Special Correspondence

[We are publishing this Special Correspondence to commemotare "WORLD LEPROSY ERADICATION DAY" on 30th January or Sunday Close to it]

World Leprosy Day : Looking Beyond MDT

Bani Prasad Chattopadhyay[1]

"Eliminating leprosy is the only work I have not been able to complete in my lifetime."

— Mahatma Gandhi

My knowledge about leprosy began in my late 20s when in 1999, I joined Gouripur Leprosy Hospital, Bankura, West Bengal as a Medical Officer in my early service life. Back then when media and the so called educated society had a belief that leprosy has declined or no longer exists, I was awed to see a 550 bedded hospital spreading across 200 acres of land (the largest leprosy hospital of Asia) actively running with patients even in waitlist. It's my confession that I've learnt about lepra reactions, complications like foot drop, ptosis etc from the caregivers, who were termed as "ex-patients"- a new salutation which I hadn't heard in relation to any other diseases. It's a burning example that even after cure, the stigma or taboo persists for lifetime . Most of the patients completed treatment settled in surrounding hospital making new village and colony due to non acceptance from family / community – same picture was persistent across the globe.

Thus to understand this social dimension, the basics of leprosy is discussed in brief.

Hansen's disease (named after Norwegian physician Gerhard Armauer Hansen) popularly known as leprosy is a chronic granulomatous and infectious disease caused by *Mycobacterium leprae*. It causes severe damage to peripheral nerve trunk [1] and to the skin which leads to deformity, impairment of function, disability and psychological disturbances, physical, mental & economical dependence and ultimately dehabilitation to destitution for developing stigma [2] . So early effective action is necessary for prevention deformities which are mild and reversible to begin with but becomes severe and permanent only later on [3].

Transmission of leprosy is poorly understood, although it is thought to be through inhalation of droplets containing the causative agent, Mycobacterium leprae (M. leprae). However, transmission via skin contact or other means cannot be entirely excluded. Leprosy has a reservoir in armadillos and a few other animals.

Up to 95% of patients exposed to M. leprae will not develop the disease, suggesting that host immunity plays an important role in disease progression and control.

The incubation time is variable, ranging from 2 to 20 years, or longer.[4]

With introduction of Multi Drug Therapy (MDT), prevalence rate has come down significantly worldwide. In India the rate has dropped from 57.8/10,000 in 1983 to 0.66/10,000 in 2016 after achieving elimination (PR < 1/10,000) at national level in 2005 [5]

India continues to account for 60% of new cases reported globally and is among the 22 "global priority countries" that contribute to 95% of world numbers of leprosy. New cases detection rate were 137,685 in 2007 and nine years later in 2016, the number remained almost the same at 135,485; a significant increase over the 127,336 cases was detected in 2015. The Grade II Disability (visible deformity as per WHO classification) rate in new case detected, which was rising till 2014-15(4.61%) was arrested in 2015-16(4.609) and though reverted in 2016-17(3.87%) indicates that the cases are being detected late in the community and there may be several cases which are lying undetected or hidden [6].Apart from initially detected new cases with grade 2 deformity (G2D), fresh G2D also occurs during or even after completion of MDT due to nurities and lepra reactions [7].Now there are more than 2 million of cases in India with G2D numbering approx 500,000 [8] 25% of leprosy patients have some degree of disability [9]

WHO launched the 5-year 'Global Leprosy Strategy 2016-2020' in April, 2016 titled 'accelerating towards a leprosy free world', with an aim to reduce the burden of leprosy by 2020 by not only reducing the case detection rate but also by reducing the number of new cases presenting with disabilities (less than one per Million) through early detection and by improving the

[1]Medical Officer, West Bengal Health Service, Department of Heath & Family Welfare, Govt of West Bengal, E-mail - bpcacademic@gmail.com

management of acute and chronic complications due to leprosy reactions, promoting self care support activities, rehabilitation and reconstructive surgery [1].

How is leprosy diagnosed? [4]

Normally, the diagnosis of leprosy rests on finding ***any one of three cardinal signs***:

- A definite loss of sensation in one or more pale (hypo pigmented) or reddish skin patches;
- One or more thickened or enlarged peripheral nerves with a loss of sensation and/or weakness in the muscles supplied by the nerve; or
- The presence of acid-fast bacilli in a slit skin smear. (though it is a less sensitive test)

The diagnosis of leprosy is often complicated by the fact that the way it presents depends on the type and strength of the body's immune response to *M. leprae* and largely based on clinical findings. No serological tests like HIV or SARS-COVID which can give instant results or to diagnose leprosy infection (latent leprosy) among asymptomatic contacts is available.

