

Challenges in Transitional Care in Inflammatory Bowel Disease: A Review of the Current Literature in Transition Readiness and Outcomes

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Transitional care for patients with IBD focuses on efforts to successfully transfer care from pediatric to adult providers while encouraging the assumption of health care responsibility. As 25% of patients will be diagnosed with IBD before the age of 18 years, many will undergo this process. Efforts to enhance this process have included transition clinics and other means to improve patient comfort with transition and develop the skill of health care self-management. Currently, most pediatric practitioners provide transition care with informal education and emphasize independence without formal programs. A variety of tools to assess transition readiness have been developed. Given the varied disease process, often varied and subjective outcomes, and lack of studies such as randomized controlled trials, further data are necessary to determine the best avenue to transition and assess outcomes. Critically relevant to providing adequate care to transitioning patients includes understanding the development of self-management skills and the developmental processes relevant to young adults with IBD. Transition represents an area for quality improvement, and although progress has been made in recognition and promotion of transition practices, future directions in research will allow improved understanding of the evidence-based practices and needs of these individuals to further enhance their care.

Key Words: inflammatory bowel disease, Crohn's disease, ulcerative colitis, adolescent, transitional care, pediatrics, chronic disease

INTRODUCTION

Transition is still best described as the “purposeful planned movement from child centered care to adult oriented health care systems”.¹ This involves 2 lasting components from which (1) the health care responsibility “transitions” from guardian to patient and (2) the patient “transfers” from pediatric to adult provider.² As 25% of the inflammatory bowel disease (IBD) population is diagnosed in childhood and managed by pediatric gastroenterologists, a substantial group of patients with eventually need to transfer to adult providers. In 2002, the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) published a position statement on transition for patients with IBD and more recently by the European Crohn's and Colitis Organization (ECCO).^{3,4} Similarly, the American Academy of Pediatrics (AAP) published a clinical report regarding transition of the adolescent to adult medical home that includes a

transition-planning algorithm and resources from the National Health Care Transition Center (gottransition.org).⁵ These reports all highlight the process of transitioning, whereas this review will focus on the current knowledge and challenges of transition. **Table 1** summarizes the current literature regarding transition practices, readiness, and interventions.

Although the physical transfer from a pediatric clinic to adult providers is typically an identifiable event, the transition to health care independence is usually a more gradual process. The AAP lists the 6 core elements of transition as (1) transition policy, (2) transition tracking and monitoring, (3) transition readiness, (4) transition planning, (5) transfer of care, and (6) transfer completion.⁵ Our best understanding of transition practices in the United States for IBD patients is based on a survey of 141 providers in the NASPGHAN database.⁶ These surveyed providers reported that 21.5% were transferring their patients to adult medicine at 18 years, 14.5% at 21 years, and 11.8% between 22 to 25 years, whereas one-third did not respond to having a set age. Interestingly, many of the recent publications surrounding outcomes after transfer of care are from centers in Canada, Europe, and Australia where managed care systems often dictate the necessity of transition at 18 years of age, where in the United States this often does not occur until a patient is well into their 20s. In regards to transition methods in the NASPGHAN survey, 89% reported introducing the concept of transfer in advance, 78% encouraged more independence, and 68% provided support for both transition and transfer. Less than 50% provided more intensive support such as discussing legal issues, insurance and financial, provision of portable medical summary, or documented transition plan. Almost all

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TABLE 1: Studies Evaluating Transition Practices, Readiness, and Interventions

Article	Aims	Population	Design	Key Findings
Survey of current practice and barriers Gray et al. (2016)	Identify current transition practices in IBD by pediatric providers.	n = 141 pediatric gastroenterology providers in the NAPSGHAN and CCFA databases. Includes physicians (82.3%), nurse practitioners, social workers, psychologists, medical assistants, and dietitians.	47-item survey developed by authors. Survey e-mailed to 1656 providers, 8.5% response rate.	Age at transfer: 21.5% at 18 years, 14.5% at 21 years, 11.8% between 22 to 25 years, 1/3 without having set age to transfer. 75.9% report use objective readiness measure. Patient and parent reluctance to transfer identified as most frequent barrier to transfer care. 65% report providers are reluctant to transfer as barrier.
Bensen et al. (2016)	Identify current transition practices for any chronic pediatric GI condition. Analyze if experience affected transition perspectives.	n = 175 pediatric gastroenterology providers in the NASPGHAN database. Includes physicians (97%) and nurse practitioners.	24 questions in 5 categories adapted from 2 prior surveys. Survey e-mailed to 1423 providers, 12% response rate. 50% in practice >10 years.	23% reported using an assessment or tool to assess transition readiness. Only 33% report ability to care for patients >21 years. No set trigger to transfer to adult care. Patient and parent attachment to pediatric provider identified as most frequent barrier to transfer care. 56% report provider's attachment to patient as barrier to transfer.
Gray et al. (2015)	Identify common barriers to transition identified by patients, parents, and providers.	15 patients with IBD ≥16 years, 16 parents of children with IBD, 13 medical professionals who care for pediatric patients with IBD, including physicians (46%), nurses (23%), social workers (15%), medical assistants, and administrators. 40% of patients had already transferred to adult care.	6 focus groups in total, with 2 focus groups for each participant (patient, parent, and provider) lead by a clinical psychologist.	4 major themes identified as barriers to transfer care: 1. Concern for receiving poorer quality of care in adult setting. 2. High parental involvement prevents development of self-management. 3. Financial and insurance concerns. 4. Loss of valued relationship with pediatric providers. Suggestions by participants: Separate patients from parents during visits. Hold adolescents accountable. Teach parents to let go and support the patient. Increase transfer education to patients and about adult providers. Create flexible transfer deadline during time of stability.

