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Time to grow up: readiness associated with improved clinical outcomes in pediatric inflammatory bowel disease patients undergoing transition

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Abstract

Background: The transition from pediatric to adult healthcare in individuals with inflammatory bowel disease (IBD) poses significant challenges mainly due to the high burden of IBD during adolescence, a critical period of psychosocial development. So far, there are few longitudinal data linking transition readiness to long-term disease outcomes.

Objective: We aimed to assess patients' readiness to transition and its impact on clinical outcomes, quality of life, and adherence to therapy.

Design: An observational, prospective study was conducted in a tertiary adult and pediatric center, including adolescents aged ⩾17 years with a diagnosis of IBD, who underwent a 'structured transition' program including two joint adult–pediatric visits.

Methods: Transition readiness skills were assessed with the Transition Readiness Assessment Questionnaire (TRAQ). All patients completed the TRAQ at the time of recruitment, which occurred during the initial joint adult–pediatric visit, to determine those deemed ready for transition *versus* those not ready. The Morisky Medication Adherence Scale and the 36-Item Short Form Health Survey Questionnaire (SF-36) were also completed at baseline and after 12 months. Clinical outcomes were collected at the 12-month follow-up.

Results: In all, 80 patients were enrolled who had transitioned through a structured transition clinic and completed 12 months of follow-up. In total, 54 patients were ready for the transition, with a mean TRAQ = 3.2 ± 0.5. The number of clinical relapses and hospitalizations at 12 months was lower in ready compared to not-ready patients ($p = 0.004$ and $p = 0.04$, respectively). SF-36 did not differ between ready and not-ready patients and pre- and post-transition clinics ($p > 0.05$). Based on the receiver operating characteristic curve, a TRAQ cutoff ⩾3.16 could predict medication adherence with a sensibility of 77%, a specificity of 82%, and an AUC of 0.81 (0.71–0.91; $p < 0.001$).

Conclusion: Patients ready for transition had better outcomes at 12 months compared to those who were not ready. Therefore, readiness assessment tools should be integrated into transition management to ensure that interventions are targeted, patient-centered, and responsive to individuals' changing needs.

Plain language summary

Transition readiness associated with improved clinical outcomes

The transition for individuals with inflammatory bowel disease (IBD) is a dynamic and complex process that must be planned and cannot simply be performed once the patient is

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18 years old. Since it does not depend solely on the patient's age but also on developmental readiness, it requires preparation and education starting from early adolescence. In the current study, a 'joint-visit' including both pediatric and adult providers yields positive clinical outcomes over 12 months. Patients ready for transition reported fewer relapses, hospitalizations, and improved therapy adherence compared to those not ready. Readiness assessment tools should be integrated into transition clinics to facilitate targeted interventions for IBD patients based on the changing needs of individuals.

Keywords: adherence, adolescence, health-related quality of life, inflammatory bowel disease, readiness, transition care

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Introduction

Inflammatory bowel diseases (IBD) are chronic-relapsing disorders that include ulcerative colitis (UC) and Crohn's disease (CD). These are characterized by progressive bowel damage that, if left uncontrolled, can result in long-term disability and decreased health-related quality of life (HRQoL), particularly in younger patients.[1,2] A global trend toward an increased incidence of IBD has been reported in Western Countries' children and adolescents over the last 35 years.[3–5] Hence, the need to improve care for these young individuals has been increasingly acknowledged.[6] Indeed, children with IBD face unique challenges in managing a highly demanding and complex disease compared to adults. These primary challenges include growth retardation, delayed puberty, as well as psychological and social issues.[7] As a result, the transfer from pediatric care to adult units could not be a simple transfer but rather a big task requiring an organized structure.[8–11]

