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Editorial

Bridging the Knowledge Gap: Accelerating the Research and Interventions in Leprosy in India

Indian Journal of Leprosy has been and continues to be published by Hind Kushth Nivaran Sangh (HKNS) since 1929. Initially published as Leprosy in India up to 1984, this journal has been part of evolution of leprology in India for the past 95 years. As we enter our 96th year, it is time to reflect on current efforts as well as needs of continued research, teaching, empowering students, scientific community, as well as the general public, on different aspects of leprosy especially in India.

After adoption of WHO recommended multi-drug treatment (MDT) regimens in 1980s, with continuous as repeated active case detection campaigns, India achieved a spectacular success in decreasing the incidence and prevalence of leprosy during intense 15 years of the programme (1990-2005). This massive reduction (more than 97%) in active leprosy cases was a success story of efforts led by National Leprosy Eradication Programme (NLEP), a vertical programme of Govt of India, implemented by States with valuable support of various national/international agencies including nongovernmental organizations (NGOs). Since then, and after merging of the vertical programme with a horizontal health care services the decline has been very slow. Pockets of continued endemicity, new pockets emerging in previously non endemic regions, delay in timely access to diagnosis and appropriate management, inadequate surveillance, less than desired response to therapy in some cases, reluctance to modify the regimens even when evidence exists, delay in implementation of proper chemoprophylaxis and immunoprophylaxis measures are some of the reasons thought to be responsible for this stagnating situation.

While old clinical expertise is dwindling, strategic decisions become very important. Continued learning and observations, backed by using newer tools available due to advances in technology, teaching and research remain the most important approaches to generate new expertise and keep it alive and up to date. Scientific publications reflect on mindset of academia and provide guidance for implementing more effective solutions. Academia – medical teachers and researchers are the real back bone & soul of any public health programme for improvements at individual and community levels. Analysis of publications in Indian Journal of Leprosy in the recent years shows that many medical colleges continue to be active in research on leprosy. Many publications deal with situation analysis of profile of leprosy cases seen at those institutions, which are usually tertiary care institutions who have been reporting continued preponderance of bacillated multibacillary disease, high disability rates and continued morbidity due to reactions. There are reports on new child cases/rates which although are reportedly coming down are yet still high in some areas. It is seen that disability rates are also falling specially after active case detection campaigns. High disability rates are observed in most of low endemic settings, and are being reported from tertiary care institutions. There is also a spurt in publications on advances in improving the ulcer care.

Interestingly atypical/also termed as uncommon presentations are being reported more often and are receiving increasing interest. These are quite informative and usually reflect deficits in expertise especially among non-dermatologists to whom many cases report first. On several occasions, experienced reviewers do not accept these as atypical or uncommon which shows the problems of dwindling expertise in low endemic situations. Impact of migration on prevalence of leprosy especially in urban and semi-urban settings is also receiving increasing attention.

There are fewer publications on other important aspects such as mental health of leprosy affected persons, urban leprosy, non-responders, improved regimens using immunotherapy, alternate/ newer drugs, newer tools for diagnosis including molecular diagnosis, molecular epidemiology, detection of drug resistance, stigma reduction, assessing nerve involvement, prevention strategies (Chemoprophylaxis, immunoprophylaxis and environmental health aspects). Occasional publications have started appearing on digital health – eHealth, mHealth and use of artificial intelligence.

Above analysis shows that active foci of academic activity are present in several parts of India. This is heartening. However, their proportion is too small considering that India has more than 700 medical colleges, many elite medical institutions and specialized centres/ institutions dedicated to leprosy research. There is no dearth of material as nearly 100,000 patients continue to reach health facilities every year and possibly twice the number is hidden in the community at a given point of time. While inadequate financial and administrative support is likely to be important hinderances, quality of questions asked and seriousness in addressing the challenges appear far more important. There is little connect with the community which is important to know the reasons for delay in timely diagnosis, access and early & timely management of cases so as to treat the patients early and appropriately to reduce the disabilities. Furthermore, interdisciplinary approach is mostly lacking to improve our understanding of disease profiles, investigating atypical/ uncommon presentations, diagnosis and treatment of reactions, disability management, and improve the access.

In 2006 (end of December 2005) India celebrated the elimination of leprosy as a public health problem (less than 1/10,000) at national level. Hoping that with mass screening approach based on experience of NLEP with strategies like leprosy case detection campaign (LCDC), asha based surveillance for leprosy suspects (ABSULS) we will connect with all cases by the end of 2027, treat them plus provide chemoprophylaxis and immunoprophylaxis for all contacts. However, outcome in terms of impact on transmission will be known possibly by 2037 considering the long incubation period of disease. Disability prevention, management and care of leprosy affected persons will need attention for at least 20 years – till 2047 or beyond.

Our National Strategic Plan and Roadmap of Leprosy 2023-27 is aligned with global strategy 2021-2030 and has a vision of leprosy free India - zero infection and disease, zero disability, zero stigma and discrimination. It is felt that even today sufficient knowledge and tools exist that can be judiciously applied to further improve the management of leprosy patients, positively impact the lives of persons affected by leprosy and overcome most of the public health challenges still posed by leprosy. However, the importance of research for improved/ better tools for diagnosis and management, prevention cannot be undermined and appreciated as per felt needs. Among all priorities, implementation research deserves to be on the top. In a scenario of competing priorities and limited human and financial resources available for leprosy the question is: can we be sure with proposed timelines? Or these remain just good and pious ideas with no definitiveness and hazy distant future? Targets of zero disabilities and zero transmission are achievable but intense diagnostic and public health efforts are needed.

We need geographic area specific current knowledge about profile of disease, epidemiological parameters linked to transmission, access for management of disease and its complication as well as surveillance and aftercare. Published data shows that we do not have sufficient information about these issues. Finally, the competency of professionals across the country and their involvement in solving the clinical and public health issues related to leprosy needs lot more improvement and/or reorientation. It is hoped that we will strengthen our teaching and research to address these vital issues so that our preventive, curative and aftercare services are properly equipped to address the short-term, medium and long terms needs of fight against leprosy.

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