The Quality of Leprosy Services from the Patient's Perspective – Result of Client Satisfaction Studies in 3 NLR-Supported States in Nigeria

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SUMMARY

Background and Purpose: An initiative was undertaken by the Netherlands Leprosy Relief (NLR) to formulate guidelines for conducting a study to assess 'quality of leprosy services for the patients' perspective'. These new guidelines were used in the end evaluation of leprosy programmes of three States (Jigawa, Kaduna and Plateau) in Nigeria.

Methodology: Qualitative methods of data collection (semi-structured interview, focus group discussion (FGD) and priority cards) were used. A total of 24 patients were interviewed (Jigawa (6), Kaduna (6) and Plateau (12) and 7 FGDs were conducted; Jigawa (2), Kaduna (2) and Plateau (3). In addition, 17 community members were interviewed.

Results: The results show that most patients were satisfied with the quality of leprosy services offered to them, but more in Jigawa and Kaduna, than in Plateau State. However the need to educate communities on symptoms of leprosy and the availability of MDT services in the health services came out as universal recommendations from all the studies. Poor knowledge regarding leprosy caused patients to continue to use a traditional healer, which is a major source of delay in reporting for treatment, with development of disability as a consequence.

Niger Med J. Vol. 50, No. 2, April – June, 2009: 25 – 28.

Key words: Iron deficiency, anaemia, pregnancy, booking, Gombe

INTRODUCTION

The introduction of multi drug therapy (MDT) has led to a considerable reduction of leprosy prevalence, although in many countries a decline in new case detection has started only much more recently. There is still evidence of recent transmission as indicated by the proportion of children among new cases detected every year. The availability of health services to ensure high quality of care is essential for an effective leprosy control programme[1]. The health system through which the service is delivered influences the quality of the leprosy servics[1]. To assess the quality of services provided, feedback from the 'clients' of these services, i.e., patients and communities, is required[2]. This feedback is considered more and more vital for service evaluation and quality assurance[3]. The information generated can serve as input for the evaluation of the programmes and lead to improvement of the perceived quality of health services[4]. The concept of 'client satisfaction' in these studies was operationalized to mean 'quality of care from the patient's perspective'[5].

During monitoring visits and leprosy project evaluations, quality of leprosy services is usually assessed from the health service provider's perspective and often no attempt is made to find out the client's perspectives. In order to understand the client's perception of leprosy services, the Netherlands Leprosy Relief (NLR) developed a guide on how to conduct a study on client's satisfaction in leprosy control programes[2]. The guide aims at getting a reasonable impression of the client's views on a range of quality aspects of leprosy services through a small scale study using rapid assessment methods. The findings lay foundation for further partnership between NLR and the respective state governments as well as assist in improving the quality of the existing leprosy services. In this article, the results of studies conducted in three (3) NLR states of Jigawa, Kaduna and Plateau, all in Northern Nigeria, are presented and discussed.

METHODOLOGY

The studies were based on limited study samples as prescribed by the guidelines. An in-depth and rapid understanding of the opinions and perceptions is required. Thus, a triangulation of methods was adopted which ensued the complementing of data from interviews and focus group discussions (FGD) by observations. The respondents were leprosy patients (the primary 'clients') but the studies also involved the community members, being potential 'clients' and health staff members in order to contrast their point of view with that of the clients[4].

STUDY POPULATION

The study population were all the health facilities in the 3 States, out of which five (5) local government areas (LGAs) were selected in each state (Jigawa 6) for the study. In each state, a total of six (6) health facilities (HF) were selected (Plateau 7). A minimum of one health worker in each facility, 2 representatives of the community and 2 patients on treatment

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were randomly selected to constitute the study sample.

SAMPLING PROCEDURE

The HFs were selected purposively (guideline[4]) based on their spread in the state and the number of leprosy patients on treatment[b] in the HF. The facilities were mostly located in rural areas with different degrees of accessibility.