Immune response and classification :

Based on immune response of the patient towards the bacilli, Leprosy can be broadly classified as- (Ridley-Jopling Classification)

1. Tuberculoid, having relatively few bacteria in skin and nerves; characterized by a few flat or slightly raised skin lesions of various sizes that are typically pale or slightly red, dry, hairless, and numb to touch (anesthetic)

2. Lepromatous, having widespread disease and large numbers of bacteria, characterized by much more generalized disease, diffuse involvement of the skin, thickening of many peripheral nerves, and at times involvement of other organs, such as eyes, nose, testicles, and bone

3. Borderline, is an intermediate between tuberculoid and lepromatous type

There are subdivisional types too, like- Borderline Lepromatous Leprosy, Borderline Tuberculoid Leprosy, Indeterminate Leprosy.

In 1982, WHO proposed a simplified classification for effective public health control program, that has only two classifications

1. Paucibacillary (PB)- Patients with 1 to 5 skin lesions, without demonstrated presence of bacilli in a skin smear,

2. Multibacillary (MB)- Patients with more than five skin lesions; or with nerve involvement (pure neuritis, or any number of skin lesions and neuritis); or with the demonstrated presence of bacilli in a slit-skin smear, irrespective of the number of skin lesions [4].

Lepra reactions- Lepra reactions are inflammatory reactions occurring in leprosy, due to circulating immune complexes, vasculitis, or T-cell reaction which may be induced by treatment.

1. Type 1 lepra reaction is a delayed type of hypersensitivity to *M. leprae* antigens, is also known as ***REVERSAL REACTION***, because the immune response initially appears to be declining and then "reverses" to become more intense. It may be a presenting feature of leprosy or may occur during treatment with MDT or even for three or four years after treatment has been completed (Rose, 1991). Starting treatment with MDT often appears to precipitate a Type 1 reaction, perhaps because the rapid killing of bacilli. It reflects a strengthening of specific cellular immunity against *M. leprae* towards the tuberculoid type.

2. Type **2 lepra reaction** is characterized by an acute immune complex vasculitis affecting the skin and other organs. It is also called ***erythema nodosum leprosum*** **(ENL).** It may be acute, recurrent or chronic and presents as a systemic illness, with high fever, systemic upset and prostration. Peripheral edema and transient proteinuria can also occur. Iritis and episcleritis, neuritis, nerve abscess, orchitis, lymphadenopathy, organomegaly, joint involvement, bone tenderness, especially over the tibia, are well recognized features of ENL.

If timely medical/surgical intervention is not done, lepra reactions can lead to organ damage resulting disability and even death.

Treatment :

Management of leprosy has evolved through different methods of management and drugs like *Chaulmoogra oil* to Dapsone immunotherapy, until universal MDT regime was proposed and implemented internationally in 1982 apart from isolation of the affected person.

MDT is followed as the standard treatment regimen as proposed by WHO GDG 2018-

Earlier it was 2 drug therapy for PB.

Usually patients are declared **RFT** (released from treatment) after completion of specific dose (smear or other laboratory investigation is not mandatory). Since 1995 WHO has provided MDT free of cost. Free MDT was initially funded by The Nippon Foundation, and since 2000 it is donated through an agreement with Novartis until at least 2020.

MDT is provided in blister packs, each containing 4 weeks' treatment. Specific blister packs are available for MB and PB leprosy, with different doses for adults and children.

Management of lepra reaction is done with appropriate dose of steroid, Thalidomide and necessary

Age group	Drug	Dosage and frequency	Duration	
			MB	PB
Adult	Rifampicin	600 mg once a month	12 months	6 months
	Clofazimine	300 mg once a month and 50 mg daily		
	Dapsone	100 mg daily		
Children (10–14 years)	Rifampicin	450 mg once a month	12 months	6 months
	Clofazimine	150 mg once a month, 50 mg on alternate days		
	Dapsone	50 mg daily		
Children <10 years old or <40 kg	Rifampicin	10 mg/kg once month	12 months	6 months
	Clofazimine	100 mg once a month, 50 mg twice weekly		
	Dapsone	2 mg/kg daily		

systemic managements.