TABLE 1: Continued

Article	Aims	Population	Design	Key Findings
Whitfield et al. (2015)	This study aimed to describe self-assessment of ability to perform tasks on transition-ready checklists to explore the relationship to patient age and disease duration.	n = 67 patients with IBD between the ages of 10 and 21 years in a pediatric gastroenterology clinic.	Survey created with Qualtrix, administered via iPad with 23 questions in regards to self-management and demographics.	Self-reported ability to conduct self-management tasks improved with age but not duration of disease. Age alone was not adequate to provide for skills of self-management.
Wright et al. (2014)	Identify perceived inadequacies in provision of transitional care.	n = 178 adult and pediatric gastroenterology providers identified via communication with members of 3 national organizations.	A web-based survey was sent with 25 questions, 41% response rate.	Respondents noted a lack in preparation for transition, with poor communication and a lack of readiness noted as barriers to successful transfer.
Assessment of transition readiness Gray et al. (2015)	Evaluate pretransition readiness in IBD.	n = 195 patients (age 16–25 years) under pediatric IBD provider care.	Recruited by transition coordinator to complete TRAQ survey.	Only 5.6% met the institutional mastery goal of 90% (18/20) correct on the TRAQ survey. Higher TRAQ scores associated with older age and female gender. No relationship between a higher TRAQ score and disease duration. Patients had lower scores overall concerning applying for and understanding health insurance, obtaining financial health, and calling a doctor's office for appointment.
Klostermann et al. (2017)	Assess transition experience of IBD patients.	n = 20 patients (age 17–20 years) after transition to adult IBD provider.	Patients completed TRAQ and IBD-Knowledge Inventory Device (IBD-KID).	Only 5% had mastery 90% (18/20) correct on the TRAQ survey. Patients want “individualized and multifaceted” transition interventions with many choices in which to obtain knowledge. Patients also support the shift in responsibility.
Rosen et al. (2016)	Compare transition readiness of IBD patients with 6-month disease outcomes.	n = 46 patients under adult care and n = 49 patients under pediatric care (18–25 years).	Patients completed 4 questionnaires including TRAQ.	Age was associated with higher TRAQ score. When controlling for age, there was no difference in TRAQ scores between pediatric and adult providers. No association between TRAQ score and ED visit or hospitalization at 6-month follow-up.

