

Transition of Care in Inflammatory Bowel Disease

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Abstract: The management of patients with chronic conditions, such as inflammatory bowel disease (IBD), requires specific attention and careful planning during the transition from pediatric to adult care. Early education about the transition process and the acquisition of self-management skills are crucial to fostering independent adolescents and young adults who have the knowledge and tools to manage life with a chronic disease. A growing body of literature describes the challenges and barriers to providing adolescent and transition care. Potential barriers to effective transition include the following: differences between adult- and pediatric-onset IBD; patients' lack of developmental maturity and readiness, self-efficacy, and knowledge of the disease; poor adherence to therapy; adolescent anxiety and depression; differences between pediatric and adult IBD care; and parental and provider reluctance to transition. Despite our ability to identify barriers and challenges, there remain significant gaps in our knowledge about how they should be addressed. Outcomes data on adolescents with IBD are limited, and there are even fewer data on how the transition of care affects long-term treatment and outcomes. More research is needed to truly understand the best way to facilitate care during transition and improve outcomes. Current research and transition guidelines acknowledge that providing support and guidance to patients and their families and establishing clear goals can ultimately equip patients with the skills needed to cope with a chronic disease as adults and can improve their long-term care. This paper provides an overview of the transition from pediatric to adult IBD care, a discussion of challenges and barriers, and recommendations and resources that can help patients, parents, and providers navigate this important process.

Keywords

Adolescent, transition, inflammatory bowel disease, Crohn's disease, ulcerative colitis

The management of patients with chronic conditions, such as inflammatory bowel disease (IBD), requires specific attention and careful planning during the transition from pediatric to adult care. Early education about the transition process and the acquisition of self-management skills are crucial to foster-

ing independent adolescents and young adults who have the knowledge and tools to manage life with a chronic disease. The successful transition of a child with IBD from the care of a pediatric gastroenterologist to the care of a gastroenterologist who treats adult patients is a process, not simply a transfer of care. The transition process is unique for each patient and will be based on his or her developmental maturity and family dynamics, as well as the pediatric gastroenterologist's assessment of the patient's and family's readiness.

Differences Between Pediatric and Adult Inflammatory Bowel Disease: Effect on Transition

With more than 163 genes identified as independent risk factors for IBD,¹ it is increasingly being recognized that IBD comprises a very heterogeneous group of diseases. This is particularly true when pediatric and adult presentations of the disease are compared and when the natural history of Crohn's disease is compared with that of ulcerative colitis. We are reminded that children with IBD are not just small adults with IBD; rather, they differ significantly in phenotype, disease extent, and outcomes. Adolescents with IBD have been shown to have more extensive involvement. Among adolescents who have Crohn's disease, 69% present with ileocolonic disease, as opposed to 28% of adults, and 23% of adolescents who have Crohn's disease present with upper gastrointestinal involvement, which is rarely reported in adults.² Compared with adults, adolescents are also more likely to have ulcerative pancolitis (67% vs 44%).² In another study comparing the natural history of adult-onset IBD with that of pediatric-onset IBD, almost twice as many children (82%) as adults (48%) with ulcerative colitis had extensive colitis, and the median time to operation was significantly shorter in children than in adults.³ Similarly, there were significant differences in patients with Crohn's disease; childhood-onset Crohn's disease was characterized by more extensive involvement than adult-onset Crohn's disease (43.2% vs 3.2%; $P < .0001$).³ Adolescents with IBD were more likely to have severe disease requiring immunosuppressive and biologic therapy than adults with IBD.²

Given these variations in the extent and severity of disease in young persons with IBD, it is not surprising that a study analyzing resource utilization in pediatric and adult patients with IBD also found significant differences. Compared with their adult counterparts, adolescent patients had fewer clinic visits, more documented noncompliance, more active IBD on endoscopic evaluation, and Crohn's disease activity that was higher than average.⁴ These significant differences between pediatric- and adult-onset IBD highlight several key