NUMBERS OF INTERVIEWS AND FGDs

A total of 21 interviews and 2 FGDs were conducted in Jigawa and Kaduna, while Plateau had 23 interviews and 3 FGDs done. The health workers (HWs) interviewed in Jigawa and Kaduna were 6 each, while 12 were interviewed in Plateau. In addition, community members were also interviewed (Jigawa (5), Kaduna (5) and Plateau (12)). The respondents were selected using random numbers. However, the researchers reported that only patients that were available at the time of the study were eligible for selection.

Box I: Aspects of quality of leprosy services explored in the studies

- Health seeking behaviour (used self or traditional cure, patient's and doctor's delay).
- Health education to community (quality, method)
- Accessibility (cost, waiting time)
- Condition of facilities (building, cleanliness, toilets)
- Diagnostic procedures (privacy, dealing with gender difference)
- Information to patients (quality, method)
- Contact examination
- Health staff attitude, continuity, technical competence
- Treatment (availability of drugs, dealing with noncompliance)
- Prevention of disabilities (quality, advice/attitude of staff)
- Stigma and socio-economic consequences (advice on dealing with stigma)

Practical and methodological problems encountered during the study as reported by the research teams

Due to instruments/tools and approach:

- Questionnaire: the administration of the questionnaire to non-literate respondents constituted a problem. Their views had to be recorded on tape by researchers and this required a lot of time and made the exercise cumbersome[c].
- The possibility of health staff in the HF 'tutoring' the patients and the community members who participated in the study cannot be overlooked[d]. All the patients interviewed in Plateau State had multibacillary (MB) type of leprosy. No paucibacillary (PB) cases were interviewed.

Due to preparation and other factors:

- The large expanse of a state made traveling time consuming.
- Language: almost no respondents were literate in English. This therefore became a barrier to effective communication as the interviewers were dependent on translators. Not all words maintain the exact meaning and interpretation when translated from English to a local language or back. This in itself limited the expression by respondents.
- Only patients available at the time of the visit could be interviewed. As the research team visited all HFs during the farming season in all the studies, some patients were on their farms and had to be asked to come to the clinics[b].
- There was a short notice for the onset of the study[b].
- Geographical coverage: The study was restricted to only two zones. The southern part in Plateau State was inaccessible because of civil unrest.

RESULTS

The studies were done as preparation to an end evaluation of the programmes and were done at different times of the year, Jigawa (June 2003), Kaduna (September, 2002) and Plateau (April, 2004). Women constituted 38.5% of the study sample of patients interviewed, 40.7% in the FGDs and 45.8% among the HWs. All the community members interviewed were men. The patients and community members in the studies were mainly of low socio-economic status[d].

Table 1: Result of some key aspects of quality of services explored in three (3) Northern States in Nigeria

Some aspects of quality of service explored	Responses (%) of the patients interviewed per State		
	Jigawa N=6	Kaduna N=6	Plateau N=12
Use of traditional medicine before going for MDT	57.1%	76.1	43.5
Health education on leprosy was given to community by HW	14.3	47.6	26.1
Problem with cost of going to clinic	14.3	66.7	34.8
Long waiting time in the clinic	28.6	42.9	43.5
Condition of health facility is good	90.5	95.2	52.2
Privacy respected during examination	85.7	95.2	74
Adequate information given to the patients on duration of treatment	81.0	71.4	43.5
Examination of patient's contacts done	57.1	33.3	17.4
Availability of drugs, always	100	100	95.7
POD activities done	85.7	100	34.8
Stigmatized because of leprosy	4.8	19.0	13.0

MAIN FINDINGS OF THE STUDIES

Almost all the patients that participated in the study in Jigawa (100%) and Kaduna (95%) States were reported to be satisfied with quality of services offered to them. However, this conclusion could not be drawn from the Plateau study since results were more varied.

