

A Case-Based Monograph Focusing on IBD

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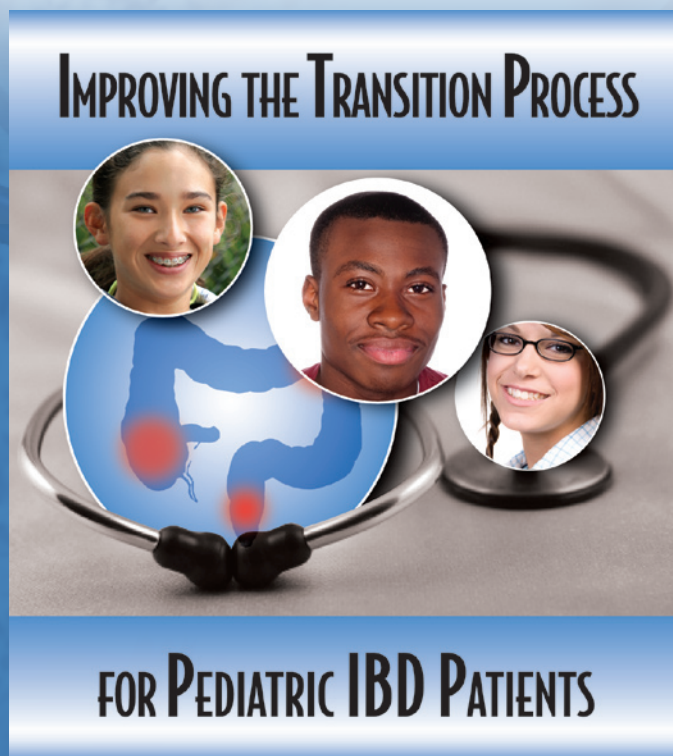
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INTRODUCTION

Inflammatory bowel disease (IBD) is complex, especially in the pediatric population. Along with facing the same risks as adult patients, children with IBD also face a number of unique social challenges. Pressure to fit in with peers can be overwhelming during the years leading up to a patient's transition into independence, and many pediatric patients are learning to balance their social life with school and possibly work. Puberty develops at a time when pediatric patients are forming a sense of identity and responsibility, and independence can be a stressful experience without proper preparation.

Ensuring a smooth transition from pediatric to adult care is an ongoing challenge for health care professionals, with many factors to consider. Pediatric patients who are not properly prepared to accept the responsibilities that come with independence often struggle in many areas of self-care, including communicating with their adult-care professionals, adhering to treatment, and becoming a self-advocate. The Children's Digestive Health and Nutrition Foundation (CDHNF) and North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) have developed physician and patient resources, which includes an age-based checklist, to help facilitate and improve this often complicated process. This monograph focuses on teaching clinicians to effectively transition pediatric patients into an adult care setting, including strategies to manage and resolve potential barriers in this challenging process.

TARGET AUDIENCE

This activity is designed for pediatric and adult-care gastroenterologists, primary care physicians, physician assistants, nurse practitioners, students, trainees, and other health care professionals who are involved in the transition of IBD patients from pediatric to adult care.

LEARNING OBJECTIVES

Upon completion of this activity, participants should be able to:

- Identify the needs of IBD patients for a successful transition from pediatric to ongoing adult care
- Explore potential barriers to this transition from the perspectives of patients, families, and medical team members
- Utilize the CDHNF and NASPGHAN checklist and patient Web resource to develop an effective transition plan for pediatric IBD patients, with a focus on developing patient independence, education, and communication
- Incorporate parents and family members of pediatric IBD patients into the planning process to ensure their support
- Develop a team approach (when available) in transitioning IBD patients from pediatric care to adult care, and utilize available transition resources

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OVERVIEW

The transition from pediatric care to adult care is an important step for teens with inflammatory bowel disease (IBD), and is often a challenging one. Health professionals face many barriers to successful transition, including the physical and emotional immaturity of patients, resistance from parents, and their own hesitations to the subsequent transfer.

A transition plan should be introduced as soon as possible in pediatric patients, allowing adequate time to facilitate a smooth process. Early preparation can help build patient confidence, assuage reservations and resistance from parents, and establish a clear set of goals for the transferring provider. Transitioning focuses on patient education and the development of the necessary skills to independently and successfully manage their IBD in a new and unfamiliar setting.

The pediatric provider should guide and prepare the patient for the new culture of adult health care. The adult patient is expected to articulate his/her medical history, tolerate minor physical discomfort, take initiative in asking questions, and participate in more decision making. The adult provider often focuses more on the disease and less on the psychosocial context, favors the patient's autonomy over nurturance, and treats the individual instead of the patient's family.^{1,2}

The Children's Digestive Health and Nutrition Foundation (CDHNF) and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) have developed recommendations based on a timeline and educational goals for the transition of pediatric IBD patients. This monograph reviews these recommendations as well as common barriers all involved parties may face.

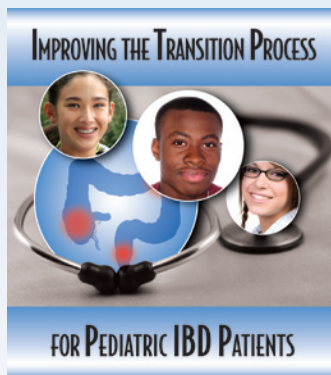
EARLY PREPARATION AVOIDS LATER OBSTACLES

Why Does Transition Matter?

