Moving On: Transition Readiness in Adolescents and Young Adults With IBD

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Background: Inflammatory bowel diseases (IBD) often begins early in life. Adolescents and young adults (AYA) with IBD have to acquire behaviors that support self-care, effective healthcare decision-making, and self-advocacy to successfully transition from pediatric to adult health care. Despite the importance of this critical time period, limited empirical study of factors associated with transition readiness in AYA exists. This study aimed to describe transition readiness in a sample of AYA with IBD and identify associated modifiable and nonmodifiable factors.

Methods: Seventy-five AYA (ages 16–20) and their parents participated. AYA and parents reported on demographics, patient-provider transition-related communication, and transition readiness. AYA self-reported on disease self-efficacy. Disease information was abstracted from the medical record.

Results: Deficits in AYA responsibility were found in knowledge of insurance coverage, scheduling appointments, and ordering medication refills. Older AYA age, higher AYA disease-management self-efficacy, and increased patient-provider transition communication were each associated with higher overall transition readiness and AYA responsibility scores. Regression analyses revealed that older AYA age and increased patient-provider transition-related communication were the most salient predictors of AYA responsibility for disease management and overall transition readiness across parent and AYA reports.

Conclusions: AYA with IBD show deficits in responsibility for their disease management that have the potential to affect their self-management skills. Findings suggest provider communication is particularly important in promoting transition readiness. Additionally, it may be beneficial to wait to transition patients until they are older to allow them more time to master skills necessary to responsibly manage their own healthcare.

Key Words: pediatric inflammatory bowel disease, transition readiness, patient-provider communication, self-efficacy

INTRODUCTION

Inflammatory bowel diseases (IBD) are chronic gastrointestinal disorders that often begin early in life and include Crohn's disease (CD) and ulcerative colitis (UC). It is estimated that as many as 1 million Americans currently have IBD[1] and recent studies indicate that the prevalence of IBD in children younger than 20 years of age was 43 CD and 28 UC cases per 100,000 in the United States.[2] Since IBD is a chronic disease, adolescent and young adult (AYA) patients eventually must transition from pediatric to adult care. Within the health care system, transition is defined as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult oriented healthcare systems."[3] Ideally, this transition should be gradual and accomplished through promotion of increasingly independent and autonomous behaviors in the patient over time.[3] Additionally, the transition process has been conceptualized as having a beginning (the decision to transition to adult care is made), middle (period of transition preparation aimed at helping AYA develop necessary behaviors that support self-care, effective healthcare decision-making, and self-advocacy), and end (actual successful transfer of care from pediatric to adult care).[4] Empirical investigation of the transition process is important since gaps in continuity of care that occur due to poorly planned transition or unpreparedness for transition can result in poorer health-related outcomes, including decreased frequency of clinic visits and greater levels of nonadherence.[5–7] Adequate preparation for transition through increasing levels of self-management during the transition readiness phase may allow patients to effectively manage their disease and can hopefully facilitate successful disease outcomes into adulthood.

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Within the pediatric IBD transition literature, several guidelines outline key factors thought to be important in promoting successful transition including importance of AYA independence and self-reliance, ongoing discussion of transition between patients and providers, and AYA knowledge of the disease and treatment.[8–10] Limited empirical studies examining transition in IBD also have highlighted several modifiable and nonmodifiable factors associated with transition readiness. For instance, nonmodifiable factors such as older age and female gender are associated with transition readiness skills and increased disease-related self-management.[11–13] Additionally, modifiable factors such as knowledge of disease and treatment history, increased communication with the provider regarding transition of care, and patient self-efficacy also are associated with transition readiness.[10,14–16] Similarly, studies of other pediatric health conditions identify patient-provider relationship factors as important in promoting adherence to treatment and attendance to appointments, self-management skills, and transition readiness.[17–24] Although the aforementioned studies support increased AYA engagement in their healthcare and self-management of their disease, in patients with IBD, it appears responsibility is still mostly or completely deferred to parents for tasks related to clinic visits and acquisition of medications.[14] Additionally, previous studies documented that AYA exhibited deficits related to managing healthcare tasks (eg, scheduling appointments, understanding insurance coverage) and self-management of the condition.[11] This poses a significant concern as it has been shown that GI providers perceive lack of responsibility for one's own care as a major barrier to successful transition.[25]

