AB1430

THE EXPERIENCE OF YOUNG PEOPLE WITH RHEUMATIC DISEASES TRANSFERRING THEIR CARE FROM PAEDIATRIC TO ADULT SERVICES AND THEIR SUGGESTED AREAS FOR IMPROVEMENT

Keywords: Health Services Research, Real-world evidence, Patient information and education

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Background: Transition of care from paediatric to adult services is a critical time period for patients with rheumatic diseases. A seamless transition process can aid young people in their development to adulthood, whilst also allowing them to gain independence in managing their rheumatic condition. Young people and their caregivers often express concerns to their paediatric rheumatology teams about the transition to adult services.

Objectives: This study seeks to explore the experience of transition from the perspective of young people with rheumatic diseases, and their suggestions for areas to address in improving the transition process. The second aim of the study is to find out whether young people want to fill out information about themselves in advance of their appointment at the adult rheumatology service, in order to help staff to get to know them better, and if so, what information they felt was important to know.

Methods: Anonymised survey questionnaires were given to young people with rheumatic diseases, via a scannable QR code, to be filled in prior to their rheumatology outpatient visit. All patients surveyed had transferred their care from paediatric to adult services. Further responses were sought by sending the survey questionnaire to young people with rheumatic diseases who had consented to be on a patient and public involvement and engagement (PPIE) mailing list. Survey data were analysed in Microsoft Excel.

Results: Average age of respondents: 18 (median), range 16-26. The majority of respondents were female (76%). 52% of patients had juvenile idiopathic arthritis (JIA), 12% had juvenile dermatomyositis, 12% had juvenile systemic lupus erythematosus, and 12% did not disclose their diagnosis. Most young people were satisfied with the transition process (satisfaction score of 8 out of 10 (mean)). Young people perceived the following aspects of transition to have been done well: “Communication about the change”, having a “named transition coordinator”, having a “personal tour of [the adult hospital]”, and having a “smooth process”. Aspects of the transition process that young people suggested could be improved included: “more transparent and understandable medical talk”, “more follow-up appointments”, “knowing how to contact [a named transition coordinator]”, feeling as though the healthcare professional was “talking to my mum rather than me”, and “the general feeling of… care not being as personal”. Overall, 60% of young people stated that they would be willing to fill out an electronic form prior to their appointment at the adult rheumatology service to give information that would allow staff at the adult hospital to get to know them better. When stratified by age, only 50% of 16-18-year-olds would be willing to fill out a form, whereas 80% of 19-26-year-olds would. The most commonly suggested pieces of information were: hobbies, sports, favourite school subject, goals, and career aspirations.

Conclusion: Most young people were satisfied with the transition process and had helpful suggestions about how this might be improved in the future. The majority of young people were willing to fill in a form to provide information about themselves in order to help adult rheumatology staff to get to know them better, especially those who were aged 19-26 years. At a critical time in young people’s development, enabling them to provide information about themselves that they feel is important, may help to improve their perception of the transition process and to reduce the anxiety about transferring care to adult services.

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AB1432

BODY MASS INDEX AND INFLAMMATORY LESIONS IN MAGNETIC RESONANCE IMAGING IN JUVENILE IDIOPATHIC ARTHRITIS: IS THERE A LINK?

Keywords: Imaging

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Background: Obesity is usually associated with low-grade inflammation in the general population. However, several studies have noted that high body mass index (BMI) in rheumatoid arthritis patients was associated with less structural damage in X-rays and in Magnetic Resonance Imaging (MRI) 

1,2. The impact of BMI on inflammatory MRI lesions in Juvenile Idiopathic Arthritis (JIA) is less studied.

Objectives: We aimed to determine the link between BMI and inflammatory MRI lesions of sacroiliac joints in JIA.

Methods: We conducted a retrospective study including 44 patients followed for JIA meeting the International League of Associations for Rheumatology (ILAR) 2001 criteria. For each patient we collected the following data: age, age at the onset of JIA, JIA subtype, disease duration, BMI, C-reactive protein (CRP) and Erythrocyte sedimentation rate (ERS) levels, and MRI data. Disease activity was assessed using the JADAS score. Statistical analysis was performed using SPSS software.