Transition to adult care is the process of developing a patient's medical independence. IBD will affect pediatric patients throughout their lives. Once in adulthood, patients are expected to communicate directly with their physician and navigate through various aspects of the medical system, including entities such as insurance carriers and pharmacies.³ Abrupt transfer may cause excessive stress in patients, insufficient confidence in parents, and frustration on the part of the adult care provider. The goal of a successful transition plan is to achieve a continuum of care that involves normalization of social and emotional development, acquisition of independent living skills, improved compliance, and effective planning for long-range needs.^{3,4}

A successful transition includes:

- Customizing an approach that takes into account the maturity and personal development of individual patients²
- Openly recognizing and addressing barriers inherent to the transition process



- Recognizing that transition is a process, not a single point in time²
- Creating a developmentally appropriate program aimed at moving adolescent patients toward self-management³
- Starting the process early to establish the necessary skills for self-management, including proper treatment adherence, a general understanding of disease activity, and recognition of flares

Obstacles to a Smooth Transition

The Patient

Children with IBD face many of the same medical risks as adult patients, but unlike adults, must also complete the task of growth and development. Studies of height velocity in IBD and its 2 main subtypes – Crohn's disease (CD) and ulcerative colitis (UC) – have demonstrated that up to 46% of children with CD will have a reduced height velocity before the onset of symptoms, contrasted with 3%-10% of children with UC.^{5,7} Quality of life is often affected by anxieties about inadequate growth, and the prospect of adult short stature can cause significant concern.^{5,8} Delayed growth and late-onset puberty may also have a significant negative impact on psychosocial, mental, and emotional development and may further delay transition from parent-dependent early adolescence to self-dependent late adolescence.

Puberty introduces an often overwhelming pressure to fit in with peers, and disease activity that sets patients apart from their social group can cause increased stress. High-risk behaviors, including experimentation with smoking, alcohol, drug use, and sexual activity, have been reported to be as common in adolescents with chronic illness as in the general population, though with an increased risk of negative outcomes.⁹ During this time of intense physical and emotional changes, adolescent patients experience their first encounter with responsibility, learning to balance their social life with school and health care management.³

Patients often lack the necessary emotional and cognitive skills to cope with treatment regimens. Adherence rates among children with chronic disease are typically reported at approximately 50% and are lowest in adolescence and during remission.^{10,11} The adolescent's limited life experiences and sense of invincibility contribute to a poor understanding of their responsibility in managing their disease state. For example, adolescents often fail to create strategies to remember medications and may refuse parental assistance due to a wish for increased independence.

Transferring into the adult care health system is a major and expected milestone in the lives of pediatric patients, yet is often accompanied by feelings of reluctance in giving up the familiar care of the past.^{2,4} Forced to face this change, patients may experience feelings of abandonment or even anger at the need to leave their comfortable environment. Some patients refuse to engage in the transition process early, waiting until the transfer is imminent. The patient may even expect the pediatric provider

to relent and allow them to stay under their care. However, remaining in the pediatric setting may delay development of independence and deprive patients of age-appropriate care.⁴

The Family

Transition is a challenging time for the patient's family, often accompanied by fear and a sense of loss.³ Family members who have been intimately involved with their child's care may feel shut out and ignored when adult providers involve them only with the patient's permission.⁴ Families often develop close personal ties with pediatric providers and their staff, forged over time through crisis and shared concerns. Understandably, they are reluctant to leave these comfortable bonds.^{4,12} Perceived lack of knowledge and experience in the adult provider can contribute to the resistance to start over with a new physician.¹ It is important to remember that these family members have previously been involved in all treatment decisions and are now faced with having to let go and gain trust as the adolescent becomes more independent.³

The Pediatric Providers

There may be medical or social reasons to choose a time for transfer, but conflicting ideas as to the best time to complete the transition may force the pediatric provider to act as mediator, striking a 3-way balance between their own opinion and the wishes of the patient and parents.^{12,13}

Pediatric providers develop strong ties to patients and their families and may feel that adult providers lack the expertise and preparation to deal with their patients' medical problems and unique psychosocial challenges.⁴ Often this is a result of the pediatric provider's focus on nurturing their patient rather than providing autonomy. Two myths that pediatric providers may have are:

- "I know my patient better than anyone else could."
- "I can best take care of my patient and if I am not available to them they might not fare well in an adult setting."

To dispel these fears it is imperative that the pediatric provider spends adequate time on the transition process so that difficulties for the patient, family, and adult gastroenterologist are avoided as much as possible.⁹ It is helpful to have the pediatric provider enumerate the positive aspects of adult-centered care.

The Adult Provider

Adult health care providers acknowledge the importance of uninterrupted health care. Yet often, they face difficulties when pediatric patients transfer into their care. A survey of adult gastroenterologists (363 responders) reported that they found deficits in patient knowledge regarding medical history (55%) and prescribed medication regimens (69%).¹⁴

Data also show that the adult provider may potentially lack the confidence or training to treat adolescents with childhood-onset disease.⁹ In the Hait et al survey, 96% of adult gastroenterologists believed awareness of medical aspects of adolescent health care was important, with only 73% reporting that they felt competent regarding those issues.¹⁴ Similarly, 89% of responders believed developmental issues were important, but only 46% felt

comfortable and competent with addressing developmental or mental health issues in this population of patients. It is not uncommon for adolescent patients to regress to a lower level of maturity in times of stress and change, thus potentially leading the adult provider to question the appropriateness of the transfer. Difficult and overly involved families may add to the adult provider's doubts about the patient's readiness for transfer. These common occurrences eventually lessen in time.

