

FIGHTING THE LEPROSY MENACE IN THE STATE OF JHARKHAND (INDIA)



BACKGROUND

In a world defined by the Sustainable Development Goals and Agenda 2030, where a significant number of key development actors are working together to create conditions for inclusive growth and progress that will not leave anyone behind, and which recognises Good Health and Well-being amongst its top priorities for action, the persistence of Leprosy on the global health landscape merits attention.

As per conservative estimates, every year, there are some 2,00,000 new cases diagnosed worldwide. Millions of people are also living with some form of disability as a result of leprosy. It is understood that many cases go unreported as countries and societies have taken their eyes off leprosy since the year 2000, when WHO confirmed that the disease has been

eliminated globally (defined as registered prevalence of less than 1 case in per 10,000 population).

KEY FACTS ABOUT LEPROSY AS PER WORLD HEALTH ORGANISATION

- Leprosy (Hanson's disease) is a chronic infectious disease caused by *Mycobacterium leprae*. The disease mainly affects the skin, peripheral nerves, mucosal surfaces of upper respiratory tract and the eyes.
- It is likely transmitted via droplets, from the nose and mouth, during close and frequent contact with untreated cases.
- *M.leprae* multiplies slowly and the incubation period of the disease, on average, is 5 to 7 years. Symptoms can also take as long as 20 years or more to occur. Depending on the bacillary load in the body, the cases are identified as pauci-bacillary leprosy or multi-bacillary leprosy.
- Clinical signs are easy to observe, in the form of skin lesions which may show loss of sensation in the skin. Since it is a painless disease that starts with skin patches, it usually requires self-identification.
- Leprosy can occur at any age and cases range from early infancy to very old age.
- Leprosy is curable with a combination of drugs known as multidrug therapy (MDT). The combination of drugs and duration of treatment depends on the classification of the disease (whether pauci-bacillary or multi-bacillary leprosy).
- Timely diagnosis and treatment in the early stages of the disease before nerve damage has occurred can prevent permanent physical disability due to leprosy.

The global commitment to 'Good Health and Well-being (Goal 3)' calls for paying more attention to the Leprosy disease in endemic regions that are also regions with high concentration of the world's poor. A disease afflicting the poor, it is potentially disabling and can affect economic prospects. Leprosy is also one of the world's most stigmatized diseases due to the prejudice that persists about it. Despite being one of the least infectious diseases for which effective treatment is available, it is thought to be highly contagious. Stigma related to leprosy prevents families from self-reporting cases and availing timely, appropriate

treatment that could reduce chances of various forms of disabilities. There is glaring neglect, exclusion and denial of basic human rights of people living with deformities and disabilities caused by leprosy, across the world. The stigma affects the overall physical, psychological, social and economic well-being of those identified in society as living with the disease.

LEPROSY IN THE INDIAN CONTEXT— CASE OF JHARKHAND STATE

India has been able to bring down the prevalence of leprosy to 1 in a 10,000 population in 2005. Still, it continues to contribute 60-65% of global new cases each year. In 2005, the Government declared that the disease has been eradicated and shifted focus to other pressing diseases like HIV and tuberculosis while leprosy has persisted in the states of Jharkhand, Orissa, Chhattisgarh and Bihar and is also showing up in other states like Tamil Nadu, Andhra Pradesh, Gujarat and Telangana. The tribal state of Jharkhand is one of the worst affected states which, according to the 2015 survey under National Leprosy Eradication Programme (NLEP), contributed to roughly 4% of India's fresh leprosy case load during 2014-15 (a prevalence rate of more than 1 in a 10,000 population).

KEY CHALLENGES

Leprosy mainly affects people in resource-limited set ups, especially those who live in crowded and unhygienic conditions. Many have difficulty accessing health care due to high costs of going to the doctor and long distances to reach providers and clinics/referral centres familiar with leprosy. Because of this, many of those affected do not complete treatment or do not receive it at all. Due to the continued stigma against people with leprosy, affected people may not seek help when first symptoms appear, causing delay in diagnosis, thus resulting in development of disabilities. Due to these reasons, despite very high prevalence rate in Jharkhand, there is low turnout rate in the government facilities.

Another key challenge is that leprosy is no longer taught in the medical curriculum and physiotherapy courses. As a result of this, medical staffs in specialised hospitals and medical colleges do not know how to identify the disease. At the community level, ASHA workers and village level health workers lack the training to identify new cases. Identification mainly takes place at the referral centres that have some old and experienced practitioners. There is also a shortage of staff specialised in reconstructive surgeries and specialised physiotherapists for post-operative care.

Addressing discrimination of patients is yet another critical requirement through awareness generation in the village community and schools and dispelling of myths associated with the disease. Lastly, long-term rehabilitation of people living with disabilities or some form of deformity caused by leprosy is needed so that people could lead a life of dignity- with social integration and decent economic opportunities. This has emerged as a key requirement of any strategic work on leprosy.

HOW IS RIZWAN ADATIA FOUNDATION (RAF) ADDRESSING THE CHALLENGES?

