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A Qualitative Assessment of Current Perception of Different Social Groups about Leprosy in High & Low Prevalent Districts of West Bengal

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Abstract:

Background: A KAP study on leprosy among leprosy patients, family members, community & service providers was conducted in both high & low prevalent district of West Bengal. As a part of the study, to corroborate its finding, a qualitative assessment on perceptions of different social groups about leprosy in the study area was undertaken. **Objectives:** To assess perception & attitude of different social groups about leprosy. **Materials & Methods**: 26 FGDs in high prevalent and 72 FGD in low prevalent districts of West Bengal were arranged with different social groups like health workers, ASHA, panchayer members, NGO repepresentatives etc. Total 274 persons in high prevalent districts & 780 persons in low prevalent districts, representing different social groups of the locality participated in the discussion. **Results**: Most of the panchayet representatives & villagers had poor knowledge & adverse attitudes & stigma towards leprosy, whereas ASHA workers were found to have inadequate knowledge about the

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disease. **Conclusion**: Community involvement, reorientation & adequate training of front line workers, proven IEC are required to address the problem..

Key words: Focus Group Discussion (FGD), KAP, Qualitative assessment, leprosy

Introduction:

As a result of sustained effort & executed activities, India has achieved the goal of elimination of leprosy as a public health problem, defined as less than 1 case per 10,000 population, at the national level in the month of December, 2005 (PR-0.95/10,000). But this was not uniform throughout the country. 115 out of 657 districts in the country have prevalence rate more than 1 per 10,000 populations with intra & inter-district varability.[1]

The programme has been integrated with general health care system in 2002-03[2], thus posing various operational challenges in programme management.[2] In spite of continuous efforts made so far, stigma, misbelieves, adverse attitude towards leprosy are still prevalent among common people of the developing countries including India.[1,3,4] Though knowledge is an important factor, there are social and cultural pressures that have an influence on decision making in treatment seeking behavior of those affected. Because of the social stigma and ignorance attached to it, this has made it difficult for our health care delivery system in their pursuit for early diagnosis and prompt treatment [5]

There are variable knowledge & attitude about the disease in different social groups, including front line health workers, teachers, religious leaders, panchayet representatives etc. Poor quality of knowledge, negative attitude, poor work performance and poor relationship with leprosy patient among health care providers are important factors that interfere patients compliance with treatment.[6] Social and cultural factors, especially stigmatization and the lack of awareness in the community of the medical basis and effectiveness of treatment for leprosy, are major contributors to the persisting burden of leprosy.[7] With a view to maximize the effectiveness of health education programme, it needs to assess current status of perception of the different social groups influencing on the attitude & practices of common people about the most stigmatized disease of the mankind i.e leprosy. In this background, a qualitative assessment was undertaken as part of already conducted study on 'Current Knowledge, Attitude and Practices (KAP) about Leprosy among leprosy patients, their family members, Service providers and

General Population: a comparative study between high prevalent & low prevalent districts of West Bengal' to corroborate the findings revealed & get additional information, by Focus Group Discussions in study area.

Objectives:

1. To understand about the perception of representatives of social groups about different aspects of leprosy
2. To explore about stigma prevalent among them
3. to get the inconsistency & variation that exist in the communities in terms of beliefs, attitude & experiences with respect to high & low prevalent districts

Materials & Methods:

Type of the Study: A qualitative study based on Focus Group Discussion (FGD)

Settings: The study was conducted in 3 high prevalent & 3 low prevalent districts of West Bengal.

Selection of Focus groups: In the 1st stage sampling, 3 out of 10 districts achieving elimination status and 3 out of 9 districts not achieving elimination status were selected randomly for the study. The selected districts in high prevalent areas were Purulia, Bankura & DakshinDinajpur and three selected districts in low prevalent areas were Howrah, North & South 24 Parganas.

In the 2nd stage of sampling one-fourth i.e 25 % blocks and 25% of municipality/ urban areas (at least one, if total urban area in the district is less than 4) were selected randomly from each district. Thus, 13 blocks & 3 municipal areas in high prevalent districts and 18 blocks & 10 municipal areas in low prevalent districts were selected. In 3rd stage of sampling, one-fourth (25%) of recorded leprosy patients receiving treatment under NLEP in each selected block/municipality of high prevalent districts were chosen randomly and all recorded leprosy patients receiving treatment in each selected block/municipality of low prevalent districts were selected. From the villages wherefrom we identified patients of leprosy, one focus group discussion was conducted. We could conduct 26 FGDs in

high prevalent and 72 FGDs in low prevalent districts of West Bengal. Total 274 persons in high prevalent districts & 780 persons in low prevalent districts, representing different social groups of the locality participated in the discussion.

Participants of the FGDs (Study subjects): Representatives from Panchayet Raj Institute, health workers, ASHA, AWW, NGO, teachers, medical officers, local practitioners practicing both modern & indigenous system of medicine, councillors from municipal bodies & local residents were among those who participated in the discussion and expressed their views.

Subject Inclusion criteria:

Participants were informed 2 days earlier about topic, place & time of FGD. Those who gave consent to participate, could manage to give time for at least 2 hours and who were willing to discuss on the subject matter of leprosy were included as participants.