Transition is defined as the intentional and carefully planned process of transferring adolescents and young adults with chronic medical conditions from pediatric healthcare systems/providers to those focused on adult care.[12] It is important to emphasize that the transition process must be planned and cannot simply be performed once the patient is 18 years old. Since it does not depend solely on the patient's age but also on developmental psychological maturity, it requires preparation and education starting from early adolescence.[13,14] To date, there is no standardized model for transition care, and there is no strong evidence indicating that one model is superior to others. The European Crohn's and Colitis Organization Topical Review on Transitional Care in Inflammatory Bowel Disease considers a joint pediatric–adult clinic as the ideal model. Nevertheless, they recommend selecting a transition model based on the local availability of resources, such as the option of single or multiple joint appointments, the site of meetings, and the number of participants involved.[15] The ideal transfer scenario involves young adults aged ⩾18 years who are experiencing disease remission with stable medical therapy, demonstrating self-management skills, and possessing the necessary knowledge to become independent and prepared for the transition to adult healthcare providers. However, it is important to recognize that adolescents differ from one another, and their timing for the transition process and their levels of readiness may vary. Therefore, the transition should be a dynamic process that occurs over time, personalized and adaptable to an individual's changing needs. The assessment of transitional readiness, the level to which one acquires the knowledge and skills necessary to self-manage disease, is a crucial element in the transition process.[14] So far, the most widely recognized tool for assessing patient readiness is TRAQ (Transition Readiness Assessment Questionnaire),[16] a 20-item self-reported questionnaire. TRAQ has been extensively utilized in research settings, including studies on several chronic conditions and it has revealed good internal reliability and validity in youth aged 14–26.[10,16–19] However, its application in clinical practice has been limited due to the absence of a clear association between TRAQ scores and long-term health outcomes. Notably, there is no definitive TRAQ indication for determining when an adolescent is adequately prepared for the transition to adult-centered healthcare.[19]

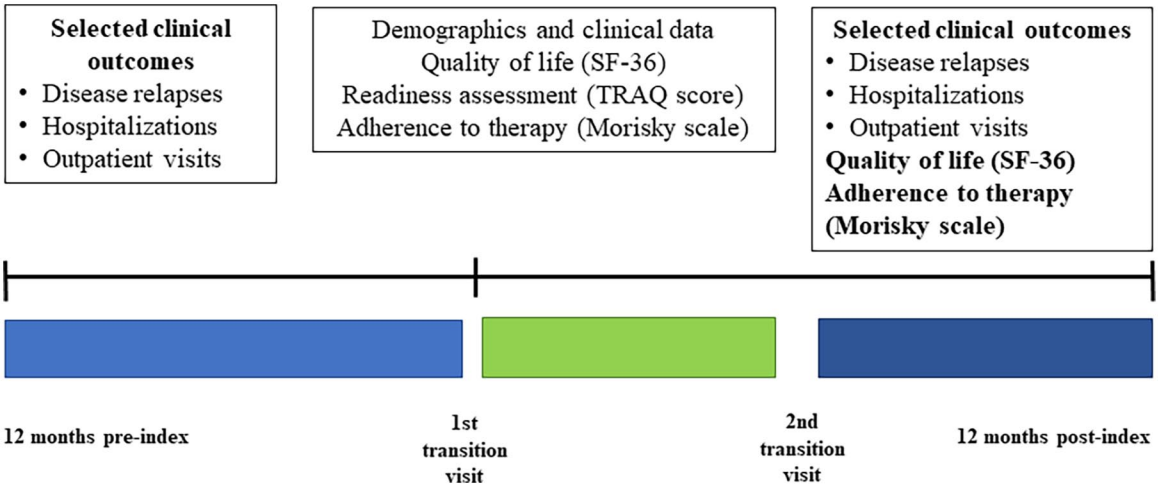

Figure 1. Study flow.

Thus, we aimed to assess the readiness of patients for the transition from pediatric to adult IBD services and investigate its correlation with clinical outcomes. In addition, we determined the impact of the transition program on clinical outcomes, medication adherence, and HRQoL at 12-month follow-up.

Patients and methods

This was an observational, prospective study conducted at the University of Naples Federico II, a tertiary academic IBD referral center. Adolescents aged 17 or older, with a confirmed diagnosis of childhood-onset IBD and currently in clinical remission, were eligible for the study if they had undergone a 'structured transition' from a pediatric to an adult IBD center.

Since 2012, the adult and the pediatric IBD Unit of the University of Naples 'Federico II' has developed a structured transitional program. This program starts by educating patients aged 12 and older regarding the concept of chronic diseases, and the significance of medication and preparing them for the differences in pediatric and adult healthcare models. Throughout this phase, physicians regularly monitor patients to assess their maturity and readiness for planning the transition clinic. The transition clinic itself consisted of two joint outpatient visits: one in a pediatric setting and the other after 3 months in the adult setting. These visits typically involve patients, family members, as well as pediatricians and adult gastroenterologists aiming to introduce the young patient aged ⩾17 years to the new doctor in a friendly and informative manner. All patients underwent both the joint transition clinic visits. During this meeting, the team discusses practical issues concerning transition, instructing the patient on subjects specifically related to disease implications, the importance of medical adherence, and special psychosocial needs/concerns in adulthood (substance abuse, alcohol, contraceptives, pregnancy, education, work).

