

Ideal Age and The Best Program for Transition Process to Adult Care in Children with Rheumatologic Disorders

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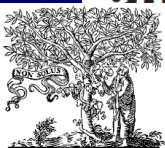
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Introduction

- Transition is a process Not an action or occurrence.
- Transition is important for all teenagers, healthy or ill
 - *The best age for this process?*
 - *The best program for this process?*
- ***Twilight zone***

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Journal of Adolescent



ELSEVIER

Original article

Change in Health Status and Access to Care in Young Adults Health Care Needs: Results From the 2007 National Survey and Health

Transitioning Wisely

Moving the Connection From Pediatric to Adult Health Care

Patience H. White¹ and Stacy Ardoin²

Anelli et al. *Pediatric Rheumatology* (2017) 15:47
DOI 10.1186/s12969-017-0176-y

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RESEARCH ARTICLE

Challenges in transitioning adolescents and young adults with rheumatologic diseases to adult Care in a Developing Country - the Brazilian experience

Pediatric Rheumatol

Open Access



Difference between Pediatric System and adult system

- Child-centered (management with supervision) vs. adult-oriented (self-management)
- From school to work
- Behavioral changes
- From home to independent living in the community

Barriers

(Patient related)

- Dependent behavior
- Changing from a well-known care provider to a new one
- Immaturity
- Severe illness or disability
- Lack of support systems
- Lack of trust in caregivers

Barriers

(Family related)

- Excessive need for control
- Emotional dependency
- Reluctance of parents to relinquish control
- Heightened perception of disease severity
- Lack of trust in adult caregivers
- Gaps in insurance coverage & loss of health insurance

Barriers

(Pediatric caregiver related)

- Economic concerns and concerns about program
- Emotional bonds with patient and family (Difficulty in 'letting go')
- Comfort with the status quo
- Distrust of adult caregiver
- Different treatment regimens
- Gaps in insurance coverage & loss of health insurance

Barriers (Adult related)

- Economic concerns
- Lack of **much** experience and familiarity with the pediatric **onset rheumatic disease**, **disease course**, **outcomes**, and/ or congenital disease
- Lack of institutional commitment

Four primary difficulties in transition

- Change in the type and level of support
- Change in decision making and consent process
- Marked reduction in family participation
- Reduced tolerance and sensitivity of health care professionals and system to the psychosocial and health issues in adolescents

Other difficulties

- Lack of adolescent medicine in many countries
- Adolescent onset disease
- Higher morbidity of rheumatic disease during adolescence and young adulthood
- Delayed psychosocial milestones (such as including vocational, social and sexual)
- Health Insurance System

The 5 Guiding Principles for Transition

- Should **never** be solely determined by chronological age
- Plan with participation by the patients, **family**, the pediatric service team, and the adult service team.
- Comprehensive and **responsive** to the needs of the patient.
- **Multi aspects of care: medical, psychosocial, educational, vocational**
- Collaboration with an **interested** adult rheumatologist

Factors Should be considered for transition age

- Physical and cognitive maturity
- Current medical status (Disease activity)
- The state of **preparation** and **readiness** of the young person and/or their family
- Depend on the **local health care system** and health care funding

Indexes for Determining patient's readiness

- Patient has relatively **stable** disease.
- Patient has adequate **understanding of the disease** and its treatments.
- Patient has demonstrated ability to make and **attend appointments** and take care of medication needs.
- Patient has developed an **independent adult relationship** with the health care providers.
- Patient **has a family physician** in the community and demonstrates the ability to use the family physician appropriately.

What do you consider the ideal age to start the transition process?	<12 years	1 (1.3)
	12–14 years	8 (10.5)
	15–17 years	46 (60.5)
	18–20 years	21 (27.6)

What do you consider the ideal age to transfer patients?	14 years	4 (5.3%)
	15–17 years	18 (23.7%)
	18 years	33 (43.4%)
	19–20 years	11 (14.5%)
	> 21 years	10 (13.2%)

Pretransitional Phase

- Assess the readiness of the patient and his/her parents (by questionnaires and interview)
- Meet patient and parent separately by the social worker and nurse.
- Review patient's medical records by Adult Rheumatologist
 - Discuss about patients' medical background with the pediatric Rheumatologist.

