

Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy

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Summary Integration of leprosy into the general health system is very much emphasized by health care planners. One prime reason stated for this is to reduce stigma attached to this disease. This study was conducted in the state of Maharashtra, India, to compare the level of social stigma towards leprosy in communities with a vertical and an integrated programme. The data were collected in three areas of five villages each. The first two areas were in an integrated programme to test for internal consistency and the third in a vertical programme. All the leprosy patients with visible deformities in these villages were enrolled in the study, and an in-depth stigma measurement scale was administered. In addition, focus group discussions were conducted among the family members of leprosy patients and participative rural appraisal was done in the communities. The data were analysed using qualitative methods. A total of 24 leprosy patients with visible deformities participated in the in-depth stigma measurement exercise from 15 villages. Fifteen focus group discussions were conducted with families of leprosy patients and an equal number of participatory rural appraisals with communities were done. The results show that social stigma was virtually non-existent among the communities with the integrated approach and minimally experienced by leprosy patients in this model. However, a high level of self-stigmatization among leprosy patients was observed in the vertical approach and equally a high level of social stigma was found in their communities, which led to reduced interaction between the leprosy patients and their communities. The integrated approach to community-based primary health care is effective in reducing leprosy stigma in society.

Introduction

Leprosy has been associated with stigma and social exclusion throughout history and on all continents,¹ although there are wide variations in the ways in which this is worked out in different communities.² Stigma can be defined as an attribute that is deeply discrediting, and the stigmatized individual is one who is not accepted and is not accorded the respect and regard of his peers; one who is disqualified from full social acceptance.¹

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There are many causes of stigma. Visible lesions or deformities, including many skin conditions,³ lead to stigma by pointing out affected individuals, but the underlying beliefs of the community are important in determining the ways in which stigma is manifested. Leprosy has at times been considered a sexually transmitted disease,⁴ an inherited condition,^{5,6} the result of witchcraft² or a punishment for sin.¹ Correct information about the disease, however, may not necessarily reduce stigma: in one study of health workers in India, doctors showed the highest level of stigma towards people with leprosy.⁷

Subtle differences in belief may have a major effect on the levels of stigma. In Myanmar, the belief that all leprosy patients will inevitably end up with deformity, seemed an important basis for stigma shown to all leprosy patients.⁸ In Sierra Leone, leprosy was connected with witchcraft in different ways in two different areas, with different results: in one area, people with leprosy were pitied as innocent victims of witchcraft, but were excluded from society because it was believed the disease could be transmitted to anyone else; in another area, people with leprosy were regarded as witches themselves, who could only pass the disease on to other witches—they were not excluded as they were not seen as a threat to ordinary people.²

An interesting unanswered question is whether stigma varies according to the personality and status of the person with leprosy.⁹ In Sierra Leone, one influential and respected leader had obvious deformities due to leprosy, but his position in the community seemed secure.² In the handbook 'The End of Isolation' interviews with two disabled men in the same community give very different pictures of stigma: one man says 'I have never felt discriminated against...' while the other faced rejection both at home, in the community and at work.¹⁰

One important result of stigma is delayed presentation of new cases of leprosy.⁶ Stigma leads people to conceal early signs of the disease, which results in more significant disability.¹¹ For the person affected, stigma leads to shame, anxiety and a lack of self-confidence,³ which can even result in suicide.¹

Stigma can be fought by using non-discriminatory terminology, by removing discriminatory legislation and by making available accurate information about the disease.¹² Self-stigma can be reduced by support, encouragement and rehabilitation of those affected. In theory at least, Naik *et al.*¹³ and Fist¹⁴ believe that integration of health and rehabilitation services will lead to a reduction in stigma, but a practical demonstration of this is lacking.

