

# Transition of Inflammatory Bowel Disease Care: Assessment of Transition Readiness Factors and Disease Outcomes in a Young Adult Population

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**Background:** Limited data exist on what factors impact transition readiness and how readiness impacts short-term disease outcomes.

**Methods:** Patients between the ages of 18 and 25 with an established inflammatory bowel disease diagnosis completed questionnaires at the time of an outpatient visit in the pediatric or adult setting, which included the Transition Readiness Assessment Questionnaire (TRAQ). After 6 months, electronic medical records were reviewed.

**Results:** A total of 95 patients were enrolled, 46 in the adult care setting and 49 in the pediatric care setting. Patients in the adult setting had a significantly higher overall TRAQ score compared with the pediatric setting (median: 4.42 [IQR: 3.9–4.6] versus 4.06 [IQR: 3.4–4.4],  $P < 0.001$ ). Logistic regression analysis demonstrated that age was independently associated with higher TRAQ scores (odds ratio: 1.49; 95 confidence interval%, 1.1–2.02). Nonadherent patients scored lower on the Managing Medications subscale (median: 4.25 [IQR: 3.3–4.8] versus 4.75 [IQR: 4.3–5.0],  $P < 0.01$ ). Logistic regression showed that patients who scored  $< 4.75$  on the Medication Management subscale were 3.8 times more likely to be nonadherent than patients who scored  $\geq 4.75$  (95% confidence interval, 1.4–10.3). This remained significant after adjusting for gender and age. During the 6-month follow-up period, 9/95 patients (10%) had hospitalizations or ED visits related to inflammatory bowel disease. There were no associations between TRAQ scores and hospitalizations/ED visits.

**Conclusions:** Age is the primary factor that drives transition readiness. Our findings suggest that administering the medication management portion of the TRAQ can be used to identify patients at risk for nonadherence. Follow-up studies are needed to determine how readiness impacts long-term disease outcomes.

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**Key Words:** pediatrics, transition, adherence

The incidence of inflammatory bowel disease (IBD) in the pediatric age group is increasing.<sup>1,2</sup> As there is a growing cohort of patients that will eventually move from pediatric to adult care, both pediatric and adult gastroenterologists need to be aware

of issues specific to adolescents. A nationwide survey of adult gastroenterologists found that while 73% felt competent with medical aspects of adolescent care, only 46% reportedly felt competent with issues pertaining to adolescent development and mental health.<sup>3</sup> In addition, 51% of adult gastroenterologists reported receiving inadequate information from pediatric providers. Patients may become lost to follow up during the transition from pediatric to adult care, as medication and visit nonadherence is not uncommon during this time.<sup>4–7</sup> This is just one of many issues that supports a need for structured transition in this population.

Transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.<sup>8</sup> This is frequently not a smooth process, as patient knowledge and preparedness for transfer to adult care is often lacking.<sup>9,10</sup> Gray et al<sup>11</sup> recently reported transition readiness in a large population of IBD patients ages 16 to 25 using the Transition Readiness Assessment Questionnaire (TRAQ) and found that most patients did not demonstrate mastery of transition readiness skills.

Research from other childhood chronic illnesses such as cystic fibrosis, diabetes mellitus, congenital heart disease, liver transplant, and renal transplant has shown that a structured transition program does improve adherence and disease control.<sup>12,13</sup>

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For example, Annunziato et al<sup>14</sup> demonstrated that pediatric liver transplant patients who had access to a transition coordinator had better medication adherence 1 year after transfer compared with patients who did not have access to a transition coordinator. Most transition studies in IBD focus on descriptive data based on expert opinion or surveys of patient, family, and/or health care provider's perceptions.<sup>15–20</sup> There is limited data on what individual patient characteristics, as opposed to characteristics of a transition program, are most important in predicting a successful transition. In addition, the association between transition and outcomes has not been properly evaluated.

The purpose of this prospective study was to assess transition readiness in a population of young adult patients and to determine what factors influence readiness. Specifically, we chose to look at age, care setting, disease activity, education level, socioeconomic status, and mental health, as it was believed that these factors might impact a patient's readiness to transition. Additionally, we sought to determine how readiness impacts short-term disease outcomes, in terms of adherence to medications and clinic visits and also emergency department (ED) visits and/or hospitalizations related to IBD. By understanding what influences readiness, we can work toward establishing targeted interventions to ensure a successful transition process.

