

Problems of Urban Leprosy Control with Special Reference to Case Holding¹

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There are a number of leprosy control problems in urban areas. Special emphasis is laid not only on the problems of case detection and case holding but also on those of case recording and duplication in registration as well as on estimation of prevalence, incidence, and case-detection rates. In the current study, attempts are made to trace 6090 highly bacillated cases registered at the Acworth Leprosy Hospital (ALH) from 1960 onward who have subsequently dropped out from treatment. Whenever the patients could be contacted, the reason(s) for the defaulting were ascertained with a view to improve case holding. Among those who were persuaded to restart treatment, multidrug therapy (MDT), wherever indicated, was started either at the clinic or at the patient's home. These efforts can be viewed in proper perspective if the problems of urban leprosy and control are realized first.

In the last quarter century, the number of estimated leprosy cases in India has increased from 2.5 million to over 4 million. The population has increased by 2.4% per year in the last ten years. The percentage of urban population has increased from 20% in 1971 to 24% in 1981. The percentage of urban population in the state of Maharashtra (of which Bombay is the capital) is the highest (35%) among all Indian states. Thus, over the years there has been a progressively increasing urban population. The population of Bombay itself has increased from 6 million in 1971 to over 8 million in 1981.

The ALH was established in 1890 to care for only vagrant or begging leprosy patients, and it was not until 1939 that an outpatient

clinic was started. Subsequently ten peripheral clinics were established in different parts of the city. Proper records of the patients were available from 1960 onward. In those years, leprosy control was aimed at mainly by increased passive case detection following health education of the medical and paramedical personnel as well as of the lay public. Field work had just started with the appointment of 12 field workers, and for the first time attempts were made to lay down baseline data regarding the prevalence and case detection rate as well as the proportion of bacillary positive and deformed cases among the new cases, etc. (4). This study revealed alarming increases in the number of cases, and also indicated an increase in the dropout cases, although the case detection was more or less satisfactory. In a further study, 42,000 cases of all types of leprosy who had dropped out over the years were retrospectively analyzed with regard to age, sex, type of leprosy, deformity, stage, occupation, etc. (5).

The increase in leprosy in Bombay was both apparent (i.e., better case detection and recording) and real (as shown by new cases detected in very early stages). This suggested that fresh infection was going on in the community chiefly because of untreated bacillated cases. Hence the study of dropped-out bacillated cases became a prime necessity.

MATERIALS AND METHODS

All of the records of positive cases were reorganized, and the cases were regrouped according to the area of their residence. The task of reorganizing 9177 positive patients registered at the ALH outpatient clinic and its eight peripheral centers during 20 years (1961 through 1980) took 5 clerks one year to complete. The field work of 15 newly recruited trained workers then became easy.

The positive cases are lepromatous (L), borderline (B) (comparable to BB and BL), and reactional tuberculoid (RT) (compara-

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TABLE 1. *Distribution of cases by age.*

Age (yrs.)	Regularity of treatment		Total	% regular
	Regular	Dropped		
<20	407	938	1345	30.3
21-55	1957	4755	6712	29.2 ^a
>55	120	397	517	23.2 ^b
Total	2484	6090	8574	29.0

^a $p < 0.01$, chi-square, compared to <20 group.

^b $p < 0.01$, chi-square, compared to 21-55 group.

ble to BT). Of these, 603 were reported dead. The remaining 8574 cases were studied from the available records and tabulated as to their age, sex, occupation, type of leprosy, deformity, and treatment status for a preliminary retrospective analysis with a view to identify, if possible, a high-risk group among defaulters.

Of the 8574, only 2484 (29%) were regular in treatment (attendance). Attempts were therefore made to trace the whereabouts of the remaining 6090 cases who had stopped attending. It took the 15 workers two years to complete the task. Wherever the patients or their relatives were contacted, the reasons for their nonattendance were requested. These patients were then persuaded to re-attend for checkups and treatment. MDT was started in those cases where it was indicated, i.e., where the bacterial index (BI) and morphological index (MI) were high, except when contraindicated due to severe debility, old age, or in those cases where administration of rifampin (RFP) could not be supervised for any reason.

RESULTS AND DISCUSSION

The prevalence of active cases in Greater Bombay is 6 per 1000 at present. The total number of bacillated cases recorded since 1961 was 8574. Regular cases are those who collect at least a 9-month supply of dapsone tablets per year for three years from the clinic. Of the 8574, only 2484 (29%) were regular. Since the number of regular cases is itself very small, significant conclusions cannot be drawn. However, statistical analysis was resorted to in order to get some idea about the high-risk group.

