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Editorial

Research on Deformities/Disabilities in Leprosy Needs to Focus on Improving the Outcomes

It is a common knowledge that since time immemorial leprosy has been a feared disease due to deformities/disabilities that occur in a proportion of leprosy patients. Publications from pre-MDT era mention about 20-25% leprosy cases getting disabilities. After the use of MDT expanded to entire country there was significant reduction in grade 2 disabilities (G2D) which decreased to 2.31% in 2001 and 1.89% in 2006 (NLEP data). After the programme was merged with general health services, there was an increase in grade 2 disability rates (4.6% in 2016) which might have been due to late diagnosis in self -reporting mode and inadequate treatment. National sample survey in 2010-11 reported that 13.9% of new leprosy cases had G2 disabilities which reflects a gap between data based on voluntary reporting and numbers discovered by surveys. After NLEP restarted active case detection campaigns, disability rates have been coming down (2.41% in 2019-20).

G2D in children is an indicator being focused nationally and internationally and zero disability in children is the target. Unfortunately, the data from the tertiary care hospitals in India shows that child leprosy cases have been coming with G2 disabilities. Recent data shows that this situation may be coming under control. In 2019-20, 0.8% of child cases has G2 disability compared to 2.41% overall figures. We can hope to achieve this target in near future if massive health education drives for awareness and empowerment, and the active case detection campaigns continue with present speed and coverage.

Our National Strategic Plan (2023-2027) as well as the global strategy aims at achieving zero disability in children as well as in other age groups. All stakeholders – public health system(s), institutions, private practitioners and academicians have to work together to achieve this goal. Success of MDT in terms of reduction in deformities/disabilities is also linked to access and proper management of reactions, neuritis and other complications, and also surgical as well as adequate after care. Over the last 70-75 years a variety of surgical methods have been developed to deal with nerve damage and correct various types of deformities / disabilities caused by leprosy. Main issue will be of access of these services to leprosy affected persons. Innovations and improvements should also continue.

A critical appraisal of the tools/techniques/ strategies used so far and their access to needy persons is required to comment on impact of these management practices individually and collectively. While such assessment(s)/ appraisal can be done by specific studies dedicated to address these questions, academicians need not wait for such calls. India has a huge network of several hundred medical colleges, elite institutions like PGI/AIIMS(s)/ equivalent, specialized hospitals/ institutes with a focus on leprosy and universities/ other institutions with interest in leprosy. Knowledge generation and application is a continuous and dynamic process. We need to reflect whether we are doing enough to deal with the problem of deformities.

Indian Journal of Leprosy, being published since 1929, is an important journal dedicated to leprosy research. During the last five years (2020-2024), 20/189 (11%) papers published in Indian Journal of Leprosy addressed the issue of deformities/ disabilities in leprosy. Of these 20 papers, 13 were regarding profiles and percentages - with G2 disability rates in medical colleges ranging from 20% to 52%; two were on quality of life (QoL) affected by disabilities or after surgery; one dealt with disabilities being cause of dehabilitation; 2 were on use of steroids and decompression in neuritis cases; one on physiotherapy, one surgery and one on factors linked with disabilities. Mostly the publications were from dermatology departments, a few collaborations with surgeons, ophthalmologists and physiotherapists. Interdepartmental collaboration was mostly missing. These figures have a meaning but cannot guide improvements. There are numbers of G1D and G2D but very little information of what could reverse G1D or could prevent G1D becoming G2D. There is very little documentation as how G2 disabilities are being handled in our medical college system across the country? It is understandable that many a disability related papers might have been published/ would be getting published in other journals. However, very few publications on disabilities were found on web search – there are reports that in a sizeable proportion disabilities occurred in follow-up period in cases released from treatment (RFT) and in some these are linked with delayed diagnosis.

While it is heartening to note that many medical colleges continue to take interest in academics of leprosy, apparently research on different aspects of disabilities (prevention, treatment and rehabilitation) is weak. Policy makers and NLEP will be benefitted by current knowledge about aspects related to health systems – timely access to diagnosis and management so that disabilities are by and large prevented. If they occur, how effectively they are handled so that medical and social consequences are minimum. Certainly, psychological and social issues deserve priority. Health professionals need to be equipped with latest working knowledge about tools and techniques. Health systems should be geared to address real life difficulties of leprosy effected people especially having disabilities/ deformities or those who are at higher risk of landing up with such complications. Medical and surgical tools/ techniques available for this purpose may be still effective but the question is their timely availability. Most of these persons with disabilities land up in dermatology clinics because of leprosy, however, to understand the problem optimally in a dynamic manner and take required measures we need partnership with community medicine/ public health professionals, various surgical specialties, sociologists as well as mental health professionals. Such partnerships appear to be quite weak. We should also remember faith-healers are important component of our cultural eco-system and their empowerment is relevant on this issue too. Good or bad lessons are not getting published. It is hoped that times will change for the better and such professional partnerships will be strengthened. Finally, such data should be in public domain so that policy makers as well as researchers are empowered to do better and better at management and research levels.

– **Vishwa Mohan Katoch,** Honorary Editor

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