Demographics and clinical data

We collected demographics, medical history, noninvasive biomarkers such as C-reactive protein (CRP) and fecal calprotectin (FC) clinical data, and endoscopic findings data at the first transition visit (T0) and after 12 months (T1). Clinical disease activity was evaluated according to Crohn's Disease Activity Index (CDAI) for CD patients and Partial Mayo Score (pMAYO) for UC patients. Endoscopic disease activity was evaluated through the main scores, Simple Endoscopic Score for Crohn's Disease, Rutgeerts score for post-operative CD, and Mayo Endoscopic Score for UC. Patients filled out the TRAQ at the time of recruitment. Furthermore, the Morisky Medication Adherence Scale (MMAS) and the 36-Item Short Form Health Survey Questionnaire (SF36) were completed baseline (T0) and 12 months after the transition clinic (T1). The study flow is summarized in Figure 1. We selected as clinical outcomes: the number of outpatient visits, disease relapses, hospitalizations, change of therapy, and body mass

index (BMI) 12 months after the transition visit. Thus, we evaluated the impact of readiness as well as the effectiveness of the transition program on clinical outcomes at 12 months for all patients who attended both joint-visits.

The report of this study conforms to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement.[20]

Transition Readiness Assessment Questionnaire

Transition readiness was assessed using the TRAQ. This is a 20-item questionnaire with a five-point Likert scale (range 20–100), measuring readiness for transitional care in adolescents and young adults affected by chronic disorders.[16] The 20 items are divided into five domains: appointment keeping, tracking health issues, managing medications, talking with providers, and managing daily activities. The questionnaire items are answered ranging from 'I do not need to do this' to 'I always do this when I need to'[16] (Supplemental Material 1). Higher scores indicate greater readiness for transitional care. Scores are calculated for both the overall measure and each domain. The overall score is derived by averaging the 20 items that constitute the total measure, while the domain scores are obtained by averaging the items relevant to each specific domain. This implies that the total scores and domain scores may vary within a range from 1 to 5. An overall readiness skill acquisition score of 3 or higher out of 5 was considered to have met our established benchmark of mastery of transition readiness skills. Conversely, an overall score of less than 3 indicated that patients were not ready.[10,21,22]

Morisky Medication Adherence Scale

Medication adherence was measured using the MMAS. This is an eight-item self-reported questionnaire, assessing adherence to therapy in patients with chronic diseases.[23] We used a modified MMAS for IBD with dichotomous response categories for each item (i.e. yes or no) and a five-point Likert scale for the last item, ranging from 'never/rarely' to 'always'. The total score is calculated as the sum of all MMAS-8 questions and ranges from 0 to 8. Adherence to therapy was defined in the case of MMAS score $\geqslant 6$.

36-Item Short Form Health Survey Questionnaire

HRQoL was assessed by SF-36, evaluating eight health dimensions, including physical function, physical aspects, bodily pain, general health, vitality, mental health, emotional aspects, and social function.[24] The score ranges from 0 to 100, with higher scores showing a more favorable HRQoL (Supplemental Material 3).

Statistical analysis

Baseline descriptive statistics were reported to assess demographics and clinical data, TRAQ score, MMAS, and SF36. Continuous data were reported as mean $\pm$ standard deviation or as medians with interquartile ranges while categorical data as percentages. The *T*-tests and Mann–Whitney *U* test were used to compare continuous variables, and chi-square test or Fisher's exact test was used to compare categorical variables.

A model to predict the high mean TRAQ value associated with medication adherence at 12 months was realized using continuous logistic regression (multivariate analysis) with stepwise selection criteria on significant parameters. An area under the receiver operating characteristic curve (AUROC) was plotted to assess the diagnostic accuracy of TRAQ for predicting adherence. Youden's index was used to identify the best cutoff value that maximizes sensitivity and specificity. Demographic and clinical variables of the transition population associated with the clinical outcome at 12 months were analyzed through univariate analysis. A level of significance was designated as a p-value <0.05.

