

# Outcomes in Patients with Inflammatory Bowel Disease Transitioning from Pediatric to Adult Care: A Scoping Review

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**Purpose:** Approximately 25% of inflammatory bowel disease (IBD) patients are diagnosed in childhood and the incidence is increasing. Thus, more patients will transition to adult care in the future. Within the literature, transition readiness has been deemed important to achieving a successful transition; however, it is unclear what outcomes define success. This scoping review aims to summarize the literature on outcomes surrounding transition from pediatric to adult care in patients with IBD.

**Methods:** A scoping review was conducted with the following steps: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting results, and (6) consultation with an additional researcher. Studies were identified from 5 databases and were included in part if (1) IBD was a disease of interest, (2) referred to transition as the movement and adjustment from pediatric to adult care, and (3) evaluated patient outcomes up to 5 years after first adult appointment and/or defined a successful or unsuccessful transition.

**Results:** Twenty-six peer-reviewed studies were included. Four studies defined transition success, while 2 studies defined an unsuccessful transition. Transition outcomes were categorized into these 6 themes: being comfortable in adult care ( $n = 4$ ); health care utilization ( $n = 19$ ); disease management ( $n = 15$ ); knowledge ( $n = 5$ ); quality of life ( $n = 6$ ); self-efficacy ( $n = 7$ ).

**Conclusions:** Most studies evaluated transition outcomes by themes of health care utilization ( $n = 19$ ) and disease management ( $n = 15$ ). Future research should focus on engaging patients along with providers in order to create a consensus on indicators of transition success.

**Key Words:** inflammatory bowel disease, pediatric to adult care, transition outcomes

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Inflammatory bowel diseases (IBD) are chronic and debilitating diseases of the gastrointestinal tract and include Crohn's disease (CD) and ulcerative colitis (UC) (1). Symptoms such as abdominal pain, cramps, and diarrhea can negatively impact daily life, employment, and relationships (2). Additionally, these individuals are at a higher risk for depression and anxiety than the general population (3,4).

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## What Is Known

- A diagnosis of inflammatory bowel disease (IBD) can have a negative impact on a patient's daily life, relationships, employment, and mental health.
- Patients diagnosed with IBD in childhood rather than adulthood face additional challenges such as delayed growth and greater extent of disease.
- It is important to prepare patients with IBD to transition from pediatric to adult care.

## What Is New

- We identified 26 peer-reviewed studies that either defined successful/unsuccessful transition or measured transition outcomes up to 5 years after first adult appointment.
- This manuscript categorized outcomes associated with the transition from pediatric to adult care for patients with IBD into themes of comfort in adult care, health care utilization, disease management, knowledge, quality of life, and self-efficacy.
- Health care utilization and disease management were the 2 most common themes in how studies measured IBD transition outcomes.

In Canada, approximately 25% of patients are diagnosed with IBD in childhood (5–7)—a frequency that is increasing (8,9). These children may face additional challenges compared to those diagnosed as adults such as delayed growth, greater extent of disease, and the need to transition to adult care (8). Typically, pediatric patients are supported by their guardians who assist in disease management, but in adult care, these patients need to take on this responsibility and make medical appointments, know their disease history, and make medical decisions.

While transfer of care generally refers to the handover from pediatric to adult care, transition of care is the gradual shift and

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ongoing process of the patient taking responsibility for their care (10). Transition typically starts in pediatric care and continues after transfer while the patient adapts to adult care. This period is challenging for young adults as it coincides with potential lifestyle changes, such as becoming financially independent, moving out, and starting post-secondary schooling or employment (11,12). Transition readiness—the appropriate preparation of an individual to transition—has been thought necessary for a successful transition, but the indicators of success have not been fully described (12,13). A common belief in the literature is that the skills associated with transition readiness are indicators transition success, but readiness itself does not necessarily correlate with success.

The goal of this review is to summarize current research surrounding outcomes after a patient has transitioned from pediatric to adult care. This review will identify overall themes of transition outcomes and provide guidance for future research.

