

# A Study of Some Factors Affecting the Attendance of Patients in a Leprosy Control Scheme<sup>1, 2</sup>

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Many leprosy control schemes face the problem of patients who attend treatment irregularly or who escape from the control program. Control officers find that efforts to bring these patients back for treatment are often discouraging. The purpose of this study was to determine factors affecting such irregular attendance and defaulting by leprosy patients in order to be able to identify "high risk" groups or to predict the chance of probable poor attendance at the time when the patients report for the first time. Factors affecting the success of home visits are also examined in an attempt to increase their effectiveness.

The Mwanza Regional Leprosy Scheme, covering a part of the southern shore of Lake Victoria, Tanzania, began in 1966 and achieved in 1971 complete coverage of the area (19,600 sq km). The main purpose of the scheme is to treat the majority of leprosy patients as near to their homes as possible. The program covers all 127 general medical units of the area and is supplemented by 75 special roadside stops. About 75% of the patients live within three miles of a treatment center. Treatment is given every four weeks. The leprosy prevalence is estimated at 1.4%, the equivalent of 0.9 patients per square kilometer. Field workers have been employed since 1969 and each covers an average area of 2,000 square kilometers.

Since the beginning of the control scheme 8,655 patients have been diagnosed. This is about 55% of the total estimated patients. Of these, 2,800 patients (32% of the total registered patients) have since defaulted. The yearly defaulter rate ranges from 10% to 20%, the irregular attendance rate from 30% to 50%.

## MATERIALS AND METHODS

1. From the patient records a random sample was taken with a uniform sample fraction. In the first instance the defaulter group was compared with the nondefaulters. 2. Then the nondefaulters were divided into regular and irregular attenders and both groups compared. For the nondefaulters a second sample was taken, from which schoolchildren were excluded (schoolchildren are treated by their headmaster and their attendance constitutes a problem of another kind as compared with the general patient population). Before 1970 a less complete patient record system was in use. As a result, there are some gaps in the data. For most data comparisons the chi-square test, or its logarithm, the lambda test, has been used. 3. Additionally, 1,162 interviews<sup>4</sup> with defaulters, irregular attenders or their relatives and neighbors, made by the field workers during their home visits, were compiled and analyzed. 4. Patients spontaneously returning to treatment were studied separately. 5. An analysis of the success of home visits was made, also separately.

**Definitions.** *Defaulters* are patients who have not attended a treatment center in our area for a period of one year or more unless information has been received as to their receiving treatment elsewhere.

*Irregular attenders* are patients who have attended one of our treatment centers less than 9 times out of the 13 possible yearly visits.

*Children* are those below the age of 15.

*Classification* of leprosy is in conformity with the Jopling-Ridley classification (<sup>3</sup>), as amended by Dr. D. L. Leiker (<sup>4, 5</sup>).

*Deformities* were classified according to the latest WHO recommendations (<sup>10</sup>).

*A home visit* is every attempt of a field worker to find a patient at his or her home.

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## RESULTS

**Defaulters and irregular attenders.** No significant differences were found between defaulter and irregular attenders as compared to regular attenders with respect to their *tribe* of origin (about six major tribes involved), *occupation* and average *distance* of patient's home to nearest treatment center (Table 6), although more regular attenders lived within a two mile zone as compared with irregular attenders ( $0.05 < p < 0.02$ ).

**Sex and age** (Table 1). Defaulters and irregular attenders were found more frequently in the age group below 20 years, particularly among males 10-19 years of age. Even when schoolchildren are excluded, since extensive school surveying gives a disproportionately large group with a higher defaulter rate, the significant differences remain though to a lesser degree. No differences were found between males and females despite the finding that males have a higher lepromatous and disability rate than females (*vide infra*).

**Marital status** (Table 2). Above the age of

19 there are more single than married defaulters. It is remarkable that the population of leprosy patients as a whole has more single and divorced persons as compared with the general population (1967 census). The stigma of leprosy is here manifest.

**Place of origin and length of residence.** Leprosy patients originating from outside the area were in higher proportion than in the general population. However, comparison of defaulting and attending patients is difficult as the information available is insufficient.

**Education** (Table 3). Defaulters had more school education as compared with nondefaulters. No differences were found between the regular and irregular attenders. It is possible that educated people are more mobile and more sensitive to the stigma attached to leprosy and therefore become defaulters more easily.

**Leprosy type and deformities** (Tables 4 and 5). Indeterminate and tuberculoid patients present the highest proportion of the defaulter group. The same can be said of irregular attenders, but to a lesser degree. In

TABLE 1. Sex and age division (percentages), schoolchildren excluded.