Ethical considerations

Our study protocol adhered to the principles outlined in the Helsinki Declaration and was approved by the local ethics committee at the University Federico II of Naples [protocol 253/18]. All patients gave their informed written consent.

Results

Demographic characteristics and clinical data at baseline

A total of 80 patients, 42 of whom were females, with a mean age of 17 $\pm$ 0.3 years and an average

Table 1. Baseline demographic characteristics of cohort at transition visit.

	Total ($n = 80$)
Sex	
Female	42 (52.5%)
Male	38 (47.5%)
Mean age (y)	17 ± 0.3
Mean BMI (kg/m^2)	22.6 ± 3.3
Mean disease duration (years)	6 ± 3.4
UC patients	44 (55.0%)
UC Montreal disease extension	
Proctitis	8 (18.2%)
Left colitis	7 (15.9%)
Pancolitis	29 (65.9%)
CD patients	36 (45.0%)
CD Montreal disease localization	
Ileal	8 (22.2%)
Colonic	5 (13.9%)
Ileocolonic	23 (63.9%)
CD Montreal disease behavior	
Inflammatory	24 (66.7%)
Stricturing	10 (12.5%)
Penetrating	2 (5.6%)
Perianal disease	6 (16.7%)
Median CDAI	80 (73–109)
Median pMAYO	3 (2–4)
SES-CD > 2	13 (36.7%)
Rutgeerts score ⩾2	5 (88.6%)
MES ⩾ 1	39 (68.1%)
Previous surgery for IBD	8 (10.0%)
Extraintestinal manifestations	6 (7.5%)
Partial enteral nutrition	5 (6.3%)
Baseline anti-TNF-α therapy	29 (36.1%)
Baseline CCS therapy	9 (11.3%)
Baseline AZA therapy	10 (12.5%)
Baseline MTX therapy	25 (31.3%)
Baseline mesalamine therapy	65 (81.3%)
Median CRP (mg/L)	2.0 (1.2–5)
Median FC (μg/g)	130 (60–375)
Mean SF-36	91.0 ± 6.1
Mean TRAQ score	3.2 ± 0.5
Ready for transition*	54 (67.5%)
Adherence to treatment[$]	52 (65.0%)

*Based on TRAQ score >3.
[$]Based on Morisky scale ⩾6.
AZA, azathioprine; BMI, body mass index; CCS, corticosteroids; CD, Crohn's disease; CDAI, Crohn's Disease Activity Index; CRP, C-reactive protein; FC, fecal calprotectin; IBD, inflammatory bowel disease; MES, Mayo Endoscopic Score; MTX, methotrexate; pMAYO, Partial Mayo Score; SES-CD, Simple Endoscopic Score for Crohn's Disease; SF-36, 36-Item Short Form Health Survey Questionnaire; TRAQ, Transition Readiness Assessment Questionnaire; UC, ulcerative colitis.

disease duration of 6 ± 3.4 years, who underwent a 'structured' transition between February 2019 and October 2022, were enrolled. Demographic and clinical data are presented in Table 1. Overall, 44 individuals (55%) were diagnosed with UC, predominantly exhibiting an extended/pancolitis extension (65.9%). In addition, 36 individuals (45%) were diagnosed with CD, the majority of whom showed an ileocolonic disease location (63.9%) and an inflammatory behavior (66.7%). The perianal disease was observed in six patients (16.7%) with CD. The average disease duration was 72.6 ± 40.3 months, with median CDAI and pMAYO scores of 80 (73–109) and 3 (2–4) for CD and UC, respectively. At baseline, 29 patients (36.1%) were treated with anti-Tumor Necrosis Factor-alpha (anti-TNF-alpha) therapy, 14 (17.5%) were on combo therapy with a traditional immune suppressant (ISS) agent, and 21 (26.3%) were on monotherapy with ISS. Overall, 52 (65.0%) were adherent to treatment, and the mean SF-36 score was 91.0 ± 6.1.

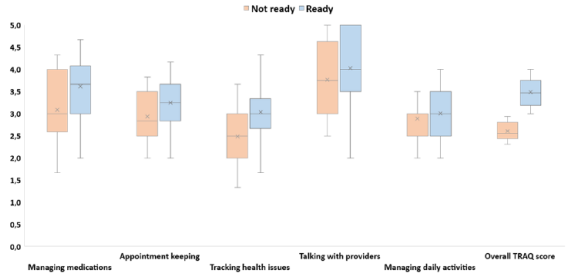

Figure 2. Mean results of TRAQ score five domains plotted for ready *versus* not-ready patients.
TRAQ, Transition Readiness Assessment Questionnaire.

