

# Management Practices of Juvenile Idiopathic Arthritis among Rheumatologists in India

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## ABSTRACT

**Introduction:** Pediatric rheumatology is a young speciality in India. There is a need to study the awareness and practice of pediatric rheumatological illnesses among practicing rheumatologists and pediatric rheumatologists in India. So a study was done to highlight this gap in health services and the need for developing pediatric rheumatology services in various parts of the country.

**Material and Methods:** A survey in the form of a questionnaire was either emailed or sent to registered rheumatologists in the Indian Rheumatology Association in all states of India by whatsapp or email. Analysis of the survey was performed. A total of 500 professionals were contacted and despatched the survey.

**Results:** A total of 141 responses (28.2% response rate) from all over India were obtained. 8.8% of responders were exclusively pediatric rheumatologists. The majority (62.5%) saw pediatric patients of all ages however only 14% reported feeling comfortable with making a diagnosis in children below 3 years of age. Only 16.7% of responded were comfortable with treating children younger than 3 years of age. 64% would consider 20mg as an appropriate dose of methotrexate in a 40 kg child. About 11.7% would refer pediatric patients to pediatric rheumatologists for initiation of disease modifying antirheumatic drug (DMARD) therapy, 28% if refractory to first line therapy and 19% for biologics therapy. 15% would prefer to refer young patients straightaway. Overall 61% would prefer to refer to a pediatric rheumatologist if one was accessible.

**Conclusion:** The majority of adult rheumatologists saw small numbers of pediatric patients and seemed to be more conservative with dosing DMARDs. A majority would prefer to refer children with pediatric rheumatological illnesses to pediatric rheumatologists if accessible. The study underlines the need to highlight the speciality and develop training pathways for pediatric skilled doctors to train in this speciality so that there can be access to pediatric rheumatologists across all zones in the country.

**Key words:** Juvenile Idiopathic Arthritis (JIA), Rheumatologists, Pediatric Rheumatologists, DMARDs, Referral

## INTRODUCTION

Based on 2017 census data showing Indian population of 1.34 billion and worldwide prevalence of rheumatic diseases in childhood the guess estimates are that there could be more than 1.3 million children with JIA and about 200,000 with lupus.<sup>1,2</sup> Unfortunately published data regarding prevalence of these diseases in India is lacking. For a country with such a huge patient load there are very few centres offering

specialist care. In India there are about only about 12 centres offering pediatric rheumatology services and 2 training programmes for doctors aspiring to train in this speciality. Rheumatology itself is a young subspecialty in India and the number of trained adult rheumatologists is also inadequate for the population. A survey in Japan with 80 pediatric rheumatologists<sup>3</sup> and in the US with 193 pediatric rheumatologists<sup>4</sup> have both reported their numbers to be extremely suboptimal, thus the comparable figures in India are extremely dismal. Overall the training programmes in rheumatology in India are largely adult patient orientated and taken up also by trainees who have not developed skills in pediatric examination and assessment. Our previous study looking at awareness of pediatric rheumatological conditions amongst general paediatricians in India (mainly answered by urban based doctors and mostly in tertiary care) has already brought out that only 50% of pediatricians had access to referral to a pediatric rheumatologist.<sup>5</sup> The aim of the study was to highlight this gap in health services and the need for developing pediatric rheumatology in various parts of the country.

## MATERIAL AND METHODS

A questionnaire designed on google forms was either emailed or circulated via social media to rheumatologists all over the country. No incentives were given for taking part in the survey. Survey was posted in state level rheumatology groups and via the mailing list obtained from the Indian Rheumatology Association. The questionnaire included 12 questions. It looked at whether they were primarily adult or pediatric based rheumatologists and also whether they did purely subspecialty or combined generalist and subspecialty work and the approximate number of pediatric patients in their clinics on a weekly basis. Using JIA as the

