

# Self-efficacy and Resilience Are Useful Predictors of Transition Readiness Scores in Adolescents with Inflammatory Bowel Diseases

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**Background:** Adolescence is a vulnerable period for those afflicted with inflammatory bowel disease (IBD). There is limited knowledge of factors influencing transition readiness in this population. We sought to determine whether self-efficacy and resilience would be informative predictors of transition readiness independent of age.

**Methods:** Patients with IBD aged 16 to 23 years cared for in a pediatric setting were prospectively enrolled. On entry, patients filled out the Transition Readiness Assessment Questionnaire (TRAQ); IBD Self-Efficacy Scale—Adolescent (IBD-SES-A); and the Connor–Davidson Resilience Scale. Demographic data and disease-specific information were collected from the medical record and by the provider. General linear modeling and autocorrelation were performed to investigate predictors of transition readiness.

**Results:** Eighty-seven patients (62 Crohn's disease and 25 ulcerative colitis) were included, with a median age of 19 years (interquartile range 1–3: 17–20; min–max: 16–23). After controlling for age, the IBD-SES-A predicted TRAQ [F(1) = 11.69, R<sup>2</sup> = 0.16, P = 0.001], accounting for 16% of the variance. The Connor–Davidson Resilience Scale also independently predicted TRAQ score [F(1) = 6.45, R<sup>2</sup> = 0.09, P = 0.01], accounting for 9% of the variance. The IBD-SES-A and Connor–Davidson Resilience Scale were significantly auto correlated (r = 0.044, P = 0.001); in the final predictive model, only IBD-SES-A was predictive of TRAQ [F(1) = 4.01, R<sup>2</sup> = 0.12, P = 0.004]. None of the patients' demographic, disease, or socioeconomic parameters informed transition readiness once self-efficacy and resilience were considered.

**Conclusions:** This is the first study to identify a reliable predictor of transition readiness scores in adolescents with IBD that does not seem to be influenced by age.

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**Key Words:** inflammatory bowel disease, transition, adolescents, self-efficacy, resilience

Adolescents with inflammatory bowel disease (IBD) including Crohn's disease (CD) and ulcerative colitis (UC) make up a growing proportion of pediatric patients with chronic illness transitioning into adult-centered care.<sup>1</sup> This segment of the population with IBD is particularly vulnerable to poorer outcomes and higher health costs, attributed in part to reduced continuity of care during the shift from pediatric to adult-centered care settings.<sup>2,3</sup> There has been increased focus on how to bolster

“readiness” for the inevitable health care transition with the goal of improving disease outcomes.<sup>4</sup> Many planned health care transition programs assess transition readiness with the validated self-report questionnaire, the Transition Readiness Assessment Questionnaire (TRAQ).<sup>4</sup> Scores on this tool are intended to facilitate discussion around the adult skills the teen must acquire before a successful transition. Unfortunately, despite several attempts to show the association between TRAQ scores and any number of clinical or demographic factors in teens with IBD, the only true predictor of transition readiness to date in IBD has been older age at the time of transfer to adult-centered care.<sup>5–7</sup> The main reason for this limitation is that several of the TRAQ items are not actually developmentally appropriate for most patients with IBD until the age of 20 years, often after transfer of care has occurred.<sup>8</sup> Age is not a modifiable characteristic, and therefore, there is strong need for alternate measures that can be used to remedy potential risk factors for poor transition readiness well before the child is at the point of transfer to adult-centered care.

Transition readiness can be thought of more broadly as a set of specific skills acquired during the course of successful lifelong disease self-management which includes 3 core domains: (1) proper medical or surgical management, (2) management of

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emotions, and (3) living a meaningful life with IBD.<sup>9</sup> Two overlapping psychological strengths, self-efficacy and resilience, have been identified as critical predictors of these 3 disease self-management skills and, when present, are associated with positive outcomes.<sup>10,11</sup> We suspect that, even though not previously tested, self-efficacy and resilience are particularly relevant to adolescents and young adults at the time of health care transition. Self-efficacy is defined by one's *perceived confidence* in his/her ability to currently perform or, in younger children, eventually perform any number of behaviors required for one to independently manage IBD (e.g., adherence, knowledge, emotion regulation).<sup>12,13</sup> *Resilience*, or one's ability to bounce back from obstacles, has been long studied as a protective factor for trauma<sup>14</sup> and has more recently been applied to health outcomes.<sup>15,16</sup>

In this study, we sought to determine whether measures of resilience and self-efficacy would offset the limitations of the TRAQ tool and serve as a novel way of approaching transition readiness.