Age	Defaulters			Nondefaulters			Regular attenders			Irregular attenders		
	M	F	total	M	F	total	M	F	total	M	F	total
0-19	47	33	39	23	20	22	17	14	15	24	17	21
20-39	38	47	44	50	53	51	61	56	58	56	48	52
40-59	12	17	14	25	24	24	19	23	22	16	31	23
> 60	3	3	3	2	3	3	3	7	5	4	4	4
Total %	100	100	100	100	100	100	100	100	100	100	100	100
Total number	994	802	1796	2148	1790	3938	163	146	309	93	84	177
M/F ratio	1.24			1.20			1.12			1.10		
chi/square	p < 0.01						p < 0.01					

TABLE 2. Marital status of persons above the age of 19 (percentages).

	Total pop.	Patient pop.	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
Single	12	19	27	16	17	24
Married/widowed	82	68	63	69	78	71
Divorced	6	13	10	15	5	5
Total %	100	100	100	100	100	100
Total no.	409,311	976	326	650	155	97
chi/square	p < 0.01		p < 0.01		0.3 < p < 0.5	

TABLE 3. Education of patients not at school (percentages).

	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
No education	54	25	21	20
Some education	46	75	79	80
Total %	100	100	100	100
Total no.	286	711	183	89
chi/square	p < 0.01			

TABLE 4. Classification (percentages).

Type	Including schoolchildren		Excluding schoolchildren			
	Defaulters	Nondefaulters	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
I, TT, T	85	52	84	52	80	85
BT	8	23	13	38		
BB, BL	4	15				
L, LL	3	10	3	10		
Total %	100	100	100	100	100	100
Total no.	1422	3258	1201	3172	5644	3195
chi/square	p < 0.01		p < 0.01		p < 0.05	

TABLE 5. Deformities (percentages).

Grade	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
0	83	60	54	70
1	10	11	15	9
2	6	16	16	14
3	1	13	15	7
Total %	100	100	100	100
Total no.	1825	3330	307	184
chi/square	p < 0.01		p < 0.01	

TABLE 6. Home-clinic distance (percentages).

Miles	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
0-1	27	26	28	23
1-2	26	27	29	23
2-3	19	21	21	24
3-5	20	18	14	23
5-8	4	7	7	6
>8	4	1	1	1
Total %	100	100	100	100
Total no.	209	399	246	153
Average miles	2.90	2.76	2.68	2.95
chi/square	0.2 < p < 0.3		0.2 < p < 0.3	



TABLE 7. *Way of entering the scheme (percentages).*

Route	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
Survey	19	10	-	1
Self-report	81	90	100	99
Total %	100	100	100	100
Total no.	2164	2720	294	178
chi/square	p < 0.01			

TABLE 8. *Attendance behavior since initiation of treatment (percentages).*

Disease course	Defaulters	Nondefaulters	Regular attenders	Irregular attenders
Stable	58	54	73	22
Unstable	8	18	11	30
Decreasing	31	20	11	35
Increasing	3	8	5	13
Total %	100	100	100	100
Total no.	647	490	306	184
chi/square	p < 0.01		p < 0.01	

the defaulter group hardly any patient had severe deformities or reactions. The same can be said for irregular attenders. This applies also to the milder deformities, though to a lesser extent. The seriousness of the symptoms of the disease was inversely proportional to the probability of defaulting or irregular attendance. Giel and Van Lwijk (2) found no correlation between disability and attendance rate in Ethiopia; the stigma forces the patients to leave their families, and once destitute, the importance of being cured is not of major concern to them.

*Way of entering the scheme* (Table 7). Patients registered after a survey show a higher defaulter rate than those registered after self-report, referral or contact examination. In this respect, the results of village

surveys are even poorer than school surveys. In the group of regular attenders there were scarcely any patients registered after a survey (schoolchildren excluded). Patients registered after a survey are more frequently registered in the indeterminate and tuberculous group. Their disability grade is usually lower.