issues that adult providers must recognize when caring for adolescents or patients with pediatric-onset disease: (1) Crohn's disease and upper gastrointestinal tract involvement are more common.² (2) Patients with pediatric-onset disease are likely to have more extensive disease,^{2,3} which, for example, can affect surveillance; flexible sigmoidoscopy alone may not adequately reveal disease extent and activity. (3) Adolescents have more severe disease that often requires more aggressive therapy and/or escalation of therapy.² (4) Their more severe disease is often complicated by increased rates of non-adherence, less regular care,⁴ and increased rates of IBD-related admissions in older adolescents.⁵ Existing studies have yet to reveal a cause for the significant phenotypic differences between childhood- and adult-onset IBD; however, research in this field is ongoing. Nonetheless, these differences reinforce the need for a transition process that is supervised by both pediatric and adult care providers who recognize the differences, with a focus on patient and family readiness, the transfer of an accurate and complete medical history, and close follow-up to ensure continuity of care, monitoring of disease activity, and support around self-management.

The complex nature of IBD and the heterogeneity of its presentation and course directly impact the transition of care. For example, the younger the patient is at diagnosis, the more likely it is that the parents or guardians will play a large role in the patient's treatment.⁶ The parent or guardian will be responsible for establishing relationships with physicians, obtaining laboratory test results, understanding insurance coverage, understanding the risks and benefits of the medications prescribed, and ensuring the child's adherence to medications. Those same caregivers will take on a different role if IBD is diagnosed in an older adolescent, who is more independent. Regardless, every patient with pediatric-onset IBD initially seen by a pediatric gastroenterologist will eventually need to transition to an adult gastroenterologist for ongoing care. Furthermore, adolescents remain the fastest-growing group of patients of all ages to present with a new diagnosis of IBD,⁷⁻¹² so awareness of the transition process is essential for both pediatric and adult IBD care providers.

Barriers to Successful Transition

The transition process is essential for ensuring a successful transfer from pediatric to adult providers.¹³ Good preparation and communication are key to a successful transition. Before the transition of care is initiated, it is important to recognize that physicians and patients may have different health priorities that affect the process. A recent study comparing health priorities in adolescents with IBD found significant differences between patients and their

physicians.¹⁴ Of the 10 health priorities included in the comparison, only 6 were identified as top concerns by both pediatricians and patients. Furthermore, physicians tended to overestimate their adolescent patients' worries. Physicians are typically focused on getting patients into remission, working toward mucosal healing, and avoiding surgery, hospitalizations, and adverse events.¹⁵ On the other hand, adolescent patients may be more occupied with being able to go to school or college, going out with friends, dating, and fitting in with others in their age group. Beyond the social realm, adolescents with a chronic disease may have distinct healthcare priorities. In a survey of 155 adolescents with a chronic disease, the issues that the young patients rated highest were the provider's honesty, attention to and treatment of pain, expertise, respect for patients, willingness to listen to concerns, and willingness to share decision-making.¹⁶ These studies, as well as current recommendations and guidelines, emphasize that education and communication are essential for a successful transition to adult care.¹⁷⁻²¹

Strong communication and education alone do not ensure a successful transition from pediatric to adult IBD care, as there are several potential barriers. Challenges specific to adolescents and transitioning patients include the following: poor adherence to therapy, adolescent anxiety and depression, inadequate self-efficacy and knowledge of disease, parental and provider reluctance to transition, differences between pediatric and adult IBD care, and insufficient developmental maturity and readiness.²²⁻²⁵ It is critical to recognize and work through these barriers; if the transition is not well planned and executed, the potential for negative outcomes is significant.² Possible negative outcomes include increased patient and family stress, loss of continuity of care, delayed psychosocial development, lapses in adherence to therapy and routine medical evaluation, and worsening of disease activity with the possibility of subsequent hospitalizations, escalation of therapy, and/or a requirement for surgery.^{2,22} Although data on the long-term prognosis of this vulnerable population are lacking,²⁶ existing studies demonstrate a greater number of IBD-related admissions among adolescents age 16 to 20 years than in younger adolescents and children,⁵ reinforcing the need for close medical management, well-planned transition of care, and further research on this important subject.²⁷