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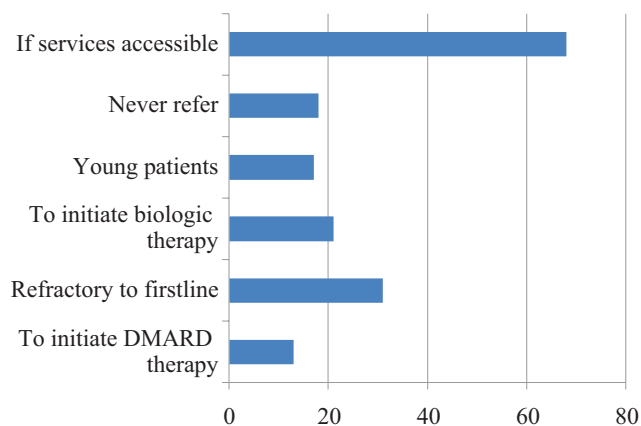
basis, questions were also focussed on whether they were comfortable with assessing children of all ages or there were age groups above which they were more comfortable both for clinical evaluation as well as starting DMARDs and biological therapy if required. Questions based on prescribing habits regarding methotrexate dosing for specific weights and sulfasalazine dosing also were given. Respondents were further asked about thresholds for referral to a paediatric subspecialist, whether at initiation of therapy or if second line or biological therapy is required. Additionally they were asked if they would refer the children in their practice to a pediatric rheumatologist, whether they would treat, refer or sometimes refer to specialists. The survey responders were allowed the option of choosing more than one answer for this query.

## RESULTS

The survey was despatched to 500 professionals of whom 141 responses were submitted (28.2%). Unfortunately, for reasons not clear 25/141 responses (18%) were devoid of any answers. Of the remaining 116 responses, there were a few variable defaulters for each question (Table 1).

Of the 116 responses, 84(74.3%) were adult rheumatologists, 8(7.1%) were physicians with interest in rheumatology, 10(8.8%) were pediatric rheumatologists, 11 (9.9%) were pediatricians with interest in rheumatology and 3 failed to specify

Looking at the practice setting, we had received 112



**Figure-1:** Circumstances physicians would consider referring patients to pediatric rheumatology services

	Total responses	Adult physicians /rheumatologists	Pediatricians/ pediatric rheumatologists
Practice setting	112 responses		
Tertiary hospital	77 (67.8%)	58	19
Private practice	35(31.3%)	33	2
No of pediatric pts/wk	112 responses		
0-5	65(58%)	63	2
5-10	17(15.2%)	17	
10-20	7(6.3%)	7	
>20	23(20.5%)	6	17
Age limits seeing pts	112 responses		
see regardless age	70 (62.5%)	50	20
do not see <3	16(14.3%)	15	1
do not see<6	14(12.5%)	14	
do not see<12	9(8%)	9	
do not see<16	3(2.7%)	3	
Comfort in making diagnosis	108 responses		
< 3 yrs	15(13.9%)	4	11
>3 yrs	45(41.7%)	37	8
>6 yrs	23(21.3%)	22	1
>12 yrs	16(14.8%)	16	
>16 yrs	9(8.3%)	9	
Comfort in treating JIA pts	108 responses		
< 3 yrs	18(16.7%)	9	9
>3yrs	47(43.5%)	41	6
>6 yrs	23(21.3%)	19	4
>12yrs	16(14.8%)	16	
>16 yrs	4(3.7%)	4	
Comfort with biologic therapy	109 responses		
<3yrs	18(16.5%)	8	10
>3yrs	27(24.8%)	19	8
>6yrs	24(22%)	23	1
>12yrs	24(22%)	23	1
>16 yrs	16(14.7%)	16	

**Table-1:** Survey of practices

	Total responses	Adult physicians	Pediatricians
Dose of MTX for 15 kg child	111 responses		
5 mg	40 (36%)	37	3
7.5 mg	42(37.8%)	33	9
10 mg	20(18%)	15	5
12.5 mg	3(2.7%)		3
15 mg	6(5.4%)	5	1
Dose of MTX for 40 kg child	111 responses		
7.5 mg	2(1.8%)		2
10 mg	5(4.5%)	5	
15 mg	33(29.7%)	28	5
20 mg	71(64%)	57	14
Dose of sulfasalazine in 50 kg child with ERA	110 responses		
500 mg OD	1(0.9%)		1
500 mg BD	10(9.1%)	8	2
500 mg TDS	17(15.5%)	16	1
1 gram BD	82(74.5%)	66	16

