

Transition of Inflammatory Bowel Disease Patients from Pediatric to Adult Care: An Observational Study on a Joint-Visits Approach

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Research

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Abstract

Background

Transition from pediatric to adult care of patients affected by Inflammatory Bowel Disease (IBD) is a critical step that needs specific care and multidisciplinary involvement. The aim of our study was to evaluate the outcome of the transition process of a cohort of IBD patients, exploring their readiness and the consequent impact on quality of life.

Methods

This observational study followed transitioned patients up for a minimum of 18 months after the beginning of transition process, from January 2014 to April 2019. Transition was carried-out through joint visits pediatricians and adult gastroenterologists. Clinical data before and after transition were collected. A subgroup of patients was submitted to an anonymous online questionnaire of 38 items drawn up based on the validated questionnaires TRAQ and SIBDQ within the first 6 months from the beginning of transition process.

Results

Eighty-two patients with IBD were enrolled, with a mean age at transition of 20.2 ± 2.7 years. Before transition, 40.2% of patients already had major surgery and 64.6% started biologics. At transition, 24% of patients were in moderate to severe active phase of their disease and 40% of them had already been treated with ≥ 2 biologics. The mean value of the TRAQ questionnaires was 3.4 ± 0.5 and the mean score of SIBDQ was 53.9 ± 9.8 . A significant association was found between a TRAQ mean score > 3 and a SIBDQ > 50 ($p=0.0129$). Overall, 75% of patients had a positive opinion of the transition model adopted.

Conclusions

A strong association has been found between TRAQ and SIBDQ questionnaires, showing how transition readiness has a direct impact on the quality of life of the young adult with IBD.

Introduction

Up to 25% of patients affected by Inflammatory Bowel Disease (IBD) receive their diagnosis before the age of 20 years and the incidence of diagnosis during childhood is constantly growing [1]. Pediatric IBD show peculiar features compared to adult ones, including a more extensive disease and a more frequent upper gastrointestinal tract involvement. Moreover, patients with an onset during childhood are more likely to receive immunosuppressive or biological therapies [2]. Children with IBD are found to have frequent mood disorders and are considered at higher risk for difficulties in social, family and school functioning [3]. A crucial phase in the management of children with IBD is the transition from the pediatric to the adult IBD care system, requiring full achievement of maturity and of self-management and healthcare skills, not occurring at the same age for each individual [4]. The “ideal” patient ready for

transition is a young independent adult on IBD clinical remission, for whom no change of medical therapy or surgical intervention are planned [5].

The guideline of the British Society of Gastroenterology on transition of young adults with chronic digestive disease recommends a shared management between pediatrician and adult center, through an educational and conscious process that involves both the patient and his/her family, verifying the readiness of the young and his/her level of awareness [6]. The Transition Readiness Assessment Questionnaire (TRAQ) is one of the most useful tool (not disease specific) for assessing patient's readiness to make the transition from the pediatric health service to adult care [7], exploring both the self-management domain (e.g. handling medications, arranging medical follow-up visits, managing finances, health insurance) and the self-advocacy domain (e.g. communication with providers and managing activities of daily living and use of school and community resources). As far as IBD are concerned, age is the best predictor of TRAQ score (lower in pediatric patients) and lower scores on the medication management section are associated with higher risk of nonadherence [8].

The Short Inflammatory Bowel Disease Questionnaire (SIBDQ) is a validated health-related quality of life (HRQoL) tool, designed to find out IBD symptoms, emotional status and limitation in social activities due to IBD in the last 2 weeks [9].

The aim of this study is to evaluate the outcomes of the transition process of consecutive patients transferred from two pediatric referral hospitals to one IBD adult hospital unit and to explore the patients' readiness and its association to the quality of life.

Materials And Methods

Data collection

The study was carried out at IBD Unit - Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome Italy. Consecutive patients with a diagnosis of IBD before the age of 19 transited from 2 different pediatric centers, the "Bambino Gesù Pediatric Hospital" (OPBG) and the "Policlinico Umberto I" Rome, Italy from January 2014 to June 2019, were included. Written and informed consent was obtained from each patient at the transition. For each patient, transition had been carried out through at least one joint visit with pediatric and adult gastroenterologists, and follow-up has been made for a minimum of 18 months.

Clinical data were collected at enrolment: gender, age at diagnosis and at time of transition, type of IBD, location of IBD according to the Montreal classification [10], previous surgery, previous and current therapies at time of transition, clinical disease activity at diagnosis and at transition visit (measured with Partial Mayo Score (PMS) and Harvey-Bradshaw Index (HBI) for Ulcerative Colitis (UC) and Crohn's Disease (CD), respectively) [11, 12] and available endoscopic and imaging reports. Relapse was defined as worsening of symptoms, change of treatment or need for surgery.

