Validation and Reference Scores of the Transition Readiness Assessment Questionnaire in Adolescent and Young Adult IBD Patients

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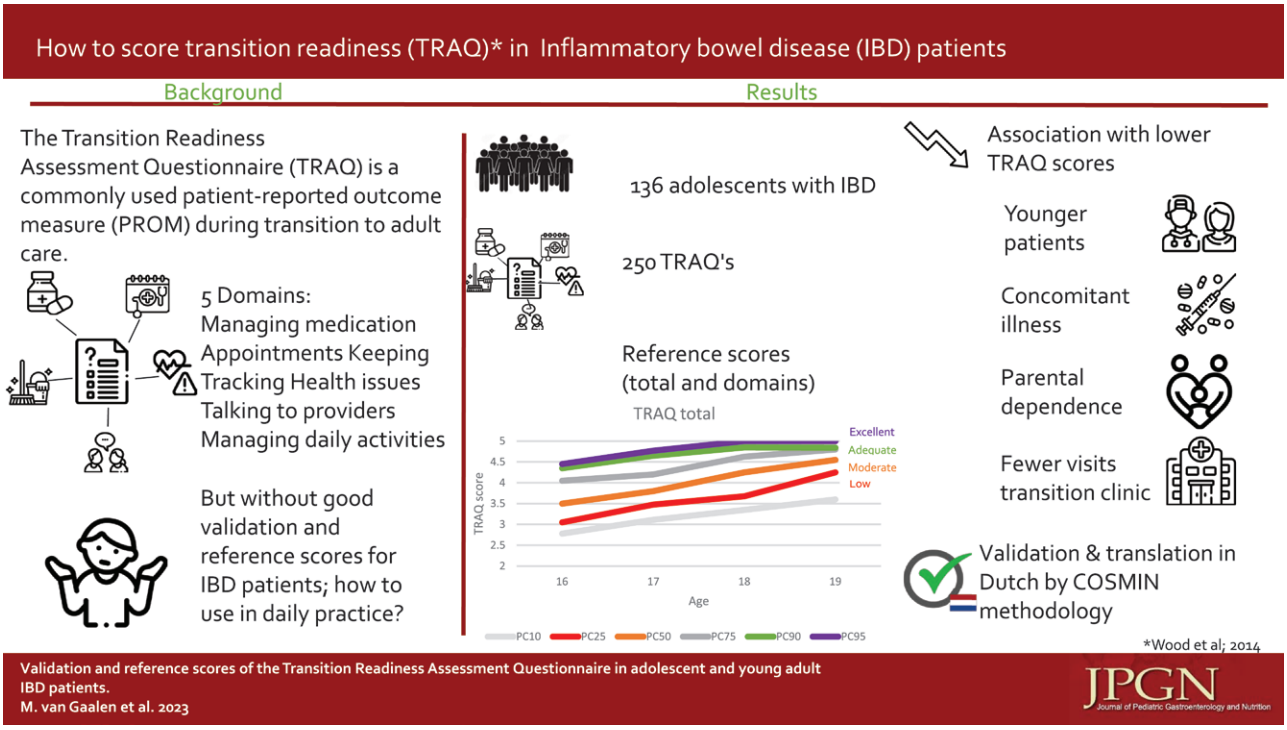

ABSTRACT

Objectives: Transition readiness can predict a successful transition from pediatric to adult care. This study aimed to validate and develop age-dependent reference scores for the (Dutch version of) Transition Readiness Assessment Questionnaire (TRAQ), in adolescents and young adults (AYAs) with inflammatory bowel disease (IBD).

Methods: TRAQ has 20 items (score 1–5) distributed over 5 domains (total sum score 100) and is completed by AYAs. Following the COnsensus-based Standards for the selection of health Measurement INstruments methodology, we conducted the translation, back-to back translation, pretesting, and validation of the final Dutch version of TRAQ (TRAQ-NL) questionnaire. We used a Rasch model for structural validation, hypothesis testing for construct validity, and Cronbach alpha to demonstrate reliability. Reference scores were calculated using percentiles.

Results: Two hundred fifty TRAQ questionnaires were evaluated in 136 AYAs with IBD [56% Crohn disease, 58% male, median age 17.5 years (range 15.7–20.4)]. The overall mean item score was 3.87 (range 1.45–5). With good reliability (Cronbach alpha 0.87), TRAQ-NL discriminated well between knowledge levels, especially in the lower levels. Transition readiness was defined as low, moderate, adequate, or excellent in patients with TRAQ percentile scores (PC) <25th (<3.375 mean item score), 25th–50th (3.375–3.9), 50th–90th (3.91–4.7), or >90th (>4.7). Younger patients, concomitant illness, fewer visits to the transition clinic, and parental dependence were associated with significantly lower TRAQ scores.

