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# Transition Readiness Skills Acquisition in Adolescents and Young Adults with Inflammatory Bowel Disease: Findings from Integrating Assessment into Clinical Practice

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**Background:** Almost 80% of adult gastroenterologists report inadequacies in the preparation of patients transferred from pediatrics. To improve transition to adult care, it is important to identify the specific deficits that patients are demonstrating before transfer. We present data from a clinic-wide assessment of transition readiness skill acquisition in adolescents/young adults with IBD.

**Methods:** A total of 195 patients (age, 16–25 yr) with IBD completed the Transition Readiness Assessment Questionnaire. Patient age, diagnosis, time since diagnosis, physician global assessment, and patient and parent disease management confidence ratings were extracted from the medical record. Transition Readiness Assessment Questionnaire scores were compared with a benchmark established by an interdisciplinary, multi-institutional Transition Task Force.

**Results:** Only 5.6% of older adolescents/young adults on the verge of transfer to adult care met our institutional benchmark (3.5% of adolescents, 7.3% of young adults). Patients reported mastery of  $9.10 \pm 4.68$  out of 20 Transition Readiness Assessment Questionnaire items. Transition readiness was associated with older age ( $r = 0.27$ ,  $P < 0.001$ ) and female gender ( $F_{(1,192)} = 13.81$ ,  $P < 0.001$ ) but not time since diagnosis, physician global assessment, or confidence ratings. Deficits in health care utilization/self-advocacy (e.g., understanding insurance, scheduling appointments/following up on referrals), and self-management (e.g., filling/reordering prescriptions) were observed.

**Conclusions:** Most patients on the verge of transferring to adult care are not demonstrating transition readiness. Deficits observed represent modifiable behaviors. Using data-driven assessments to guide interventions to enhance transition readiness may minimize the retention of young adult patients in pediatrics and result in patients who are better prepared for adult care.

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**Key Words:** pediatric IBD, transition to adult care, adolescents, young adults

Transitioning adolescents and young adults with IBD to adult care is an important step in ensuring that patients receive timely and developmentally appropriate care.<sup>1</sup> As 25% of IBD diagnoses occur in childhood or adolescence<sup>2</sup> and prevalence is rising,<sup>3</sup> a significant and growing number of patients will inevitably make this transition. When managed poorly, transfer to adult care results in treatment nonadherence,<sup>4,5</sup> increased disease severity,<sup>4,6</sup> and undue stress for patients, families, and health care providers.<sup>7</sup>

Although pediatrics oversees preparing patients for adult care, the impact of poorly managed transition primarily impacts the clinical care of adult providers. In a recent survey of adult gastroenterologists, 79% reported inadequacies in the preparation of patients transferred from pediatrics.<sup>8</sup> Many adult providers struggle with patients who have a limited understanding of their IBD and treatment history and whose families are overly involved in their care.<sup>8,9</sup> They find themselves spending more time with these patients providing information they either consider redundant or focusing on management skills they expect for patients to have already mastered on their own.<sup>1</sup>

In light of the challenges experienced on both the pediatric and adult end of transition, a local Transition Task Force was formed. This Task Force, resulting from collaboration between pediatric IBD care at Cincinnati Children's Hospital Medical Center and adult IBD care at the University of Cincinnati Health (UC Health), was comprised 15 individuals, including pediatric and adult clinicians, administrators, and patients with IBD and their parents. The Task Force met semimonthly across an 8-month period to review current transfer practices, establish a process to transfer patients to local adult providers, identify strategies to overcome

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barriers to transfer, and establish objective benchmarks of transition readiness to guide decision making regarding the timing of transfer. This latter goal was important as there was significant variability across providers regarding transfer. Benchmarks were established taking the existing IBD transition literature, previously published position statements on transition, and the diverse expertise of Task Force members into account. Based on consensus among the Task Force members, a patient would be considered ready for adult care when (1) they had mastered 90% of transition readiness skills, (2) they were in mild or quiescent disease state, (3) they had identified a primary care physician, and (4) the pediatric team was confident in their ability to succeed in an adult care setting.