## MATERIALS AND METHODS

### Patients and Procedures

Patients between the ages of 18 and 25 with an established diagnosis of Crohn's disease, ulcerative colitis, or IBD-undefined followed at a tertiary care IBD center were asked to complete 4 questionnaires at the time of a scheduled outpatient visit with a pediatric or adult gastroenterologist in either the pediatric or adult setting. Questionnaires were administered while the patient was waiting to be seen by the physician. Patients were excluded if they did not have an established diagnosis of IBD, were hospitalized, were coming for an outpatient endoscopy visit, or were second opinions not planning to establish care at our institution. After 6 months of completing the survey, electronic medical records were reviewed.

### Measures

The 4 questionnaires included self-reported disease information and questions relating to the subject's own transition experience, a socioeconomic status survey (*Four Factor Index of Social Status*, Hollingshead 1975), a mental health inventory (MHI-38, Davies 1998), and a transition readiness assessment (*Transition Readiness Assessment Questionnaire*, Wood 2014).

The TRAQ was chosen based on its construct validity, reliability, and disease neutrality.<sup>21–23</sup> An overall average TRAQ score and average scores for each of the 5 subscales were calculated for each patient. Although no overall score has been established that serves as a cutoff for readiness to transition, a higher score corresponds to greater transition readiness. To access the full TRAQ please see <http://www.hscj.ufl.edu/JaxHATS/TRAQ>.

Overall score and subscales for the MHI-38 were calculated according to the corresponding manual.<sup>24</sup> The MHI-38 provides an overall raw score from 38 to 226. Although no cutoff values have been described, a higher score corresponds to greater psychological well-being and relatively less psychological distress. Two items relating to suicidal ideation were omitted from the questionnaire as we did not have the resources to address an affirmative answer to these questions, giving a total possible score of 215. The MHI-38 can also be used to generate scores for specific subscales, which include anxiety and depression. The anxiety subscale raw score ranges from 9 to 54, with a higher score indicating greater anxiety. The depression subscale raw score ranges from 4 to 23, with a higher score indicating greater depression. The Hollingshead<sup>25</sup> index for socioeconomic score was generated based on a weighted factor scale that includes parent occupation and education level, and accounts for parental marital status. Medical records were accessed to record physician global assessment (PGA) at the time of enrollment for which disease activity was classified as quiescent, mild, moderate, or severe. It was also recorded whether the patient was being seen in the pediatric or adult outpatient setting, and if seen in the adult outpatient office whether it was their first visit with an adult gastroenterologist.

### Outcomes

The primary outcome of this study was the association of demographic and disease-related factors with transition readiness. Demographic factors included age, patient education level, and socioeconomic status. Disease-related factors included disease subtype (Crohn's disease, ulcerative colitis, or IBD-undefined), disease activity assessment by PGA, and care setting (adult versus pediatric). The secondary outcome was to predict whether transition readiness was associated with adherence to visits and/or medications and also hospitalizations or ED visits for IBD. To assess nonadherence, medication nonadherence and visit nonadherence were classified together. Medication nonadherence was defined as failure to adhere to medication dosages as documented in the medical record by the physician and included patients who did not show to a scheduled infliximab infusion. Visit nonadherence was defined as patients who had a scheduled follow-up appointment but did not show. A missed appointment due to an ED visit or hospitalization was not classified as nonadherence. Any ED visits or hospitalizations for IBD were recorded, whether at the primary institution or at an outside hospital if documented in the medical record. Reason for ED visit or hospitalization was also recorded, for example, whether the patient came to the ED acutely with abdominal pain versus admission for elective ileocolic resection.