Baseline assessment of readiness

At the baseline visit, 54 (67.5%) patients were considered ready for the transition. In the overall cohort, the mean TRAQ score was 3.2 ± 0.5, with different means for each questionnaire domain between those who were ready and those who were not (Figure 2; Supplemental Table 4). 'Talking with providers' domain had the highest score with no difference observed between the ready and not-ready groups ($p = 0.2$). Yet, patients who were ready reported higher scores in the 'Managing medications' and 'Appointment keeping' domains compared to those who were not ready ($p = 0.003$; $p = 0.02$, respectively).

Relationship between baseline readiness and disease measures

Patients with CD who were ready for transition had significantly lower CDAI scores than those who were not ready ($\Delta = 17.5$; $p = 0.007$). While for UC, the mean pMAYO score was comparable in the two groups ($p = 0.81$). Moreover, the disease relapses in the previous 12 months were significantly lower in the ready group compared to the not-ready group ($p = 0.004$). No significant differences were found between the two groups in terms of the number of outpatient visits ($p = 0.48$) and hospitalizations ($p = 0.87$) during the previous 12 months. Among the ready patients, 42 (77.7%) were adherent to therapy, in contrast to 10 individuals (38.4%) in the not-ready group ($p < 0.001$). The SF-36 score did not differ between them ($p = 0.9$) (Table 2).

Impact of readiness on clinical outcomes at 12 months

The median number of disease relapses and hospitalizations was lower among the ready than those in the not-ready group ($p = 0.004$; $p = 0.04$, respectively).

Clinical disease activity, measured with CDAI and pMAYO, showed no difference between the ready and not-ready groups (CDAI $\Delta = 2.5$; pMAYO $\Delta = 0$; $p = 0.7$) at 12 months. Similarly, there was no difference in terms of number of outpatient visits ($p = 0.6$). Despite being not statistically significant, CRP and FC were lower in the ready group compared to the not-ready group (CRP Δ: 0.5, $p = 0.7$; FC Δ: 58, $p = 0.098$). In addition, there were no statistically significant differences between the two groups regarding SF-36 ($p = 0.6$) and BMI ($p = 0.2$) (Table 3).

Predictive value of TRAQ score on adherence to therapy

Patients who were adherent to therapy after 12 months had a significantly higher mean TRAQ score of 3.4 ± 0.4 compared to non-adherent patients with a mean TRAQ score of 2.9 ± 0.4 ($p < 0.001$). Among the patients who were ready for the transition, 45 (83.3%) maintained therapy adherence after 12 months, whereas only 8 (30.8%) in the not-ready group did so ($p < 0.001$). Logistic regression analysis revealed that the TRAQ score was a significant predictor of adherence to therapy after 12 months, with an odds ratio of 13.1 [95% confidence interval (CI): 3.7–46.0] ($p < 0.005$). When incorporated into the prediction model, the AUROC was 0.81 (95% CI: 0.7–0.9) (Figure 3). The best TRAQ score for predicting adherence to therapy after 12 months was determined to be 3.16 with a sensitivity of 0.77 (95% CI: 63.8–87.7) and a specificity of 0.82 (95% CI: 61.9–93.7) (Youden index = 0.59). Regarding therapy, 16 (45.7%) out of the 35 patients who initially received azathioprine or methotrexate, discontinued ISS therapy at 12 months ($p = 0.001$); 2 patients started ISS after the transition clinic. Overall, 21 patients (26.3%) were receiving ISS treatment at 12 months, and among them, 8 patients (38.0%) were undergoing combination therapy with anti-TNF-α. In terms of biologics, 31 patients (38.8%) were treated with anti-TNF, whereas 3 patients (3.8%) started vedolizumab at 12 months.

Table 2. Baseline characteristics of ready and not-ready patients.