The present study sought to describe transition readiness in AYA ages 16 to 22 with IBD using a multireporter approach to provide reliable assessments of the various domains of transition readiness. The study also sought to identify bivariate relationships between select nonmodifiable (demographic and disease factors) and modifiable (self-efficacy, patient-physician transition-related communication), and transition readiness. A final goal of the study was to identify the best set of correlates of transition readiness including the aforementioned nonmodifiable and modifiable factors. Such research is a critical first step in providing an evidence-based approach for identifying AYA at risk for low levels of transition readiness and, thus, those who may benefit from targeted interventions. Not only is identification of AYA who are at risk for low transition readiness important, but also, given the focus of this study on modifiable barriers to transition readiness such as self-efficacy and communication, this study has the potential to identify mechanisms by which transition readiness may be improved among AYA with IBD.

MATERIALS AND METHODS

Research Design

This study was a descriptive cross-sectional study examining factors associated with AYA and parent report of transition readiness in a sample of patients with IBD ages 16–22. All AYA were being treated at outpatient pediatric IBD clinics at 3 Midwestern children's hospitals.

Participants

Participants were recruited based on the following inclusion criteria: 1) endoscopically confirmed IBD diagnosis for at least 1 year; 2) age 16 to 22 at time of study enrollment; and 3) parent or legal guardian also willing to participate in the study. AYA participants were excluded who had h significant communication or cognitive impairment, did not speak English, a nonEnglish speaking parent, or any other chronic medical condition requiring daily prescription medication.

Procedure

During a routine outpatient pediatric GI clinic appointment, eligible participants were contacted in person by a study research assistant and given information about the study. AYA and parents provided written consent or assent in accord with Institutional Review Board (IRB) policies. Enrolled AYA and parents completed a one-time questionnaire following the clinic visit. Participants were compensated for their participation.

Materials

Demographic information

AYA self-reported sex, race/ethnicity, and age. Parents provided information on annual family income, parent sex, and parent race/ethnicity.

Participant disease information

Medical records were reviewed for type of IBD (CD, UC, or indeterminate colitis) and diagnosis date, which was defined as date of initial diagnostic endoscopy. Treating physicians also provided a physician global assessment (PGA) rating[26] of clinical disease activity at the time of study enrollment. PGA ratings were provided on a 4-point scale where 0 is no symptoms, 1 is mild disease activity, 2 is moderate disease activity, and 3 is severe disease activity.[26]

IBD self-efficacy

AYA completed the Inflammatory Bowel Disease Self-Efficacy Scale (IBD-SES),[27] a 29-item measure of self-efficacy in IBD self-management. Responses are rated on a 10-point Likert scale ranging from "not sure at all" to "totally sure." Total scores range from 29–290, with higher scores reflecting higher disease-management self-efficacy. Internal consistency of the total score was high in the current sample ($\alpha = 0.97$).

Patient-provider transition-related communication

AYA and parents completed a 2-item study-developed questionnaire of time spent discussing transition-related issues with their IBD provider. Item 1 assessed the frequency of

communication about transition during medical appointments over the past 1 year. Item 2 addressed the typical length of transition-related discussions (measured in minutes) during medical appointments as reported by the patient and parents. A total score for each reporter was computed by multiplying the frequency of transition-related discussions by the length of transition-related discussion, with higher scores reflecting a greater amount of transition-related communication.

Transition readiness

AYA and parents each completed the Readiness to Transition Questionnaire (RTQ)[28] a 26-item measure of transition readiness. In the current analyses, the 2-item Overall Transition Readiness score (RTQ-Overall) and the 10-item Adolescent Responsibility (RTQ-AR) domain score were utilized. Participants rated each item on a 4-point Likert-type scale. Item scores were summed within each domain; composite scores for the RTQ-AR ranged from 10 to 40, and the RTQ-Overall ranged from 2 to 8. Higher scores indicated either greater transition readiness (RTQ-Overall) or greater adolescent responsibility in self-management (RTQ-AR). In the initial validation study, overall transition readiness and domain scores evidenced high internal consistencies (αs = 0.79–0.94 for AYA report, αs = 0.85–0.89 for parent report).[29] Similarly, high internal consistencies were demonstrated in the present sample (αs = 0.76–0.89 for AYA report, αs = 0.86–0.89 for parent report).