Conclusion: TRAQ(-NL) is reliable and valid, with age-dependent PC to identify (in)adequate transfer readiness. TRAQ can now be more easily used as a patient-reported outcome measure to monitor transition readiness longitudinally in routine care for AYAs IBD patients.

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What Is Known

- Absence of good transition care is associated with a risk of adverse disease outcomes.
- TRAQ is a patient-reported outcome measure reflecting transition readiness in AYAs with chronic disease.
- Transition readiness may be an important predictor of the outcome of transition from pediatric to adult care.

What Is New

- TRAQ is now validated for IBD patients.
- Younger patients, concomitant diseases, fewer visits to the transition clinic, and parental dependency are associated with lower TRAQ scores, indicating less transition readiness.
- Age-dependent percentile scores facilitate the use of TRAQ in monitoring transition readiness during routine care for adolescent IBD patients.

Key Words: Crohn disease, IBD, transition, ulcerative colitis

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Most pediatric inflammatory bowel disease (IBD) patients present during adolescence (1). During this period, in most European countries, the transition to adult health care is organized around the age of 18. Pediatric health care tends to be more family-centered, holistic, supportive, and focused on growth and development, with an important role for parents, while adult health care is patient-centered, focused on new biological treatments, cancer surveillance, and reproductive health. Most importantly, patients transitioning to adult health care are suddenly expected to be self-reliant and self-managed (2–5). To ensure that these changes are not so "sudden," it is essential that adolescents are offered a structured transition program (2,5). Transition is defined as a period during which the purposeful, planned movement of adolescents with chronic medical conditions into adult-oriented health care systems is organized (6). Adequate preparation on disease relevant knowledge, help in development of self-management skills, and coaching of parents to gradually loosen their grip are issues that make a patient more transfer ready, so they are at less risk of adverse health outcomes (2,7–10).

A commonly used patient-reported outcome measure (PROM) during transition is the Transition Readiness Assessment Questionnaire (TRAQ-20), a generic questionnaire (3,11–18). TRAQ has good internal reliability and has been validated in adolescents and young adults (AYAs) with various chronic diseases (19), but not in IBD. Although TRAQ scores are likely to increase with age, it would be helpful to have age-dependent reference values and cut-off scores that can guide the transition process in individual patients. TRAQ has been translated into several languages (20–23), but not into Dutch. With all this in mind, our research goal was to translate and validate Dutch version of TRAQ (TRAQ-NL) and facilitate its use in clinical care by providing age-dependent reference scores specifically for IBD.

MATERIALS AND METHODS

The study was a single-center, longitudinal, prospective validation study that followed the COnsensus-based Standards for the selection of health Measurement INstruments methodology (24): translation with back-to-back translation, pretesting, performance assessment, and development of baseline scores.

The Research Ethics Review Board of Erasmus MC approved this study (MEC-2017-459). Patients were asked for written informed consent for recruitment into the study.

TRAQ

TRAQ is divided into 5 domains: Managing medication (5 questions about prescriptions and how to take the medication); Appointments keeping (7 questions about making an appointment, calling the hospital with questions, checking the results and insurances); Tracking health issues (4 questions about medical history form, making a list of questions and financial help); Talking to providers (2 questions about conversation with health care providers); and Managing daily activities (3 questions about doing household chores). Each question is rated on a 5-point Likert scale, ranging from score 1 ("No, I don't know how") to score 5 ("Yes, I always do this when necessary"), with higher scores indicating better readiness for transition.

Translation of the TRAQ

The TRAQ was translated into Dutch after a cross-cultural adaptation process (25). Figure 1 shows the overview of the stages of development and the changes that were made. Based on cultural differences, question 9 from the original TRAQ (19) "Will you apply for health insurance if you lose your current coverage?" was changed to "When you turn 18, there will be changes regarding your health insurance; Do you know how to arrange health insurance as an adult?"

The final version of the TRAQ-NL has 20 questions with a 5-point Likert scale (identical to the original TRAQ version) (19).

