

Satisfaction of leprosy patients on integrated MDT services: as evaluated by Bargarh Integrated Community Health Project (BICHP)

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Functional integration can be viewed successful if general health system (GHS) delivers services to the satisfaction of leprosy patients. The study elicits responses from 307 leprosy cured persons of 3 blocks and one town covering a population of about 3,50,000 in district Bargarh, Orissa. 229 (74.6%) MB and 78 (25.4%) cured PB cases were the respondents. About 80% patients diagnosed and received treatment within half an hour, 89.9% respondents spent adequate time with providers for clarifying different aspects of leprosy, 85.0% felt the discussion very useful. About 94% had comfortable time at the health institutions. About 97% of persons were regular and completed FDT in time while 25.0% experienced some discrimination mostly at the health institutions. Trunk nerves were involved in 57% cases at detection which subsided during treatment in 33% of cases. Skin patches disappeared in 74.6% and became inactive in the rest. Majority (90.2%) were convinced about cure by MDT. Clients' satisfaction in terms of quality treatment and cordial patient provider relation in GHS should be a strong indicator for successful integration.

Key words: Integration, Client's satisfaction, Cure, Patient feedback, Stigma

Introduction

From the year 1990, LEPRO India strengthened the leprosy control activities in the western and southern parts of Orissa with projects in Koraput and Bolangir districts. As a part of expansion, a leprosy eradication unit (LEU) was started at Bargarh district in 1991. Functional integration of leprosy control activities into general health system (GHS) was initiated in Orissa in the year 2000 and completed in 2004 (Govt of Orissa 1998). The LEU actively supported the integration

process. In 2005, the LEU was renamed as Bargarh Integrated Community Health Project (BICHP) due to a strategic change of strengthening community participation in improvement of health.

Integration can be viewed as successful only when certain criteria are fulfilled. Two important ones are: acceptance of the beneficiaries to the system and capacity of the health facilities in delivery of the services to the clients' satisfaction (Feenstra and Visschedijk 2002). These factors

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are crucial to popularise services and draw the patients into the health institutions. After integration the strategy for case detection was changed to voluntary reporting and referral from village and sector level health functionaries. The success of this approach depended on patient friendly service provision in terms of easy access to treatment and attitude of the service providers. The present system of evaluation mostly relies on epidemiological indicators and often falls short of such quality components. Hence, it was thought appropriate to assess the quality of services in the perspective of clients' satisfaction in the area where integrated service was provided with some additional support from the LEPRA project. The objectives were to assess the satisfaction of the beneficiaries on the technical qualities of MDT services and interpersonal interaction between the service providers and patients.

Materials and Methods

The staff of BICHP supported the GHC system of the three blocks as per the guidelines of Leprosy Division, Government of India. The areas of support were capacity building of primary health centres (PHCs) staff through training to the medical officers of the PHCs, multipurpose health workers and anganwadi workers (AWW). The training in addition to covering the basic aspects of leprosy emphasised on a referral system in which the cases suspected by AWW reach through the MPHWS to the PHCs. After diagnosis by the medical officers these cases were registered in the PHCs. The subsequent doses were collected by the patients both from the sub-centres and PHCs. This system was expected to ensure easy accessibility to diagnosis and treatment in a patient-friendly environment. On this background, the operation research was undertaken to evaluate quality of service mostly in primary health centres in terms of patient satisfaction.

Before the field exercise, a couple of preliminary discussions were undertaken involving the investigators. In these meetings, the study

