as a Public Health Problem. WHO, Geneva, 2000, pp. 7–16. www.who.int/lep (accessed September, 22, 2005).
[4] Meima A, Richardus JH, Habbema JD. Trends in leprosy case detection worldwide since, 1985. *Lepr Rev*, 2004; **75**: 19–35.
[5] WHO, The final push towards elimination of leprosy: strategic plan, 2000–2005. WHO, Geneva, 2000.
[6] Lockwood D, Reid AJC. The diagnosis of leprosy is delayed in the United Kingdom. *Q J Med*, 2001; **94**: 207–212.
[7] Saunderson P. The epidemiology of reactions and nerve damage. *Lepr Rev*, 2000; **71**: 106–110.
[8] Meima A, Saunderson PR, Gebre S *et al.* Factors associated with impairments in new leprosy patients: the AMFES cohort. *Lepr Rev*, 1999; **70**: 189–203.
[9] Schreuder PAM. The occurrence of reactions and impairments in leprosy: experience in the leprosy control program of three provinces in north-eastern Thailand, 1978–1995. I Overview of the study. *Int J Lepr Other Mycobact Dis*, 1998; **66**: 149–158.
[10] Chen X-S, Li W-Z, Jiang C, Ye G-Y. Leprosy in China: delay in the detection of cases. *Anns Trop Med Parasitol*, 2000; **94**: 181–188.
[11] De Rojas V, Hernandez O, Gil R. Some factors influencing delay in leprosy diagnosis. *Bull PAHO*, 1994; **28**: 156–162.
[12] Al-Kandari S, Al-Anezi A, Pugh RN *et al.* Leprosy in Kuwait: an epidemiological study of new cases. *Ann Trop Med Parasitol*, 1990; **84**: 513–522.
[13] Nicholls PG, Wiens C, Smith WCS. Delay in presentation in the context of local knowledge and attitude towards leprosy – the results of qualitative fieldwork in Paraguay. *Int J Lepr Other Mycobact Dis*, 2003; **71**: 198–209.
[14] Wu XS, Ning Y, Shi L *et al.* An epidemiological analysis of leprosy from, 1951–1996 in Sichuan. *Ind J Lepr*, 2000; **72**: 63–74.
[15] Muller P, Frederic M, Salzer B, Strobel M. Lepre en Guadaloupe: maladie en decline, delai diagnostique en hausse. *Ann Dermatol Venereol*, 2003; **130**: 619–621.
[16] Lastoria JC, Macharelli CA, Putinatti MSMA. Leprosy: reality of the clinical diagnosis. *Hansen Int*, 2003; **28**: 53–58.
[17] Da Silva Souza C, Bacha JT. Delayed diagnosis of leprosy and the potential role of educational activities in Brazil. *Lepr Rev*, 2003; **74**: 249–258.
[18] Pimentel MIF, Nery JAC, Borges E *et al.* Impairtments in multibacillary leprosy: a study from Brazil. *Lepr Rev*, 2004; **75**: 143–152.
[19] Kumar A, Girdhar A, Girdhar BK. Nerve thickening in leprosy patients and risk of paralytic deformities: a field based study in Agra, India. *Lepr Rev*, 2004; **75**: 135–142.
[20] Robertson LM, Nicholls PG, Butlin R. Delay in presentation and start of treatment in leprosy: experience in an out-patient clinic in Nepal. *Lepr Rev*, 2000; **71**: 511–516.
[21] Secretaria Executiva de Saude Publica – SEEPS. http://www.sespa.pa.gov.br/Situa%C3%A7%C3%A3o/situacao_hanseniase.htm (accessed May 04, 2005).
[22] WHO. *Expert Committee on Leprosy* 7th Report, 1998, pp. 1–43.

[23] Becx-Bleumink M. Priorities for the future and prospects for leprosy control. *Int J Lepr Other Mycobact Dis*, 1993; **61**: 82–101.
[24] Li HY, Wang XM, Li T, Zheng DY, Mao ZA, Ran SP, Liu FW. Long-term effect of leprosy control in two prefectures of China, 1955–1993. *Int J Lepr Other Mycobact Dis*, 1995; **63**: 213–221.
[25] Bekri W, Gebre S, Mengiste A *et al.* Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia. *Int J Lepr Other Mycobact Dis*, 1998; **66**: 1–9.
[26] Sadeghi P, Marsha D, Carlson JA. Delay in diagnosis: indeterminate leprosy presenting with rheumatic manifestations. *J Cutan Med Surg*, 2000; **4**: 26–29.