Patients were submitted to an anonymous online questionnaire of 38 items drawn up based on the validated questionnaires TRAQ and SIBDQ within the first 6 months from the beginning of transition process. Questions from TRAQ about health insurance covers had been removed, due to the Italian public healthcare system. The SIBDQ consists of 10 questions, scored of a seven-point scale with higher scores indicating a better quality of life. Good HRQoL was defined as a score above 50 points [13].

Two final questions were added in order to evaluate the quality of transition process: 1) When do you think the transition process from your pediatrician to your gastroenterologist should have taken place? 2) What do you think are the most important necessary conditions for an ideal transition?

The study protocol conforms to the ethical guidelines and it has been approved by the ethical committee at the "Fondazione Policlinico Universitario A. Gemelli IRCCS". A written informed consent has been obtained from all patients.

Statistical analysis

Categorical variables were synthesized with frequencies and percentages, continuous variables with averages and the measurement of the standard deviation (SD). The statistical association of the events, the graphical representation of the same ones and the evaluation of the significance had been carried out with MATLAB and Statistics Toolbox (The MathWorks, Natick, Massachusetts, US). Associations with a p-value < 0.05 were considered significantly different from zero.

Results

Patients' characteristics

Before transition

Eighty-two patients were enrolled, of whom 42 were males (51.2%) and 49 (59.8%) were affected by CD. The mean age at diagnosis was 11.8 ± 3.5 years. Among 49 patients with CD, 32 patients (65.3%) had a penetrating or stricturing disease, 21 (42.9%) showed growth failure at the time of diagnosis and 15 (30.6%) had a perianal disease. Of 33 patients with UC, 26 (78.8%) had pancolitis. *Table 1* summarizes baseline patients' clinical characteristics.

With regard to medications before transition, 75% of patients received corticosteroids for more than 3 months, 56 (68.3%) began an immunosuppressive therapy with thiopurines (still ongoing at transition only in 8 patients, 14.3%), 9 patients received also other types of immunosuppressants (cyclosporine, methotrexate, thalidomide).

Fifty-three patients (64.6%) underwent at least one biological therapy (ongoing in 62% of patients at time of transition) and 15 (28%) ≥ 2 different type of biologics

Up to 40.2% of patients underwent one or more surgical intervention, more frequently for CD patients compared to UC (58% vs 15%, $P=0.0003$). A complicated (both stricturing and penetrating) CD ($p=0.015$), two or more types of biologics employed before transition ($p=0.005$) and a more severe clinical activity at diagnosis ($p=0.001$) correlated with a higher risk of major surgeries in the pediatric age (Figure 1).

At time of transition

The average age observed at transition was 20.1 ± 2.7 years, with an average time between the diagnosis and the transfer to the adult center of 8.3 ± 4.6 years. Only 22% of patients who carry out transition between ages 14 and 18 years were in clinical remission phase, compared to 60% of those who carried it out between ages 19 and 24 years ($p=0.002$, Figure 2). No significant association was found between the age at transition and other parameters such as type of disease ($p=0.89$), previous surgery ($p=0.44$), clinical activity at diagnosis ($p=0.78$) and early onset (<6 years) disease s ($p=0.66$).

Overall, 24% of patients carried out transition while on a moderate or severe disease activity and 40% of them had already been treated with ≥ 2 biologics. 29% of patients transitioned while in clinical and endoscopic remission, while 20.3% showed residual endoscopic activity despite a clinical well-being. 47.5% had to change or start a new biologic therapy before within one year from transition, and 21% of patients needed IBD-related surgery within the first two years after transition.

Transition while on moderate to severe active disease was significantly correlated with worsening of symptoms during the first year of follow-up visits at the adult center ($p=0.002$).

Assessment patients' readiness and quality of life

A selected group of fifty-three of patients, comparable for age and disease's characteristics to the population of the study, answered the online anonymous questionnaires. Among them, up to 70% still go to medical visits at the adult center along with their parents, and 89% of them report that parents still have an important role in the management of therapy.

Table 2 summarizes patients' answers.

The mean value of the TRAQ questionnaires was 3.4 ± 0.5 , and the mean score of SIBDQ was 53.9 ± 9.8 . After considering a low score of transition readiness as a TRAQ score < 3 , significant association was found between a TRAQ mean score > 3 and a SIBDQ > 50 ($P=0.0129$), in particular: 80.5% of patients with TRAQ mean score > 3 have a score > 50 of SIBDQ, compared to the 41.7% of patients with TRAQ mean score ≤ 3 (Figure 3). On the other hand, among patients with a TRAQ mean score ≤ 3 , 46.7% of them had a SIBDQ ≤ 50 and only 13.2% > 50 .

No significant differences were observed among TRAQ mean score of patients who completed transition within the age of 19 (3.3 ± 0.5) compared to those who passed after 20 years (3.4 ± 0.5), with $p=0.36$.

