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Socio-Economic and Health Status of Leprosy Affected Person: A Study in Jharkhand

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The study has been conducted in the Potka Block of East Singhbhum district of the state of Jharkhand. The district is mainly dominated by indigenous tribes, such as, Santhal, Munda, Ho, Bhumiz, Kharia, and Sabar. The unit of analysis of the study was an individual. The objectives were to: a) Understand the socio-economic and health status of LAP, b) Know the health seeking behavior and problems faced by the LAP, c) Assess the utilization of the programs related to Leprosy eradication in the study area and d) Suggest various measures for improving the socio-economic and health status of LAP. Fifty Leprosy affected persons (LAP) from the Potka block, comprising of 20% of LAP of that area have been selected as the study sample by using the method of Multi-Stage Random Sampling, with equal representation of men and women. The LAPs included leprosy patients, leprosy treated people and their family members. 39/50 (78%) of the respondents are illiterates and only 3/11 (6%) among the literate population have crossed matriculation and above. This seems to have resulted in the respondent's low level of awareness about the disease, resulting in delayed treatment. 14/25 (56%) percent of female and 13/25 (52%) of male respondents are considered untouchable by their natal families, thus forced to stay in congested leprosy colonies resulting in other social and health related issues. It was observed that leprosy cured children and also children of LAP are being denied admission in any school, due to the social stigma attached to it. 27/50 (54%)of leprosy patients and leprosy cured people (mostly with visible deformities) were found to practice begging as their sole means of livelihood. Many LAPs are also engaged in cultivation and small scale business particularly among the rural population. An amount of gender disparity was also observed in the employment pattern among the LAPs. Among the respondents 15/25 (60%) of the females are beggars as compared to 12/25 (48%) of the male respondents, 5/25 (25%) of males are each engaged in cultivation and small scale businesses in comparison to 1/25 (4%) of female and 6/25 (24%) of the female respondents are unemployed as compared to 2/25 (8%) of male respondents. It was observed that only 30% of the respondents were satisfied with the government treatment, 26% partially satisfied and rest were not satisfied with the government leprosy care system. Most of them wanted to seek treatment from the private health care providers. Overall this study reflects the poor socio-economic conditions of the LAPs. Though results of this exploratory study cannot be extrapolated to country or region or state without studying the situation in detail, it highlights the need for more in-depth studies and of government intervention in the form of encouraging awareness activities in the communities, engaging NGOs in case detection and after care service provision and rehabilitation of the LAPs.

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Introduction

Leprosy is a disease which has been stigmatized throughout history and across all continents, although there are wide variations in which this is worked out in different communities. According to WHO, "Leprosy is a disease which has struck fear into human beings for thousands of years. This is partly because it causes considerable deformities and disabilities". In 1991, the 44th World Health Assembly adopted a resolution to eliminate the disease as a public health problem by the year 2000 (WHO 1991a). However, one of the major obstacles to achieving this objective is the stigma associated with the disease. Stigma attached with the leprosy patients affects all aspects of leprosy control program. This stigma constitutes the different dimensions of leprosy in India. In India and world over Leprosy Affected Persons (LAPs) are subordinated and oppressed socially, economically and psychologically by the rest of the society. Here attitudes become a major factor as leprosy is a stigmatized disease. The attitude can be judged in two ways, i.e. the attitude of the sufferer towards his family/ colleagues/community and vice versa, which becomes a reciprocal process (Sinha 2000). These may be among the reasons for India continuing to record the highest number of new leprosy cases in the world followed by Brazil and Indonesia. While globally in 2008, 2.5 lakh new cases of leprosy were recorded, India accounted for 1.37 lakh of those cases followed by 38,914 cases in Brazil and 17,441 in Indonesia (Arole et al 2002). Despite major success till 2005, situation in India has not changed much during last 10 years.

Leprosy is not a hereditary disease, as people believe it to be. Nor all leprosy affected people are infectious where as majority of them are non infectious in nature (Noordeen 1985). Leprosy infection is not carried by air, food or water; it is usually transmitted as a result of close and repeated contact with infectious patients. Infection is also believed to spread through nasal discharges (Sinha 2000). Leprosy affects all socio-economic strata, however, mostly the people from lower economic strata are more prone to be infected by the disease as most of them stay in crowded and unhygienic conditions in both rural and urban areas (Park 2007).