Lagging Developmental Maturity and Readiness

The timing of the transition of care is a complex issue, but the transition may begin in early adolescence, with the patient taking a more active role in the visit and the physician introducing the idea of conducting part of the visit without parents in the room.¹⁷ Pregnancy, marriage, hospital policies, or healthcare system age limits may

affect the timing of the transition. Ultimately, however, the decision of when to transition should depend on the patient's age and developmental maturity.¹⁷ A recent study by Wright and colleagues found that pediatric and adult gastroenterologists rated psychological maturity and readiness as 2 of the most important factors in assessing transition readiness.²⁸ Unfortunately, many adolescents still do not feel prepared for transition. In fact, in a qualitative study of adolescents with chronic diseases, including IBD, most expressed concerns that they felt unprepared for transition.²⁹ Readiness to transition will directly impact the adolescent's ability to become independent, as well as the adult provider's ability to address the adolescent's medical and psychosocial needs. In a study based on a survey sent to 1132 gastroenterologists treating adult patients (34% response rate), 55% reported that their young adult patients with IBD had incomplete knowledge of their medical history, while only 15% of the providers of adult care were concerned about the ability of patients to attend office visits by themselves.³⁰ In addition, although the gastroenterologists treating adults perceived adolescent medical and developmental issues as important, only 46% felt competent to address these issues, which highlights the potential benefits of transitional clinics staffed by specialists in both adult and pediatric IBD.

Concerns that adolescents may not have the knowledge and skills to manage their disease are not entirely unfounded. Several groups in Europe and North America have looked at adolescents and their parents and assessed their disease-specific knowledge; knowledge of their medical history (including procedures, imaging, and hospitalizations); and recollection of names, doses, and adverse effects of medications, as well as pharmacy and insurance information. In a cross-sectional study evaluating the knowledge of 78 patients with IBD and 64 parents, the 2 groups were equally likely to answer questions regarding disease characteristics and treatment correctly but were unable to identify disease location, prior investigation results, or health service resources accurately.³¹ Not surprisingly, parents were more likely than their children to name insurance providers and pharmacy locations correctly. Fishman and colleagues surveyed 94 adolescents age 16 to 18 years who had IBD and, in assessing the patients' knowledge of and confidence in their own health information, found that 43% could name their medication and dose with confidence but had very poor knowledge of important adverse effects.³² Three-quarters or more of patients mostly or completely relegated responsibility for scheduling appointments, requesting refills, or even contacting a provider between visits to their parents, reinforcing the importance of teaching these skills as part of the transition process.

Table 1. Knowledge and Skill Sets Needed Before Transitioning From Pediatric to Adult Care⁷⁸

Knowledge of the illness
Knowledge related to medications
Knowledge related to procedures and tests
Basic medical knowledge
General self-management skills
Ability to make health and lifestyle decisions

Several useful reviews have outlined age-based recommendations for the acquisition of certain skills and disease- and health-based knowledge.^{17,21} The specific timing for each patient will vary based on his or her cognitive and developmental maturity and emotional capability. The pediatric gastroenterologist and healthcare team should confirm that these skills have been acquired and are adequate before transitioning the patient. Table 1 provides an overview of the age-based knowledge and skill sets. Clearly, the acquisition of such knowledge and skills is fundamental and necessary to ensure a successful transition.

Lack of Self-efficacy and Knowledge of Disease

Self-efficacy is the belief in one's ability to attain specific goals and to be successful in certain situations.³³ Self-efficacy influences how people feel about themselves and what they think, and it ultimately impacts motivation and behavior. A high degree of self-efficacy has been shown to correlate not only with academic and job performance but also with stress reduction, self-management, and the use of productive coping skills in response to chronic illness and chronic pain.^{33,34} Self-efficacy is also associated with improved health status and decreased healthcare utilization and costs.^{35,36}

Several small studies have looked at self-efficacy as well as knowledge of medication and disease in adolescents with IBD and their parents.^{32,37,38} In a survey of 16- to 18-year-olds with IBD, 98% were able to indicate their diagnosis, 87% were able to describe their disease, and 87% to 92% had confidence in naming their medications. These same adolescents, however, had significantly less knowledge about adverse effects of medication, with only 36% to 56% reporting confidence in recognizing adverse effects.³² Unfortunately, large-scale studies measuring the impact of self-efficacy and knowledge of disease on outcomes are lacking. Preliminary work in establishing and validating measures of self-efficacy in IBD is ongoing,^{39,40} and it is hoped that future research will provide further insight into how these tools can improve outcomes and facilitate transition of care in IBD.

