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# EVALUATION OF QUALITY OF LIFE IN INDIAN CHILDREN WITH JUVENILE RHEUMATOID ARTHRITIS

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## Abstract

**Aim**: The aim of this study was to quantify the degree of disability in juvenile rheumatoid arthritis (JRA) in Indian children.

**Background**: Juvenile rheumatoid arthritis is a multi-system disorder rather than a condition which merely affects the joints.

**Materials & Methods**:This prospective study includes 50 children of 3-16 years with juvenile rheumatoid arthritis, who were diagnosed on the basis of a specific criteria of American College of Rheumatology and who were on long term follow up of the Paediatric rheumatology and immunology clinic of our institute, Detailed assessment of the disability state as well as the quality of life was carried out with validated and standardized questionnaire specifically designed for children.

**Results**: Children with JRA not only have significant physical disability but also have a seriously impaired overall quality of life.

**Conclusion**: These children therefore required comprehensive interventions in addition to their medical and orthopaedic management.

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## 1. INTRODUCTION

Juvenile Rheumatoid Arthritis is defined as an inflammatory arthritis occurring in children under 16 years of age and involving one or more joints that lasts for more than six weeks1. It is the most frequent of all Paediatric connective tissue disorders.[1] JRA is a heterogeneous condition that results in considerable morbidity in children and is a leading cause of disability in children[1]. JRA is not uncommon, but the exact incidence and prevalence rates in general population are not available. The reported figure in Western literature varies from 10-20 cases per 100.000 children below age at risk per year. [1,2] Similar epidemiological data from India are not available.

The diagnosis and classification of children with chronic arthritis most frequently is according to the criteria proposed by a committee of the American College of Rheumatology (ACR) [1,3] . Thesecriteria define the arthritis, the age limit, the duration of disease necessary and the types of onset and indicate the need to exclude other diseases.

It has been estimated historically that 70-90% of children with JRA make a satisfactory outcome without serious disability [4-8]. A small percentage (perhaps 5%) have a recurrence of arthritis as adult [9-11] .

To the best of our knowledge there are no data available regarding health assessment in children with JRA from developing countries. The present study was carried out to fill up the lacunae in the literature.

## 2. MATERIALS AND METHODS:

The universe of this study consists of 50 children of either sex, who were diagnosed to have juvenile rheumatoid arthritis (JRA) and were on regular follow-up in the Paediatric Rheumatology and Immunology clinic of the Advanced Paediatric Centre. The subjects included in this study were children of 3-16 years of age at the time of diagnosis, diagnosis of JRA based on criteria given by American College of Rheumatology, age at onset < 16 years, arthritis (swelling, or effusion, or presence of two or more of following signs (tenderness, pain on motion, increased local temperature, restricted range motion) in one or more joints, Duration of the disease 6 weeks or longer, Onset type defined by type of disease in the first 6 months, polyarticular – 5 or more inflamed joints, Oligo/pauciarticular<5 joints, Systemic: Arthritis with characteristic fever, subjects with other forms of Juvenile arthritis, presence of an overlap syndrome, presence of any other significant medical condition in addition to JRA.

At the time of enrolment a detailed questionnaire was filled in to record the important clinical details as well as results of laboratory investigations which had been carried out on the individual as a part of routine work-up in the Paediatric Rheumatology and Immunology clinic. In addition, a detailed assessment was done using a modified version of the Stanford health assessment questionnaire used to assess the disabilities related to activities of daily living (ADL) in 8 specific areas, namely dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. Each of these components was evaluated for the degree to which the daily functions were affected. The use of special aids or devices and activities for which assistance of another person (usually the parent) is required were noted. To eliminate the disability due to or related to growth and development, parents were asked to note only those difficulties that were caused by the arthritis per se. Each question were scored from 0-3 in parallel with Steinbroker functional classification scores with the degree of difficulty. The scores for each of 8 functional areas were averaged to calculate the disability index.

In addition to the disability index, to objectively assess the quality of life of the children with JRA the questionnaire containing 14 components and each component was scored from 1-5 according to the standard protocol were administered to assess the quality of life

The disability questionnaire as well as the quality of life questionnaire were administered on the same visit of the patients by the principal investigator. Ethical clearance was obtained from the institutional ethics committee. Informed consent was obtained from the parents before inclusion of the patients in this study. Children who did not co-operate fully or were unable to follow the instructions of the examiner were excluded from the study.

## 3. RESULTS:

The study subjects were 50 children who were clinically diagnosed as JRA and were on regular follow-up. In the Paediatric Rheumatology and Immunology clinic among them majority were male children (68%). Eighty percent of the children belong to the age group of 7-16 years, with the overall mean age of 9.26 years. Majority of the patientshaemoglobin was more than 10 gm% (52 %). However 14 % of them were severely anaemic (Hb<8gm%).Erythrocyte sedimentation rate (ESR) estimated by Western method showed 90 % of the patients had raised ESR but fifty percent of them had significant rise. Out of 47 patients who were tested for rheumatoid factors (RF) only 6 % of the patients. Out of forty patients tests for HLA-B27; 17.5% showed positive results. Forty eight percent of the children had more than or equal to 5 joint involvement (polyarticular), 44% of them had less than 5 joint involvement (pauciarticular). Majority of the children were brought to seek medical advice at about 2 years or more (70%). 52% of the patients were not having any disability inspite of the disease. However 8% of them were severely affected. Among the 8 components assessed most affected was the activity component (23 children) followed by hygiene and walking, least affected was dressing, grooming and grip (Table 1 & 2).

