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Planned Transition of Adolescent Patients with Inflammatory Bowel Disease Results in Higher Remission Rates

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ABSTRACT

Purpose: To evaluate the effect of our current transition process on clinical outcomes in adolescent patients with inflammatory bowel diseases (IBD).
Design and methods: Two groups of patients with IBD diagnosed in pediatric care were compared retrospectively: Group A patients did not attend the transition process, while Group B patients entered the planned transition service. Outcomes at 1-year after transfer to adult care were evaluated.
Results: Forty-five patients with IBD diagnosed under the age of 18 years were identified of whom 35 had Crohn's disease and 10 had ulcerative colitis. Twenty-four patients were in Group A (without transition), and 21 patients in Group B (with at least one planned transition visit). Mean age at diagnosis was 15.1 ± 2.2 and 13.7 ± 3.0 years ($p = 0.086$), respectively. There were no significant differences in disease duration before transfer, Montreal classification at diagnosis, body mass index, anti-TNF therapy usage, and disease status at transfer between the two groups. A significantly higher number of Group B patients were in remission at 12 months after transfer when compared to patients in Group A (11 vs. 18, respectively, $p = 0.037$). There was a significant difference between groups regarding the number of scheduled visits within the examined period (9 vs. 16, $p = 0.011$, respectively).
Conclusions: Planned transition visits resulted in higher disease remission rate at 1-year follow-up after transfer from pediatric to adult health care system in adolescent patients with IBD.
Practice implication: Well-established transition programs in IBD are needed.

Introduction

Inflammatory bowel diseases (IBD) including Crohn's disease (CD) and ulcerative colitis (UC) are chronic relapsing and remitting conditions. Children and adolescents represent an important subgroup of patients with IBD: about 25% of all cases are diagnosed under the age of 18 years while about 25% of these cases are under 10 years (Benchimol, Fortinsky, et al., 2011), with an observed steady increase of IBD prevalence in Western and Eastern Europe (Henderson et al., 2012; Hope et al., 2012; Muller et al., 2013; Pozler et al., 2006). The phenotype of childhood-onset IBD differs from that of the adult-onset disease. The former has a more severe disease course with worse prognosis: young patients might suffer from growth retardation, delayed puberty, and weight loss; surgery and hospitalization are more often required as well as immunomodulatory and biological therapy (Benchimol, Guttmann, To, Rabeneck, & Griffiths, 2011; Hartman, Eliakim, & Shamir, 2009; Radke, 2015; Van Limbergen et al., 2008; Zeisler & Hyams, 2014).

In chronically ill children, movement from pediatric to adult health care services is an unavoidable step with time. The timing of this transfer has to be scheduled for the age of 18 years in many European countries (van Rheenen et al., 2017). In the preceding years of transfer (between 16 and 18 years of age), adolescents are in a vulnerable phase when failing to receive sufficient care may result in a drop in adherence, therapy discontinuation, and a consequent increase in complication rates. Since transfer to adult care has several pitfalls, suitable transition models with structured programs have been introduced (Dabritz, Gerner, Enninger, Classen, & Radke, 2017). The benefits of these models have long been confirmed in chronically ill adolescents with cystic fibrosis, type 1 diabetes mellitus, juvenile rheumatoid arthritis, and congenital heart diseases (Afzali & Wahbeh, 2017; Hewer & Tyrrell, 2008; Monaghan & Baumann, 2016). Papers on type 1 diabetes reported significantly lower HbA1c levels, better compliance with higher clinical attendance rate, and less frequent hospitalization in patients participating in coordinated transition programs (Crowley,

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Wolfe, Lock, & McKee, 2011; Nakhla, Daneman, To, Paradis, & Guttmann, 2009). Similar beneficial effects of coordinated transition were reported on the quality of life of adolescents with juvenile rheumatoid arthritis (McDonagh, Southwood, Shaw, British Society of Paediatric and Adolescent Rheumatology, 2007).

