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TRANSITION CHALLENGE: THE ROUGH ROAD TO ADULTHOOD IN JUVENILE IDIOPATHIC ARTHRITIS—EXPERIENCE FROM TWO CENTERS

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The transition process to adulthood is a challenging but crucial period for the future well-being of patients with chronic diseases. The objective of this study was to evaluate whether specific clinical variables and disease activity status are associated with improved transition readiness among patients with juvenile idiopathic arthritis (JIA) and their parents. JIA patients aged 12–18 years were enrolled in this cross-sectional study. Patient characteristics and laboratory data were collected, and disease activity was assessed using the Juvenile Arthritis Disease Activity Score (JADAS-10 and JADAS-27). All patients and their parents completed the Serbian version of the Transition Readiness Assessment Questionnaire (TRAQ) simultaneously. A total of 91 JIA patients (including 27 males and 64 females; median age 15.32 years, range 11.58–18 years), along with their respective parents, were enrolled in the study. Our results demonstrated that increased patient age and the use of biologic therapy, particularly etanercept, were significantly associated with higher TRAQ scores and improved transition readiness in both JIA patients ($p < 0.001$; $p = 0.038$) and their parents ($p < 0.001$; $p = 0.035$). Patient and parent TRAQ scores showed a strong positive correlation ($\rho = 0.676$, $p < 0.001$). No significant associations were found between other clinical variables (gender, JIA disease subtype, disease duration, disease activity status, extraarticular comorbidities, and autoimmune diseases in the patient's family) and transition readiness. Older patient age and the use of biologic therapy, particularly etanercept, are positively associated with transition readiness in both JIA patients and their parents.

Keywords: transition readiness, juvenile idiopathic arthritis, disease activity, biologics

Submitted: June 29, 2025 **Accepted:** April 29, 2026
Published online: June 22, 2026

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INTRODUCTION

The most common chronic rheumatic condition in children is juvenile idiopathic arthritis (JIA) (1). It is a lifelong disease requiring continuous, regular appointments with both pediatric and adult rheumatologists until a definitive transition to the adult healthcare system occurs. Unfortunately, over 50% of JIA patients have active disease when entering adulthood. Despite this, many stop taking medications and attending regular appointments with adult rheumatologists, resulting in worse disease outcomes (2–11). To prevent permanent disability, there is an urgent need to improve transitional healthcare and ensure the successful transfer of young JIA patients to the adult healthcare system.

This transition is a complex, long-lasting, and challenging process (12). It occurs during a particularly vulnerable period of life when young people are growing up, trying to build their personal identity and become fully independent from their parents. Over the last two decades, significant advances have been made in recognizing the needs of JIA patients and their families. Detailed analyses have identified the problems and barriers to a successful transition. Nowadays, we are fully aware of the importance of providing continuous medical and psychosocial support to young people and their families, guiding them toward becoming independent and responsible adults. It is important to start education early, provide psycho-emotional and mental health support through well-defined multidisciplinary teams, and improve communication between pediatric and adult healthcare providers with individualized, well-organized transitional programs (13–17).

In recent years, assessing the transition readiness of young people with chronic diseases has become possible thanks to the development of transition readiness tools, such as the Transition Readiness Assessment Questionnaire (TRAQ) (18–20). In the current study, we aimed to extend our previous research, in which we showed that biologic use and higher academic achievement are associated with better transition readiness (21). Specifically, we aimed to evaluate the transition readiness of patients with JIA and their parents and to determine whether certain clinical variables, different biologic therapies, and disease activity status could be predictive of this challenging process.

METHODS

This cross-sectional study was approved by the Ethics Committees of the Institute of Rheumatology, Belgrade (No. 29/8, Date: 24/03/2021) and the University Clinical Centre Niš (No. 38788/8, Date: 21/12/2021), and was conducted in accordance with the principles of the Declaration of Helsinki. Between April 2021 and February 2022, we enrolled 91 patients with JIA (27 males and 64 females; median age: 15.32 years; range: 11.58–18 years) from two outpatient pediatric rheumatology clinics, along with their parents. All participants provided written informed consent after receiving a detailed explanation of the study objectives and procedures. Patient characteristics (gender, age, JIA subtype, disease duration, disease activity, extra-articular comorbidities, ongoing therapies, and family history of autoimmune diseases) were obtained from medical records. All patients and their parents completed the Serbian version of the Transition Readiness Assessment Questionnaire (TRAQ) simultaneously. During the same visit, blood samples were collected for monitoring treatment efficacy and safety. Disease activity was assessed using the Juvenile Arthritis Disease Activity Score (JADAS-10 and JADAS-27) (22).

