Treatment Defaulters in Leprosy: A Retrospective Study of 42,000 Cases [1]

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In an earlier study ([1]), antileprosy measures adopted in Bombay by the Acworth Leprosy Hospital (ALH) and its ten peripheral clinics were described. An attempt was made to compute prevalence and case-detection rates, and proportions of infectious and early cases. Efforts made in the direction of health education, case detection and case holding were described. Since an alarming number of cases drop out after varying periods of treatment, a retrospective study of these defaulters was considered a prerequisite for improving case holding.

MATERIALS AND METHODS

Data was collected from the patient registers of the ALH for a period of 25 years (January 1, 1950 through December 31, 1974) comprising a total of 79,943 cases. Of these 23,698 were not resident in Bombay, 1,143 had died, 574 left Bombay during this period, and 1,859 had completed a ten year recommended period of treatment. Thus, the records contained 52,669 active resident cases. Of these, 2,225 had been referred to other centers, and on 2,099 no information was available, leaving a final total of 48,345 active resident cases.

Of this total of 48,345 only 6,345 (13.12%) were taking treatment regularly on the basis of taking treatment for nine months a year for a minimum period of three years. This compares to the report by WHO ([2]) which states, "Of the total number of estimated cases (in the world), at least 17.9 percent have been treated regularly or otherwise." Forty-two thousand patients (86.9%) had dropped out of treatment. These latter two groups form the basis of a search for factors related to regularity of attendance.

RESULTS

The two groups of active cases were analyzed with respect to age, sex, infectivity, degree of deformity, stage of their disease, source of referral and occupation.

Table 1 relates to patient sex. By statistical analysis $X^2 = 1.72$; $p > 0.1$. This is not significant and sex presented no bearing on regularity of attendance. In contrast, age, as tabulated in Table 2, was significantly related to regularity of attendance. Patients in the age group of 30 to 59 years were more regular than the other groups.

Of the total of 48,345 cases being analyzed, 13,316 (27.5%) were bacteriologically positive. Regular attenders comprised 14.8% of positive cases and 12.5% of negative cases (Table 3); X^2 is 43.4, $p < 0.001$. This difference is highly significant and thus comparatively more of the infectious cases seemed to be regular attenders but equally significant is the fact that 85.2% of the bacillary positive cases were drop-outs.

Regularity of treatment as related to the type of leprosy is presented in Table 4. Of the intermediate type cases, 20.8% were regular in treatment as compared to 12.5% for the tuberculoid, and 11.5% for the lepromatous. The X^2 value analysis comparison between the intermediate and tuberculoid groups was 247.1 with $p < 0.001$ (highly significant).

TABLE 1. *Distribution of regular and drop-out cases according to sex.*

Sex \ Regularity	Regular	Drop-out	Total
M	4,990 13%	33,332 87%	38,322 100%
F	1,355 13.5%	8,668 86.5%	10,023 100%
Total	6,345	42,000	48,345

TABLE 2. *Distribution of regular and drop-out cases according to age.*

Age \ Regularity	Regular	Drop-out	Total	% Regular	X^2	p
0-14	735	4,779	5,514	13.3		
					3.98	< 0.05 (significant)
15-29	2,332	16,599	18,931	12.3		
					21.0	< 0.01 (highly significant)
30-44	2,280	14,040	16,320	14.0		
					0.16	not significant
45-59	863	5,221	6,084	14.2		
60+	135	1,361	1,496	9.0		
Total	6,345	42,000	48,345	13.1	49.3	< 0.01 (highly significant)

TABLE 3. *Distribution of regular and drop-out cases according to bacteriologic status.*

Bacteriology \ Regularity	Regular	Drop-out	Total
Bacillary positive	1,966 14.8%	11,350 85.2%	13,316 100%
Bacillary negative	4,379 12.5%	30,650 87.5%	35,029 100%
Total	6,345	42,000	48,345

In the comparison of regularity of treatment between the intermediate and lepromatous cases, $X^2 = 213.03$ and $p < 0.001$, which is also significant. It is evident that of the infectious cases the group comprising the intermediate type of leprosy comprised the most regular attenders. It is likely that this was due to the unstable nature of this type of leprosy, they having more frequent and severe reactional episodes requiring clinic visits.