Procedure: Eight to twelve participants constituted a group. One moderator & one assistant moderator were assigned to conduct the discussion. Moderator facilitated discussion, whereas assistant moderator acted as rapporteur & run the tape recorder to record the whole discussion to decode it later for report writing. Care was taken by the moderators to maintain neutral attitude & appearance, and to put participant at ease so that they could evenly participate to answer questions in their own words.

Ten questions were carefully structured so that they were short & to the point, one dimensional, unambiguous, non-embarrassing, and worded in such a way that could not be answered with simple 'yes' or 'no' responses: They are-

-What is leprosy?

- What is its clinical presentation?

-What causes leprosy- is it hereditary?

-How does a person get leprosy?

-If any sign is detected, what should the patient/ Family members do?

-What is its treatment?

-What are practices regarding marriage & social relation with leprosy patients/ their family members?

-Is ostracism prevalent among community? If yes, in what way?

-What are your views & experience regarding Government health facilities for treatment of leprosy patients?

- What are your views & experience regarding private health facilities for treatment of leprosy patients?

Time allotted for FGD were about one hour.

Ethical clearance was taken from Institutional Ethics Committee of Institute of Post Graduate Medical Education & Research, Kolkata

Result:

To corroborate the findings revealed from survey & get additional information, focus group discussion was conducted in study area. Total 26 and 72 focus group discussions were arranged in high prevalent (e.g Bankura, Purulia & Dakshin Dinajpur districts) and low prevalent (Howrah, South & North 24 Parganas) districts of West Bengal respectively. Total 274 persons in high prevalent districts & 780 persons in low prevalent districts, representing different social groups of the locality participated in the discussion. Representatives from Panchayet Raj Institute, health workers, ASHA, AWW, NGO, teachers, medical officers, local practitioners, villagers were among those who participated in the discussion and expressed their views.

Table-1 Distribution of participants in FGDs

Participants	High prevalent districts No (%)	Low prevalent districts No (%)	Total No (%)
Panchayet members	58(21.17)	120(15.38)	178(16.89)
NGO representative	6(2.19)	23(2.95)	29(2.75)
Health workers	110(40.15)	336(43.08)	446(42.31)
ASHA	17(6.20)	83(10.64)	100(9.49)
AWW	4(1.46)	17(2.18)	21(1.99)
Local practitioners (RMP, Homeopath)	11(4.01)	13(1.67)	24(2.28)
Teachers	33(12.02)	65(8.33)	98(9.30)
Villagers	31(11.31)	104(13.33)	135(12.81)
Doctor	1(0.36)	15(1.92)	16(1.52)
Others	3(1.09)	4(0.51)	7(0.66)
Total	274(100.00)	780(100.00)	1054(100.00)

In the high prevalent districts, particularly in Bankura & Dakshin Dinajpur, most of the panchyet representatives were found to have poor knowledge about leprosy, its treatment, & NLEP and high stigma & adverse attitude toward leprosy with few exceptions in Purulia district. Health workers, in most areas except in one block in Bankura, have good knowledge and favourable attitude towards the disease. Out of 110 health workers participating in the discussion, few have idea that leprosy can be spread by sharing article, soap in particular, with leprosy patients and isolation of the patients is mandatory.

Teachers participating in focus group discussion have come out with moderate to good knowledge & attitude excepting few cases in Dakshin Dinajpur district. Most of the villagers participating in FDG have poor knowledge & high stigma for leprosy, though some exceptions were there. A majority of villagers mentioned that people should avoid a leprosy patient & a leprosy patient should neither get married nor attend any social functions. Member from NGO working at the locality, though have poor knowledge, but less stigma towards the disease. Through the focus group discussion, few important social problems were revealed. Health supervisors participating in the discussion admitted that stigma related to the disease was still highly prevalent in some areas. Leprosy patients in Barjora block were not allowed to use water bodies in public places. One driver posted in a BPHC refused to get treatment in fear of being marked as a leprosy patient. One people representative in Balurghat of Dakshin Dinajpur, categorically mentioned that leprosy patients should be kept away from community.

From most of the FDG done in low prevalent districts, it was revealed that panchyet representatives have poor understanding as well as motivation towards leprosy. Few members were in favour of isolating leprosy patients from any social function. Health workers, similar to high prevalent districts, were found to have moderate to good knowledge about leprosy excepting one municipality in North 24 parganas. ASHA workers participating in the discussion have shown some knowledge about leprosy, its management as well as NLEP. Unlike the findings in high prevalent districts, with few exceptions, teachers participating discussion

were not found to have good knowledge and favourable motivation towards the disease. Four out of 65 teachers expressed their opinion that leprosy patients should be isolated and restricted from attending any public gathering. Most of the NGO representatives (excepting one having good knowledge) working in other fields in this locality, key community persons, and ICDS workers have poor knowledge. Few doctors were present in FDG. It was revealed that though they had good knowledge about the disease, its causal factor, but failed to contribute about current management protocol of NLEP.