Statistical Analysis

All analyses were conducted using IBM SPSS Statistics v. 20. Descriptive analyses were conducted to ascertain whether assumptions underlying parametric analyses were met and to describe the sample with respect to demographic and disease characteristics. Square root transformations were performed to resolve nonnormal distributions for AYA and parent-reported transition-related communication total score and AYA self-efficacy total score. To evaluate Aim 1, descriptive statistics were computed for the RTQ-Overall and RTQ-AR measures as reported by AYA and parents. To evaluate Aim 2, we conducted bivariate correlations to examine associations between nonmodifiable (demographic variables, disease variables) and modifiable (self-efficacy, patient-provider transition-related communication) factors and RTQ scores. To evaluate Aim 3, multiple regression analyses with forward entry were performed to assess the proportion of variance that each of the independent variables of interest contributed to transition readiness; probability of F was used to determine each variable's entry into the regression equation. Separate analyses were conducted for RTQ-Overall and RTQ-AR scores and for each reporter (AYA, Parent) for Aims 2 and 3. Analyses of effect sizes were computed via squared semipartial correlations (r_{sp}^2), which provides the proportion of unique variability predicted by each independent variable whereas controlling for other independent variables. Values of 0.0.01 to 0.089 denote a small effect; values of 0.09 to 0.249 denote a medium effect; and values ≥0.25 denote a large effect.

ETHICAL CONSIDERATIONS

Approval for the study was obtained from the IRBs of participating sites prior to the initiation of any study procedures. Participants ages 18 and older, as well as all parents who chose to participate, provided written consent. Participants ages 17 and younger were asked to provide written assent, and parents provided written consent for their minor child's participation.

RESULTS

Preliminary Analyses

The 122 AYA/parent dyads were approached to participate, and 106 (87%) consented to participate in the study. Of those, 75 completed study questionnaires. Those who did not complete the questionnaires either failed to respond to repeated reminders or informed us they were no longer interested in participating in the study. Demographic information about the final analytic sample of 75 is provided in Table 1.

Readiness for Transition

Table 2 provides descriptive information about parent- and AYA-reported levels of transition readiness. Paired samples *t* test revealed that AYA- and parent-reported RTQ-Overall scores did not significantly differ; however, AYA reported significantly greater RTQ-AR scores than parents

TABLE 1: Participant Demographic Information

Variable	N	Percentage (%)
AYA Gender		
Male	35	53.3
AYA Race/Ethnicity		
Black or African American	3	4.0
Caucasian	65	86.7
Hispanic or Latino	1	1.3
Multicultural or Other Race/Ethnicity	6	8.0
Participating Parent		
Mother	63	84.0
Type of IBD		
CD	56	74.7
UC	17	22.7
Indeterminate colitis	2	2.7
PGA Rating		
No disease activity	43	57.3
Mild disease activity	14	18.7
Moderate disease activity	15	20.0
Severe disease activity	2	2.7

(Table 3). Item analysis of AYA transition readiness (based on the 10 RTQ-AR) items indicated that parents perceived the following tasks as areas of highest AYA responsibility: attending medical appointments (67.1%) and taking medication daily as prescribed (50.1%). The following items, as reported by AYA, were those in which more than 50% of the sample indicated they were regularly assuming responsibility: attending medical appointments (73.7%), taking daily medication as prescribed (71.1%), communicating with medical staff (51.3%), and explaining their medical condition to others (51.3%).

Areas of lower parent-reported AYA responsibility included: knowing details about insurance coverage (68.4%), scheduling primary care appointments (55.3%), and scheduling specialty care appointments (53.9%). AYA-reported the following as areas of weakness with respect to taking primary responsibility: knowing details about insurance coverage (59.2%) and calling in or ordering refills (50.0%).

Factors Associated with Transition Readiness

Older AYA age, higher AYA disease-management self-efficacy, and greater AYA- and parent-reported patient-provider transition communication were each associated with higher AYA- and parent-reported RTQ-Overall and RTQ-AR scores in bivariate analyses (Table 4). Effect sizes ranged from small to medium. In contrast, AYA sex, disease duration, and disease severity were not significantly related to AYA or parent RTQ-Overall or RTQ-AR scores.