TABLE 1: Continued

Article	Aims	Population	Design	Key Findings
Izaguirre et al. (2017)	Validate the IBD-SES-A as a tool that is important due to patient-centeredness and inclusion of IBD-specific tasks.	n = 103 patients from 2 clinics and online were recruited and consented to the study; 95 completed the study.	Experimental measure was IBD-SES-A, with 4 other scales assessing self-esteem, depression, anxiety, and quality of life. Subset of patients repeated IBDSES 2 weeks later to assess test-retest reliability.	IBD-SESE-A demonstrated validity with modest correlations with other outcomes measures, and higher scores correlated with decreased depression/anxiety and lower IBD symptom severity.
Carlsen et al. (2017)	Determine if self-efficacy and resilience are predictors of transition readiness in IBD independent of age.	n = 87 patients under pediatric care (age 16–23 years).	Patients completed TRAQ, IBD-SES-A, and CD-RISC.	IBD-SES-A and CD-RISC predicted TRAQ scores independent of age. Patients age ≥18 years had significantly higher TRAQ scores.
Impact of transition intervention				
Yerushalmy-Feler et al. (2017)	Evaluate self-efficacy of patients with IBD before and after a transition clinic.	n = 36 patients (age 17–27 years) who participated in a pilot transition clinic, average of 3–4 visits per patient.	Completed “IBD-yourself” questionnaire before and after transition.	Knowledge of IBD, self-efficacy, and knowledge of the transition process all improved with the transition clinic and correlated with the number of clinics attended.
Fu et al. (2017)	Evaluate adolescent perspective of medications for IBD.	n = 112 patients, 59 of whom participated in a transition clinic vs 53 controls.	Completed Beliefs about Medicine Questionnaire (BMQ).	Patients in the transition clinic had better recognition of medication necessity. Self-reported adherence was poor in both groups at 67% (transition clinic) and 57% (control, $P = 0.54$).
Schmidt et al. (2016)	Evaluate effect of transition workshop on adolescent self-efficacy and quality of life.	n = 274 adolescents with chronic disease (type 1 diabetes, cystic fibrosis, or IBD); 172 participated in workshop vs 153 controls.	Participated in 2-day workshop across 12 sites in Germany. Assessed self-efficacy, quality of life, and health-related transition competence at baseline and 6 months.	Patients who participated in the workshop had improved scores in transition competence and self-efficacy vs controls. No change in quality of life after the workshop. No disease-specific outcomes analyzed.
Cole et al. (2015)	Assess disease-specific outcomes in a cohort of IBD patients diagnosed as children, following their transfer to adult medicine, with variable of with or without transitional care program.	n = 72 patients with IBD, 44 patients in the transition program, and 28 with no formal transition program. The time period of the study was 2006–2014, with the transition program instituted in 2009.	Retrospective review of patient records of patients who received care for pediatric IBD within this clinic from 2006 to 2014.	89% of patients from transition clinic vs 46% not with standard clinic reported adherence to medicine and lower rates of missed clinic (29 vs 78%), surgery (25 vs 46%), and admission (29 vs 61%) but treatment differences including higher rate of biologic therapy (18 vs 7%) and thiopurine (56 vs 46%); shorter duration of disease may impact these outcomes.

TABLE 1: Continued

Article	Aims	Population	Design	Key Findings
Dabadie et al. (2008)	Explore the views of patients with IBD and caregivers after they have transitioned to adult providers.	n = 34 patients with IBD and 34 caregivers. 20 patients had participated a 1-hour joint visit with pediatric and adult providers.	Questionnaire mailed to patients and caregivers evaluating their perception of transition.	85% of patients felt they were ready to transfer to adult care. All patients agreed that the joint visit was beneficial. 93% reported that the joint visit built confidence in the new provider. 85% were following with the same adult practitioner that they originally transferred to.

(99.3%) of these providers reported some barrier to a transition program, with patient factors being the most prominent, including patient (94.3%) or parent (95%) reluctance to transfer followed by a lack of resources (82.9%), poor coordination between adult providers (70%), and a lack of qualified adult providers to accept patients (46%). Even with patient and parental barriers, 65% of the pediatric providers themselves were reluctant to transfer as well.⁶ A similar survey of pediatric gastroenterologists regarding any patient with a chronic condition requiring transfer reported a high rate of parent (81%), patient (74%), and provider (56%) attachment as barriers to a successful transition.⁷ The high rate of perceived barriers is staggering in the face of an inevitable and—most would agree—necessary event.

Self-management is defined as the “interaction of health behaviors and related processes that patients and families engage in to care for a chronic disease” and is considered to be important to transition of health care responsibility and successful transfer.⁸ A critical aspect of self-management includes adherence, which is defined as behaviors of following the advice of health care professionals in regards to medications, diet, and lifestyle.⁹ Multiple factors have been identified as increasing risk of failed transition. McManus et al. in a survey of youth with chronic medical conditions found that male patients and those with developmental, physical, or psychological impairment were less likely to successfully transition, whereas those with a family income greater than 400% of poverty, white race, and private insurance were more likely to be successful.¹⁰ Lotstein et al. found racial and ethnic disparities in successful transition.¹¹ Although social and financial constraints often dictate the time of transfer, most providers believe that chronological age should not be the main indicator of appropriateness of transition, but age is known to have an impact on possession of skills needed for transition. Stollon et al. examined the age at which patients acquire their transition skills.¹² They found that by 12–14 years, half of the required health care skills had been acquired, but only after 18 years were skills of self-management usually mastered. In general, it may be that those at risk of failed transition are also those who will need additional assistance with the skills needed for self-management.