The Health System

Barriers inherent to the medical health care system often create obstacles in the transition process, such as difficult access to medical records. Additionally, patients who are followed by multiple subspecialists for comorbid conditions require a well-coordinated transfer across specialty areas, which is often logistically difficult to prepare. Hait et al reported that 51% of adult gastroenterologist responders reported receiving inadequate medical histories from pediatric providers.¹⁴ The pediatric gastroenterologist should provide a detailed and informative medical summary to both the patient and the adult provider. Such a summary is a key component in effectively transferring care. Patients who see multiple specialists for comorbid conditions may experience an inconsistency in the transition process because of a lack of collaboration across specialty areas. An improper or untimely transfer of a patient's medical history complicates this process further.

The decision on whether to pursue higher education after high school can alter the timing for transition as well. Patients who attend college in different states will receive a greater amount of care by telephone or the Internet than those who remain closer to home.⁴ Transfer to an adult provider under these circumstances can prove difficult as the new provider may not have sufficient time to become familiar with the patient or their medical condition. Temporary transition to a physician who is closer to the patient, while convenient, may not provide the consistency necessary for a continuum of quality care. Thus, ongoing care will likely require the cooperation of the pediatric provider with either the adult provider or a local physician.

Insurance coverage and policies must also be factored into the transition process. Private health insurance is most often linked to parents' employment and typically ends for the patient between ages 18 and 23 years.¹ Due to the recent US health care reform legislation, insurers may allow coverage of dependents younger than age 26 years with their parents' health care plans.¹⁵ Many medical insurers require hospital admissions in the location where the insurance holder resides, forcing college students to come home if inpatient hospital care is necessary.⁴ The level of coverage may also be reduced at age 18 years for some patients, especially those in government assistance programs such as Medicaid.¹ As minors, adolescents are often unable to legally provide informed consent and are granted limited access to confidential medical care until they reach age 18 years. Some team members (eg, nurse practitioners) may have practice restrictions that would prevent them from seeing patients after a certain age. Other countries, including Canada, require transition by age 18 years or once high school is completed. This demarcating line can often create confusion and mixed messages about the patient's abilities, as well as the rights of the patient, parents, and health care providers.¹⁶

PREPARING THE PEDIATRIC PATIENT FOR TRANSITION

Early Steps

The transition process should begin in early adolescence, or from the time of diagnosis, to allow the idea of developing independence and leaving the familiar pediatric environment to take shape in the patient’s mind.^{4,13,17-19} Parents can help prepare children even before adolescence by teaching proper medication use and delegating responsibility to the patient to carry out specific medical self-care tasks.¹ This communicates to the adolescents that caregivers have confidence in their ability to eventually learn these skills. Focus group interviews of posttransition patients, family members, and health care providers recommended starting the process early. In their experience, it contributed to patients’ improved self-confidence.

NASPGHAN Recommendations

NASPGHAN has developed general recommendations for an effective transition of patients with IBD from pediatric to adult care, including taking early steps to facilitate the transition process, involving the parents in transition planning, and aiding in the selection of the adult provider.⁴ These recommendations are summarized in Table 1 and will be detailed further in the age-specific timelines in the next section.

Table 1: NASPGHAN Transition Recommendations^{4,12}

1. Start seeing the patient without their parents to build a relationship that promotes independence and self-reliance
2. Discuss benefits of transition to an internal medicine gastroenterology practice with the patient and family
3. Select an adult gastroenterologist who cares for young adults and identifies with the special considerations in childhood-onset disease
4. Provide all necessary medical records and summaries so that the family will recognize that all providers are working together to deliver excellent care
5. Allow flexibility in transition timing according to individual patient needs

Healthy young adults are typically expected to develop complete independence by age 21 years and this expectation is the same for the pediatric IBD patient.¹ Starting in early to middle adolescence, the pediatric provider should begin seeing patients without their parents.^{4,12} One-on-one conversations with the patient build a relationship that promotes the patient’s independence and self-reliance, prepares them for the relationship they can expect from their adult provider, and helps to establish self-care skills well in advance of the eventual transfer of care.

Patients and family members should be informed that an adult-care gastroenterologist is better qualified in the long run to address problems both directly and indirectly related to their underlying condition during the adult years.⁴

Conditions such as pregnancy and fertility, ongoing cancer surveillance, and various common adult health problems will be more adequately addressed by the adult care provider.

After the decision is made to start the transition process, a skilled adult provider should be identified.⁴ The ideal physician is one who has experience with young adults and recognizes the different expectations of patients with childhood-onset IBD and patients with a more recent onset of IBD.

At the time of transfer, the pediatrician should provide necessary medical records and summaries to the adult provider.⁴ Sending a letter that summarizes the patient’s medical history to the new physician is also recommended and, if appropriate, a copy should be sent to the patient, especially if they choose to seek care from a different adult care provider. These steps help the patient and family to appreciate that both the pediatric and adult providers are in collaboration to provide the most optimal care for the patient.