### Statistical Analysis

SAS 9.4 was used for all statistical calculations. To assess differences among the overall TRAQ score and TRAQ subscores, the nonparametric Wilcoxon test was used. Additionally, to control for the overall type I error at 0.05, the Holm's step-down procedure was used, which adjusted the significant level

for each tested hypothesis among the subscores. The Holm's step-down procedure was preferred to the Bonferroni adjustment as the TRAQ scale domains were correlated with each other (Cronbach correlation  $\alpha = 0.78$ ). Pairwise testing was performed to look at the correlation between PGA and age. To evaluate associations between binary outcomes (hospitalizations/ED visits and adherence) and the dichotomized TRAQ domain scores to indicate readiness (high versus low), Chi-square test of association was used. Logistic regression analysis was applied to look at overall TRAQ scores as a dichotomous variable (high defined as overall TRAQ score  $\geq 4.0$ , low defined as overall TRAQ score  $< 4.0$ ) in relation to age, care setting (pediatric versus adult), education level (completed high school versus completed college), and PGA score (quiescent, mild, or moderate/severe). Logistic regression was also used to predict adherence using age as a continuous variable and gender, overall TRAQ score and TRAQ subscores as dichotomous variables (high versus low with cutoff of 4.0 for overall TRAQ score and cutoff of 4.75 for TRAQ subscores). To assess hospitalization or ED visit outcomes, time to hospitalization was modeled using the Kaplan–Meier survival analysis method. The survival experience, defined as the rate of hospitalization or ED visits between the different TRAQ domain groups (high versus low), was evaluated using the log-rank test.

## Ethical Considerations

The study was approved by the Institutional Review Board of the Icahn School of Medicine at Mount Sinai.

## RESULTS

### Patient Population

A total of 95 patients were enrolled, 46 in the adult care setting and 49 in the pediatric care setting. The average age in the adult setting was 23.5 (SD  $\pm 2.2$  yr) versus 20.5 (SD  $\pm 1.6$  yr) in the pediatric setting ( $P < 0.001$ ). Average age at diagnosis was 15.8 (SD  $\pm 5.2$  yr) in the adult setting and 14.2 (SD  $\pm 3.86$  yr) in the pediatric setting ( $P = 0.02$ ). Gender, IBD diagnosis, and socioeconomic scores were not statistically different between patients seen in the adult setting compared with the pediatric setting (Table 1).

Within the adult care setting, 17 (37%) patients had never been followed by a pediatric gastroenterologist. Nineteen of the remaining 29 patients (66%) reported that their pediatric gastroenterologist had discussed transitioning with them, and approximately half of patients said that records were sent in advance of their visit by their pediatric gastroenterologist. The remaining patients said that records were not sent or were unsure. Of the 49 patients in the pediatric setting, 51% (25/49) said that transition had been or was being discussed by their pediatric gastroenterologist, and only 2 patients (4%) had been giving the name of an adult gastroenterologist to contact.

### TRAQ Scores

The TRAQ overall and subscale scores for patients in the adult versus pediatric setting are shown in Table 2. The

**TABLE 1. Patient Demographic Information**

	Adult n = 46 (48%)	Pediatrics n = 49 (52%)	P
Age			
Mean (SD)	23.5 ( $\pm 2.2$ )	20.5 ( $\pm 1.6$ )	$< 0.001$
Median (interquartile range)	24.1 (22.4, 25.2)	20.5 (19, 21.8)	
Age at diagnosis			
Mean (SD)	15.8 ( $\pm 5.2$ )	14.2 ( $\pm 3.86$ )	0.02
Median (interquartile range)	17.2 (12.6, 19.8)	14.4 (12.6, 17)	
Gender			
Male	20 (43.5)	26 (53.1)	0.41
Diagnosis			
Crohn's disease	28 (60.9)	39 (79.6)	
Ulcerative colitis	14 (30.4)	8 (16.3)	0.13
Indeterminate colitis	4 (8.7)	2 (4.1)	0.13
Socioeconomic score			
Mean (SD)	56.6 ( $\pm 12.4$ )	56 ( $\pm 10.5$ )	0.56
Median (interquartile range)	61 (53.5, 66)	59 (50, 66)	
MD mentioned transition <sup>a</sup>			
Yes	19 (65.5)	25 (51)	0.24
Given adult name to contact <sup>a</sup>			
Yes	19 (65.6)	3 (7.5)	$< 0.001$
Records sent <sup>a</sup>			
Yes	15 (51.7)	3 (7.1)	$< 0.001$

Transition data = adult versus pediatrics (n = 95).