First data on the transition of patients with IBD came from small-scale observational study 15 years ago (Mamula, Markowitz, & Baldassano, 2003). Since, the European Crohn's and Colitis Organisation (ECCO) has published an evidence-supported consensus guideline on important clinical practice points for transitional care (van Rheenen et al., 2017). The optimal model for IBD transition is currently unknown but the operation of a joint pediatric-adult clinic is considered to be the most promising option (van Rheenen et al., 2017). The ECCO guideline recommends adapting a transition model that is optimal for each institution, depending on local availability of resources (e.g., single or multiple joint appointments, site of meetings, participants) (van Rheenen et al., 2017). However, limited research is available about the disease course and patients' adherence after the transition at adult gastroenterology clinics (Cole, Ashok, Razack, Azaz, & Sebastian, 2015). The aim of this study was to investigate the efficacy of our transition service offered to adolescents with IBD in order to ease the transition from pediatric to adult gastroenterology care.

Methods

Design

Participants

Our study is a retrospective cohort study including patients diagnosed with IBD in childhood and admitted to the pediatric and adult Gastroenterology Departments of University of Pécs, Hungary. The mandatory timing of transfer from pediatric to adult healthcare services is 18 years of age in Hungary. Included patients were divided into two groups based on the reception of transition service.

Group A includes patients transferred to the adult gastroenterological clinic between March 2012 and March 2014, before our transition service had been introduced. Hence, these patients did not undergo transitional care: the pediatrician wrote a clinical letter detailing the past medical history at the last pediatric visit and gave a recommendation about when to present at the adult clinic for follow-up. The next appointment by the adult gastroenterologist had to be arranged by the patients themselves. Receiving biological therapy and/or developing a more aggressive phenotype of disease, management strategies were discussed between the physicians over the phone.

Group B includes patients attended our transition clinic between March 2014 and March 2016. Our transition clinic has been running a program with joint sessions of experts including pediatric and adult gastroenterologists, an IBD nurse, the patient, and an adult next of kin of the patient. These meetings take place regularly every six months at our pediatric gastroenterology outpatient clinic, at the Department of Pediatrics, University of Pécs. Initially, patients turning 18 years of age in the concomitant six months participated in a transition program including one joint visit with both physicians. Then, we realized that the continuity of transition can only be secured by introducing multiple joint visits started at a younger age; therefore, we involved 16 years old adolescents. This strategy allowed us to explore and fill the gaps in self-efficacy of patients better, making the transition process more effective. Joint transition sessions are held twice a year; six to seven patients are seen and discussed per occasion. Each participating IBD patient has one to three appointments on average. The objective of the transition clinic is to prepare patients, relatives, and the physician in charge off the transition to the adult health care service. In addition to standard care, physicians and nurses strive to improve disease knowledge and self-management skills of patients as well as to discuss the potential sites of available adult care in relation to secondary education. No specific questionnaires were used about that time in our transition clinic but the key items of the IBD Self-Efficacy Scale (Keefer, Kiebles, & Taft, 2011) and the IBD-yourself questionnaire (Zijlstra et al., 2013) were employed during routine practice.

Data and parameters

Data were retrieved from the electronic files of the eMedSolution system. We reviewed a 12 months period starting from the last visit in the Pediatric Department. The following parameters were recorded: diagnosis (CD or UC), gender, Montreal-classification, body weight, body height, body mass index (BMI), age at diagnosis, disease duration, and drug history before, during, and after transfer. We categorized disease activity at the time of transfer, as follows: (1) remission, (2) active disease on treatment, and (3) active disease without treatment. Since these patients' activity indices (i.e., Crohn's Disease Activity Index [CDAI] or Mayo-scores) were not recorded at every visit, we failed to investigate the effect of transitional care on them.

Data on laboratory studies included the levels of hemoglobin (Hb), hematocrit (Htc), C-reactive-protein (CRP), albumin, platelet counts (PLT), and erythrocyte sedimentation rate (ESR).