Finally, the maturity of the patient is a critical factor when determining if they are ready for additional responsibility or independence and requires careful assessment on the part of the pediatric provider. The timing of transition coaching and ultimate transfer is dependent on many variables and the process must be flexible and individualized for each patient.^{4,9} Pediatric providers are recommended to follow up with young adults who have additional growth potential resulting from delayed puberty.⁴ In contrast, a young adult who has completed their education, is financially independent, and has progressed to the adult social sphere should be followed by an adult provider.

Suggested Timelines for Transition

As stated, an appropriate timeline for transition must be tailored specifically to the developmental abilities of the patient. A joint effort by the CDHNF with NASPGHAN has produced a general timeline and checklist that reflects the commonly accepted developmental stages, roughly defined by chronological age.

Ages 12-14 Years (Table 2)

Case Study I: Initiating Transition



Kathleen is 13 years old and has recently been diagnosed with UC. She has recently finished tapering off of prednisone and is now on mesalamine monotherapy for maintenance and considered to be in remission. During visits, Kathleen often looks to her father to provide information to her pediatric provider.

Case Question:

How would you introduce the transition process into Kathleen’s standard care?

- Review baseline information about the digestive system and UC with Kathleen
- Discuss with Kathleen how to recognize symptoms that warrant medical attention
- Help Kathleen and her parents understand the medications being used for her maintenance therapy and their possible adverse effects

- Discuss specific self-management goals and help Kathleen to balance her medical tasks (eg, taking medication) with school and social responsibilities
- Discuss the idea of Kathleen attending some of the interview and examination without her parents present

Between the ages of 12 and 14 years, patients, such as Kathleen in case study 1, should demonstrate an age-specific understanding of their gastrointestinal (GI) condition and the medications they are currently taking.² As recommended in Kathleen's case, this understanding should include disease-specific education and a firm understanding of the possible adverse effects of her pharmacologic treatment. Patients should also be familiar with self-management tasks, such as using and reading a thermometer and identifying strategies to take their medications as directed.

The idea of independent visits should be introduced, acknowledging the patient's privacy by having their parents leave the room for part of their appointment.² Anticipatory guidance should be provided on the impact of fitness, sexuality, and possible substance use and the potential effect it could have on the patient's underlying condition.

Table 2: Patient and Provider Checklist for Ages 12-14 Years²⁰

Age Range	Patient	Health Care Provider
12-14 years*	<ul style="list-style-type: none"> Can describe GI condition Can name medications, dosage, and times to take them Can describe common side effects to medications Knows doctors' and nurses' names and roles Can use and read a thermometer Can answer at least 1 question during health care visit Can manage regular medical tasks at school Can call doctor's office to make or change an appointment Can describe how GI condition affects them on a daily basis 	<ul style="list-style-type: none"> Discusses idea of visiting office without parents or guardians in the future Encourages independence by performing part of the examination with parents or guardians out of the room Begins to provide information about drugs, alcohol, sexuality, and fitness Establishes specific self-management goals during office visit

*It is ultimately up to the provider to determine when the patient is ready to move to the next stage of transition.

Ages 14-17 Years (Table 3)

During this stage, patients should be able to identify the procedures and tests used to evaluate their IBD, as well as their purpose.² Education should also include adequate communication of their parents' relevant medical histories, articulation of the risk of nonadherence to their prescribed medical regimen, and understanding the impact drugs and alcohol could have on their illness.

Questions and explanations should be directed to the patient, ensuring that body language and eye contact are also directed initially to the patient and not the parents.² It should be explained to the parents that the patient will be asked for input first and then feedback will be solicited from the parents. If not initiated earlier, the health care professional should commence the discussion about the eventual transfer of care and the patient's plans after graduating from high school.

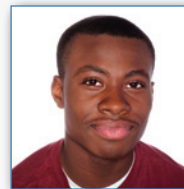
Table 3: Patient and Provider Checklist for Ages 14-17 Years²⁰

Age Range	Patient	Health Care Provider
14-17 years*	<ul style="list-style-type: none"> Knows the names and purposes of routine tests Knows what can trigger disease flares Knows medical history Knows need to transition to adult caregiver Reorders medications and calls doctor for refills Answers many questions during health care visit Spends most of time alone with doctor during visit Understands risk of medical nonadherence Understands impact of drugs and alcohol on condition Understands the impact of GI condition on sexuality 	<ul style="list-style-type: none"> Always focuses on patient instead of parents or guardians when providing explanations Allows patient to select when parent or guardian is present for examinations Informs patient of what the parent or guardian must legally be informed about in regards to condition Discusses importance of preparing patient for independence with parents or guardians and addresses any anxieties Continues to set specific goals, including filling prescriptions and scheduling appointments and keeping a list of medications and provider contact information in wallet and backpack Discuss in more depth: <ul style="list-style-type: none"> Impact of drugs, alcohol, and nonadherence on disease Impact of disease on sexuality and fertility Future plans for school/work and impact on health care Coordination of care transfer with future school or work plans

*It is ultimately up to the provider to determine when the patient is ready to move to the next stage of transition.

Ages 17 Years and Older (Table 4)

Case Study 2: Leaving Home



Marcus is an 18-year-old high school senior who will be moving to an out-of-state university in 3 months. He was diagnosed with CD at age 12 years and since that time has gone through 2 recurrences. He is currently in remission, but often has missed days of medication and admits that he resents his dietary restrictions.