The establishment of the Indian Council of the British Empire Leprosy Relief Association in 1925 (Renamed as Hind Kusht Nivaran Sangh in 1947) laid the foundation of organized leprosy work in India (Mutatkar 1979). The availability of Dapsone monotherapy for leprosy laid the foundation of National Leprosy Control Program in 1955 with the main objective of controlling leprosy through domiciliary treatment with Dapsone. But due to social obstacles, non-availability of drugs, lack of primary prevention (vaccination) and resistance of Mycobacterium leprae to Dapsone caused program failure (Rao 2004). In 1981, Govt. of India (GoI) launched the National Leprosy Eradication Programme (NLEP) in the year 1983 with the objective to eliminate leprosy as a public health problem by the year 2000 AD. Later WHO in 1991 adopted a resolution calling for elimination of leprosy as a public health problem by the year 2000 AD (reducing prevalence to less than one case per 10,000 population)" (WHO 1991b). NLEP of GoI has been supported by the World Bank (2nd phase 2000-2004), the WHO, DANLEP and nine other international leprosy NGOs (ILEP). During the 2001-2004 periods, the objectives were to decentralize the NLEP responsibilities to the states/union territories, to accomplish integration of leprosy services in to the General Health Care (GHC) system, and to achieve elimination at the national level (NLEP, 2008). NLEP announced elimination of leprosy as a public health problem in India in December 2005

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(http://mohfw.nic.in/National_Leprosy_Eradicat ion_Programme/LEP_SET_SCH.htm). However many research findings have documented the existence of endemic areas despite the achievement of the elimination status of leprosy (Gupte et al 2004, Shetty et al 2009). Many new cases has been reported in different hospitals in India, which is probably due to the discontinuation of adequate surveillance activities, distribution of multi drug therapy, deformity prevention and management performed by leprosy workers during the NLEP phase (Bharat Seva Ashram Sangha 2007).

Knowledge regarding socio-economic condition of the LAP becomes crucial in understanding the nature of accessibility of leprosy related health care services in India, esp. after India has been declared Leprosy free. In this context this exploratory study has been carried out in the state of Jharkhand. Jharkhand is one of the most backward states of India with recurring cases of leprosy in the past decade. The study has been conducted with the objectives to: a) Understand the socio-economic and health status of LAP, b) Know the health seeking behavior and problems faced by the LAP, c) Assess the utilization of the programs related to Leprosy eradication in the study area and d) Suggest various measures for improving the socioeconomic and health status of LAP.

Materials and Methods

Study Setting

The study has been conducted in the Potka Block of East Singhbhum district of the state of Jharkhand. The district is mainly dominated by indigenous tribes, such as, Santhal, Munda, Ho, Bhumiz, Kharia, and Sabar. This is an industrialized area but the amount of poverty and ill health is quite high due to indiscriminate mining operations conducted throughout the district (Sonowaland Jojo 2003). The block comprises of 1 Primary Health Centers (PHC) and 1 Referral Hospital. There are 7 Privately run Hospitals, 1 Government tertiary level Hospital,



1 Medical College and a NGO run Leprosy Rehabilitation and Promotion Unit at Jamshedpur (district headquarter). Two distinct NGOs work in the district (Jamshedpur) in the sphere of leprosy eradication, namely Swami Vivekananda Seva Trust and Bharat Seva Ashram Sangha. Potkais a high leprosy endemic block of East Singhbhum district of the state of Jharkhand.

Study design

A Mixed Method Approach has been used to conduct the study (combination of quantitative and qualitative research methods). The tools used for quantitative part is, semi-structured interview schedule for the leprosy patients and Leprosy Affected Persons (LAP), and for qualitative part is case studies, in-depth interviews of key informants and observation. The study involves multiple stakeholders comprising of LAP, Health care providers, NGO officials and community leaders.

The interview schedule was created in English and then translated in Hindi and Bengali. The interviews were conducted in English, Hindi or Bengali as per the preference of the respondents. The semi-structured interview schedules were filled up directly in English, while the questions were administered in the respondent's preferred language. The in-depth interviews were tape recorded and then transcribed and translated into English.