*Attendance behavior* (Table 8). In the defaulter group the average period of treatment before defaulting was short: 65% attended for only half a year or less; 85% for one year or less; and, 27% attended only once. The mean period of treatment was two to six months. This suggests that the tedium of prolonged treatment is not an important reason for defaulting. It stresses the importance of the first attendance with respect to health edu-

TABLE 9. *History of onset (percentages).*

Duration (years)	All patients		Patients found in surveys excluded	
	Defaulters	Nondefaulters	Defaulters	Nondefaulters
< 1	42	32	40	32
1-2	19	16	18	17
2-5	29	26	30	25
< 5	10	26	12	26
Total %	100	100	100	100
Total no.	1479	2575	1202	2446
chi/square	p < 0.01		p < 0.01	

cation. Defaulters and regular attenders showed a stable treatment habit. Once irregular they remained irregular, once regular they continued to be regular. The irregular attendees were mostly unstable, or their attendance rate decreased. Amongst the defaulters there were many patients with a decreasing attendance rate before they defaulted. The regular attendance rate of defaulters before they defaulted was 37%, while the average attendance rate of nondefaulters

during the last four years was about 62%.

*History of onset* (Table 9). The time between the patient's first awareness of having leprosy and his registration was shorter in the defaulter group. However, if the patients found by a survey are excluded the difference remains significant. Patients with a short history of onset are likely to have no severe deformities.

*Seasonal factors* (Table 10). Most defaulters stopped their treatment in the period

TABLE 10. *Seasonal factors (percentages).*

Month	Defaulters	Regular attenders	Irregular attenders	Agricultural activities	Visits to relatives
1	5	11	8	16	10
2	4	9	8	16	0
3	5	8	8	10	0
4	5	8	9	7	0
5	6	6	8	7	1
6	9	6	8	9	3
7	10	6	7	8	3
8	11	7	8	5	6
9	12	7	8	3	6
10	12	8	9	3	19
11	12	10	10	4	37
12	9	14	9	13	15
Total %	100	100	100	100	100
Total no.	1793	1942	2996		
chi/square	$p < 0.01$	$p < 0.01$	$0.02 < p < 0.1$	$p < 0.01$	$p < 0.01$

TABLE 11. *Size of the clinic (percentages).*

Number patients on register	Attendance rate	Defaulter rate	Defaulter plus irregular attendance rate
0-20	67	12	45
21-50	56	22	66
51-80	65	16	51
>80	62	23	61
Total %	58	18	60
Total no.	4844	2124	6968

TABLE 12. *Character of the clinic (percentages).*

Type	Defaulters	Nondefaulters	Regular attendance	Irregular attendance
Roadside stop	7	9	12	11
Clinic	93	91	88	89
Total %	100	100	100	100
Total no.	1556	1983	312	175
chi/square	$0.7 < p < 0.8$		$0.90 < p < 0.95$	

TABLE 13. *Reasons for defaulting or irregular attendance.*

Reasons	Defaulters		Irregular attenders	
	%	Age/sex mostly involved	%	Age/sex mostly involved
A. Patients not met personally	48		29	
1. Migrated	69	< 40	45	< 20
2. Temporary safari	-		31	> 40, males
3. Unknown	27	20-40	21	< 20, females
4. Died	4		3	-
B. Patients personally met	52	> 40, males	71	> 40, males
1. Temporary safari	27	20-40, males	32	20-40, males
2. Sickness or disability	12	> 40	16	> 20, females
3. Forgotten clinic date	6	males	20	> 40, females
4. No confidence	16	20-40, females	7	< 20
5. Fear/shame	6	< 20, females	3	< 20, females
6. Schemes failure	3	schoolboys	6	
7. Received DDS elsewhere	6	> 40, males	3	> 20
8. Thought cured	8	schoolboys	1	
9. Work at home	-		8	20-40
10. Clinic too far	5	> 40, males	1	< 20, females
11. Ignorance	3		2	
12. Registered twice	3	< 20, males	1	< 20, males
13. Thought having no leprosy	3	20-40, females	-	
14. Treatment too long	1	> 40, males	-	
15. Complaints about DDS	1		-	
Total %	100		100	
Total no.	635		527	
Total mobility (A1, A2, B1)	47	< 20	44	20-40, males
Mobility plus unknown	60	< 40	50	20-40

between July and November (56%). This is the period in which the agricultural activity is the least and, likewise, the period in which the majority of migrations take place (6). If regular attenders missed a few months of treatment, these months were usually November, December, January and February (43%). In this period visits to relatives are very frequent and agricultural activities increase. Irregular attenders are irregular throughout the year, although irregularity increases slightly during the period with a high frequency of visits to relatives.

*Geographical distribution.* Some sub-areas show a low defaulter or irregular attendance rate while in others a high rate was found. The coverage of the leprosy scheme does not differ in these areas, and no correlation was found between the defaulter rate or attendance rate and the activities of the field workers.