protocol which included the selection criteria, sample size and content of the questionnaire was designed. It was difficult to define the range of services basing on which clients' satisfaction could be assessed. A more practical approach was to choose the criteria which meet the patients' expectations in terms of medical need and interpersonal interaction as suggested in the context of patient satisfaction (Donabedian 1980). Accordingly the patient's view on his reception, time spent by the provider, availability of medicine, non-discriminative attitude and evidence of relief (cure) were identified as important criteria of patient satisfaction. A format was designed accordingly and field tested. Three blocks namely Attabira, Bargarh and Veden along with Bargarh town of Orissa constituted the study area. The total population was 3,53,898 as per the 2001 census. Total 480 MB cases released from treatment (RFT) from April 2003 to March 2004 and 209 PB cases from October 2003 to March 2004 were included in the study. All these patients were diagnosed and completed treatment in the PHCs by the GHC staff. Four persons with long experience in leprosy were selected as field investigators and appraised about the project by the Principal Investigator and Co-Investigators. Hence, the investigators were unaware (blinded) about the disease particulars of the persons to be contacted. The information collection was done by listing the target persons from the PHCs and contacting them in person within a period of about 4 months. After collection of information from the field, baseline clinical information from the institutions was collected from the previous records to find out the effect of treatment. The compilation of the information from the field and comparison with the previous clinical status was done by the Principal Investigator. The study was thus based on independent observation.

Results

The study elicits responses from 307 patients which include 199 males (64.8%) and 108 females (35.2%). Age-wise, there were 279 (90.9%) adults

and remaining 28 were (9.1%) children which included 17 males and 11 females. The caste segregation showed general 20 (6.5%), OBC 103 (33.6%), SC 75 (24.4%), ST 109 (35.5%). The education profile indicated illiterate 109 (35.5%), primary 99 (32.2%), middle standard 51(16.6%), matric 44 (14.3), graduate 4 (1.3%). The overall rate of literacy was found to be 62.8%. As high as 188 (61.2%) respondents are poor and below poverty line (Table 1).

The classification showed 229 (74.6%) MB and 78 (25.4%) PB. Number of cases with disability grade 2 was 15 (4.9%). The duration of the disease varied widely. 114 (37.1%) cases were diagnosed within 6 months followed by 133 (43.3%) patients were detected between 6 months to 1 year, 35 (11.4%), 1 year to 2 years, 11 (3.6%) 2 year to 3 years and 14 (4.6%) cases were delayed for more than 3 years. For as high as 80.1% persons, waiting

time at health facility was less than half an hour while 14.0% received treatment between half an hour to one hour and for the remaining 5.9% persons it took more than an hour to receive the treatment (Table 2).

276 (89.9%) persons stated that health provider spent adequate time with them for clarifying about the disease and care to be taken during treatment and follow-up (Table 3). As per the opinion of 273 (88.9%) persons, the discussion was exclusively on leprosy and 261 (85.0%) persons felt the discussion very useful. About 94% were comfortable in the health facilities and were dealt as any other patient (Table 3).

Regularity and completion of treatment was seen in as high as 297 (96.7%) cases. 77 (25.1%) persons experienced some discrimination mostly at the health institutions. Trunk nerve was not

Table 1 : The detail responses on demography

Age and Sex	Male			Female			Total		
	Adult	Child	Total	Adult	Child	Total	Adult	Child	Total
	182 (59.3)	17 (5.5)	199 (64.8)	97 (31.6)	11 (3.6)	108 (35.2)	279 (90.9)	28 (9.1)	307 (100)
Caste	General		OBC	SC		ST			
	20 (6.5)		103 (33.6)	75 (24.4)		109 (35.5)			
Education	Illiterate		Primary	Middle std.		High school		Graduate	
	109 (35.5)		99 (32.2)	51 (16.6)		44 (14.3)		4 (1.3)	
Economic status	Below poverty line				Above poverty line				
	188 (61.2)				119 (38.8)				

Figures in the parenthesis indicate percentage

Table 2 : Type of leprosy and duration of disease

Type of leprosy	PB		MB		
	78 (25.4)		229 (74.6)		
Duration of disease	Within 6 months	6 months to 1 year	1 to 2 years	2 to 3 years	More than 3 years
	114 (37.1)	133 (43.3)	35 (11.4)	11 (3.6)	14 (4.6)