IBD Transition Clinic

In the Netherlands, youngsters with a chronic disease are transferred from pediatric to adult care around the age of 18. Transitional care is organized depending on the local situation of the health care providers of both departments (pediatric and adult). In our academic hospital, where the pediatric and adult hospital are under one roof, we see all IBD patients aged 16–18 years for their regular appointments at the IBD outpatient transition clinic, located in the adult gastroenterology department. In addition to providing regular medical care by the pediatric team, the transition clinic aims to guide adolescents in developing self-management skills, while parents receive assistance in gradually releasing their grip. The adult IBD team gets to know their future patients through a multidisciplinary meeting prior to each (biweekly) clinic, and an introductory meeting around age 17. Around age 18, both the pediatric and adult IBD teams meet with the patient and parents for a warm transfer of care. About 75% of our IBD patients are transferred within our academic hospital. The remaining 25% are referred to a hospital closer to home or near the school or university the patients chooses to go to. For these patients, a detailed transfer letter is made (with a copy sent to the patient). As of today (but not yet during the time of this study), a warm handover of care is organized as a web consultation where the pediatric IBD nurse specialist (in our clinic) and IBD nurse in adult care (in the receiving hospital) join virtually to meet with the patient and parents.

Testing of the TRAQ

Pretesting TRAQ-NL

The final stage in translation process (25) was pretesting of TRAQ-NL.

Thirty IBD patients, who visited the IBD transition clinic, completed TRAQ-NL. The time to complete the TRAQ was about

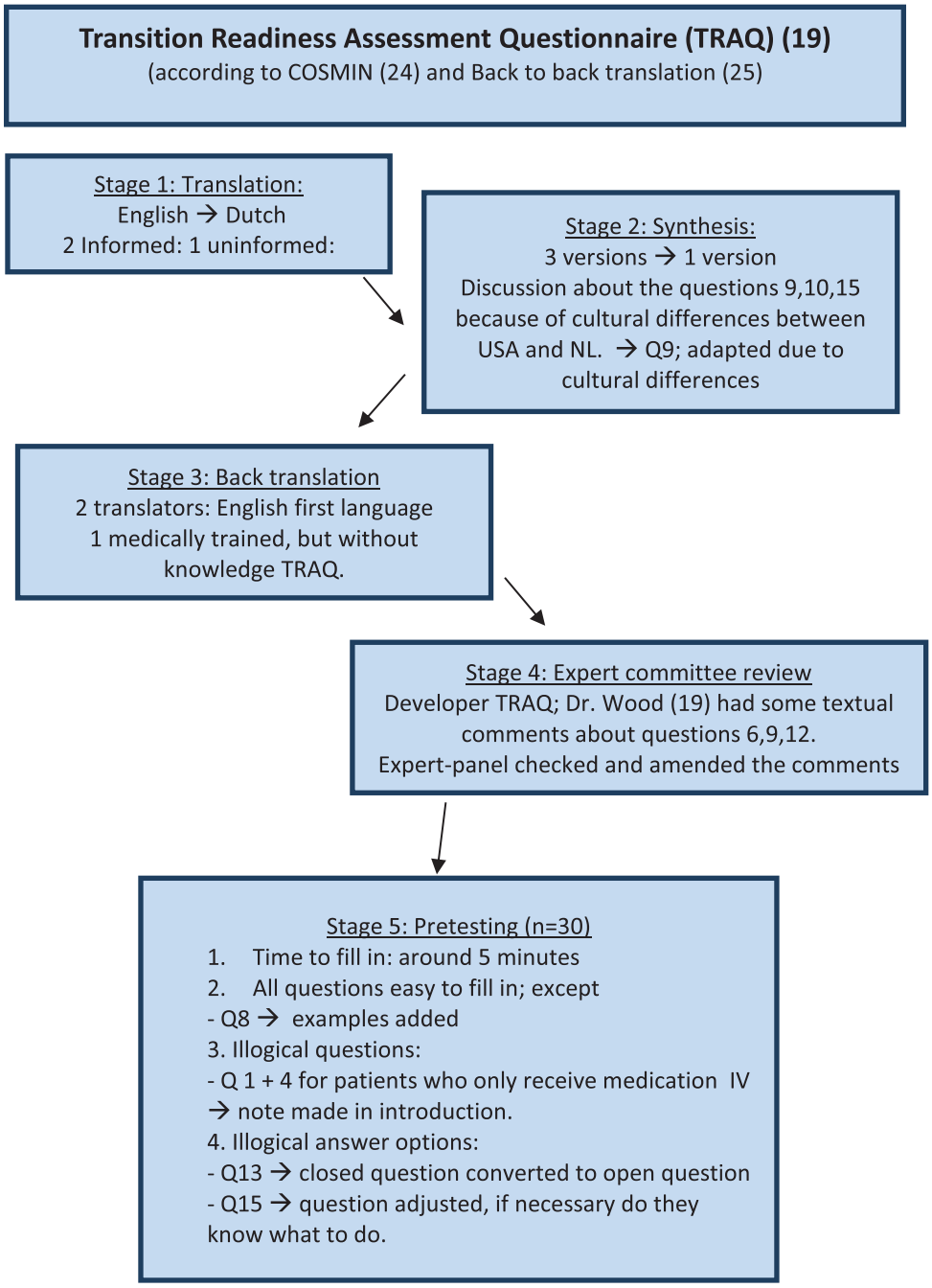


FIGURE 1. Overview translation process.