*Clinic characteristics* (Tables 11 and 12). Clinics having the number of registered patients below 20 or between 51-80 have a higher attendance and a lower defaulter rate

than clinics with 21-50 or over 80 registered patients. Factors such as privacy, anonymity and urban or rural way of life probably intermingle with each other. No significant difference was found in defaulter or attendance rate between roadside stops and general dispensaries. The same factors as mentioned under the size of clinics may play a part. There is the possibility that a patient registered at a roadside stop may more easily lose touch with the time schedule of the mobile team.

**Motives for defaulting and irregular attendance** (Table 13). Disproportionately more home visits and interviews were made with borderline and lepomatous patients (as a matter of epidemiological importance), with males and with those in the age-group of 20-40. It is very difficult to obtain reliable answers from patients to questions about the reason for defaulting or not attending. The field workers are not specially trained for this kind of work. Beyond doubt, however, the most important reason for defaulting is migration; for irregular attendance (of which



a large proportion will enter the defaulting group), migration and temporary safaris (which often cover a long period of time) are similarly significant. The mobility of the population of Mwanza Region (with the exception of Ukerewe district) is very high (6), and we have the impression that the mobility of leprosy patients is even higher.

Remarkable also is the high number of patients who are not traceable because they are unknown in the village they said they lived in. They may have given a false name or the wrong village, or they may have emigrated secretly. The stigma of leprosy is probably responsible.

Patients claim that sickness, disability or forgetting the date of the clinic constitute important reasons preventing them from staying regular. No confidence in modern treatment was reported by 16% of the interviewed defaulters, particularly by females. Two thirds of these patients went to a native practitioner. Other reasons are of less importance but are interesting to note (Table 13).

**Patients spontaneously returning to treatment.** Few patients after having defaulted return for treatment. Of those who do return, about half do so after a home visit, the other half return spontaneously. Compared with the total, the defaulters who spontaneously returned were 71% males, 56% in the age-group of 20-39, 36% in the borderline-lepromatous group, 24% with severe deformities (grades 2 and 3), 84% lived within three miles of the treatment center, and 81% had been absent from treatment for less than two years. It is clear that those defaulters who return to control spontaneously have charac-

teristics which made their first act of defaulting rather unlikely; in other words, they do not belong to the high risk group (Table 14).

**Home visits.** When a field worker goes out to trace a defaulter or irregular attender, he will succeed in returning the patient to regular treatment for one year or more (long-term success) in only 11% of his attempts. For defaulters the success rate is 2%, for irregular attenders 21%. In addition to this, the patients will return for treatment irregularly or for only a short period in 14% of his visits (defaulters 11%, irregular attenders 25%). He faces no success with 74% (87% defaulters and 54% irregular attenders). A second or third home visit to the same patient is, on the average, no more successful. Of all irregular patients, 34% are paid a home visit. For defaulters this figure is 25%. Sixty percent of all home visits result in an encounter between the field worker and patient (for defaulters 52%, for irregular attenders 71%). Some field workers have a long-term success rate of 33%, others not more than a few percent.

Home visits are more successful in cases where the patient is under the age of 20, a male, classified as lepromatous, severely disabled (grade 3) or unstable with respect to attendance rate. Males between 20-39 years of age are the most difficult to persuade to return to treatment. The success of home visits is negatively correlated with the probability of becoming a defaulter or irregular attender, with the exception of the age division. Patients below the age of 20 are more likely to be persuaded to change their minds.

TABLE 14. *The high risk groups.*

Characteristics	Defaulters	Irregular attenders
Age/sex	males, 5-19 years	males, 10-19 years
Marital status	single	single
Education	some	- <sup>a</sup>
Classification	I, TT	I, TT, BT
Deformities	nil	nil
Home-clinic distance	- <sup>a</sup>	> 2 miles
Registered via	survey	survey
Treatment course	decreasing, irregular	unstable, decreasing
Length of treatment	short	- <sup>a</sup>
History of treatment	short	- <sup>a</sup>
Type of clinic	- <sup>a</sup>	- <sup>a</sup>

<sup>a</sup>No influence.

### DISCUSSION

The problem of defaulting and irregular attendance is faced everywhere where medical treatment is given. This particularly applies to chronic diseases and preventive services. In the case of leprosy the consequences of the leprosy stigma compounds the problem.

In the Mwanza Regional Leprosy Scheme the problem of nonattenders and poor attendance is numerically large. Epidemiologically, it is a less serious problem because a disproportionately smaller number of the nonattenders or poor attenders are potentially infectious, while these patients respond better to patient-holding efforts. It is difficult to predict the patient's chances of becoming a defaulter or an irregular attender<sup>(2)</sup>, but the combination of characteristics as compiled in Table 14 as "the high risk groups" may be helpful in this respect. Patient-finding methods such as surveys are not a way of controlling leprosy, since hardly any patient is still on regular treatment one year after the survey.

