

# Spotlight on Transition in Patients With Inflammatory Bowel Disease: A Systematic Review

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**Background:** Transition of adolescents from pediatric to adult care is of great importance in the management of inflammatory bowel disease (IBD). Our aim was to review and summarize the currently applied interventions and outcomes related to transition practices in IBD.

**Methods:** A systematic review was performed in accordance with the PRISMA Statement. We searched PubMed, EMBASE, CENTRAL, and Web of Science databases up to February 15, 2019. Controlled studies evaluating adolescents and young adults with IBD participating in structured transition interventions or patient educational programs and single-arm (before-after) studies were included. Several individual, health care, and social outcomes were assessed. The PROSPERO registration number is CRD42019118520.

**Results:** A total of 23 articles were eligible for qualitative synthesis. Eleven studies compared an intervention to a control group, whilst 12 studies were uncontrolled before-after studies. The age of the participants varied from 11 to 25 years. The most common structured transition interventions were joint visits and patient education programs. IBD nurses were operating as nominated transition coordinators in the transition process. Quality of life, patient satisfaction, self-efficacy, disease-specific knowledge, adherence rate, and nonattendance rate at outpatient clinic were identified as main health care transition outcomes besides disease-related outcomes. Despite the various study designs and methodological limitations, outcomes improved with the application of structured transition interventions in eleven of the studies.

**Conclusion:** These results facilitate the design of randomized controlled trials along better standards in transitional care in IBD.

**Key Words:** inflammatory bowel disease, transitional care, adolescents, structured transition intervention, patient education program

## INTRODUCTION

Transition is defined as a purposeful, planned movement of adolescents and young adults suffering from chronic physical and medical conditions from child- to adult-orientated health care systems.<sup>1</sup> Providing transitional care should be considered as a complex intervention.<sup>2</sup> Recently, nondisease-specific

studies aimed to determine the corner stones and main outcomes of the transition process.<sup>3,4</sup> In 2015, an international Delphi study was carried out to identify the key elements and indicators of a successful transition.<sup>3</sup> Based on the agreement of the panelists, essential and very important elements of a successful transitional program were specified (eg, good coordination, early planning, self-management and education, personalized transition plan, and discussion of risk behaviors). The most important indicator was the avoidance of loss of follow-up (F/U).<sup>3</sup> In another 3-stage Delphi process, quality of life was identified as the highest-rated outcome measure besides other individual, health service, and social outcomes (eg, disease-specific knowledge, self-management, adherence to medication, attendance on medical appointments, and social network).<sup>4</sup>

In recent decades, structured transition interventions (STI) have been in the focus in long-lasting conditions, especially in type 1 diabetes,<sup>5</sup> cystic fibrosis,<sup>6</sup> congenital heart diseases,<sup>7</sup> or inflammatory bowel diseases (IBD).<sup>8</sup> STI is a complex, multidisciplinary intervention designed to provide additional support in the transition period.<sup>9</sup> Although several reviews have been published and recommendations have been proposed, there is no gold standard on how to provide transitional care in IBD. In the topical review of the European Crohn's and Colitis Organization, based on expert opinion, 14 practice points were identified as critical elements of transition programs.<sup>10</sup> Accordingly, the ideal model of transition

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Abbreviations: AGE, adult gastroenterologist; CG, control group; F/U, follow-up; IBD, inflammatory bowel disease; IG, intervention group; MDT, multidisciplinary team; PEP, patient education program; PGE, pediatric gastroenterologist; STI, structured transition intervention.

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includes a joint pediatric-adult clinic. As for the primary goals during the transition process, adolescents should be empowered to make decisions, be self-efficacious, and develop disease-specific knowledge. Education of patients and parents should start at least 1 year before transfer. Application of validated and adapted tools and questionnaires are recommended for the F/U of the success of the targeted interventions. Patient education and the maintenance of remission during transfer are also highlighted.<sup>10</sup>

Several pitfalls may occur during the transition, disrupting the continuity of medical care and resulting in poor long-term outcomes. Failed transition was described in chronically ill adolescents, leading to loss of F/U,<sup>11</sup> decreased adherence,<sup>12</sup> poorer disease control,<sup>13</sup> and an increased risk of disease-related hospitalization.<sup>14</sup>

To obtain a comprehensive picture about the currently applied transition strategies in IBD, this systematic review purposed to provide an overview of the applied interventions throughout transition in IBD and to test their effect on health care transition outcomes related to IBD patient care.

## MATERIALS AND METHODS

This systematic review was performed and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement<sup>15</sup> (Supplementary Table 1). The protocol was registered in the International Prospective Register of Systematic Reviews (PROSPERO) under the identification number of CRD42019118520.

### Search Strategy

An extensive systematic search was conducted in 4 electronic databases: PubMed ([ncbi.nlm.nih.gov/pubmed](http://ncbi.nlm.nih.gov/pubmed)), Web of Science ([webofknowledge.com](http://webofknowledge.com)) EMBASE ([embase.com](http://embase.com)), and Central Cochrane Register of Controlled Trials (CENTRAL) ([cochranelibrary.com](http://cochranelibrary.com)). The search was last updated on February 15, 2019, with the following query combining free-text terms and Medical Subject Headings: “*inflammatory bowel disease*” OR IBD OR “*Crohn disease*” OR “*ulcerative colitis*” AND transition\*. Additionally, the reference lists of relevant articles were reviewed to find relevant records. The search was limited to articles in English and human studies.

### Eligibility Criteria

Studies conducted on patients with IBD focusing on the transition process as an intervention method and assessing different outcome measures were eligible for inclusion. Any study published as a full-text article or a conference abstract was selected if it (1) examined a population of adolescents or young adults with IBD ranging in age between 15 and 20 years who were subjected to the transition process, (2) applied STI during the period of transition from pediatric to adult care, (3)

compared the results of an intervention group (IG) to that of a control group (CG) consisting of patients with IBD transferred to the adult gastroenterologist (AGE) with unstructured transition process or evaluated the effectiveness of STI with before-after design, (4) examined the efficacy of patient education programs (PEPs) related to IBD transition process, and (5) either reported on the change of individual, health care and social outcomes, or the satisfaction and the perceptions of IBD patients throughout transition.

### Selection and Data Extraction

Search results were imported into a reference management software (EndNote X8, Clarivate Analytics, Philadelphia, PA, USA). First, overlapping records and duplicates were removed by one of the authors (AE). Then the potentially eligible records were screened by title and abstract independently by 2 authors (AE and PS). Remaining full-text articles and abstracts were screened for eligibility (AE and PS). Disagreements were resolved by third-party arbitration at any stage of selection (PH).