In regression analyses with forward entry, with AYA-reported RTQ-Overall scores as the dependent variable, AYA-reported transition communication entered the model first and uniquely explained 25.7% of the variance, a medium effect. Age entered second and explained 7.6% of the variance, a small effect. The overall regression model containing AYA transition communication and age was significant [Multiple $R = 0.58$; F (4, 63) = 16.48, $P < 0.001$], and it accounted for 33% of the variance in overall AYA RTQ-Overall scores, a large effect.

With parent-reported RTQ-Overall scores as the dependent variable, AYA age entered the model first and uniquely explained 21.3% of the variance, a medium effect. AYA-reported transition communication was entered second and explained 8.9%, a small effect, while self-efficacy was entered third and uniquely explained 6.7% of the variance, a small effect. The overall regression model containing AYA transition communication, age, and AYA disease-management self-efficacy was significant [Multiple $R = 0.61$; F (4, 63) = 12.29, $P < 0.001$], and it accounted for 37% of the variance in overall parent-reported RTQ-Overall scores.

With AYA-reported RTQ-AR scores as the dependent variable, age entered the model first and uniquely explained 26.1% of the variance, a large effect. AYA-reported transition communication entered second and uniquely explained 4.2% of the variance, a small effect. Gender was entered third into the model and uniquely explained 4.5%, a small effect, while self-efficacy was entered fourth and uniquely explained 3.9% of the variance, a small effect. The overall regression model was significant [Multiple $R = 0.59$; F (4, 63) = 11.58, $P < 0.001$], and it accounted for 39% of the variance in overall AYA-reported RTQ-AR scores.

With parent-reported RTQ-AR scores as the dependent variable, age entered the model first and uniquely explained 29.1% of the variance, a large effect. No additional variables were added to the model in subsequent steps. The overall regression model was significant [Multiple $R = 0.54$; F (4, 63) = 26.61, $P < 0.001$], and it accounted for 29% of the variance in overall parent-reported RTQ-AR scores.

TABLE 2: Mean, Range, and Standard Deviation of Untransformed Transition Readiness Outcome Variables

Variable	Mean	Range	SD
IBD Self-efficacy	222.94	37–290	52.68
AYA-Reported RTQ-Overall	4.65	2–8	1.64
AYA-Reported RTQ-AR	26.19	12–40	6.84
Parent-Reported RTQ-Overall	4.59	2–8	1.77
Parent-Reported RTQ-AR	23.37	11–40	7.35

Note. RTQ-Overall = Readiness to Transition Questionnaire—Overall Transition Readiness score; RTQ-AR = Readiness to Transition Questionnaire—Frequency of Adolescent Responsibility score; AYA = adolescent and young adult.

TABLE 3: Paired Samples *T*Tests Examining Differences in AYA and Parent Transition Readiness and Adolescent Responsibility Within Reporters

Variables	AYA Report M (SD)	Parent Report M (SD)	t (df)	*P*
RTQ-Overall	4.70 (1.63)	4.59 (1.77)	.53 (72)	0.600
RTQ-AR	26.2 (6.91)	23.27 (7.35)	3.50 (72)**	0.001

RTQ-Overall = Readiness to Transition Questionnaire—Overall Transition Readiness score; RTQ-AR = Readiness to Transition Questionnaire—Frequency of Adolescent Responsibility score.

TABLE 4: Correlations Among Age, Disease Duration, and Transition Readiness Variables

Variables	1	2	3	4	5	6	7	8	9	10	11
1.Age	1	--	--	--	--	--	--	--	--	--	--
2.Gender	0.03	1	--	--	--	--	--	--	--	--	--
3.Disease Duration	0.010	-0.06	1	--	--	--	--	--	--	--	--
4.Disease Severity	0.01	- 0.10	-0.15	1	--	--	--	--	--	--	--
5.Self-Efficacy	0-.02	-0.28	-0.04	0.29[a]	1	--	--	--	--	--	--
6.(AYA) Transition Communication	0.28	0.34	0.07	-0.12	0.01	1	--	--	--	--	--
7.(PR) Transition Communication	0.21	-.11	0.01	-0.03	.02	0.67[b]	1	--	--	--	--
8.(AYA) RTQ-Overall	0.39[b]	0.12	0.28	-0.10	-0.20	0.40[b]	0.17	1	--	--	--
9.(PR) RTQ-Overall	0.39[b]	0.03	0.21	-0.21	-0.26	-0.34[b]	0.20	0.46[b]	1	--	--
10.(AYA) RTQ-AR	0.52[b]	-0.19	0.17	-0.06	-0.13	0.29[a]	0.30[b]	0.53[b]	0.35[b]	1	--
11.(PR) RTQ-AR	0.53[b]	-0.05	-0.02	-0.06	-0.08	0.16	0.16	0.38[b]	0.57[b]	0.49[b]	1