Poor Adherence to Therapy

Analysis of adherence to therapy in young people with chronic diseases has demonstrated that adherence and self-management decline during periods of transition,

increasing the potential for complications and adverse outcomes.^{41,42} Not surprisingly, adherence is a challenge in IBD, with nonadherence rates ranging from 7% to as high as 72% based on a systematic review.⁴¹ Nonadherence is a significant issue; it has been shown to negatively affect disease outcomes and is associated with increased medical costs.⁴³⁻⁴⁵ Two recent studies have shown that nonadherence is increased in adolescents with IBD.^{46,47} Adherence issues are particularly relevant in patients of transition age because these patients, by virtue of their age and developmental status, are likely to have several risk factors for nonadherence, including the following: young adult age, single status, high level of disease activity, heavy pill burden, high cost of medication, refill inconvenience, perception of lack of benefit, feeling of being uninformed about the effect of medication, low socioeconomic status, psychological comorbidity, and perception of social stigma.⁴⁸⁻⁵¹

Parents play an important role in adolescent adherence. They may want to maintain control over their child's medical care yet feel conflicted because they also want their child to take on more responsibility for his or her own medical care and are worried about the child's ability to self-manage effectively. Because nonadherence is complex and a major challenge, especially in patients of transition age with chronic disease,^{52,53} parents and healthcare providers should engage these young patients and educate them on the importance of adherence and how it can positively influence their disease outcome. In fact, several studies have shown that a simple intervention of encouragement and support from providers can improve adherence and, therefore, patient outcomes.⁵⁴⁻⁵⁷

Specialists in both pediatric and adult IBD should be aware of the challenges related to patient adherence and know how to address issues of nonadherence. Education, simplification of the medication regimen, and the use of reminders and organizational tools, such as pill boxes, were found to be best suited for addressing accidental nonadherence.⁵¹ On the other hand, for patients with intentional nonadherence, addressing motivational issues and emotional and behavioral problems, teaching problem-solving skills, and addressing problematic patterns of family functioning are more likely to be beneficial.^{46,58,59} There are also numerous pharmacy automatic refill programs and a number of mobile and smartphone applications that facilitate medication refills, tracking, and reminders. Although the impact of these applications has yet to be demonstrated, they offer tremendous potential benefits to patients and providers and may prove to be important tools to improve adherence.⁶⁰

Adolescent Anxiety and Depression

Adolescent patients present with a novel set of challenges during the shift to adult care. These patients are

undergoing cognitive, developmental, emotional, and physical changes.^{61,62} In addition, adolescents with IBD may feel “different” from their peers⁶³ or may experience more anxiety because of issues related to their disease.⁶⁴ A survey of Italian adolescents with IBD found that more than one-third were preoccupied with IBD-related concerns, including worry about the need for surgery (43%), fatigue (39%), fear of hospitalization (36%), and fear of developing complicated disease (29%).¹⁴ Beyond these significant disease-related concerns, adolescents may experience increased anxiety about normal life changes, such as moving away from home or starting a new job, school, or stage of life. It is essential that providers of pediatric and adult care be aware that anxiety and depression are common in adolescents with IBD. In a meta-analysis, Greenley and colleagues found that young persons with IBD had higher rates of depressive disorders than young persons with other chronic conditions.⁶⁵ Mackner and colleagues also demonstrated that, compared with healthy peers, adolescents who had IBD reported more anxiety and depressive symptoms and increased social problems.⁶⁶ This finding has been further validated in a study that compared adolescents who had IBD with adolescents who had juvenile idiopathic arthritis and found that the adolescents with IBD had significantly more depressive symptoms than those with juvenile idiopathic arthritis.⁶⁷ This increase was especially noteworthy in the adolescents with active IBD. Additional work has demonstrated the negative impact of depression and anxiety on adherence.²⁵ Patients with depressive symptoms and/or anxiety should be referred to a counselor, psychologist, or social worker for psychosocial support, which may help them overcome barriers to adherence and facilitate the transition process.