The number and type of surgeries and the length of hospitalization after hand over were evaluated. Reasons for admission were categorized, as follows: (1) acute flare, (2) emergency surgery, (3) elective surgery (e.g., seton insertion), and (4) elective procedures and investigations (i.e., disease-reassessment, infusion, and planned colonoscopy). Data were collected on the safety profile of applied medications, dose escalation, and the number of performed diagnostic procedures, such as endoscopies and imaging studies (ultrasound, X-ray, computed tomography, and magnetic resonance imaging). Medical records on nutritional status or the application of exclusive enteral nutrition were not available for all patients.

This study has been approved by the Regional Ethical Committee at the University of Pécs, Hungary (REC# 6916).

Statistical analysis

Data were analyzed using SPSS software package (24.0, IBM Inc., Chicago IL, USA). Continuous and categorical variables were presented as mean ± standard deviation (SD) and frequencies (%), respectively. Pearson's chi-squared test and Fisher's exact test were used for the comparison of categorical variables in Groups A and B, laboratory studies of the groups (Hb, Htc, PLT, CRP, and albumin) were compared with paired sample *t*-test, independent Student t-test, and Welch-test. A p-value ≤ 0.05 was considered statistically significant for all tests.

Results

Patient and disease characteristics

Baseline data are shown in Table 1. Nine out of 45 patients' data (6 and 3 from Groups A and B, respectively) could not be evaluated in detail due to non-attendance for appointments in adult gastroenterology service in Pécs after transfer or transition.

Mean age at diagnosis was 15.1 years (range: 11–18 years) in Group A and 13.7 years (range: 8–18 years) in Group B, without significant difference between groups ($p = 0.086$). Average disease duration before transfer was 40.6 months (range: 2–105 months) in Group A and 51.2 months (range: 2–118 months) in Group B ($p = 0.284$). Groups did not differ in BMI (20.1 [range: 13.3–28.7] and 21.4 [range: 15.2–32.8] for Groups A and B, respectively; $p = 0.375$), Montreal class of CD and UC; and medications used before, during, and after transfer (i.e., 5-aminosalicylates, 5-ASA; azathioprine, AZA; budesonide, methylprednisolone, and anti-tumor necrosis factor, anti-TNF) (Table 1).

Nine patients from Group A and 7 from Group B received biological treatment (anti-TNF agent) at the time of transfer ($p = 0.690$), whereas 3 patients from Group A and 7 from Group B received anti-TNF therapy at 12 months ($p = 0.460$).

Table 1
Baseline characteristics of the non-transition group (Group A) and the transition group (Group B).

	Group A (n = 24)	Group B (n = 21)	*p*-Value
Diagnosis	CD = 22 (92%) UC = 2 (8%)	CD = 13 (62%) UC = 8 (38%)	**0.029**
Number of males (male %)	12 (50%)	6 (29%)	0.143
Age at diagnosis in years, mean (SD)	15.1 (2.2)	13.7 (3.0)	0.086
Disease duration before transfer in months, mean (SD)	40.6 (28.7)	51.2 (34.7)	0.284
Montreal class for CD	L1 = 5; B1 = 14 L2 = 7; B2 = 0 L3 = 10; B3 = 8 L4 = 5; p = 8	L1 = 5; B1 = 11 L2 = 5; B2 = 1 L3 = 3; B3 = 1 L4 = 3; p = 2	
Montreal class for UC	E1 = 0 E2 = 1 E3 = 1	E1 = 1 E2 = 3 E3 = 4	
Medication before transfer			
5-ASA	23	20	1.000
Steroids	20	17	0.693
AZA	15	14	0.919
Anti-TNF (biologics)	11	8/21	0.600
Medication at transfer			
5-ASA	22	18	0.335
Steroids	8	8	0.739
AZA	9	10	0.493
Anti-TNF (biologics)	9	7	0.690
Medication at 12 months			
5-ASA	13	13	0.600
Steroids	7	7	0.763
AZA	6	6	0.787
Anti-TNF (biologics)	3	7	0.460

5-ASA: 5-aminosalicylates, AZA: azathioprine, Anti-TNF: anti-tumor necrosis factor, m: male, CD: Crohn's disease, UC: ulcerative colitis, L: location, B: behaviour, p: perianal disease, E: extent, SD: standard deviation. $p < 0.05$ is shown in bold.

