



REVIEW

## Transition of children with inflammatory bowel disease: Big task, little evidence

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### INTRODUCTION

The relapsing and remitting nature of inflammatory bowel disease (IBD) with its high morbidity makes transition of children with IBD into adult care a mandatory step in their care<sup>[1]</sup>. As young people move to maturity, their medical and psychological needs change and it is crucial for them to receive age-appropriate medical care<sup>[2]</sup>. This highlights the importance of what is called health-care transition. Preparing older children and young adults for this process is very important as they need to develop a sense of independence and maturity<sup>[3]</sup>.

There have been several definitions of the process of transition of medical care but the most quoted one is that by Blum *et al*<sup>[3]</sup> "the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems<sup>[4]</sup>".

The aim of the transition program is to achieve for each chronically ill patient a continuum of care that includes normalization of social and emotional development and acquisition of independent living skills<sup>[5]</sup>.

Several hurdles may interfere with this process. As the patients and their families are used to dealing with certain faces, they may be reluctant to move to an adult health care system. A strong sense of bonding usually develops over years of care under pediatric service. On the other hand, pediatric caregivers may also find it difficult to give up their patients after years of care and strong ties. They may feel that the adult caregivers are unable to provide the same quality of, not only medical, but also psychological care during this critical period<sup>[6]</sup>.

In addition, the adult caregivers may feel that patients and their families with pediatric-onset disease may be too demanding. The adult caregivers may assume that patients should take a large part of responsibility for the details of their care. Adult care normally lacks the multidisciplinary team approach that pediatric service usually offers<sup>[7,8]</sup>.

### WHAT IS THE BEST STRATEGY OF TRANSITIONING CHILDREN WITH IBD?

Most of the available pediatric IBD transition literature is

### Abstract

Children with chronic long-term disorders need to move to the adult practice at some point in their life. Establishing a smooth and efficient transition process is a complicated task. Transition of medical care to adult practice is defined as the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems. This step is of the utmost importance for several reasons. There is an obvious deficiency of research in this area especially when it comes to pediatric inflammatory bowel disease (IBD). There is a considerable difference in individual practice among different centers. Also, age of transition varies among different countries and sometimes, even within the same country, transition age may vary among different provinces and districts! Interestingly, local politics and many factors other than children's welfare often play a role in deciding the age that older children move to adult practice at. This review discusses transition of children with IBD in view of the available evidence.

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**Table 1** Checklist of tasks for the patients and the medical team based on chronological age as suggested by Hait *et al*<sup>[8]</sup>

Age	Patient	Medical team
11-13	Able to articulate his or her GI condition Able to name medications, doses, side effects Knows strategies to take his or her medications Able to use and read a thermometer Articulates impact of IBD on school and daily life	Introduces idea of future independent visits Asks parents to remain in waiting room for a portion of the visit Anticipatory guidance about fitness, sexuality, and substance abuse
14-16	Able to identify medical team Knows names and purposes of procedures and tests done on him or her Knows his or her medical history Knows names of IBD social support groups and community organizations Understands the medical risk of no adherence Understands the impact of drugs and alcohol on the illness	Directs all questions and explanations to patient Patient ask for input first Explores family's apprehensions about patient taking in primary role Clarifies to patient what must legally be disclosed to parents Determines when the patients wants his or her parents in and out of the room Initiates discussion about eventual transfer of care Determines post-high school plans (social, employment, education) Instructs patient to keep names of medications, dosages, and medical team contact in wallet/purse/backpack Instructs patient on how to get prescriptions filled and how to call and schedule appointments
17-19	Knows how to gather information about IBD Demonstrates consistent ability to book own appointments, fill prescriptions, contact medical team Able to name his or her insurance coverage and plans for next 2 years of coverage Carries insurance information in wallet/purse/backpack	Initiates conversation about potential barriers to transition Identifies potential adult GI providers Encourages patient to meet and interview providers Reminds patient and family that at age 18 the patient has the right to make his or her own health choices
20-23	Has had a telephone conversation with potential adult GI providers Initial visit with adult GI is scheduled while IBD stable	Provides patient with medical summary and checklist (see Table 2) Transfers medical records to adult provider

IBD: Inflammatory bowel disease; GI: Gastrointestinal.