CATEGORIZATION OF PATIENTS WHO TRANSITION

To our knowledge, no one has directly characterized the types of transition and patients who transition from inflammatory bowel disease. Some studies have suggested transition clinics to be recommended to patients with more complex disease who might be considered higher risk.¹³ Based on our experience, we could describe transitions among wide categories, acknowledging that this includes gross generalization without data. These might include:

Types of transfer:

- typical: young adult age ≥ 18 years, independent, disease in remission, ready to move on to adult provider with subcategories of:
 - mild to moderate disease vs severe disease or requiring surgery;
 - significant parental involvement vs independent of family;
- nonengaged: patient not strongly involved in clinic, few or no recent clinic visits, eventually—when either calls for refill or with flare—is advised to schedule appointment with adult provider;
- crisis transfer: uncontrolled disease and needing surgery or newer medications (as available in a clinical trial), pregnancy, conflict with referring provider, substance abuse;
- special needs: intellectual disability or other comorbidities that provide a challenge to adult medicine practitioners who have less experience in this care.

We suggest that the epidemiology of transitioning patients be rigorously studied and reported to create a better framework to assess risk of transition failure and need for increased transitional assistance. This would require a full assessment of transition readiness to determine the individual needs of the patient accompanied by categorization into the proposed types of transfer. This would help not only distribute the scarce resources a transition clinic might require but also avoid the cost of time and potentially money for participants who did not need them.

TRANSITION CLINICS AND PROGRAMS

A variety of efforts at enhancing the transition process have been described. The most common transition process

occurs when the pediatric provider recommends that the patients transfer their care to an adult provider and that referral is made without any overlap of care.⁶ In most instances, the patient is seen by the accepting adult gastroenterologist at a separate visit from the originating pediatric provider and, if needed, has a final additional visit with the originating provider to review any concerns.¹⁴ The most commonly recommended transition clinic is a joint visit with the pediatric and adult providers meeting in combination with the patient and family. Some surveys find that most patients prefer this model.^{13, 15} However, only 20% of 141 pediatric IBD providers reported using a joint visit for transfer of care.⁶ A transition-based clinic often includes nurse navigators or other coordinators and mental health experts. Other than a formalized clinic, many other transition programs have been reported and include workshops, paper-, web-, and message-based education programs, transition care coordinators, and even music therapy.¹⁶

The data surrounding the efficacy of transitional clinics and other interventions for young adult patients with IBD remain limited but have increased in the past few years. A systematic review by Clarke et al. found that only 6 of 238 studies screened through March 2014 pertained to IBD transition research.¹⁷ Of these, only 1 study, by Dabadie et al., evaluated the impact a transition clinic may have by assessing attitudes of transitioning patients who participated in a transition clinic compared with those who did not.¹³ Since that systematic review, several interesting studies have been published. A study by Cole et al. is unique in reporting clinically relevant outcomes in patients before and after transition clinics.¹⁸ Seventy-two patients diagnosed with IBD before 16 years of age were followed from 2006 to 2014. Starting in 2009, a structured transitional clinic was created, providing a series of visits incorporating disease-specific education and assessments of transition readiness, followed by a transition to a traditional adult clinic. They discovered that patients in the transition clinic were more adherent to medication (89% vs 46%, $P = 0.002$) and recorded lower rates of missed clinic (29% vs 78%, $P = 0.001$), surgery (25% vs 46%, $P = 0.01$), and hospital admission (29% vs 61%, $P = 0.002$). Although these data are striking, the groups had different clinical characteristics, and their medical care was not the same. The patients in the transition clinic enjoyed a shorter duration of disease and a higher rate of anti-TNF (18% vs 7%, $P = 0.04$) and thiopurine (56% vs 46%) use, which may have impacted the clinical outcomes. In another study of transitional clinics, Fu et al. reported a case-control study of young adults with IBD referred to a joint pediatric-adult IBD transition clinic in regards to medication attitudes.¹⁴ They found that there was no statistical difference in self-reported adherence but that attitudes toward the medicine itself were more favorable with less skepticism in the transitional clinic patients. Yerushalmy-Feler et al. reported on the impact of a multidisciplinary clinic with both pediatric and adult providers who offered 4 structured visits over 6 months, including an

educational visit and a treatment plan visit.¹⁹ They found an increase in self-efficacy via the “IBD-yourself” questionnaire after the clinic. In regards to clinical outcomes, as there is no comparison with other populations, one cannot draw conclusions, but they also noted an increase from 21% to 58% of biologic use following the clinic intervention. In brief, several studies have recently been published to detect the impact of transition clinics on clinically significant outcomes.