Overall, 75% of patients had a positive opinion of the transition model adopted. About the question of what were the most important aspects for an ideal transition (max 3 answers): 52% of patients answered the timing of transition in a phase of stable remission, 49% the access to scheduled joint visits with both pediatricians and adult gastroenterologists and 34% the presence of psychologist and nutritionist figures in the adult center. Less important, according to our patients were: the short distance between the two centers (24%), the possibility to choose independently the adult gastroenterologist (9%) and the protraction of transition for longer than 1 year (8%).

Forty percent of patients believe that the disease has delayed their educational and professional pathway, and 90% of patients who underwent surgery believe that surgery has overall improved their quality of life. The 88% of patients say they feel better now than they did in pediatric age, and 70% report an actual clinical well-being. The 45% of patients finally reported the presence of other cases of IBD in the family.

Discussion

We have explored the outcome of the transition process of 82 consecutive IBD patients from two pediatric referral hospitals to one IBD adult university hospital center, their readiness and the consequent impact on quality of life. Our model included at least one joint pediatric–adult visit at children’s hospitals, which are at a different location from our IBD center, in presence of parents. Despite there is no evidence that this model of transitional care is superior over others, it has been shown to be associated with a more effectiveness on transmitting clinical data and building confidence in adults’ clinicians [14].

No chronological criteria have been considered in order to plan the timing of transition, but a case by case selection according to IBD pediatricians’ judgment has been used.

The mean age observed at transition was 20.1 ± 2.7 years, exceeding the recommended ideal interval of the age of 17 and 19 [6]. However, patients with a moderately to severely active disease were transitioned earlier (average age 19.3 ± 2.4 years) compared to those with a mild or absent activity (average age 20.2 ± 2.5 years). This could be attributed to a lower engagement and attitude towards transition process by patients and caregivers. Conversely, we observed that patients transitioned in active phase of disease, defined as “crisis transfer model” were at higher risk of worsening during the first year after transition.

The main risk factors linked to a higher rate of surgery within the first year from transition are the CD phenotype (particularly B2 and B3 behavior phenotypes), the number of biologics drugs assumed in pediatric age, the clinical activity at diagnosis and in particular the absence of an endoscopic or clinical remission at the beginning of the process.

Active disease at the time of transition had been previously associated with an unsuccessful transition [15]. Accordingly, patients should complete transition to the adult center while in clinical remission or mild disease activity. Conversely, the transition of active patients should be rather delayed until resolution of acute phase, in order to avoid traumatism and to favorite a greater confidence in the adult doctor and a good compliance with therapy management. [16].

The acquisition of specific skills in self-management and self-efficacy domains (e.g. monitor and report symptoms, handle medications) is a crucial step for the transition process. It has been recently observed in an US cohort the absence of association between TRAQ scores and measures of health [17]. In our cohort, instead, even if we did not observe significant differences in terms of TRAQ mean scores among patients of different age, with the same level of independence and awareness of disease from the age of 19, we found a significative positive association between TRAQ and SIBDQ questionnaires, highlighting the importance to assess a real readiness in order to not impair patients' HRQoL.

Our patients expressed generally great satisfaction about the transition process adopted, in particular about the opportunity to join pediatric-adult visits. Parents seem to still play a central role in patients' lives and in their relationship with disease, especially for managing scheduled appointments, medications (including also keeping in memory of previous side effects or intolerance) and talking with providers.

This confirms the urgent need to structure educational programs during childhood, including also parents, in order to stimulate the acquisition by patients of a greater independence and capability of self-management.

Our study has some limitations: the inclusion of two pediatric centers with different approach to care, the single model of transition analyzed and the recall bias since patients were enrolled within the first 6 months from their transition.

In conclusion, our data support that mild activity of disease at transition and a high level of adolescent's autonomy skills are the most important aspects of considering for transition and for assuring a better HRQoL in this difficult phase of care.

Declarations

Ethics approval and consent to participate

The study was approved by the Ethical Committee of "Fondazione Policlinico Universitario A. Gemelli IRCCS". The procedures were in accordance with the ethical standards of the Declaration of Helsinki.

Consent for publication

All authors have read and approved the content and agree to submit for consideration for publication in the journal.

Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

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Authors' contributions

AC, DP and AA made substantial contributions to conception and design, acquisition of data and analysis and interpretation of data. AC and DP wrote the manuscript. AA, LG and AG reviewed and revised the manuscript. FB, DK, BP, MA and SC were involved in the recruiting of patients. All authors read and approved the final manuscript.

Acknowledgement

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Tables

Table 1. Baseline patients' characteristics

Number of Patients	82
CD	49 (59.8%)
UC	33 (40.2%)
Sex	42 M, 40 F
CD	30 M (61.2%)
UC	21 F (63.6%)
Age	
At diagnosis	11.8±3.5 years
At transition	20.1±2.7 years
Localization CD	
Ileal- n (%)	9 (18%)
Colic- n(%)	6 (12%)
Ileo-colic- n(%)	30 (61%)
Upper GI- n (%)	4 (8%) exclusive 8 (16%) in addition
Perianal Disease	15 (30.6%)
Phenotype Pattern CD	
Inflammatory (B1)	17 (34.7%)
Stricturing (B2)	24 (49%)
Penetrating (B3)	8 (16.3%)
Growth Failure	21 (42.9%)
Localization UC	
Ulcerative Proctitis (E1)	1 (3%)
Distal colitis (E2)	6 (18.2%)
Pancolitis (E3)	26 (78.8%)

Due to technical limitations, table 2 is only available as a download in the Supplemental Files section.

