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ORIGINAL ARTICLE

Transition readiness in adolescents with juvenile idiopathic arthritis and their parents: Our single-center experience

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ABSTRACT

Objectives: We aimed to identify characteristics of juvenile idiopathic arthritis (JIA) patients associated with good self-management skills in the transition readiness process and to investigate the readiness of JIA patients and their families for the transition into the adult healthcare system.

Patients and methods: Between March 2021 and June 2021, a total of 44 JIA patients (9 males, 35 females; median age: 15.1 years; range, 12.3 to 19.3 years) admitted to the pediatric rheumatology outpatient and inpatient clinics and their parents were included. Transition Readiness Assessment Questionnaire (TRAQ) was cross-culturally adapted. The TRAQ was administered to all JIA patients and their parents at one point. Demographic and clinical data were collected.

Results: Fourteen (31.8%) of 44 JIA patients had a concomitant disease, while 10 (22.7%) of them had uveitis. Eleven (25%) of them had a family history of autoimmune diseases. In total, 21 (47.7%) of JIA patients were receiving biologics. There was a strong correlation between older age and total TRAQ scores among patients (ρ=0.799, p<0.001) and a moderate correlation between older patient age and total TRAQ scores among parents (ρ=0.522, p<0.001). Patient and parent total TRAQ scores were strongly correlated (ρ=0.653, p<0.001). There was no significant association of JIA patient characteristics (JIA disease subtypes, disease duration, gender, concomitant diseases, uveitis, family history of autoimmune diseases, number of hospitalizations, and treatment with biologics) with TRAQ scores and JIA patients' and parents' readiness for transition.

Conclusion: Transition readiness of JIA patients increases with advancing age. There is no significant difference between transition readiness for JIA patients and their parents.

Keywords: Adolescents, juvenile idiopathic arthritis, transition readiness assessment, Transition Readiness Assessment Questionnaire.

Healthcare transition is defined as purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems.[1] This transfer from pediatric to adult healthcare represents a very vulnerable period for juvenile idiopathic arthritis (JIA) patients and their families. Juvenile idiopathic arthritis is a heterogeneous group of diseases that encompasses all forms of arthritis of unknown origin with onset before the age of 16 years.[2] It is one of the most common childhood chronic rheumatic diseases that affects the quality of life of children and their families and causes much disability.[3] Patients with this disease frequently need specialized treatments and psycho-emotional

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support during their lifetime. The critical moment for JIA patients is transition from pediatric to adult-oriented healthcare system. This complex process occurs over the time, while growing up, and is characterized by consolidation of personal identity, striving to gain complete independence from parents in decision making, establishing personalized communication skills, raising levels of responsibility, ability to make independent decisions related to their health, choosing professional orientation and family planning.[4] To achieve responsibility for their own health, young individuals with JIA need to be provided with continuous medical and psychosocial support. Therefore, to enable optimal functioning of JIA patients in adulthood, it is necessary to provide continuous adapted care and treatment, through appropriate transition programs. Transitional programs should be individualized and adjusted to the national healthcare needs.

The latest recommendations of the European League Against Rheumatism (EULAR) and the Pediatric Rheumatology European Society (PReS) propose that transition would be more successful, if it starts as early as possible: from early adolescence (11 to 14 years) or directly after the diagnosis has been established.[5] In our setting, transfer starts when young adults finish high school. First, we inform patients and their families of the necessity of continuous healthcare in adult oriented institutions. Then, we contact adult rheumatologists, familiarize them with the patient's medical record, and arrange the patient transfer. Unfortunately, many studies have demonstrated unsuccessful transitional care of pediatric rheumatology patients.[6] In practice, young adults with a stable disease often fail to attend their regular appointments with a rheumatologist, which results in a worse outcome of the disease.[7] Lack of adult rheumatologists' knowledge on transitional process, a high patient burden, decreased access to patient information, insufficient communication with pediatric rheumatologists, and the lack of parental supervision are additional barriers to the successful transition. Failure from pediatric to adult healthcare transition can lead to severe consequences such as joint damage, disability, increased number of hospitalizations, and impairment in the quality of life.[8] Approximately 37 to 60% of young adults with JIA reach adulthood with active disease and functional disability.[9-16] To avoid the occurrence of permanent disability, it is important to adequately educate and provide psycho-emotional support to JIA patients and their parents as early as possible by implementing the Six Core Elements of Healthcare Transition, including the assessment of transition readiness.[17] Therefore, it is necessary to assess the readiness of young patients with JIA to accept the transition from pediatric to adult rheumatologist using certain transition readiness tools, including the Transition Readiness Assessment Questionnaire (TRAQ).[18-20] The TRAQ is a validated 20-item questionnaire, which assesses the patient's disease self-management and healthcare skills. It is used in patients with chronic diseases to measure transition readiness in five different domains: managing medications, appointments keeping, tracking health issues, talking with providers, and managing daily activities.[21] Patients rate their ability level on a five-point Likert scale, with 1 being a minimum and 5 being a maximum score. Overall, the TRAQ scores are calculated as average scores of 20 questions in each domain. A higher overall score indicates greater readiness for transition.