In regards to other studied interventions that were not based on a clinic construct, there are 2 of interest that provided programs to young adults with chronic disease including IBD that are relevant. Huang et al. conducted a study to assess the efficacy of an intensive technology-based intervention of web- and text-based programs to provide training in disease self-management for 81 adolescents with a chronic disease including IBD.²⁰ These patients did show mild improvement in their disease self-management skills and health care independence after the intervention, as assessed with survey and an increase in the number of patient-initiated provider contacts. Schmidt et al. randomized adolescents with chronic diseases including IBD to a 2-day workshop on transition or care as usual.²¹ They reported that participants noted improved transition competence, self-efficacy, and satisfaction but no difference in quality of life (QoL) and patient activation compared with controls. With these limited reports, an educational program does appear to benefit overall patient disease knowledge, though further studies are needed in particular to examine outcomes. Since the advent of the ubiquitous smart phone, use of text messaging and social media as a clinical tool, including as a means to improve adherence as a crucial aspect of self-efficacy in chronic disease self-management, has certainly drawn attention. In fact, a Cochrane study in 2012 was able to detect some impact of message-based programs in promoting self-management.²² In application to IBD patients, a study of children reflected a positive impact of a text message program on adherence.²³

The team at the University of Pittsburgh Medical Center led by Miguel Regueiro has constructed the IBD “medical home” care model for adult patients.²⁴ This essentially replaces the primary care physician with a multidisciplinary team focused on all aspects of care for a patient with IBD, including behavioral health, pain management, and dieticians, in addition to IBD physicians and surgeons. This model is born out of a collaboration with an insurance provider rather than the health care system in an effort to improve care through lower utilization of high-cost resources, including the emergency department leading to hospitalization. Although Regueiro has specific aims of the medical home model, outcomes have not yet been published.²⁵ If this model does prove to be beneficial, it could extend to a joint pediatric-adult IBD venture with a significant improvement in continuity of care.

Given the lack of disease-specific data, we look to transition data from other chronic disease processes. Although there is now enough data to allow the existence of a number

of systematic reviews, unfortunately the final conclusions of these reviews seem to reflect the heterogeneity of interventions, widely variant outcomes measured, and very few randomized controlled trials.^{26–28} In the analysis by Prior et al., 2282 studies were identified, 33 met criteria, 27 reported population health measures, 15 reported cost, and 8 measured experience of care, but only 3 studies reported on all 3 measures (health, cost, and experience). This group has suggested that outcomes of interventions to improve transition must assess all 3 areas.

The AAP advises that pediatric practices develop a transition policy as part of a transition program, but the impact of such a policy also is not known (<https://www.aap.org/en-us/about-the-aap/Committees.../Policy-Resources.aspx>). From the survey by Gray and Maddux, 68.1% of responding providers report preparing a patient and participating in the actual transfer of a patient to adult care, yet only 14.1% stated that they had some type of written framework for a transition and 82.9% lacked the resources to create or maintain a transition program.⁶ Of interest, not all providers believe that such programs are necessary. In a survey of UK gastroenterologists, although 79% of pediatric providers believed a structured program was important, only 49% of adult providers agreed with that assumption.²⁹ In 2017, 15 years after the publication of the NASPGHAN position statement, we found that although we have made progress, we have far to go in terms of rigorously validating our transition recommendations, although the study of Gray et al. does suggest that most of the participants surveyed are educated to the need of transition and provide certain care in that effort. The ongoing dearth of data to direct these practices or justify them remains to be addressed, although progress has been made.

TOOLS TO ASSESS TRANSITION READINESS

The AAP recommends that practitioners assess transition readiness. Most tools to assess transition readiness focus on knowledge of disease, though self-efficacy has also been identified as being important indicator of mature health care skills.³⁰ There are surveys that apply to all chronic disease processes and those that are specific to IBD. Gray and Maddux found that 75.9% of pediatric IBD providers surveyed reported making use of a transition readiness assessment tool, most commonly the Transition Readiness Assessment Questionnaire (TRAQ) or the NASPGHAN transition checklist.⁶ Interestingly, only 23% of pediatric gastrointestinal (GI) providers surveyed by Bensen et al. reported use of any transition readiness tool, a stark contrast to the previously reported number, which raises the question of over-reporting the use of such tools.⁷

The TRAQ was developed as a practical tool for providers to assess a patient's ability to manage their own disease with questions pertaining to navigating the health care system, knowing one's disease and medications, ability to talk with health care providers, and activities of daily living based on responses to 20 questions that are not disease specific.³¹

The main weakness that has been noted is that the data is based solely on self-report without clinical correlation. Carlsen et al. also pointed out that it was not developmentally appropriate for patients with IBD until the age of 20 years.³⁰ Zhang et al. conducted a systematic review identifying 10 transitional tools, which were both disease specific and neutral.³² They found that the TRAQ was the best transition tool, having been appropriately validated for content and construct and demonstrating internal consistency. Several studies have reported on the use of TRAQ scores in IBD patients. Rosen et al. found that age is the best predictor of TRAQ scores in patients with IBD age 18–25 years under either pediatric or adult care, though there were no differences in hospitalization or emergency department (ED) visits in the following 6 months between the groups. In addition, patients who scored lower on the medication management portion of the TRAQ were more likely to be nonadherent.³³ The TRAQ survey can be downloaded for free after registration at <https://www.etsu.edu/com/pediatrics/traq/download.php>.