## METHODS

Guidelines used for this scoping review were first described by Arksey and O'Malley and then modified by Levac et al. Essential steps include (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing, and reporting results, and (6) consultation (optional) (LO) (14,15). Although consultation is optional, we introduced an additional researcher to screen title and abstracts for inclusion and to review results.

Scoping reviews differ from systematic reviews as study quality is not assessed and can identify gaps in literature before pursuing a systematic review (14). As this was not a systematic review and included diverse study populations, interventions, and outcome measures, a meta-analysis was not within the scope of this review.

The overarching research question used was: what is known in the literature about the outcomes of transition from pediatric to adult care in patients with IBD?

### Identifying Relevant Studies

Databases searched were Medline (OVID), Scopus, CINAHL, Embase (OVID), and PsycINFO. Search terms were identified through consultation within the team and with a librarian. Keyword terms were searched through title and abstract for sources of research. Search strategies for each database are in Appendix A <http://links.lww.com/MPG/C897>. Studies were included in this scoping review if they met the following criteria: (1) written in English, (2) published from database inception to January 10, 2021, (3) IBD as a disease of interest, (4) referred to transition of care as the ongoing movement and adjustment from pediatric to adult care, and (5) evaluated outcomes up to 5 years after first adult appointment and/or defined a successful or unsuccessful transition. All original published peer-reviewed literature, including abstracts, were included in this study.

### Study Selection

Study references were entered into Covidence, a review management system (<https://www.covidence.org>). Title and abstracts were independently screened by 2 reviewers according to inclusion criteria (AB & LO). Disagreements were discussed and if consensus could not be reached, a third reviewer was introduced (KK). From this process, 26 studies underwent final review (Fig. 1).

### Charting the Data and Collating, Summarizing, and Reporting Results

Studies were divided into 4 categories based on the study focus (Table 1): studies that defined a successful and unsuccessful

transition; studies with controlled implementation of a transition program; studies with implementation of a transition program with no control; and studies that measured transition outcomes.

A descriptive analysis of the studies was done for themes relating to transition outcomes (14,15). Outcomes were grouped together based on similarity until an overall theme was created. Before finalizing themes, a second reviewer screened the results and provided further input. Themes were created with no precedent, by the authors, based on how outcomes related to one another.

## RESULTS

Of the 26 studies moved to full text review, 73% were published between 2017 and 2020 with a range of 2013 and 2020. Most were conducted in the United States ( $n = 8$ ) with the remainder published in the Netherlands ( $n = 4$ ), Canada ( $n = 4$ ), Israel ( $n = 2$ ), United Kingdom ( $n = 3$ ), Hungary ( $n = 3$ ), Italy ( $n = 1$ ), and Germany ( $n = 1$ ). In addition to studies that provided a definition of a successful or unsuccessful transition, there were 6 themes surrounding transition outcomes. Themes were (1) comfort in adult care; (2) health care utilization; (3) disease management; (4) knowledge; (5) quality of life; and (6) self-efficacy (Table 1).

### Themes of Transition Outcomes

#### Comfort in Adult Care

Four studies measured patient's comfort in adult care as an outcome of transition (16–19). Eros et al employed an IBD specific questionnaire (CACHE), which uses a 5-point Likert scale to explore patient's attitudes toward the medical team, accessibility, and facilities of the center (17). Mollah and Giles developed the IBD Patient Satisfaction Questionnaire (18). This questionnaire had questions composed of categories relating to satisfaction with doctor-patient communication, clinic expectations, and clinic logistics. Other studies either explored patients' transition experiences using the On Your Own Feet Transition Experience Scale and a subscale of American Consumer Assessment of Health Plan surveys to explore the perceived patient-centeredness of care (16) or a questionnaire conducted virtually (19).