Figures in the parenthesis indicate percentage

Table 3 : Patient service and dealing of service providers

Patient counselling	Adequate	Inadequate	
	285 (92.8)	22 (7.2)	
Patient examination	Regular	Irregular	
	273 (88.9)	34 (11.1)	
Nerve lesion improvement	Patients having nerve lesions	Patients noticed improvement	
	175 (100)	58 (33.1)	
About own disease	Aware of suffering from leprosy	Unaware of suffering from leprosy	
	295 (96.1)	12 (3.9)	
Perception as cured	Convinced on cure of leprosy	Not convinced about cure	
	277 (90.2)	30 (9.8)	
Felt discriminated	Persons felt discriminated	Discriminated at home	Discriminated at institutions
	77 (25.1)	8 (2.6)	69 (22.5)
Waiting time	Getting services within one hour	Getting services beyond one hour	
	246 (80.1)	61 (19.9)	
Health provider spending time	Time spent was adequate	Inadequate	
	276 (89.9)	31 (10.1)	
Area of discussion	Leprosy and its complications	Not on leprosy	
	273 (88.9)	34 (11.1)	

Figures in the parenthesis indicate percentage

involved in 132/307 (43%) and involved in 175/307 (57%) cases at the time of detection. Nerve thickening subsided in 58/175 (33.1%) of cases (Table 3). Skin patches completely disappeared in 229 (74.6%) and became inactive and started fading in remaining 25.2% of cases. Majority (90.2%) were convinced of cure of their disease by MDT and 96% knew that they were suffering from leprosy (Table 3).

Discussion

Evaluation of leprosy control programme heavily depends on the findings related to epidemiological rates and ratios. The control programme lacks the scope to capture the ideas and opinions of the patients. The present study presents the responses of 307 treated persons. Regarding gender, male and female patients

constituted 64.8 and 35.2% respectively. Low proportion of female cases is a common observation and has multiple causes including lower risk of infection and programme strategy like mode of detection. If the method is self reporting, female specific rate decreases indicating low health seeking behaviour by the women (Rao et al 2006). The gender distribution of the state also is similar with female proportion around one third of the total cases. Among the respondents, there were 28 (9.1%) child cases of leprosy with 11 (39%) in female children, though sex difference is said to be less in child leprosy cases (Thorat and Sharma 2009). The overall literacy rate was found to be 62.8%. Cases belonging to other backward class (OBC), schedule caste (SC) and scheduled tribe (ST) constituted 33.6, 24.4 and 35.5% respectively.

Majority of the respondents are poor with 61.2% cases belonging to below poverty line category. All these observations indicate the higher prevalence of leprosy in the socio-economically disadvantaged community. The proportion of MB leprosy was found to be quite high indicating late detection of cases. This is further supported by about 5% cases with grade 2 disability in newly detected cases. Both of these indicators reflect the unsatisfactory service seeking behaviour of the affected persons in the area. Responses on time lag between onset of the symptoms and diagnosis showed that 37.1% cases were diagnosed within 6 months followed by detection of 43.3% patients in the subsequent 6 months meaning that as high as 20% cases were backlog cases detected after at least 1 year.

To improve quality, patient feedback is rarely taken into consideration to evaluate the services in leprosy. How easily they access to the service and attitude of the service providers towards them are not adequately studied. There is no adequate mechanism to capture such information in the present epidemiological reports. If their expectations are adequately met, that will be a strong motivation for early detection and regular treatment. Attempt was made in this study to explore some of these issues. For as high as 80.1% persons, waiting time at health facility was less than half an hour while 14.0% received treatment between half an hour to one hour and for the remaining 5.9% persons it took more than an hour to complete the formalities treatment. Generally, the health units are understaffed in the states like Orissa and the outpatient attendance is no less. In view of these, the delay observed in getting the complete service seems reasonable. Long waiting time for consultation was also experienced by leprosy patients of Thailand (Kampirapap et al 2005) as well as Brazil (Project Department NLR 2001).