The current study presents findings from our initial work assessing benchmark no. 1: transition readiness skill acquisition. Readiness skill acquisition in our older adolescents and young adults is compared with our benchmark of transition readiness (90% mastery of skills). We specifically wanted to know, before the implementation of a formal transition program at our institution: (1) What percentage of our patients were meeting our benchmark? and (2) Were there any demographic correlates associated with readiness? It was expected that readiness skill acquisition would increase with age, with a greater percentage of young adults ( $\geq 18$  yr) meeting our benchmark than adolescents (16–17 yr). Exploratory analyses including gender differences in skill acquisition and associations with disease activity, time since diagnosis, and self-efficacy are also presented. Finally, we present our data in terms of (1) commonly mastered readiness skills and (2) areas for continued growth. Areas youth were least likely to master were identified to help guide development of our own transition program and future interventions to improve transition readiness in youth with IBD.

## MATERIALS AND METHODS

### Ethical Considerations

Data presented in this study were the result of a review of anonymous data collected through a clinic-based quality improvement effort. According to institutional policies, IRB review was not required.

### Clinic Structure and Status of Transition to Adult Care Services at Our Institution

The Schubert-Martin Inflammatory Bowel Disease Center at Cincinnati Children's Hospital has one of the largest patient volumes in the nation, providing care for approximately 500 pediatric patients with IBD. Of these, 292 patients are aged  $\geq 16$  years. Currently, standard care consists of regular outpatient appointments with the pediatric gastroenterologist focused on managing current symptoms. IBD education is primarily provided at diagnosis and consists of a welcome packet providing an overview of IBD and clinic-specific services and a copy of the *IBD Self-Management Handbook* (available at: <https://www.improvecarenow.org/patients/self-management-handbook>).

Our institution is in the beginning stages of creating a program to improve transition to adult care for our patients with IBD. Initial steps have included conducting the aforementioned Transition Task Force and hiring a social worker to serve as our transition coordinator. Current responsibilities of the transition coordinator are to screen all pediatric patients aged  $\geq 16$  years with the Transition Readiness Assessment Questionnaire (TRAQ)<sup>10</sup> and coordinate the hand-off to adult care. Currently, there is neither formal curriculum in place to address transition readiness nor is there a set age at which a patient must transfer to adult care. Decisions to transfer to adult care are currently made based on mutual agreement between the family and the provider. Thus, there is considerable variability in the timing of transfer with some patients remaining in pediatric care until their mid-20s.

### Participants and Procedure

Adolescent and young adult patients (age,  $\geq 16$  yr) with Crohn's disease and ulcerative colitis were asked by the IBD transition coordinator to complete an assessment of transition readiness skills during their regularly scheduled medical appointment. Routine assessment of transition readiness skills began in December 2012 as part of an institutional-level quality improvement effort to improve care for adolescents and young adults with chronic illnesses. Data presented in this study were collected between December 2012 and January 2014. Participants were invited to participate if they attended a routine outpatient care appointment during this time. Thus, the aim of this study was to gather a representative sample of our clinical population aged  $\geq 16$  years.

Patients aged  $\geq 16$  years were selected as the initial target of IBD quality improvement efforts as they were several years away from any potential transfer to adult care. Age 16 was judged by the Task Force to be the ideal time to educate patients about their illness, as they would be old enough to retain and understand the medical information provided to them. Being at least 2 years, pretransfer also provided patients with the opportunity to develop and practice independent self-management skills with the safety and backup support of their parents and the pediatric team still in place. All adolescents and young adult patients who met with our Transition Coordinator (N = 201) underwent transition readiness skills assessments from December 2012 to January 2014. Six patients were excluded before data analysis, 3 of which were due to significant missing data (missing more than 20% of responses). In addition, 3 patients were removed from the database because they were younger than 16 years, resulting in a final sample of 195 adolescents and young adults with IBD.

### Measures

#### Transition Readiness Skills

Transition readiness skills were assessed with the TRAQ 5.0.<sup>11</sup> The TRAQ is a 20-item patient self-report measure, which assesses patients' mastery of skills needed to independently