5 minutes. The AYAs were then interviewed whether the questions and answer options were clear. Some questions and answer options required textual adjustments (see Fig. 1).

Validity Testing

In 2016–2020, all patients attending the IBD transition clinic were asked to complete the TRAQ annually during the years of their transition process (up to 4 time points: age 16, 17, at the last visit to the transition clinic (around 18)). Post-transfer TRAQ data were only collected in patients who were transferred within our hospital and who reached the 1-year post transfer moment within the timeframe of this study. So patients who went to other facilities were not asked to fill in a TRAQ questionnaire after their transfer.

A Rasch analysis was used for structural validation. Rasch analysis assesses the characteristics of the questions, identifies whether questions need further modification, and assesses the ability of the questions to discriminate between different levels of transfer readiness (26). The construct validity of TRAQ-NL was tested using several hypotheses concerning relationships between TRAQ sumscore and hypothesized surrogate markers of transition readiness (Table 1) (2,3,5,13,14,27). The information needed for the hypotheses was obtained by additional questions on disease acceptance (4-point Likert scale to the question, "I can accept that I will

TABLE 1. Hypothetical constructs and assessment of validity and discriminatory ability of transition readiness (TRAQ)

Construct	Statistic
Association of total mean TRAQ scores of patients with IBD with specific variables:	
Scores should correlate positively with patient age	Pearson correlation coefficient
Scores should correlate positively with disease duration	Pearson correlation coefficient
Scores should not differ between CD and UC patients	ANOVA
Females often score better in questionnaires than males	*t* test
Patients with lower educational levels score lower than those with higher educational levels	Post-hoc Tukey test
Scores should correlate positively with repeated TRAQ administration	Rasch model
Scores should correlate positively with higher VAS self-management	Spearman correlation coefficient
Scores should correlate positively with higher VAS transfer readiness	Spearman correlation coefficient
Patients who were without parents for more than two nights should score higher (independency score)	*t* test
Patients who accepted having IBD should score higher	*t* test

CD = Crohn disease; IBD = inflammatory bowel disease; TRAQ = Transition Readiness Assessment Questionnaire; UC = ulcerative colitis; VAS = visual analog scale.

have this disease for the rest of my life"), dependence on parents asking, "Have you ever been away from your parents for at least one weekend (eg, sleepover or holiday)?," a 10-point Visual Analogue Score to self-assess readiness for transition and self-management, and a chart review (on IBD type and education level).

TRAQ (combined with the supplementary questions) was sent via a secure online survey program (LimeSurvey version 3.1.1, LimeSurvey GmbH, Hamburg, Germany). Questionnaires obtained during pretesting were included in the final validation analysis, as the TRAQ version used during pretesting was essentially identical to the final version (Fig. 1).

Reliability Tests

Cronbach alpha was used to assess the internal consistency of TRAQ-NL, which indicates the extent to which different items of a scale assess one whole.

Measuring Instruments for TRAQ Responses of Adolescents with IBD

Pediatric Ulcerative Colitis Activity Index (28) and Pediatric Crohn's Disease Activity Index (29), with values >10 defined as active disease, assessed clinical disease activity at the time of completing TRAQ. Exacerbation of IBD was noted when increased symptoms or presence of endoscopic disease activity led to escalation of treatment in the year prior to assessment of TRAQ. Extra-intestinal disease (such as dermatological disorders or primary sclerosing cholangitis) and other diseases (such as asthma) were recorded as concomitant disease when it led to an outpatient appointment with a specialist or new medical treatments.

Reference Scores

To make TRAQ more practical in routine clinical care, age-related reference scores (between 16 and 18 years) were generated. Reference scores for both total TRAQ score and individual domains were calculated using percentiles based on TRAQ mean scores. Transition readiness was defined as moderate in patients with scores between the 25th and 50th percentile, adequate in scores between the 50th and 90th percentile, and excellent in scores above the 90th percentile. Transition readiness was low for scores below the 25th percentile.