Further analysis of the disease type in terms also of severity of the disease is presented in Table 5. It is evident that in the tuberculoid (noninfectious) group, the advanced cases were more regular attenders ($X^2 = 30.1$, $p < 0.001$), whereas in the infectious group (intermediate and lepromatous), the early cases were significantly more regular ($X^2 = 128$, $p < 0.001$).

The influence of deformity is tabulated in Table 6. Of the 48,345 cases, 17,947 (37.1%) were recorded as having deformities. Among these, 12.4% were regular in seeking treatment while among those without deformity 13.5% were regular; $X^2 = 14.7$, $p < 0.01$, which is significant. Thus, in this series, contrary to common belief, nondeformed cases were more regular in following treatment.

When combined deformity and infectivity were evaluated against regularity (Table 7) it was found that those who were most regular were those who were in the infectious but nondeformed category. However, the percentage differences were not great.

Of all cases, 37.1% had deformity. This is higher than the national average of India which is usually given as 20-25%. The higher prevalence of deformity in this group of patients may be related to the fact that the ALH is a specialized institution having facilities for physiotherapy and surgery and thus more deformities are brought to its attention. The largest number of deformities were found among the beggar class while those with least deformities were from the student, industrial

TABLE 4. *Regular and drop-out cases according to type of leprosy.*

Regularity \ Infectivity & type	Noninfectious Tuberculoid	Infectious Intermediate	Infectious Lepromatous	Total
Regular	4,379 12.5%	978 20.8%	988 11.5%	6,345
Drop-out	30,650 87.5%	3,713 79.2%	7,637 88.5%	42,000
Total	35,029 100%	4,691 100%	8.625 100%	48,345 100%

TABLE 5. *Regular and drop-out cases according to the stage and type of the disease.*

Regularity \ Type & stage	Tuberculoid Early	Tuberculoid Advanced	Intermediate Early	Intermediate Advanced	Lepromatous Early	Lepromatous Advanced	Total
Regular	1,292 11.1%	3,087 13.2%	552 23.1%	426 18.5%	128 14.7%	860 11.1%	6,345 13.1%
Drop-out	10,322 88.9%	20,328 86.8%	1,833 76.9%	1,880 81.5%	743 85.3%	6,894 88.9%	42,000 86.9%
	11,614 100%	23,415 100%	2,385 100%	2,306 100%	871 100%	7,754 100%	48,345 100%
Total	35,029		4,691		8,625		

TABLE 6. *Regular and drop-out cases according to deformity.*

Regularity \ Deformity	Deformed	Non-deformed	Total
Regular	2,218 12.4%	4,127 13.6%	6,345
Drop-out	15,731 87.6%	26,269 86.4%	42,000
Total	17,949 100%	30,396 100%	48,345

worker and white collar class. This is summarized in Table 8. The comparison of the two occupational groupings in this table yielded $X^2 = 183.8$, $p < 0.001$, which is highly significant. Thus, those in the grouping of students, industrial workers and white collar classes were more regular in treatment than those from the other combined occupational group.

In the student-industrial worker-white collar class grouping, regularity was directly related to the presence of both infectivity and deformity. In the grouping of all other occupations regularity, while directly related to infectivity, was only indirectly related to deformity. It seemed that the first class grouping, perhaps because of their educational status, attended more regularly and attended without waiting for deformity to occur.

Patients attending the ALH come either on their own cognizance or are referred by doctors, employers, other institutions or others. Of all cases surveyed, 27.5% were infectious. Of those coming of their own volition 35% were infectious while 23.2% of those referred were so involved. Of all the cases 37.1% had deformity. The percentage of deformity

TABLE 7. *Regular and drop-out cases according to deformity and infectivity.*

Regularity \ Infectivity & deformity	Infectious Deformed	Infectious Nondeformed	Noninfectious Deformed	Noninfectious Nondeformed	Total
Regular	976 14.3%	990 15.3%	1,242 11.2%	3,137 13.1%	6,345 13.1%
Drop-out	5,856 85.7%	5,494 84.7%	9,875 88.8%	20,775 86.9%	42,000 86.9%
Total	6,832 100%	6,484 100%	11,117 100%	23,912 100%	48,345
	13,316		35,029		

TABLE 8. *Occupational broad groups and regularity.*

Occupational sub-groups \ Regularity	Regular	Drop-out	Total
Students, industrial and white collar workers	2,183 16.5%	11,032 83.5%	13,215 100%
Others	4,162 11.8%	30,968 88.2%	35,130 100%
Total	6,345 13.1%	42,000 86.9%	48,345 100%

in those arriving independently was 44.6 while of the referred cases, expectedly, only 32.8% had deformity.