Study sample and Time frame

The unit of analysis of the study was an individual. 50 Leprosy affected person (LAP) from the Potka block has been selected as the study sample by using the method of Multi-Stage Random Sampling, with equal representation of men and women. The LAPs included leprosy patients, leprosy treated people and their family members. The East Singhbhum district has 11 Community Development Blocks (CDB). At the first stage of sampling, one CDB has been selected by applying required logistics. As a next stage of sampling, out of the total villages in the selected CDB, 5% of total villages of the selected CDB were selected at random. A door-to-door survey for a rapid enumeration of households having cases of leprosy affected persons was carried out in the selected villages of the district. From this exercise a list of 200 LAPs was developed. From this, a sample of 20 leprosy affected persons (LAPs) was selected at random (10% of the total population). Then with the help of Block Development Officer, a list of Leprosy colonies and hospitals located in the selected CDB were developed. Three leprosy colonies and one hospital were identified, which had 300 LAPs. As a next step of sampling 10% population was selected as additional sample, i.e. 30 LAPs.

Apart from the above mentioned sample, 15 Health workers from local NGOs and 5 public Health officials have been interviewed and their statements recorded for the purpose of the study. The data were collected over a period of one month, which has taken four to five hours of field visit per day to finish the entire process of data collection. As this was a MA research thesis, the size of the sample was small.

Approach to analysis

The study has been conducted with a combination of quantitative and qualitative research methods. SPSS computer software was used to manage and analyze the quantitative data set. The data set consisted of translated interviews, which were imported, coded and further subcoded in SPSS. Coding helped to access the interview content on the socio-economic and health status of the Leprosy Affected Persons and the extent of involvement of NGOs and other health care delivery mechanism for leprosy care. The qualitative part of the data also consisted of translated interviews of select participants, which were further developed as case studies. The combination of quantitative and qualitative methods of data analysis helped to compare opinions of different segments of stakeholder groups to assess the socio-economic and health condition of the Leprosy Affected Persons of the study area.

Human Subject Protection

The study was a part of the M.A. (Social Work) research dissertation submitted to Tata Institute of Social Sciences (TISS). The purpose of the research was explained to all the stakeholders and a signature/thumb print of all the respondents was taken on a consent form before the interview was started.

Results and Discussion

Qualitative and quantitative interviews have yielded interesting data on various aspects of the socio-economic conditions and health status of the Leprosy Affected Persons (LAP) among the study population in the Potka block of the East Singhbum district of the state of Jharkhand.

Socio-economic conditions of the respondents

In this study the term socio-economic conditions of the respondents refers to the socio-economic background of the LAPs and the status of their access to the shared resources of the community (acceptance among the family and community and livelihood and educational options of the LAPs).

The study area is dominated by people from Scheduled Tribe (ST) and Other Backward Caste (OBC), followed by Scheduled Caste (SC) and General category population. It has been found that all the respondents profess Hinduism, among whom 50% of them belong from ST category, 28% OBC category and rest 22% SC and General category. Both men and women were equally affected by and vulnerable towards leprosy. The disease burden has been found common across age groups. Among the respondents 4% of the LAP contracted leprosy below the age of 10 years. This shows that till today children are vulnerable towards this disease along with adults. It has also been noted that 20% of the respondents have contracted this disease at the age of 21-35 years, which is economically the most productive age group of the society. Such type of results were also observed by Bhat and Chaitra (2013).

The study shows that the education level of the respondents is very low. 39/50 (78%) of the respondents are illiterates and only 3/11 (6%) among the literate population have crossed matriculation and above. This has also resulted in the respondent's low level of awareness about the disease, resulting in delayed treatment. This findings corroborates with the findings of Kerr-Pontes et al (2006) a study conducted in Brazil.

The majority of the urban LAPs in this study were migrants from rural area, after they have been isolated from their family of origin and deprived of their traditional means of livelihood. Among them most of the LAPs had remarried after shifting to a leprosy colony and hence started a new family. This is same in regards to the LAPs settled in rural leprosy colonies too. It was also observed that 13/33 (39.4%) of the LAPs got married below the age of 16 years in both rural and urban areas.

Fifty six percent of female and 52% of male respondents were considered untouchable by their natal families, thus they were found to stay in congested leprosy colonies, where they did not have access to pure drinking water and lacks proper ventilation in their houses, resulting in other health related issues.