Figures

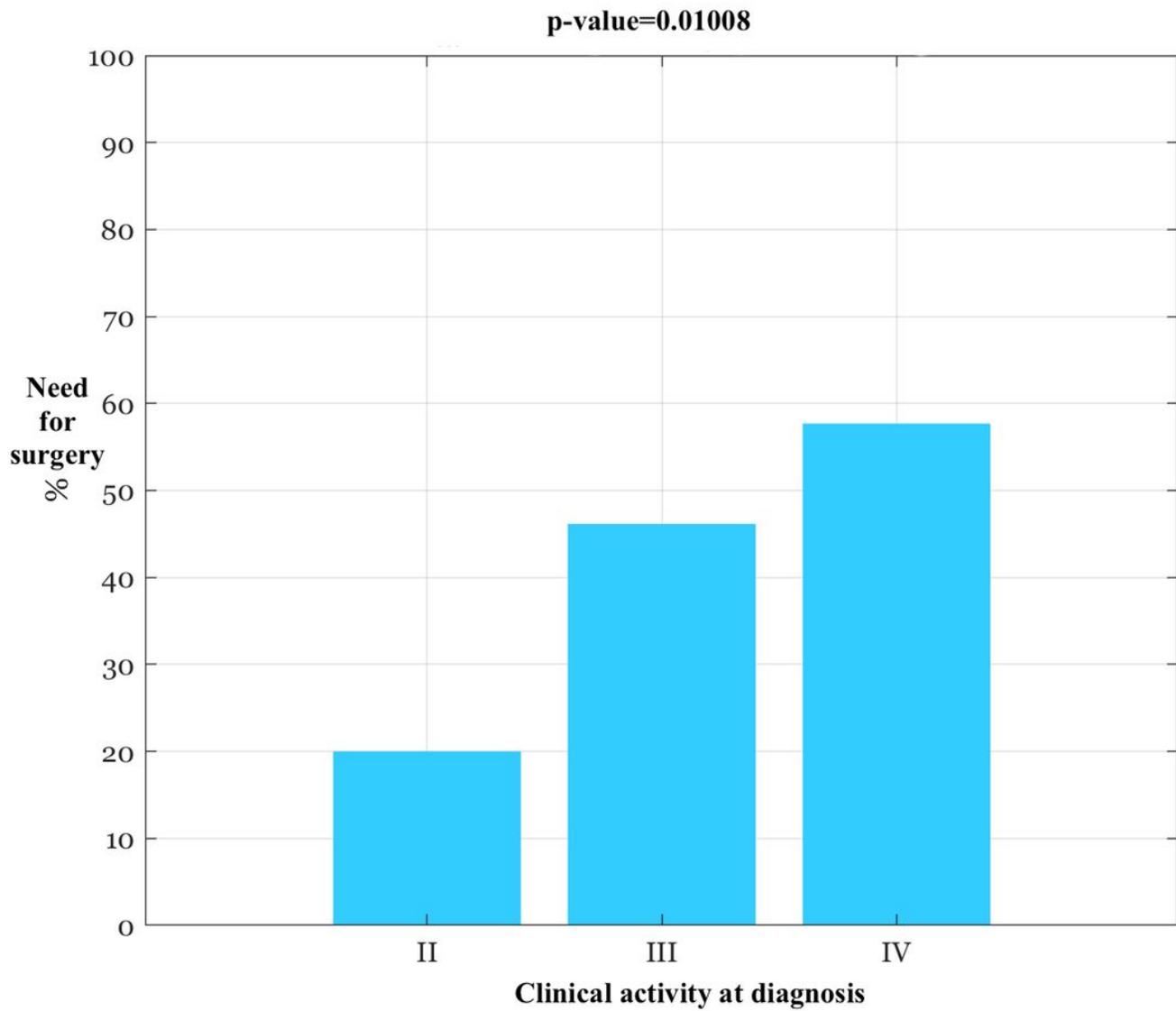


Figure 1

Association between probability of undergoing surgery before transition and clinical activity at diagnosis (HBI and PMS)