<sup>a</sup>17 patients who did not undergo transition of care were excluded.

distributions of the overall TRAQ scores for the total population and by care setting are shown in Figures A and B, Supplemental Digital Content 1, <http://links.lww.com/IBD/B158>. Patients in the adult setting had a significantly higher overall TRAQ score compared with patients in the pediatric setting (median: 4.42 [IQR: 3.9–4.6] versus 4.06 [IQR: 3.4–4.4],  $P < 0.001$ ). Patients in the adult setting scored significantly higher in the domains of managing medications (median: 4.75 [IQR: 4.3–5.0] versus 4.5 [IQR: 3.8–4.8],  $P < 0.002$ ) and appointment keeping (median: 4.0 [IQR: 3.4–4.4] versus 3.1 [IQR: 2.1–3.9],  $P < 0.001$ ). There were no significant differences between the 2 groups for tracking health issues, talking with providers, and managing daily activities. Patients were then stratified by age to determine whether the difference in TRAQ scores was a factor of age versus a reflection of care setting. The Spearman correlation for overall TRAQ score versus age is shown in Figure 1, and box plots for overall TRAQ score and each age group are shown in Figure 2. Patients 24 and older scored significantly higher on the overall TRAQ score compared with patients of age 18 to 20 years old (median TRAQ score 4.64 [IQR: 4.3–4.8] versus 3.97 [IQR: 3.4–4.4],  $P < 0.0001$ ). Of note, all patients (n = 21) in the 24 to

**TABLE 2. TRAQ Scores for Adult Versus Pediatric Settings**

	Total (n = 95)	Adult (n = 46)	Pediatric (n = 49)	Two Sample Wilcoxon Test (P)
Overall TRAQ Score (median-IQR)	4.26 (3.9–4.6)	4.42 (4.1–4.8)	4.06 (3.4–4.4)	<0.001
Managing medications (median-IQR)	4.75 (4.0–5.0)	4.42 (4.3–5.0)	4.50 (3.8–4.8)	0.002
Appointment keeping (median-IQR)	3.57 (2.9–4.3)	4.00 (4.3–5.0)	3.10 (2.1–3.9)	<0.001
Tracking health issues (median-IQR)	4.00 (3.0–4.3)	4.00 (3.5–4.5)	3.50 (3.0–4.0)	0.07
Talking with providers (median-IQR)	5.00 (5.0–5.0)	5.00 (5.0–5.0)	5.00 (5.0–5.0)	0.09
Managing daily activities (median-IQR)	4.67 (4.0–5.0)	5.00 (4.0–5.0)	4.67 (4.0–5.0)	0.08

Transition Readiness Assessment Questionnaire for IBD patients.

25-year-old group were seen in the adult setting, whereas most (33/42) of the 18 to 20 years old patients were seen in the pediatric setting. We then looked at the group of patients of age 21 to 23 years old, as there were equal numbers of patients in each setting (n = 16/group), to discern whether the differences in TRAQ scores observed between the adult and pediatric groups were due to the different care settings versus a reflection of age. When controlled for age, there was no difference in overall TRAQ score or TRAQ subscores observed between the adult and pediatric care settings (median: 4.39 [IQR: 4.1–4.6] versus 4.28 [IQR: 4.0–4.7], P = 0.43). There were no observed differences in TRAQ scores among those whose pediatric gastroenterologists had discussed transition versus those who had not, in either the pediatric or adult settings.

Patients who had completed college scored significantly higher on the TRAQ score compared with those who had completed high school (Kruskal–Wallis P = 0.005). As expected, education level was strongly correlated with age in a pairwise comparison, with a mean age of 22.3 (SD ± 2.2) in the group that had completed college to a mean age of 18.5 (SD ± 1.9) in the group that had completed high school (P < 0.0001).

To examine PGA scores, patients with moderate and severe disease were grouped together, as only 3 patients were labeled as

severe. Overall TRAQ score was significantly higher in the moderate–severe group compared with the other groups (Kruskal–Wallis P = 0.047). A pairwise comparison test showed a significant difference between the moderate–severe group and the quiescent group (P < 0.01) after correcting for multiple comparisons using the Holm’s step-down procedure (adjusted alpha = 0.017). Medication management subscore was also significantly higher in the moderate–severe group compared with the quiescent group (Kruskal–Wallis P = 0.048). However, there again was a significant association with age, as those patients with moderate–severe disease had a mean age of 23.4 (SD ± 1.9) compared with a mean age of 20.7 (SD ± 2.3) in the quiescent and mild groups (P < 0.001).