	Ready for transition ($n=54$)	Not ready for transition ($n=26$)	p Value
Female gender	31 (57.4%)	11 (42.3%)	0.16
Median CDAI	75 (52.5–94.5)	92.5 (80–135)	0.007
Median pMAYO	3 (2–4)	3 (2–3)	0.81
Median FC (μg/g)	130 (56.5–377.0)	135.5 (62–373.7)	0.93
Median CRP (mg/L)	2 (1.2–5.0)	2 (1.1–7.25)	0.85
Median number of outpatient visits in prev 12 months	2 (2–3)	3 (1–3)	0.48
Median number of disease relapse in prev 12 months	1 (0–1)	1 (1–2)	0.004
Median number of hospitalizations in prev 12 months	0 (0–1)	0 (0–1)	0.87
Mean BMI (kg/m^2)	22.9 ± 3.6	22.2 ± 2.8	0.09
Mean SF-36	91.0 ± 5.9	91.0 ± 6.7	0.9
Adherence to therapy	42 (77.7%)	10 (38,4%)	<0.001

BMI, body mass index; CDAI, Crohn's Disease Activity Index; CRP, C-reactive protein; FC, fecal calprotectin; pMAYO, Partial Mayo Score; SF-36: 36-Item Short Form Health Survey Questionnaire.

Table 3. Selected clinical outcomes at 12 months after transition clinics in ready and not-ready patients.

	Ready for transition ($n=54$)	Not ready for transition ($n=26$)	p Value
Median number of outpatient visits	2 (1–2)	2 (1–2)	0.6
Median number of disease relapses	0 (0–1)	1 (0–2)	0.004
Median number hospitalizations	0 (0–0)	0 (0–1)	0.04
Mean BMI (kg/m^2)	23.0 ± 3.5	22.1 ± 3.0	0.2
Mean SF-36	92.2 ± 4.4	92.2 ± 4.4	0.6
Adherence to therapy	45 (83.3%)	8 (30.8%)	<0.001

BMI, body mass index; SF-36, 36-Item Short Form Health Survey Questionnaire.

Effectiveness of transition clinic on clinical outcomes at 12 months

After 12 months from the first transition visit, there was a reduction in the number of outpatient visits and hospitalizations ($p=0.001$; $p=0.001$, respectively), as well as a decrease in the number of disease relapses ($p=0.004$). However, no significant differences were observed in BMI between the baseline and the end of the follow-up period (mean difference $\Delta=0.1$; $p=0.6$). In addition, the SF-36 score showed no significant difference between baseline and at 12 months (mean difference $\Delta=1.1$; $p=0.06$).

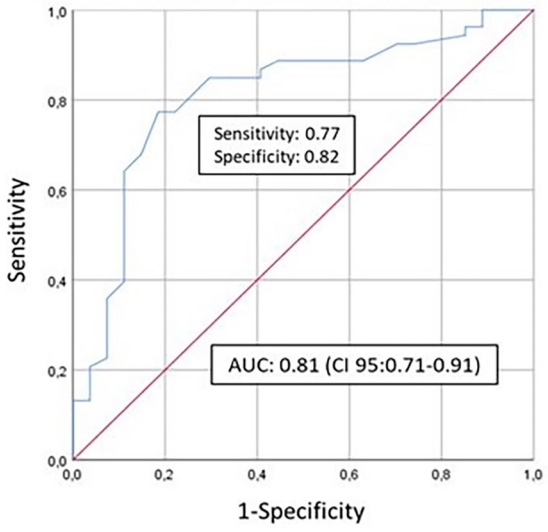

Figure 3. Diagnostic accuracy of TRAQ score for predicting adherence to therapy at 12 months.
TRAQ, Transition Readiness Assessment Questionnaire.

Table 4. Effectiveness of transition clinic on clinical outcomes at 12 months.

	First transition outpatient visit	After 12 months	*p* Value
Median number of outpatient visits	2 (1–3)	2 (1–2)	0.001
Median number of disease relapse	1 (0–1)	0 (0–1)	0.004
Median number hospitalizations	0 (0–1)	0 (0–0)	0.001
Mean BMI (kg/m^2)	22.6 ± 3.3	22.7 ± 3.3	0.6
Mean SF-36	91.0 ± 6.1	92.2 ± 4.4	0.06
Adherence to therapy	52 (65.0%)	53 (66.3%)	0.9

BMI, body mass index; SF-36, 36-Item Short Form Health Survey Questionnaire.

Finally, the rate of patients adherent to therapy was comparable at baseline and 12 months [52 (65.0%) *versus* 53 (66.3%); $p = 0.9$] (Table 4). In the univariate analysis, no demographic and clinical variables were significantly associated with clinical outcomes ($p > 0.05$).