As noted in Table 9, of 48,345 cases, 14,870 (30.8%) were in an early stage of the disease. The X^2 value between early and advanced cases as related to patients referred as compared with those admitted on their own cognizance was 628.4, $p < 0.001$. This is highly significant and indicated that the earlier cases were predominantly referred cases. Not surprisingly, 71.4% of early cases, or compared to 59.9% of advanced cases were referred patients.

Among the early cases coming on their own, more cases belonged to the lepromatous group (43.4%) as compared with 32.0%

TABLE 9. *Referral, stage and type of disease.*

Source of referral \ Type & stage of disease	Lepromatous Early	Lepromatous Advanced	Intermediate Early	Intermediate Advanced	Tuberculoid Early	Tuberculoid Advanced	Total
Referred	493 56.6%	3,605 46.5%	1,622 68.0%	1,405 60.9%	8,495 73.1%	15,057 64.3%	30,677 63.5%
Own cognizance	378 43.4%	4,149 53.5%	763 32.0%	901 39.1%	3,119 26.9%	8,358 35.7%	17,668 36.5%
Total	871 100%	7,754 100%	2,385 100%	2,306 100%	11,614 100%	23,415 100%	48,345 100%

TABLE 10. *Referral and regularity.*

Source of referral \ Regularity	Regular	Drop-out	Total
Own cognizance	2,031 11.5%	15,637 88.5%	17,668 100%
Referred	4,314 14.1%	26,363 85.9%	30,677 100%
Total	6,345 13.1%	42,000 86.9%	48,345 100%

intermediate and 26.9% of the tuberculoid groups. This is surprising since early lepromatous cases with only shiny skin are difficult to diagnose. The finding may be due to better educational efforts for lay people in Bombay where over many years these early signs have been emphasized.

Among the early cases referred by doctors and others, more cases belonged to the lepromatous group (43.4%) as compared with 32.0% intermediate and 26.9% of the tuberculoid group. This may also be due to better educational efforts directed at doctors and health services in Bombay.

As noted in Table 10, more of the cases referred to the clinic were more regular in their attendance than those coming in on their own cognizance. Thus, $X^2 = 64.5$, $p < 0.001$, this being highly significant. This is at variance with the common belief that a self-referred patient is more regular because he is already motivated.

DISCUSSION

The drop-out rate in Bombay is alarming. Intensive health education, special interviewing of patients and their relatives, and increased visits to the homes of the patients are the steps that are being adopted. The management is also recruiting additional medical social workers and field visitors in sizeable numbers to meet the requirement, as the present staff of 2 social workers and 16 paramedical workers is far from adequate for Greater Bombay (population 7 million; prevalence rate over 13 per 1,000; estimated prevalence 25-30 per 1,000).

Although regularity is better among infec-

tious and nondeformed patients, attention is also paid to these groups since even a small number of infectious cases could be an important source of infection. Some of the nondeformed drop-out cases can become deformed, and more attention is also paid to the age groups from 30 to 59 years since people in this age group are economically more productive.

Students, the white collar class and industrial workers are more regular, as are the referred cases, therefore, care is taken to interview on the first visit all cases who come on their own cognizance or those who are unemployed. Unexpectedly, more of the beggars are infectious and the government is being advised to take steps to rehabilitate beggar patients in special beggar homes.

One impression, not mentioned above, is that parenteral therapy is more appreciated than oral therapy in a serious disease like leprosy, particularly by uneducated patients. It is felt that more regularity is then assured. Hence, on a trial basis, DDS given intramuscularly once a week is being used in infectious cases for at least the first six months. This has the added advantage of ensuring adequate tissue drug levels. Long-acting injections of DADDS (once in 77 days) cannot have the psychological advantage of weekly or fortnightly injections.

SUMMARY

In a chronic disease like leprosy, many patients drop out from treatment sooner or later. Hence, a retrospective study of 48,345 cases registered in Bombay over 25 years is undertaken with respect to their age, sex, infectivity, deformity, stage of the disease, occupation and their source of referral. The following conclusions are made.