**Table-2:** Survey of treatment

responses, the majority of whom were based in tertiary hospital 77(67.8%), 35(31.3%) were in private practice. Most of the pediatric rheumatologists who responded, 10/11 pediatricians with interest and 9/10 pediatric rheumatologists were tertiary hospital based as were the majority of adult rheumatology responders -6 general physicians and 52 adult rheumatologists tertiary practice and 2 gen physicians and 31 adult rheumatologists were in independent private practice. State wise responses from 16 states and union territories in total, the largest came from Kerala 19 (20.2%) and TN 18(19.1%), then Maharashtra 11 (11.7%), Karnataka 10(10.6%), West Bengal 7(7.4%), Gujarat 6(6.4%), Uttarpradesh 5 (5.3%), Jammu and Kashmir 4 (4.3%), Delhi 3(3.2%), Telangana 3(3.2%), Pondicherry and Rajasthan 2(2.1%), Orissa, Chattisgarh, Chandigarh, Haryana 1 (1.1%)

We looked at the number of pediatric patients per week seen by respondents. Of 112 responses, 65(58%) saw 0- 5 patients, 17(15.2%) saw 5- 10 patients, 7(6.3%) saw 10-20 and 23 (20.5%) saw > 20 pediatric patients/week. Among the 23 who see > 20 patients /week, 17 are pediatric rheumatologists or pediatricians with special interest and 6 are adult based professionals and another 7 adult based professionals saw between 10-20 pediatric patients/week.

We looked at whether respondents had age limits for seeing pediatric patients and of the 112 responses, about 70(62.5%) see patients regardless of age of whom 20 were purely pediatric rheumatologists/pediatrician with interest in rheumatology. 16 (14.3%) do not see children < 3 years, 14(12.5%) see only > 6 years, 9(8%) see only children above 12 years and 3(2.7%) do not see any children < 16 years. Among the adult based specialists, 50/91 see children of all ages.

We tried to elicit at what age the various professionals were comfortable in clinical evaluation and making a diagnosis. Of 108 responses, only 15 (13.9%) were comfortable in very young children below 3 years of age of whom 11 were pediatric rheumatologists and pediatrician with interest and 4 were adult based rheumatologists. 45(41.7%) of

respondents were comfortable with children above 3 years of age of whom 8 were pediatric trained professionals and 37 were adult based, 23(21.3%) were comfortable above 6 years of age which comprised 1 pediatrician with interest and the remainder adult based professionals. 16 (14.8%), all adult based respondents were comfortable only in children above 12 years of age and 9(8.3%) in children > 16 years only. Assessment of comfort in treating JIA patients was done. We received 108 responses, of which 19 were pediatric professionals and 89 were adult medicine professionals. 18(16.7%) were comfortable with treating all age groups which included 9 pediatric based professionals and 9 adult based. 47(43.5%) were comfortable in treatment of children above 3 years of age of which there were 6 pediatric based and 41 adult based professionals. About 23(21.3%) were comfortable only in children above 6 years of age of whom 4 were pediatricians with interest and rest were adult based. 16(14.8%) of adult based rheumatologists were only comfortable with treating children above 12 years of age and 4 (3.7%) in children above 16 years.

Looking at initiating and monitoring biologic therapy, we received 109 responses, 20 pediatric based and 89 adult based. 18(16.5%) including 10 paediatric professionals (6 pediatric rheumatologists and 4 pediatricians with interest) and 8 adult based professionals were comfortable to use biologics in children of all ages. 27(24.8%) were only comfortable in using biologics in children above 3 years of which of whom 8 were pediatric professionals and 19 were adult based. 24 (22%) were comfortable in children above 6 years of which 1 was a pediatrician with interest in pediatric rheumatology. A similar figure 24 (22%) were comfortable in children above 12 years of age, 1 of whom was a pediatrician and the rest adult based and 16 (14.7%) adult based rheumatologists were only comfortable prescribing biologics to children above 16 years of age.