The following data were extracted from the included articles: first author, year and format of publication (full-text article/conference abstract), study sites, study design (prospective/retrospective; randomized/nonrandomized; controlled/uncontrolled), study population, and the number of patients in IG and CG. The applied transition process (STI or PEP) was described in detail. The number, structure, and location of the joint visits, attending members of the multidisciplinary team (MDT), and length of the F/U were recorded. The reported outcomes were extracted separately for the IG and CGs with *p* values for comparisons (if available). In the case of uncontrolled before-after studies, baseline and postintervention results were extracted with *p* values for the comparison of before-after values (if available).

### Quality of Evidence

The GRADE approach<sup>16</sup> was applied for the assessment of the quality of the evidence for all internationally identified health care transition outcomes.<sup>4</sup> In accordance with the Grade Handbook,<sup>16</sup> outcomes of interest were tested against 6 main criteria: study design, risk of bias, indirectness, inconsistency, imprecision, and publication bias. At baseline, “high” confidence was given for randomized controlled trials, whereas “low” confidence was given for any other design. The baseline grade was downgraded by 1 level for serious concerns or by 2 levels for very serious concerns as per the rules and recommendations of the handbook. Finally, the overall quality of the evidence for each outcome was graded as “high,” “moderate,” “low,” or “very low.”

Grading was first performed independently by 2 of the authors (AE and PS), and then disagreements were discussed by involving a third party (ZS) to reach a consensus.

## RESULTS

### Study Selection

Our electronic literature search identified a total of 2709 records (PubMed: 404, Web of Science: 934, EMBASE: 1329, and CENTRAL: 42), complemented with 6 potentially eligible records identified by hand search (PRISMA flow chart; Fig. 1). After the removal of duplicates, 1668 articles remained, 1602 of which were excluded based on title and abstract. According to our eligibility criteria, 66 potentially eligible records were assessed for inclusion. During the full-text evaluation, 43 were excluded: studies not reporting the outcome of interest (n = 23), studies without CG, intervention, or detailed data on patients with IBD, studies reporting only preliminary results (n = 19), and a previously published systematic review (n = 1). Finally, 23 studies fulfilled the inclusion criteria and were included in the qualitative synthesis.

### Characteristics of the Studies Included

The studies included were published in the last 10 years, 13 of which were published as conference abstracts only.<sup>17-29</sup> Eleven studies were conducted outside Europe.<sup>18, 22, 24-26, 28-33</sup> Among the European articles, trials were identified from the

United Kingdom,<sup>20,21,34</sup> Italy,<sup>17,23</sup> Spain,<sup>19,27</sup> France,<sup>35</sup> Germany,<sup>36,37</sup> the Netherlands,<sup>38</sup> and Hungary.<sup>39</sup> (Tables 1 and 2).

The age of the patients in the included studies ranged between 11 and 25 years, but most patients were between 17 and 19 years old at the time of the transfer to AGE. The number of participants in the studies varied from 10<sup>25</sup> to 245.<sup>29</sup> In most of the trials, the F/U period lasted from 6 months to 2 years after transition. The longest F/U period was 6 years (median),<sup>27</sup> whereas the shortest was 1 month for all participants.<sup>28</sup>

The studies varied in terms of design. However, there remains a lack of strong evidence because only 2 randomized studies, published as conference abstracts, have examined the efficacy of transition and patient education, including a small series of patients.<sup>22, 28</sup> Six of the included articles had case-control design,<sup>17, 19, 30, 34, 35, 39</sup> 4 had cohort design,<sup>21, 31, 36, 37</sup> and another 4 had uncontrolled before-after design.<sup>18, 20, 25, 38</sup> In 7 studies, we were unable to determine the study design.<sup>23, 24, 26, 27, 29, 32, 33</sup> Eleven studies compared IG and CG (Table 1).<sup>17, 19, 21, 22, 24, 30, 31, 34, 35, 37, 39</sup> Twelve studies provided data on transition outcomes of a single group of patients before and after the transitional care (Table 2).<sup>18, 20, 23, 25-29, 32, 33, 36, 38</sup>

### Intervention Types

The studies reported a wide variety of transition interventions; of these, joint visit with PGE and AGE was the most

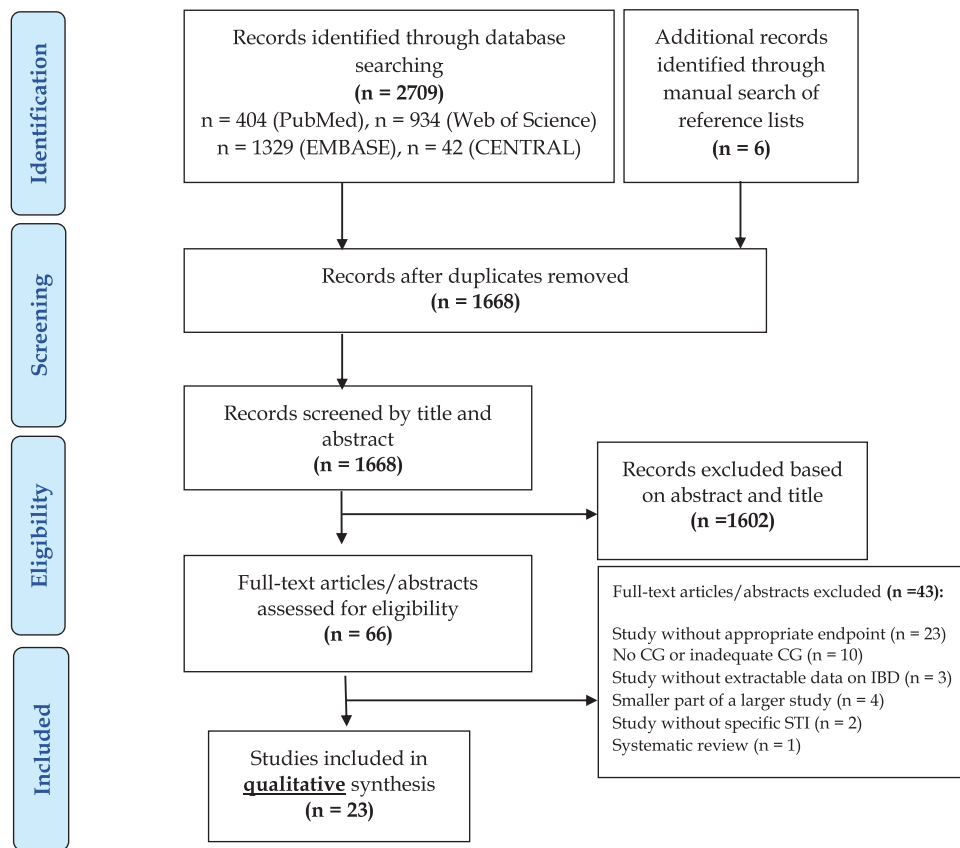


FIGURE 1. Flow chart for study selection.