Case Question:

How would you address the barriers to Marcus's proper treatment adherence?

How would you prepare Marcus for his move to college?

- Patient "buy-in" is critical for maintaining consistent adherence to the treatment regimen. Various communication techniques may help Marcus assess and advance his readiness to take ownership of his health care by exploring personal barriers to regimen adherence and engaging in problem solving to improve adherence and reduce the risk of relapse.
- Provide the patient with a medical summary for work, school, and transition, and provide a list of potential providers to encourage/facilitate the initial visit

- Discuss with Marcus how he will obtain medication (eg, local pharmacy or mail order service). He should have the name, address, and phone number of a local pharmacy in the event he needs a new medication. He should be aware of what medications he cannot take as they might interact with the medications he is currently taking for IBD. He should also be aware of the effects of alcohol on the medications he is taking.
- Discuss where Marcus will have routine blood work done and where he will go if he becomes seriously ill (eg, school health center or local emergency department)
- Discuss how Marcus will explain his disease to his roommate. Even if he does not expect to share this information, it is likely that the many medications, frequent bathroom trips, and bandages after blood draws may provoke questions. He should have an answer in mind.
- Discuss how Marcus will communicate with his doctor if privacy is not easily found. He may prefer to use e-mail to send messages so he does not need to speak embarrassing details.
- Discuss sexual health and alcohol/drug use with Marcus. This is a time when many young people experiment and take risks; thus, the possible consequences these choices could have on his health must be presented.

During late adolescence, patients should be able to identify ways of independently gathering more information about their illness and demonstrate a consistent ability to access and coordinate medical needs, including appointment scheduling and filling prescriptions.² Patients should also be able to identify their insurance carrier and plans for medical coverage.

Conversations concerning potential barriers to the transfer, including financial issues, patient attitudes, health care access, and family resistance, should be revisited at this time.² The patient should have identified a potential adult care provider and scheduled an initial visit during a period of stability from IBD activity. It may be helpful for patients to meet adult provider candidates in advance of the transfer. Some patients may choose to schedule a final visit with the pediatric provider to discuss their first experience with the adult provider. During this last visit, the pediatric provider can help troubleshoot remaining concerns with the patient and family. The patient should have a copy of their medical summary (Table 5) and make the pediatric provider aware of the new provider's name and address.

Educating Patients for an Effective Transition

In patients who developed IBD in early childhood, much of the initial disease education may have been directed primarily to the parents.⁹ Disease education must often be reviewed repeatedly, taking into consideration the changing cognitive development that lends itself to poor retention of information. Concrete examples are more effective in young adolescents than abstract discussions, which become more appropriate as the patient develops into young adulthood.

Inviting general inquiry from patients is important to assess their baseline knowledge and fill in any existing knowledge gaps. The patient should be well-versed on their various test results, multiple changes and adaptations of their treatment regimen, and any allergies or intolerances that may have emerged from treatment. Resources designed to help educate and prepare pediatric IBD

patients for transition are available from CDHNF and NASPGHAN and include Webcasts, brochures, and information on such topics as disease education, coping strategies, and the transition itself.²¹ Interactive resources include a personal IBD notebook to

Table 4: Patient and Provider Checklist for Ages 17 Years and Older²

Age Range	Patient	Health Care Provider
17 years and older*	<input type="checkbox"/> Knows which medications to avoid due to interactions with currently prescribed medications <input type="checkbox"/> Is alone with the doctor for entire health care visit or chooses who is present <input type="checkbox"/> Can name new legal rights and responsibilities gained at age 18 years <input type="checkbox"/> Manages all medical tasks outside the home (eg, work, school) <input type="checkbox"/> Knows how to get more information about IBD <input type="checkbox"/> Can book own appointments, refill prescriptions, and contact health care provider <input type="checkbox"/> Can communicate length of coverage under parents' health insurance plan and necessary steps to maintain coverage over next 2 years <input type="checkbox"/> Carries insurance information in wallet/purse/backpack	<input type="checkbox"/> Reminds patient and family that age 18 years grants patient right to make personal health choices <input type="checkbox"/> Develops specific plans for self-management outside the home (eg, work, school) <input type="checkbox"/> Provides patient with medical summary for work, school, or transition <input type="checkbox"/> Discusses plans for insurance coverage <input type="checkbox"/> If transitioning during this stage, provides list of potential providers and encourages/facilitates initial visit

*It is ultimately up to the provider to determine when the patient is ready to move to the next stage of transition.

assist the patient and family in tracking important information (eg, details about diagnosis, medications, and procedures) and a searchable database of pediatric gastroenterologists. The Crohn's and Colitis Foundation of America (CCFA) also offers patient education resources that include articles and comics geared specifically toward educating adolescents.²²

IBD University (IBD U; <http://www.ibdu.org>) provides additional resources specifically for teenagers with IBD and includes articles on education, health care, lifestyle, and self-management.²³ Resources are also available for parents, friends, employers, teachers, and health care professionals. Recently, IBD U added a YouTube video channel that provides experiences and tips from adolescents with IBD and includes videos on preparing for college, employment, and independence. Patients should learn to routinely update their personal medical history and IBD U offers a "health passport" that patients can download, print, and carry with them to appointments.²⁴

Building a Team Approach to Transition: The Medical Home Model

When available, a team approach to ongoing care and transitioning should also be utilized. Well-coordinated care by an interdisciplinary team allows for more time to address important patient concerns. A team may consist of physicians and nurses or can incorporate a broader range of medical subspecialists, such as social workers and nutritionists. This variety of specialties provides a greater opportunity for problem solving and may maximize the ability to solicit concerns from the patients and family.