## MATERIALS AND METHODS

### Patient Population

Patients aged 16 to 23 diagnosed with CD or UC willing to participate were enrolled between April and August 2016 at a tertiary IBD center as part of an open-label transition intervention study, whose aim was to identify transition-aged patients who were not adequately prepared for transfer and to provide competency-directed interventions for more than a 6-month period to improve the patients' TRAQ score. Competency-directed interventions included the following: managing medication, appointment keeping, tracking health issues, talking with providers, and managing daily activities. The study was approved by the Institutional Review Board at the Icahn School of Medicine at Mount Sinai (HS#15-00555, GCO#15-1141).

### Data Collection

This study reports on the data collected at baseline only. Demographic data were collected at baseline as well, including sex, current age, age at diagnosis, years from diagnosis, and disease type. Socioeconomic data included parental education and number of siblings. School absence in the last 3 months and an overall health rating were reported by the patients. The provider assessed disease activity with either the Harvey-Bradshaw Index<sup>19</sup> for patients with CD or the Simple Clinical Colitis Activity Index<sup>20</sup> for patients with UC at the time of the visit. Disease extension and location were assessed using the Montreal Classification.<sup>21</sup>

### Questionnaires

TRAQ consists of 20 items with a 5-point Likert scale (range 20–100). Items are divided among 5 domains: appointment keeping, tracking health issues, managing medications, talking with providers, and managing daily activities. There is no exact cutoff for readiness, but a higher score represents better performance. IBD Self-Efficacy Scale—Adolescent (IBD-SES-A)<sup>17</sup> is

**TABLE 1. Demographics**

	Median	IQ1–IQ3 (min:max)
N = 87 (%)		
Male/female	51/36	(59/41)
UC/CD	25/62	(29/71)
	Median	IQ1–IQ3 (min:max)
Age	19	17–20 (16:23)
Frequency of age <18/18+ (%)	26/61	(30/70)
Age of the < 18 yr group	17	16–17 (16:17)
Age of the 18+ yr group	19	19–20 (18:23)
Age at diagnose	14	11–16 (2:20)
Years from diagnose to inclusion	5	2–7 (0:17)
Disease extension, N (%)		
UC		
E1, proctitis		2 (8)
E2, left-sided		3 (12)
E3, extensive		20 (80)
CD		
A1, disease onset ≤16 yr		56 (90)
A2, disease onset 17–40 yr		6 (10)
L1, terminale ileum		7 (11)
L2, colon		13 (21)
L3, ileocolon		24 (39)
L4, upper gastrointestinal disease		2 (3)
L1, L2, L3 + L4		2/0/14 (3/0/23)
P, perianal disease modifier		8 (13)
B1, nonstricturing, nonpenetrating		49 (79)
B2, stricturing/B3, penetrating		8/6 (13/10)
Disease activity at inclusion: (missing 1), N (%)		
SCCAI, UC		
0–2, remission		17 (71)
3–4, mild–moderate		5 (21)
>4		2 (8)
HBI, CD		
0–4, remission		59 (95)
5–7, mild disease		2 (3)
8–16, moderate		1 (2)
>16, severe		0 (0)
Socioeconomic demographic: (missing 18), N (%)		
Parents' highest education		
Less than high school/high school		5 (7)
Some college or associated degree		6 (9)
College		23 (33)
Postgraduate degrees		32 (46)
Do not know		3 (4)

HBI, Harvey-Bradshaw Index; IQ, interquartile range; SCCAI, Simple Clinical Colitis Activity Index.

**TABLE 2.** Mean of the Total Score

	N (%)	All, Mean ± SD	<18 yr, Mean ± SD	18+ yr, Mean ± SD
TRAQ total score (20–100)	73 (84)	75.14 ± 13.87	65.90 <sup>a</sup> ± 15.78	78.62 <sup>a</sup> ± 11.40
IBD-SES-A (13–65)	68 (78)	52.49 ± 5.43	51.11 ± 5.47	53.00 ± 5.39
CD-RISC (0–40)	73 (84)	30.45 ± 5.49	29.6 ± 5.75	30.77 ± 5.42

<sup>a</sup>Significant difference between the age group <18 years and 18+ years, *P* value <0.05.

disease-specific and consists of 13 items with a 5-point Likert scale (range 13–65) and measures confidence in various self-management tasks: managing medical care, managing everyday life with IBD, managing feelings, and managing the future with IBD. A higher score represents better performance. Ten-item Connor–Davidson Resilience Scale (CD-RISC)<sup>18</sup> contains 10 items with a 5-point Likert scale (range 0–40). Items are not disease-specific and measure one’s ability to bounce back from adversity. A higher score represents greater resilience.