It was found that 27/33 (81.8%) of leprosy cured children and children of LAP are being denied admission in any regular school due to the social stigma attached to it. It has been reported that

children of LAP are also affected by their parent's disease in the field of employment; 25/29(86.2%) were being denied jobs by the employers, leading to unemployment and self employment, while 4/29 (13.8%) were denied job in their own city owing to their residential address.

27/50 (54%) of leprosy patients and leprosy cured people (mostly with visible deformities) practice begging as their sole means of livelihood. Many LAPs are also engaged in cultivation and small scale business particularly among the rural population. An amount of gender disparity has also been found in the employment pattern among the LAPs. Among the respondents 15/25 (60%) of the females are beggars as compared to 12/25 (48%) of the male respondents, 5/25 (25%) of males are each engaged in cultivation and small scale businesses in comparison to 1/25 (4%) of femaleand 6/25 (24%) of the female respondents are unemployed as compared to 2/25 (8%) of male respondents.

Most of the respondents (34/50, 68%) earn below Rs. 25,000 p.a. which is a meager income for supporting their families and at times families of their children who are denied jobs due to the social stigma attached to their parent's disease.

Health status and health care provision of the respondents

In this study the health status and the health care provision of the respondents refer to the existing health status of the LAPs and the status of the existing health care provisions of leprosy care provided by both government and private bodies to the LAPs and its impact on the lives of the affected population. It is not only important to detect a disease, its source of detection is equally important. This study shows that 34/50 (68%) of the cases have been detected by medical officers, these are the cases of active case detection carried out by different government agencies and NGOs working in the area. This also highlights the low level of awareness regarding leprosy among the respondents, till the disease has been actually detected. Apart from the above mentioned method, 16/50 (32%) of the cases were detected by the family members and the villagers of the LAP and were reported voluntarily. Most of the time, the villagers and the family members detected the leprosy cases, when the deformities and ulcers of the LAP became visible to the people at large.

In 32/50 (64%) of the cases, the LAP has been isolated from their families and villages due to societal pressure on their family members. Thus instead of taking the respondent for treatment the family members have isolated them due to their physical aliment. This shows the lack of awareness in the society regarding the disease and its curability.

The study also highlighted that majority (39/50, 78%) of the respondents who were then under medication are not at all aware regarding the care required to tackle the disease apart from consumption of regular medicines. The 29/50 (58%) of LAPs also shared that the doctors and para-medics at the health centers do not explain them the proper ways to take care of the ulcers and manners to avoid further injuries. At the same time they reported that they had to wait in long queues in the PHCs, due to which most of the time they avoid visiting there. This result in delayed recovery and Relapse from Treatment (RFT) cases among the LAPs.

It has been found that 11/50 (22%) of the respondents were Relapse from Treatment (RFT) cases. The LAPs have already completed their MDT course once, upon which the disease has relapsed. In such cases it has been observed that when such LAPs try to seek healthcare services but the treatment is being denied to them at the

Public Health Centers (PHC). These RFT cases in turn act as the hidden sources of infection for the society at large.

It has been observed that only 15/50 (30%) of the respondents were satisfied with the government treatment, 13/50 (26%) partially satisfied and rest were not satisfied with the government leprosy care system. Many of them (17/44, 38.63%) wanted to seek treatment from the private health care providers, due to which they visits health care centers administered by local NGOs working in the study area. These NGOs on the other hand are not fully equipped to cure the LAPs due to the integration of leprosy care with the General Health Care (GHC) system. This results in only partial care in the form of ulcer treatment and physiotherapy to the LAPs.

Government policies and rehabilitation

A qualitative study on the attitudes of the villagers regarding awareness level of policies for leprosy care and rehabilitation has been conducted. It has been found that all the respondents including the community leaders are not completely aware about the government policies regarding leprosy and its rehabilitation. Another government policy in this regard is the integration of the leprosy services with the General/Primary Health Care system (GHC). Here the active case detection system has been replaced by the routine voluntary reporting of cases during the regular health program operations. Under this program the GHC staffs are trained for leprosy cure and rehabilitation work which were previously done by bands of volunteers employed by the local NGOs working in the sector. This in turn has rendered such volunteers unemployed, 27/50 (54%) among them were LAPs, thus rendering a severe blow towards their rehabilitation.