Age is related to regularity of treatment. More patients in the 30 to 59 years of age group are regular. Regularity of treatment is not related to sex. More of the infectious cases are regular, particularly those belonging to the borderline (dimorphous) group. In the infectious group, more of the early cases are regular, whereas in the tuberculoid group advanced cases are more so.

Deformity and regularity, contrary to expectations, are inversely related except in the cases of students, industrial workers and the white collar class. On the whole, more of the infectious but nondeformed cases are regu-

lar. Among students, industrial workers and the white collar class of cases, less are infectious or deformed and more are regular. More of the patients who are beggars are deformed and irregular than any other class of patients. Unexpectedly, many of the beggars are infectious.

Infectivity, deformity and irregularity are more common among patients coming on their own than among those who are referred by their doctors. More of the referred cases are in the early stages of the disease.

RESUMEN

En una enfermedad crónica como la lepra, muchos pacientes desertan del tratamiento tarde o temprano. Para tratar de entender este problema se hizo un estudio retrospectivo de 48,345 casos registrados en Bombay a lo largo de 25 años. Se tomaron en cuenta edad, sexo, infectividad, deformidad, estado de la enfermedad, ocupación, fuenta de referencia y se sacaron las siguientes conclusiones:

La edad esta relacionada con la regularidad en el tratamiento. La mayoría de los pacientes en el grupo de 30 a 50 años de edad, son regulares. La regularidad en el tratamiento no esta relacionada con el sexo. La mayoría de los casos infecciosos son regulares, particularmente aquéllos del grupo intermedio (dimorfos). En el grupo infeccioso, la mayoría de los casos tempranos son regulares, mientras que en el grupo tuberculoide los casos avanzados son los más regulares.

Contrario a lo que se esperaría, deformidad y regularidad están inversamente relacionados, excepto en los casos de estudiantes, trabajadores industriales y empleados de oficina. En general, la mayoría de los casos infecciosos pero no deformados son regulares. Entre los estudiantes, los trabajadores industriales y los empleados de oficina, la mayoría son no infecciosos o deformados, a la vez que son regulares. La mayoría de los pacientes que son pordioseros estan deformados y son más irregulares que cualquier otra clase de pacientes. Muchos de los pordioseros son infecciosos.

Infectividad, deformidad e irregularidad son más comunes entre los pacientes que acuden por sí mismos a los centros de salud que entre aquellos que son canalizados a través de sus médicos. La mayoría de los casos canalizados por doctores estan en las etapas tempranas de la enfermedad.

RÉSUMÉ

Dans une maladie chronique telle que la lèpre, beaucoup de malades abandonnent le traitement tôt ou tard. Dès lors, on a mené une étude rétrospective de 48.345 cas enregistrés à Bombay durant une période de 25 ans, en étudiant l'influence de l'âge, du sexe, du caractère infectieux, des mutilations, du stade de la maladie, de l'occupation et de la source de référence. Les conclusions qui suivent ont été établies.

L'âge est en relation avec la régularité du traitement. C'est dans le groupe d'âge de 30 à 59 ans que l'on trouve le plus de malades réguliers. La régularité du traitement n'est pas en relation avec le sexe. La plupart des cas infectieux sont réguliers, et particulièrement ceux qui appartiennent au groupe borderline (dimorphe). Dans le groupe infectieux, la plupart des cas précoces sont réguliers, alors que dans le groupe tuberculoïde ce sont les cas avancés qui le sont davantage.

Les mutilations et la régularité au traitement, sont reliées de manière inverse chez les étudiants, les travailleurs de l'industrie, et la classe des employés. Dans l'ensemble, ce sont les cas infectieux mais sans mutilation qui sont les plus réguliers. Parmi les étudiants, les travailleurs de l'industrie et le groupe des employés, on trouve moins d'infectieux ou de malades avec mutilation, et davantage de malades réguliers au traitement. Plus que dans n'importe quels groupes de malades, c'est parmi les mendiants que l'on trouve le plus de malades avec mutilations et irréguliers au traitement. On a eu la surprise de constater que la plupart des mendiants étaient infectieux.

L'infectivité, les mutilations et l'irrégularité sont plus communes parmi les malades qui viennent de leur propre chef consulter que parmi ceux qui sont référés par leur médecin. On trouve davantage de cas précoces de la maladie parmi les malades référés par autrui.

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