TABLE 1. Summary of Studies With Control Group Evaluating Structured Transition Interventions in Adolescent Patients With IBD

Study type	Study population	Number of patients		Intervention	F/U	Measured outcomes		Results		Key findings
		IG	CG			IG	CG	IG	CG	
Alfano <i>et al</i> <sup>h</sup> 2016, Italy, case-control study	Patients diagnosed <18 years; current age ≤25 years; transfer to AGE ≥1 year	13	8	<b>Centralized and structured transition program</b> involving PGE and AGE	NA	Self-assessment with multiple specific scored items: perceived support from the PGE more supported satisfaction with the process more satisfied self-assessment of IBD related better/better well-being at the time of transfer / one year after transfer	NA	0.046 0.003 <0.001/ 0.005	Relationship between perceived preparation and number of specific transition preparation items received.	
Bennett <i>et al</i> <sup>h</sup> 2016, Australia, case-control study	Patients >18 years, who moved from PGE to AGE within 10 years	46	35	Hospital information sent to the patient, telephone introduction call by an <b>adult IBD service nurse</b>	NA	IBD complications since diagnosis, n (%) Surgery since diagnosis, n (%) Hospital admissions, n <sup>c</sup> Noncompliance since diagnosis, n (%) Flares requiring steroids, n <sup>c</sup> Social and occupational outcomes (Relationship status, Educational level, Employment)	12 (26) 15 (33) 1.5 3 (7) 0.5	0.27 0.81 0.67 0.46 0.31 NS	No differences in disease burden, disease outcomes, adult roles and responsibilities. 54% of the patients in the IG knew their transition plan but the majority felt they were not strongly prepared.	
Blázquez <i>et al</i> <sup>h</sup> 2018, Spain, case-control study	Adolescents enrolled 2 years before transfer	23	9	<b>Transition care program:</b> at least 2 joint visits with PGE and AGE	5 (1.5–14) years <sup>c</sup>	Patients' satisfaction: Receiving enough information, n (%) Feeling prepared for the transfer, n (%) Declaring themselves reluctant to change, n (%) Expression of a "good" or "very good" level of satisfaction n (%)	22 (95) 19 (82) 10 (45) 20 (90)	in all aspects <0.05	Results of the IG were significantly better than those of the CG. Joint consultation was one of the best-valued items.	
Cole <i>et al</i> <sup>h</sup> 2015, UK, case-control study	Patients at least 15 years old when attended the clinic	44	28	<b>Transition clinic:</b> - visits held alternatingly at PGE or AGE - joint visits with PGE and AGE - support from IBD nurse, dietician and clinical psychologist	2 years	Admission within 2 years of transfer (total), n (%) Admission for acute flare up and/or emergency surgery, n (%) Admission for elective/planned surgery, n (%) Disease in remission with or without medications at transfer, n (%) Nonattendance at clinics, n (%) Confessed being fully compliant, n (%)	13 (29) 3 (7) 8 (18) 30 (69) 13 (29) 39 (89)	0.002 0.001 NS 0.01 0.001 0.002	In the IG; reduced surgery, hospitalizations and drug nonadherence, improved attendance rates at AGE, disease specific and developmental outcomes. Higher estimated maximum growth potential achieved	

(Continued)

TABLE 1. Continued

Study type	Study population	Number of patients		Intervention	F/U	Measured outcomes	Results			Key findings
		IG	CG				IG	CG	P	
Dabadie <i>et al</i> 2008, France, case-control study	Patients aged: <b>IG:</b> 17.7 ± 18 years (15.5–19) <sup>i</sup> <b>CG:</b> 17.7 ± 18 years (16–20) <sup>j</sup>	20	14	<b>One-hour joint visit</b> in the adult gastroenterology unit with PGE and AGE	1 year	Disease activity at transition: Remission/active/complications Surgery, n Subjective evaluation of patients with a questionnaire: Feeling informed “early enough” about transition, n (%) Feeling “ready” for the change to adult-care, n (%) Attending medical visits alone, n (%) Online questionnaire regarding: Disease-specific knowledge: Diagnosis, n (%) Prior GI surgery, n (%) Self-reported adherence to medical therapy, n (%) Beliefs about medicine: Specific-Necessity <sup>b</sup> Specific-concern <sup>b</sup> General-Overuse <sup>b</sup> General-Harm <sup>b</sup> Attitudes toward medicine: Accepting, n (%) Ambivalent, n (%) Skeptical, n (%) Indifferent, n (%) Scores of specific questionnaires: Short Inflammatory Bowel Disease Questionnaire <sup>c</sup> Inflammatory Bowel Disease Control Questionnaire (IBDCQ) <sup>c</sup> IBDCQ-VAS <sup>c</sup> Anxiety Scale (HADS) <sup>c</sup> Depression Scale (HADS) <sup>c</sup> Work Productivity and Activity Index: WPAL, n (%) Days of education missed/patient/year <sup>c</sup> Socioeconomic status: Index of Multiple Deprivation <sup>e</sup>	9/6/5	13/0/1	<0.05	All patients considered the joint medical visit beneficial, mostly because it was beneficial for building confidence in the AGE.
Fu <i>et al</i> 2017, Canada, cohort study	Patients aged: <b>IG:</b> 19.7 ± 1.3 years <sup>b</sup> <b>CG:</b> 20.6 ± 1.2 years <sup>b</sup>	59	53	<b>Transition clinic</b> - joint visits with AGE, PGE and nurses - twice in the patients’ last year at PGE	NA		44 (78.6)	44 (80.0)	1.00	Similar levels of disease-specific knowledge, self-reported adherence rates between cohorts.
McCartney <i>et al</i> <sup>h</sup> 2017, UK, cohort study	Patients aged ≥ 16 years with a confirmed diagnosis before age 16 and under the care of AGE ≥ 12 months at recruitment	95	34	<b>Transition process:</b> - ≥ 2 transition visits - involving clinical staff from both pediatric and adult services	<b>IG:</b> 2.1 years <sup>e</sup> <b>CG:</b> 2.3 years <sup>e</sup>		17.2 ± 3.8	15.0 ± 4.0	0.0035	Stronger beliefs in the IG that medications were necessary.
							16.1 ± 4.0	15.3 ± 3.5	0.29	Adolescents in IG less skeptical of and more ambivalent to treatment.
							9.7 ± 2.5	9.4 ± 2.9	0.63	Patient-reported quality of life, perceived IBD control, time lost from education and socioeconomic status similar in IG and CG.
							14.9 ± 2.7	14.7 ± 2.8	0.70	
							10 (16.9)	12 (22.6)	0.45	
							36 (61.0)	18 (34.0)	0.004	
							4 (6.8)	11 (20.8)	0.03	
							9 (15.3)	12 (22.6)	0.32	
							52 (12.7)	51.2 (11.1)		
							10.9 (4.7)	11.7 (4.4)		
							76.4 (23.6)	75.8 (25.9)		
							6.2 (4.6)	6.3 (3.9)	for all	
							2.8 (3)	3.2 (2.8)	>0.05	
							7 (16)	4 (27)		
							14.5 (7.6–26.9)	13.3 (5–20)		
							5 (3–8)	7 (5–8)		

