

Leprosy control in the post leprosoaria abolition years in Nigeria: Reasons for default and irregular attendance at treatment centres

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Summary

A questionnaire was administered to all patients with leprosy seen at the four leprosy clinics in Anambra State in a face to face interview. The questions covered, among other items, the clinic attendance behaviour and the single most important reason, monthly, for absenteeism in the preceding year. The total and individual frequencies of the reasons for absenteeism were determined for the various behavioural subgroups. The differences in frequencies and associations were analysed. Values of $P < 0.05$ were considered as significant.

The results showed that 27 females and 26 males were interviewed. 39.6% of the patients were irregular attenders 7.5% were defaulters. Attendance at meetings ($P < 0.001$); work at home ($P < 0.01$) fear/shame/indignation ($P < 0.05$); no confidence in treatment ($P < 0.025$) were significant reasons for absenteeism among irregular attenders inter-current illnesses as reasons for absenteeism did not differ significantly between regular and irregular attendees. The association between clinic attendance behaviour and lesion location (revealed Vs concealed) was not statistically significant ($X^2 0.3$). The findings in this study indicate that in the post leprosoaria abolition years, default and irregular clinic attendance by patients with leprosy are numerically large and may compound the problems of control programmes, and thus negate the realization of the global goal of intercepting leprosy transmission.

Keywords: *Leprosy control, Post leprosoaria abolition, Nigeria, Irregular attendance, Default.*

Résumé

Une questionnaire a été distribué aux malades souffrant de la lèpre, venant de quatre cliniques de la lèpre, au Nigéria à travers une entrevue face-à-face avec ces malades. Les questions sont basées sur l'habitude de fréquenter la clinique et la question la plus importante, mensuelle, par rapport au absentéisme dans l'année précédente. On avait noté la fréquence des raisons relatives au absentéisme au niveau individuel ainsi que général à l'égard du behaviorisme des sous-groupes diverses. On avait analysé les différences entre les fréquences et ses données. On a noté les chiffres $P < 0,05$ très remarquables.

Il en résulte que 27 femelles et 26 mâles ont été entrevus. 39,6% des malades avec fréquentations irrégulières, 7,5% retardataires. Assistance à des réunions ($P < 0.001$); travaux domestiques ($P < 0,01$) la peur la honte indignation ($P < 0,025$) étaient des raisons valables pour l'absentéisme chez les malades avec fréquentations irrégulières, des maladies de temps en temps sont des raisons communes pour l'absentéisme chez les deux groupes. L'habitude de la fréquentation de la clinique par rapport à la situation de la lésion (révélée par rapport à la cachée) n'a pas indiquée des données remarquables ($X^2 0,3$).

On arrive à la conclusion que dans les années de la lutte contre la lèpre, le taux de la défiance et de la fréquentation irrégulière à la clinique par les malades souffrant de la lèpre est élevé ce qui pourrait poser un problème énorme pour le programme de la lutte contre cette maladie, ce qui pourrait également empêcher l'objectif global

pour déraciner l'attaque de la lèpre.

Introduction

Leprosy is a major health problem in Nigeria and the resurgence of the disease is a source of concern to health care providers. Control measures are hinged on mutually complimenting efforts of governments and non-governmental organizations. It is however a common experience that in spite of enormous spending towards control and rehabilitation measures, many leprosy patients still shun these facilities. Since the formal abolition of the leprosoaria, some patients have continued to reside around the immediate vicinity of the largely abandoned leprosoaria, in a new patient to patient co-operation. Others stay back among their kinsmen in a concerted concealment effort².

Among the latter group, various factors are believed to contribute to the phenomenon of defaulters and irregular attenders. Age, sex and distance traveled to arrive at the clinics have been shown to affect clinic attendance rate². In most cultures, for the patients with leprosy, the matter is opprobrious; for it has come to be associated with sin defilement punishment and group stigma^{2,3,4}. These up-heavals in the patients often manifest as behavioural disturbances. For instance, subconscious feeling of guilt may drive the patient towards accepting leprosy as divine punishment the mechanism of negation may produce an unwilling patient, while overcompensation may produce an aggressive and difficult patient³.