The most studied disease-specific tool is the IBD self-efficacy scale–adolescent (IBD-SES-A), developed by Izaguirre and Keefer.³⁴ This is a 13-question survey developed with patient input and use of a previously validated adult self-management tool, along with other input from self-efficacy experts. Carlsen et al. identified it as a reliable predictor of a higher TRAQ score in adolescents, and a validation study has been published.^{30, 35} They also found resilience to be a predictor of transition readiness using the refined Connor-Davidson Resilience Scale (CD-RISC), which contains 10 questions on a 5-point Likert scale.³⁶ Both the IBD-SES-A and CD-RISC predicted a higher TRAQ score independent of age.

The NASPGHAN Healthcare Provider Transitioning Checklist focuses on age-dependent disease knowledge starting in early adolescence and moving toward independence in early adulthood (https://www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf). Although this is widely used and very sensible, it has not been validated. The “IBD-yourself” is a questionnaire from a group in the Netherlands aimed at assessing self-efficacy.³⁷ Further study to validate these assessments is warranted.

YOUNG ADULT AND ADOLESCENT MEDICINE FOR THE TRANSITIONING PRACTITIONER

Adherence and Other Challenges to Self-Management

The adolescent and young adult present a notable challenge of care to both pediatric and adult providers. The success of transition is often evaluated by outcomes post-transfer, whereas these outcomes may be independent of the transfer given the social and psychological growth (or barrier) of each patient. Independence and adherence are areas for growth.

A systematic review of 25 studies published since 2005 found a prevalence of oral medication nonadherence rate of up to 93% in adolescents, a striking rate.³⁸ This review by Spekhorst et al. focused on studies evaluating adherence to oral medications using self-reported adherence, pharmacy refill information, and, when possible, medication assay levels. Even so, it is difficult to validate adherence without directly observed therapy. The authors rightly point out that nonadherence may be mistakenly perceived as treatment failure, prompting unwarranted escalation to biologic therapy. Certainly, medications given at an infusions center will greatly escalate adherence rates for a high-risk population. There is currently no evidence evaluating the escalation in therapy solely due to nonadherence. Adherence may be a function of both age and maturity. From Australia, Jeganathan et al. reported that medication adherence in transitioned patients (<25 years) is lower than pediatric patients (12–18 years) yet higher than young adults diagnosed in adulthood (<25 years, 87% vs 92% vs 76%).³⁹ In contrast, Bollegala et al. from Ontario, Canada, reported higher rates of noncompliance in adults after transition to adult care (43% vs 29%, $P = 0.01$).⁴⁰ This emphasizes that all patients in young adulthood may be at risk of nonadherence, having transitioned or not.

Common Deficiencies in Transition Readiness

It is up to the medical team, including providers and parents, to ready a patient for transition to adulthood. Whitfield et al. surveyed patients age 10 to 21 years with IBD, and although patients age ≥ 18 years had higher scores pertaining to ability to perform self-management tasks than their younger counterparts, this was not influenced by duration of disease, and communication with the medical team did not improve with age.⁴¹ Gray et al. had similar findings, that transition readiness was associated with age but not disease duration.⁴² This study even set a benchmark score of 90% (mastery of 18/20 TRAQ questions) pertaining to transition readiness skills, which only 5.6% of older adolescents/young adults (age 16–25 years) passed.⁴² Patients rated better on skills of communication and worse on skills involving health care utilization. Klostermann et al. reported similar findings regarding deficiencies in transition readiness among young adults who had already transitioned, in which 95% did not meet 90% mastery of transition readiness skills.⁴³ A tool such as TRAQ may be of better use administered well before a transition is anticipated in order to begin the discussion of not only what is expected of the patient but what the patient needs are as well.

In most cases, the parent or guardian will be involved with the transition to some degree. Teenagers are likely to use a parent for help if the parent is continually involved. A focus group interview of patients, parents, and providers reported a consensus concern that parents have a tendency to dominate the visit with the adult provider, hence the need to separate the patients and parents for at least part of a visit. In addition, both patients and parents agree that the patient needs to

be held accountable.⁴⁴ As an example of health care adherence, Heida et al. reported that 59% of surveyed teenagers ($n = 72$) with IBD required parental initiation to obtain stool samples, a skill the authors believe to be an “essential skill” for successful transition.⁴⁵ Accountability is the key theme in moving from assessment to success in transition. This does not refer to just the patient but additionally to the provider and parent for preparing the patient, in addition to the patient obtaining and retaining the tools for independence.