manage their chronic illness in the adult health care system.<sup>10</sup> As the TRAQ was designed to be used across various chronic illness populations, items focus on assessing mastery of skills common to most chronic conditions including disease self-management (e.g., taking medications as prescribed, scheduling medical appointments) and health care utilization/self-advocacy (e.g., knowing what health insurance covers, communicating with providers). For each item, patients are asked to rate their ability level in completing that item/skill using a 5-point Likert scale ranging from 1 (No, I do not know how) to 5 (Yes, I always do this when I need to). Scores can then be summed across the entire measure (range = 20–100) or by subscale to generate a transition readiness score. Although no score has been established to serve as a cutoff for readiness to transfer to adult care, higher scores indicate greater readiness. For the purpose of comparing TRAQ data with our institutional benchmark of 90% mastery of transition readiness skills, the TRAQ was examined on an item-by-item basis. Only those items rated as a “5” (Yes, I always do this when I need to) were considered skills that had been mastered as all other responses (0–4) indicated either a complete or partial inability to complete the skill independently. For each patient, a readiness skill acquisition score was calculated based on the number of skills mastered (possible range = 0–20). Based on our institutional benchmark of 90% mastery of transition readiness skills, readiness skill acquisition score of 18 or above was considered to have met our benchmark. The TRAQ has undergone 2 validation studies with large samples of youth (age, 16–26 yr) with special health care needs. For a copy of the TRAQ and additional information regarding measure development, validation, and subscales, please see <http://www.hscj.ufl.edu/JaxHATS/TRAQ/>. Initial findings suggest that the TRAQ is a reliable ( $\alpha = 0.93$ ) measure of transition readiness skills. Internal consistency for the TRAQ in the current sample was good ( $\alpha = 0.89$ ).

### Medical Record Abstraction

For each patient, the following information was abstracted from their medical record corresponding to the date in which they completed the TRAQ: (1) Diagnosis (Crohn’s disease, ulcerative colitis, indeterminate colitis), (2) Time since diagnosis (in years), (3) Physician global assessment of disease severity, and (4) Patient- and parent-reported confidence rating. For the latter, patients were asked to rate their confidence in their ability to manage their disease using a 0 (not at all confident) to 10 (extremely confident) scale. Similarly, parents were asked to use the same 0 to 10 scale to rate their level of confidence managing their child’s care.

### Data Analysis

Before data analyses, all measures were screened for missing data. Case mean substitution was used for those participants whose TRAQ data were at least 80% complete (i.e., missing only 1 or 2 items;  $N = 43$ ). By using the each case’s own data to provide information about missing items, case mean substitution acknowledges interindividual variability. This approach has been found to be an appropriate, robust method for managing

missing items in psychometric measures,<sup>12</sup> particularly when no more than 30% of data are missing.<sup>13</sup> TRAQ forms that had more than 20% missing data were removed before analyses ( $N = 3$ ).

Patients with incomplete/unusable data did not significantly differ from those patients with complete data regarding age, gender, diagnosis, time since diagnosis, physician global assessment, or confidence rating. Descriptive data analyses were used to examine the percentage of patients meeting our institutional benchmark of 90% mastery of transition readiness skills. A chi-square test compared the differences rates of meeting our benchmark by age group. To examine gender differences in transition skill acquisition, an analysis of covariance was conducted with age entered as a covariate to control for age effects. A regression was used to examine the relationship between transition skill acquisition and age. Pearson’s product correlations examined the associations between transition readiness skill acquisition scores, disease activity, and self-efficacy.

## RESULTS

### Participant Characteristics

In total, 195 patients were included in the study. Patient age ranged from 16 to 25 years, with the mean age of  $18.08 \pm 1.86$  years. Approximately 53.1% of the sample was male, and a majority had Crohn’s disease (75.1%). On average, patients had been diagnosed with IBD for 4.74 years. Of a possible range of 0 to 20, patients reported an average mastery of approximately  $9.10 \pm 4.68$  skills. Regarding disease activity, most patients had quiescent disease (79.1%), with smaller percentages rated as having mild (14.4%) or moderate (6.4%) disease. Patient- and parent-reported confidence ratings were high (8.74/10 and 8.85/10, respectively). Although information about socioeconomic status and education of participants was not available, our clinic population tends to be well-educated and from a high socioeconomic status background.

### Percentage of Patients Meeting Institutional Benchmarks

When compared with our institutional benchmark of 90% mastery of transition readiness skills, only 5.6% of our entire sample met our criteria. This analysis included youth as young as age 16 along with young adults up to age 25. Because of the differences expected in an adolescent versus a young adult regarding disease management, those who were legally considered adults (age  $\geq 18$  yr), and thus on the verge of transferring to adult care, were separated from the rest of the sample and our analysis was rerun. When examined separately, only 3.5% of youth ages 16 to 17 years and 7.3% of young adults (age, 18–25 yr) were currently meeting institutional benchmarks of transition readiness. There was no significant difference, however, between adolescents and young adults regarding percentages meeting our benchmark,  $\chi^2(1, N = 195) = 1.34, P > 0.05$ . These data are presented in Table 1.