While these factors no doubt contributed to the problem of irregular attenders and defaulters, other reasons might contribute to the absenteeism especially among patients who apparently were well adjusted to the illness. Giel and Van Zluejk⁵ believed that unconvincing reception at hospital and frustration as regards the factual duration of treatment might have been responsible for the disappearance of about a quarter of their patients even before they had been properly examined. Other authors have found that the most important reasons for defaulting among leprosy patients were migration and no confidence in modern treatment, while for irregular attenders, disability, non remembrance of clinic days, social stigma and religious functions were contributory factors^{3,6}. In Nigeria the dimensions of absenteeism in the treatment of patients with leprosy have not been well documented. The present report describes the magnitude of some of the reasons for defaulting and for irregular attendance among leprosy patients registered in a control programme in two local government areas (LGA) of Anambra State, Nigeria. It also discusses implications of the phenomenon as regards continuing transmission of the disease in the post leprosoaria abolition years, as well as proffering some remedial measures.

Subjects, materials and methods

Four clinics located in Nnewi and Ihiala LGAs of Anambra State, Nigeria have been in use for the leprosy control programme since early 1950s. The leprosy control team consisting of a Rev. Sister/Nurse, a trained leprosy worker, an assistant and a driver make monthly rounds through the clinics dispensing drugs and supervising their ingestion and distributing gift items (clothing and foodstuffs). Each clinic was visited on a particular day of a specified week in the month through out the year. The visits were more frequent during the Christian festival periods of Easter (March/

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April) and Christmas (December/January). The authors joined the control team in their monthly rounds through the leprosy clinics six months preceding the study.

At the inception of the study in January 1992 there were 115 registered patients in all four clinics and in the first half of the same year the mean monthly attendance at all 4 clinics was 72% of the registered number (25 of the patients were regular inmates living around the clinics). By 1997, the mean monthly attendance had dropped to 56%. The patients were all Ibos of the eastern part of Nigeria and shared similar cultural and social backgrounds. A questionnaire was administered to the patients in a face-to-face interview in Ibo language by the authors. Each interview lasted about 40 minutes and the questions covered included demographic information, means of transportation to the clinic; clinic attendance behaviours - (regular versus irregular) - and the single most important reason month by month for absenteeism in the previous one year; expectations from treatment; reasons for attending the clinic other than for treatment, opinion on improved services at the clinics. All patients attending the clinics on the days of the study were recruited into the study and interviewed. They were examined and classified (depending on presence or absence of lesions on exposed parts of the body) into revealed or non-revealed (i.e. concealed).

The total frequencies of the reasons for absenteeism as well as the individual frequencies of the particular reasons among the regular and irregular attenders and defaulters were analyzed to determine whether some particular reason(s) or groups of reasons were typical of any of the groups of leprosy patients. The differences in frequencies (regular and irregular attenders) were analyzed and the null hypothesis tested approximately by using X² statistics and fisher's exact test where appropriate. The P value was set at 0.05. Association between lesion types (revealed and non revealed and clinic attendance behaviour was tested by estimating the X² statistics.

Definitions

1. Regular attender: Patients with leprosy who have missed clinic appointments less than three times in the previous 1 year.
2. Irregular attenders: Patients with leprosy who have missed clinic appointments three or more times in the previous 1 year.
3. Defaulters: Irregular attenders who have missed clinic attendance and not receiving any anti-leprosy drug for the previous one-year or more.
4. Revealed: Patients with lesions on the exposed parts of the body.
5. Non-revealed (concealed): Patient without lesions on the exposed parts of the body.

Results

A total of 78 patients (43 females and 35 males) were seen. 25 of them were living within the immediate vicinity of the leprosy clinics and were of necessity regular attenders since those who fail to attend clinic were visited in their rooms by the control team. Thus 53 patients who live beyond the vicinity of the leprosy clinics were interviewed and were the subject of the resent report. They consisted of 27 females and 26 males. The mean age of the patients was 53.4 ± 13.7 years. Table 1 shows male and female distribution of the regular and irregular attenders.