Logistic regression analysis showed that older age was independently associated with higher TRAQ scores (odds ratio: 1.49; 95% confidence interval, 1.1–2.02), whereas care setting, education level, and PGA score were not.

**Mental Health Data**

The median MHI score for the total population was 171 (range: 87–214). The median anxiety score for the population was 20 (9–46), and the median depression score was 7 (range: 4–18).

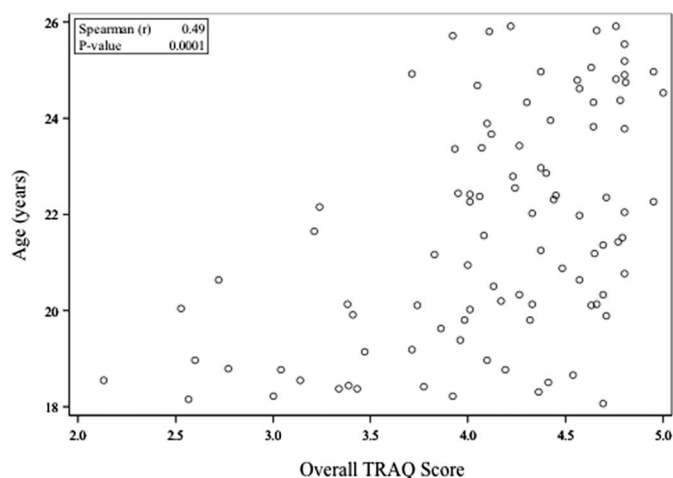


FIGURE 1. Correlation between TRAQ score and age.

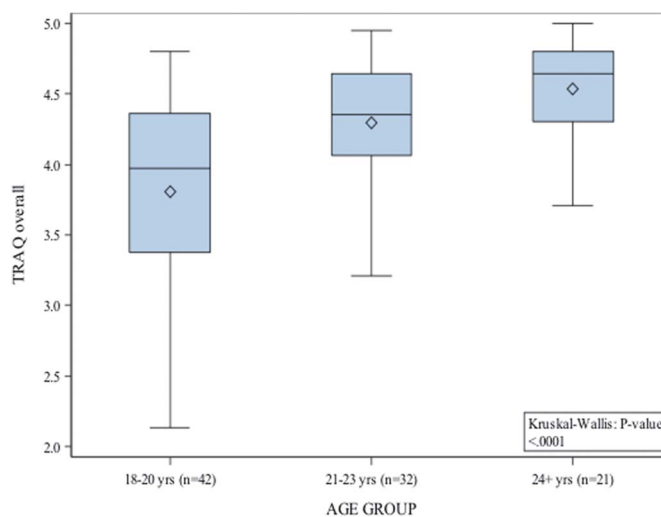


FIGURE 2. Overall TRAQ scores by age group.



Overall, there was a correlation between age and depression ( $r = 0.2$ ,  $P = 0.04$ ). Patients who scored higher on the MHI (better mental health) were less likely to talk with providers ( $r = -0.02$ ,  $P = 0.04$ ), whereas those subjects who scored higher on the depression scale (higher risk for depression) were more likely to talk openly with providers ( $r = 0.29$ ,  $P = 0.004$ ). No correlation was observed between TRAQ scores and anxiety or depression subscores.

## Disease Outcomes

Overall TRAQ score was not statistically different between adherent and nonadherent patients ( $n = 30$ ); however, nonadherent patients scored significantly lower on managing medications (median: 4.25 [IQR: 3.3–4.8] versus 4.75 [IQR: 4.3–5.0],  $P < 0.01$ ). Although talking with providers was significantly higher in the adherent patients compared with the nonadherent group ( $P$  value 0.04), this was not significant at the Holm's adjusted alpha level of 0.0125. During the 6-month follow-up period, a total of 9/95 patients (10%) had hospitalizations or ED visits related to IBD. There were no associations between TRAQ scores and hospitalizations/ED visits. Two of the hospitalizations during the study period were for elective ileocolic resections; excluding these 2 patients failed to demonstrate any significant differences in TRAQ scores compared with patients who had no hospitalizations/ED visits.