[a]$P < 0.05$, [b]$P < 0.01$; Overall = Readiness to Transition Questionnaire—Overall Transition Readiness; RTQ-AR = Readiness to Transition Questionnaire—Frequency of Adolescent Responsibility; AYA = adolescent and young adult report; PR = Parent report.

DISCUSSION

This study examined modifiable and nonmodifiable correlates of transition readiness in a sample of AYA with IBD. Specific strengths of the study included collecting both AYA and parent report of transition readiness and exploring the role of patient-provider communication, an understudied contributor to transition readiness. Results yielded several important findings. As AYA transition to adult care and attend clinic visits on their own, they will become solely responsible for communicating with and effectively explaining their IBD to their new medical team. In the present study, AYA reported strengths in communicating with medical staff and explaining their medical condition to others. This is a positive finding given that more optimal communication with adult providers has been shown to be associated with a more successful transition overall in patients with other pediatric chronic medical conditions, such as diabetes.[30] Additionally, better patient-provider communication has been documented as positively influencing overall self-management and clinical outcomes.[31]

In contrast, although both medication adherence and appointment attendance are central to independent self-management of a chronic medical condition, both parents and AYA in the present study reported low AYA responsibility for the tasks required to execute optimal medication adherence and appointment attendance in contrast with reported strengths in daily medication adherence and medical appointment attendance. Notably, both parent and AYA reports of adolescent responsibility also indicated low knowledge of insurance coverage details. Overall, these findings are consistent with previous research suggesting that adolescents with IBD demonstrate knowledge deficits related to health care resources and executing self-management tasks, including the number to call to make an appointment, pharmacy name and location, and insurance company.[29,32] Therefore, in AYA with IBD, there may still be deficits in adolescent responsibility for their disease management that have the potential to affect their self-management skills. This is problematic given that parent involvement tends to continue to decrease over the course of the transition to adult care[33] and a lack of clear role expectations between patients and their parents is perceived as a significant barrier to optimal transition readiness.[34]

Additionally, results indicated the importance of older AYA age and greater patient-provider transition-related communication as the most salient predictors of both AYA responsibility for disease management and overall transition readiness across parent and AYA reports. Specifically, age was associated with all 4 transition readiness outcomes. Age also has been documented as a correlate of both transition readiness and IBD-related knowledge in other studies.[29,35,36] The current findings add to the body of literature suggesting that it may be beneficial to wait until patients are older to transition them to the adult medical setting to allow them more time to master the skills necessary to take responsibility for managing their own healthcare from both their own perspective and their parents' perspectives. AYA reported patient-provider communication also was associated with all 4 transition readiness outcomes, whereas parent-reported patient-provider communication was only associated with 2. Of note, information on whether the participating parent was present for entire medical visits was not gathered, which may have impacted how well parents are able to report on transition-related communication. Nonetheless, our results highlight the importance of the patient's perspective of their provider's communication and is consistent with a body of other work supporting relationships between more optimal patient-provider relationship variables and better disease self-management across various chronic medical conditions.[37,38]

TABLE 5: Forward Regression Analyses Evaluating Best Predictors of Readiness to Transition