Rehabilitation and disability prevention :

Nerve damage in leprosy causes physical impairments, mostly in eyes, hands and feet. Along with physical impairments, socio-economic conditions also stand as a barrier. The challenge in rehabilitation is to lessen or even reverse the bodily impairment, activity limitation and participation restriction that result from leprosy, so that the person can live as normal a life as possible. Rehabilitation focuses on the functioning of the individual rather than the disease, so leprosy rehabilitation programmer need to be multi-faceted. They may involve corrective surgery, physiotherapy and occupational therapy, and assistive devices. But they are also likely to involve aspects of individual empowerment – enabling people to manage self-care, develop new livelihoods, and other adaptations – and community education and advocacy that work towards enabling people to again participate fully in society. (*https://ilepfederation.org/about-leprosy/#prevention*)

- *Self care-* People with nerve damage need to examine feet and hands daily, checking for cracks, wounds, calluses and swollen areas, and have a daily routine of soaking the feet, scraping off dry skin, and applying oil. If ulcers develop, then resting and protecting the wound are essential to avoid further damage. Many patients find it helpful to join self-care groups. The right footwear can greatly reduce the risk of foot damage.
- *Physical rehabilitation*- Physical rehabilitation seeks to help people affected by the muscle weakness or physical damage caused by leprosy, in the normal activities of daily life. Physiotherapy exercises, occupational therapy, use of assistive devices, also sometimes accompanied by special training, are important to protect the weak muscles or anesthetized body parts. Surgery can correct some damaging consequences including paralysis and clawing of hands, foot drop and lagophthalmos (paralysis of lid preventing eyes from closing). Patients suffering from neuritis and foot ulcers benefit from splints and special footwear designed to assist in healing.
- *Socio-economic rehabilitation-* Many people affected by leprosy face the loss of their livelihoods as a result of prolonged hospitalization or the loss of physical capacity or the ongoing risk of damage to hands and feet. Socio-economic rehabilitation seeks to help people affected by leprosy to rebuild their lives through vocational training, micro-finance and business creation schemes, provision or improvement of appropriate housing, and advocacy at various levels to ensure that persons affected by leprosy and their family members are fully included in society.
- *Community-based rehabilitation*- community-based rehabilitation has been introduced for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion. The essence of CBR is the 'twin-track' approach: mainstreaming (including people with disabilities, including leprosy, in mainstream community development as much as possible) plus disability-specific services and care where they are needed. CBR therefore includes factors like gaining or regaining a livelihood and becoming fully included in the life of the community.

Government, NGO, *policy makers plays a pivotal role here.*

Global leprosy situation :

The latest update from the WHO titled "Global leprosy update, 2016: accelerating reduction of disease burden: states that – although there has been a significant reduction in prevalence of the disease worldwide since the mid-1980s to elimination levels, new cases continue to arise indicating continued transmission[10] The registered global prevalence rate at the end of 2016 was 0.23 per 10,000 population, based on reports filed by 143 countries from different regions of the world.

To effectively manage the prevalent problems of

delay in diagnosis, discrimination etc, the Global strategy of 2016-2020 is built around three pillars-

(i) to strengthen government ownership, coordination, and partnership;

(ii) to stop leprosy and its complications; and

(iii) To stop discrimination and promote inclusion.

There is a special focus on women and children, strengthening referral systems, more effective contact tracing, assessing the value of chemoprophylaxis, and monitoring drug resistance [9].20th international leprosy Congress held at Manila Philippines September 2019 with the theme "Global Partnership in Addressing Current Challenges"promised to fulfill globally the slogan of Zero Transmission, Zero Disability and Zero Stigma and Discrimination.

We are eagerly waiting to host 21st international leprosy Congress at India

Targets of the Global Leprosy Strategy :

- Zero disabilities among new pediatric patients.
- A grade-2 disability rate of less than 1 case per 1 million people.
- Zero countries with legislation allowing discrimination on basis of leprosy.

Current strategies for leprosy treatment and prevention in India :

In India, the National Leprosy Eradication Programme (NLEP) is the centrally sponsored health scheme of the Ministry of Health and Family Welfare, Government of India; it is formulated centrally and implemented by state and Union Territories. After the implementation of MDT, India by the end of March 2011–2012 succeeded in achieving elimination at the state level in 34 states/UTs out of the total of 36 states/ UTs, in addition to achieving the national elimination target by the end of 2005. MDT treatments are highly effective- it cures 98% of patients with leprosy infection, relapse rate is very low and there are few reports of multi-drug resistance.

Vertical leprosy control program has been integrated to general health programs from sub center level.

The NLEP in its recent evaluation have acknowledged four alarming trends –

1. Presence of pockets of high endemicity,

2. Presence of hidden cases in the community,

3. The new case detection rate has remained almost the same since 2005,

4. Rising disability rates in new cases due to a delay in diagnosis.

The reasons for delay in diagnosis and treatment are[12] –

1. Medical (painless and insidious initial symptoms),

2. Cognitive (lack of awareness, inadequate knowledge about treatment availability, ignorance, lack of motivation),

3. Socio economic (work constraints, reluctance to lose daily wages due to hospital visits),

4. Psychological due to (stigmas and denial)

To address these challenges, NLEP advocated a three-pronged approach-

(a) "leprosy case detection campaign (LCDC)" in highly endemic districts;

(b) focused leprosy awareness campaign using ASHA and multipurpose health workers in "Hot Spots," where new cases with Grade 2 Disability (G2D) are detected; and

(c) area-specific plans for case detection in hard to reach areas.