In the medical home model, developmentally appropriate care is provided continuously as the patient moves along and within health care systems from adolescence to adulthood.²⁵ One physician provides first contact and continuous, comprehensive care, and is backed by a team of individuals at the practice level who collectively take responsibility for the patient's ongoing care.²⁶ Care is coordinated across all elements of the health care system (eg, subspecialty care and hospitals) and the patient's community (eg, family, public, and private community-based services). The medical home model is centered around patient advocacy and patients actively participate in decision-making, providing feedback to ensure their needs are met.

However, a team approach may present its own set of barriers. With multiple individuals tasked with preparing the patient for transition, clear and complete communication becomes critical to ensure that all aspects of the transition plan are properly completed. Team care is also atypical in the management of IBD in adults because of cost and the likelihood that adults will assume responsibility for the details of their care.⁴

Not all physicians have access to the resources and staff to create a team approach to transition, but resources such as the previously mentioned checklists and online materials available through NASPGHAN, CDHNF, and CCFA can provide valuable assistance to the singly responsible pediatric provider.

EMPOWERING PATIENTS TO OVERCOME PERSONAL BARRIERS

Disease self-management can be problematic during adolescence and treatment adherence often declines.²⁷ Rates of poor adherence among adolescents with IBD range from 50% to 88%. Developmental demands during this period (eg, decline in parental supervision and increase in peer influence and autonomy) likely contribute to these high rates of adherence failure. In a study of 74 adolescents diagnosed with IBD, participants were asked to report the barriers they faced to proper treatment adherence (Figure 1). The most commonly reported barriers included forgetting, being away from home, and interference with an activity. Identifying and overcoming treatment adherence barriers are important for patients to become empowered and independent. Through proper education and motivational interviewing,

patients can learn to assess their own readiness to change self-care behaviors. Simply put, motivational interviewing is a form of information exchange that closely resembles a balanced conversation.²⁸ Patients are encouraged to describe their behavior, ask questions, indicate what they would like to know, or disclose what they do and do not know about their medication. Once the patient has finished, the health care provider becomes active in conveying clear, nonjudgmental information, which, in turn, the patient is then given an opportunity to absorb and reflect upon. Alternately, a patient can also be encouraged to tell a story about a typical day in their life; however, this method can be time-consuming and may not be practical for many consultations.

Addressing Parent and Family Member Resistance

Case Study 3: Protective Parents



Renee is 16 years old and was diagnosed at age 11 years with CD. She hates having her mother "nag" her to take her medications all the time. "She follows me around and keeps asking if I've taken my meds," she complains. "If she'd just leave me alone, I'll take them later." The mother insists that, "If I don't remind her, she never takes them. When Renee says 'later,' she always forgets and I end up finding the pills on the table where I left them." The discussion quickly escalates into a heated argument that appears familiar to Renee and her mother.

Case Question:

How would you introduce the idea of independence to Renee and her mother?

- Involve Renee's mother in the transition process by teaching her methods of helping Renee to develop independent responsibility for her care (eg, using a pill box or other methods of remembering her medication, having her call the pharmacy for prescription refills, having her detail important medical information on an emergency card, and encouraging her to ask questions at medical appointments)
- Build time into appointments to talk alone with Renee. Help her to build her knowledge base concerning her disease as well as her communication skills. Allow Renee to share her current perceptions about having a chronic illness and the possible adversity she may face in maintaining her ongoing care.
- Explore her mother's fears to ensure that her expectations are realistic (eg, Renee waiting 3 days to report blood in her stool may not do irreparable harm to her body; however, this is an example of a red flag that the pediatric provider needs to be made aware of immediately)
- Consider counseling or motivational interviewing for the mother to help assess and understand her own reservations
- Have Renee take an active role in future visits, allowing time for her to answer several questions before the parents jump in to "correct" her or possibly be seen alone first. Remind her mother that adolescents may take more time to respond and may amend their answers after a few questions.

Table 5: Suggested Documents for Patients to Bring to Adult Provider at First Appointment²

Medical summary letter from pediatric provider that contains the following: <ul style="list-style-type: none">• Date of diagnosis• Location and severity of disease• Surgeries and complications• Medical therapies used, including dose and duration• Adverse reactions to medications
Health insurance information
Calendar/scheduling book for appointments and tests
Important names and contact information, including: <ul style="list-style-type: none">• Primary care provider• Pharmacy• Home health company (if relevant)• Other subspecialists• Transportation company (if physically disabled)