	B	SE	β	t	R	R^2	F	ΔR^2	ΔF
(AYA) RTQ-Overall									
Step 1					0.51	0.26	23.14[c]		
(AYA) Transition Communication	0.72	0.15	0.51	4.81[c]					
Step 2					0.58	0.33	16.48[c]	0.08	7.56[b]
(AYA) Transition Communication	0.58	0.15	0.41	3.87[c]					
AYA Age	0.42	0.15	0.29	2.75[c]					
(PR) RTQ-Overall									
Step 1					0.46	0.21	17.67[c]		
AYA Age	0.71	0.17	0.46	4.20[b]					
Step 2					0.55	0.30	13.87[c]	0.09	8.13[b]
AYA Age	0.56	0.17	0.37	3.33[b]					
(AYA) Transition Communication	0.48	0.17	0.31	2.85[a]					
Step 3					0.61	0.37	12.29[c]	0.07	6.68[a]
AYA Age	0.56	0.16	.36	3.44[b]					
(AYA) Transition Communication	0.47	0.16	0.31	2.98[a]					
IBD Self-Efficacy	-0.14	0.05	-0.26	-2.58[a]					
(AYA) RTQ-AR									
Step 1					0.51	0.26	23.71[c]		
AYA Age	2.93	0.60	0.51	4.87[c]					
Step 2					0.55	0.30	14.38[c]	0.04	3.99[a]
AYA Age	2.52	0.62	0.44	4.05[c]					
(AYA) Transition Communication	1.24	0.62	0.28	2.00[a]					
Step 3					0.59	0.35	11.58[c]	0.05	4.47[a]
AYA Age	2.42	0.61	0.42	3.98[c]					
(AYA) Transition Communication	1.37	0.61	0.24	2.26[a]					
AYA Gender	-2.86	1.35	-0.21	-2.11[a]					
Step 4					0.62	0.39	10.11	0.04	4.06[a]
AYA Age	2.39	0.60	0.42	4.02[c]					
(AYA) Transition Communication	1.42	0.59	0.25	2.39[a]					
AYA Gender	-3.61	1.37	-0.27	-2.63[a]					
IBD Self-Efficacy	-0.41	0.20	-0.21	-2.02[a]					
(PR) RTQ-AR									
Step 1					0.54	0.29	26.61		
AYA Age	3.37	0.65	0.54	5.16[c]					

[a]$P < 0.05$; [b]$P < 0.01$; [c]$P < 0.001$; RTQ = Readiness to Transition Questionnaire. RTQ-AR = Readiness to Transition Questionnaire—Frequency of Adolescent Responsibility; AYA = adolescent and young adult report; PR = Parent report.

This finding also is consistent with recent work documenting the importance of patient-provider communication on AYA knowledge of condition.[29] Patient-provider transition-related communication likely leads to increased discussions regarding illness management and healthcare resources. Given that both parents and AYA reported these domains as areas of low adolescent responsibility in the present study, it may be more important for providers to focus discussions of transition readiness on AYA patients rather than their parents. This approach may ultimately help to enhance both patient-transition readiness and responsibility for disease management.

Self-efficacy was also associated with transition readiness; however, it appeared a less salient correlate compared to age or transition-related communication, as evidenced by the fact that it was associated with just 2 of 4 transition-readiness outcomes in regression analyses. Self-efficacy has been shown to

be associated with greater IBD-related knowledge among AYA with IBD[29] and self-efficacy is known to influence the degree to which a person engages in their healthcare or takes responsibility for the management of their illness.[27] Notably, our sample reported high IBD-related self-efficacy. Therefore, low variability on this measure may be why this metric appeared less salient than age and patient-provider communication and may have impacted the utility of this metric as a predictor. However, enhancing AYA self-efficacy still ought to be considered when developing interventions to increase adolescent responsibility to disease management and overall transition readiness[39] given that when it was linked to transition readiness, effect sizes were of similar magnitude to those for age and patient-provider communication.

Findings from the present study should be interpreted within the context of several limitations. First, the limited diversity of the sample may hamper the generalizability of our findings across all AYA with IBD. Therefore, future research ought to attempt to include AYA from a wider range of socioeconomic levels and racial/ethnic groups. Second, all participants were recruited during their outpatient GI clinic or infusion clinic visits. Therefore, our sample may better represent AYA with IBD who are adherent in seeking and receiving outpatient care to manage their IBD. This subgroup of patients may have higher levels of transition readiness than their counterparts who do not consistently attend outpatient appointments, particularly since appointment attendance accounted for significant variance in transition readiness as measured by the RTQ in adolescents who had undergone kidney transplants.[28] Third, since participants were recruited during their outpatient visits and parent participation was required for inclusion in the study, our sample consisted of AYA who still attend their pediatric outpatient visits with their parents and, as such, they tended toward the younger range of the AYA spectrum. Thus, our sample may be somewhat less responsible for their disease management and less ready to transition than older AYA who attend their clinic visits independently. Future research ought to employ a recruitment strategy that includes AYA who both attend outpatient visits without a parent present and those who have difficulty regularly attending their clinic visits in an effort to fully capture the AYA IBD population. Fourth, our study relied on self-report measures, which may be vulnerable to social desirability biases, particularly on items asking AYA about their communication with their GI providers. In future studies, it would be beneficial to employ observational assessments to corroborate AYA report. Lastly, while this study shed light on factors that are associated with transition readiness, it did not address whether these factors actually predict successful transfer of care or improve self-management once in adult care. Future research evaluating the impact of transition readiness factors on subsequent transfer to adult health care is needed.