In the Comprehensive Rural Health Project (CRHP), Jamkhed, India, leprosy care has been integrated with other conditions for the last 30 years,¹⁵ while it is still a vertical programme in the rest of the country, except in the state of Tamil Nadu. The difference between vertical and integrated is that leprosy control activities are performed by a separate staff structure and are not incorporated into other health systems in vertical approach. It is a vertically administered programme. Often, trained personnel will carry out all the leprosy related activities, and community involvement is minimal. In integrated approach, leprosy control activities are either incorporated into a few other programmes such as TB, HIV/AIDS or into general medical and public health services. Integration does not automatically mean that there is maximum community involvement.

In the CRHP, it is not merely integration of leprosy with other conditions, but it is an integrated community-based primary health care (PHC) approach was adopted. It emphasizes empowering people with knowledge and skills. For instance, the grassroots workers who are a part of their community have been trained in case detection. The Mahila Mandal (Women's Club) and the Tharun Mandal (Farmer's Club) in the villages are actively

involved in integrating leprosy patients into their community. In every community, the village people have to learn to recognize and diagnose leprosy. The philosophy behind this approach is to empower the community with knowledge and skills, which will allow people to come into partnership with health personnel and work towards effective leprosy control and stigma elimination. CRHP also emphasizes community integration. It means integration of the people affected by leprosy are integrated into their families and their community.

This study had been developed to compare the level of stigma faced by persons affected by leprosy and their families in vertical and in integrated community-based PHC approaches.

Materials and methods

STUDY VILLAGES AND POPULATION

Data collection was in three areas. The first two areas of five villages each are in the integrated PHC approach area, called model and random villages. The third area of five villages has the vertical approach, called vertical villages. All these villages were situated in the state of Maharashtra, India.

Selection of model villages

Twenty-five villages with the integrated PHC approach at CRHP, Jamkhed, Maharashtra had more than one person affected by leprosy with visible deformities, including ulcers. The officials of this project were asked to select their five model villages from among these 25 villages, based on grassroots workers attending monthly meetings regularly and maintaining up-to-date health records. Then they identified one patient from each of these villages with visible deformities for key informant interview. These five people formed the sample population of the model villages.

Selection of random villages

The second area consisted of simple random selection, by an independent investigator, of another 5 villages from the remaining 20 villages, using a sample number table. All the leprosy patients with visible deformities in these villages were enrolled in the study.

Selection of vertical villages

The third area selected consisted of five villages where qualified health personnel exclusively provide leprosy care. The criteria for selection of vertical villages were that they were near the project area and matched the integrated villages in terms of population, occupation, religion, caste, language and geographical terrain. The adjacent district of Osmanabad in Maharashtra state fulfilled these criteria. Five villages from Paranda and Bhoom government leprosy control units of this district were selected for this study. These units were adjacent to CRHP's integrated villages. All the leprosy patients with visible deformities in these villages were enrolled in the study.

DATA COLLECTION

Deformities of the patients in this stigma study were classified as follows: 1, no deformities; 2, ulcers; 3, visible deformities of face, hands or feet. Subjects with no deformities were excluded from the study, as stigma is minimal in this group of patients.

Three methods were used for eliciting data. First, an in-depth stigma measurement scale with open-ended questions was administered to the subjects. It covered (i) relationships with family members and self; (ii) economic and social interaction; (iii) location of subject's house; (iv) involvement in government; and (v) access to local services.

Second, focus group discussions (FGD) were conducted among the family members of subjects, covering the following three areas: (i) facts about leprosy, (ii) the kind of assistance the person affected by leprosy received from either integrated or vertical programmes; and (iii) the level of independence of the person affected by leprosy.

Third, the degree of reintegration into the community was measured by conducting participatory rural appraisal (PRA) in the study villages. The key points covered were: understanding of facts about leprosy, schemes by service providers for persons affected by leprosy, and the acceptance level of persons affected by leprosy in the community. The second and third areas of data collection were audiotaped and transcribed.