HEALTH-SEEKING BEHAVIOUR

Patients in all three states delayed from 4 months to 3 years after noticing the leprosy symptom(s) before presenting to health facilities for treatment. More than half of the respondents in Jigawa and Kaduna said to have used herbs to get rid of their symptoms. The practice of using herbs was attributed to the easy access that the people in the communities have to traditional healers and to the perceived high cost of treatment at the health facilities. More than half of the leprosy patients interviewed in all states reported that they did not receive any information about leprosy before they were diagnosed. In answer to the question on how to improve health education (HE) on leprosy to the communities, the frequently mentioned responses were using previously treated leprosy patients, using HWs to educate people in communities, and places of worship and by broadcasting messages on the radio.

ACCESSIBILITY TO HEALTH SERVICES

The majority of the patients interviewed in Jigawa (85.7%) and Plateau (65.2%) states indicated that they incurred no cost while those that paid, considered it reasonable and affordable. However, in Kaduna State, patients had problems with cost of travel to clinics, particularly among patients going to the referral centres. Only 33.3% considered the travel cost as affordable. Waiting time at the facility was said to be reasonable; more than half of the respondents said they got their treatment as soon as they reach the HF. When asked to assess the conditions of their HFs, except in Plateau, most of the respondents reported that the condition was good. Although the majority of the respondents felt satisfied with the condition of the facilities, researchers' observations suggested that quite a number of the facilities needed some maintenance services.

PATIENT MANAGEMENT

Most of the respondents had no problem with the clinical examinations conducted on them, even though some patients were examined by staff of the opposite sex. However, patients felt that more privacy should be ensured during clinical examinations. The information given to patients in Jigawa and Kaduna States was said to be adequate, as more than 70% of the respondents said they had been properly briefed on leprosy as a disease, on duration of treatment and the need for regularity of treatment. However, in Plateau State, only 44% of the patients interviewed considered HE to be adequate. Regarding the method used to educate the patients, most of them said the information was delivered to them individually. During FGDs, the community members also corroborated the effort of the HWs in educating patients. Examination of contacts of patients, though considered to be very important by the respondents, is not practiced regularly. The same was true of home visits. Friendliness, respect and willingness to help were recognized attributes of the HWs in the HFs visited, according to the patients and community members. The technical competence was also reported to be good. However, periodic training was suggested, to enable HWs meet new challenges. The drugs (MDT) were always available and the patients believe in their effectiveness. Prevention of disability (POD) was reported to be good in Jigawa (85.7%) and Kaduna (100%) states. However, only 34.8% of the respondents in Plateau State expressed satisfaction with POD activities.

Stigmatization, isolation and discrimination are recognized social consequences of leprosy. However, most respondents claimed that leprosy had not much influence on their lives, as they had all the necessary support from family members. The percentages of respondents reporting stigmatization were 19% in Kaduna and 13% in Plateau. These are still substantial and a reason for intervention. When patients were asked to list their priorities of the quality of leprosy services, using the priority card system, those most commonly mentioned were: friendly HW, short waiting time, low cost of travel to access leprosy services and adequate information on their disease.

Researchers' experiences with the study method

The researchers were requested to express their personal experiences with the instruments used during the conduct of the research. Although the same instruments were used, they had divergent views and experiences. For example:

- "The study is indeed well adapted to investigating and evaluating the quality of service given to leprosy patients"[b].
- "It is recommended that all agencies involved in service provision to the community to periodically conduct this type of study." The recommendations, if taken seriously, will further augment existing care given to the patients[d].
- The qualitative research approach adopted for the purpose of this study is very insightful[b].
- "The communities were generally not knowledgeable in most aspects of leprosy control activities. Thus, the clients did not know what to expect or what to assess. Yet they were required to answer questions on competence of staff[c]."

DISCUSSION

The studies revealed that most patients were satisfied with the quality of leprosy services offered to them, moreso in Jigawa and Kaduna States, than in Plateau State. However, the need to educate communities on symptoms of leprosy and availability of MDT services in the health facilities came out as universal recommendations from all three studies. The poor knowledge had led patients to patronizing traditional healers, which is a major source of delay in reporting for treatment, with development of disability as a consequence.