Adolescent Developmental Health Care: A Potential Knowledge Gap for Adult Providers in Adolescent Health Care

Patients diagnosed with IBD as children present multiple challenges as they transition to adulthood that must be addressed by the adult provider. Studies suggest that both adult and pediatric practitioners find the adult practitioners lacking in sufficient knowledge of adolescent development and health care.⁴⁶ Although these areas are vast, we will briefly review these areas and some key resources that may be of use to adult practitioners invested to improve their knowledge in these areas. One of the reasons that adult practitioners need to understand adolescent psychological development is that it may be delayed in chronically ill individuals, so it may be after transition that the patients are able to achieve the milestones of fully fledged adulthood in regards to vocation, relationships, and education. This is critical because the period of time during adolescence is second in dramatic neurodevelopment only to that of infancy.⁴⁷

Adolescents with IBD are at higher risk of psychosocial impairment. Greenley et al., in a meta-analysis of 19 studies, found that young adults with IBD had a higher rate of depressive disorders and internalizing than individuals with other chronic diseases and lower QoL than healthy peers.⁴⁸ Of interest, they had no difference in self-esteem or social functioning. Reigada et al. reported that patients with IBD and anxiety had an increased number of disease exacerbations and increased health care utilization.⁴⁹ They may also have more difficulty with educational and vocational advancement. A survey by Almadani et al. found a higher rate of difficulty in adjustment to college in IBD patients, in particular those with Crohn's disease (CD), and with a not unexpected inverse relationship to disease activity.⁵⁰ As these patients become adults, the assumption is that they may have trouble with employment, and in fact multiple studies do suggest lower rates of employment in IBD patients, as reviewed by Marri et al. In contrast, an encouraging study more recently of Canadian patients specifically evaluating those diagnosed in childhood or adolescence found that these patients had higher rates of education and income and similar rates of employment to the general population.^{51, 52} This information would suggest that adult practitioners assuming the care of young adult IBD patients might consider seeking a relationship with a mental health care practitioner to whom

they could refer these patients and who would also recognize, if a patient was struggling in certain aspects, that part of their difficulty might be due to incomplete progression to full adulthood and provide them the support that they need.

Substance abuse, opiate dependence, and reproductive health need attention as well, all issues that within pediatrics require dedicated training. Studies suggest that adolescents with chronic diseases have similar rates of risky behavior to those without chronic disease.⁵³ Buckley et al. found that 5.6% of children with IBD compared with 2.3% of the general population used chronic narcotics that increased with older age and psychological dysfunction.⁵⁴ These rates are lower than for adults with IBD. In terms of at-risk behavior,

adolescents with IBD have been found to drink alcohol (39%) and smoke marijuana (33% have tried, 13% chronically use), and the behaviors were associated with increased risk of non-adherence.⁵⁵ Finally, in regards to tobacco use, available data suggest that individuals with IBD aged 18–24 years smoke at lower rates than the general population for both CD and UC, yet 19%–24% at this age with CD were still smoking.⁵⁶ Reproductive health care for all IBD patients, both male and female, is important in particular in this age group as pregnancy rates in the United States remain highest for women in their 20s.⁵⁷ Both adult and pediatric gastroenterology providers caring for young adults require adequate training in these areas to best serve their patients.

TABLE 2: Age-Specific Goals in Transitional Care With Barriers and Possible Solutions