STATISTICS

The stigma measurement scale, FGDs, PRAs and the internal consistency of the integrated PHC programme were analysed using qualitative methods for in-depth analysis, and a frequency chart was made to calculate the coherent answers.

Results

DEMOGRAPHY

The prevalence rate of leprosy in the state of Maharashtra in 1999–2000 was 3.7 per 10,000 population, 2.64 per 10,000 in the integrated PHC approach area and 4.7 per 10,000 in the vertical approach area. During this period 58 patients were under treatment (13 MB and 45 PB cases) in the integrated area and 95 (33 MB and 62 PB cases) in the vertical area.

The total number of leprosy patients interviewed was 24, with five in the model villages, nine in the randomly selected villages of the integrated PHC programme of CRHP at Jamkhed, and 10 in the control villages with the vertical approach. A total of 15 FGDs were held with the family members and 15 PRAs with the community. The sex ratio was three men to two women in all these villages, with the age ranging from 35 to 90. The median age in model, random and control villages was 60 years. The deformity status in vertical and integrated programmes was comparable (Table 1). The integrated and vertical villages were also similar in terms of occupation, caste, religion, language, socioeconomic status, and geographical terrain.

Among the total study group, only one person remained unmarried due to leprosy. In the integrated villages, nearly one-fifth (3/14) were separated from their spouses due to leprosy and one in ten in the vertical area. Two subjects remarried, one each from the integrated and the vertical approach villages. Parents or family members, except in one case, arranged all the marriages. In most instances, leprosy was diagnosed after the marriage, as Table 2 shows.

Table 1. Deformity status of the sample groups

Type of deformity	Integrated	Vertical
No deformity	0	0
Ulcers	2	1
Visible deformities	12	9
Total	14	10

INTERNAL CONSISTENCY IN THE INTEGRATED APPROACH

Sixteen facets were taken from the model and random villages to see the difference within the integrated PHC approach. Table 3 indicates that there was a very minimal difference within the integrated PHC approach areas.

SELF-ESTEEM OF SUBJECTS

The level of self-stigmatization among subjects was measured by asking two open-ended questions. The first was whether they considered leprosy like any other disease. In the integrated approach 12 (85.7%) felt that it was like any other disease. A similar situation (at 60%) was also observed in the vertical programme. However, with the question 'can you discuss your disease sitting in a tea-shop?' only one (10%) in the vertical programme said he could do that, whereas 11 (78.6%) in the integrated programme said they could. It clearly showed that in the vertical approach they were not able to freely discuss their disease.

ATTITUDE OF FAMILY MEMBERS

In-depth questions were asked to elicit the attitude of the subject, spouses, children and relatives. In both vertical and integrated villages the subject's family members had positive attitudes. However, in the vertical approach they did not involve the PALs in decision making, whereas in the integrated approach family members took decisions along with the subjects, and they were also involved in conducting family functions. Female persons affected by leprosy did all household activities, including cooking, in the integrated approach villages.

Maruthi Mule, a 60-year-old male from a model village with PB leprosy and grade 2 deformities in his hands and feet, recollected his story as follows. His wife deserted him when he was diagnosed as having leprosy at the hospital in Jamkhed. He lived in a small temporary hut outside the village, as the people did not accept him in the village. When the Jamkhed

Table 2. Timing of leprosy diagnosis in relation to marriage

Samples	Before marriage	After marriage
In model villages	3	4
In random villages	1	8
In control villages	3	6