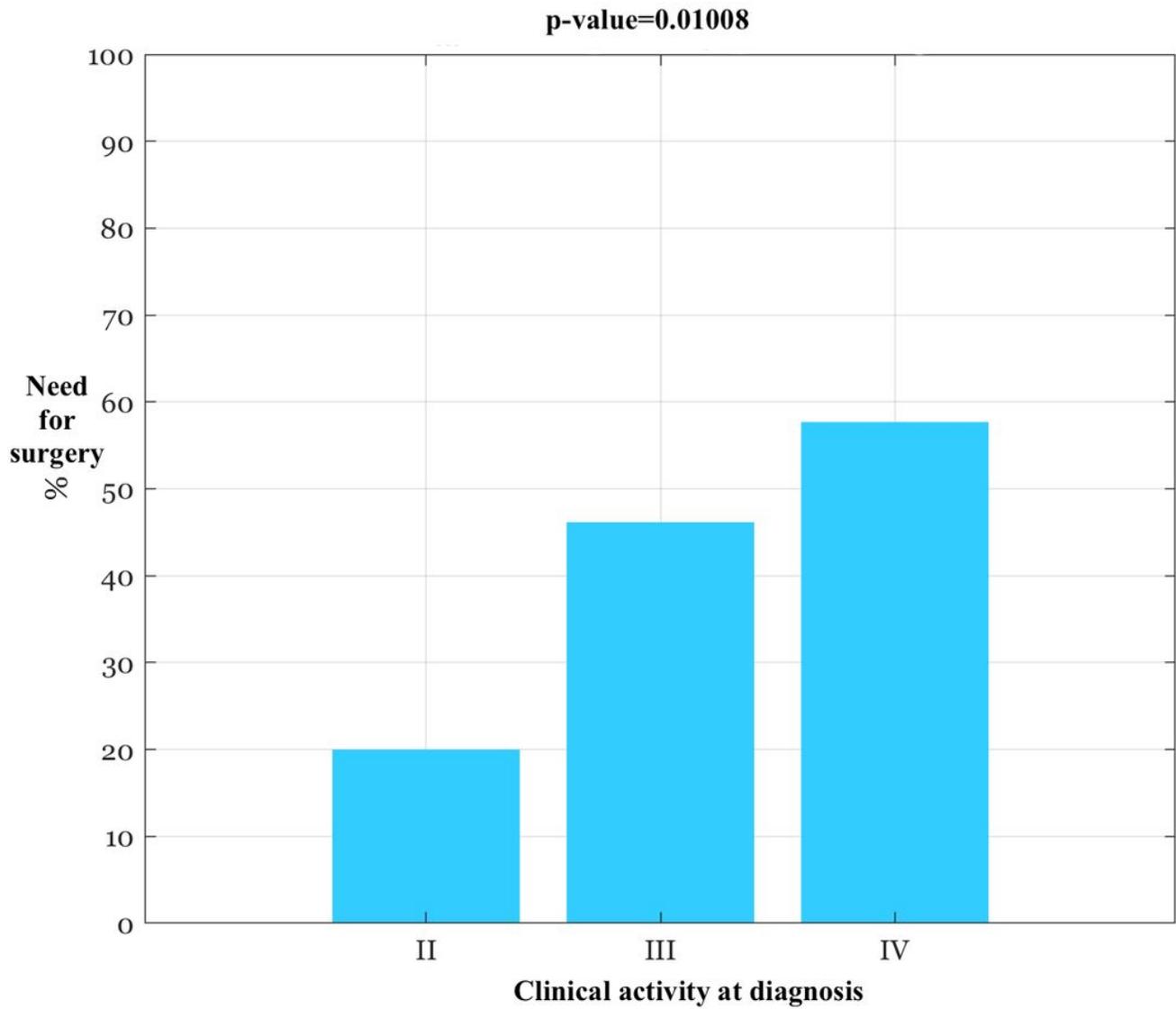


Figure 1

Association between probability of undergoing surgery before transition and clinical activity at diagnosis (HBI and PMS)