**Statistical Analysis**

Frequency, median, mean, and SDs were used to describe the data. Given the dependence of TRAQ scores on age, independent sample *t* tests were used to compare age groups (older and younger than 18 years) when appropriate. General linear modeling and autocorrelation were performed to investigate

associations among the questionnaires and patient characteristics. *P* values <0.05 were considered significant. Analyses were performed using SAS Enterprise Guide 7.

**RESULTS**

**Study Population**

A total of 87 (51 males and 36 females) of 112 eligible patients seen during the time period of the study were enrolled: 25 UC and 62 CD. There were no demographic differences (age, disease type, and provider) between those who enrolled versus those who refused. Primary reasons for refusal were not having enough time before the doctor saw them, running late (*N* = 16), or not feeling well enough to participate in research (*N* = 9). The median age of the participants was 19 years (interquartile range

**TABLE 3.** Results: General Linear Modeling Between Questionnaires and Patient’s Characteristics

	TRAQ			TRAQ, 18+ years <sup>a</sup>			IBD-SES-A <sup>b</sup>			CD-RISC <sup>c</sup>		
	F(1)	R <sup>2</sup>	<i>P</i>	F(1)	R <sup>2</sup>	<i>P</i>	F(1)	R <sup>2</sup>	<i>P</i>	F(1)	R <sup>2</sup>	<i>P</i>
<b>Patient characteristics</b>												
Gender	0.02	0.0003	0.89	0.66	0.01	0.43	1.18	0.02	0.28	0.51	0.01	0.48
Age	16.88	0.19	<b>0.0001</b>	3.57	0.07	0.06	2.85	0.04	0.10	0.01	0.0001	0.92
Disease (CD/UC)	0.12	0.002	0.73	0.70	0.01	0.41	0.98	0.01	0.32	1.09	0.02	0.3
Age at diagnose	0.56	0.008	0.46	5.50	0.10	<b>0.02</b>	0.14	0.002	0.71	0.14	0.002	0.71
Years from diagnose to inclusion	0.72	0.01	0.40	2.70	0.05	1.11	1.07	0.02	0.30	0.21	0.003	0.65
<b>Disease activity</b>												
SCCAI, UC	0.15	0.02	0.86	1.49	0.13	0.25	0.05	0.01	0.95	0.56	0.07	0.56
HBI, CD	1.23	0.05	0.30	2.42	0.12	0.10	0.30	0.01	0.74	0.32	0.05	0.33
Overall health rating	2.01	0.09	0.12	2.35	0.14	0.09	2.64	0.11	0.06	1.26	0.06	0.3
School absence	4.26	0.31	<b>0.001</b>	3.59	0.34	<b>0.006</b>	1.32	0.12	0.26	1.89	0.17	0.10
<b>Socioeconomic demographic</b>												
Highest educated parent’s education	1.94	0.17	0.09	0.99	0.08	0.43	1.10	0.10	0.37	0.70	0.07	0.65
Siblings	0.64	0.07	0.72	0.32	0.04	0.90	1.11	0.12	0.37	0.98	0.11	0.45

Bold indicates significant *P* values.

<sup>a</sup>No significant results in the age group <18 years.

<sup>b</sup>No significant results in the analysis of IBD-SES divided in age <18/18+ years.

<sup>c</sup>No significant results in the analysis of CD-RISC divided in age <18/18+ years.

HBI, Harvey–Bradshaw Index; SCCAI, Simple Clinical Colitis Activity Index.