Table 3. Internal consistency in the integrated approach

Sr. no.	FACETS	Positive responses from		Sr. no.	FACETS	Positive responses from	
		Model	Random			Model	Random
1	Freely discussing about leprosy	5	4	9	Wedding alliance of children	5	4
2	Leprosy like any other disease	5	3	10	Way food is served at home	4	3
3	Attitude of spouses	5	4	11	Colleagues' interaction at work	4	5
4	Attitude of children	3	5	12	Ties with friends	4	5
5	Attitude of relatives	3	5	13	Meeting government officials	4	5
6	Housing of subjects	5	5	14	Accessibility to local tea-shop	4	5
7	Invitation to social functions	5	3	15	Accessibility to hair cut in village	5	4
8	Attendance at social functions	4	5	16	Accessibility to the local clinic	4	5

people came to organize a Farmer's Club in the village, he was included in it as a member. In the meantime, his financial position started improving with the economic improvement programme of the leprosy project. He started appreciating changes in the attitudes of the community when they sat next to him in the Farmer's Club meeting and offered tea in common tumblers. Soon he married again, and 5 years after their wedding his wife was diagnosed with PB leprosy. She does not have any deformity. They have two sons and a daughter. All of them have married within the same village. Mule takes care of his grandchildren, when their parents go for work.

ECONOMIC INTERACTION

As the median age is 60 in all groups, 40% of subjects have retired from active work and are dependent on their family members. The remaining 60% of subjects either continued in the same job or downgraded their work due to old age or deformity. Only one person in the random village was dismissed from the railway due to leprosy, 20 years ago. Focus group discussions with the family members revealed that in the integrated approach all the families were independent and also received economic support from the service providers in some form or other, e.g. goats (Table 4).

Vitthal Sathe, 62-year-old male, is an example of successful economic integration in a model village, and the excerpt from his case history is as follows: 'I am originally from Zikree and was diagnosed with leprosy by the Jamkhed mobile team. At that time I was working as a labourer and had two daughters. After taking treatment for 3 years, I asked for a job in the hospital, and they took me as a watchman. They also gave me money to buy three goats.

Table 4. Focus group discussions and participatory appraisals: frequency of responses concerning service provision, from the families and communities

Response	Families		Communities			
	PHC approach		Vertical approach	PHC approach		
	Model	Random		Model	Random	Vertical approach
Moral support and confidence building	1	1	–	2	–	–
Economic support	5	5	–	4	–	–
Prevention of deformities	1	1	–	–	–	–
Diagnosis of treatment	5	2	3	5	2	3
Care from grassroots workers	–	1	–	2	1	–
Attended seminars on leprosy	–	1	–	–	1	–
Nothing/we don't know	–	–	2	–	–	5
Survey	–	–	–	1	1	–
Health education	–	–	–	2	3	–
Educated us how to diagnose leprosy	–	–	–	1	–	–
No new person affected by leprosy in the village	–	–	–	3	2	–
We think leprosy is like other disease	–	–	–	1	–	–

I multiplied it into 15 in 3 years. Then I purchased a cow. Now we have four cows and five buffaloes. With the income from livestock and my savings, I had sufficient money to buy land for cultivation. Since there was no land available in my native village, I moved to my wife's village to settle. There I first purchased a house and a piece of land from a relative of mine to build another house for my son. Then I bought 5 acres of land for cultivation. Though I belong to low caste people, people from other castes come to my house when I invite them for functions; similarly, we also attend their functions. My eldest daughter got married; at that time I only paid the wedding expenses, which came to Rs 11,000/-, and did not pay dowry. The other two girls were married to my relatives, so I did not pay dowry for them either.

The situation in the vertical approach was different. In only two families the person affected by leprosy was economically independent, and the others were all dependent. Some comments from family members were, 'he is sitting at home and depending on us', and 'if leprosy patients have deformities, they have to depend on family members'.

SOCIAL INTERACTION

Social interaction issues, for example, the location of the subject's house, invitation to social functions, and attendance in such functions, were analysed. Wedding alliances of the subject's children, how food is served in their houses, interaction with colleagues at work, and the subject's initiative in local affairs were also analysed. In the vertical approach, 4/10 people affected by leprosy or their family members moved out of the house after the diagnosis of leprosy, and 2/10 were allowed to use only a specific area in the house. This clearly

indicated that isolation in one form or another is being practised by 6/10 the families. In the integrated programme such isolation was observed in 3/14 families.