**TABLE 1.** Transition Readiness Skills by Diagnosis, Disease Activity, Age, and Gender

	N	% Patients Meeting Benchmark		Readiness Skills Mastered (M ± SD) <sup>a</sup>
		Yes	No	
<b>Diagnosis</b>				
Crohn's disease	141	2.84	97.16	8.96 ± 4.50
Ulcerative colitis	43	11.63	88.37	9.33 ± 4.89
Indeterminate colitis	4	0	100	7.25 ± 1.26
<b>Disease activity</b>				
Quiescent	147	5.44	94.56	9.09 ± 4.69
Mild	27	3.70	96.30	9.00 ± 4.03
Moderate	12	0	100	8.00 ± 3.86
<b>Age, yr</b>				
<18	86	3.49	96.51	7.97 ± 4.20
≥18	109	7.34	92.66	9.98 ± 4.85
<b>Gender</b>				
Male	103	2.91	97.09	8.06 ± 4.45
Female	92	8.70	91.30	10.23 ± 4.65

<sup>a</sup>Maximum possible transition readiness skills mastered = 20; Task force-established transition benchmark for readiness = 18.

## Demographic Correlates of Transition Readiness

### Time Since Diagnosis

Time since diagnosis was not correlated with transition readiness skill acquisition ( $r = 0.08$ ,  $P = 0.27$ ). Thus, this variable was not included in further analyses.

### Age

A regression was conducted to examine the relationship between transition readiness skill acquisition and age. Consistent with study hypotheses, transition readiness skill acquisition increased with age,  $r = 0.27$ ,  $P < 0.001$ . Mean skill acquisition by age is illustrated in Figure 1. As seen in Figure 1, although transition readiness increases by age, mean scores for all ages fall short of our benchmark (indicated by dashed line). If the linear relationship between age and skill acquisition (transition readiness score =  $0.68 \times (\text{age}) - 3.17$ ) were extended from the current data to see the age at which patients would reach 90% mastery of transition readiness skills, patients would not be considered ready for adult care until age 32.

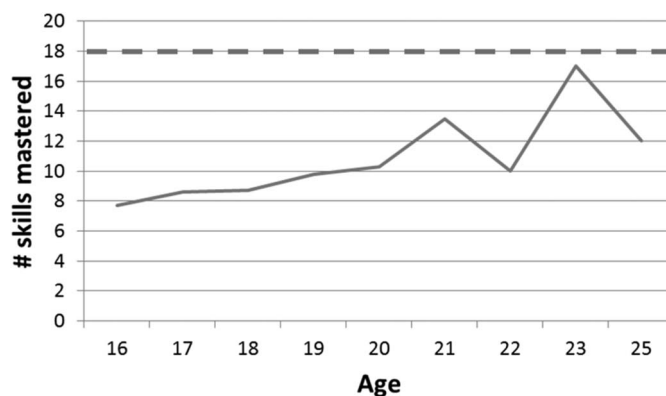
### Gender

Gender differences in transition readiness skill acquisition were examined using an analysis of covariance. Due to the significant association between age and transition readiness skill acquisition, age was entered into the model as a covariate. After accounting for the effects of age, there was a significant main effect of gender,  $F_{(1,192)} = 13.81$ ,  $P < 0.001$ . In general, females demonstrated an average mastery of 2 more skills than males

(Table 1), suggesting that females tend to have more independence in their IBD management than males.

## Associations Between Transition Readiness, Disease Activity, and Patient- and Parent-reported Confidence Ratings

Associations between transition readiness skill acquisition, disease activity, and patient- and parent-reported confidence in disease management were examined by Pearson's product correlation. As seen in Table 2, relations between disease activity, patient-reported confidence, and parent-reported confidence were moderate to strong. However, there was no significant association between transition readiness skill acquisition and other variables



**FIGURE 1.** Transition readiness skill acquisition by age. Dashed line indicates our institutional benchmark of 90% mastery of transition readiness skills.