#### Health Care Utilization

Nineteen studies examined health care utilization as an outcome of transition (16–18,20,21,22–34). The most common measures was whether the young adult required IBD-related hospitalization (16,17,20,22–29,34) and whether there was a need for surgical intervention (17,20,22–24,29). Procedures such as diagnostic imaging and associated radiation exposure were measured (17,22,24,28–30); as well as the need for endoscopies (17,22,23,29,32). Another measurement of health care utilization was emergency department (ED) visits (16–18,23,30,34). Paine et al conducted semi-structured interviews with pediatric and adult IBD providers to define transition success. Key outcomes that arose were appropriate ED use, maintaining standard of care in terms of lab tests and endoscopies, while minimizing hospitalizations and surgeries (21).

#### Disease Management

Fifteen studies measured outcomes categorized as disease management (7,16,17,20,21,23,24,26–33,35,36). The most common outcome was disease activity. Within 3 studies, disease activity was measured by indices, such as Pediatric Crohn's Disease Activity Index, Pediatric Ulcerative Colitis Activity Index, Crohn's Disease Activity Index (CDAI), Mayo score, and Perianal CDAI (17,33); and Partial Mayo score or Harvey Bradshaw index (36). Disease activity was also measured by laboratory parameters, such as C-reactive protein, and stool calprotectin

