

## **TITLE OF THE PROJECT**

Current Knowledge, Attitude and Practices (KAP) about Leprosy among General Population: a comparative study between high prevalent & low prevalent districts of West Bengal

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### **RATIONALE OF THE STUDY:**

Leprosy is probably the oldest disease known to mankind. In India leprosy is known since ancient time as 'Kustha roga' and attributed to punishment or curse from God.

With introduction of Multi Drug Treatment (MDT), the program was renamed as National leprosy Eradication program (NLEP) in 1983. Though India achieved the status of elimination in the year 2005 but India still continues to record the highest number of new leprosy cases in the world.

The goal of the program has now been shifted to "Leprosy Free India" and to achieve eradication i.e. zero endemic of Leprosy, where elimination is achieved. Since 2001, MDT services in India were integrated with the general health services, thus posing various operational challenges in program management .

The disease comes with so many myths and carries great social stigma of ostracism which compels the patients to hide the diseases resulting in deformities.

So, with a view to make more effective community based strategies, maximize the effectiveness of health education program, it needs to assess current status of perception and practices of patients, family members, and community as well as service providers. Moreover, community survey will give an opportunity to identify hidden cases if any unnoticed to health services. The finding of such study will definitely help the policy makers to get an idea about perception, prejudices, practices as well as attitude of the community towards the most stigmatized disease so as to adopt appropriate changes accordingly. In this background this study was undertaken with the following objectives.

### **OBJECTIVES:**

#### **General Objectives:**

To assess knowledge, attitude, and practices about leprosy among general population of the study areas.

**Specific objectives:**

1. To assess perception and practices about leprosy among general populations
2. To compare KAP of the respondents between low & high endemic districts of West Bengal
3. To identify factors contributing to gap in KAP in the community..
4. To identify hidden cases, if any while conducting KAP survey among general population with a view to put them to early treatment.

**MATERIAL & METHODS**

**Type of the Study:** A cross sectional observational study

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

**Study subjects:**

1. General population of the same villages where selected leprosy patients live, for assessment of their perception and practices regarding leprosy and finding out hidden cases, if any.
2. Members from Panchayet Raj Institutions, NGOs, self help groups, ASHAs, community or religious leaders and local practitioners practicing both modern & indigenous system of medicine for focus group discussion.

**Sample size:** 25% of leprosy patients getting MDT in 25% blocks of 3 high prevalent & all patients in 25% blocks in 3 low prevalent districts of West Bengal, 20% of households of the villages or wards where the selected patients live. In each selected villages, members from Panchayet Raj Institutions, NGOs, self help groups, ASHAs, community or religious leaders and local practitioners practicing both modern & indigenous system of medicine were included for focus group discussion. Based on the available records, sample size was estimated as under-

185 patients from high endemic districts & 115 patients from low endemic district were selected (Vide Annexure-II). Thus about 300 patients, about 40 community members from each community where patient lives ( considering 1000 population in each village with 5 family members in each family) totaling 12000 community members. In addition, 300 FGD was proposed to be held.

**Sampling techniques:** Multi-stage sampling technique was adopted.

**Subject Inclusion criteria:**

- 1) Those who could communicate verbally
- 2) Those who has given informed consent
- 3) Patients currently under treatment were selected.

**Subject exclusion criteria:**

- 1) Critically ill patients
- 2) Migrated to elsewhere during the period of data collection.

Separate schedules containing open and close ended questions, were used for collecting relevant data form community members.

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

Necessary permission was taken from Dept of Health & Family Welfare to conduct the study in the selected districts and cooperation from the district authority was requested.

**Focus group discussions** were conducted with the Members from Panchayet Raj Institutions, NGOs; self help groups, ASHAs, community or religious leaders and local practitioners practicing both modern & indigenous system of medicine in the communities to broaden the range of respondents and to supplement some of the findings in already taken interviews with different respondents concerning perceptions, beliefs & health seeking behavior.

**Outcome variable:** Knowledge, attitude, practices about leprosy, including treatment seeking behavior, no of newly diagnosed hidden cases, social stigma & discrimination of patients among different category of respondents; differences of KAP among respondents with respect to low & high prevalent areas, and other independent variables.

**Indicators:**

**Community members:**

- Proportion of persons knowing major signs of leprosy
- Proportion of persons having correct knowledge of causal agents
- Proportion of persons having correct knowledge of transmission
- Proportion of persons having correct knowledge of MDT
- Proportion of persons having idea about rehabilitation
- Proportion of persons making discrimination to leprosy patients

**ANALYSIS:** Data were entered and analyzed in the MS Excel starter 2010 version. Percentage of positive responses (outcome) was computed with respect to different independent variables and differences were tested by Chi-square tests.

**TIME PLAN:**

**Total duration: one year**

**Preparatory phase: 2 months**

1. Meeting with state & district health authorities
2. Developing Schedules & its pre-testing
3. Training of Investigators

**RESULT**

**Knowledge, Attitude & Practices of the Community:**

Total 4460 adult persons were interviewed to assess knowledge & perception of people residing in the same villages wherefrom leprosy patients were identified. From each village, 40 households were visited to interview 40 adult respondents preferably heads of the families. 1530 persons in high prevalent districts and 2930 persons in low prevalent districts were interviewed. Most of the

respondents were between 20 to 50 years. People interviewed were equally distributed by age in both groups. ( $p=0.339$ ). 50.3% was male and 49.7% were female. Proportion of male respondents in high prevalent areas was found to be more. 39.82% respondents were housewives, and 27.35% service holders. 50% of the respondents completed primary education, 15% were illiterate and very few (4.8%) were graduate or above. 27% respondents in high prevalent districts were illiterate, which is much higher in comparison with those of low prevalent districts (8.98%), difference is highly significant. 79.6% were Hindu & 20.4% were Muslim. 59.7% belonged to general caste, whereas rest came from socially backward community. 55% respondents were from socially backward classes in high prevalent districts, whereas proportion was much low in low prevalent districts (33%), difference was found to be highly significant. 37.78% people were living below poverty line, BPL families were more in high prevalent districts. 85% respondents were married.