Since 2017, Rizwan Adatia Foundation (RAF, India) has partnered with Bharat Sevashram Sangh (BSS), an organisation that has decades of experience in leprosy work in the district of East Singhbhum and surrounding areas, for strengthening Community Access to Specialised Leprosy Care in the remote rural location of Debanki, Jharkhand. Spread in 4 blocks of East Singhbhum district, the intervention has covered 4.5 lakh populations constituting of low-income and disadvantaged communities.



- Jointly, RAF and BSS give primary focus to active case finding, identifying the patients in time and putting a stop to transmission. Early detection of Leprosy patients is done through screening camps and OPDs
- RAF supports critical leprosy patients in taking care of their illness with treatment, as well as in maintaining good health through preventive measures and health care education.

- Its advanced detection camps have identified 995 cases so far, who were successfully treated and more detections are taking place on a regular basis for those who require urgent care, support and treatment.
- RAF has successfully contributed to changing lives of the patients suffering from leprosy and removing the stigma attached to it in the community. This has been achieved by refurbishing the BSS run hospital and equipping it with all basic healthcare facilities. It has financed the operation of a 20 bedded hospital that provides Leprosy care and specialized treatment to patients, who are mostly extremely poor and hail from nearby villages. The resident patients are provided with all meals that are sourced from the organic farm run by BSS.
- RAF supports organising of regular health camps in surrounding villages, making health care accessible to nearly half a million vulnerable people in the area. In addition to providing general treatment and medicines to people, the health camps also identify new cases of Leprosy and build awareness of villagers about leprosy care, its transmission and that it is completely curable with the MDT treatment. Such village level health camps and awareness programs promote good health as well as minimize the stigma associated to leprosy.

For its invaluable service in the area of leprosy, RAF's partner, Bharat Sevashram Sangha (BSS) has recently been conferred with Nikusth Sangharsh Seva Samman 2021 by National Leprosy Eradication Programme.

SUSTAINING THE ENDEAVOUR AND SCALING UP

During the 3 year engagement with leprosy work in East Singhbhum, RAF has positively impacted the lives of 995 leprosy patients from low-income as well as disadvantaged backgrounds through a process of continuous engagement and follow-up lasting at least 6 months to 1 year or more. Considering the increasing prevalence rate in the project location as well as in surrounding areas, RAF seeks to extend the coverage of its specialised services now, to West Singhbhum and Saraikela Kharsawan, the two adjoining districts of East Singhbhum. We urgently need your support to strengthen the hospital services with the following features:

- **Expand the care and treatment facility in the hospital with additional beds**

Currently, the hospital is equipped with 20 beds. Considering the increasing prevalence rate of cases, an additional construction is urgently needed to increase the hospital capacity with at least 100 beds and associated services.



- **Establishment of an Operation Theatre for Reconstructive surgeries to prevent further deterioration, disability and deformity in leprosy identified cases**

Reconstructive surgery (RCS) has made a significant improvement in deformities and disabilities management among leprosy patients. RCS corrects the deformity and is expected to help in reducing the stigma in society and reintegrate the affected persons into society so that they become economically self-reliant and carry out their normal livelihood activities without any prejudice. Several studies have established that post the reconstructive surgery, performance of patients has improved due to better mobility of limbs. Majority of patients have reported that they are self-reliant and do not require help in performance of daily activities, after correction of the deformity. Patients also reported that they were socially accepted with respect to family, relatives and peers.

AN APPEAL TO SUPPORT

Leprosy is the least infectious of diseases that can be cured with timely, appropriate treatment of MDT (Multi-Drug Therapy). However, left unattended, it could lead to permanent nerve damage, ulcers/chronic infection requiring amputation and permanent disability or forms of deformity that will impair normal functioning, stigmatize one for life and prevent one from leading a happy, fulfilling life in society.

Do You Know?

Girls and women living with Leprosy face added issues of gender and social discrimination which may also delay detection of the disease

People living with Leprosy are unable to work due to disability caused by the disease or may face stigma that prevents them from gainful, economic engagement.

Leprosy is curable with Antibiotics. Education and improving access to basic health services for all are key to successful elimination of the stigma and disability associated with the illness.

YOU CAN CHANGE IT ALL...

Your generous support, particularly during Covid-19 pandemic (when many health services have closed) can transform many lives at risk through early detection of cases, appropriate care & treatment and reconstructive surgeries as per the need. Your donation will be used for the following:

- Early detection/advanced detection & community outreach
- Expanding the care and treatment facility at BSS-run hospital with more beds (so that we reach out to more in-house patients)
- Setting up of a state of the art Operation Theatre for carrying out Reconstructive surgeries to prevent further deterioration, disability and deformity

ABOUT RIZWAN ADATIA FOUNDATION

Rizwan Adatia Foundation (RAF) is a not for profit organisation, registered under Section 8 of Companies Act, 2013, in India. All donations to RAF are eligible for 50% tax exemption under Section 80G of the Income Tax Act. Tax Exemption is valid only in India.

Any trust or person who will extend support to us will get 80G certificate for Income Tax Exemption in India. The donations will be utilized entirely and exclusively for the project with complete transparency. No administrative costs will be incurred from the donations as

RAF and BSS contribute towards administrative expenditures. Therefore, you may rest assured that 100% of your donation will be directly reaching to the affected persons in need.

To know more & donate, please write to Mr.Pratik Narsidani (RAF India) at pratik.narsidani@rafglobal.org