in the form of some guidelines based on personal experience. The North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) indicates its recommendations for this process as<sup>[6]</sup>: (1) The pediatric gastroenterologist should start seeing adolescent patients without their parents in order to build some sort of relationship that promotes independence, so the patient will have this well-established before going to adult practice. Nevertheless, it is not clear at what age pediatric gastroenterologists should start implementing this recommendation. (2) Introduction of the patients subject to transition, and their families, to a gastroenterologist who is trained in internal medicine. Emphasis placed on benefits of transition to the patients and their families, including exposure to a physician experienced in aspects that pediatricians are not exposed to such as pregnancy, fertility and cancer surveillance. (3) Selection of an adult gastroenterologist who cares for young adults and identifies what this sector of patients may need that differs from newly diagnosed young adults. (4) The transition process should include a detailed letter from the pediatric to the adult gastroenterologist with a copy to the family. (5) The timing of the transition should be flexible according to patients' individual needs, e.g. the pediatric gastroenterologist should continue to follow those patients with delayed puberty who still have some potential to grow.

In a recent report, Hait *et al*<sup>[8]</sup> recommended some tasks and knowledge that pediatric patients at different age groups should be able to accomplish and be familiar with through the help of the medical team (Table 1).

This work has not been validated.

In a similar report, Pinzon *et al*<sup>[7]</sup> also recommended a certain amount of information pediatric patients should know in certain age groups (Table 2).

Dabadie *et al*<sup>[9]</sup> have recently conducted a survey on a small sample of young adults with IBD. Their mean age of transition was  $17.9 \pm 0.9$  years. Eighty five percent of patients and 74% of their parents felt they were ready to move to adult practice. The transition model they were using involved having one joint pediatric-adult care visit before moving completely to adult care. The majority of patients felt comfortable with this model<sup>[9]</sup>.

Many other centers are using the same model. In fact some hospitals may have more than one visit per patient to the joint clinics before transitioning children to adult practice. Most of these clinics take place in hospitals where both adult and pediatric gastroenterology departments exist. The problem with this system is the diversity of patients' location especially in large countries. As the number of adult gastroenterology centers exceeds that of pediatric centers, some patients may choose to move to an adult gastroenterologist near where they live, in which case they would not see the same gastroenterologist from the transition clinic. Available health resources may interfere with arranging transition clinics where patients reside.

Another survey by Hait *et al*<sup>[10]</sup> was done among 1132 adult gastroenterologists in the Netherlands. The response rate was only 34% but the majority of these gastroenterologists reported a lack of medical knowledge among young adults with IBD. They also reported receiving inadequate

Table 2 Clinical transition framework<sup>[9]</sup>

	Early (10 to 12 years of age )	Middle (13 to 15 years of age)	Late (16 to 18 years of age )
Self-advocacy	Describe GI condition	Name and describe the role of those involved in care	Review successful changes achieved in life
Independent behaviors	Learn about transition process	Learn about rights and responsibilities	Review GI conditions and ways to stay informed
	Name medications and doses Choose method to remember to take medication	Describe tests and reasons for them Plan and prepare for appointments Discuss differences in pediatric and adult care Encourage self-reporting	Demonstrate knowledge in dealing with own care needs (e.g. booking appointments, refilling prescriptions)
Sexual health	Discuss puberty and changes related to GI condition and medication side effects	Discuss safer relationships and dating	Aware of sexual capability and ability to have children
		Name places for reliable sexual health information	Understands sexual behaviors and its risks
Social supports	Describe role of family in transition process	Discuss family medical history Discuss ways to benefit from peer support	Enrolls in GI support associations Identifies contacts in case of need of emotional support
		Review restrictions for education or work Discuss volunteering opportunities at school or community	Aware of work opportunities Discuss further plans for insurance coverage
Educational/vocational planning	Discuss school attendance, goals and strengths		
Health and lifestyles	Review healthy active living	Review ways of coping with stress	Describes exercise/activity routines
	Tobacco use or other substances	Learn of risks associated with driving and GI condition	Discuss importance of planning ahead for trips and being away from home

Adapted from the ON-TRAC abo model at the British Columbia Children's and women' Health Center.

medical history from their pediatric colleagues.

We recently started conducting a survey looking at the level of disease-related knowledge among older children and young adults with IBD. We asked patients and their parents to complete the same questionnaire forms independently. The preliminary results showed a significant lack of knowledge among those children and a significant knowledge deficit between children and their parents. This was the case despite the presence of a meticulous program for educating newly diagnosed children with IBD. The problem is that patients in this age group are often highly dependant on their parents on selecting and filtering all the information they need. Consequently we started seeing older patients with IBD on their own without their parents early before transitioning them to our adult colleagues. We are also evaluating a new strategy for patients' education to see if the outcome can be improved.