Disease activity and laboratory studies

At the time of transfer, 19 (79%) and 17 (81%) patients were in remission in Group A and B, respectively, without significant difference between groups ($p = 1.000$). However at 12 months, a significantly higher remission rate was observed in Group B when compared to that in Group A (95% vs. 65%, respectively [$p = 0.037$]) (Fig. 1). In the subgroup of CD at 12 months, 9 (60%) and 12 (100%) patients were in remission in Groups A and B, respectively; with a significant difference between groups ($p = 0.02$). Unlike in the subgroup of UC at 12 months, where this difference could not be observed: 2 (100%) and 6 (86%) patients were in remission in Groups A and B, respectively ($p = 1.00$).

Patients in clinical remission at 12 months were older in Group A (15.7 years [range: 13–18 years]) than in Group B (13.1 years [range: 8–18 years]) ($p = 0.004$), and had shorter disease duration (30.9 months [range: 8–68 months] for Group A and 58.1 months [range: 3–118 months] for Group B) ($p = 0.009$).

PLT and CRP were higher at 12 months as compared to the baseline values in Group A (baseline PLT 282.1 ± 108.9 vs. 12 months PLT 331.3 ± 106.9 × 10^9/L, $p = 0.039$ and baseline CRP 9.1 ± 13.3 vs. 12 months CRP 23.4 ± 32.9 mg/L, $p = 0.048$), but not in Group B (shown in Table 2). Baseline and 12 months levels of Hb, Htc and, serum albumin were not different significantly between groups.

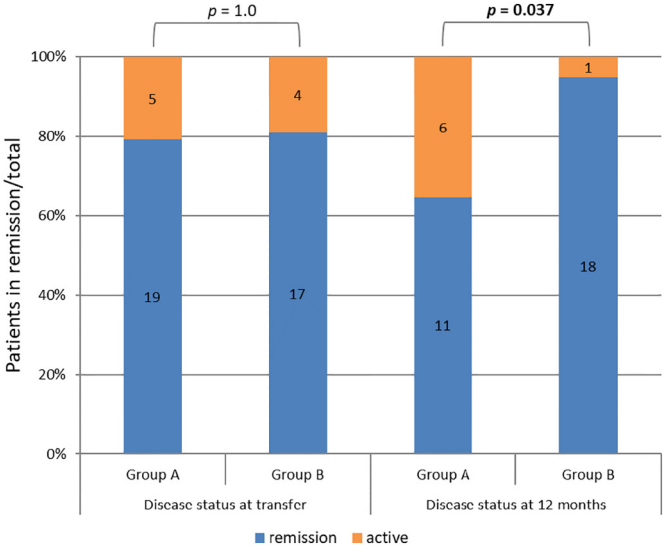

Fig. 1. Disease activity at the time of transfer and at 12 months following transfer in the non-transition group (Group A) and the transition group (Group B) $p < 0.05$ shown in bold.

Critical outcomes

Nine of 18 patients in Group A and 4 of 20 patients in Group B required acute hospital admission during 12 months follow-up (Table 3). Although the difference failed to reach the level of significance, there was a trend towards an increased admission rate of those not using transition service ($p = 0.083$). However, the attendance rate of scheduled visits was more frequent in Group B than in Group A (16 patients in Group B vs. 9 patients in Group A, $p = 0.011$).

Within the 12 months follow-up, the total number of diagnostic procedures was also recorded (Table 3). While 27 imaging procedures were performed in 18 patients from Group A, 43 were in 18 patients in Group B ($p = 0.260$ for the number of imaging procedures). Out of the 18 patients underwent imaging in each group, the number of endoscopies was 7 and 11, in Groups A and B respectively ($p = 0.182$).