In the present study, we aimed to evaluate the characteristics of JIA patients that may lead to the improvement in self-management skills in the transition readiness process and to explore the readiness of JIA patients and their families for the transition process into the adult healthcare system.

PATIENTS AND METHODS

This single-center, cross-sectional study was conducted at Institute of Rheumatology, Department of Pediatric Rheumatology between March 2021 and June 2021. A total of 44 JIA patients (9 males, 35 females; median age: 15.1 years; range, 12.3 to 19.3 years) admitted to the pediatric rheumatology outpatient and inpatient clinics and their parents were included. The TRAQ was cross-culturally adapted.

Demographic data and clinical characteristics, including JIA disease subtype, sex, age at the time of diagnosis, disease duration, disease activity, previous and current therapies, comorbidities,

family history of autoimmune diseases, number of hospitalizations, number of active joints, physician and parent/patient global assessment were obtained from the patients' medical records and physical examination. In this cross-sectional study, paper version of the TRAQ was administered to all JIA patients and their parents at one time point (the patients and parents filled in the questionnaires independently). We obtained blood samples for routine laboratory monitoring of drug treatment safety. Disease activity was evaluated using the Juvenile Disease Activity Score (JADAS 10, JADAS 27, JADAS 71).[22-24]

Statistical analysis

Statistical analysis was performed using the IBM SPSS version 20.0 software (IBM Corp., Armonk, NY, USA). Continuous data were expressed in median (min-max), while Categorical data were expressed in number and frequency. Categorical variables were compared using the chi-square test. The Mann-Whitney U test was used to compare continuous variables between two groups. The association between numeric variables was assessed using the Spearman rank correlation coefficient (ρ_s). A *p* value of <0.05 was considered statistically significant.

RESULTS

Among 44 JIA patients, two (4.5%) had systemic JIA, 16 (36.4%) had oligoarticular/extended oligoarticular JIA, 15 (34.1%) had polyarticular JIA, 10 (22.7%) had enthesitis-related arthritis, and one (2.3%) had psoriatic JIA. Fourteen (31.8%) patients had a concomitant disease: two had Hashimoto thyroiditis, two had epilepsy, while 10 of them (22.7%) had uveitis. Eleven (25%) had a family history of autoimmune diseases. At the time TRAQ was administered, 19 (43.2%) patients had active arthritis, while 23 (52.3%) of JIA patients had active disease status according to the JADAS 10 and JADAS 27.

All patients were treated with diverse disease-modifying drugs: 32 (72.7%) patients were receiving methotrexate, 10 (22.7%) receiving sulfasalazine, and two (4.6%) receiving hydroxychloroquine. Twenty-six (59.1%) patients were treated with intra-articular corticosteroid injections, while 19 (43.2%) were taking oral prednisone. In total, 21 (47.7%) of JIA patients were receiving biologics; 12 were treated with tumor necrosis factor inhibitors (etanercept n=4; adalimumab n=8), and nine were receiving interleukin-6 (IL-6) inhibitors (tocilizumab). A detailed demographic and disease data are presented in Table 1.

There was a strong correlation between older patient age and total TRAQ score among patients (ρ=0.799, p<0.001) and a moderate correlation between older patient age and total TRAQ score among parents (ρ=0.522, p<0.0001). Patient and parent total TRAQ scores showed a strong correlation (ρ=0.653, p<0.001).