(Continued)

TABLE 1. Continued

Study type	Study population	Number of patients		Intervention	F/U	Measured outcomes	Results			Key findings
		IG	CG				IG	CG	P	
Moulton <i>et al</i> <sup>h</sup> 2013, USA, randomized study	Patients ≥16 years	13	19	<b>Progressive transition:</b> 1. visit only with PGE 2. combined visit with PGE and AGE, led by the PGE 3. combined visit, led by the AGE	<b>IG:</b> 223 ± 107 days <sup>b</sup> <b>CG:</b> 232 ± 110 days <sup>b</sup>	Hospitalization for IBD, n (%) Need for the therapy escalation, n (%) Patient satisfaction (on a 10-point scale): Satisfaction with transition as 10/10, n (%) Knew the medication names, doses, side effects, monitoring requirements, and insurance provider, n (%)	2 (10.5) 9 (47.4)	7 (35) 13 (71)	0.7 0.7 0.3 0.18	A progressive transition program did not impact rates of hospitalizations or disease exacerbations, but it may result in improved patient knowledge and satisfaction.
Otto <i>et al</i> 2018, Hungary, case-control study	Patient aged 16–19 years	21	24	<b>Transition clinic</b> - joint visits with PGE and AGE - held every 6 months at the pediatric gastroenterology outpatient clinic	1 year	Bowel resection within 12 months after transfer n (%) Drug toxicity, n (%) Dose escalation of anti-TNF- $\alpha$ , n (%) Acute flare up or emergency surgery, n (%) Elective appointments, n Diagnostic procedures, n Number of endoscopies, n Patients in remission 12 months after transfer, n (%)	1 (4.8) 0 (0) 2 (9.5) 4 (19) 16 43 11 18 (85.7)	1 (4.2) 3 (12.5) 1 (4.2) 9 (37.5) 9 27 7 11 (45.8)	1.000 0.236 0.550 0.083 0.011 0.260 0.182 0.037	Transition program resulted in higher disease remission rate and higher attendance rate at elective, scheduled visits.
Schmidt <i>et al</i> 2018, Germany, cohort study	Patient aged 14–20 years	53	46	<b>Educational program:</b> a two-day transition workshop	6 months	The Health-related Transition Competence (TCS) Scale scores (scale from 0 to 100) <sup>a</sup> Quality of life (DISABKIDS Chronic Generic Measure, DCGM short-form; scale from 0 to 100) <sup>a</sup>	79.38 69.35	63.04 76.72	<0.001 <0.01	Transition competence significantly improved to a higher extent in the IG. Significant increase in QoL only in the IG
Williams <i>et al</i> <sup>h</sup> 2017, USA, NA	Patients aged 19 ± 1 years <sup>a</sup>	35	NA	<b>Transition Clinic:</b> - initial visit with PGE - multidisciplinary meeting (with AGE, PGE, nurse, social worker, nutritionist)	NA	Patients transitioned to the adult care, n (%) Retention rate prior to establishment of the clinic (%) No show rates, % Number of clinical visits <sup>a</sup>	28 (80) NA 0 8.2	NA 33 46 5	NA NA	A formalized IBD transition clinic can have significant impact on retention and no-show rates.

<sup>a</sup>abstract form only, <sup>b</sup>mean ± SD, <sup>c</sup>median (IQR), <sup>d</sup>median (range), <sup>e</sup>median ± SD, <sup>f</sup>mean ± SD (range). Abbreviations: AGE, adult gastroenterologist; CG, control group; F/U, length of follow-up; IG, intervention group; NA, non-available; PGE, paediatric gastroenterologist.

**TABLE 2. Characteristics of Studies Evaluating Structured Transition Interventions in a “Before and After Design”**

Study type	Study population	Number of patients	Intervention	F/U	Measured outcomes	Results		P value	Key findings
						Baseline	After the intervention		
Avni-Biron <i>et al</i> <sup>a</sup> 2016, Israel, single arm study	<18 years	50	<b>One joint visit</b> with PGE and AGE in a tertiary hospital	1 year	Successful transition (continued F/U throughout the first year at AGE), n (%) Active disease at the time of transfer, n (%) Drug treatment modified by the AGE, n (%) Hospitalisation, n (%) Surgery, n (%)	NA NA 37 (74) 10 (20) 4 (8)	47 (94) 27 (54)	NA	Patient adherence to F/U at adult care was excellent.
Boamah <i>et al</i> 2010, USA, NA	13–17 years	21	<b>Educational program</b> (interactive multi-media CD-ROM)	9 months	Disease specific knowledge: Crohn’s and Colitis Knowledge, CCKNOW questionnaire baseline scores <sup>h</sup> CCKNOW scores after 30 minutes of self-directed education <sup>b</sup>	12.2 (5.14; 3–24) NA	NA 19.8	<0.00001	Knowledge of medications, disease complications, and gastrointestinal structure and function gained and retained upon retesting at 9 months.
Chan <i>et al</i> <sup>a</sup> 2013, USA, single arm study	≥17 years	10	<b>Transition program:</b> transition visits designed to: - educate - review disease process - develop communication skills - anticipate future health insurance - establish care with AGE	none	Survey completing with a scoring system (scale 1–5): How prepared do you feel you are to transition? How much do you know about your medical condition? How comfortable do you feel talking to your doctor? How comfortable do you feel about transitioning to adult health care?	NA NA	17.5 (5.9; 12–26)	<0.001	Patients’, parents’ and AGEs’ comments were positive about the transition process.