Differences Between Pediatric and Adult Inflammatory Bowel Disease Care

The pediatric team is often multidisciplinary and family-centered, with parents as the primary caregivers and decision makers, who may or may not fully appreciate an adolescent's increasing independence and increasingly adult behavior. On the other hand, adult care is provided by a single physician and is primarily patient-centered; in this situation, as a result of the acknowledgement of patient autonomy and independence, family concerns may be neglected, without a full recognition that the patient's ongoing developmental process and brain maturation continue into young adulthood.⁶⁸ Preparing patients and their families for the significant differences between pediatric and adult IBD care will help them to set expectations for their care; this is a very important step in the transition process and is recommended in current guidelines.¹⁸⁻²¹

In pediatric patients with chronic disease, the model of care is based on a triad that includes the provider, the par-

ent, and the patient.⁶⁹ This model differs significantly from the dyad model used in adult care, in which the 2 decision makers are the patient and the provider. It is important to consider that not only do the models of care differ but also that the goals of each party vary over time as the adolescent patient takes on increasing responsibility and independence, and the parents or guardians transition out of the role of primary decision makers. Understanding and acknowledging these differences in care may help ease the transition and should be discussed before this process starts.²²

Parental and Provider Reluctance to Transition

Parents may be anxious about transitioning to a new provider and reluctant to do so, especially if they have had a long-standing relationship with their pediatric care team. Such anxiety and stress are multifactorial and likely relate to comfort with the current provider, anxiety about “starting over” with a new provider, differences in the style and approach of providers to adult vs pediatric IBD care, increasing autonomy of their child and a corresponding decrease in the role that they play in their child's health-care, and fears about worsening of disease during transition. Dabadie and colleagues found that 32% of parents of persons of transition age with IBD felt apprehensive about the transition to an adult provider, even though they felt that they had received sufficient information about the process.⁷⁰ Additionally, the apprehension and anxiety of parents may be amplified by psychological factors and their child's disease activity. Herzer and colleagues found that the depressive symptoms of adolescent patients with IBD contribute significantly to parental stress.⁷¹ In a study of 130 adolescents and their caregivers, Gray and colleagues found that parental stress is significantly associated with the severity of Crohn's disease.⁷² Transition clinics and joint visits with the providers of adult and pediatric care may help mitigate parental stress. A study of adolescent transition through a joint visit vs transfer of care alone found that the joint visit was beneficial according to both the patients and parents surveyed, again emphasizing the importance of a coordinated transition.⁷⁰

Pediatric gastroenterologists also may be reluctant or apprehensive about transferring their patients to providers of adult care.⁷³ Pediatric gastroenterologists often have had a long-standing relationship with the patient and his or her family, and they may have concerns about the transition. These concerns may be about patient readiness, particularly in the setting of developmental delay; psychiatric or psychological comorbidities; or the lack of a well-developed transition program or a provider of adult IBD care with whom they can coordinate the transition.⁷³ Nonetheless, the transition of care in IBD should be initiated by the pediatric provider and is a critical step in the management of pediatric and adolescent IBD.

Recommendations for Successful Transition

Numerous resources are available to provide guidance and tools that help promote a successful transition from pediatric to adult IBD care (Table 2). Providers of adult and pediatric care, as well as adolescents and their parents, may find these resources both helpful and informative. Specifically, the guidelines^{17,18,20} recommend that the provider of pediatric care begin to introduce the concept of transition in early adolescence. Discussions should include an overview of the process, including the challenges and benefits of a well-planned transition. Starting this process early will help the patient and family realize that all providers are working together to deliver the best care for the patient. As the patient and family move closer to the actual transfer to adult care, the pediatric team should prepare a thorough medical summary and compile any necessary medical records for the provider of adult care and the patient.^{17,18,20}

Beyond addressing the barriers outlined in this paper, a successful transition will require adequate resources and/or a specialized transition program designed to facilitate and support the process. Unfortunately, transition programs or designated transition clinics are unique and offered at only a handful of centers across the United States and abroad. If the program does not offer an IBD transition clinic, the pediatric specialist should work to develop a relationship with a gastroenterologist providing adult care who is knowledgeable about treating young adults with childhood-onset IBD. For those trying to identify IBD specialists outside their local community, the Crohn's & Colitis Foundation of America offers an online physician finder.⁷⁴

Virtual transition clinics may also be useful in communities where access to IBD specialists is more challenging. The virtual clinic can facilitate coordinated transition care by using telemedicine, linked electronic medical records, or other technology-based tools. Virtual clinics have been piloted with success for patients with diabetes and for patients in rural areas,^{75,76} and they may be useful for patients requiring transition of care.