This study explored the socio-economic and health status of the Leprosy Affected Persons (LAPs) of the study area, which is endemic in nature. It also tried to assess the awareness level of the LAP regarding the Leprosy Health Care Services and the rehabilitation policies as outlined by the Government of India (Gol). All the stakeholders including Leprosy Affected Persons, health care personals, NGO administrators and district level health care officials shared their views regarding the various facets of leprosy care, rehabilitation and the socio-economic condition of the LAPs before and after contracting the disease.

The study has been conducted in a tribal area, which is mostly inhabited by people belonging to Schedule Tribes (ST) and Other Backward Class (OBC) communities. This is the reason majority of the case load has been reported among them. These communities are extremely poor and mostly stay in rural areas surrounded by small scale industries and hazardous mines. They mostly depend on agriculture as their means of livelihood, followed by employment in the local industries and mines. Their low standard of living, widespread illiteracy, availability of poor basic infrastructure and lack of proper health care facilities are the reasons for the prevalence of many public health problems among them (DHFW, Jharkhand, 2008). Among all the public health issues leprosy is the most stigmatized disease still prevalent in the area. In a report about historic profiles and perspectives of leprosy in India, Jacob and Franco-Paredes highlighted the need towards identification of interventions to dispel stigma of the world's most misunderstood disease (Jacob and Franco-Paredes, 2008). This has led to the delay in seeking treatment of the same. The stigma attached to the disease is so much that LAPs are under constant fear of their being identified as a leprosy affected person in their community, least they will be outcast from their society and will lose their employment. This attempt to hide the disease results in its advancement and deformities starts taking place and their fear comes true. Most of the LAPs upon being identified by the villagers were forced to leave their villages and settled in various leprosy colonies located in both urban and rural areas.

These leprosy colonies are very congested unhygienic slums leading to many opportunistic diseases. One of the most common diseases found among the LAPs staying in the colonies is tuberculosis (TB). Due to the existence of the vertical health programs of GoI, the LAPs find it difficult to visit different clinics for seeking treatments. This results in discontinuation of treatment for either of the disease. This highlights the need for integrating leprosy care with TB treatment.

This This study with all its limitations of small sample size and time constrain has tried to gather critical accounts of the socio-economic and health condition of the LAPs belonging to the study area. This study highlights that leprosy affected persons in this tribal pocket of Jharkhand face many social problems which are to be tackled effectively so that leprosy no longer adversely affects anyone. In fact the experts have suggested that reductions in prevalence may be an artifact of elimination campaign strategies instead of a real reduction in the number of cases (Fine 2007, Penna et al 2011). The rehabilitation of the LAPs is inadequate in the study area and there is widespread lack of awareness regarding signs and symptoms of leprosy among the community people. The study reflects that the government needs to escalate its Information, Education and Communication (IEC) activities among the people of the study area, mainly to make them aware about the disease and its symptoms, so that they can voluntarily report about the disease without any hesitation and ask the community as a whole to participate in the case detection. The study also made efforts to show that there is a need to

improve the public health delivery system in the state related to health services provided to the leprosy affected persons, i.e. the NLEP needs modifications related to relapse cases.

It will be apt to conclude by suggesting few measures which can be helpful in enhancing the socio-economic and health conditions of the Leprosy Affected Persons. One of the most important measures is government intervention in the realm of rehabilitation of the LAPs by providing vocational trainings to the youths, facilitating admissions of children in regular schools and by fixing a higher rate of pension for the aged leprosy patients and leprosy cured people, so that they can use it for seeking timely ulcer treatment and leading their lives in a dignified manner. Secondly, Government can initiate a Private Public Partnership (PPP) model in healthcare practices by encouraging not-forprofit organizations to become a link between the public health centers and the LAPs. Within this ambit the private organizations can detect new cases and refer them to the nearest public health centers. At the same time they can be allowed to store medicines with them, so that it can be provided to the patients within their reach, thus avoiding going all the way to health centers. This measure can check the discontinuation of their treatments and allowing them to distress themselves. Last but not the least, it can be really helpful if a social worker or a psychologist can be appointed at the public health centers to provide counseling facility to the leprosy patients and their family members as a means to provide them with adequate psychological strength to cope with the illness.

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