**TABLE 2.** Associations Between Transition Readiness Skills, Disease Activity, and Parent- and Patient-reported Confidence in Disease Management

Variable	1	2	3	4
Number of readiness skills mastered	—			
Physician global assessment	-0.05	—		
Parent confidence rating	-0.02	-0.47 <sup>a</sup>	—	
Patient confidence rating	-0.13	-0.30 <sup>a</sup>	0.50 <sup>a</sup>	—

<sup>a</sup>Correlation significant at the  $P < 0.01$  level.

of interest. Of note, there was a trend in the percentage of patients meeting our benchmark within each disease activity category, with the number of patients meeting our benchmark decreasing with more active disease (Quiescent—5.7% meeting benchmark; Mild—3.8% meeting benchmark; Moderate—0% meeting benchmark). Regarding number of skills mastered by disease activity category, however, there were no significant differences between groups. This may have been due to uneven sample sizes across groups.

### Patient-reported Strengths and Areas for Improvement in Transition to Adult Care Preparation

Mean scores were calculated for each item on the TRAQ to identify those skills patients with IBD are generally mastering compared with those least often mastered. Findings from this analysis are presented in Table 3. In general, patients reported greater mastery of skills associated with (1) in-person communication (e.g., answering doctor’s questions, telling provider how they are feeling), (2) taking medication, and (3) managing daily activities (e.g., using neighborhood stores/services, cleaning up after themselves). Youth were least skilled in areas involving health care utilization/advocacy (e.g., knowing what health insurance covers/how to apply for insurance if coverage is lost, obtaining financial assistance). Finally, youth reported themselves to be in learning stages (TRAQ score between 3 and 4) of several skills associated with being proactive in health management, such as filling prescriptions/reordering refills before running out, calling to schedule a medical appointment/report unusual changes in health, making a list of questions to ask before the doctor’s visit, and following up on referrals for tests/check-ups/laboratory results.

### DISCUSSION

Preparing youth with IBD for the transition from pediatric to adult care is a challenging and ongoing clinical care issue. Although many commentaries and opinion pieces have been published about what should be done to improve transition efforts, very few studies present original data. Our study is the first to

**TABLE 3.** Mean Scores on Transition Readiness Skills (From Most-to Least-mastered)

Readiness Skill	Mean Score
Answering questions asked by doctor/nurse/clinic staff	4.88
Telling doctor how you are feeling	4.84
Taking medications correctly and on own	4.66
Using neighborhood stores/services	4.62
Keeping home/room clean/cleaning up after meals	4.60
Arranging for ride to medical appointment	4.39
Help prepare meals/food	4.22
Know what to do when having a bad reaction to medication	4.09
Filling out medical history questionnaire	4.06
Keeping a calendar/list of medical appointments	3.83
Managing money and budgeting	3.69
Calling doctor about unusual changes in health	3.64
Reordering and getting refills on time	3.60
Filling a prescription when needed	3.44
Making list of questions to ask before doctor’s visit	3.44
Following up on referrals (tests/check-ups/laboratory results)	3.39
Calling doctor’s office to schedule an appointment	3.09
Getting financial help with school or work	2.92
Knowing what health insurance covers	2.60
Applying for health insurance if coverage lost	2.44

For ease of interpretation, the following point values are used to score the TRAQ: 1 = No, I do not know how; 2 = No, but I want to learn; 3 = No, but I am learning to do this; 4 = Yes, I have started doing this; 5 = Yes, I always do this when I need to.

present data from a clinic-wide assessment of transition readiness skills in adolescents and young adults with IBD. Our findings show that very few patients are meeting our readiness benchmark, and there are distinct strengths and areas of weakness regarding skill acquisition.

Overall, the percentage of patients meeting our benchmark was small (5.6%). Even among patients legally considered adults, the percentage of patients meeting our benchmark of readiness was modest (7.3%), suggesting that our adolescents and young adults with IBD are not reaching the mastery level necessary to manage their health independently in adult care. Although data presented in this study are based on the patient sample at our site, it is likely that these findings are not site-specific. Research conducted at a large northwestern children’s hospital in the United States has documented significant deficits in self-management among older adolescents and young adults with IBD.<sup>14</sup> Specifically, most of their sample deferred to their parents to manage major parts of their IBD care such as scheduling appointments (85%) or requesting medication refills (75%). Significant knowledge gaps were also observed. Not all patients knew their diagnosis and less than half could confidently name their medications

and doses. These findings, along with our own, suggest that there are many opportunities to improve patient knowledge and skills before transfer to adult care.