Patients and clinical activity related to age

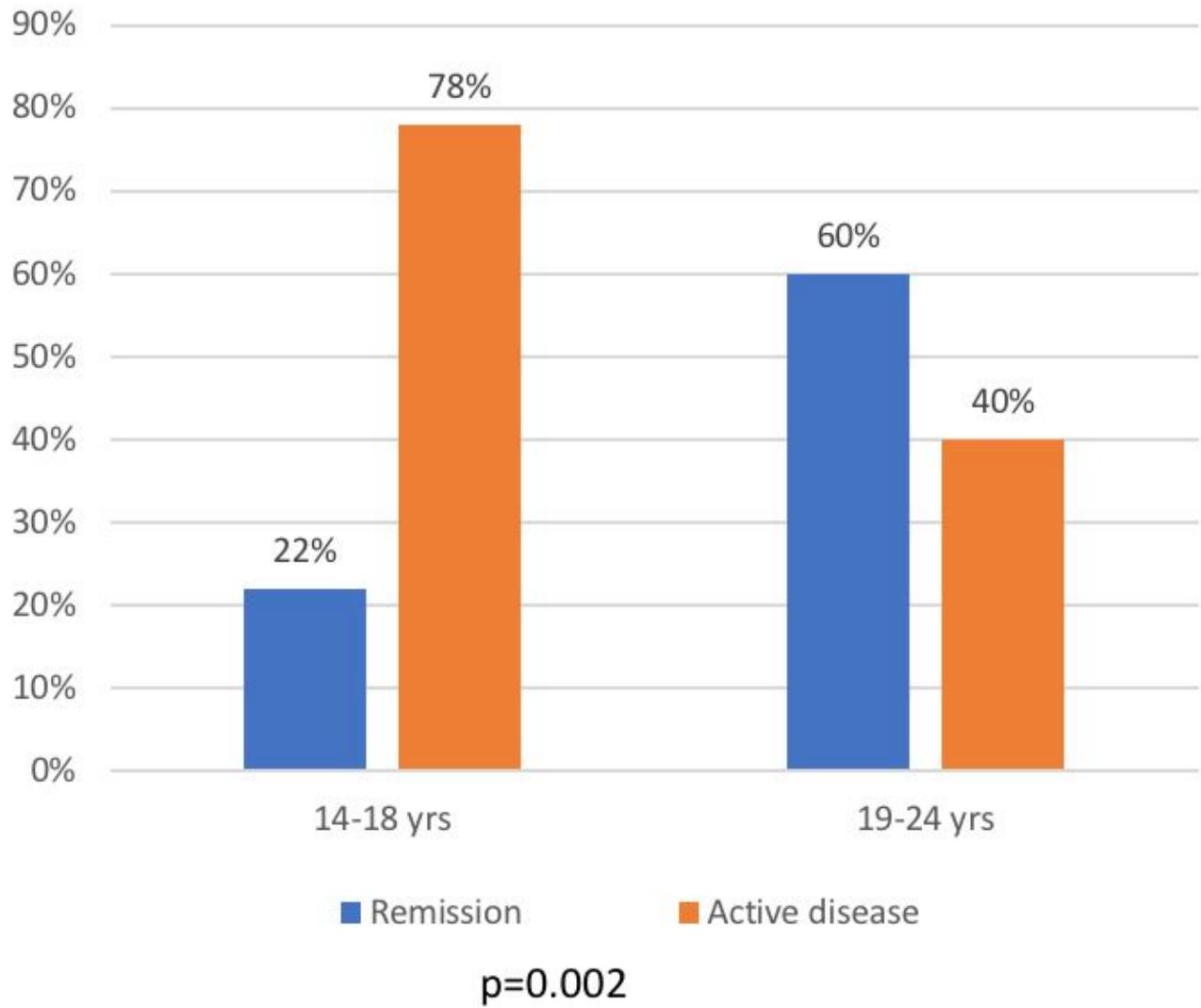


Figure 2

Transitioned patients divided by age and clinical disease activity

Patients and clinical activity related to age