The motivation of patients to consult health facilities for a service is strongly influenced by their knowledge, expectations and satisfaction with past experience of the health services. The studies conducted in the three states have given an insight to the programme managers and implementers on what their clients feel about their services. Data on patient satisfaction alerts health care providers to patient concerns, needs and perceptions of treatment[6]. Although the sample sizes were small and the selection of the sample was not wholly random, the findings provide valuable insights and can be used for assessing program performance and planning for the future. As the studies are based on a newly developed tool, the practical and methodological problems encountered during the studies as well as the personal experiences of the researchers will assist in further adapting it to achieve the desired results.For example, the questionnaire instrument was not validated locally before use in this study. It should be done before any further use locally.

The approach of the study, involving health workers and community members in addition to patients has strengthened the community's perception of being a stakeholder in service delivery in their clinics. This has the potential of strengthening community support and participation against the usual trend of awaiting for the government to decide on the future of health facilities located in the communities. The conduct of the study could also have a positive impact on service delivery. In general, the health sector in the study areas has suffered a long period of neglect from the authorities with resultant infrastructural weakness and poor motivation of health staff. The fact of the team of researchers visiting to find out about their services, and what the patients and community members feel about these services, was seen as a positive development and a moral boost. The recommendations made by the research teams, particularly on infrastructural development of the facilities, can be a valuable tool to use during advocacy for infrastructural improvement. As such, the impact of the study is not limited to leprosy services but also the health services in general will benefit.

In a study of this nature done on limited samples, biases cannot be ruled out. The convenient sampling method is a source of selection bias. The fact that patients that defaulted from treatment were not interviewed during the study, on average, the patients interviewed will have been more satisfied than the total patient group. The discussion of the researchers with the programme managers gave them confidence that the result of the studies reflected the real situation and unveiled some issues that the programme managers were not aware of. The health workers should empower leprosy patients to talk to community members about symptoms, curability of leprosy and where to report for treatment. As has been said, "the best people to talk about leprosy are those who have had the disease[7]". Furthermore, traditional healers need to be educated on the symptoms of leprosy and the need for early referral of patients to the health facilities. This is necessary because of the tendency of leprosy patients to depend on the traditional healers. Continuing reliance on traditional medicine further complicates decisions to seek help in the health facilities[8]. Such orientation training has already been planned. Cost of travel to the clinic was not a limiting factor to access leprosy services in Jigawa and Plateau States. However, in Kaduna State, patients had problems with cost of travel particularly among patients attending the referral centres. The programme needs to devise a realistic approach to address the problem in order to improve case holding. Waiting time at the facility was said to be reasonable, as more than half of the respondents said they got their treatment as soon as they reached the HF. The clients interviewed in Jigawa and Kaduna States seem to be more satisfied than that of Plateau. The possible reasons could be due to low motivation of health workers in Plateau State as a result of non-payment of staff salaries for many months during the time the study was carried out, as well as frequent civil unrest. The programme management particularly supervision also needed to be strengthened.

CONCLUSION

In conclusion, we feel that the gains of the client satisfaction studies in the 3 States have surpassed the intended objective. In addition to knowing what the patients feel about the services and generating information to use for a future plan, the findings are also a useful tool for advocacy to improve health services in general.

Some important recommendations from the studies include:

- Health education to the communities in which HFs are located should be improved.
- Traditional healers should be target groups for health education because most of the patients used herbs before coming to the HFs.
- Patients on MDT or released from treatment (RFT) should be encouraged to play an active role in early case finding
- There is a need to improve in the area of prevention of disability (POD) particularly in Plateau State.
- Contact examination and home visits should be supported and more mandatory.
- There should be periodic training for health staff on leprosy to enable them meet new challenges.

Limitations of the study

The error in not validating the study/questionnare instrument in the locality of the study , as well as not producing and validating it in the exact language understood and spoken by the clients in the study is acknowledged as a limitation of the study.

ACKNOWLEDGEMENT

We like to thank Dr. Wim van Brakel of KIT (Royal Tropical Institute), Amsterdam for the valuable comments on the manuscript.

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