Age is significantly related to regularity (Table 1). Those less than 20 years of age are more regular than those who are older than 55. The elderly cannot attend for var-

TABLE 2. *Distribution of cases by sex.*

Sex	Regularity of treatment		Total	% regular
	Regular	Dropped		
Male	2029	4940	6969	29.1
Female	455	1150	1605	28.4
Total	2484	6090	8574	29.0

ious reasons; whereas parents or guardians see to it that their young ones take treatment regularly. It should be noted, however, that in other studies (Table 6), age is not related to regularity. Gender is not associated with regularity of treatment (Tables 2 and 6).

The occupation of the patient is associated with regularity of treatment (Table 3). As in our earlier studies, students, white collar class patients, and mill and factory workers are more regular than the others. The difference, although small, is significant ($p < 0.01$) and also confirms our earlier observation (⁵). Regular health education in leprosy has been imparted in schools and colleges and in industrial establishments in Bombay since 1960. Students and the white collar class of patients are also educated generally and are aware of the dangers of stopping treatment on their own. The employers or industrial physicians of mill and factory workers see that their patients take regular treatment, as well as attend for three or six monthly checkups, as required by their regulations.

Among positive patients, borderline (BB or BL) cases were more regular than L or RT (BT) cases ($p < 0.001$) (Table 4). It is felt that borderline-type disease is relatively

TABLE 3. *Distribution of cases by occupation.*

Occupation	Regularity of treatment		Total	% regular
	Regular	Dropped		
None	630	1848	2478	25.4
Students	157	314	471	33.3
Mill and factory workers	586	1082	1668	35.1
White collar class	236	436	672	35.1
Porters and laborers	592	1573	2165	27.3
Others	283	837	1120	25.3
Total	2484	6090	8574	29.0

TABLE 4. *Distribution of cases according to type of leprosy.*

Type	Regularity of treatment		Total	% regular
	Regular	Dropped		
L	1153	3182	4335	26.6
B	865	1477	2342	36.9
RT	466	1431	1897	24.6
Total	2484	6090	8574	29.0

more dynamic and unstable, and this may induce these patients to seek treatment more regularly than those patients with the more stable and static types of the disease. Patients with serious symptoms or discomfort are less likely to default (3). Deformity is associated with regularity (Table 5). It is well known that the unstable B cases are more likely to get deformity than L or RT cases and since B cases are more regular, those with deformity are also regular. Hertroijs (3) also found that the deformed cases are more regular. Further, deformity gets in the way of the earning capacity of a patient, who then seeks treatment. In our study, students and the white collar class of patients, who are also educated, are more regular. Hertroijs (3) also found that school graduates are more regular. Our study is only confined to resident patients, but Collier (1) and Gopal (2) have found that more of the non-residents or patients from out of the project area are defaulters. In our earlier study (5), self-reported cases are less regular. This is contrary to expectations, since self-reported cases are already motivated and should be more regular. In another study (3) self-reported cases are more regular. However, among cases detected through various surveys, those detected through house-to-house surveys are less regular than those detected through other surveys.

Fate of 6090 dropped-out bacillary positive cases. Of the 6090 cases, in 4745 cases (78%) nothing further could be done since 922 had left Bombay permanently because of loss of jobs, retirement, marriage (in the case of women), etc.; 900 patients shifted elsewhere in Bombay without leaving forwarding addresses. This was also because of loss or change of jobs, retirement of the head of the family of the patient, and collapse or demolition of the patient's residence; 327

TABLE 5. *Distribution of cases according to deformity.*

Deformity	Regularity of treatment		Total	% regular
	Regular	Dropped		
Deformed	1416	3237	4653	30.4
Non-deformed	1068	2853	3921	27.2
Total	2484	6090	8574	29.0

cases could not be traced because of wrong addresses given in fear of the social stigma or because of incomplete addresses. In 678 cases, the given addresses were not found, and in 862 cases the addresses were found but the patients were not because those who did not have their own residences had given an "in care of" address of some nearby, well-known eating house or shop, etc.; 56 patients had given instructions for the hospital not to visit them because of the stigma.