Examination of TRAQ scores by item allowed for the identification of strengths and weaknesses regarding readiness skill acquisition. Overall, adolescents and young adults with IBD had the highest mastery scores in areas that involved speaking directly with providers (e.g., telling doctor how they are feeling and answering questions) and taking their medication. These findings are consistent with previous research on self-management, which found that 79% of older adolescents/young adults with IBD are primarily responsible for talking during clinic visits and 90% are in charge of remembering to take their medications.<sup>14</sup> However, adolescents with IBD generally have poor adherence to treatment,<sup>15</sup> with “forgetting” being a major barrier to adherence.<sup>16,17</sup> Thus, although increased adolescent responsibility in these areas should be commended, adolescents need better preparation for these responsibilities.

As a whole, adolescents reported the lowest mastery levels areas in areas of health care utilization and advocacy. The 2 lowest rated items on the TRAQ both focused on health insurance coverage (i.e., knowing what it covers and how to apply for coverage). These are general knowledge deficits that could easily be addressed by a social worker or nurse in clinic and complemented with written materials on health insurance literacy. Furthermore, encouraging parents to educate and involve adolescents in the financial aspects of their health care, paying special attention to explaining insurance terms (e.g., premium, deductible, co-pay), may help to increase knowledge and skill level in this area. Other areas of transition readiness that were suboptimal involved proactive health management skills including: scheduling appointments, making a list of questions before a doctor’s visit, following up on referrals, filling/refilling medications in a timely manner, and communicating with the medical team about unusual changes in health. These all represent modifiable behaviors and skills that can be addressed with families within the context of clinical care.

This study had several notable strengths. First, our study is the largest clinic-based assessment of transition readiness skills in youth with IBD. By incorporating readiness assessment into our clinical services, we have gained valuable data on our progress toward helping our patients meet our benchmark. Our future work, which includes the development of a transition program sponsored by a grant from the Crohn’s and Colitis Foundation of America (285083), will help us gauge future progress toward helping our patients prepare for adult care. The second strength is our use of a well-validated, objective measure of transition readiness. Only one other study has focused on skills related to transition in IBD.<sup>14</sup> However, use of an unvalidated measure and potential selection bias (only 43% response rate) were a concern. Finally, our data highlights areas of strength and weakness regarding transition readiness skill acquisition; thus, we have now identified distinct areas for improvement that can be targeted in our clinical work.

There are important methodological limitations that warrant discussion as well. First, as most participants in this study had quiescent disease, study findings cannot be extended to more severe populations. Second, as recruitment only occurred during clinic visits, patients who are nonadherent to clinic appointments may have been excluded. Third, lack of parent report to assess transition readiness is also a limitation. Transition to adult care is a bilateral process and studies including all key stakeholders including parents, pediatric providers, and adult providers are greatly needed. Fourth, as we are in the beginning stages of transition programming at our institution, not all benchmarks have been implemented in clinical practice. Only data related to our first benchmark have been assessed. It is important to note, however, that decisions to transfer a patient to adult care should not be made solely on the results of one datum but rather as a result of multiple converging pieces of information including, but not limited to, disease status, availability of an adult provider, and occurrence of life events (e.g., moving away to college). The final limitation is that the predictive validity of our benchmark is unknown. We do not know whether meeting this benchmark leads to eventual success in adult care or what level of mastery is “good enough” before leaving pediatrics. Thus, it is possible that our benchmark, though derived from review of the literature and Task Force consensus, may be too stringent. Currently, the TRAQ has no published cutoff score to guide clinical decision making regarding the timing of transfer. A long-term goal of our research program is to examine the relationship between transition readiness skill acquisition scores and posttransfer outcomes to guide future refinement of our benchmark.

Study findings have important clinical implications that should be considered when working with transition-age youth with IBD and their families. First, the skills assessed in our readiness assessment all represent modifiable behaviors and are thus amenable to intervention. Second, our findings allude to the central role that parents play in IBD management in youth with IBD. Although we did not specifically assess parental involvement in care, it is likely that most of the skills that have not been mastered are being handled by parents. Thus, providers should broaden their focus from “transitioning the patient” to “transitioning the family.” Including parents in transition preparation, as well as transition of treatment responsibility from parent to patient, by providing them with guidance as to how they can be support their child, may help to allay some of the concerns about transition. As previous research shows that parents have later expectations for their adolescent’s autonomy than youth have for themselves,<sup>18</sup> parents may need specific guidance on when and how to involve their adolescent in their own IBD care, particularly in early adolescence. Providing parents with a copy of the “Healthcare Provider Transitioning Checklist (Jointly published by the Children’s Digestive Health Network Foundation (CDHNF), the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN), and Digestive Health for Life and available from: [http://www.naspgan.org/user-assets/Documents/pdf/CDHNF%20Old%20Site/IBD%](http://www.naspgan.org/user-assets/Documents/pdf/CDHNF%20Old%20Site/IBD%20Transitioning%20Checklist.pdf)

20Medical%20Professional%20Resources/Checklist\_Patientand-HealthcareProvider\_TransitionfromPedtoAdult.pdf)” and discussing current division of IBD care within the family may help to guide the development of age-appropriate expectations for involvement. We have begun emphasizing this in our work with younger adolescents (12–15 yr) and their families.

