

---

*The Art of Transitioning Pediatric Patients  
with Rheumatic Diseases to Adult Rheumatologists*

**Florence Kanakoudi-Tsakalidou,  
Polyxeni Pratsidou-Gertsis**

**Mediterr J Rheumatol 2016; 27(2):55-8**



E-ISSN: 2459-3516



## The Art of Transitioning Pediatric Patients with Rheumatic Diseases to Adult Rheumatologists

Florence Kanakoudi-Tsakalidou, Polyxeni Pratsidou-Gertsis

Pediatric Immunology and Rheumatology Referral Center, First Department of Pediatrics, Aristotle University, Hippokraton General Hospital, Thessaloniki, Greece

### ABSTRACT

The process of transitioning adolescents or young adults with rheumatic diseases from pediatric to adult Rheumatology clinics is an art. Its success requires bilateral special handling and coordinated cooperation. According to Greek legislation, transition is implied at the challenging age of 18 years, i.e., at the borderline of adolescence and adulthood. Therefore, the physician has to adopt a specific attitude towards the patient in order to achieve patient compliance to his guidelines and treatment participation. The process begins with the periodic updating of the patient/family on the disease progress and, in case of immunosuppressive therapy, on documented information regarding potential treatment consequences: this policy aims to motivate the adolescent to take responsibility and participate consciously in decision-making. Thereafter, the patient/family will be educated on the need for future periodic assessments by an adult Rheumatologist, who has the skills and experience to manage adult patient problems. The pediatric Rheumatologist identifies and records the patient/family capability to respond to the circumstances and overcome probable obstacles. Additionally, he or she estimates the potentials of the future patient care center/clinic. By co-estimating all these factors, a personalized “transition policy” is scheduled. Various models of transition have been proposed over time. Independently of the model applied, the critical factors for a successful transition are the patient’s readiness for self-management and psychosocial maturity as well as the family’s acceptance to let the young adult cope with his/her own life.

#### Corresponding author:

Florence Kanakoudi-Tsakalidou, MD, PhD  
Professor Emeritus  
First Department of Pediatrics  
Aristotle University of Thessaloniki  
M. Botsari 2  
54643 Thessaloniki, Greece  
Tel.: +30-2313-312439  
e-mail: filkan@auth.gr

*Mediterr J Rheumatol* 2016; 27(2):55-8

<https://doi.org/10.31138/mjr.27.2.55>

**Keywords:** Transition, pediatric Rheumatologist, Rheumatologist, young adults, rheumatic diseases.

Advances in the early detection and treatment of pediatric rheumatic diseases have led to an increasing pool of patients who leave adolescence and reach adulthood, still having an active disease. These patients need to be further followed-up by adult Rheumatologists who are trained and skilled in handling and coping with adult patient problems.<sup>1-3</sup> The transition of such adolescent or young adult patients from a pediatric to an adult Rheumatology clinic is not a simple task.<sup>1,4,5</sup> It requires special handling and bilaterally coordinated cooperation. In fact, the process of transition is an art. When a chronic rheumatic disease (CRD) starts at childhood, usually the patient has more time to familiarize with it and probably accept it. This is more difficult if the disease begins in the pre-adolescent or adolescent period, when the patient is struggling with the hormonal impact on his/her body and personality, along with the unexpected changes that the disease has caused to his/her life. Adolescence, in general, is a challenging period, during which the physical and hormonal alterations make many adolescents feel that they are aware of everything, so that they don't need any consultation from adults. They believe that there is nothing to be afraid of. Some of them may be communicative, obedient and able to meet their obligations, whereas others are rebellious and tough in their cooperation with adults, for several reasons.<sup>5,6</sup> Moreover, as in all chronic diseases, achievement of long-term compliance of the adolescent with CRD for follow-up assessments and therapies is very difficult, since this is a good chance for the patient to display his/her rebellion by challenging and doubting the physician's instructions and counseling.<sup>6</sup>

Therefore, the pediatric Rheumatologist should adopt a special attitude towards the adolescent patient in order to *ensure his/her compliance to guidelines and participation in the treatment decisions*. In detail, the physician should give priority to periodic updating of the patient/parent regarding the disease progress. Furthermore, in case of introducing an immunosuppressive therapy - perhaps "off-label" for pediatric patients, sometimes - evidence-based information in respect to treatment consequences should be provided. This is the only way for the physician to ensure that both the patient and the parents will not just give their consent/assent but will also co-decide for the individual optimal management. Such a procedure could be the foundation of the adolescent's accountability and could lead to the entrance in the adulthood path through his/her personal choice of the way of living.<sup>2</sup> In addition, this process prepares the patient to uneventfully accept the switch to another health provider (namely, an adult Rheumatologist) when entering adulthood (or even earlier if so requested).<sup>2,3,7</sup> According to the national legislation, this takes place at 18 years of age. At that age, most of the patients are receptive to the procedure of

transition, provided a previously appropriate preparation has been accomplished.<sup>7-9</sup>