(Continued)

TABLE 2. Continued

Study type	Study population	Number of patients	Intervention	F/U	Measured outcomes	Baseline	Results		Key findings
							P value	After the intervention	
Cole <i>et al</i> <sup>a</sup> 2013, UK, single arm study	Patients diagnosed before age 16 who went through the transition process	57	<b>Transition service</b>	27 (6–54) months <sup>f</sup>	Medication adherence, n (%) “Did not attend” rate for clinic visits, n (%) Need for surgery, n (%) Clinic attendance without parents, n (%) Attainment of adult height within 2 SD of mid parental height, n (%) Normal BMI at the last visit of the F/U, n (%) Continuing education and/or employment at the last visit of the F/U, n (%) Alcohol and/or drug dependency, n (%)	NA NA	47 (93) 2 (4) 7 (14) 34 (64) 40 (79)	<0.05 NA	Transition in IBD patients may aid in achieving excellent clinical and developmental outcomes in the post-transfer follow up period in adult IBD services.
Mollah <i>et al</i> <sup>b</sup> 2017, Australia, NA	18.7 years (16.2–22.1)	48	<b>Young adult IBD clinic</b>	1 year	IBD-specific emergency department visits, n (%) Patient satisfaction (measured with Patient Satisfaction Questionnaire, Likert scale 1–5)	19 (38.7) NA	7 (14.3) 5	<0.05 NA	Absolute reduction in emergency department attendances. Participants satisfied with the level of care delivered.
Romeo <i>et al</i> <sup>b</sup> 2014, Italy, NA	18–25 years	20	<b>Transition model</b> (3 visits): 1. only with PGE 2. in the adult centre with PGE and AGE 3. in the adult centre with only AGE	NA	Patients with successful transition (all three visits completed), n (%) Scores of different Questionnaires: IBD yourself-disease knowledge IBDQ scores Perceived independence (VAS-score) Resilience scale scores Scores of perceived wellbeing Scores of perceived anxiety	NA NA	8 (40) better higher higher higher higher lower	Proposed transition program seems to be feasible. Patient seems to be ready to transition, but they are not sufficiently confident in knowledge about IBD.	

(Continued)



TABLE 2. Continued

Study type	Study population	Number of patients	Intervention	F/U	Measured outcomes	Results			Key findings
						Baseline	After the intervention	P value	
Sanchez <i>et al</i> <sup>b</sup> 2017, Spain,	NA	32	<b>Transition program:</b> - 2 clinic visits with PGE and AGE - 2 years prior to transfer	6 (1.5–14) years <sup>f</sup>	Phone surveys: Patients with active disease at transfer, n (%) Reported having received enough information prior to transition, n (%) Felt adequately prepared, n (%) Reported reluctance, n (%) Expressed a “good”/“very good” satisfaction degree, n (%) Both sections positively assessed, n (%)	NA	4 (12.5) 27 (84) 25 (78) 14 (44) 30 (94) 30 (95)	NA	Joint clinic visits facilitate the transition process. The transition program entails better patient information as well as a better perception of sections.
NA									
Schmidt <i>et al</i> 2016, Germany, cohort study	14–20 years	89	<b>Educational program:</b> transition workshop focusing on adult care settings, organization of future disease management, career and partnership	6 months	Health-related transition competence scale <sup>e</sup> German version of the General Self-Efficacy Scale scores <sup>e</sup> Patient activation measure -13 scores <sup>c</sup> Care Questionnaire on Satisfaction, Utilization and Needs, CHS-SUN <sup>d</sup>	37.02 (9.63) 51.85 (11.39) 64.03 (10.3) 3.89 (0.86)	46.13 (10.81) 55.37 (14.62) 70.75 (14.68) 4.04 (0.92)	NA	The workshop has significantly affected transition competence, self-efficacy and satisfaction, but did not significantly affect patient activation and quality of life 6 months after the intervention.

(Continued)

TABLE 2. Continued

Study	Study population	Number of patients	Intervention	F/U	Measured outcomes	Results			
						Baseline	After the intervention	P value	
van den Brink <i>et al</i> 2018, The Netherlands single arm study	16–18 years	35	<b>IBD transition clinic:</b> - located in the adult gastroenterology department - multidisciplinary team (a PGE, a pediatric IBD nurse, an AGE and a family therapist) - PGE visits at least four times a year - AGE visit once a year	1 year	Transition Yourself Score: Time to first outpatient visit to AGE, n (%) Unknown or after 12 months After 6–12 months Within 3–6 months Nonattendance rates at outpatient clinic <12 months after transfer, n (%) >25% 10–25% None/<10% Adherence to medication, n (%) Low Medium High No medication prescribed Quality of transition (grade 0–10), n (%) <5.5 5.5–7.5 <7 Successful transition, n (%) Moderately successful transition, n (%) Failed transition, n (%)	NA	NA	1 (2.9) 3 (8.6) 31 (88.6) 2 (5.7) 3 (8.6) 30 (85.7) 4 (11.4) 17 (48.6) 5 (14.3) 9 (25.7) 0 (0) 11 (31.4) 24 (68.6) 22 (63) 11 (31.4) 2 (5.6)	The modest success ratio indicates that there is room for improvement in IBD transition strategy.  The study indicated that female patients and patients with an active disease before transfer might be at risk for unsuccessful transition.  Successfulness of transition: A total score <5 indicated a failed transition, 5–6 scores: moderately successful and scores >6 was successful transition.

(Continued)