**TABLE 4.** Mean Score of Items in the IBD-SES-A and CD-RISC Questionnaires

	Mean ± SD
<b>IBD-SES-A</b>	
1. I understand what IBD is	4.49 ± 0.70
2. If someone asked me, I could explain what a colonoscopy is for	4.52 ± 0.72
3. Remembering to take my IBD medication is hard	3.62 ± 1.27
4. I can get through my day, even if I have symptoms like abdominal pain or fatigue	4.06 ± 0.95
5. I worry about how IBD will affect my future	2.72 ± 1.19
6. When asked, I can remember the names of my current IBD medications and what they are used for	4.30 ± 0.93
7. When I am feeling frustrated about having IBD, I have someone I can turn to	4.19 ± 0.96
8. I feel comfortable talking to a IBD doctor about my questions or concerns	4.57 ± 0.61
9. No matter where I am, I can find foods that I can eat	4.25 ± 0.98
10. I know what to do when I think a flare is starting	3.77 ± 1.00
11. I know where to find reliable answers if I do not understand what my IBD doctor tells me	3.75 ± 0.88
12. I know what will make me feel better even when I am sad, frustrated, scared, angry, or annoyed	3.96 ± 0.76
13. I am hopeful that my IBD symptoms will get better	4.46 ± 0.72
<b>CD-RISC</b>	
1. Able to adapt to change	3.12 ± 0.74
2. Can deal with whatever comes	3.10 ± 0.77
3. See the humorous side of things	2.92 ± 0.91
4. Coping with stress strengthens	2.68 ± 0.97
5. Tend to bounce back after illness or hardship	3.09 ± 0.81
6. You can achieve your goals	3.45 ± 0.66
7. Under pressure, focus and think clearly	2.80 ± 0.97
8. Not easily discouraged by failure	2.70 ± 1.04
9. Think of self as a strong person	3.29 ± 0.74
10. Can handle unpleasant feelings	3.03 ± 0.96

1–3: 17–20; min–max: 16–23), with a median age of disease onset of 14 years (interquartile range 1–3: 11–16; min–max: 2–20). The median duration of percent life lived with the disease was 23.5% (interquartile range 1–3: 11.8–38.9; min–max: 0–89.5). Most participants (88%) were in clinical remission. See Table 1 for demographic data.

**Transition Readiness**

The mean score (SD) of the TRAQ questionnaires was 75.14 (13.87) (Table 2). TRAQ total scores were significantly different between the age group <18 years and 18+ [t(df) = 26.84, P = 0.003], with the older group exhibiting higher levels of readiness. We investigated associations between demographic data and the TRAQ score and found a significant positive association between TRAQ and age [F(1) 16.88; R<sup>2</sup> 0.19; P = 0.0001; estimate 3.53; 95% confidence interval 1.81–5.24] and

a significant negative association with absence from school [F(1) 4.26; R<sup>2</sup> 0.31; P = 0.001; estimate –24.43; 95% confidence interval –36.52 to –12.33]. None of the disease or socioeconomic parameters were found to be predictive of the TRAQ score. Dividing patients into 2 groups depending on age (<18/ and 18+ years), we found a significant association between age at diagnosis and the TRAQ score in the group 18 years or older [F(1) 5.50; R<sup>2</sup> 0.10; P value 0.02; estimate 0.93; 95% confidence interval 0.13–1.73] (i.e., a higher age at diagnosis was associated with a higher TRAQ score) (Table 3).

**Self-efficacy and Resilience**

The mean scores (SD) of the SES-IBD-A and CD-RISC were 52.49 (5.43) and 30.45 (5.49), respectively. There were no differences between scores when divided into the 2 age groups (<18 and 18+ years). The IBD-SES-A and CD-RISC items and mean scores are listed in Table 4. The mean scores (SDs) of the domains in the IBD-SES-A, from lowest to highest score were as follows: managing the future with IBD (3.34 [0.88]), managing everyday life with IBD (4.02 [0.24]), managing feelings (4.07 [0.16]), and managing medical care (4.21 [1.64]).

In the investigation of predictors of IBD-SES-A and CD-RISC, none of the patients’ demographic, disease, or socioeconomic parameters were found to be significant, Table 3. Dividing patients by age group (18+ versus <18 years) did not alter the nonsignificant findings.

**Predictors of the TRAQ Score**

We investigated whether the IBD-SES-A and CD-RISC could predict transition readiness. The IBD-SES-A score,

**TABLE 5.** GLM Between the Questionnaires

	F(1)	R <sup>2</sup>	P
<b>GLM of TRAQ</b>			
IBD-SES-A	11.69	0.16	<b>0.001</b>
+adjusted for age	11.47	0.27	<b>0.006</b>
CD-RISC	6.45	0.09	<b>0.01</b>
+adjusted for age	11.13	0.25	<b>0.009</b>
<b>Total model of TRAQ</b>			
	4.01	0.12	0.02
IBD-SES-A <sup>a</sup>			0.04
CD-RISC			0.40
<b>Total model of TRAQ</b>			
	6.06	0.24%	<b>0.001</b>
IBD-SES-A			0.12
CD-RISC			0.21
Age			<b>0.004</b>

Bold indicates significant P values.

<sup>a</sup>The autocorrelation of IBD-SES-A and CD-RISC: r 0.044 P value 0.001.