Transition guidelines for AYA with IBD highlight the importance of consistent follow through with disease-management tasks and effective patient-provider communication in addition to IBD-related knowledge.[8] Furthermore, several studies have highlighted the need for a systematic, gradual transfer of responsibility for disease management from parent to child in addition to better communication between patients and providers during the transition process.[40] Our findings suggest that families of AYA with IBD also may benefit from interventions designed to target salient modifiable individual and patient-provider factors, or self-efficacy and patient-provider communication, to support the systematic, gradual transfer of responsibility for key disease-management tasks, especially surrounding medication adherence and appointment attendance. A recent review highlights potential avenues for increasing self-efficacy in patients with IBD and includes interventions such as: problem-solving skills training to increase treatment adherence; promotion of health literacy; supportive counseling by health care team members aimed at increasing engagement in their healthcare, developing self-management plans, and reducing anxiety by increasing coping skills; and engaging patient's family members to help model successful self-management and reinforce patient's efforts at self-management.[41] Additionally, during preparation for transition, AYA with IBD should receive education about their insurance coverage to address the deficits in knowledge in this domain of transition readiness. AYA also may benefit from waiting until they are older to transition. Last, IBD providers ought to engage in frequent and thorough communication regarding transition when preparing their patients for the process, especially given that patient-provider communication has the potential to increase IBD-related knowledge[29] that will in turn promote more optimal levels of transition readiness.

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REFERENCES

1. Loftus CG, Loftus EV Jr, Harmsen WS, et al. Update on the incidence and prevalence of Crohn's disease and ulcerative colitis in olmsted county, minnesota, 1940-2000. *Inflamm Bowel Dis*. 2007;13:254–261.
2. Kappelman MD, Rifas-Shiman SL, Kleinman K, et al. The prevalence and geographic distribution of Crohn's disease and ulcerative colitis in the united states. *Clin Gastroenterol Hepatol*. 2007;5:1424–1429.
3. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the society for adolescent medicine. *J Adolesc Health*. 1993;14:570–576.
4. Telfair J, Alexander LR, Loosier PS, et al. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*. 2004;15:443–461.
5. Bollegala N, Brill H, Marshall JK. Resource utilization during pediatric to adult transfer of care in IBD. *J Crohns Colitis*. 2013;7:e55–e60.

