Transition in a paediatric rheumatology unit – experience from a tertiary unit

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Dear Editor,

The transition from paediatric to adult health care has been recognized as a priority in recent years. Health care transition (HCT) is defined as the process of moving from a paediatric to an adult model of health care, with or without a transfer of follow up to a different clinician[1,2]. The paediatric care is family oriented and relies on a significant parental involvement, while adult care is patient-specific and requires autonomy and independent skills. Consequently, this process is often challenging, especially in children with chronic medical conditions[3,4]. Adolescents and young adults (AYA) should acquire skills and access resources to ensure that their physical, psychosocial, educational and vocational needs are met during transition to adulthood. For AYA with chronic illnesses (including juvenile-onset rheumatic and musculoskeletal diseases [jRMDs]) the same principle is applied, but they have to acquire additional skills in order to independently manage their chronic illness[5-7]. Some studies demonstrated that approximately half of young people with jRMDs enter adulthood with active disease or develop disease flares as young adults[5-9]. In our center, the transition begins around 11 years, when the patient education process starts and at the same time enables AYA to acquire knowledge to manage their disease. By the age of 18 the transfer to adult care is made.

This study aims to evaluate the transition process and the transfer from paediatric to adult rheumatology care at our center. We included patients registered in Rheumatic Diseases Portuguese Register (Reuma.pt) between 2011 and 2018, who had been transferred from paediatric to adult care in this period. Demographic data, clinical features, therapeutics and global assessment of transition process were collected. The global assessment of patient' satisfaction (How do you classify your level of satisfaction with the transition process?) before and after transfer of care was evaluated by a telephonic interview in an ascending scale of 0 to 10 (0 =very bad and 10=excellent).

Dropout was defined as not attending the clinic for 2 consecutive visits after transfer. Variables were analysed

TABLE I. DEMOGRAPHIC AND CLINICAL DATA OF PATIENTS

Demographic and clinical data (n=126)	
Female, n (%)	78 (61)
Mean age, year ± SD	3.1±3.2
Mean disease duration, year ± SD	2.7±5.3
DMARDs, n (%)	92 (73)
Biologic therapy, n (%)	35 (29)
Diagnosis	**N (%)**
JIA	77 (61.1)
Persistent oligoarthritis	22 (17.5)
Enthesitis related arthritis	22 (17.5)
Rheumatoid factor negative polyarthritis	11 (8.7)
Extended oligoarthritis	9 (7.1)
Systemic	6 (4.8)
Psoriatic Arthritis	4 (3.2)
Rheumatoid factor positive polyarthritis	3 (2.4)
Systemic lupus erythematosus	14 (11.1)
Vasculitis	9 (7.1)
Autoinflammatory syndrome	5 (4)
Dermatomyositis	3 (2.4)
Other diagnosis*	19 (15.1)

DMARDs - conventional disease modifying antirheumatic drugs; JIA - Juvenile Idiopathic Arthritis; SLE – systemic lupus erythematosus; n - number; SD - standard deviation
*Mixed connective tissue disease, Systemic sclerosis, Overlap syndrome, Osteoporosis, Osteogenesis imperfecta, Spondyloarthritis

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as means, medians and frequencies as appropriate.

We included 126 patients, 78 (61%) were female, with a mean age of 23.1±3.2 years. One hundred and four patients (83%) were transferred to a young adult clinic. Seventy-seven patients (61.1%) had juvenile idiopathic arthritis (JIA), and a mean disease duration of 12.7±5.3 years. The remaining had others jRMDs (Table I). During transfer of care, 92 (73%) patients were treated with conventional disease modifying antirheumatic drugs and 35 (27.8%) with biologic therapy (Table I). Sixty-nine (54.7%) patients missed at least one clinical appointment and the dropout rate was 9%, which was associated with longer disease duration (15.9 *vs* 12.3 years, p=0.024). Seventeen (14%) patients changed hospital during transition. Eleven (8.7%) patients worsened clinical activity: 5 patients with polyarticular JIA had arthritis flare (ΔJADAS-27 4.76 ± 4.13); 4 patients with oligoarticular JIA had new onset uveitis and 2 patients with juvenile systemic lupus erythematosus had a SLEDAI increase from 5 to 16 points. Regarding patient satisfaction questionnaire, paediatric rheumatology appointments had a median evaluation of 9 (7-10), adult rheumatology appointments of 8 (5-10) and the transition process of 8 (5-10). The majority of patients (68%) reported more time spent at the waiting room as the major negative aspect after transition, followed by greater hustle in the waiting room (15%).

In our center, the transition of care was associated with a high degree of satisfaction, with just a 10% decrease in patient satisfaction between paediatric and adult care. We had a low dropout rate, which was associated with longer disease duration. Few patients had worsening of disease activity. Our data reinforce that education and training in transitional care and having a transition program are important to optimize health outcomes in AYA with chronic diseases.

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