## LESSONS FROM OTHER SUBSPECIALTIES

Taking in consideration the huge advances in patient care and management, children with chronic disease are expected to live longer. Consequently, the area of transition has been explored in most other pediatric subspecialties.

In a recent multicentre audit from the UK, Robertson *et al*<sup>[11]</sup> reported some improvements in their transition program after highlighting the aspects of care provisions in transition through a national UK service framework of children. Improvements took place in the documentation of transition issues and in some educational needs of patients and their parents that were related to their disease. The concept of independent clinic visits was introduced at an earlier age (mean of 15.8 years *vs* 16.8 years before provision).

A service model for adults with congenital heart disease was recently published stressing the importance of close communication between local district general hospitals, tertiary specialist centers and primary care clinics. The authors suggested that transition clinics should start at the age of 12 years<sup>[12]</sup>.

McDonagh and Kelly summarized determinants of the timing of transition as follows<sup>[13]</sup>: (1) Chronologic age; (2) Maturity; (3) Current medical status; (4) Adherence to therapy; (5) Independence in health care; (6) Self-advocacy skills; (7) Preparation; (8) Readiness of the young person and (9) Availability of an appropriate adult specialist.

Clearly it is not an easy task for pediatric gastroenterologists to determine the exact maturity status for each child with IBD. Moreover, even when we feel that some children are not mature enough to move to adult service at the age of 16-17 years; it is not easy to convince health authorities to keep seeing these children in pediatric services. In fact, the differences between transition services in different health care systems were proven to inhibit a smooth and successful transition process in a recent study by Reiss *et al*<sup>[14]</sup>.

There have been some attempts to create a self-efficacy/independence scale to facilitate assessing older children with chronic disease for maturity. Schlosser and Havermans created and validated a self-efficacy scale for children with bronchial asthma between 10-18 years of age<sup>[15]</sup>. The scale consisted of 38 items partly taken from a self-efficacy scale by Grossman *et al*<sup>[16]</sup> for diabetics. Older children scored higher on the total scale. One major flaw in this study was the lack of adjustment for obvious confounders like social class or IQ. These points were partially taken into consideration in another independence-scale that was designed for children with cystic fibrosis (SCIS). The scale consisted of 44 items. An initial interview was done to screen for children with an average or high cog-

nitive function<sup>[17]</sup>. The study was conducted among CF patients aged from 14-17 years. Based on age, two different intellectual screening tools were used. There was a positive correlation between SCIS scores, patient's age and the number of years since diagnosis<sup>[17]</sup>. A similar study with a larger sample size was conducted among patients with diabetes not only for children but also for parents assessing independence of their children<sup>[18]</sup>. Approximately 25% of parents of children 6 years-old, 50% of parents of children 8 years-old and 75% of parents of 14 year-old children reported that their children had mastered their disease-related skills<sup>[18]</sup>.

Another tool was developed by the Boston Children's Hospital, USA to allow older children to evaluate their readiness for transition. This tool consisted of 15 questions<sup>[19]</sup>. Validation of this tool remains questionable.

Two case studies were recently published demonstrating the concept of "a medical home"<sup>[20]</sup>. This concept was highlighted in a statement by the American Academy of Pediatrics. It was stated that all children and youth with special health care needs should have a medical home where health care services are accessible, family centered, continuous, comprehensive, coordinated and compassionate<sup>[21]</sup>. The authors tried to set a model for transitioning older children with chronic, disabling medical problems using the above concept.

Currently there is a residency program in the United States (combined Medicine-Pediatrics Residency Program) that helps in qualifying physicians to look after children with chronic disorders during this critical period<sup>[22]</sup>. Training includes pediatric and adult subspecialty experience. Spreading this program to other countries may help in smoothing the transition process.

## CONCLUSION

Transitioning adolescents with IBD to adult gastroenterologists requires an understanding of the specific issues and challenges involved in the management of pediatric IBD<sup>[23]</sup>. Currently there is no consistency in transition practice among different centers.

The best strategy for health education or patients' transition is yet to be determined. Assessing children with IBD for maturity could be a challenge in view of the lack of validated scales. Current guidelines and suggestions are based on personal opinions. More research addressing best strategy for education, transition and building bridges with adult gastroenterologists are needed.

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