That people have stigma about *leprosy, came out from FDG held in North 24 parganas. One GP Pradhan expressed his opinion that he was against including Leprosy Patients in any Social event*. Same opinion was expressed by local Homeopath doctor, but health worker went against this view. In one FDG, it was revealed that out of 9 participants, only two persons (health workers) have some knowledge about leprosy. One Municipality chairperson did not have any idea about the disease. 104 villagers taking part in different focus group discussion showed poor perception and high stigma toward leprosy. A high proportion of then expressed their opinion that leprosy patients should not be allowed to move freely in the community or to attend any social events.

In Shyampur-I & Amta block of Howrah district, most patients were not aware that they were being treated for Leprosy. The BMOH accepted the fact that there was high stigma in the area and people would try to hide themselves if they knew the truth.

In Shyampur-II, Patient and family members avoided talking to the Investigating team with the fear of being marked and stigmatized. A college student was getting treatment, but tried to keep it a secret to avoid being tagged as a Leprosy Patient. In some blocks of south 24 parganas districts, patient avoided mixing with neighbours in fear of being branded as a leprosy patient. Patients with deformity in Magrahat of south 24 Parganas, were not allowed to participate in social events. One patient in south 24 parganas district complained of being ill-treated by everyone in the family excluding his wife. He even avoids talking to the neighbors.

Discussion:

Though India has achieved elimination status in 2005, many districts & blocks still lag behind. Knowledge & favourable attitude of all sections of population towards this most stigmatised disease are required to eliminate leprosy as a public health problem. To explore knowledge & perceptions about leprosy among different social groups including local common people, FGD was conducted in both high & low prevalent districts in West Bengal. Health workers participating in FDG have shown good knowledge and favourable attitude toward leprosy in both high & low prevalent districts. Similar finding was seen in a study done in Satara district of Maharastha revealing that more than 88.31% MPWs had good knowledge about leprosy and NLEP activities under national leprosy eradication programme.[6] ASHA workers who have been involved in bringing out suspected leprosy cases from their villages for diagnosis, treatment & follow up[2] were found to have inadequate knowledge about the disease. Verma & Rao in their study found that only 3-6% of the ASHA workers in the NRHM had taken an active interest in leprosy[8]

Teachers from high prevalent districts were found to exhibit better knowledge compared to their counterparts from low prevalent districts. Panchayet representatives from both high & low prevalent districts have poor understanding as well as motivation towards leprosy. Villagers participating in FDG representing the common people have shown poor perception and high stigma toward the disease. Similarly, a study reflected the poor awareness and negative attitudes towards leprosy in leprosy colony dwellers and urban slum dwellers in South District of Delhi[4]

In a qualitative study undertaken in the Kanchipuram district of Tamil Nadu in South India, respondents including patients, healthcare providers, policymakers and community leaders referred to problems arising from both health system and behavioral factors.[7] A study conducted in urban slum of Kolkata showed that a majority had some knowledge of leprosy but hardly knew early signs or symptoms or where to get proper diagnosis and treatment. Glaring gaps were noticed between knowledge and practice of slum population regarding leprosy.[9] Similarly in rural Tamilnadu family member's knowledge about different aspect of leprosy varied from 37% to 82%.[5] Another study conducted in Delhi showed inadequate knowledge of the respodents.[10]

In the current study, stigma was found to be prevalent not only among common people, but equally among people representatives also; teachers and workers attached to health system were not totally free from this problem. Different studies conducted in different states of India & outside of it expressed similar concern.[3,4,10,11,12,13,14] In urban slum of Delhi, myths and belief such as "leprosy can occur spontaneously", "due to past sins", "curse of

God" and "hereditary were still prevalent in the study subjects [4] In brazil, Hansen's disease is treated as a case of impurity. Some of the patients used to hide the disease from neighbours and co-workers for fear of their reactions. Feeling like annoyance, silence, stigma, and aversion were found to contribute to the failure of treatment, noted by a poor adherence to the therapies.[3] In another study conducted in Kolkata among adolescents showed the role of social stigma in hiding, delay in starting of MDT & defaulting[11]

All community-based rehabilitation workers in South Africa rightly commented that social stigma was a stumbling block to leprosy elimination as expressed in the following comments, "The leprosy patient rejects his/herself first by shying away from people and sitting at corners in gatherings, followed by the family and the community".[12]

The factors associated with higher stigma were found to be illiteracy, perceived economical inadequacy, change of occupation due to leprosy, lack of knowledge about leprosy, perception of leprosy as a severe disease and difficult to treat[13] As a consequence of both enacted and perceived stigma, a person over a long period of time develops a self-stigma or internalized stigma, thus lowering self esteem & respect.

Conclusion:

From Focus Group Discussion, the findings came out that most of the panchayet representatives & villagers had poor knowledge & adverse attitudes towards leprosy, whereas ASHA workers who were supposed to spread awareness in the village were found to have inadequate knowledge about the disease. Stigma about the leprosy was still prevalent among groups with inter group & intra-group variation. With the community involvement at all stages of a programme, from planning to evaluation, proper reorientation & adequate training of front line workers, removing enacted & perceived stigma among people through proven IEC, we can address the problem to reach the desired goal.

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