Statistical Analysis

All statistical analyses were performed using SPSS for Windows, version 28.0.1.0 (IBM SPSS Statistics for Windows, Armonk, NY). Results were considered significant at a P value <0.05. The total mean score of TRAQ was used for the analyses. Bivariate or multivariate analyses evaluated associations between a number of independent variables and mean TRAQ scores. For some question items the response categories were merged to 2 options. The independent variables were the same as the hypothetical constructs in Table 1. For comparisons of the independent variables, *t* test (dichotomous), Pearson (continuous), and Spearman (non-normally distributed) correlation coefficients were used. To examine whether education level (categorized as low, medium, or high) was related to TRAQ score, we conducted an analysis of variance. TRAQ was considered as the dependent variable, and education level as the categorical predictor. The reliability of the overall TRAQ was assessed using Cronbach alpha. If an item was missed, it was not included in the analysis, which was reflected in a reduction in the number of participants (n) for that particular analysis.

RESULTS

Testing the TRAQ

We prospectively collected 250 TRAQs from 136 adolescent patients who consecutively visited the IBD outpatient clinic (87% response rate). The median age at diagnosis was 14.5 years [interquartile range 3.07 (range 2.7–17.5)], 58.1% were male and 55.9% had Crohn disease. Table 2 shows the demographic data at the time the TRAQ was completed. 136 TRAQs (54.4%) were completed for the first time and almost all TRAQs (212; 84.8%) were completed before transfer to adult care. Data from one outlier (AYA scored very low, total mean score 1.45) were not used to obtain evenly distributed data (mean score range 2.25–5).

Structural Validation of TRAQ-NL

The Rasch model (ranging from 0 to 1) showed that the TRAQ discriminated well between different levels of transfer readiness, with the best discrimination between low/absence (0) and high (0.75) levels of transfer readiness. This implies that the TRAQ is best used to identify patients with low transfer readiness. Questions that provided little information on differences between knowledge levels were questions on transport to hospital (Q7), financial overview (Q11), and preparing dinner (Q18).

Construct Validity with Hypothesis Testing

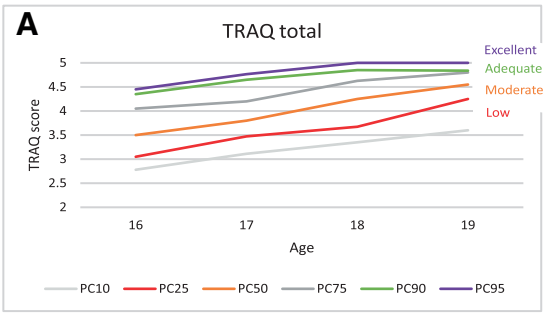
Significant positive correlations of TRAQ total mean scores (score 1–5) were found with the following hypotheses (Table 1):

TABLE 2. Demographics at the time of completing transition readiness (TRAQ) [250 questionnaires in 136 inflammatory bowel disease (IBD) patients]

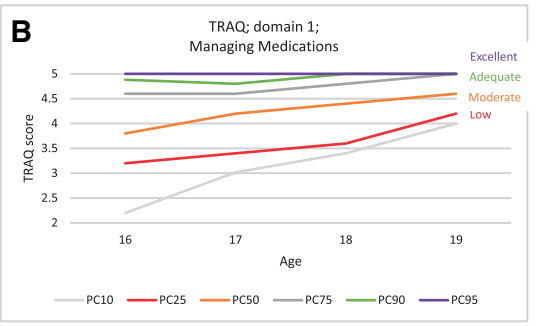
		N (%) or median
Age, y	Range	15.67–20.38
	Median; IQR	17.53; 1.36
Disease duration, y	Range	0.12–14.71
	Median; IQR	3.14; 3.48
Timepoint of filling in TRAQ	Before transfer	212 (84.8%)
	After transfer	38 (15.2%)
Timepoint of filling in TRAQ	First time	136 (54.4%)
	Second time	77 (30.8%)
	Third time	31 (12.4%)
	Fourth time	6 (2.4%)
Duration of transitional care: time since first visit to the IBD transition clinic, y	Range	0–4.02
	Median; IQR	0.91; 1.63
Educational level	Low (lower secondary)	142 (56.8%)
	Medium (upper secondary)	56 (22.4%)
	High (pre-university)	52 (20.8%)
Clinical disease activity	Remission	162 (64.8%)
	Mild	68 (27.2%)
	Moderate	20 (8.0%)
	Severe	0
Current medication use	Aminosalicylates	63 (25.2%)
	Immunomodulators	124 (49.6%)
	Biologics (infusions/ injection)	112 (44.8%)
	Subcutaneous injections at home	27 (10.8%)
	Corticosteroids	25 (10%)
	Topical treatment	8 (3.2%)
	No medication	23 (9.2%)
Induction treatment with EEN/steroids used within 3 months before completing TRAQ	EEN	3 (1.2%)
	Steroids	35 (14%)
Prior surgery (peri-anal or bowel resection)	Yes	57 (22.8%)
Concomitant diagnosis	Yes	64 (25.6%)
	Joint disease	12 (18.8 %)
	Liver disease (PSC/AIH)	11 (17.2%)
	Joints + Liver	1 (1.6%)
	Skin disease	16 (25%)
	Other (such as asthma, epilepsy)	24 (37.5%)
Being without parents for more than 2 d	Yes, without problems	198 (79.2%)
	Yes, but with problems/ inconveniences	21 (8.4%)
	Never	31 (12.4%)
Acceptance of disease (n = 247)	Yes, always or often	198 (80.2%)
VAS independence (n = 246)	Range	0–100
	Median; IQR	80; 15
VAS transfer readiness (n = 246)	Range	10–100
	Median; IQR	80; 35