6. Berquist RK, Berquist WE, Esquivel CO, et al. Non-adherence to post-transplant care: prevalence, risk factors and outcomes in adolescent liver transplant recipients. *Pediatr Transplant*. 2008;12:194–200.
7. 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.
8. 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.
9. Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. *Inflamm Bowel Dis*. 2011;17:2169–2173.
10. Hait EJ, Barendse RM, Arnold JH, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*. 2009;48:61–65.
11. Gray WN, Holbrook E, Morgan PJ, et al. Transition readiness skills acquisition in adolescents and young adults with inflammatory bowel disease: findings from integrating assessment into clinical practice. *Inflamm Bowel Dis*. 2015;21:1125–1131.
12. Whitfield EP, Fredericks EM, Eder SJ, et al. Transition readiness in pediatric patients with inflammatory bowel disease: patient survey of self-management skills. *J Pediatr Gastroenterol Nutr*. 2015;60:36–41.
13. Rosen D, Annunziato R, Colombel JF, et al. Transition of inflammatory bowel disease care: assessment of transition readiness factors and disease outcomes in a young adult population. *Inflamm Bowel Dis*. 2016;22:702–708.
14. 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.
15. Dabadie A, Troadec F, Heresbach D, et al. Transition of patients with inflammatory bowel disease from pediatric to adult care. *Gastroenterol Clin Biol*. 2008;32:451–459.
16. Carlsen K, Haddad N, Gordon J, et al. Self-efficacy and resilience are useful predictors of transition readiness scores in adolescents with inflammatory bowel diseases. *Inflamm Bowel Dis*. 2017;23:341–346.
17. Janz NK, Becker MH. The health belief model: a decade later. *Health Educ Q*. 1984;11:1–47.
18. Litt IF, Cuskey WR. Satisfaction with health care. A predictor of adolescents' appointment keeping. *J Adolesc Health Care*. 1984;5:196–200.
19. Hazzard A, Hutchinson SJ, Krawiecki N. Factors related to adherence to medication regimens in pediatric seizure patients. *J Pediatr Psychol*. 1990;15:543–555.
20. Crowley R, Wolfe I, Lock K, et al. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child*. 2011;96:548–553.
21. Binks JA, Barden WS, Burke TA, et al. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil*. 2007;88:1064–1073.
22. Fredericks EM, Lopez MJ. Transition of the adolescent transplant patient to adult care. *Clin Liver Dis*. 2013;2:223–226.
23. Shaw KL, Southwood TR, McDonagh JE; British Paediatric Rheumatology Group. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)*. 2004;43:770–778.
24. Freyer DR, Brugieres L. Adolescent and young adult oncology: transition of care. *Pediatr Blood Cancer*. 2008;50:1116–1119.
25. Wright EK, Williams J, Andrew JM, et al. Perspectives of pediatric and adult gastroenterologists on transfer and transition care of adolescents with inflammatory bowel disease. *Int Med J*. 2014;44:490–496.
26. Hanauer S, Schwartz J, Robinson M, et al. Mesalamine capsules for treatment of active ulcerative colitis: results of a controlled trial. Pentasa study group. *Am J Gastroenterol*. 1993;88:1188–1197.
27. Keefer L, Kiebles JL, Taft TH. The role of self-efficacy in inflammatory bowel disease management: preliminary validation of a disease-specific measure. *Inflamm Bowel Dis*. 2011;17:614–620.
28. Gilleland J, Amaral S, Mee L, et al. Getting ready to leave: transition readiness in adolescent kidney transplant recipients. *J Pediatr Psychol*. 2012;37:85–96.
29. Gumidyala AP, Plevinsky JM, Poulopoulos N, et al. What teens do not know can hurt them: an assessment of disease knowledge in adolescents and young adults with IBD. *Inflamm Bowel Dis*. 2017;23:89–96.
30. Monaghan M, Hilliard M, Sweenie R, Riekert K. Transition readiness in adolescents and emerging adults with diabetes: the role of patient-provider communication. *Curr Diab Rep*. 2013;13:900–908.
31. Plevinsky JM, Greenley RN, Fishman LN. Self-management in patients with inflammatory bowel disease: strategies, outcomes, and integration into clinical care. *Clin Exp Gastroenterol*. 2016;9:259–267.
32. 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.
33. Visentin K, Koch T, Kralik D. Adolescents with type 1 diabetes: transition between diabetes services. *J Clin Nurs*. 2006;15:761–769.
34. Clarizia NA, Chahal N, Manlhiot C, et al. Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider. *Can J Cardiol*. 2009;25:e317–e322.
35. Butcher RO, Law TL, Prudham RC, et al. Patient knowledge in inflammatory bowel disease: CCKNOW, how much do they know? *Inflamm Bowel Dis*. 2011;17:E131–E132.
36. Eaden JA, Abrams K, Mayberry JF. The Crohn's and colitis knowledge score: a test for measuring patient knowledge in inflammatory bowel disease. *Am J Gastroenterol*. 1999;94:3560–3566.
37. Zolnierek KB, Dimatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. *Med Care*. 2009;47:826–834.
38. Kerse N, Buetow S, Mainous AG 3rd, et al. Physician-patient relationship and medication compliance: a primary care investigation. *Ann Fam Med*. 2004;2:455–461.
39. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (part II). *Health Promot Pract*. 2005;6:148–156.
40. Huang JS, Gottschalk M, Pian M, et al. Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams. *J Pediatr*. 2011;159:994–998.e2.
41. Plevinsky JM, Greenley RN, Fishman LN. Self-management in patients with inflammatory bowel disease: strategies, outcomes, and integration into clinical care. *Clin Exp Gastroenterol*. 2016;9:259–267.