We also looked at a few prescribing habits and differences between pediatric and adult based professionals (Table 2). One question was on the starting dose of methotrexate in a

15 kg child with JIA for which 111 responses were received. 40(36%) including 37 adult rheumatologists and 3 pediatric professionals would initiate with 5 mg, 42(37.8%) of whom 33 were adult based and 9 were pediatric based would initiate with 7.5 mg, 20(18%) of whom 15 were adult based and 5 were pediatric based would initiate with 10 mg, and only 3(2.7%) would initiate with 12.5 mg all of whom were paediatric based and 6(5.4%) of whom 1 was pediatric and 5 were adult based would straightaway initiate with 15 mg. We received 111 responses (21 pediatric, 90 adult) to a question looking at the optimal weekly dose of methotrexate in a child weighing 40 kgs. 2(1.8%) felt it was 7.5 mg which were both pediatric based professionals, 5 thought it was 10 mg (4.5%) all of whom were adult based, 33(29.7%) thought it was 15 mg of whom 5 were pediatric professionals and 28 were adult based and the majority 71(64%) opted for 20 mg of whom 14 were pediatric professionals and 57 were adult based.

We looked at the optimal daily dose of sulfasalazine in enthesitis related arthritis (ERA) in child weighing 50 kgs. Of the 110 responses (20 pediatric and 90 adult), 1 felt it was 500 mg once daily, 10(9.1%) felt it was 500 mg twice daily of whom 2 were pediatric and 8 adult based, 17 (15.5%) felt it was 500 mg three times a day of whom 1 was pediatric and 16 were adult based and 82 (74.5%) felt it was 1 gram twice daily of whom 16 were pediatric and 66 were adult based responses.

The last question to which multiple responses were possible was regarding when referral to a pediatric rheumatologist would be considered (Figure-1). Only 13(11.7%) would consider referral for all cases for initiation of DMARD therapy, 31(27.9%) would want to refer if first line therapy failed, 21(18.9%) would refer if a they felt a child needed biologics, 17(15.3%) felt they would refer all young children for treatment. 18(16.2%) felt they would never refer any child to a pediatric rheumatologist. However, 68(61.3%) felt that they would prefer to refer pediatric patients if a pediatric rheumatologist was accessible

## DISCUSSION

Web based surveys remain an important way of research to gather information about physicians knowledge, attitudes, and to evaluate the impact of clinical research on practice.<sup>6</sup> Looking at statistics from abroad, the best response rate to physician surveys has been found to be around 35% and the nature of topic and presence of incentives have been found to improve this further.<sup>7</sup> Even an OMERACT international survey on musculoskeletal ultrasound practices in children has yielded a 36% response to a questionnaire survey.<sup>8</sup> A survey performed during a Pediatric Rheumatology European Society Congress meeting yielded 25% responses.<sup>9</sup> We have obtained around a 28% response rate but due to incomplete answering an overall 24% analysable response rate. As this was a non incentivised survey, it's a reasonable response rate.

The majority of respondents (82%) were adult rheumatologists and adult physicians, which reflects the general paucity of

trained pediatric rheumatologists in India. The majority of responses (2/3rds) were from doctors practicing in tertiary hospitals compared to private practice. This can perhaps also reflect on the numbers of pediatric age group patients seen in their practice.

Not unsurprisingly the maximum responses were received from the participating states of the investigators (Kerala 20% and Tamil Nadu 19%). it would have been more meaningful to have obtained a more uniform response rate from all states.

Most adult rheumatologists saw very small numbers of pediatric patients/week (60% <5/week), while the pediatric rheumatologists were the main ones seeing > 20 pediatric patients /week. Considering that the numbers of pediatric rheumatologists are indeed very small, this does raise the question as where all the pediatric rheumatology patients are indeed treated and the need to strengthen access to trained rheumatology care.

Among the adult based specialists about 54.9% (50/91 of adults) of the respondents were willing to see children of all ages. However only 13.9% of total respondents were comfortable with making diagnosis in children below 3 years of age of which 75% were paediatric rheumatologists. Another 42% of adult rheumatologists were comfortable with diagnosing JIA in children above 3 years of age, another 25% in children above 6 years while 10% were comfortable with making a diagnosis only in children above 16 years. This is reasonable considering that clinical assessment examination and differential diagnosis in childhood illnesses are easier for those who have been trained in pediatrics.

When we looked at the comfort in treating children with JIA, only 16.7% were comfortable in treating children below 3 years of age (of which 50% were pediatric professionals) and 43% in children above 3 years of age (including some pediatric specialists were comfortable above 3 years of age only) and even more interestingly, when looking at biological therapy the comfort in initiating the same in children under the age of 6 was significantly lower than for DMARD therapy.

