




Transitioning from Pediatric to Adult IBD Care

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Outline

- Understand Transition Challenges
- Learn Current Practices
- Planning, Preparing and Communication
- Transition



Opening Conversations and Setting Expectations

Pediatric	Adult
<ul style="list-style-type: none"> • Family-focused¹ • Parental decision making • Passive patient role with little autonomy • Lengthy appointments • Proactive monitoring of pubertal and growth milestones • Limited focus on fertility and pregnancy² • Multidisciplinary team involvement¹ 	<ul style="list-style-type: none"> • Patient-focused¹ • Individual decision making • Active patient role emphasizing autonomy² • Business-like, short appointments¹ • Limited focus on developmental delay and/or growth failure • Increased awareness of fertility, contraception, and family planning • May lack resources for a multidisciplinary team³



Share Proposed timeline and plan for transfer of care

Age 11-13	Age 14-16	Age 17-19	Age 20-23
<ul style="list-style-type: none"> • Articulate condition • Knowledge of medication • Can use and read thermometer • Articulate impact of disease 	<ul style="list-style-type: none"> • Identify medical team • Knows <ul style="list-style-type: none"> • Names and purpose of procedures/tests • Medical history • Support groups • Understands risks of nonadherence • Understands impact of drugs/alcohol on illness 	<ul style="list-style-type: none"> • Knows how to gather info about disease • Demonstrates ability to book appointments, fill prescriptions, contact medical team • Can name his/her insurance coverage and plans for coverage • Carries insurance information 	<ul style="list-style-type: none"> • Has had a telephone conversation with potential adult GI • Schedules initial visit with adult GI while disease is stable



Setting Expectations

- Create a written transition plan together with patient and family
- Checklist of age-appropriate knowledge expectations
 - Emma study = creating an electronic based question game to evaluate patient knowledge
- Perform regular assessment of patient readiness
 - Emotional age VS Chronological Age
 - GI Psychology
 - Transition Readiness Assessment Questionnaire (TRAQ)


Autonomy

- Begin seeing the patient in the absence of the caregiver
 - In my IBD clinic, all patients over the age of 16 get roomed by themselves, the parents are then involved after an initial assessment and discussion is had with the patient.


NASPGHAN/CCFA Recommendations for Collaboration of Care

- Identify an adult GI who cares for young adults
- Collaborate prior to transfer of care
 - Provide patient's medical records and a summary letter
 - Communicate directly with accepting doctor/office
- Identify gaps that are not being properly communicated
 - Study we did internally at UTSW
 - Thought we created a great transition summary letter
 - 6 month follow up with adult team identified surgical notes and steroid history was not being easily transferred




Transition is about the right setting for your medical care

- Pediatric health care providers should follow up with patients who have additional growth potential
- Adult health care providers should manage young adults who have completed their education and are financially independent
- Fertility and pregnancy issues
- Pediatric surgeons vs Adult Colorectal surgeons
- Still leaves a grey area in between, further muddled by insurance practices



Co-Management of Care

- Formalized transition care models in IBD are being developed nationally; however there is NO consensus on the ideal model of transitional care.
- Transition models include:
 - Joint adult/pediatric clinics
 - Alternating visits
 - Coordinator-initiated transition
 - Advance tour of adult facilities
 - Chronic disease transition clinics
 - Regular face to face meetings/conference driven transitions



TRANSITION



Thank you!

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