AIH = autoimmune hepatitis; EEN = exclusive enteral nutrition; IQR = interquartile range; PSC = primary sclerosing cholangitis; TRAQ = Transition Readiness Assessment Questionnaire; VAS = visual analogue scale.

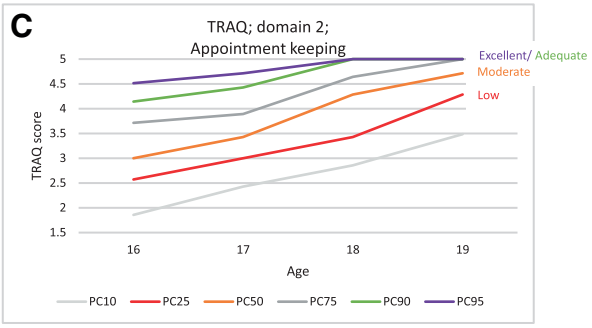
older age (Pearson correlation coefficient 0.47, $P < 0.001$), more frequent visits to the transition clinic (Pearson correlation coefficient 0.42, $P < 0.001$), higher visual analog scale (VAS) of self-management (Spearman correlation coefficient 0.34, $P < 0.001$), higher VAS of transfer readiness (Spearman correlation coefficient 0.37, $P < 0.001$), having experienced transfer of care



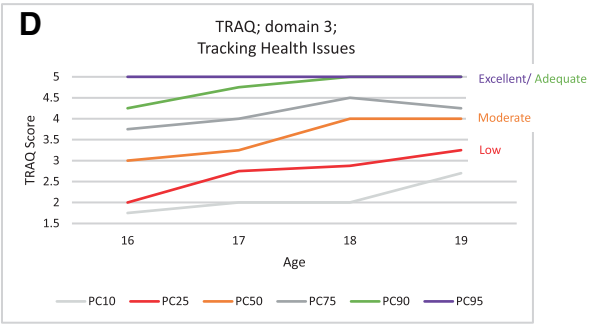
age (years)	PC10	PC25	PC50	PC75	PC90	PC95
all ages	3	3,375	3,9	4,4	4,7	4,85
16	2,78	3,05	3,5	4,05	4,35	4,45
17	3,11	3,475	3,8	4,2	4,65	4,767
18	3,35	3,675	4,25	4,625	4,85	5
> 18	3,6	4,25	4,55	4,8	4,84	5



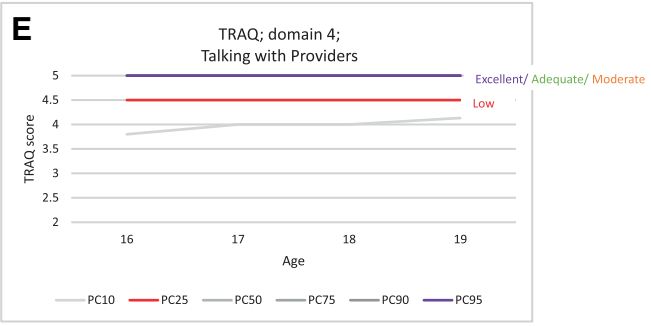
age (years)	PC10	PC25	PC50	PC75	PC90	PC95
16	2,2	3,2	3,8	4,6	4,88	5
17	3,02	3,4	4,2	4,6	4,8	5
18	3,4	3,6	4,4	4,8	5	5
> 18	4	4,2	4,6	5	5	5