### GENERAL PRINCIPLES OF TRANSITION

For a successful "change of the therapeutic token," namely the patient's "passing" from the family-focused pediatric setting to the respective adult-focused one, the pediatric Rheumatologist has to design and implement specific procedures.<sup>1,2,7</sup> In English, the whole process is termed "Transition" or "Transitional care", in order to elucidate that it is not just a formal patient referral or a transfer to another health-care setting. Transition is a long-term process and not an instantaneous event. It requires, beyond the patient/parent familiarity with the chronic disease and disease progress, their psychological empowerment and persuasion to accept that the disease monitoring and management is going to be continued uneventfully following the switch to the novel setting.<sup>2,3,10</sup>

Transition from pediatric to corresponding adult care has to be carefully and gradually performed, otherwise certain risks may arise. Some adolescents, knowing that they are going to move soon to an adult clinic, discontinue or postpone their regular follow-up visits to the pediatric Rheumatology clinic even though the transition has not been completed; resulting in their disease worsening. On the contrary, their smooth integration into adult-oriented settings improves their long-term outcome and quality of life.<sup>3,5,8,11</sup>

### INDIVIDUALIZED TRANSITION-POLICIES, ESSENTIAL STEPS

The transition-policy scheduled by the physician has to be individualized, including some essential steps, common in all schedules:<sup>12</sup> primarily, the pediatric Rheumatologist is recording the patient's medical, psychosocial and educational or professional needs, the patient/family interrelations and the family's overall capacity to cope with the circumstances and overcome all obstacles. Thereafter, based on the data recorded, the pediatric Rheumatologist educates the patient and family about the disease and its progress over time. The importance for future follow-up by an adult Rheumatologist is emphasized, by providing examples of the prohibitions that a pediatric Rheumatologist faces during the routine care of a patient aged over 18 years: i.e., inability of having access to electronic prescriptions, to give medical reports for the patient's capability to perform military or professional assignments or for getting a health related subsidy. Additionally, it is stressed that only an adult Rheumatologist could give proper counseling in the domains of family planning, pregnancy and management of co-morbidities. Lastly, the pediatric Rheumatologist estimates the experience, knowledge and skills of the health care providers involved in the

transition procedure, as well as the potentials of the center/clinic that will take over the patient's follow up. Taken together, a patient-tailored transition-policy is then planned.<sup>2,3,7,8,13,14</sup>

### TRANSITION "MODELS"

Various transition-models have been proposed over time depending on the culture and contemporary health-care system of different countries.<sup>1-3,7-9</sup> One of these models is a *joint patient assessment by both a pediatric and an adult Rheumatologist in the same setting* (joint clinic or young people clinic or transition clinic) which can be applied either early or late in adolescence, or during the final phase of transition or just in the last patient evaluation. Another transition-model is to refer *the patient from the pediatric to the adult Rheumatologist without any joint and simultaneous patient assessment, but with only a medical report on the overall disease course*. This model has been rated as ineffective. Some authors propose *stepwise visits of the adolescent to the adult outpatient clinic* in order to enhance his/her familiarization with the new setting and support personal communication with the new staff. Finally, an online visit to relevant informational websites describing the operation and activities of the new clinic should be also suggested.<sup>2,3</sup> If the patient/parents wish to expand their knowledge regarding CRD, apart from the face-to-face and in-print personal information by the physician, accessibility for online education is also available. Such portals have been developed by International Organizations, either from Northern European countries and North America, or from PRINTO (Pediatric Rheumatology International Trials Organization, <http://www.printo.it/pediatric-rheumatology/>); the latter also available in the Greek language. It is the pediatric Rheumatologist's responsibility to inform the family and patient for such reliable websites.<sup>2,3,15</sup>