In the integrated approach villages, all the persons affected by leprosy were invited to social functions, whereas only half of them were invited in the vertical approach. Among those who were invited, 12/14 in the integrated approach made it a point to attend and participate in the meal; only 3/10 did so in the vertical approach villages.

In the vertical programme villages, half of the leprosy patients took the initiative to meet government officials regarding local problems, while the figure was as high as 13/16 in the integrated approach. In the vertical approach, food was served on separate plates for 7/10 of persons affected by leprosy, but only one out of 14 in the integrated approach. Almost the same situation was observed in colleague's interaction with subjects at work and their ties with their friends.

Another social interaction measurement looked at was the accessibility of the local services, such as haircut in the village, local teashops and local clinics. On the whole, for the majority of the subjects in both groups, the first two were accessible. However, the local clinics were accessible to 6/10 in the vertical approach, while they were open to every person affected by leprosy in the integrated approach.

Parigabai Neurti Salunke, 36-year-old female MB leprosy patient from an integrated PHC village, narrated the changes she had observed in her community over the years: 'My mother died when I was small, and I assumed that this was the reason for my disease. My father married again soon. For my skin disease I was taken for divine cure and then to a hospital in Beed district and from there to Jamkhed hospital. I was admitted there for 6 months because I was getting repeated reactions. My father knew that I was suffering from leprosy, but no one told me. Some of the villagers also knew my diagnosis and wanted nothing to do with me. I was given a separate room in my house to live. Muktabai, our Village Health Worker (VHW), visited me frequently and took care of me, treated me, and made sure that I took my MDT regularly. I was having problems with my stepmother, who was not treating me well; she used to just throw food into my living area. I was admitted in the hospital on and off. In the meantime, I took tailoring classes and got a sewing machine from a government programme. I got five goats also. This made me financially independent. Soon Muktabai had to leave the village, and the VHW position became vacant. The villagers and Muktabai suggested my name for this post, and I was selected. I had training for this voluntary job at Jamkhed. Now I also diagnose leprosy cases in the village. When the village headman was diagnosed with leprosy that further helped villagers to accept leprosy like any other disease. Now I take care of my elderly father and stepmother, and also I am responsible for health and development activities in my village.

AWARENESS OF ACTIVITIES OF SERVICE PROVIDERS

Family and community perceptions of the schemes operated by service providers for people affected by leprosy were obtained through FGDs and PRAs. Both vertical and integrated PHC approach groups were aware of the diagnosis and treatment services provided by the respective organizations. All the families in the integrated approach received economic assistance, and the communities of the model villages perceived this fact (Table 4). The aspect of economic assistance was totally lacking in the vertical approach. Half of the integrated PHC community appreciated the health education activities, and they proudly declared that there were no new patients. In the vertical approach all their community

members and 2/5 families said that they were not at all aware of the activities of the service providers (Table 4).

KNOWLEDGE AMONG FAMILY AND COMMUNITY MEMBERS OF FACTS ABOUT LEPROSY

In the integrated approach, the community members were fully aware of the facts about leprosy; the grassroots workers and women and men's club members disseminated the facts about leprosy.

In the vertical programme, on the other hand, the facts about leprosy have not reached the family members or the community. Answers like 'it is a contagious disease' 'if you eat from a leprosy patient's plate and stay with them, you will get leprosy' 'it is dangerous because people lose fingers' 'it is a very big disease' 'leprosy cannot be cured' 'keep them separate for 6 months to cure' indicate this. Half of the family members answered that there is no cure available.

STIGMA LEVEL IN THE COMMUNITIES

Ten participatory rural appraisals were conducted among communities of the integrated approach, and these communities uttered no stigma-eliciting statements. A few key statements were as follows: 'We don't separate patients at all; they are part of the community.' (8/10); 'Here no leprosy patients are thrown out of their family, and we treat them as normal persons.' (2/10); 'They are accepted in all social functions and we allow them to cook.' (5/10); 'Previously we thought that it is an infectious disease. Now we have changed our attitude.' (2/10); 'Now we know that it is totally curable.' (1/10); 'Community can help in case detection.' (2/10); 'My wife had leprosy. She took medicines. She is cured. Now I declare it.' (one testimony).