Statistical Analysis

Data were analyzed using IBM SPSS Statistics, version 20.0 (IBM Corp., Armonk, NY, USA). Continuous and categorical variables were evaluated. Continuous variables were presented as mean ± standard deviation (SD) or median (range), depending on the data distribution. Categorical variables were expressed as absolute numbers and percentages. Comparisons between categorical variables were performed using the Chi-square (χ^2) test. Student's t-test, the Mann–Whitney U test, and ANOVA were used to compare continuous variables, as appropriate. Associations between numerical variables were assessed using Spearman's rank correlation coefficient (ρ). Statistical significance was set at $p < 0.05$.

RESULTS

A total of 91 patients with JIA were enrolled, with a female predominance (64, 70.3%). Among them, 25 (27.5%) had concomitant diseases, and 17 (18.7%) had uveitis, which was the most common extra-articular disease manifestation. A family history of autoimmune diseases

was recorded in 24 (26.4%) patients. All patients received disease-modifying antirheumatic drugs (DMARDs), while 51 (56.0%) underwent treatment escalation with biologic therapies. During the follow-up period, biologic agents were switched in some patients due to therapeutic ineffectiveness; overall, 56 patients received TNF inhibitors (etanercept, n = 28; adalimumab, n = 28), and 14 received the IL-6 inhibitor tocilizumab. The analyzed data showed a strong correlation between patient and parent total TRAQ scores ($\rho = 0.676$, $p < 0.001$) (Figure 1).

Patient age and the use of biologic therapy were shown to have a statistically significant impact on TRAQ scores, resulting in higher scores and greater readiness for transition among patients with JIA ($p < 0.001$ and $p = 0.038$, respectively) and their parents ($p < 0.001$ and $p = 0.035$, respectively). We also found that total TRAQ score values were statistically significantly higher among patients with JIA treated with etanercept and their parents ($p = 0.012$; $p = 0.018$) (Table 1).

There was no statistically significant association between clinical disease variables (JIA subtype, gender, disease duration, extra-articular comorbidities, family history of autoimmune diseases, and disease activity status assessed using JADAS-10 and JADAS-27) and total TRAQ scores or readiness for transition in either group.

DISCUSSION

In recent decades, significant efforts have been made to improve the transition process. Nowadays, we know that transition should occur gradually, beginning several years in advance, and be facilitated by well-organized multidisciplinary teams whose role is to provide psychosocial and mental health education and support for young adults and their families. This approach helps them accept the new adult rheumatologist and increase their level of self-responsibility for their health. Transition represents a challenging bridge between childhood and adulthood that children with chronic conditions, including JIA, must cross together with their families. Throughout this journey, pediatric and adult rheumatologists must support young people with chronic rheumatic conditions to help them achieve a successful transition and become responsible adults with regard to their health.

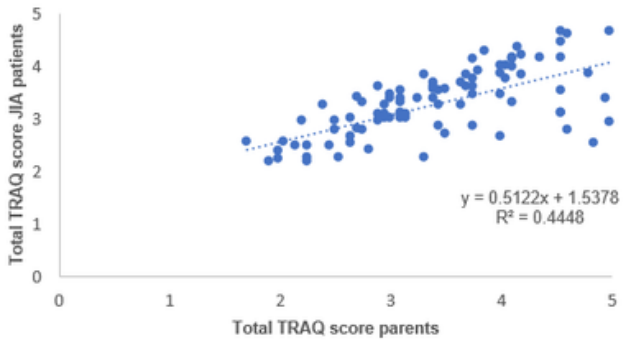

Figure 1. *Strong positive correlation between total Transition Readiness Assessment Questionnaire (TRAQ) scores among JIA patients and their parents*

The main focus of our study was to identify clinical variables associated with JIA that positively predict transition readiness in patients with JIA and their parents. To our knowledge, this is the first study to evaluate transition readiness among parents of patients with JIA. Our results revealed that total TRAQ scores did not differ significantly between patients with JIA and their parents and that the scores were strongly correlated, which may be explained by the tendency of parents to be overprotective of children with chronic diseases (23). This finding is consistent with those reported by a group of Turkish authors (24). Our results also suggest that age improves self-management skills and transition readiness among patients with JIA, indicating that older patients have a higher level of responsibility. Similar findings have been reported by other authors (23, 25–27). In contrast, Jensen et al. (28) and Sonmez et al. (24) found that increasing patient age was not associated with better transition readiness.