The survival curve for patients with hospitalizations/ED visits and overall TRAQ score is shown in Figure 3A, and survival curve for medication management subscore among these patients is shown in Figure 3B. Neither the overall TRAQ score nor any of the subscores were predictive of hospitalization, using a cutoff of  $<4$  or  $<4.75$  depending on the subscore. Logistic regression analysis showed that patients who scored  $<4.75$  on the medication management subscale were 3.8 times more likely to be nonadherent with medications or visits than patients who scored 4.75 and above (95% confidence interval, 1.4–10.3). This remained significant after adjusting for both gender and age.

## DISCUSSION

The transition period from pediatric to adult care can be a difficult time for some young adults with IBD. Although other pediatric subspecialties have established transition programs and protocols that have led to improved outcomes,<sup>12–14</sup> pediatric gastroenterologists have little guidance on optimizing readiness and what factors are most impactful on the process. Moreover, there are no longitudinal data tying readiness to disease outcomes. This study is unique in that it is the first to examine factors that may impact readiness in IBD patients being cared for in either an adult or pediatric care setting. Our study demonstrated that older patients scored higher on the transition readiness assessment, as age was independently associated with higher TRAQ scores. The linear relationship between age and transition readiness is consistent with findings from other studies on the transition process for IBD patients.<sup>11,16</sup> We found that patients who scored  $<4.75$  on the

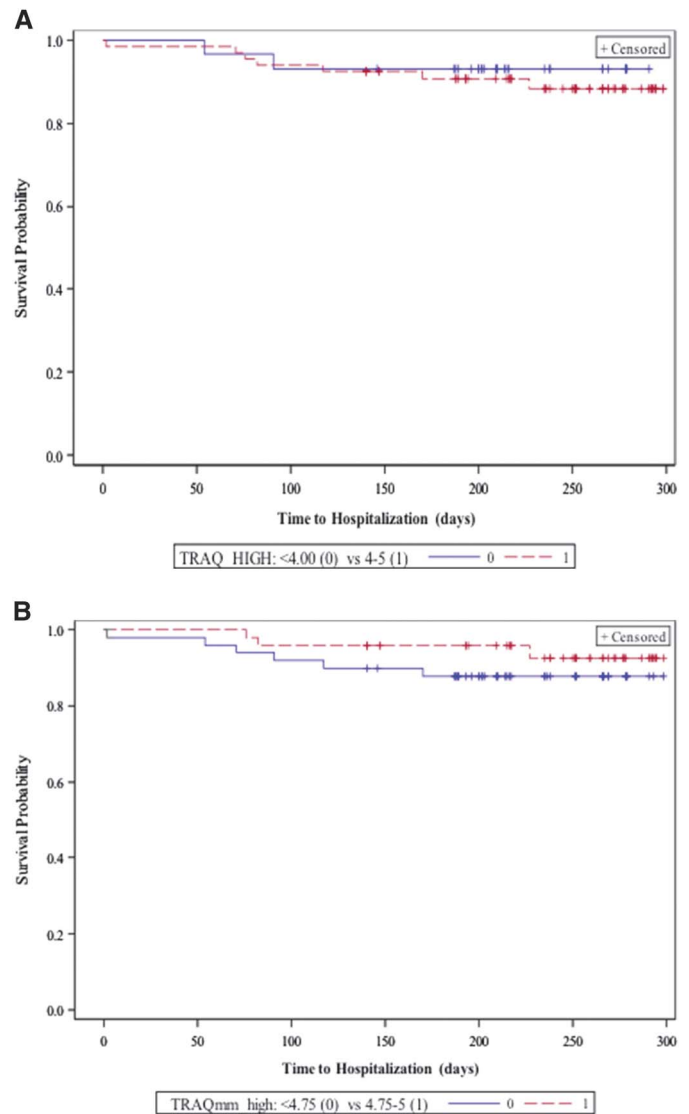


FIGURE 3. A, Time to hospitalization survival curve for overall TRAQ score among patients with ED visits/hospitalizations. B, Time to hospitalization survival curve for medication management TRAQ subscore among patients with ED visits/hospitalizations.

medication management portion of the TRAQ were 3.8 times more likely to exhibit medication or visit nonadherence compared with patients who scored  $\geq 4.75$ . Although Gray et al and the Transition Task Force proposed a mastery level of 90% of transition readiness skills, which would correlate to an overall score of 4.5, perhaps 4.75 is a better cutoff to use as we were able to demonstrate a difference in adherence outcomes at this level.