Table 1 Sex distribution of the regular and irregular clinic attenders

	Irregular	Regular
Male	16	10
Female	9	18
Total	25	28

X² = 4.23; P < 0.05

About 18.8% of the patients traveled to the clinic using their own private means of transportation (bicycles, motorcycles and motor vehicles). One of the patients who owned and operated a goods van for hired delivery services usually parked the van along the highway some half a kilometer away from the clinic and walked the rest of the distance through alternative bush paths to the clinic. The remaining 81.2% of the patients wether trekked to the clinic entirely (61%) or joined public transport vehicles for some part of the journey (20.2%).

Without exception all the patients were convinced that regular supply of drugs and provision of material gifts would enhance patients confidence in the control programme. All the patients resented incorporation of the leprosy clinic into the general hospital system, for reasons of delays before being attended to (31%), shame (61%) and indifferent attitude of personnel (27%). 39% of the patients would rather stay at home than attend a general hospital clinic for reasons of identification and shame. Two of the patients employed domiciliary drug delivery services from health superintendent on several occasions. Both patients preferred this mode of drug delivery but for the financial implications. All the patients commended the satisfactory conduct of the members of the control team.

7.5% of the patient were indifferent about expectations from the drug treatment of leprosy; and believed in religious cleansing. 51% were expecting a cure of their disease from drug treatment, while 41.5% believed that drug treatment could only work when combined with religious cleansing. None of the patients believed that traditional herbal remedy had curative abilities in leprosy treatment.

Table 2 Occupational (after diagnosis) Distribution of the regular and irregular clinic attenders

Occupation	Irregular	Regular
Farmers (Peasants)	15	15
Drivers	1	3
Artisans	3	4
School Pupils	1	-
Civil Servants	-	2
Petty Trading	2	3
Unemployed (Destitution)	3	6
Total	25	28

Table 2 shows the distribution of the regular and irregular attenders among the various occupational categories encountered in the present study. Table 3 shows the distribution of the reasons for absenteeism among the regular and irregular attenders. 3.8% of the patients interviewed were attending the clinic for the first time after over 12 months default. The commonest observed reasons for absence from clinic were work at home and attendance at meeting for regular attenders, and fear/shame/indignation, inter-current illnesses, and work at home for the irregular attenders.

Table 3 Reasons for absence from clinic on appointment days

Reasons	Frequencies		Fisher's Exact Probability
	Regular Attenders	Irregular Attenders	
Attendance at meetings (Village/Church)	3	5	P<0.001
Death of a Close Relation	2	0	N.S
Intercurrent illness	1	65	P>0.05
Migration	0	1	NS
Fear/Shame/Indignation	1	77	P<0.05
Thought (Patient) curred	0	3	P<0.05
Forgotten clinic day	1	3	N.S
Work at home	4	11	P<0.01
No Confidence in treatment	0	4	P<0.025
Deformity	0	4	(IN)
No Reason	0	4	P<0.025

NS - Not significant

IN - Insufficient Numbers

P - Probability

Table 4 shows the frequency of inter-current illness among the leprosy patients. There was no significant difference when inter-current illnesses were compared as reasons for absenteeism among the regular and irregular attenders.

Table 4 Frequency of intercurrent illnesses among the leprosy patients (in the previous one year)

Illness	Frequency (%)
Upper Respiratory infection	12
Gastroenteritis	10
Seizures	3
Fever	65
Foot ulcers	15
Trauma	20

**(Many patient had multiple health problems)*

Table 5 Frequencies of clinic attendance patterns of the patients with revealed vs concealed lesions

	Attendance	
	Regular	Default/Irregular
Concealers	6	5
Revealers	29	13

$\chi^2 = 0.3$ N.S.

The relationship between lesions locations in the patients and clinic attendance patterns is shown in Table 5. There was no significant association between clinic attendance pattern and lesion location (revealed Vs concealed in the patients with leprosy (χ^2 0.3).

Discussion

61.5% of males and 35.3% of the females were irregular attenders in this study. This finding re-echoes and earlier observation on the male factor in the prediction of default and irregular attenders in treatment.