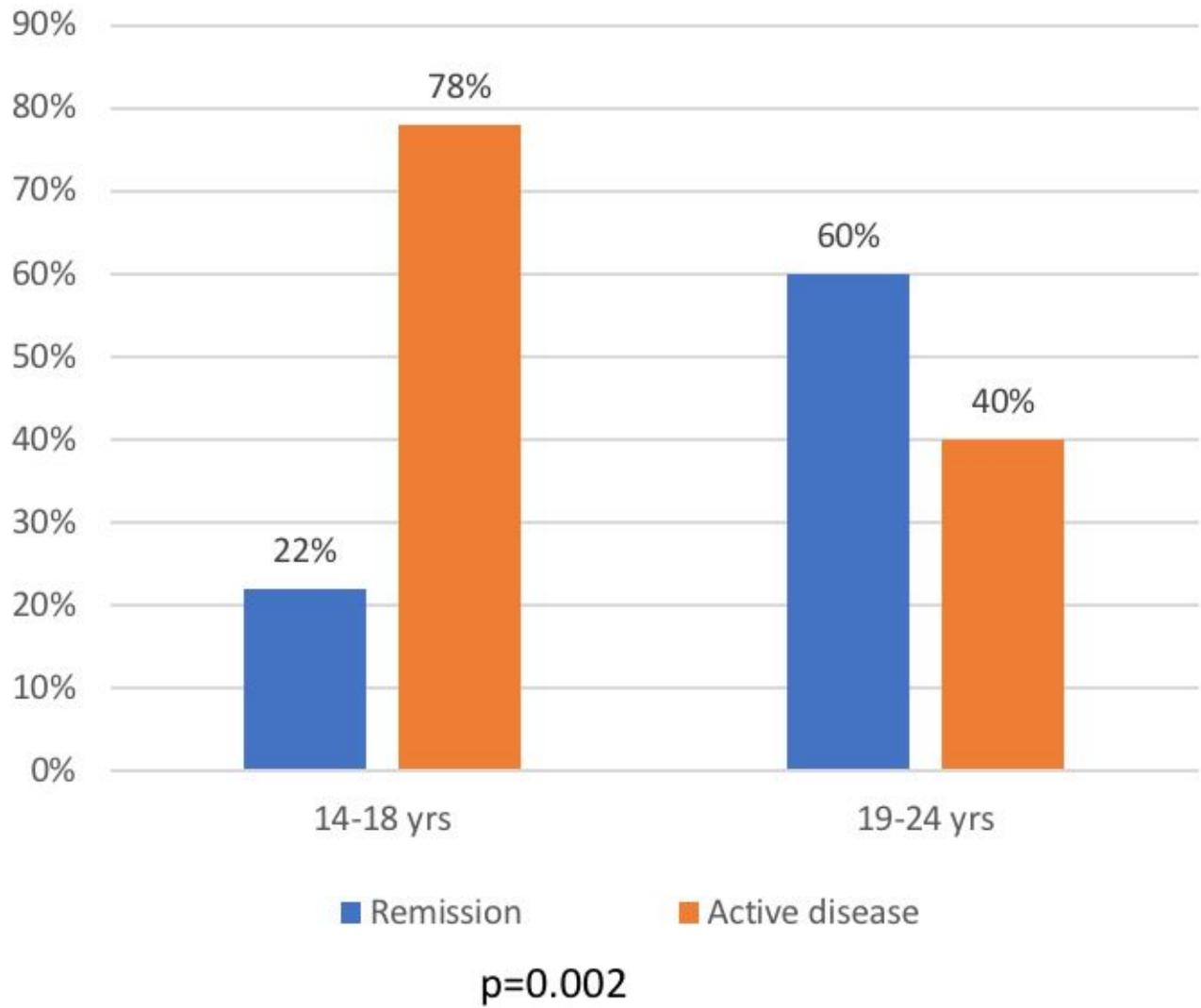


Figure 2

Transitioned patients divided by age and clinical disease activity

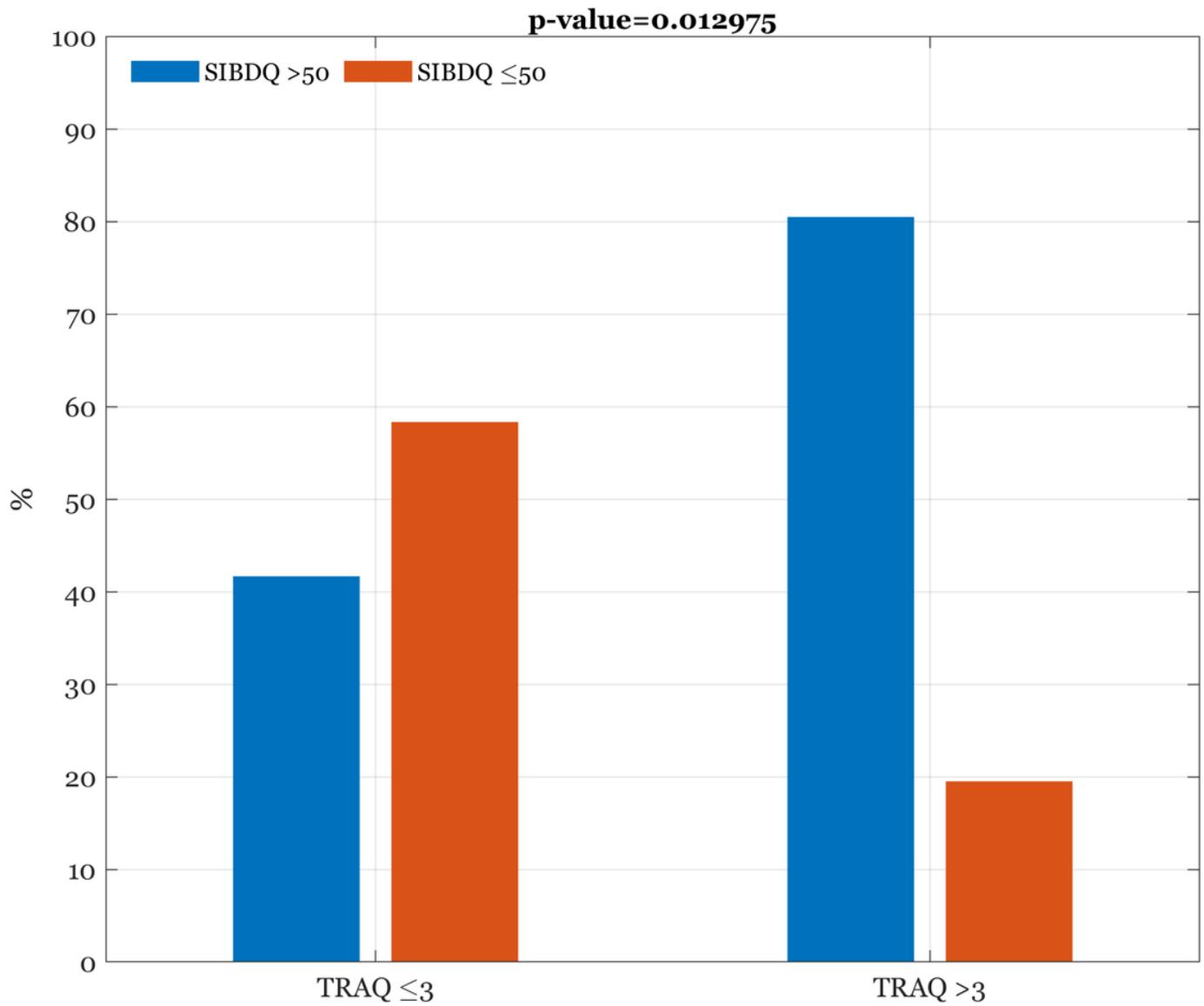


Figure 3

Association between TRAQ and SIBDQ scores