Age	Goals	Examples of Patient Skills	Examples of Provider Tasks	Barriers	Solutions
Early adolescence, 12–14 years	Develop basic knowledge and skills for assumption of responsibility for health care.	<ul style="list-style-type: none"> Name medicines and disease. Participate in health care discussions. 	<ul style="list-style-type: none"> Introduce concept of transition. Provide resources for health care independence skills. Conduct part of visit with patient alone. 	<ul style="list-style-type: none"> Lack of resources to provide education in disease and self-management. Lack of interest or time on part of patient, family, and provider. 	<ul style="list-style-type: none"> Web-based modules to provide information on disease and independence skills. Dedicated time during visit to approach these concepts, further education for care providers, identification of provider such as nurse or social worker to provide support for process.
Midadolescence, 14–17 years	Solidify knowledge and skills to assume of health care responsibility.	<ul style="list-style-type: none"> Ability to perform tasks (eg, refill medicines, contact physician). Know causes and signs of flare. Understand impact of missing medicines and tobacco and alcohol use on disease. 	<ul style="list-style-type: none"> Orient visit with goal of patient being the primary communicator. Continue to assess and educate for transition readiness. Address age-appropriate health care surveillance and education, including reproductive health care and substance use. 	<ul style="list-style-type: none"> Patient and family still prefer that parents or caregivers serve as primary to interact with physician. Transition readiness assessments tools are unclear as to which is best and are unwieldy/time-consuming. Lack of adequate resources to allow development of necessary skills of health care independence. 	<ul style="list-style-type: none"> Ongoing education as to the importance of patient development of these skills and reassurance to family and patients that at no point, unless the patient so desires, will the family cease to be welcome in the process of health care provision. Ongoing development of these resources including web-based media and transition clinics to provide experience focused on health care independence, such as: Crohn's & Colitis Foundation: http://www.justlikemeibd.org/living-with-crohns-and-colitis/preparing-for-adult-care.html MyIBD: https://myibd.com/about-my-ibd.php
Late adolescence/young adulthood, >17 years	Transfer primary responsibility of care to patient, and transfer care to adult provider.	<ul style="list-style-type: none"> Assume primary responsibility for managing care (managing medications, scheduling, making appointments, communicating with caregivers). 	<ul style="list-style-type: none"> Provide resources to enhance transfer to adult provider, including communication and referral. Ongoing training and assessment for transition readiness and health care self-management. 	<ul style="list-style-type: none"> Financial and social constraints prevent patient from assuming primary responsibility. Lack of adult provider to assume care that meets patient and family needs. Pediatric provider reluctant to transfer. 	<ul style="list-style-type: none"> Planning and social work involvement to provide better education and support to patient. Better education of adult providers as to the process of transition and active collaboration and communication with adult and pediatric providers.

CONCLUSIONS

The successful transition of pediatric IBD patients requires both a successful transfer to an adult-centered care provider and, for most, the successful development of health care independence and disease self-management. It is challenging to define a successful transfer based on outcomes alone in a chronic disease such as IBD with a difficult natural history. A successful transfer would be better defined if it included patient-driven outcomes such as trust in a new system and maintaining autonomy. Researchers have previously found that accurate evaluation of outcomes should include health, cost, and patient experience.

Transition has been identified as a quality improvement area. Transitional care programs that we speculate would be effective are expensive in terms of personnel, cost, and time, both for providers and potentially for patients. The ideal transition clinic is usually described as involving both adult and pediatric physicians and a nurse coordinator and includes serial educational visits and assessments of transition readiness. In the meantime, from what is available in the data from Gray et al. and personal observation, most patients are transitioned by informal efforts on the part of their pediatric providers and much less commonly via formalized transition plan or clinic. Of note in relevance to this issue, in the Gray et al. study, 82.9% of respondents reported lack of resources as one of the obstacles to transition.⁶ As new paradigms of integrated IBD care such as the medical home, as practiced by Miguel Regueiro's group, progress to the point of being more readily implemented at other institutions, this may provide other ways to provide this care.²⁴ On the other hand, as the current political and financial situation of health care is unlikely to change soon in a way that more resources would be available to care for these individuals, and the resource of a transition clinic is likely to remain scarce, we recommend that part of the development of transition programs should include efforts to determine who will benefit from different intensities of transitional care. Although all patients deserve and will benefit from basic education about transition, not all may require intensive transition clinic visits or self-management educational programs. Part of our future must include providing the levels of care appropriate to patients of different needs.

Since the publication of statements in regards to this process in 2002 by the AAP and NASPGHAN, numerous reviews and studies have been published, but there is much to overcome. We still need to know how best to educate these patients to develop these skills, at what age they should transition, and how to identify when they are ready. Table 2 presents a diagram of some of the basic steps in this process over time, along with barriers and potential solutions.

In 2018, we recommend, as the bare minimum:

- For the pediatric provider: use some form of transition readiness assessment, introduce the topic of transition early, make use of the

currently available resources for health care independence, discuss accountability with the patient and parent, and identify providers able to accept patients.

- For the adult practitioner: become familiar with the challenges to care of adolescents and young adults with IBD, including health care self-efficacy and adherence, and identify available resources, including for mental health care.
- For the researcher: determine a mechanism to evaluate transition programs that include both patient satisfaction and clinical outcomes in a transition assessment that is easy to use. A vocabulary should be developed to better describe types of transfer, and outcomes should be assessed in terms of clinical outcomes, health care cost, and patient satisfaction. Use these methods to assess programs for efficacy in regards to clinics and other forms of intervention to improve outcomes in transitioning patients and determine which patients will benefit most from intensive services compared with basic services.

The increasing awareness of the need for transitional care has certainly resulted in a more informed effort on the part of IBD providers, and with ongoing study, we expect that we shall be better able to provide evidence-based care to maximize the ability of transitioning patients to be well-adjusted, functioning adults with good QoL and minimized impact of their disease on their life trajectory.

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