A number of transition clinic models exist that depend on both the healthcare system and the providers of pediatric and adult care who are involved.^{22,70,77} A few small studies have found that attendance by both parents and young patients at joint visits with providers of pediatric and adult gastrointestinal care, as part of the transition program, is beneficial.⁷⁰ Joint visits that included support from a dietician, a psychologist, and/or an IBD nurse specialist were well received by patients and parents and reportedly reduced anxiety and improved the transition process.

As this field continues to evolve, it is likely that additional validated tools and measures will be developed to improve outcomes and help patients, families, and providers navigate this critical step in life.

Table 2. Resources and Tools for Successful Transition

Educational Resources for Providers
<ul style="list-style-type: none"> • A Case-Based Monograph Focusing on IBD. Improving Health Supervision in Pediatric and Young Adult Patients With IBD⁷⁹ • Transition in IBD. http://www.ibdtransition.org.uk/
Transition Guidelines for Providers
<ul style="list-style-type: none"> • Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care¹⁷ • Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition¹⁸ • Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist²⁰
Transition Readiness Assessment and Tools
<ul style="list-style-type: none"> • Transitioning a Patient With IBD From Pediatric to Adult Care⁸⁰ (includes a healthcare provider checklist for transitioning a patient with IBD from pediatric to adult care) • Preparing to Transition From a Pediatric to Adult Care Practitioner: Transitioning to Adulthood With IBD⁸¹ (includes a patient checklist for preparing to transition from a pediatric to an adult care practitioner) • TRxANSIT Scale and STARx Transition Readiness Questionnaire. http://pediatrics.med.unc.edu/transition/files/
Resources and Tools for Adolescents and Parents
<ul style="list-style-type: none"> • IBD U (IBD University). http://www.ibdu.org/ • CCFA (Crohn's & Colitis Foundation of America) Campus Connection. http://www.cdfa.org/campus-connection/ • CCFA I'llIBDetermined. http://www.ibdetermined.org/ • CCFA GI Buddy (symptom tracker). http://www.ibdetermined.org/Tracker.aspx/ • myIBD (symptom tracker). http://www.sickkids.ca/IBDacademy/IBD-Mobile-App/ • Good 2 Go Transition Program—MyHealth Passport. https://www.sickkids.ca/myhealthpassport/ • American Academy of Pediatrics. How to Help Your Teen Transition to Adult Health Care. http://www.healthychildren.org/English/family-life/health-management/Pages/How-to-Help-Your-Teen-Transition-to-Adult-Health-Care-Video.aspx/
Transition Advocacy and Support for Patients, Parents, and Providers
<ul style="list-style-type: none"> • Got Transition. http://gottransition.org/ • Society for Adolescent Health and Medicine. Transition to Adult Care. http://www.adolescenthealth.org/Topics-in-Adolescent-Health/Transition-to-Adult-Care.aspx/

Conclusion

Existing studies on the transition of care in IBD show a large gap in the knowledge base and skills needed to attain independence in a majority of transitioning adolescent patients. In addition, data on the most effective transition tools, measures, and programs, as well as on how to improve adherence and outcomes in this vulnerable population, are limited. The transition process needs to be improved through support and guidance, with clear guidelines and goals established for patients, their families, and their providers. Progress should be monitored and encouraged for each patient as he or she moves toward independence and self-management. This strategy will ultimately provide adolescents who have IBD with the skills needed to cope with a chronic disease as adults and will improve their long-term care beyond the transition period. Future research efforts should focus on providing objective data about adolescent and transition outcomes, including health services utilization, hospitalizations, and surgery. We hope that further characterization of this vulnerable population will enable providers to offer more targeted interventions to promote self-management, as well as dedicated transition clinics and programs that will improve patient outcomes.

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