Given the unpredictability that the transition period can bring, patients are at risk of being lost to follow up and may struggle with adhering to medication and clinic protocols.<sup>6–9</sup> This time of instability may result in more ED visits with subsequent hospitalizations. However, in our short-term follow-up period, TRAQ scores were not associated with these outcomes.

We chose to study an older population of patients as even though there is some debate as to when is the appropriate time to begin transitioning. Our theory was that by age 18 patients generally have completed high school and the topic of transitioning to adult care has been broached by providers. When we asked patients whether the topic of transition had ever been addressed, pediatric gastroenterologists were not routinely having this discussion. Only half of the patients in the pediatric care setting reported that transition had been discussed, and a significant proportion (1/3) of patients managed in our adult care setting were transferred from their pediatric gastroenterologist without a transition plan in place. However, simply increasing pediatric provider awareness and discussing transition with patients may not be enough to improve self-management skills and increase readiness.<sup>26</sup>

The Transition Task Force consensus recommends that patients should be in a quiescent or mild disease state at the time of transfer. Most of the patients in our study had quiescent or mild disease, and so while the findings may not apply to those with more severe disease, our population is representative of young adults who should be ready to transition to adult care. We chose to focus only on patients coming for a scheduled outpatient visit, which may explain the low disease severity in this population. The linear relationship between disease severity and higher TRAQ scores is counterintuitive, as it was believed that patients with worse disease severity would have lower TRAQ scores. Pairwise comparison testing showed that this was primarily driven by age as older patients had more moderate–severe disease, and so further studies are needed to look at TRAQ scores and PGA when controlled for age.

This study had several strengths. It is the first study to look at short-term outcomes in IBD patients prospectively during the transition period. The fact that TRAQ scores were independently associated with age suggests that although older patients may have the maturity and organizational skills to take control of their disease, expectations should be managed as younger patients may not have developed these self-management tools. The cutoff score of <4.75 on the medication management portion of the TRAQ has important clinical implications as well, as these findings suggest that administering specifically the medication management portion of the TRAQ can be used as a screening tool to identify patients at risk for nonadherence and potentially worse long-term outcomes later on.

A principal limitation of this study was the short-term follow-up, which resulted in a small number of patients who were either hospitalized or had ED visits within 6 months. With a longer follow-up period, we may have been able to demonstrate a significant association between TRAQ scores and disease-specific outcomes. Hospitalizations or ED visits at outside hospitals may have been missed if not reported to the physician or not documented. Nonadherence to medications may also have been underreported if not disclosed to the physician or not documented in the medical record. In addition, physician selection bias may have contributed to the lack of association of mental health scores and transition readiness. The treating physician was

first asked if the patient should be approached and occasionally a physician reported that for psychosocial or mental health reasons, a patient would not be a good candidate to complete the survey. However, patients who scored higher on the depression screening were more likely to speak openly with providers; thus patients at risk for depression who are willing to talk about their concerns should not be dismissed.

Long-term follow-up studies in young adults are needed to follow IBD patients longitudinally through the transition period to document how readiness impacts disease outcomes. The TRAQ is 1 tool that can be used to identify domains of readiness skills that need improvement. Targeted interventions can then be used to improve areas in which patients are deficient and are currently being developed at our institution. TRAQ scores can be monitored over time to see whether readiness improves throughout the transition process. Little is known about the utility of the TRAQ in adult patients, and so future studies could look at an older cohort of patients to see at what age maximum TRAQ scores are achieved. The ultimate goal is to create a successful transfer from pediatric to adult practitioner without lapses in care. By optimizing readiness, a smooth and continuous transition process can be ensured for all patients.

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