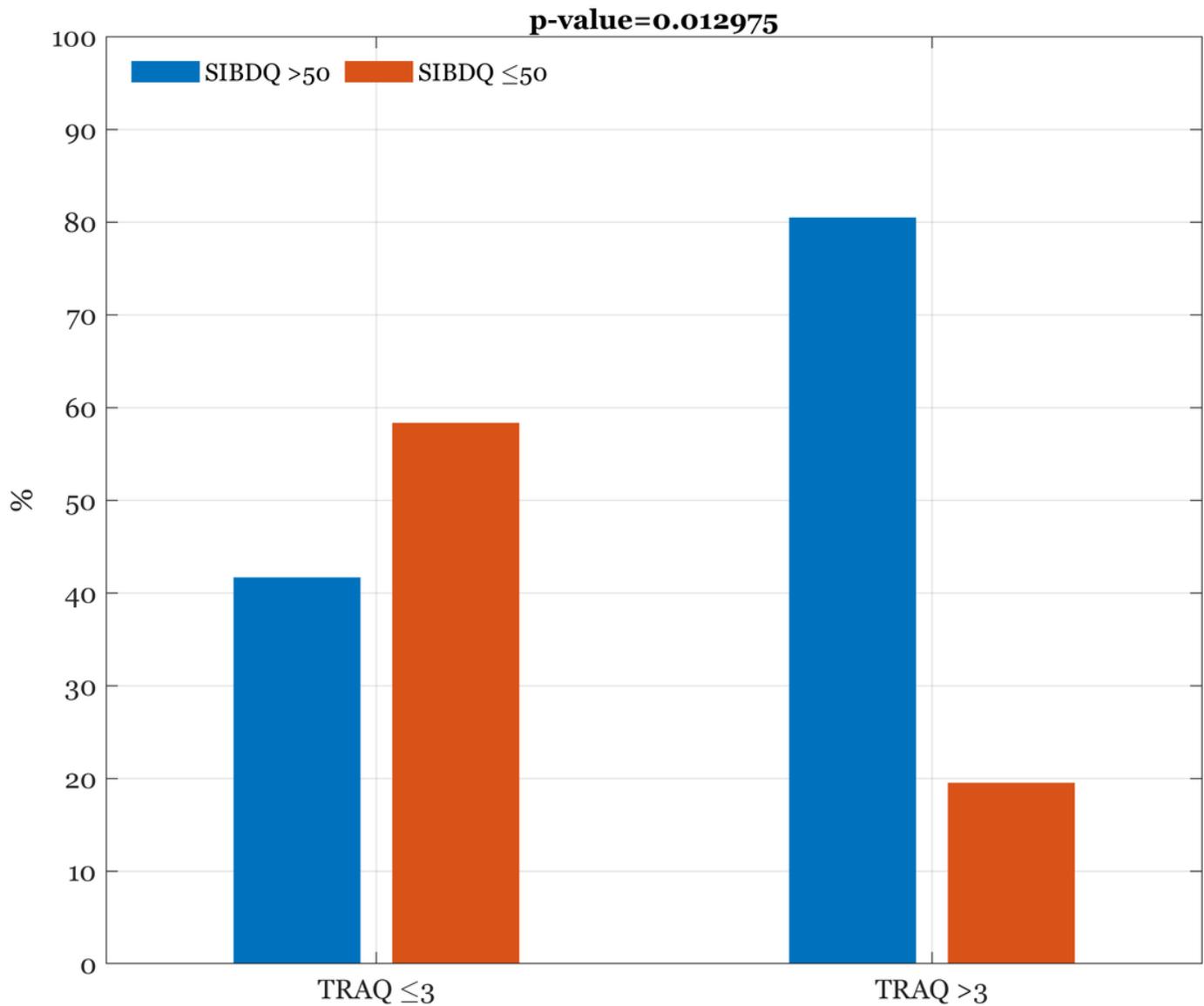


Figure 3

Association between TRAQ and SIBDQ scores

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Table2.xlsx](#)
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