Discussion

So far, the transition is not yet standardized. The existing recommendations mainly rely on scientific speculation, and the quality of evidence supporting each outcome is found to be very low. In addition, the long-term benefits of transition programs and interventions to improve the transition readiness of adolescent and young adult patients have yet to be established. In a web-based survey by Wright *et al.*,[25] caregivers identified psychological maturity and readiness as the primary factors influencing transition timing. Nevertheless, there are few longitudinal data linking readiness to long-term disease outcomes. To address these considerations, we conducted a prospective observational study involving adolescents with IBD who underwent a 'structured transition' program to assess their readiness and the impact on clinical outcomes at 12 months. Readiness was measured by the TRAQ tool, which is a reliable instrument with adequate content validity, construct validity, and internal consistency.[16,17,26–28] A systematic review by Zhang *et al.*[27] among 10 transitional tools, which were both disease-specific and neutral, found that the TRAQ was the best evidence-based tool that has been designed to assess readiness with additional benefits of disease neutrality. However, a limitation to acknowledge is that the TRAQ data rely solely on self-report.[13] Recently, Huang *et al.*[29] have shown that the self-reported transition checklist may not provide accurate information and has no better than chance accuracy when compared with an objective assessment of select transition-related knowledge and skills. This suggests that subjective assessments may not comprehensively reflect readiness for transition, and a significant number of adolescents may overstate their capabilities regarding transition knowledge and skill sets. Accordingly, additional studies should consider integrating an objective assessment of readiness alongside TRAQ for better identifying individual needs.

In our cohort, approximately two-thirds of the patients were ready for transition and exhibited adherence to medical treatment at the baseline visit. Overall, the domain with the highest score among both ready and not ready patients was related to the 'talking with providers'. These findings are supported by early education in adequately preparing patients for the transition process and developing motivational communication. Indeed, our transition program starts in early adolescence by educating on the concept of chronic disease and the importance of taking medicine. Collaborative management between pediatricians and gastroenterologists is crucial to

ensure that young patients and their caregivers are well-informed through a clearly defined educational process. It is noteworthy that patients ready for transition had fewer relapses in the previous 12 months and higher adherence to therapy compared to those not ready. Indeed, a stable clinical remission at baseline can further facilitate continuity of care. However, the domains in which transition readiness was lacking included tracking health issues and managing daily activities. Therefore, TRAQ score domains could serve as a guide for identifying patients who are struggling with transition readiness and targeting support appropriately.

In the current study, the HRQoL did not show significant differences between ready patients and those who were not, nor before and after the transition. Yet, Corsello *et al.*[10] reported a strong correlation between TRAQ and the Short Inflammatory Bowel Disease Questionnaire, a validated tool for assessing IBD's HRQoL. This discrepancy may be explained by the use of the SF-36, which is deemed too generic and broad to thoroughly capture the impact of living with a chronic condition on daily activities.[30] The SF-36 has further limitations in detecting deterioration or improvement over time.[31] Hence, a disease-specific questionnaire may be more sensitive to changes over time in disease conditions than a generic questionnaire. A randomized controlled trial (RCT) [NCT04290156] is ongoing to define to which extent the joint-visits can improve individual HRQoL of the adolescents.[32] Albeit transition models are variable and depend on local implementation, structure, and healthcare systems, numerous studies have shown that the 'joint-visit' model, involving both pediatric and adult care providers, leads to positive clinical outcomes.[9,33–35] However, there are currently no RCTs aimed at providing evidence regarding the superiority of joint-visits over other models.

In a pioneering study by Cole *et al.*,[35] patients who attended the joint transition clinic were more adherent to medication (89% *versus* 46%, $p = 0.002$) and recorded lower rates of missed clinic (29% *versus* 78%, $p = 0.001$), surgery (25% *versus* 46%, $p = 0.01$), and hospital admission (29% *versus* 61%, $p = 0.002$).

Similarly, in a retrospective study conducted by our group,[9] we found a significant decrease in exacerbations and hospitalizations in the 12 months following the transition clinic. Of note, no significant differences were observed in body weight and BMI between the pre- and post-transition periods.[9] Consistently, in the current study, it was confirmed that BMI did not differ in pre- and post-transition clinics. Thus, maintaining a stable body weight and BMI indicates a state of well-being for the patient and reflects appropriate height–weight growth, which is one of the key therapeutic goals in managing pediatric patients.