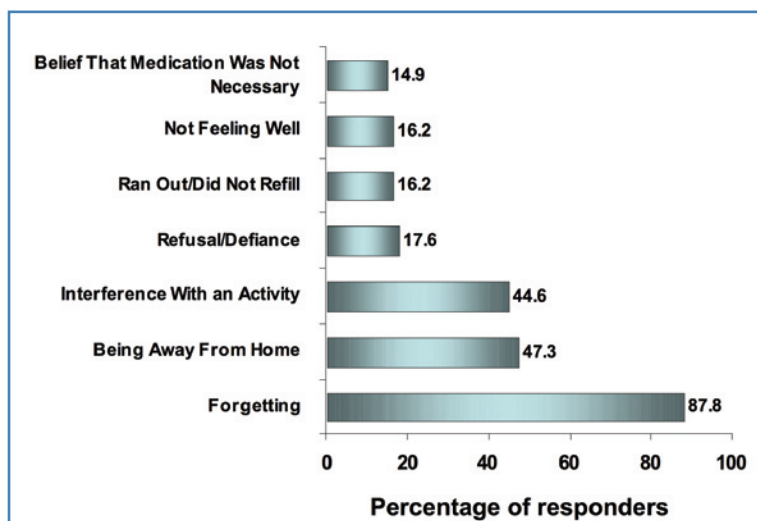
- Explore how Renee can explain her disease and treatment to peers (eg, why she takes so much medication, why her face has been looking so full, and why she was in the hospital for a week). Have her practice discussing these issues to build her comfort level and self-esteem for when she faces her peers.

The transition process is additionally stressful for the family members (as with Renee's mother in case study 3) and can foster anxieties and reservations about the adolescent's developing independence.⁴ Family members must be included in the planning and should be aware of the process, understanding the rationale and eventual goal, which can help prepare them for the difficult life change.²

Counseling, which often involves motivational interviewing, may help the family face their reservations and fears in the same way it helps patients understand their limitations.²⁸ Counseling may also help families problem-solve around common concerns and provide for their unique needs, addressing the specific barriers that may exist for different families.

Gaining parental support is important during transition, because lack of support has been associated with negative outcomes such as poor treatment adherence.⁹ Parents need the pediatric provider's support in the understanding of adolescent development in the context of chronic illness, their important and dynamic role in the process, renegotiation of personal boundaries, and the provision of resources available through medical organizations and within the local community. Transition is very much a family matter and parents should be coached to have faith in their child's newly achieved self-management and that the eventual transfer to an adult care provider will be successful. Parents need to be reminded of their uniquely important role, ensuring that the measures taken by the pediatric provider to develop the patient's independence are supported and continued at home.

Figure 1: Patient-Reported Barriers to Medication Adherence in IBD²⁷



SCHEDULING A JOINT VISIT TO IMPROVE TRANSITION OUTCOMES

Paired with effective planning, a joint medical visit with the patient's pediatric and adult care providers may be ideal to foster discussion between the former and future providers of the patient's medical situation.¹³ In a joint visit, the pediatric physician will summarize the patient's record for the new physician and allow the patient and/or parents to contribute whatever further information they feel is necessary. This opens up the possibility for the adult provider to discuss current and future treatment

options with all parties involved. Due to geographic barriers or increased time commitment, joint medical visits will not always be practical, but when possible, have shown benefits in the patient transfer.

In a small survey of 34 responding youths with IBD who attended a joint visit at Rennes University Hospital Center in France, 85% felt that they were properly prepared to transfer into adult care.¹³ All patients considered the joint medical visit beneficial for transmitting medical records and information and 93% considered it helpful in building confidence in the new gastroenterologist. At the time of the survey, 85% continued to be followed up by the same adult gastroenterologist to whom they were transitioned. However, most of these clinics took place in hospitals where both adult and pediatric gastroenterology departments exist. The problem with this system is the diversity of patient location, especially in larger 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.

A similar study on joint visits involving pediatric IBD patients in the United States is currently underway.²⁹ In addition to measures of a successful transition, this study will also assess whether or not the joint visit has any effect in reducing the risk of disease flares during and after transition.

SUMMARY

Transitioning IBD patients from pediatric to adult care is a challenging but critical process with many factors to consider. An effective transition plan develops the patient's independence and understanding of their own disease state and improves overall patient adherence and interaction with their adult care provider. Although many barriers to an effective transition exist, techniques such as including parents in the planning process, motivational interviewing, and visiting jointly with the adult care gastroenterologist may help to avoid or manage the many obstacles that may interfere with a smooth transition. Preparing and implementing a developmentally appropriate transition plan as early in the patient's care as possible promotes essential skills and has been shown to improve patient outcomes in the long-term care of this disease process.

Clinical Pearls

- Assess your patient's level of independence before implementing a transition plan
- The pediatric and adult clinicians must play an active role in support and encouragement towards the patient
- Relieve anxiety in the patient and the family by providing positive support throughout the transfer process
- Empower the patient by providing appropriate education about their disease and promoting communication skills that will be needed in the adult health care setting

