Paediatric rheumatology in India: challenges and opportunities

Where we are now

According to the 2010 census data [1], India has a population of 1.15 billion people, accounting for ~17% of the world’s population, second only to China. With its current growth rate, by 2050 it could surpass China to become the most populous nation in the world. More than half the population is <25 years of age and about one-third <14 years of age. The prevalence of various childhood rheumatic diseases varies across different regions of the world, with the prevalence of JIA ranging from 0.07 to 10/1000 children and that of SLE from 0.4 to 0.6/100,000 children [2, 3]. Epidemiological data from India about childhood rheumatic diseases are lacking, but on the basis of the above population data, we could estimate ~1.3 million children with JIA and 200,000 with SLE alone.

The types of paediatric rheumatic diseases seen in India are protean, with JIA being one of the common conditions. In the early 1990s it was suggested that the spectrum of juvenile arthritis in India is different from that seen in Western countries. Studies on JIA in the mid- and late 1990s highlighted that polyarticular JIA and enthesitis-related arthritis (ERA) were the common subtypes, unlike in the West where oligoarticular disease predominates [4]. The only community-based study of JIA found a high prevalence of ERA and revealed that <50% of these children were examined during the first year of their illness, pointing to a significant delay in diagnosis [5]. Among 967 children with JIA seen in one institution, 391 had ERA (Aggarwal, data not published). Chronic anterior uveitis is also less common in Indian children with JIA, probably related to the low prevalence of oligoarticular disease [6].

SLE is reported to be more severe in Asians, including Indians, living in developed nations (although data from India are limited) [7]. Renal and CNS involvements are more common than those reported from the West and associated with higher morbidity and mortality [8]. Infections, particularly tuberculosis (TB), are important contributors to difficulty in the management, especially if they occur concurrently with severe active disease. Rheumatologists are often faced with the difficult problem of controlling severe disease flares, balancing immunosuppression and the risk of opportunistic infections.

Infection-associated vasculitis and arthritis are common, e.g. Chikungunya arthritis, hepatitis B-associated PAN, tropical pyomyositis and lepra reactions. TB is still a major factor that masquerades and presents with chronic monoarthritis, oligoarthritis, arthritis of the tarsal bones and inflammation of SI joints because of a high background infection rate. Acute rheumatic fever (ARF), although its incidence has decreased over the years, is not uncommon. Children with JIA can be misdiagnosed with TB or ARF, and be treated with penicillin or anti-TB therapy for their arthritis, because of the lack of awareness about rheumatic diseases.

The cost involved in the care of a child with JIA was estimated to vary between $4150 (£2547) and $11250 (£6903) per year, in comparison with a patient with RA, which costs around $7375 (£4528) per year [9]. The only study from India that looked at the cost involved in having a rheumatic disease found the direct cost of treatment of RA to be approximately $340 (£209) per year; with only 10% of patients having complete reimbursement for their medical expenses from their employer and none having medical insurance [10]. In India, costs of drugs alone account for ~20–60% of health-care costs, and are paid out of pocket by the patients, resulting in reduced access to medicines. Since JIA affects children, and in one-third the disease persists into adulthood, the cost to society is even more due to loss of productivity in adult life. For a resource-poor country like India, these are substantial costs.

However, there is more than a glimmer of hope. With increasing education and awareness among the growing middle class, there is greater demand for better health care. Furthermore, increased awareness of the specialty of rheumatology among the medical fraternity, the recent increase in fellowship programmes on rheumatology and clinical immunology by the Medical Council of India, and an increase in government spending on research will lead to the provision of good quality research studies and overall improved care.

The large patient pool available in India is an untapped clinical resource that could provide the basis for good research studies both in the clinical field and to investigate the pathogenesis of rheumatic diseases. International collaborations with established paediatric rheumatology centres in Europe, Canada and the USA are needed to develop world class centres of excellence in management and research in India.

The need of the hour is to introduce a module on rheumatology in both undergraduate and postgraduate training so that a paediatrician is equipped to recognize and manage common rheumatic problems and refer children to a specialist early. India is a hub for information technology, and the government’s decision to link all medical colleges by a telemedicine network could provide
an opportunity to disseminate knowledge to all across this vast country even with limited trained manpower. Paediatric rheumatology in India is at a crucial juncture where, if opportunities are maximized, it will lead to significantly better care for children with rheumatic diseases.

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Shabina Habibi¹, Amita Aggarwal² and Athimalaipet V. Ramanan³

¹Department of Rheumatology, Nizams Institute of Medical Sciences, Hyderabad, ²Department of Clinical Immunology, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, India and ³Bristol Royal Hospital for Children & Royal National Hospital for Rheumatic Diseases, Bath, UK

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Correspondence to: Athimalaipet V. Ramanan, Department of Paediatric Rheumatology, Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol BS2 8BJ, UK. E-mail: avramanan@hotmail.com

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