TABLE 2. Continued

Study type	Study population	Number of patients	Intervention	F/U	Measured outcomes	Results		Key findings	
						Baseline	After the intervention		
Yerushalmy-Feler <i>et al</i> 2017, Israel, NA	19 ± 1.8 years <sup>e</sup>	27	<b>Transition clinic:</b> - located in the PGE's department - multidisciplinary team (PGE, AGE, an IBD nurse, a psychologist, nutritionist) - Visit 1: reviewing patient's history, improving the patients' knowledge of IBD - Visit 2: educating the patients on IBD, medications, disease management - Visit 3: short and long-term planning	6.9 ± 3.5 months <sup>b</sup>	Change in the weighted average of the IBD-yourself questionnaire's domains <sup>c</sup> VAS on general independence <sup>d</sup> VAS on perceived disease burden <sup>d</sup> Knowledge of IBD <sup>d</sup> Knowledge of diagnostic tests <sup>d</sup> Knowledge of treatment <sup>e</sup> Self-efficacy in medication use <sup>d</sup> Skills for independent outpatient clinic visits <sup>d</sup> Actual behaviour at the outpatient clinic <sup>d</sup> Coping with IBD <sup>d</sup> Knowledge of the transition process <sup>d</sup>	1.85 ± 0.3	1.41 ± 0.21	<0.0001	Self-efficacy scores in all domains were significantly higher after completion of the transition.
Vaz <i>et al</i> <sup>h</sup> 2016, USA randomized	11–18 years	NA	<b>Educational program:</b> the IBD Pocket Guide on medication adherence, IBD knowledge and transition readiness	1 month	Transfer readiness—patient <sup>d</sup> Transfer readiness—parents <sup>d</sup> Adherence IBD knowledge Knowledge of osteoporosis	2	improved improved improved	0.004 0.005 NA NA 0.0476	Families and patients found the IBD Pocket Guide to be useful and informative.
Zhu <i>et al</i> <sup>h</sup> 2016, China NA	Adolescent patients	245	<b>Transitional nursing:</b> in-hospital instruction, home visits, telephone follow-up and WeChat group	6 months	Chronic disease self-management inventory scores (CDSMS): Self-management behaviour score <sup>e</sup> Self-management effectiveness score <sup>e</sup> Quality of life (inflammatory bowel disease questionnaire, IBDQ) <sup>e</sup>	80.78 ± 11.54	89.45 ± 12.02	<0.05 <0.05 <0.05	Transitional nursing significantly increased self-management ability and quality of life in patients with IBD.

<sup>a</sup>abstract form only, <sup>b</sup>mean, <sup>c</sup>mean ± SD, <sup>d</sup>median, <sup>e</sup>median (IQR), <sup>f</sup>median (range), <sup>g</sup>median ± SD, <sup>h</sup>mean ± SD (range), <sup>i</sup>mean (range). Abbreviations: AGE, adult gastroenterologist; CG, control group; ED, emergency department; F/U, length of follow-up; IG, intervention group; NA, non-available; PGE, pediatric gastroenterologist.

common type. One of the first studies aiming to examine the effects of joint visits was conducted in France.<sup>35</sup> All patients considered a single, 1-hour joint medical visit with PGE and AGE beneficial, mostly because it was helpful in building up confidence in AGE.<sup>35</sup> On average, 2 to 4 visits were arranged before the transfer as part of a transition clinic<sup>31, 34, 39</sup> or a structured transition program.<sup>19, 21–23, 25, 27, 28</sup> In the Netherlands, adolescent patients visited the transition clinic at least 4 times a year, while they also saw the AGE once a year.<sup>38</sup>

Joint visits were mainly designed to review patients' history and disease progression to educate the patient on IBD medication and disease management and to discuss short- and long-term plans.<sup>25, 33, 39</sup> Some transition clinics focused on improving communication skills of the adolescents and establishing a relationship with the AGE.<sup>18, 23, 27, 39</sup> During joint visits, the impact of the interventions was controlled by both the nurse and the doctor by filling a transition checklist and assessing disease-specific knowledge or self-efficacy.<sup>23, 31, 33</sup> Unfortunately, the majority of the abstracts did not provide sufficiently detailed data on the joint visits.

In the evaluated studies, joint visits were hosted at various locations. The joint visit was located either in the usual pediatric environment<sup>33, 39</sup> or in the adult gastroenterology department.<sup>38</sup> In the study of Cole et al and Romeo et al, alternating joint visits were held at pediatric and adult gastroenterology departments.<sup>23, 34</sup>

Besides the presence of a PGE and an AGE, other professionals also participated as stakeholders at the transition clinics. The additional members of the MDT were most often IBD nurses,<sup>24, 33, 34, 38, 39</sup> dietitians,<sup>24, 33, 34</sup> and psychologists.<sup>33, 34</sup> In few trials, social workers<sup>24</sup> and family therapists<sup>38</sup> were involved, as well.

The other transition intervention methods in the trials were PEPs.<sup>28, 32, 36, 37</sup> In Germany, the intervention was a 2-day workshop held for the adolescent patients with chronic conditions (IBD, type 1 diabetes, and cystic fibrosis) aiming to provide information about the adult care, coordination of future disease management, career choices, and partnership.<sup>36, 37</sup> In the study of Boamah et al, an interactive multimedia CD-ROM was distributed, summarizing different IBD-related topics like disease knowledge, symptoms, diagnosis, complications, medications, nutrition, and social functioning.<sup>32</sup> In another study, a new guide called "IBD Pocket Guide" supported patients' medication adherence, IBD knowledge, and transition readiness.<sup>28</sup>

In 2 studies, the intervention was the involvement of IBD nurses in the transition process<sup>29, 30</sup> who were functioning as appointed transition coordinators during transition. In 1 trial, the IBD nurse made only an introductory phone call aiming to facilitate the arrangement of the first visit with the AGE.<sup>30</sup> In China, the IBD nurse had a wider range of activities including giving instructions to patients in the hospital, visiting patients at home, maintaining WeChat groups, and making phone calls to promote F/U.<sup>29</sup>

## Measured Outcomes

The measured outcomes substantially varied across studies. In our review, we categorized the outcomes based on the previously identified international health care transition outcome groups.<sup>4</sup> Quality of the evidence for each outcome is shown in Table 3, with the details of rating by the GRADE approach<sup>16</sup> in Supplementary Table 2.

## Individual outcomes

Health-related quality of life as a patient-reported outcome was examined in 4 studies.<sup>21, 23, 29, 37</sup> Scores generated with the Short IBD Questionnaire<sup>40</sup> and the DISABKIDS instruments<sup>41</sup> were significantly higher among patients after participating in a "transition nursing" program,<sup>29</sup> a 2-day transition workshop,<sup>37</sup> or an STI<sup>23</sup> compared with controls. Furthermore, Schmidt et al perceived a significant decline in the quality of life of the control patients not participating in the program.<sup>37</sup> In contrast, McCartney et al failed to detect any difference in the health-related quality of life between the IG and CG 2 years after the transition process.<sup>21</sup> Scores generated with the Anxiety Scale<sup>42</sup> and the Work Productivity and Activity Index<sup>43</sup> were also similar between the 2 groups.<sup>21</sup>

The level of disease-specific knowledge has been rarely evaluated. The IBD-yourself<sup>44</sup> and the Crohn's and Colitis Knowledge questionnaires<sup>45</sup> were used in 3 before-after studies.<sup>32, 33</sup> In a study from the United States, 21 patients acquired disease-specific knowledge of medications, complications, and gastrointestinal function thanks to the self-directed multimedia education; recollection of the knowledge was successful when retesting 9 months later.<sup>32</sup> An improvement in the specific IBD-yourself domains, (eg, knowledge of IBD, diagnostic tests, and medication use) was also identified in 2 reports in which patients completed the transition process.<sup>33</sup> In the study of Fu et al, similar levels of disease-specific knowledge were found in patients who did and did not undergo STI.<sup>31</sup>

An increasing self-efficacy around self-management was confirmed 6 months after the educational intervention<sup>36</sup> and after the completion of the transition process.<sup>29, 33</sup> The German version of the General Self-Efficacy Scale,<sup>46</sup> chronic disease self-management inventory scores,<sup>47</sup> and IBD-yourself questionnaires<sup>44</sup> were applied for outcome assessment.