The most important reason for poor attendance is the mobility of patients. Little can be done about this, unless nationwide leprosy control is established. Ruysenaars *et al*<sup>(6)</sup> observed that the majority of migrations take place under the age of 30 (peak age of 15-19 for females and 20-24 for males), involving slightly more females and mostly occurring in the dry season. The main reasons for migration were found to be marriage and divorce, death, disease, fear or witchcraft and land shortage or infertile soil. School attendance accounts for only a small number of migrations. If these details are compared with the characteristics of our defaulters and irregular attenders, there are both similarities and dissimilarities. Defaulters and irregular attenders do not show the "marriage-peak" for females or males at the ages of 15-19 and 20-24, respectively. Schoolchildren are relatively highly represented. It would be useful to investigate the motives for migration of leprosy patients as compared with the general population and to investigate to what extent the leprosy stigma plays a role. This stigma manifests itself in several data (marital status, untraceability) but the consequences of the stigma seem not to be as great as others<sup>(2,7)</sup> report, and it may not constitute a major factor in the problem of

defaulting and irregular attendance in Mwanza Region. In spite of traditional beliefs, modern treatment is often accepted<sup>(1,8,9)</sup>, and in our area this is particularly the case with patients who suffer from severe deformities and who, therefore, are most obviously stigmatized.

In order to raise the effectiveness of our antileprosy campaign, the following actions should be taken:

1. Extra attention should be given to patients who report for the first time, with special emphasis on the chronic character of the disease and its slow cure, its slow clinical response to treatment and the need for uninterrupted and prolonged treatment. The possibility of getting treatment elsewhere in case of migration or safari should be emphasized. For the latter, a transfer letter may be issued with an explanation of the time schedule of the mobile team. Even more attention should be given to those patients having the characteristics of the "high risk group."
2. When new patients are registered, efforts should be made to obtain reliable information as to the actual name and the residence of the patient.
3. The establishment of more roadside stops should be studied to bring more patients within the two or three mile zone.
4. More and better health education should be given to the general public with one of its targets being the removal of the stigma attached to the disease. Van Etten and Anten mentioned some guidelines for this health education<sup>(9)</sup>.
5. Home visits should be made according to a priority list: to irregular attenders more often than defaulters, to patients of the high risk group in case they are potentially infectious.
6. A better selection of field workers should be established or criteria for this selection studied.
7. Ways of better contact and reporting with neighboring control schemes in view of the mobility of the patients should be studied.
8. In addition, more research into motivation and patterns of behavior of leprosy patients (participation) is indicated.



### SUMMARY

Personal, clinical, geographical and epidemiological data of defaulters, nondefaulters, irregular and regular attenders are compared. An analysis of 1,162 interviews with defaulters and irregular attenders is made to establish the reasons for poor attendance. Some factors affecting the success of home visits are studied. An attempt is made to predict the patient's chances of becoming a defaulter or irregular attender. Finally, guidelines are given to increase the effectiveness of the leprosy control scheme under study.

### RESUMEN

Se comparan los datos personales, clínicos, geográficos y epidemiológicos de rebeldes y no rebeldes y de concurrentes regulares e irregulares. Se hace un análisis de 1162 entrevistas con rebeldes y concurrentes irregulares para establecer las razones de la concurrencia defectuosa. Se estudian algunos de los factores que inciden en el éxito de las visitas domiciliarias. Se hace un intento de predecir las posibilidades del paciente de convertirse en un rebelde o en un concurrente irregular. Finalmente, se dan normas para aumentar la efectividad de los planes para el control de la lepra que están bajo estudio.

### RÉSUMÉ

On a comparé les données personnelles, cliniques, géographiques et épidémiologiques relevées chez les malades se soustrayant au traitement, chez ceux qui ne se soustraient pas au traitement, chez ceux qui sont réguliers, et chez ceux qui sont irréguliers. L'analyse de 1.162 interviews avec des malades se soustrayant au traitement ou avec des malades se présentant irrégulièrement à celui-ci, a été menée en vue d'établir les raisons d'une participation peu satisfaisante. Certains facteurs qui peuvent intervenir dans la réussite des visites domiciliaries ont été étudiés. On a essayé de

prédire la probabilité qu'un malade avait de se soustraire au traitement, ou de s'y soumettre de façon régulière. Enfin, des directives ont été données en vue d'augmenter l'efficacité des méthodes utilisées pour le contrôle de la lèpre.

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