GLM, general linear modeling.

independent of age, predicted TRAQ [F(1) = 11.69, R<sup>2</sup> = 0.16, P = 0.001], accounting for 16% of the variance. CD-RISC also independently predicted TRAQ score, distinct from age [F(1) = 6.45, R<sup>2</sup> = 0.09, P = 0.01], accounting for 9% of the variance (Table 5). IBD-SES-A and CD-RISC were significantly auto correlated (r = 0.044, P = 0.001); in the final model, only self-efficacy was significantly predictive of TRAQ [F(1) = 4.01, R<sup>2</sup> = 0.12, P = 0.004].

## DISCUSSION

Previous studies have consistently demonstrated that the only predictor of transition readiness, as measured by the TRAQ, is the nonmodifiable characteristic of age.<sup>5–7</sup> This study is the first to identify a reliable predictor of transition readiness in teens and young adults with IBD that does not seem to be influenced by age. By focusing more on psychological characteristics affecting lifelong successful self-management and choosing a strength-based model of transition care, we were able to preliminarily demonstrate the utility of assessing self-efficacy and resilience in pediatric patients with IBD as they approach transition age.

We found that self-efficacy or confidence in one's ability to meet the changing demands of IBD accounted for almost 40% of the variance in transition readiness. This mirrors previous work among youth aged 6 to 17 years with mixed chronic disease attending a summer camp, which showed that internal (versus external) health locus of control, or feeling one is responsible for the management of one's disease, was a primary predictor of transition readiness.<sup>22</sup> Another study from the same group showed that self-efficacy predicted the likelihood that a child would learn new information about disease self-management from their health care provider.<sup>8</sup> Self-efficacy has previously been shown to be highly sensitive to change with behavioral intervention in IBD.<sup>23</sup> We used a disease-specific self-efficacy scale, the SES-IBD-A, which has been validated in children as young as 10 years,<sup>13</sup> whereas this study restricted participation to 16 years and older; we suspect that it is possible to begin preparing a child for independent self-management and subsequent transition readiness at a much earlier age.

Resilience is an important strength-based construct that has relevance to chronic disease management including IBD. Resilience, as measured by the CD-RISC-10, predicted transition readiness scores independent of age, but when incorporated more broadly with self-efficacy, it did not seem to have added value. This is likely due to (1) resilience and self-efficacy being overlapping constructs (in this study, both were significantly auto correlated—however, these 2 constructs may not be as highly correlated in other settings or in younger patients) and (2) the self-efficacy scale being focused very specifically on disease self-management tasks which directly related to the outcome measure of transition readiness; however, resilience is associated with improved health and quality of life across a wide range of physical and mental health conditions<sup>14–16</sup> and should probably still be considered in transition readiness assessment.

Consistent with previous reports, we found that the TRAQ score was affected by age. Interestingly, we also found that younger

age of diagnosis did impact the TRAQ score negatively once the sample was stratified by 18 years old. This finding highlights the negative impact of IBD on maturity and the need to empower patients during childhood. Another possibility explaining this difference is that patients diagnosed earlier had a more severe disease course; however, these data were not available for interpretation.

The main limitation of our study was the cross-sectional design such that a longitudinal data set would have offered more complete information on the impact of self-efficacy and resilience on transition readiness over time. Because of the lack of longitudinal data, we have chosen general linear modeling analyses to measure the predictive values. Moreover, the data were collected from only one tertiary IBD care center, with the risk of an overly homogenous patient population.

This is the first study to identify predictors of transition readiness independent of age. Reconceptualization of the transition challenge from a broader self-management theory provides an opportunity to think about how psychological strengths can be bolstered well before transition to adult-centered care would occur. Self-efficacy was a strong predictor of transition readiness and has been shown to be both predictive of disease outcomes and modifiable with behavioral intervention. There are currently limited opportunities to prepare the pediatric patient with IBD for adult-centered care, and given all the other health care needs of the emerging adult with IBD,<sup>24,25</sup> we recommend using a strength-based approach to IBD care focused on building confidence in one's independent self-management skills and fostering resilience in the face of adversity. For example, interventions focused on teaching patients disease-specific self-management skills (pill swallowing, injections, symptom tracking, and appointment making and keeping) as well as tools for coping with managing the emotions that come from the disease and obstacles along the way (deep breathing, cognitive restructuring, and flexible problem solving exercises). Self-efficacy and resilience can be assessed and altered well before transition would occur, to ensure a smoother less time-intensive transition process especially among the highest risk patients.

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