**Table 1**: Distribution of study subjects according to disability score and components of disability.

| | **Number (n=50)** | **Percent** |
|---|---|---|
| **Disability score** | | |
| ≤ 1 No disability | 26 | 52 |
| 2-5 Mild disability | 10 | 20 |
| 6-9 Moderate disability | 10 | 20 |
| ≥ 10 Severe disability | 4 | 8 |
| **Disability Components** | | |
| Activity | 23 | - |
| Hygiene | 19 | - |
| Walking | 12 | - |
| Reach and arising | 10 | - |
| Eating, dressing and | 5 | - |
| grooming | 2 | - |
| Grip | | |

**Table 2**: Relation between type of disease and disability.

| **Type of disease** | **No disability (score ≤ 1)** | **Disabled (score > 1)** | **Total** |
|---|---|---|---|
| Polyarticular | 9 (34.7%)(37.5 %) | 15 (62.5%)(62.5%) | 24(48%)(100%) |
| Pauciarticular | 15(57.6%)(68.2%) | 7(29.2%)(31.8%) | 22(44%)(100%) |
| Systemic arthritis | 2(7.7%)(50%) | 2(8.3%)(50%) | 4(6%)(100%) |
| Total | 26(100%)(52%) | 24(100%)(48%) | 50(100%)(100%) |

$X^2 = 4.33$, $P=0.037$ (for polyarticular and pauciarticular only).

Second most component affected was hygiene especially in polyarticuar JRA. Majority of the disability was seen in polyarticular type (29.2%). The association was statistically significant ($X^2$= 4.33, P = 0.037).Disability increased with the increase in duration of illness. Duration of illness ofmore than 3 years were 2.36 times more chances of having disability when compared to less than 2 years of illness. Physical status was also normal in 76% of the patients, affecting only 14% of them. In spite of treatment 20% of the patients continued to have serious disability. However 80% of them were able to manage to perform activities of daily life (Table 3).

**Table 3**: distribution of children according to quality of life score ( n=50)

| **Quality Of Life Index Score** | **Number** | **Percentage** |
|---|---|---|
| ≤ 50 | 4 | 8 |
| 51-57 | 9 | 18 |
| 58-64 | 10 | 20 |
| ≥ 65 | 27 | 54 |

## 4. DISCUSSION:

Juvenile Rheumatoid Arthritis (JRA) is the commonest rheumatological disorder inchildhood. It is believed to affect 6 to 19.2 per 1,00,000 children less than 15 years of age per year. [1,2]JRA is a systemic disorder and many systems other than the joints are affected by this disease process. The disease itself being chronic in nature results in long term morbidity not only due to articular involvement but also due to its extra articular complications (generalized growth retardation and multi-organ involvement).[1]

The assessment of disability in children is associated with special problems not seen in studies performed in adults.[12] Children had been symptomatic for varying periods at the time of the study. The duration of illness was between 7 months to 10 years with varying disability. Majority of children were having symptoms for more than 2 to 3 years (36%). There is a positive relation between the duration of disease and the disability. As the duration increased the disability also increased. This was probably due to the development of deformities associated with joints. If not treated in the early stages disease will progresses to serve deformities. Most of our children had polyarticular form of JRA (48%) followed by pauciarticular (44%) and systemic onset JRA (8%). This is in contrast to the western pattern of the disease where pauciarticular are more common (48.61%) followed by polyarticular (29%) and systemic onset (22.22%). JRA as reported by Singh et al.[13]

Among the 50 children studied for disability assessment using the modified Stanford CHAQ, 48% of the children with JRA had disability and remaining were able to perform the activities of daily living inspite of the disease. In this study 8% of the children who were severely affected by the disease and were almost crippled, (not attending school) and dependent on their parents for their activities of daily living. When correlated the type of disease, with disability it was found that 62.5% of polyarticular JRA were disabled, when compared to the pauciarticular JRA (29.5%) who are least affected. These results are consistent with the study reported by singh et al. 13The difference between the type of JRA is because, polyarticular JRA is severe, affects maximum number of joints and limits the activities.

When each component of the eight questions in the questionnaire independently and correlated with the type of JRA. The most affected was the “activities component followed by hygiene and least affected is the grip. Again in each and every component, children with polyarticular JRA were more affected. The activities component and the hygiene components involve the functions related to joints of lower limbs. The study reported by lovell et al. 12 using the juvenile arthritis functional assessment scale for children with JRA have shown a similar pattern of response. This was because maximum numberwere having knee joint involvement. Therefore, the activity involving knee joint were affected more.

Quality of life score indicated that physical dimension is affected in 24% and remaining children scored normally. The 8% of the study population had disturbances in their mental status. JRA does not affect the mental functions. Because of the physical disability they have restricted activities which in turn leads to social limitation. There is isolation also from the parents which might have influenced the mental health. Eighty percent of the children were symptomatically better when they were on medication. In certain patients the disease activity was not under control. There were remissions and relapses.

## 5. CONCLUSION:

Children with JRA not only have significant physical disability but also have a seriously impaired overall quality of life. The results of this study would be helpful in designing appropriate management algorithms for JRA in the Indian set up. This study has therefore filled up a major lacuna in the existing literature on JRA in India. Further studies on this aspect of JRA can be designed to focus on not only the progression of disability and change in quality of life associated with the natural course of the disease, but also to see the effect of treatment (both medical as well as surgical) on the study parameters

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