Discussion

The transition from pediatric to adult health care service can be challenging for young patients with chronic diseases. Current evidence suggests that structured transition models should be used during this process (van Rheenen et al., 2017). Although a favorable effect of transition care on self-efficacy and autonomy in IBD was reported (Keefer et al., 2011; Wright et al., 2014; Zijlstra et al., 2013), the question as to whether this strategy improves disease outcomes has remained understudied. To answer this question, we aimed to investigate the effect of our recently introduced transition program on the disease course of IBD and the adherence to visits at the adult gastroenterology clinic after the transition.

Our transition clinic has been running with the cooperation of a pediatric gastroenterologist, an adult gastroenterologist, and an IBD nurse contributing to the continuity of the work with essential administrative support. At other transition clinics, IBD nurses are appointed coordinators of the transition process, tasks include psychological guidance, organizing appointments, ensuring phone contact, and nursing interventions for symptoms and complications (Cole et al., 2015; van Rheenen et al., 2017). Also, the involvement of a dietitian and a clinical psychologist is desirable.

Our study showed that the provision of a transition service can lead to a decreased disease activity in chronically ill IBD adolescents. Patients with IBD entering a planned transition program exhibited a significantly higher remission rate at 12 months posttransfer than those not using this service. In CD, remission rates were significantly higher at 12 months in the transition group compared to the non-transition group. This lets us conclude that particularly patients with CD benefit from transition care. Differences in the distribution of CD and UC within groups may limit the strength of this conclusion. Since mean age at diagnosis of patients in clinical remission was significantly lower in the transition group when compared to those in the non-transition group, their disease duration was significantly longer. Despite this, patients

Table 2
Laboratory studies of the non-transition group (Group A) and the transition group (Group B) at baseline (at the time of transfer) and at 12 months (following transfer).

	Group A			Group B		
	At transfer	At 12 months	*p*-Value	At transfer	At 12 months	*p*-Value
Hb mean (SD) in g/L	128.2 (20.2)	128.9 (15.9)	0.720	138.8 (45.2)	128.8 (24.5)	0.512
Htc mean (SD) in %	37.5 (5.0)	37.9 (4.1)	0.325	38.2 (4.7)	38.8 (5.7)	0.156
PLT mean (SD) × 10^9/L	282.1 (108.9)	331.3 (106.9)	**0.039**	299.1 (92.9)	303.3 (102.7)	0.825
CRP mean (SD) in mg/L	9.1 (13.3)	23.4 (32.9)	**0.048**	5.9 (11.9)	4.3 (7.1)	0.454
Serum albumin mean (SD) in g/L	43.7 (4.3)	40.6 (3.8)	0.491	45.6 (5.1)	45.4 (4.4)	0.111

Hb: hemoglobin, Htc: hematocrit, PLT: platelet count, CRP: C-reactive protein. $p < 0.05$ shown in bold. *p*-Values reflect the difference between the baseline and the 12 months values within groups.

achieved higher remission rates which can be explained by the effect of a transition.

Patients' data including disease status (active or remitting) and laboratory markers (Hb, Htc, PLT, CRP, and albumin) were used for assessing disease activity. A significant decrease in the level of inflammatory markers was observed in the transition group, contrasting the non-significant change of those in the non-transition group. Thus, using a transition service may be beneficial for patients with IBD by mitigating the course of the disease.

In accordance with the recommendation of an international Delphi study (Suris & Akre, 2015), we used the attendance rate of scheduled visits in adult care as an indicator of a successful transition. Significantly improved attendance rates were observed in patients falling in the scope of the transition program, implying a beneficial impact of transition service on compliance. According to a report, 20% of young patients with congenital heart diseases did not attend their planned appointments (Goodhand et al., 2010). Another study dealing with type 1 diabetes revealed that 40% of their patients were lost to be followed up after transfer (Van Walleghem, Macdonald, & Dean, 2008). It can be concluded that a successful transition, as a planned and targeted process, has a protective effect against the lost-to-follow-up barrier. Although non-significant results were gained for diagnostic procedures in our study, the absolute number of procedures was higher in the transition group as compared to the non-transition group. This may be explained by the fact that the transition group already showed improved attendance rates of planned appointments when various imaging methods were ordered.