In the vertical approach, five PRAs were conducted in their communities. More than 80% of statements indicated a high level of stigma and also no community contribution towards reintegration. A few key negative statements were as follows: 'It (leprosy) is our fate.' 'Keep them separate. We don't allow them to mix with the community.' 'They should not stay with the family.' Two groups felt that leprosy patients should be taken outside the village and kept there. 'If husband or wife has leprosy they should be separated.' 'We should not have close contact with leprosy patients.' 'Our patients also feel awkward to take part in community activities.' 'We don't eat with them.' 'We don't accept or touch patients.' 'We cannot say 'no' to them if they come and sit next to us, but from our hearts we don't want them to do that, because we will get the disease.' 'We have two patients in our village now. It may become five tomorrow.' 'We keep early cases in the village, and advanced cases have to stay outside the village.' Two groups felt that if leprosy patients have gross deformities, their bed and eating utensils should be separate. There were also positive statements: in two PRAs participants also mentioned that that they will accept persons affected by leprosy in their community, and one group felt that that they can stay with their family and family members could share vessels.

Discussion

The results clearly indicate that with the integrated community-based PHC approach, social stigma was minimal for people affected by leprosy. However, there was a high level of

divorce rate in both study and control villages. Most of them took place 25 years ago, before the integrated PHC approach was initiated and the government commenced their vertical programmes. There is evidence that stigma against leprosy is gradually reducing worldwide for a variety of reasons.¹⁶

The results also indicate that there were very few negative attitudes among family members towards their leprosy spouses. Similarly, all those who had disease before marriage knew their diagnosis, but none of them disclosed it to their spouses. When their spouses came to know the diagnosis, one deserted her husband in the integrated approach; and one in the vertical approach refused to accept her husband's diagnosis of leprosy despite the fact that he had visible finger contractures. The wife believed that the contractures were due to burns. All others mentioned that they were suspicious of leprosy even before marriage, but they still married, as it was their second or third marriage. Both these findings indicate that if there is a need, stigma may be overcome, irrespective of their knowledge of the facts about leprosy.

The PRA in communities very clearly indicates that unless the programme is community based, the stigma tends to be very high. Statements like 'We have two patients in our village now. It may become five tomorrow' indicate that they were not aware that these two deformed patients were released from chemotherapy long ago and there may be a few others in the village with infectious type of leprosy. In-depth interview with subjects also corroborated the social de-integration in the vertical approach.

In contrast, certain statements in the integrated PHC approach villages like 'My wife had leprosy. She took medicines. She is cured. Now I declare it' among his villagers shows that he considers leprosy like any other ailment. Another statement was 'If they don't take regular treatment, we will throw them out of the village' indicating the community involvement in case holding. The proud declaration of half of the integrated approach communities that there were no new people with leprosy in their villages reveals their active role in the elimination of this disease.

As far as the leprosy eradication activities are concerned at CRHP, surveys were conducted in an integrated fashion, checking the communities and families for general health, TB and Leprosy. Due to this method, there was no suspicion that they were checking only for leprosy. The grassroots workers were trained to show love and care towards leprosy patients and they practiced this in their communities. Therefore, the community learned to accept leprosy patients back into their families and communities. If patients had ulcers, they were taken care of in the referral hospital of CRHP. In every community the village people trained to recognize and diagnose leprosy. The women and men's groups give other village people education about leprosy and teach that it is not a dreaded disease. Our findings conclude that the problem of social stigma in leprosy can be dealt with through an integrated, community based approach and this approach may be considered by others to implement in their programmes.

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