It was felt that the major cause of hidden cases is low voluntary reporting in the community due to a lack of awareness as well as the continuing fear, stigma, and discrimination against leprosy. The **SPARSH Leprosy Awareness Campaign (SLAC)** was launched on 30th January 2017 and is a program intended to promote awareness and address the issues of stigma and discrimination[13]

Contact management is now considered an essential component of effective programme. For this, NLEP has undertaken various prevention strategies, like:

- *Chemoprophylaxis of contacts-* Leprosy Post Exposure Prophylaxis (LPEP) was launched globally in the year 2014 with an aim to evaluate the feasibility and efficiency of contact tracing and the provision of preventative treatment for leprosy under routine conditions in several countries and to determine the impact this has on leprosy incidence[14]The program has three prime components – contact tracing, screening and single-dose rifampicin (**SDR**) administration. Once a new patient has been diagnosed, health services actively screen household members and neighbors of the patient and examine them. Symptomatic persons are promptly referred for MDT and asymptomatic "contact persons" are offered a post-exposure prophylaxis (single-dose rifampicin) to reduce their risk of developing leprosy by 50–60%. It is designed to complement and be integrated into the NLEP rather than operating vertically[15]. Contact of leprosy for this programme is defined as someone who has had prolonged regular or interrupted contact with an index case during the last 1 year. A single dose of 600 mg of rifampicin is advocated as LPEP to household contacts above 35 kg body weight, 450 mg to individuals of 20 to 35 kg weight, and for those with

<20 kg body weight, 10–15 mg/kg of rifampicin as single dose.

• *MiP Immuno-Prophylactic Vaccine-* NLEP has introduced the *Mycobacterium Indicus Prani* (MiP) vaccine in a project mode in India from the year 2016. MIP vaccine has been shown to have both immunotherapeutic and immune-prophylactic effects in multibacillary leprosy patients and their contacts in both hospital and population-based trials. It also reduced the bacillary load, upgraded the lesions histopathologically, led to complete clearance of granuloma, reduced reactions, and neuritis and reduced the duration of MDT in leprosy patients[11]

• Nikusth, a web-based reporting system for leprosy- *For the ease of reporting and data management of registered leprosy cases, NLEP has launched "Nikusth," a web-based reporting system in India.[16] In addition, "Nikushth" will be helpful in keeping track of all the activities being implemented under the NLEP. NLEP is also planning to develop online training software for leprosy workers[17]*

Discrimination faced by leprosy patients :

Since ancient times, leprosy has been linked to taboos and stigmas and the persons affected by leprosy have faced intense rejection, fear, shame and resultant exclusion. This takes a toll on their mental health. Social discrimination leads to isolation of leprosy patients and often their families; as a result they cannot freely access the social resources of sanitation, water, education, markets etc. Apart from this *Legal* discriminations -As of 2019, there are 132 laws across 23 countries including India in respect of marriage ,employment, education ,transport that discriminate leprosy patients. The laws have their origin in 19th centuries and needs amendments.

Females generally face more social problems than males; unmarried girls with leprosy are often considered burden by her own family. Affected mothers are denied rights and isolated from her children.

Areas of concern :

1) There is a misconception in general public as well as policy makers about 'eradication' and 'elimination',

2) Lack of trained healthcare personnel at grass root level, which are based on ASHA and ANM workers, as dedicated leprosy workers have been shifted elsewhere after integration,

3) No special fund for dedicated leprosy work,

4) It is also true that newer generation health workers including doctors lacks hands on training on leprosy. So diagnosis of leprosy, which is almost entirely dependent on clinical findings, is often missed. Delayed diagnosis initiates most of the future problems.

World Leprosy Day :

The French humanitarian Raoul Follereau selected the date for World Leprosy Day. He wanted to pay homage to the life of Mahatma Gandhi and his death on 30th January 1948.Gandhiji dedicated his life for leprosy patients. There's a well known picture of Gandhiji nursing a leprosy patient- respected scholar Parchure Sastri; Gandhiji arranged his stay at Ashram in Sevagram, along with other residents. Gandhiji thus showed the path of care and rehabilitation simultaneously almost a century back. Let us pledge to fulfill Gandhi's dream-

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