Routine assessment of transition readiness skills should be considered as tool to track patient readiness and institutional-level progress in improving transitional care. Because it is brief, the TRAQ is easy to administer and can be visually scanned by the clinician to identify areas of strength and weakness. Use of the TRAQ in patient care can help to make discussion of transition readiness a routine practice, facilitate the setting and tracking of small goals for families to focus on between clinic visits, and examination of patient progress over time, enabling clinicians to meet their patients’ evolving needs. We have recently begun to administer the TRAQ electronically. All transition-aged patients now complete the TRAQ on a tablet at check-in. These data are then integrated directly into our electronic medical record for review by our transition coordinator before meeting with the patient. This has streamlined our assessment process and enhanced our ability to track patient skill acquisition over time. While improving transition to adult care in IBD is a complex clinical issue, by partnering with our patients and parents, using our transition readiness assessment data to drive intervention efforts, and integrating technology to optimize care, we aim to improve transition readiness and increase patient, parent, and provider confidence in the transfer process.

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## REFERENCES

- 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.
- Griffiths AM. Specificities of inflammatory bowel disease in childhood. *Best Pract Res Clin Gastroenterol.* 2004;18:509–523.
- Benchimol EI, Fortinsky KJ, Gozdyra P, et al. Epidemiology of pediatric inflammatory bowel disease: a systematic review of international trends. *Inflamm Bowel Dis.* 2011;17:423–439.
- Annunziato RA, Emre S, Shneider B, et al. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant.* 2007;11:608–614.
- Pai ALH, Ostendorf HM. Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: a literature review. *Child Health Care.* 2011;40:16–33.
- Bryden KS, Peveler RC, Stein A, et al. Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care.* 2001;24:1536–1540.
- Goodhand J, Dawson R, Heffernon M, et al. Inflammatory bowel disease in young people: the case for transitional clinics. *Inflamm Bowel Dis.* 2010;16:947–952.
- Sebastian S, Jenkins H, McCartney S, et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. *J Crohns Colitis.* 2012;6:830–844.
- Hait EJ, Barendse RM, Arnold JH, 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.* 2008;48:61–65.
- Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ—Transition Readiness Assessment Questionnaire. *J Pediatr Psychol.* 2011;36:160–171.
- Wood DL, Sawicki GS, Miller MD, et al. The Transition Readiness Assessment Questionnaire (TRAQ): Its factor structure, reliability, and validity. *Acad Pediatr.* 2014;14:415–422.
- Roth PL, Switzer FS, Switzer DM. Missing data in multiple item scales: a Monte Carlo analysis of missing data techniques. *Organ Res Methods.* 1999;2:211–232.
- El-Masri MM, Fox-Wasylyshyn SM. Missing data: an introductory conceptual overview for the novice researcher. *Can J Nurs Res.* 2005;37:156–171.
- Fishman LN, Barendse RM, Hait E, et al. Self-management of older adolescents with inflammatory bowel disease: a pilot study of behavior and knowledge as prelude to transition. *Clin Pediatr (Phila).* 2010;49:1129–1133.
- Hommel KA, Davis CM, Baldassano RN. Objective versus subjective assessment of oral medication adherence in pediatric inflammatory bowel disease. *Inflamm Bowel Dis.* 2009;15:589–593.
- Hommel KA, Baldassano RN. Brief report: barriers to treatment adherence in pediatric inflammatory bowel disease. *J Pediatr Psychol.* 2010;35:1005–1010.
- Gray WN, Denson LA, Baldassano RN, et al. Treatment adherence in adolescents with inflammatory bowel disease: the collective impact of barriers to adherence and anxiety/depressive symptoms. *J Pediatr Psychol.* 2012;37:282–291.
- Feldman SS, Quatman T. Factors influencing age expectations for adolescent autonomy: a study of early adolescents and parents. *J Early Adolescence.* 1988;8:325–343.