Table 1. Demographic data of JIA patients (n=44)

Characteristics	n	%	Median	Range
Age at JIA diagnosis (year)			11.54	1.5-16.0
Sex				
Female	35	79.5		
Male	9	20.5		
Age at the study enrolment (year)			15.12	12.33-19.33
Median JIA duration (year)			4.29	0.42-17.5
Concomitant diseases	14	31.82		
JIA associated uveitis	10	22.73		
Family history of autoimmune diseases	11	25		
Duration of methotrexate treatment (year)			2.0	0-12.5
Dose of methotrexate (mg/m^2/week)			11.0	0-20.0
Dose of corticosteroids (mg/day)			5.80	0-30.0
Patients receiving biologics	21	47.7		

JIA: Juvenile idiopathic arthritis.

There was no statistically significant association between JIA patient characteristics including JIA disease subtypes, sex, disease duration, disease activity, concomitant diseases including uveitis, family history of autoimmune diseases, number of hospitalizations and the use of biologics with total TRAQ score in both the patient and parent groups.

DISCUSSION

Children and young adults with JIA need to be supported in preparation for and during the transition period from the pediatric to adult healthcare system. To foster this challenging process, it is important to prepare them to be independent and responsible for their own health in adulthood. In 2002, the American Academy of Pediatrics (AAP) published recommendations for the successful transition. Additionally, EULAR and PReS developed standards and recommendations for successful transition of JIA patients in 2017.[5] However, more than half of JIA patients still do not have a successful transition to the adult healthcare system.[25-27] It is, therefore, important to identify potential indicators of successful transition. In this study, we explored the transition process of JIA patients and their parents using TRAQ to identify which patient characteristics might lead to the improvement in self-management skills in the transition readiness process. Our results revealed that total TRAQ scores among patients increased with increasing age, suggesting that older adolescents have higher levels of self-management skills than younger adolescents. This can be explained by increased responsibility that increases with age. Similar observations were reported by several authors.[4,6,28] In contrast, Jensen et al.[29] showed that the increase in TRAQ score was not associated with increasing age in patients with chronic health conditions. Sönmez et al.[30] also reached the same conclusion. In our study, total TRAQ scores among parents also increased with increasing age and total TRAQ scores did not significantly differ between patients and parents. This might be explained by the fact that parents of children with chronic diseases are overprotective in caring for their children. Sönmez et al.[30] also reported similar results.

Lazaroff et al.[28] showed that sex may impact transition readiness and that female JIA patients had higher total TRAQ scores and better transition readiness than male patients. This is similar to the finding of Varty and Popejoy[31] who studied the transition process in patients with various chronic diseases. Similar to our results, the other authors found no significant difference in total TRAQ scores between female and male JIA patients.[4,29,30]

In contrast to our findings, Bingam et al.[6] reported that having a concomitant disease, family member with autoimmune disease, and longer disease duration was associated with higher self-reported independence and transition readiness. We found no significant association between disease activity or number of previous hospitalizations and readiness for transition. As opposed to our findings, Turkish authors showed that active disease and the increasing number of previous hospitalizations were associated with lower TRAQ scores and the decreased readiness for transitional care.[30] To the best of our knowledge, this is the first study to show that JIA disease subtypes, JIA associated uveitis, and treatment with biologics are not associated with TRAQ scores and JIA patients' and parents' readiness for transition.

This study was subject to some limitations, including the cross-sectional design, small sample size, short participant recruitment period, and the heterogeneous study sample.

In conclusion, our study results show that advancing age of JIA patients has a positive impact on patient's and parents' readiness for transition. It seems that both patients and their parents have the same capacity to accept the transition from a pediatric to adult rheumatologist. Future studies with a larger sample size and new insights are needed to facilitate this challenging transition process.

Ethics Committee Approval: The study protocol was approved by the Ethics Board of the Institute of Rheumatology, (No: 29/8, Date: 24/03/2021). The study was conducted in accordance with the principles of the Declaration of Helsinki.

Patient Consent for Publication: A written informed consent was obtained from each patient.

Data Sharing Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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