All studies examining medication adherence as an endpoint<sup>28, 30, 31, 34</sup> found better adherence rates among patients who underwent STI or PEP compared with CG or the baseline values in before-after studies. Fu et al found that patients in the IG had significantly stronger beliefs in the necessity of the prescribed medications, despite that similar self-reported adherence rates were detected between the cohorts of patients.<sup>31</sup>

Although the knowledge of health care insurance was identified as one of the main outcomes of transition by the Delphi process,<sup>4</sup> only 1 study assessed this issue. Here, 100% of the patients participating in the progressive transition program

**TABLE 3.** Categorization of the Measured Outcomes According to the Internationally Identified Health Care Transition Outcomes<sup>4</sup> and the Quality of the Evidence Assessed According to the GRADE Approach<sup>16</sup>

Main group of outcomes	Specified outcomes	Articles investigating the specified outcomes	Quality of the evidence <sup>a</sup>
<b>Individual outcomes</b>	- quality of life	McCartney <i>et al</i> (2017), Schmidt <i>et al</i> (2018), Schmidt <i>et al</i> (2016), Zhu <i>et al</i> (2016), Romeo <i>et al</i> (2014)	<b>very low</b>
	- understanding the characteristics of the condition	Fu <i>et al</i> (2017), Boamah <i>et al</i> (2010), Romeo <i>et al</i> (2014), Ron <i>et al</i> (2015), Yerushalmy-Feler <i>et al</i> (2017), Vaz <i>et al</i> (2016)	<b>very low</b>
	- knowledge of medication	Moulton <i>et al</i> (2013), Ron <i>et al</i> (2015), Yerushalmy-Feler <i>et al</i> (2017)	<b>very low</b>
	- self-management	Ron <i>et al</i> (2015), Zhu <i>et al</i> (2016), Schmidt <i>et al</i> (2016), Yerushalmy-Feler <i>et al</i> (2017),	<b>very low</b>
	- adherence to medication	Cole <i>et al</i> (2015), Cole <i>et al</i> (2013), van den Brink <i>et al</i> (2018), Yerushalmy-Feler <i>et al</i> (2017), Vaz <i>et al</i> (2016), Fu <i>et al</i> (2017)	<b>very low</b>
<b>Health service outcomes</b>	- understanding health insurance	Moulton <i>et al</i> (2013)	<b>very low</b>
	- attending medical appointments	Cole <i>et al</i> (2015), Otto <i>et al</i> (2019), Williams <i>et al</i> (2017), Cole <i>et al</i> (2013), van den Brink <i>et al</i> (2018)	<b>very low</b>
	- having medical home	not reported	<b>N/A</b>
	- avoidance of unnecessary hospitalization	not reported	<b>N/A</b>
<b>Social outcome</b>	- having social network	Bennett <i>et al</i> (2016), McCartney <i>et al</i> (2017)	<b>very low</b>

<sup>a</sup>Based on the GRADE approach, for details see also [Supplementary Table 2](#); N/A: nonapplicable.

knew their insurance provider, whereas this rate was only 71% in the CG.<sup>22</sup>

### Health service outcomes

Despite the low quality of evidence, STIs can improve patients' willingness to attend medical visits. Some studies showed that the nonattendance rate at outpatient clinics in the post-transfer F/U period was higher in patients without STI compared with those receiving STI.<sup>24, 34, 38</sup> The rate of successful transitions was lowest in the Romeo *et al* study (40%), moderate in the van den Brink *et al* study (63%), and highest in the Avni-Biron *et al* study (94%).<sup>18, 23, 38</sup> The difference may have occurred because diverse types of tools were used for the assessment of successfulness.

### Social outcomes

Outcomes related to social network and other social functions were examined in only 2 of the trials included. No significant differences were observed between IG and CG with respect to social and occupational outcomes (eg, employment, education, relationship status),<sup>30</sup> and socioeconomic status.<sup>21</sup>

### Other outcomes

Patient satisfaction was measured with specific scores or on a 10-point Likert scale.<sup>17, 19, 22, 25–27</sup> Patients in the IG receiving STI were significantly more satisfied with the quality of the transition process than those in the CG receiving standard care.<sup>17, 19, 22</sup> Joint medical visits were found beneficial for receiving enough information about transition.<sup>35</sup> Furthermore, in the study of Sánchez *et al*, nearly all of the STI participants (94%) achieved a good or a very good “degree of satisfaction” after completing the transition program.<sup>27</sup>

Another outcome was perceived readiness for transition. While Dabadie *et al* found no benefit of the 1-hour joint visit regarding transition readiness, Sánchez *et al* reported that a high percentage of patients undergoing STI have received enough information before transition (84%) and felt adequately prepared for transition (78%).<sup>27, 35</sup> Moreover, Schmidt *et al* could detect an improvement in the mean score of health-related transition competence scale 6 months after the educational program.<sup>37</sup>

About one-third of the included studies measured outcomes related to disease activity, such as the number of IBD-related hospital admissions and emergency department visits, need for surgery, or treatment modification/escalation.<sup>18, 20, 22, 24, 26, 30, 34, 39</sup>

Considering these endpoints, no significant difference was found between the progressive transition group and the CG in the Bennett et al and Moulton et al studies.<sup>22, 30</sup> Conversely, other studies demonstrated a beneficial impact of STIs on IBD outcomes.<sup>24, 26, 34, 36, 37, 39</sup> The need for surgery, the hospitalization rate,<sup>34</sup> and the attendance rate at the emergency department<sup>26</sup> were significantly reduced among patients undergoing STIs compared with those in CG. According to Otto et al, significantly more patients were in remission 12 months after transfer in the IG than in the CG.<sup>39</sup>

## DISCUSSION

The aim of this systematic review was to summarize the current transition practices in IBD and to comprehensively assess their effects on transition-related outcomes.