The remaining 1345 patients (22% of the total) could be traced. Of these, nothing further was required to be done in 981 cases (16.1%) because they were found to be taking treatment at other voluntary antileprosy organizations in Bombay, or with family physicians or consultants, etc. Between 1969 and 1981, six new voluntary organizations were established in different parts of Greater Bombay, and all have well-demarcated geographic areas of operation. Hence, some of our patients were found to be taking treatment in other organizations (without our knowledge). It is also a common observation that in a chronic disease like leprosy where the results of treatment are not dramatically evident but slow and subtle, there is a tendency for a patient to go from one place of treatment to another, particularly to a newly established one, in the hope of observable cure. After an initial therapy in the clinic, some patients prefer to continue treatment privately with their family physician for the sake of convenience or secrecy.

Occasionally, the lack of desirable rapport between doctor and patient could also induce the patient either to drop out or to seek treatment from other centers or just to become apathetic to treatment. It may be added that not all patients would necessarily prefer to take treatment from their nearby

TABLE 6. *Some risk factors among defaulters in different studies.*

Factors	Hertroijs, 1974 (3)	Gopal, 1976 (2)	Collier, 1983 (1)	Koticha and Nair, 1979 (2)	Present study
Place of study	Mwanza, Tanzania	Kumbhakonem, South India	14 centers in Asia	Bombay, India	Bombay, India
Number of patients	8655	3365	15,980	48,345	8574
Percentage defaulted	32.4	10.4	78.4	86.9	71.0
Percentage of defaulters within first year	—	4.5	47.7	—	—
Percentage of defaulters in first year to total defaulters	—	42.9	60.8	—	—
Age	Not related	Not related	Not studied	Related; <30 and >59 defaulters are more	More defaulters in >20
Sex	Not related	Not related	Not studied	Not related	Not related
Occupation	Not related	62% of defaulters were earning members	—	More of the employed and beggars defaulted	More of the unemployed, laborers, etc., defaulted
Place of origin	Insufficient information	80% of defaulters were non-local	More of the non-locals defaulted than locals	Only residents studied	Only residents studied
Type of leprosy	Tuberculoid more defaulted	—	Not related	Positive cases, particularly B type, more regular	BB and BL cases more regular than LL or BT cases
Deformity	More defaulters among non-deformed	59% of defaulters had deformity	—	More defaulters deformed	Deformed cases more regular

centers for fear of being recognized and ostracized by the neighborhood.

In 364 cases (5.9% of the total) causes for defaulting could be ascertained. Three cases refused to accept their diagnosis because of lack of deformity. In 18 cases, they had no faith in the treatment because of the lack of obvious improvement or reactions or, occasionally, poor staff-patient relationships, or because they had faith in other forms of therapy (nature cure or supernatural forms of treatment). Thirty cases stopped attending because they felt cured. Thirteen cases had no time to attend the clinic because of their work hours, long distances, seasonal

occupations such as farming, or they were free to attend only on Sunday or in the late evening hours, etc.; 81 cases were not willing to attend and were not ready even to discuss the matter. In 19 cases, they were too handicapped or too sick to attend, or somebody else in the family was too sick, or because of other familial responsibilities. The remaining 200 were just apathetic but were persuaded to attend.

As early as 1962, Surty (7) of this hospital studied the reasons for nonattendance of 3830 patients. Other studies (1, 2, 3) are also noteworthy. Some comparison of these studies is shown in Table 6.

Multidrug therapy (MDT). Those 364 cases who could be contacted and some additional cases from the years 1981 and 1982 (407 cases in all) were revisited. Nine had died; 41 had moved back to their native homes; and 57 were regular at other anti-leprosy organizations. Twenty-five could not be given MDT because of their extreme work hours; 15 were too ill or too old to take MDT; and in 73 cases the BI and MI were considered too low for MDT. Forty patients were not willing at all even after persuasion, and 58 belonged to areas where other organizations had begun anti-leprosy work. In 7 patients MDT was started at the main clinic since they were ready to come, and in 102 cases MDT was started at the homes of the patients.

The MDT was given along the lines recently described by us (⁶). During an initial aggressive phase of 30 days, dapsone 100 mg and rifampin (RFP) 600 mg daily and clofazimine 100 mg thrice a week were given. Subsequently, dapsone and clofazimine were continued as such but RFP 600 mg was given once a week for 3 more months. After that, RFP 1200 mg once a month is being given for another 2 years, dapsone and clofazimine being continued as before. RFP administration is supervised. Up to April 1984, a total of 398 L and B cases (re-attending dropped-out cases as well as new cases) are on aggressive therapy, followed by pulse therapy (285 at clinic and 113 at the homes of patients) with good improvement in their MI; 244 are on straight pulse therapy (232 at clinic and 12 at the homes of the patients) with comparatively poor improvement in their MI.