Subsequently, a retrospective study conducted by McCartney *et al.*[34] in the United Kingdom compared 95 transition patients with 34 non-transition patients. The study revealed that in the 12 months after the index visit, transition patients had fewer disease flares, were more likely to be steroid-free, and had a lower likelihood of requiring emergency department visits leading to hospital admissions.[34] Moreover, Annunziato *et al.*[36] demonstrated that pediatric liver transplant patients who had access to a transition coordinator exhibited better medication adherence 1 year after transfer compared to patients without access to a transition coordinator. Recently, numerous other transition programs have been documented, encompassing workshops, paper-based, web-based, and message-based education initiatives, transition care coordinators, and even music therapy.[13] However, regardless of the model, assessing the patient's profile, risk factors, and readiness is the first step to determining the appropriate frequency for regular monitoring of their progress in skill development, self-management, and knowledge acquisition.

A further critical aspect of transition includes medication adherence. Adherence is a complex behavior, and it can be challenging to measure accurately. There is no gold standard, though using validated self-report adherence questionnaires is a common method for assessing medication adherence. In the current study, we used the MMAS since it is relatively simple and practical to use in clinical settings.[23] We did not include drug levels as this was not covered by our institution. However, we believe that self-report measures can capture psychosocial factors, such as patient beliefs, motivation, and self-efficacy which that cannot be captured by objective measures.

This study has several notable strengths. First, this is the first prospective study to examine the impact of readiness on clinical outcomes at

12 months in IBD patients undergoing transition. Previous studies[10,22,28] have investigated how readiness impacts short-term outcomes within a 6-month follow-up. However, an extended follow-up period is essential for discerning the true benefits of a successful transition program.

Notably, the majority of patients were ready at baseline, suggesting that early education and a well-structured transition clinic can empower patients and promote readiness, leading to improved clinical outcomes. The identified cutoff score of 3.16 for the TRAQ tool exhibited good sensitivity and specificity for predicting medication adherence, making it a valuable screening tool for identifying patients at risk for non-adherence with potential long-term negative outcomes.

Nevertheless, we are aware that this study has several limitations. The reported data are derived from a single academic institution, which may limit the generalizability of the findings. In addition, the cohort of patients included in the study underwent transition within a well-established and consolidated program, which likely facilitated their attendance at transition clinics. Thus, the results may not fully represent all IBD patients undergoing transition even in smaller centers. Finally, the lack of RCTs limits our ability to fully understand the true magnitude of the benefit of the joint-visit model compared to other models. Therefore, future studies are needed to validate these findings and determine their generalizability to a broader population with a longer follow-up.

Conclusion

The TRAQ can be used to identify specific domains of readiness skills that require improvement, allowing for targeted interventions to enhance deficient areas.[37] It could be used also as a monitoring tool, providing valuable insights into the progression of readiness throughout the transition process. However, to move forward with better-designed transition programs, it is pivotal to include readiness questionnaires, such as the TRAQ, or similar tools in regular assessments of transitioning patients. Further objective assessments of health knowledge and disease self-management skills should be integrated alongside the TRAQ and routinely performed in the clinic to gain a more accurate understanding of the individual's changing needs. This approach will help identify knowledge gaps and guide the selection of appropriate interventions to optimize and enhance the overall success of the transition process.

Declarations

Disclosures

OMN has served as a speaker for Janssen, Ferring, Takeda, Pfizer, and Fresenius Kabi; advisory board for Nestle. AR: Advisory board for Abbvie, MSD, Takeda, Janssen, Pfizer. AT: Advisory board for Abbvie, Takeda, Janssen; FC: Advisory board for Abbvie, MSD, Takeda, Janssen, Pfizer. All other authors have no disclosures to declare.

Ethics approval and consent to participate

Our study protocol was consistent with Helsinki's ethical declaration and was approved by the local ethical committee. All patients gave their written informed consent.

Consent for publication

Informed consent for publication was provided by participants.

Author contributions

Olga Maria Nardone: Conceptualization; Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing.

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Roberto de Sire: Data curation; Writing – original draft; Writing – review & editing.

Giulio Calabrese: Data curation; Formal analysis; Writing – review & editing.

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Availability of data and materials
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