97.58% People from high prevalent districts & 59.45% in low prevalent districts had heard about leprosy, the difference was found to be highly significant. Correct knowledge about cause of leprosy was found in 37.11 % of general population. 33.4% people from high prevalent districts and 39.04% people from low prevalent districts told bacteria to be the causal factors. A large number of people (29.3%) have the idea that it is caused by curse, sin, heredity and bad blood, whereas 21.4% people did not have any idea about the cause of leprosy. 27.6 % people thought that close contact with the patient could be responsible in spreading the disease, whereas a large no of people considered that cough & sneezing (28.47%), sharing article (14%), casual touch /hugging might spread leprosy, whereas 23.9% did not have any idea about its spread. 31.3 % people said that anaesthetic patch was the presenting symptoms of leprosy, and 32.2 % mentioned hypo-pigmented patch to be the presenting symptoms of leprosy, whereas 16.8% have no idea about symptoms which a patient might present with. 18.9% people thought that all leprosy patients were infectious to others, 51.2% people had idea that few patients were infectious, this idea did not vary much between people of high and low prevalent districts.

81.4% said that leprosy was a curable disease, whereas 6.25% said that it had no cure. More people (83.41%) residing in low prevalent areas knew the fact that leprosy was a curable disease. Large no of people (42.1%) did not hear about MDT. 54.18% people in high endemic districts & 59.45% people in low endemic area heard about MDT, the difference was found to be significant ( $p=0.0000$ ). 47.13% people did not have any idea about duration of treatment of leprosy. That 6 to 12 months are required to complete the treatment of leprosy was known by 39.74% people in high prevalent districts & 38.33 % people in low prevalent districts, difference was not significant ( $p=0.358$ ). 48.29% people preferred medical officers for treatment, in case they got the disease. This preference differs between people from low and high prevalent districts, 52.66% people in low endemic area choose Medical Officers for treatment, whereas 39.93% people in high endemic area had the same choice. Most of the community members (98.7%) preferred to go to Government health facilities including hospital (69.7%), PHC (6.77%) and sub-centres (22.2%) for treatment of leprosy. Order of their preferred

institutes for treatment was hospital, sub-centre, PHC & private chamber; this was observed in both the areas.

77.57% mentioned either deformity or ulcer as complication of leprosy. People from high prevalent districts mentioned deformity as a complication of leprosy in higher proportion (54.84%) compared to those from low prevalent districts (40.92%). 90% people in high & low prevalent groups gave their opinion that deformity as consequence of leprosy could be avoided by early diagnosis and treatment. 6.2% people mentioned worshipping God as a way to avoid complication. Few people (2%) preferred treatment by traditional healer for prevention of complication.

Main sources of information about leprosy were found to be radio (30.7%), TV (58.7%) & folk media (11%). Majority of people heard about leprosy either from health workers (28.1%), ASHA (16.5%) or from neighbours (30.8%).

12.4% respondents in high prevalent districts & 8.7% in low prevalent districts mentioned divine curse was behind the causation of the disease, whereas 20.8% population considered the disease as an outcome of own fault of the patients. 16.67% people in high endemic zone compared with 8.16% in low endemic zone considered that patient should be kept separated from family & community, difference was statistically significant ( $p=0.0000$ ).

### **FINDINGS OF FOCUS GROUP DISCUSSION**

In the high prevalent districts, particularly in Bankura & Dakshin Dinajpur, most of the panchayet 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, Teachers participating in focus group discussion have come out with moderate to good knowledge & attitude excepting few cases in Dakshin Dinajpur district.

From most of the FDG done in low prevalent districts, it was revealed that panchayet 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.*

## **DETECTION OF HIDDEN CASES DURING HOUSE TO HOUSE SURVEY**

Field investigators, while conducting house to house survey, asked the head of the families, whether there was any hypo-pigmented patch on the body of any family members. If response was positive, the investigator thoroughly examined the persons. If leprosy was suspected, was reviewed by a dermatologist/experienced medical officers to confirm diagnosis and sent the patients to respective sub-centre for registration. Thus, total 42 cases (15 from low endemic & 27 from high endemic districts) were suspected for leprosy, 40 cases were confirmed and 17 patients, 6 MB & 11 PB cases, registered for treatment. 2 patients were under observation. Out of 42 suspected cases, 11 cases were children (26.2%). Of these suspected cases two patients from low endemic districts, had deformity, but in spite of repeated effort made from the investigating team, they could not be registered.

## **CONCLUSION**

In the struggle against leprosy, stigma has been one of the major concern over the years. New tools are required to address the issues of stigma; otherwise our sincere effort of combating the age old problem of leprosy will achieve slow progress.

A high proportion of patients with disability were found to be uncared. In view of the new priority, prevention & appropriate management of the disability needed urgent & timely attention. Concerted and focused research on pertinent areas like childhood leprosy, disability due to leprosy-its prevention, management & rehabilitation, community survey in low endemic district to identify their perception & practices, and searching for hidden cases, is urgently needed to get rid of the age-old problem of leprosy in our country.

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