Results: We included 28 boys and 16 girls. The mean age was 13.65 ± 4.62 years. The mean age at the onset of the disease 9.57 ± 3.97 years. The mean diagnosis delay was 4.34 ± 3.09 years. There was enthesitis-related arthritis in 61% of the cases (n=27), oligoarticular JIA in 14% of the cases (n=6), polyarticular JIA in 11% of the cases (n=5), and psoriatic arthritis in 7% of the cases (n=3). JIA was undifferentiated in 7% of the cases (n=3). The mean BMI was 20.22 ± 5.6kg/m². Four patients had overweight (9%). The mean CRP and ESR were 14.42 ± 19.67mg/L and 26.56 ± 20.87mm, respectively. The mean JADAS was 6.6 ± 4.7, respectively. The diagnosis delay was positively correlated to the patient’s age (r=0.561, p<10^-3) and negatively correlated to the ESR level (r=-0.331, p=0.037). Besides, diagnosis delay was associated with extra-articular manifestations (4.45 ± 3.12 versus 2 ±0.1 years, p<10^-3). Besides, ERA patients had longer diagnosis delay compared to other JIA subtypes but the difference was not significant (p=0.061). However, diagnosis delay was not associated with low back pain, enthesitis, or sacroiliac joint pain.

Conclusion: Our results are consistent with Kurt et al. study [1]. Older age, the occurrence of extra-articular manifestations, and low ESR level could lead to diagnosis impediment.


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AB1433

FACTORS ASSOCIATED WITH DIAGNOSIS DELAY IN PATIENTS WITH JUVENILE IDIOPATHIC ARTHRITIS

Keywords: Descriptive Studies

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Background: The diagnosis delay is very variable in Juvenile Idiopathic Arthritis (JIA). The duration between the occurrence of symptoms, the diagnosis time, and the establishment of the treatment is very important in disease progression. To determine the diagnosis delay in JIA and study the factors affecting this delay.

Methods: We conducted a retrospective study including patients with Juvenile Idiopathic Arthritis (JIA) meeting the International League of Associations for Rheumatology (ILAR) 2001 criteria. For each patient, we collected the following data: age, gender, age at the onset of JIA, JIA subtype, diagnosis delay, clinical examination data, extra-articular manifestations, C-reactive protein (CRP) and Erythrocyte sedimentation rate (ERS) levels. Disease activity was assessed using the JADAS score. Statistical analysis was performed using SPSS software.

Results: We included 44 patients. They were 28 boys and 16 girls. The mean age was 13.65 ± 4.62 years. The mean age at the onset of the disease was 9.57 ± 3.97 years. The mean diagnosis delay was 4.34 ± 3.09 years. There was enthesitis-related arthritis in 61% of the cases (n=27), oligoarticular JIA in 14% of the cases (n=6), polyarticular JIA in 11% of the cases (n=5), and psoriatic arthritis in 7% of the cases (n=3). JIA was undifferentiated in 7% of the cases (n=3). The mean CRP and ESR were 14.42 ± 19.67mg/L and 26.56 ± 20.87mm, respectively. The mean JADAS was 6.6 ± 4.7, respectively. The diagnosis delay was positively correlated to the patient’s age (r=0.561, p<10^-3) and negatively correlated to the ESR level (r=-0.331, p=0.037). Besides, diagnosis delay was associated with extra-articular manifestations (4.45 ± 3.12 versus 2 ±0.1 years, p<10^-3). Besides, ERA patients had longer diagnosis delay compared to other JIA subtypes but the difference was not significant (p=0.061). However, diagnosis delay was not associated with low back pain, enthesitis, or sacroiliac joint pain.

Conclusion: Our results are consistent with Kurt et al. study [1]. Older age, the occurrence of extra-articular manifestations, and low ESR level could lead to diagnosis impediment.


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