A cross section of the predominant occupational groups in the study locations was encountered in this study. An overwhelming proportion of the patients were peasant farmers (45.3%), belonging to the low socioeconomic group. Among this group, economic activities mainly serve to maintain subsistence living. Yet affliction by leprosy demands abdication of these activities to attend clinic on days that from time to time may coincide with major market days. Ekambaram found that from time to time may coincide with major market days. Ekambaram found that many of their patients being poor daily paid labourers could ill afford to spare even half a day to attend clinic. The finding of a significant association between work at home and irregular clinic attendance in the present study agrees with the above observation.

Participation in village and church activities were significantly associated with irregular clinic attendance among patients with leprosy. It is unlikely that their various communities have become more tolerant to the leprosy phenomenon. In some cases concealed lesions may encourage involvement in village activities. In others the various religious groups may be less hostile to such patients with revealed lesions.

Attendance at village meetings by such revealer patients in defiance of the stigma and ostracism that often prevail will hardly enhance the patients' status. Giel and van Luejk pointed out that there was no virtue in being a revealer and setting an enlightened example to other chronically disabled people; the only advantage in revealing the disease and wounds being in the extent to which it supported attempts at alms begging. In both situation of the revealers and concealers the frequency of such village and religious meeting and activities will determine to some extent the clinic attendance behaviour of the patients. There is the potential risk of converting regular attenders to irregular attenders in situation of very frequent meetings.

More flexible and more frequent clinic sessions and the provi-

sion of individual appointments with alternative appointment days may help to encourage regular attenders. Similarly patients who forget one clinic day may opt to attend the clinic on the alternative days.

Inter-current illnesses accounted for 37.6% of the reason absenteeism among irregular attenders. Although this proportion falls short of the 5% significance level, it presents a unique clinical problem. The environmental risks suffered by leprosy patients and the major causes of inter-current morbidity have not received adequate attention.

However, our observations showed that fevers (malaria, etc) trauma (from falls) and ulcerations were the commonest causes of inter-current morbidity among leprosy patients. Other studies have suggested that sexually transmitted diseases and human immuno-deficiency virus infection were rare among patients with leprosy^{7,8}.

A more detailed longitudinal study will be required to clearly identify the risks suffered by leprosy patients as regards other prevalent health problems in their communities. Nevertheless, incorporation of other elements of primary health care activity in leprosy clinic will help to encourage the patients to present their other health problems.

Death and illnesses among relatives of leprosy patients may pose additional hardship to these patients. In Nnewi and Ihiala communities, as in other parts of Nigeria, death and illnesses are communal concerns^{2,9}. However the extent of community participation in the burial of the dead and care of the sick relation of the leprosy patients largely reflects the level of social stigma attached to the disease. A more comprehensive health care scheme for these patients and their dependants, allowing them access to treatment at subsidized cost may reduce the effect of this factor on irregular attendance at leprosy clinic.

Fear, shame, and indignation (related aspect of behaviour in the evolution of the patients reaction to his disease) were reason for irregular attendance in the present study in 44.5% of the times. In the contemporary Nigerian Ibo literature, leprosy is a much stigmatized illness¹⁰. In the ancient past in both occidental and oriental culture, it is not so much the medical witness as the social reactions that gave evidence of the presence of leprosy^{3,11}. Skinsness et al¹¹; had hypnotized that where the patterns of reasons (to a disease socially designated leprosy) were such that there was strong aversion towards the affected individual and as a group; those were evidences of the presence of leprosy, the lack of convincing medical evidence of the diseases not withstanding⁴.

Leprosy compounds medical and social problems to a unique degree. For the society and individual the psychological change required is formidable in historical and literary rather than the medical sense⁴. These social reactions derive from the characteristic mutilation associated with progressive debilitation and the hitherto prevalent notion of incurability. Fortunately the most potent therapy for this social pathology of leprosy rests on recent and continuing advances in the leprosy treatment and surgical reconstruction. They break the cycle of transmission and render the condition subject to management and control. Nevertheless in this study absenteeism from treatment is significantly associated with fear, shame and indignation. In the individual patient these factors may lead to total resignation and indifference to control measures. In 2.3% of the instances of absenteeism no reasons were proffered while in one instance the patient had migrated to the northern part of the country in the bid to settle unidentified.