Our study showed higher admission rates in the non-transition group due to an acute flare-up or an urgent surgery when compared to the transition group. Although we failed to find a significant difference, there was a trend towards an increased number of acute hospitalization in the non-transition group. In contrast to our findings, reduced hospital admission rates were described in a previous IBD study (Cole et al., 2015), especially concerning the urgent causes of hospitalization. Similarly to our results, hospitalization rates reduced by 80% in a study of 1500 patients with type 1 diabetes undergoing a transition program (Nakhla et al., 2009).

Table 3
Critical outcomes of the non-transition group (Group A) and the transition group (Group B).

	Group A (n = 24)	Group B (n = 21)	*p*-Value
Bowel resection (before transfer)	4/24	3/21	1.000
Bowel resection (within 12 months after transfer)	1/24	1/21	1.000
Drug toxicity	3/24	0/21	0.236
Dose escalation of anti-TNF-α	1/9	2/7	0.550
Acute flare-up or emergency surgery	9/18	4/20	0.083
Elective appointments	9/18	16/20	**0.011**
Diagnostic procedures (ultrasound, X-ray, endoscopy, computed tomography, magnetic resonance imaging)	27/18	43/18	0.260
Endoscopies	7/18	11/20	0.182

$p < 0.05$ shown in bold.

No difference was observed between the groups in the rates of surgical interventions in our study. Only 1 patient in each group underwent bowel resection within the 12 months period after transfer. In contrast, Cole et al. found significantly increased surgery rates in their non-transition cohort within 2 years after transfer (Cole et al., 2015). Therefore, they attributed a favorable effect to the transition program on the clinical outcomes of young patients with IBD. The divergence from our results may be explained by the shorter follow-up of 12 months and the small number of cases in our cohort of patients. Confounding factors, such as the adherence to the prescribed medications and the variable response to treatment in the population, should be taken into account, as well.

We acknowledge that our study has several limitations, the most important one is the retrospective nature of data collection and the non-randomized design. Although our results show important trends, firm conclusions cannot be drawn from the collected data. It should also be noted that the unknown status of patients lost to be followed up may distort the results. Pediatric patients with IBD are always treated in tertiary referral centers in Hungary. In contrast, adult care is not necessarily centralized; therefore, some patients rather prefer to attend the nearest local adult clinic after the transition, which might contribute to the lost-to-follow-up phenomenon.

An additional limitation of our study was that the transition program has been running since March 2014 in our practice. Assessment of a sufficient number of patients required the restriction of follow up period to 12 months whereas at least 2–5 years would have been ideal due to the chronic nature of IBD. In this way, the validity of our work is also limited by the small case number of 45 patients. Furthermore, we were unable to evaluate important characteristics, such as adherence to treatment, compliance, smoking, nutritional habits, physical development, sexual maturity, psychological development, socioeconomic status, and how satisfied the patients were with the care (e.g., with self-completion feedback questionnaires).

These limitations do not allow us to draw firm conclusions on the broad effect of transition care; however, our results indicate its positive impact on the progression of IBD. These results underline the need for well-established transition programs, shedding light on new perspectives in the management of IBD. Our work aimed to advance progress in transition models.

Future prospective studies are required to appropriately evaluate the effect of transition care.

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CRediT authorship contribution statement

Caroline Otto: Data curation, Formal analysis, Writing - original draft. **András Tárnok:** Investigation, Validation, Writing - review & editing. **Adrienn Erős:** Data curation, Writing - original draft. **Zsolt Szakács:** Methodology, Visualization. **Áron Vincze:** Validation, Resources. **Nelli Farkas:** Formal analysis, Software. **Patricia Sarlós:** Conceptualization,

Investigation, Funding acquisition, Project administration, Supervision, Writing - review & editing.

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