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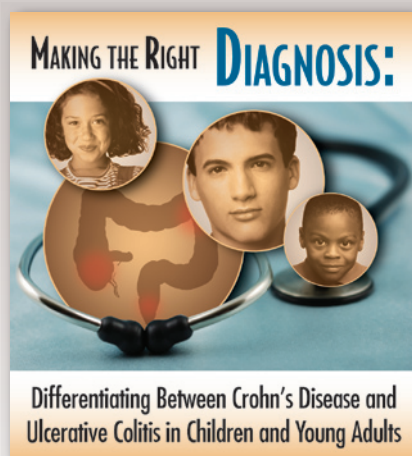
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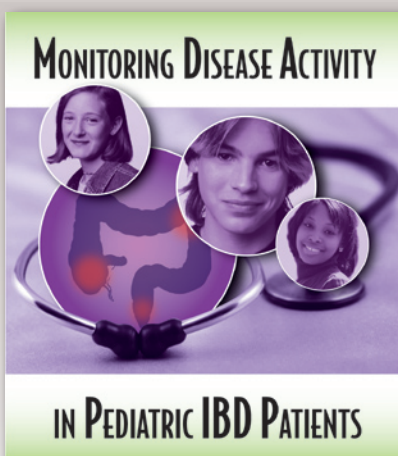
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1. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005;115:112-120.
2. Hait E, Arnold JH, Fishman LN. Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care. *Inflamm Bowel Dis*. 2006;12:70-73.
3. Escher JC. Transition from pediatric to adult health care in inflammatory bowel disease. *Dig Dis*. 2009;27:382-386.
4. Baldassano R, Ferry G, Griffiths A, et al. Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2002;34:245-248.
5. Heuschkel R, Salvestrini C, Beattie RM, et al. Guidelines for the management of growth failure in childhood inflammatory bowel disease. *Inflamm Bowel Dis*. 2008;14:839-849.
6. Kanof ME, Lake AM, Bayless TM. Decreased height velocity in children and adolescents before the diagnosis of Crohn's disease. *Gastroenterology*. 1988;95:1523-1527.
7. Hildebrand H, Karlberg J, Kristiansson B. Longitudinal growth in children and adolescents with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr*. 1994;18:165-173.
8. Otley A, Smith C, Nicholas D, et al. The IMPACT questionnaire: a valid measure of health-related quality of life in pediatric inflammatory bowel disease. *J Pediatr Gastroenterol Nutr*. 2002;35:557-563.
9. McDonagh JE. Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant*. 2005;9:364-372.
10. Dubinsky M. Special issues in pediatric inflammatory bowel disease. *World J Gastroenterol*. 2008;14:413-420.
11. Rapoff MA. *Adherence to Pediatric Medical Regimens*. New York, NY: Kluwer Academic; 1999.
12. El-Matary W. Transition of children with inflammatory bowel disease: big task, little evidence. *World J Gastroenterol*. 2009;15:3744-3747.
13. Dabadie A, Troadec F, Heresbach D, et al. Transition of patients with inflammatory bowel disease from pediatric to adult care. *Gastroenterol Clin Biol*. 2008;32:451-459.
14. Hait E, Barendse RM, Arnold JH, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009;48:61-65.
15. Health reform for young adults. White House Web site. http://www.whitehouse.gov/files/documents/health_reform_for_young_adults.pdf. Published April 1, 2010. Accessed July 1, 2010.
16. Hartman RG. Coming of age: devising legislation for adolescent medical decision-making. *Am J Law Med*. 2002;28:409-453.
17. Davies IH, Jenkins HR. Transition clinics for adolescents with chronic gastrointestinal disease in the UK and Ireland. *J Pediatr Gastroenterol Nutr*. 2003;36:505-506.
18. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics*. 2002;110:1315-1321.
19. Dommergues JP, Alvin P. Transition from pediatric to adult care in severe chronic diseases in children. *Arch Pediatr*. 2003;10:295-299.
20. Transitioning a patient with IBD from pediatric to adult care. CDHNF Web site. <http://www.cdhnf.org/user-assets/documents/pdf/TransitionPatAndPhysCombo.pdf>. Accessed July 1, 2010.
21. Inflammatory bowel disease (IBD) patient and parent resources. CDHNF Web site. <http://www.cdhnf.org/wmspage.cfm?parm1=111>. Updated February 25, 2010. Accessed July 1, 2010.
22. Resources. UC and Crohn's Web site. http://www.ucandcrohns.org/src_landing.php?c=6. Updated February 26, 2010. Accessed July 1, 2010.
23. IBD U: Graduating to independence. IBD U Web site. <http://www.ibdu.org>. Updated July 1, 2010. Accessed July 1, 2010.
24. Health passport. IBD U Web site. http://www.ibdu.org/uploads/pdfs/IBDUniversity_HealthPassport.pdf. Updated February 26, 2009. Accessed July 1, 2010.
25. What is a medical home? National Center for Medical Home Implementation Web site. <http://medicalhomeinfo.org>. Updated July 1, 2010. Accessed July 1, 2010.
26. Joint principles of the patient-centered medical home. National Center for Medical Home Implementation Web site. <http://medicalhomeinfo.org/downloads/pdfs/JointStatement.pdf>. Updated March 5, 2007. Accessed July 1, 2010.
27. Ingerski LM, Baldassano RN, Denson LA, et al. Barriers to oral medication adherence for adolescents with inflammatory bowel disease. *J Pediatr Psychol*. 2010;35:683-691.
28. Rollnick S, Mason P, Butler C. Exchange information and reduce resistance: two ongoing tasks. *Health Behavior Change: A Guide for Practitioners*. Edinburgh, UK: Harcourt Publishers Limited; 1999:105-129.
29. Transition study of inflammatory bowel disease (IBD) patients from pediatric gastroenterologist to adult gastroenterologist. ClinicalTrials.gov Web site. <http://www.clinicaltrials.gov/ct2/show/NCT00360022?term=ibd+transition&rank=1>. Updated June 14, 2010. Accessed July 1, 2010.



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