Transition Phase

- Perform **transition clinic** in the **adult rheumatology center** (once every 3 months).
- The pediatric team **introduces the adult rheumatologist** to the patient and his/her family (for minimize anxiety about new physician).
- **Final interview** by the nurse and social worker of the pediatric team
- The nurse and social worker may remain involved with the teenagers and their families even after the transfer of care.

Models of Transition

- **Primary care–coordinated** care spanning adolescent to adult care, and
- Generic adolescent health services (**Adolescent Medicine subspecialist coordinated**)
- Disease-focused transition from pediatric care to an adult subspecialist
 - **Focus is on one transition clinic**
 - **Focus is on transition process**

Ref:

Tucker LB, Cabral DA. Transition of the adolescent patient with rheumatic disease: issues to consider. *Rheum Dis Clin North Am.* 2007;33(3):661-72.

Rettig P, Athreya BH. Adolescents with chronic disease. Transition to adult health care. *Arthritis Care Res.* 1991;4(4):174-80.

Focus is on one transition clinic

- Preparation of patient and family by pediatric team for transition
- Transition plan discussed with pediatric nurse and social worker
- Readiness to transfer established
- **Appointment for transition clinic given**
- Introduction to adult rheumatologist by pediatric team
- Pediatric nurse and social worker meet with adolescent and family for final interview
- Follow-up care with adult rheumatologist without pediatric team
- **Held once every 3 months**

Focus is on transition process

- Multiple joint visits with pediatric team and adult Rheumatologist
- Transition plan implemented over the course of several transition clinics
- Readiness to transfer established
- **Appointment for adult rheumatologist given**
- Initial visit in adult center without pediatric team
- Follow-up care with adult rheumatologist only
- **Held once every month**

Tips for a Successful Transition Process

- Consider not only the patient's **chronological** age but also their **maturity level** when choosing the right moment to transfer.
- **If possible**, wait until the disease is under control or stable to transfer the patient.
- Reinforce **independence** and **adherence** during the transition years.
- Address **important issues** such as alcohol, drugs, and risky sexual behaviors.

Ref: White PH, Ardoin S. Transitioning Wisely: Improving the Connection From Pediatric to Adult Health Care. Arthritis Rheumatol. 2016;68(4):789-94.

Rettig P, Athreya BH. Adolescents with chronic disease. Transition to adult health care. Arthritis Care Res. 1991;4(4):174-80.

Tips for a Successful Transition Process

- Take into account the patient's preferences.
- Establish a fluent, bidirectional, trustworthy, and satisfactory relationship with the adult care provider.
- Provide an environment where they can meet other young people in the transition process.
- Ideal transition planning begin between ages 12-14 years, and that transfer out of pediatric care between ages 18 and 21 years (take for 3 to 5 years)

Ref: White PH, Ardoin S. Transitioning Wisely: Improving the Connection From Pediatric to Adult Health Care. Arthritis Rheumatol. 2016;68(4):789-94.

Rettig P, Athreya BH. Adolescents with chronic disease. Transition to adult health care. Arthritis Care Res. 1991;4(4):174-80.



Table 2 Examples of web based resources for transition

UK

<http://www.transitioninfonetwork.org.uk>

<http://www.dh.gov.uk/transition>

<http://www.dreamteam-uk.org>

<http://www.transitionpathway.co.uk>

<http://www.youngminds.org.uk/publications/booklets/adulthood.php>

<http://www.tsa.uk.com>

Australia

<http://www.rch.org.au/transition>

USA and Canada

<http://www.door2adulthood.com>

<http://hctransitions.ichp.edu>

<http://depts.washington.edu/healthtr/index.html>

<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