Table 1. *Effect of different biologic therapies on Transition Readiness Assessment Questionnaire (TRAQ) scores in patients with juvenile idiopathic arthritis (JIA) and their parents*

Biologic treatment usage	TRAQ JIA patients	TRAQ parents
Yes	3.4 ± 0.62	3.48 ± 0.83
No	3.13 ± 0.61	3.3 ± 0.81
p	0.038	0.035
Adalimumab		
Yes	3.16 ± 0.55	3.13 ± 0.77
No	3.34 ± 0.66	3.52 ± 0.82
p	0.228	0.335
Etanercept		
Yes	3.53 ± 0.57	3.71 ± 0.75
No	3.17 ± 0.62	3.27 ± 0.82
p	0.012	0.018
Tocilizumab		
Yes	3.48 ± 0.86	3.31 ± 0.63
No	3.51 ± 0.82	3.62 ± 0.66
p	0.867	0.678

Data are expressed as mean ± standard deviation; $p < 0.05$ was considered statistically significant.

We also found that the use of biologics (21), particularly etanercept, had a statistically significant positive effect on transition readiness in both patients with JIA and their parents. This may be explained by the fact that biologic therapy can lead to better disease control and more rapid achievement of remission. Similar to Batu et al. (29), we found no significant association between disease activity scores (JADAS-10 and JADAS-27) and transition readiness. In contrast, a group of Turkish authors reported that active JIA was a predictor of lower transition readiness, while a group of Thai authors found that disease inactivity predicted lower transition readiness (30). Our data demonstrated that patient gender was not significantly associated with TRAQ scores or transition readiness, which is consistent with findings reported by other authors (23–25, 28). However, some studies have shown that female patients with JIA have better transition readiness than males (27, 31–33). Other clinical variables (JIA subtype, disease duration, extra-articular comorbidities, and family history of autoimmune diseases) also showed no association with TRAQ scores or transition readiness. In contrast, Bingham et al. (26) reported that longer disease duration, extra-articular comorbidities, and a family history of autoimmune diseases were associated with higher TRAQ scores and greater transition readiness.

Transition is a highly challenging process that requires cooperation not only among healthcare professionals but also between patients with JIA and their families. This sensitive process takes time and requires patience and understanding of the evolving needs of young people with chronic diseases, supported by appropriate medical and psychosocial care. Transition should be individualized for each patient and family and adjusted to the healthcare system of each country.

In summary, we conclude that older age and the use of biologic therapy, particularly etanercept, have a positive impact on transition readiness among both patients with JIA and their parents. Future studies should include larger patient cohorts and well-organized transitional clinics to facilitate and improve this challenging and complex process.

Acknowledgements

This study was not supported by any sponsor or funder.

Author Contributions

Conceptualization: D.L.; Methodology: D.L., G.S., and H.S.; Investigation and data curation: D.N., D.L., and S.Dj.; Formal analysis: H.S. and S.Dj.; Literature search: M.Z.; Writing – original draft: D.L.; Writing – review & editing: D.N. and S.Dj. All authors have read and approved the published version of the manuscript.

Statement of Ethics

The study was reviewed and approved by the Ethics Committee of the Institute of Rheumatology, Belgrade (approval No. 29/8, issued on March 24, 2021) and the Ethics Committee of the University Clinical Centre Niš (approval No. 38788/8, issued on December 21, 2021). The study was conducted in accordance with the ethical principles of the Declaration of Helsinki, and written informed consent was obtained from all participants.

Statement of Competing Interest

The authors declare no relevant conflicts of interest.

Statement of Data Availability

All data analyzed in this study are presented in the Results section. Additional data are available from the corresponding author upon reasonable request.

Statement of Generative AI Technologies Use

No generative AI was used.

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