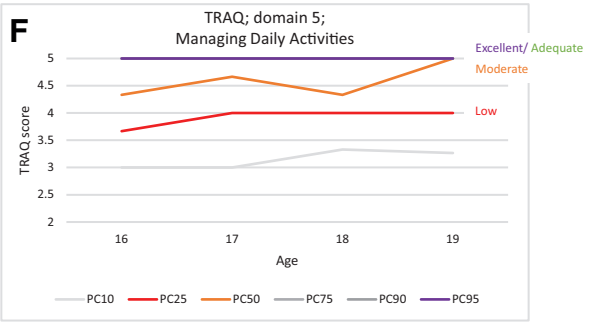
age (years)	PC10	PC25	PC50	PC75	PC90	PC95
16	1,86	2,6	3	3,7	4,1	4,5
17	2,43	3	3,4	3,9	4,4	4,7
18	2,86	3,4	4,3	4,6	5	5
> 18	3,49	4,3	4,7	5	5	5



age (years)	PC10	PC25	PC50	PC75	PC90	PC95
16	1,75	2	3	3,75	4,25	5
17	2	2,75	3,25	4	4,75	5
18	2	2,88	4	4,5	5	5
> 18	2,7	3,25	4	4,25	5	5



age (years)	PC10	PC25	PC50	PC75	PC90	PC95
16	3,8	4,5	5	5	5	5
17	3	4	4,67	5	5	5
18	3,33	4	4,33	5	5	5
> 18	3,27	4	5	5	5	5



age (years)	PC10	PC25	PC50	PC75	PC90	PC95
16	3	3,67	4,33	5	5	5
17	3	4	4,67	5	5	5
18	3,33	4	4,33	5	5	5
> 18	3,27	4	5	5	5	5

FIGURE 2. Age-related percentile scores on the total transition readiness (TRAQ) and the domains. (A) TRAQ total. (B) TRAQ domain 1: Managing medications. (C) TRAQ domain 2: Appointment keeping. (D) TRAQ domain 3: Tracking health issues. (E) TRAQ domain 4: Talking with providers. (F) TRAQ domain 5: Managing daily activities. TRAQ = Transition Readiness Assessment Questionnaire.

(4.38 ± 0.43 vs 3.78 ± 0.63, P <0.001), and being without parents for more than 2 days (3.91 ± 0.64 vs 3.61 ± 0.64, P = 0.007). Using the Rasch model, we also evaluated changes over time in the level of transfer readiness of patients who completed the TRAQ at 2 time points, during their transition process. This showed an increase in the level of transfer readiness; this increase was smaller in patients who already scored well on the TRAQ at the first completion time. Some patients scored lower during the second time the TRAQ was completed. Female patients scored almost significantly higher than male patients (3.95 ± 0.64 vs 3.82 ± 0.63, P = 0.06). Acceptance of living with IBD seemed to correlate with transfer readiness, with (almost significantly) higher scores in those who accept compared

with patients who experience acceptance problems (3.91 ± 0.64 vs 3.75 ± 0.6, $P = 0.06$). Education level showed no correlation with TRAQ results (data not shown).

Reliability of Total TRAQ score

Internal consistency was measured using Cronbach alpha of 0.87 (good reliability of the total TRAQ).

Responses of Adolescents with IBD on TRAQ

The mean total TRAQ score for all age groups was 3.88 (range 2.25–5.0; SD 0.64). Question 9 (about impending changes in health insurance) was scored lowest [mean score 2.82 (SD 1.49)]. Bivariate analysis showed that adolescents with concomitant disease scored significantly lower on the overall mean score TRAQ (score 1–5) [concomitant disease (n = 63); 3.7 ± 0.71 standard deviation score vs no concomitant disease (n = 186); 3.93 ± 0.60 standard deviation score, $P = 0.02$]. Other IBD-specific characteristics such as (type of) medication, disease activity, surgery, and disease type showed no correlation with TRAQ score (data not shown).

Reference Scores

The graphs in Figure 2 show the age-specific percentile scores (PC) on the total TRAQ and its domains. Both total TRAQ and domain scores increased with age, and the gap between pc10 and 95 decreased with age. AYA of all ages had the most difficulty with domain 3 (keeping track of health issues) and 2 (keeping track of appointments), while domain 5 (talking to health care providers) seemed the easiest. Domain 4, managing daily activities, distinguished the least between the different levels of transfer readiness. Transition readiness was moderate in patients with scores between the 25th and 50th percentile (total mean score 3.375–3.9), adequate scores in the 50th and 90th percentile (total mean score 3.91–4.7), and excellent scores above the 90th percentile (total mean score >4.7). Transition readiness was low with a score below the 25th percentile (total mean score <3.375).