The total duration of MDT is less than 3 years, which is substantially less than 10 years of dapsone monotherapy which was being given in all lepromatous cases before the introduction of MDT. This reduction in the treatment period itself will reduce the defaulter rate of those cases who were dropping out after 3 years or so of therapy. However, this reduction of duration will be of no help in those cases defaulting in the earlier period of treatment. For example, 43% (?) and 61% (!) of defaulters do so within the first year of registration.

Some measures to improve case holding. Intensive health education of the patients and their relatives when they visit the clinic

for the first time is considered to be most vital for several reasons: The subjects will know of sequelae following lack of treatment (which is usually told to them in all projects), but more important is the information that they should expect slow improvement in this disease. (Patients usually expect dramatic improvement as in acute diseases or they expect observable improvement as in tuberculosis.) They should also be told to occasionally expect some complications of treatment which are easily treatable, otherwise they are likely to be discouraged and try non-allopathic or other forms of therapy. Repeated interviews with the patient in the first few visits will also establish a better rapport between the patient and the medical personnel. These intensive interviews will diminish defaulter rates in those cases who drop out either because of their lack of faith in the diagnosis or the treatment. The individual interviews will also encourage some patients to start modern therapy in preference to other forms of therapy. In the interviews, the minimum course of treatment to ensure complete cure should also be explained to the patients repeatedly so that they will not stop treatment on their own just because they feel better. Clinics in the evening or on holidays may be established in some areas for those patients who cannot attend because of their occupations. More than the usual quantities of drugs are given to the patients to cover the extra period of time during which they may not be able to attend because of seasonal occupations such as farming or traveling, etc. Home treatment is given in those cases where the patients cannot attend clinics for reasons such as old age, being too ill or too handicapped, or having excessive domestic responsibilities.

SUMMARY

The prevalence of leprosy and the proportion of bacteriologically positive cases in different parts of endemic and highly dense Bombay, India, are presented. The attendance of 8574 cases is retrospectively analyzed with respect to age, sex, occupation, type of leprosy, and presence or absence of deformity. Defaulters (6090) were traced, and the reasons for nonattendance were ascertained in 22% of the cases. In those cases who could be contacted and in those who

had high bacterial and morphological indexes, multidrug therapy was being given at either a clinic or, if not possible, at their homes by experienced field workers under supervision. Recommendations are made for improving urban leprosy control work in general and for case holding in particular.

RESUMEN

Se presentan datos sobre la prevalencia de lepra y la proporción de los casos bacteriológicamente positivos en diferentes partes de Bombay, India, una zona endémica altamente poblada. Se hizo el estudio retrospectivo de 8574 casos y se tomaron en cuenta edad, sexo, ocupación, tipo de lepra y presencia o ausencia de deformidad. Se localizaron los desertores (6090) y se establecieron las razones de la deserción en el 22% de los casos. Cuando fué posible, los casos con índices bacterianos y morfológicos altos se trataron con una combinación de drogas en la clínica o en sus casas por trabajadores de campo. Se hacen algunas recomendaciones para mejorar el trabajo urbano de control de la lepra y la retención de casos.

RÉSUMÉ

On a étudié la prévalence de la lèpre, de même que la proportion de cas bactériologiquement positifs, en différentes parties de la ville de Bombay, en Inde, une région très dense et endémique. On a analysé de manière rétrospective l'assiduité de 8.574 malades, en fonction de l'âge, du sexe, du travail, du type de lèpre, et de la présence ou de l'absence de mutilations. Les malades absents au traitement (6.090) ont été repérés, et les raisons de leur manque d'assiduité ont été établies chez 22 % de ces cas. Chez les malades qui ont pu être contactés, de même que chez ceux qui présentaient un index bactériologique et morphologique élevés, des tra-

vailleurs de terrain ont été chargé d'administrer sous supervision une chimiothérapie multiple dans les cliniques, ou lorsque cela n'était pas possible, au domicile des malades. Des recommandations sont émises en vue d'améliorer la lutte contre la lèpre en milieu urbain, en particulier en ce qui concerne le maintien des malades au traitement.

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