276 (89.9%) persons stated that health provider spent adequate time with them for clarifying about the disease, complete treatment and follow-up. With about 90% of persons, the

discussion was exclusively on leprosy and 85.0% persons rated the discussion very useful. The respondents of the study in Brazil also are of the view that health providers discussed about the disease which was helpful (Project Department NLR 2001). Regular patient counselling is more than 92% whereas regular patient examination is around 89%. Almost all were comfortable in the health facilities and were dealt as any other patient. In a study conducted in Nepal, the treatment seemed to have been influenced by the social status of the patients. Only the people of upper status not only get better medicines but also could negotiate the mode of service per their choice (Heijnders 2004b). From the provider's side, there was also less interest to discuss about the disease. Another study in Nepal revealed how the patient's interpretation influencing on their coping with the diagnosis and treatment (Heijnders 2004a). Though majority of the interviewees believed in the effectiveness of the medicines, they faced many problems in the health posts for which 29 of the 76 patients were not able to complete the treatment. In a study in Thailand involving 29 patients, it was found that most of the interviewed patients had the tendency to apply home remedies which reflects poor health seeking behaviour and such tendency was found to be due to ignorance about leprosy (Kampirapap et al 2005).

To elicit the perception on relief from the disease by the patients is also crucial particularly in leprosy due to continuing residual lesions. This aspect is encouraging as per the observation of this study. At the time of detection, trunk nerves were thickened in 175 (57%) cases and with treatment improved in 58 (33.1%) cases. The skin lesions disappeared in 229 (74.6%) cases and inactive patches were seen in remaining 25.4%. None of these persons showed signs of activity of the disease. While 96% expressed about their initial worry, the subsidence of nerve and skin lesions convinced that the treatment was effective. All respondents knew that they were suffering from leprosy and about 90% of them

stated to have been convinced about cure. In the pilot study in Brazil (Project Department NLR 2001) interviewing 19 patients (NLR Dhangadhi 2001), the responses were positive about drug stock, contact examination and defaulter tracing through phone. In a similar study conducted in a rural set up in Orissa, only 10% of patients were not convinced of cure due to persisting skin lesions and sequel of nerve damage (Sahu et al 2003). Waiting times was short in many health facilities. About half of them opined that behaviour of health workers was good and they were adequately skilled to treat leprosy. The study on patient perspectives in Orissa (Sahu et al 2003) showed about 80% patients preferred to initially consult the local health workers and only about 40% of the beneficiaries expressed trust on the efficiency of medical officers and facilities in the primary health centres. As revealed in the study long distance and frequent absence of drug providers were the main barriers for regular treatment.

In the present study, 77 (25.0%) persons experienced some discrimination mostly at the health institutions. In the study of Brazil (Project Department NLR 2001), more than half of the patients stated that they suffer from the stigma at workplaces, sometimes at home and in the communities. Some even lost their jobs. Such a study involving 21 patients at Nepal (NLR Dhangadhi 2001) revealed slightly improved picture with greatly reducing stigma due to health education in spite of few complain about social discrimination. Stigma and discrimination are continuing problems as observed in several studies.

Various studies including the present one have attempted to evolve some working criteria to measure the outcomes of the treatment and assess patients' perceptions of the benefits. We agree with the view that in the domain of health delivery, patient is the most valued customer and his satisfaction contributes in defining the quality (Willson and McNamara 1982) in spite of difference of opinions (Kols and Sherman 1998).

Patients given the opportunity to express their views gain a sense of awareness that they have the ability to improve their situation (van Dijk et al 2003). Data on patient satisfaction alert the providers to patient concerns, needs and perceptions of treatment. This leads to improvement of the health provision in an area. In other words, they are helpful in planning, valuation and identification of bottlenecks/ areas for improvement. Well planned studies are required to explore the clients' potentiality to improve health sector.

Conclusion

This study indicates that the leprosy services are successfully integrated in the GHC system. A very good percentage of people, got regular MDT services, satisfied with the nature of treatment, know that they are suffering from leprosy and perceived they are being cured. Most important part is, all of them feel that they are treated like any other patient and they are comfortable at health institutions. The referred literature indicates an evolving protocol for such study and inclusion of patient feedback is strongly recommended.

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