The treatment survey consisted of 3 questions regarding DMARD therapy in JIA.

Looking at the initial dose of methotrexate in a 15 kg child-while literature recommends starting at 10-15mg/m<sup>2</sup>/week, pediatric rheumatologists tend to start at higher doses of 7.5 or 10 mg/week in the majority while adult based specialists are more conservative with the majority opting for 5 mg. More aggressive management has been shown to reduce time to remission and reduce duration of requirement for induction therapies like steroids/ NSAIDS. However doses beyond the recommended absolute maximum of 20mg/m<sup>2</sup>/week have not been shown to be beneficial in recruiting more children into remission. We did not ask about the availability of intra-articular injections in children as we were unsure how many clinical settings had provision for these particularly for younger children.

For a 40 kg child the majority of pediatric and adult specialists were comfortable with a maximum methotrexate dose of 20

mg /week though a few (surprisingly pediatric specialists also) would stop at lower doses.

Similarly in a 50 kg child with ERA the majority in both groups were comfortable with sulfasalazine dose of 1gram twice daily which is the ideal dose of choice. At higher ages and weights the overall concordance between adult based and pediatric based specialists seem to be matched.

The final question which was to do with referral to a pediatric rheumatologist.16% would never refer (the majority of these were pediatric rheumatologists themselves).15% of the respondents answered that they would refer young patients (<3 years) and 11% for initiation of DMARD therapy.28% respondents said that they would refer if refractory to first line therapy-usually methotrexate.20% respondents would refer for consideration and initiation of biological therapy. This is distinct from the previous because perhaps the ability to give intra-articular steroids to children or try combination DMARDs are ways to manage children who are unable to afford biological therapy. Most interestingly, 68% (largely comprising the adult based specialists) would definitely like to refer to pediatric rheumatologists if a service was available.

There has been a similar study reported by Van Mater et al<sup>4</sup> in the US where a cross sectional questionnaire study was done looking at attitudes and comfort in JIA diagnosis and treatment amongst adult and pediatric rheumatologists. A random 500 adult rheumatologists and all 193 pediatric rheumatologists were mailed the survey and despite a response of 65%, ultimately 23% of adult rheumatologists and 93% of pediatric rheumatologists responses were analysed. Results are interestingly similar with the majority of adult rheumatologists treating in the majority children over 10 years of age in whom they were quite comfortable to make diagnosis but lesser comfort rates to treat. A significant difference was found in that pediatric rheumatologists were more likely to use methotrexate or biologics in the first consultation and have a higher threshold to add anti TNF treatment for polyarticular JIA compared to adult rheumatologists. 58% of adult rheumatologists stated that they see children only because of the lack of suitably trained pediatric rheumatologist and the ones based in areas which had no pediatric rheumatologist for a radius of 50 miles were more likely to see children of all ages. The survey conducted during the Pediatric Rheumatology European Science congress meeting<sup>8</sup> also identified that 46% of the responders felt their training process was unsatisfactory which might also be an area of improvement in the quality of pediatric rheumatological care.

## CONCLUSION

Despite the obvious shortcomings of a cross sectional questionnaire survey and an overall response rate of 24% analysable results, there are still significant differences between the approach to pediatric rheumatology patients and the approach to a child with juvenile idiopathic arthritis that we noted. A significant majority of adult rheumatologists see only small numbers of children in the practice. Only

(54.9%) were comfortable with seeing children of all ages. However only 13.9% of all respondents were comfortable with evaluating and treating children below 3 years of age of whom 75% were paediatric rheumatologists. In young children the comfort in making a diagnosis, and initiating therapy were sequentially reduced. Pediatric rheumatologists were more aggressive in dosing methotrexate both in initial dose as well as the maximum dose a fact that is important in that use of prolonged systemic steroids or longer time to remission are associated with greater long term outcome impairments in children. 68% of adult rheumatologists would prefer to refer children to pediatric rheumatologist if such a service was available in their area. This highlights the need to increase awareness and educational opportunities to train more pediatric rheumatologists for the vast Indian population which is currently a very insignificant number overall.

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