The patient's continuing participation in the scheduled transition process contributes to a smooth integration into the new environment and makes him/her optimistic for the future. Through this policy, both the patient and family will realize that they will not be abandoned by their "family" pediatric Rheumatologist. On the contrary, the gradual "transition" to age-appropriate structures will contribute to the patient's development of confidence and independence from parental surveillance.<sup>2,7</sup> According to British experience, any model can be rated as efficient regardless of the preferred transition-policy, provided it ensures respect to the patient/parent's individual way of adapting in the transition-process and enables them to wean from the pediatric Rheumatologist clinic.<sup>3</sup>

### CONTRIBUTION OF "TRAINED PERSONS" TO THE TRANSITION-PROCESS

The American Academy of Pediatrics recommends the participation of a trained person who will serve as a liaison between the physicians and the patient/parent setting. This person may be a social worker, a specialized nurse or even a member of the Association of "Adult Patients with Pediatric Rheumatic Diseases" who will act as a "safe-guard" of the transitioning patient, and in parallel informs the staff of the pediatric Rheumatology clinic on the transition-process.<sup>2,3</sup> The latest instructions have been published in 2015 as a "Clinical Report on Transition Core Elements of Health Care Transition 2.0".<sup>16</sup>

### ESTIMATION OF THE TRANSITION SUCCESS

For estimation of a successful transition, data from US and Canada have shown that certain indices have to be considered: how quickly the patient's care by the adult Rheumatologist was taken over, if the patient's health insurance was retained, and, unquestionably, the patient's survival.<sup>8,9</sup> Furthermore, it is crucial to denote that a fulfilled transition is proven only when the young adult has followed and complied with the regulations of the new setting and/or participates in the relevant Associations for patients with rheumatic diseases.<sup>10,14,17</sup>

In conclusion, the critical factors for a safe transition are the patient's readiness for self-independence, his/her psychosocial maturity, and in parallel, the parent's decision to assign to their child the right to manage his/her own life.

### CONFLICT OF INTEREST

The authors declare no conflict of interest.

### REFERENCES

1. McDonagh J E. Transition of care from paediatric to adult rheumatology. *Arch Dis Child* 2007;92:802-7.
2. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from Adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182-200.
3. Nagra A, McGinnity P M, Davis N, Salmon A P. Implementing transition: ready steady go. *Arch Dis Child Educ Pract Ed* 2015;100:313-20.
4. Lewis J, Slobodov G. Transition from Pediatric to Adult Health Care in Patients with Chronic Illnesses: An Integrative Review. *Urol Nurs* 2015;35:231-7.
5. McDonagh J E, Kaufman M. The challenging adolescent. *Rheumatology* 2009;48:872-5.
6. Sattoe J N T, Hilberink S R, van Staa A, Bal R. Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *J Adolesc Health* 2014;54:397-403.
7. Calvo I, Antón J, Bustabad S, Camacho M, de Inocencio J, Gamir M L, et al. Consensus of the Spanish society of pediatric

- rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset. *Rheumatol Int* 2015;35:1615-24.
8. Chira P, Ronis T, Ardoin S, White P. Transitioning youth with rheumatic conditions: perspectives of pediatric rheumatology providers in the United States and Canada. *J Rheumatol* 2014;41:768-79.
  9. Hilderson D, Moons P, Westhovens R, Wouters C. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. *Rheumatol Int* 2012;32:3887-96.
  10. Jordan A, McDonagh J E. Recognition of emerging adulthood in UK rheumatology: the case for young adult rheumatology service developments (Editorial). *Rheumatology* 2007;46:188-91.
  11. McDonagh J E. Lost in transition? Between paediatric and adult services. *BMJ* 2006;332:435.
  12. Jensen P T, Karnes J, Jones K, Lehman A, Rennebohm R, Higgins G C, et al. Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology* 2015;13:17. DOI: 10.1186/s12969-015-0013-0.
  13. Moore Hepburn C, Cohen E, Bhawra J, Weiser N, Hayeems R Z, Guttman A. Health system strategies supporting transition to adult care. *Arch Dis Child* 2015;100:559-64.
  14. Stringer E, Scott R, Mosher D, Mac Neill I, Huber A M, Ramsey S, et al. Evaluation of a Rheumatology Transition Clinic. *Pediatr Rheumatol* 2015;13:22. DOI: 10.1186/s12969-015-0016-x.
  15. Leanza F, Hauser D. Teens, technology, and health care. *Prim Care* 2014;41:559-66.
  16. McManus M, White P, Barbour A, Downing B, Hawkins K, Quion N, et al. Pediatric to Adult Transition: A Quality Improvement Model for Primary Care. *J Adol Health* 2015;56:73-8.
  17. Suris J C, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. *J Adolesc Health* 2015;56:612-8.