A rather curious observation in this study was the non-contribution of deformities and revealed lesions as reason for absenteeism among the regular and irregular attenders. Giel and van Luejk⁵ similarly had found no correlation between disability and attendance rate in Ethiopians with leprosy. Hertroijis³ however found that in Tanzanian patients with leprosy, the seriousness of the symptoms of the disease was inversely proportional to the prob-

ability of defaulting or irregular attendance.

While some of the deformed and disable patients we encountered in the present study may have been concerned with the importance of being cured others may have been primarily concerned with the material gifts that were distributed on each clinic day. Ultimately both groups being motivated by different factors may have other factors play the decisive role in determining their clinic attendance pattern.

In a disease condition where the duration of treatment may of necessity be prolonged, relapses after apparent quiescent period are apt to encourage the notion of incurability and at least may cast doubt on the effectiveness of current (modern) therapy³. Patients so affected may be less inclined to accord the necessary priority to clinic attendance. Yet the key to changing this perverse attitude is regular clinic attendance and strict drug compliance. In our study, no confidence in treatment was significantly associated with irregular clinic attendance. Patients' education organized by clinic staff in a continuing manner may provide ample information on the expectations from the treatment schedules.

In conclusion the problems of default and irregular attendance at clinic by leprosy patients are numerically large in this study. 39.6% of the patients were irregular attenders while 7.5% of them were defaulters. These findings indicate that even in the post leprosania abolition years, default and irregular clinic attendance by patients with leprosy may compound the problems of control programmes and negate the realization of the global goal of breaking the cycle of transmission.

The introduction of more flexible and frequent clinic days; comprehensive health care scheme for patients relations and dependants; strict adherence to multi drug treatment scheme; effective and continuing patient education and reintroduction of social motivational factors as well as functional rehabilitation are proffered as some of the measures aimed at modifying patients' negative clinic attendance behaviour pattern.

Acknowledgements

We owe many thanks to the Most Rev. Dr. Stephen Ezeanya (Late) the former Archbishop of Onitsha. To Rev. Sr. M. Kizzito

and other members of the leprosy control team, Rev. Sr. M. Francis Anaduaka, the Onitsha Archdiocesan Ethics Committee and our secretarial staff, our sincere gratitude.

References

1. Benebo SN. National tuberculosis and leprosy control programme: an overview. *The Nig. J. Med.* (Jan suppl) 1991; 12-14.
2. Nwosu MC, Nwosu SNN. Socio-cultural factors in leprosy: implications for control programmes in the post leprosania abolition years in Nigeria. *West Afr. J. Med.* 1997; 15: 126-132.
3. Hertroijs RA. A study of some factors affecting the attendance of patients in a leprosy control scheme, *Int. J. Leprosy* 1994; 42: 419-428.
4. Kalisch AP. The strange case of John early - a study of the stigma of leprosy. *Int. J. Leprosy*, 1972; 40: 291-305.
5. Giel R, Van Luijk JN. Leprosy in Ethiopian society. *Int. J. Leprosy*; 1970; 38: 187-198.
6. Ekambaram V. Absenteeism for treatment: their causes and suggested measures. *Lepr. India*, 1974; 46: 46-48.
7. Leonard G, Sangure A, Verdier M. The prevalence of HIV infection among patients with leprosy in African countries and Yemen. *J. Acquire Immune Defic Syndr*; 1990; 3: 1109-13.
8. Nwosu MC, Nwosu SNN, Okoye KC. Human immunodeficiency virus and *Treponema palladium* infections in Nigerian patients with leprosy. *Inter JJ STD and AIDS*, 1994; 5: 48-51.
9. Odebiyi AI. The socio-cultural factors affecting health care delivery in Nigeria. *J. Trop. Med. HYG*, 1997; 80: 249-254.
10. Chinua Achebe. *Arrow of God*, 2nd Edition, Ibadan, Heinemann Educational Books (Nig) Ltd. 1987; 140-152.
11. Skinsness O. Leprosy in society III. The relationship of social to medical pathology of leprosy. *Lepr. Rev.* 1964; 35: 175-181.