

## **KRAeb cohort study**

### **Harshini AS, Vineeta Shobha**

This project stands as one of our most ambitious and potentially impactful initiatives, with the capacity to influence government policies significantly. In February 2023, we commenced preparations for the Karnataka Rheumatology Association (KRA) presentation at IRACON 2024, scheduled to take place in Bangalore. We solicited research ideas from KRA members and ultimately selected the theme of the “Economic Burden of Rheumatoid Arthritis (RA)”. Recognising that this area was relatively unexplored within the field of rheumatology, we sought expertise from the Department of Community Medicine at St. John's, under the guidance of Dr. Farah Fathima, to assist in designing the Case Report Form. With their guidance, we were able to gather comprehensive data not only on direct medical and non-medical costs but also on indirect expenses, utilising the standardised IMTA Productivity Cost Questionnaire.

This collaboration was strategically designed to encompass patients from all districts of Karnataka, ensuring representation from both rural and urban populations, individuals across diverse educational backgrounds, and a broad spectrum of socioeconomic statuses to obtain a comprehensive and realistic dataset. To standardize data collection, the research team at St. John's created instructional videos in both English and Kannada, providing detailed guidance on capturing various data points accurately and consistently.

**Challenges:** In multicentric studies, the issue of incomplete or inaccurate data is a persistent challenge. Additionally, certain centers providing medications at reduced or no cost have introduced confounding variables into our data analysis. Another significant challenge is the reluctance of patients to disclose accurate information regarding their family income and expenditure, which further complicates the interpretation of these factors.

#### **Publications:**

We presented preliminary data from this effort @ IRACON 2023 as oral platform and subsequently at APLAR 2024 in Singapore (<https://aplarcongress.com/wp-content/uploads/2024/08/Poster-listing-Friday.pdf>). Currently, we have completed data collection for more than 2000 patients and have submitted 4 abstracts to IRACON 2024.

*Summary of abstract presented at APLAR is presented below.*

### **Unveiling the Financial Toll of Rheumatoid Arthritis: A Study from Karnataka Chapter of Indian Rheumatology Association**

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**Summary:**

A cross sectional study was conducted across 17 rheumatology centers of the state to analyse the 'cost-of-illness' in patients with RA, in order to determine the magnitude of economic impact and determinants of catastrophic health expenditure( defined as  $\geq 20\%$  of annual income). 1543 RA patients were included with mean age  $50.5 \pm 12.1$  years (88.2% women). Mean duration of follow-up was  $48.6 \pm 41.8$  months and the median annual expenditure towards RA treatment including all direct and indirect costs was INR33680(IQR24000,46600). Of this, cost of medications was INR16000(IQR10000,24000). CHE was noted in 447/1543(29.6%) patients with lower SES and multimorbidity being associated with higher odds of it. Methotrexate and tofacitinib were prescribed in 1223(79.3%) and 450(29.2%) respectively. A significant interaction effect was noted between methotrexate and  $DAS28 \leq 3.2$ ,  $CDAI \leq 10$ ,  $HAQ-DI \leq 0.5$  (all  $p < 0.01$ ) indicating that methotrexate achieved lower disease activity and better quality of life at a lower annual medical expenditure. For tofacitinib, similar interaction effect was not noted

**Delayed referral and poor accessibility to healthcare services under National Health schemes hinders optimal care for Rheumatoid Arthritis**

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**Summary:**

Among 1543 RA patients included from 17 rheumatology centers across the state, almost half of which ( $n=777, 50.1\%$ ) hailed from rural geographic regions of Karnataka. The health care costs were largely borne by themselves as out-of-pocket expenditure in 50% ( $n=775$ ) of patients. Only 7% ( $n=108$ ) were availing Government Health schemes (GHS). About two-thirds [ $n=991(64.2\%)$ ] reported being Below Poverty Line (BPL). About half of our cohort ( $n=828; 59.2\%$ ) took  $\geq 1$  year to get a referral to rheumatologist. Median expenditure incurred prior to referral to rheumatologists was INR50,000(IQR 20,000;125,000) which amounted to catastrophic expenditure ( $>20\%$  of their annual income) for 414(26.8%) patients. The high expenditure is probably attributable to the low level of awareness resulting in late specialist referral and poor penetration of Government Healthcare Services amongst the population.