Altogether, 23 studies met our inclusion criteria, only 10 of which were published as a full-text article. We found a high diversity across the studies both in the applied interventions and the outcome. The joint visit was the most common form of STI, performed solely or as a part of a complex transition program. A notable heterogeneity was observed in the number and the setting of the performed joint visits. None of the studies investigated whether the arrangement of 1 visit is more advantageous over that of multiple visits for adolescents.

Patient education should be a key element in the transition process. In our review, PEPs were diverse, including workshops and the application of web-based or text-delivered learning materials.<sup>28, 32, 36, 37</sup> The implementation of these programs resulted in better disease-specific knowledge, transition competence, and medication adherence. Recent guidelines mention information technology as a potential tool for facilitating education.<sup>48</sup>

The MDT is central to the optimal management of IBD patients. An MDT dedicated to transition process should consist of a dietician, an IBD nurse, a psychologist, a social worker, a family therapist, a PGE, and an AGE.<sup>10</sup> To establish a good partnership between stakeholders, the continuity of coordination is mandatory. It seems that the transition is best coordinated by an IBD nurse ensuring the continuity of care.

Recently, the establishment of medical homes came into the focus of attention, which target to better adapt health care services to the patients' needs. Having an IBD medical home means that patients have continuous access to a well-organized, high-quality health care service at a hospital (24/7 service) where an MDT is responsible for providing preventive, acute, and chronic care.<sup>49</sup> Furthermore, mood disturbances, which are common among patients with IBD, can contribute to the worsening of the disease symptoms.<sup>50</sup> Maladaptive cooperation with the pain and difficulties caused by IBD may result in unnecessary hospitalizations, which could be prevented by involving the patients in the decision-making process, by educating them on stress reduction and coping techniques, and by securing continuous medical supervision via telemedicine (either via phone

or the internet).<sup>49</sup> The role of having a medical home and the relevance of avoidance of unnecessary hospitalizations were not investigated in the studies included at all.

Similarly to the internationally identified health care transition outcomes, a wide variety of individual, health service, and social outcomes were addressed in the studies included.<sup>4</sup> Despite the heterogeneous study designs and methodological limitations, 11 of the studies demonstrated that various types of transition interventions were favorable. Interestingly, quality of life, as considered the most important one among outcomes, was measured only in 17% of the studies. In contrast, outcomes related to disease activity were assessed in 30% of the studies included, despite the fact that these were not even mentioned among the top 10 transition outcomes in the literature. For the assessment of the impact of interventions, various widely accepted and reliable tools were used, such as the Short IBD Questionnaire,<sup>40</sup> the DISABKIDS,<sup>41</sup> the IBD-yourself,<sup>44</sup> and the General Self-Efficacy Scale.<sup>46</sup>

However, there is still no clear definition of the term "successful transition." Romeo et al considered the transition successful if the patient completed all 3 transition visits.<sup>23</sup> Avni-Biron et al defined successful transition as complete F/U throughout the first year with an AGE.<sup>18</sup> Van den Brink et al used a newly developed, composite score system to evaluate the success of transition, which has not yet been validated. The Transition Yourself Score is created by adding several subscores (eg, patients' satisfaction, medication adherence, nonattendance rates at outpatient clinic, and time to first outpatient visit to an AGE).<sup>38</sup> It is notable that all the mentioned studies highlighted the importance of the continuity of patient care (ie, uninterrupted health care services). Recently in a multinational Delphi study, the 3 most important items of successful transition were decision-making regarding IBD, independent communication, and patient satisfaction.<sup>51</sup> Remarkably, self-management skills were regarded as more important than IBD-specific items.<sup>51</sup>

There are several limitations of the evidence we need to mention. Given that the number of studies conducted on this topic is limited, we also included trials published in abstract form only. In most of the abstracts, the detailed features of the interventions were not reported, making the comparison of the studies problematic. Instead of using a risk of bias tool, we attempted to collect the limitations of the included studies in the limitation section of the article. However, our review is also limited by the methodological quality of included studies (mostly observational design), including small sample size, trials without appropriate CGs, and the lack of randomization. In addition, the tools of outcome measurement were often not validated (eg, Transition Yourself Score). Most of the studies were single-centered and did not have the required length of F/U to detect the long-term effects of the interventions. High dropout rates were observed in some of the trials, whereas the results of the pilot surveys were distorted by low response rates and recall bias. Selection bias,

the ignorance of patients' socioeconomic status, and the statistically significant differences in clinical characteristics between the IG and CG groups (eg, disease duration) could also have affected the results. Furthermore, language barriers (eg, educational material only available in the English language) and country-specific transition approaches resulted in limited generalizability of the results. Similar limitations were seen in other literature reviews on the field of transitional care in type 1 diabetes, cystic fibrosis, and congenital heart disease.<sup>52–55</sup>

A strength of this systematic review is that data extraction was performed as comprehensively and as accurately as possible. The examined patient population, the number and the aim of each joint visit, the core elements of the applied PEPs, the lengths of the F/U period, and the measured outcomes were collected in detail. To compensate for the lack of risk of bias assessment, all reported limitations of each study were annotated. Another strength of our review is that the certainty of the evidence was examined for all international health care transition outcomes according to the GRADE approach.<sup>16</sup> Based on our strict and consistent grading, the quality of the evidence for each outcome proved to be very low. These findings highlight the lack of high-quality evidence in this field and draw attention to the urgent need for reliable data related to STIs.

In conclusion, our review suggests that the implementation of STIs and PEPs in patients with IBD may improve patients' adherence, disease-specific knowledge, willingness to attend clinical visits, and self-efficacy and may result in a higher level of patient satisfaction. Although there is very little published research about long-term health care outcomes after transition, it can be supposed that patients not lost to F/U will have a decreased number of disease-related emergency department visits, reduced hospitalization rates, and a less frequent need for surgery or therapy escalation. In contrast, not participating in a transition process may result in adverse consequences (eg, higher rate of hospital admissions due to acute flare-up and/or emergency surgeries).<sup>34</sup>

The complexity of the transition process makes it difficult to determine which components of the intervention are responsible for any potential benefit. Therefore, it is important for future research to clearly identify these interventions and outcomes in detail. Because the quality of evidence proved to be very low for each outcome, the results of ongoing studies are awaited, and further trials are needed to determine the best setting and the long-term impact of these interventions.

## SUPPLEMENTARY DATA

Supplementary data is available at *Inflammatory Bowel Diseases* online.

**Supplementary Table 1.** PRISMA Checklist for Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

**Supplementary Table 2.** Investigation of Quality of the Evidence for All Included Outcomes (GRADE).

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