DISCUSSION

This longitudinal, prospective study aimed to facilitate the use of TRAQ in daily practice in the AYA IBD population, with a scoring model and reference values. Following the stages of back-to-back translation (25), we showed that TRAQ-NL is a valid and reliable tool to detect (in)adequate transfer readiness in adolescents with IBD transitioning to adult care. TRAQ-NL is now available for routine clinical care and research purposes (Supplement, *http://links.lww.com/MPG/D217*). Age-dependent PC facilitate the interpretation of TRAQ and put into perspective the transfer readiness and specific needs of individual patients. Longitudinal monitoring of TRAQ as a PROM will contribute to patients' understanding of their transition readiness and self-management skills. As previous studies have shown (12–15,19–21,30), age is the most important factor influencing patients' transition readiness. Although others have shown that girls score higher than boys (12–14,20,21) this difference is not significant in our cohort ($P = 0.06$), and thus we did not show gender-specific reference data. As described in the study by Hart et al (14), the gender difference becomes smaller as adolescents get older. This may explain why we did not find the age difference in our 16-plus cohort. We found that having concomitant diseases resulted in a significantly lower score on TRAQ. With more complicated illness, parents may be more concerned and protective, leaving less room for the development of self-management skills (13,31). Along this line, AYA with IBD and concomitant disease were less independent of their parents (never 2 nights without parents; 15.6%) than AYA without concomitant disease (11.3%). The VAS score of transfer readiness and independence was significantly related to the transfer readiness score, as shown previously (13,21).

As described by others (12,14,20,21,30) domain 2 "Keeping an appointment" and 3 "Detecting health problems" have the lowest scores, implying that more attention should be paid to these domains during a structured transition program.

TRAQ is an extensively validated questionnaire used in different diseases and in different languages (21–23). Until now, we did not know which cut-off scores identify patients who are not yet ready for transfer. With age-specific reference PC, results from the TRAQ domains will guide the type of support to be provided to individual patients transitioning to adult care. Comparing our results with US data (14),the only other study that has produced TRAQ reference data for IBD patients, our cohort appears to score higher than US patients in all domains. One explanation is the different patient selection in the US data, that was extracted from a large database of the patient organization, with no information on availability or type of transitional care that was offered. The largest "transcontinental" difference in mean TRAQ score occurred at age 17. This may be due to the success of the structured transition program we offer at the IBD transition outpatient clinic, starting at age 16. The patients in the US may not have had similar high quality transitional care, and in our opinion this emphasizes the need to organize transitional care in a structured way.

The program aims to increase disease-related knowledge and independence to prepare AYA for adult care. What underlines this line of thought is that having more appointments at the transition clinic correlated positively with TRAQ score (Pearson correlation coefficient 0.42, $P < 0.001$). The difference between the US cohort and ours disappeared on almost all domains around age 18. This may again indicate that age is the most important determinant of transition readiness. Looking at the increase in TRAQ score during the adolescent years, the upward curve in TRAQ score in our cohort is more gradual than in the US cohort. Our overall mean TRAQ score varies by age from 0.2 to 0.4 per year, while in the US it ranges between 0.1 and 0.6, with the largest increase between 17 and 18 years (0.6). This may be an indication that a transition outpatient clinic (starting at age 16) leads to a smoother increase in self-management skills.

TRAQ states that it measures transition readiness, but the question remains: when is a patient truly "transfer-ready?" And one can also question whether our adolescent IBD patients can and should be completely ready at age 18, at the time of transfer. In our opinion, transition and transfer should be organized together with a co-responsible adult care team that is well informed about the readiness of their new patient. That way, the adult care team does not simply accept a "perfect patient," but (in the ideal situation) continues to provide transitional care as usual. In current practice, however, not all hospitals have a transition clinic with a structured program, and pediatricians need to know when their patient can be safely and properly transferred to adult care with minimal risk of dropping out of medical care. To truly know the implications of a patient's readiness for transition, we need to prospectively study the relationship between transfer readiness and the outcome of transition (32), which we intend to do in the near future.

Our study has some limitations, the first being age as a confounding factor in TRAQ monitoring. This also makes it difficult to say what is the exact effect of transition interventions over time, such as frequency of appointments on the IBD transition clinic, repeated completion of TRAQ, or assessment of TRAQ after transfer (in patients older than 18 years). Another limitation is the single-center design. All our patients were offered the same high quality structured transitional care which may have affected the level of TRAQ scores. Thus, the reference values we generated may be

higher than in other cohorts and should be validated in a larger multicenter study. In addition, to make TRAQ useful in daily practice, we developed a digital dashboard in our electronic patient record. Each time the AYA completes the TRAQ digitally (once or twice a year, always prior to a visit to the transition clinic), the progression of total and domain scores is displayed against a background of age-related reference values. The TRAQ dashboard is part of a value-based health care dashboard that facilitates monitoring of self-management skills, quality of life, and mental health issues.

CONCLUSIONS

In conclusion, TRAQ-NL is a valid and reliable PROM of transfer readiness. It can support both pediatric and adult caregivers in guiding individual AYA with IBD toward independence and self-management. Finally, engaging patients by repeatedly asking them to self-report transition readiness will have a positive effect on skill development.

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