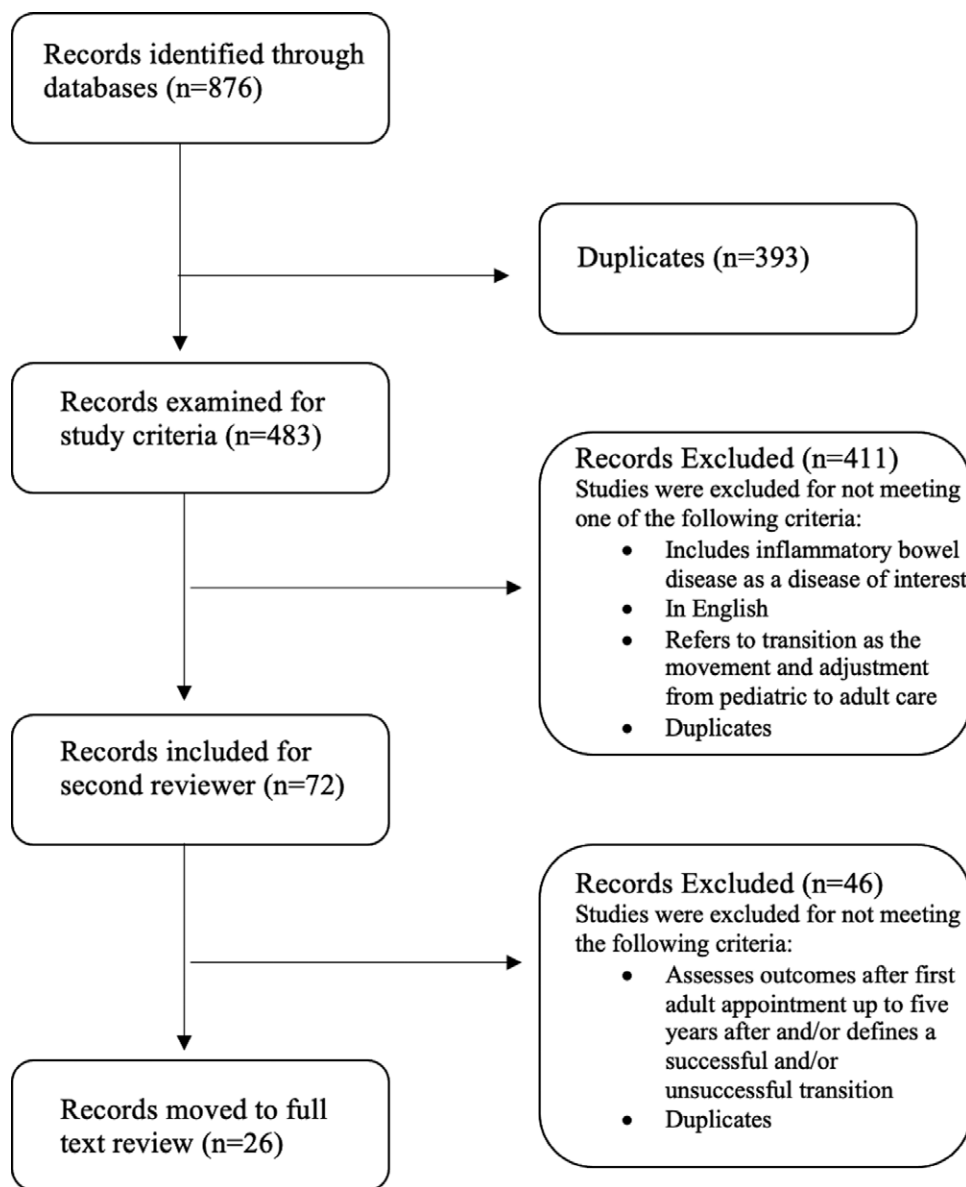


FIGURE 1. Study Selection. .

(17,28). Shaikh et al used therapy escalation, such as the requirement for steroid or anti-TNF initiation, as a marker for disease activity (31). Without specifically referring to the measurement of disease activity, other studies examined therapy escalation leading to initiation of steroid treatment, anti-TNF and azathioprine or modification of the previously established treatment regimen (17,20,26,32). Disease exacerbations such as moving into an active flare, and developing intestinal complications or extra intestinal manifestations were also measured (17,26,27,29,33,35). Medication adherence was also measured (16,24,35). Two studies measured adherence through patient reports in either clinic notes or through a medication adherence rating scale (16,24). In a 3-stage Delphi study, the ability to refill prescriptions on time and then adhere to medication was thought to be important for success (7). Paine et al found that avoiding steroid treatment initiation and having stable symptoms and laboratory results were indicative of successful transition (21).

### Knowledge

Five studies examined knowledge outcomes (7,20,21,27,37). Avni-Biron et al conducted a telephone survey assessing patients' knowledge of their diagnosis, dose and side effects of medications, and disease location (20). Moulton et al measured knowledge of medication names, doses, side effects, monitoring requirements, and insurance information (27). Other studies implemented a questionnaire to assess patient's IBD knowledge, their treatment, and diagnostic tests (21,37). In a multinational Delphi study, included in the final list was the patient's ability to recall medication doses and frequency (7).

### Quality of Life

Six studies measured patients' quality of life (QoL) (7,16,17,21,29,36). To assess QoL, 4 studies implemented questionnaires, such as validated IMPACT-III Questionnaire (17); Inflammatory Bowel Disease Disability Index (36); IBD Questionnaire

TABLE 1. Study characteristics and summary of outcomes measured

		Themes and measured outcomes						
Author (year)	Sample size	Method	Comfort in adult care	Health care utilization	Disease management	Knowledge	Quality of life	Self-efficacy
<b>Studies focused on defining a successful or unsuccessful transition:</b>								
Van den brink et al (7)	Health care providers: 74 Patients: 61	Multinational Delphi study						
Pearlstein et al (42)	Patients: 104	Retrospective chart review		Return to pediatric care; ED visits	Therapy escalation		Health related	Appointment attendance; independence (decisions & communication)
Paine et al (41)	Health care providers: 12	Semi structured interviews		ED visits; hospitalizations; surgery; laboratory testing; endoscopies; return to pediatric care	Therapy escalation; disease activity (biomarkers); symptom stability; insurance		Meets demands of daily life	
<b>Controlled studies of a transition program</b>								
Dijoseph et al (25)	<b>Intervention:</b> Retrospective chart review <b>Control:</b> Patients: 50 Patients: 65			Hospitalizations; appointment no-show rates	Therapy escalation			
Sarlos et al (28)	<b>Intervention:</b> Outcome evaluation of structured transition program <b>Control:</b> Patients: 24 Patients: 21			Diagnostic imaging	Disease activity (biomarkers)			
Mccartney et al (26)	<b>Intervention:</b> Retrospective case note review; Patients: 95 <b>Control:</b> cross-sectional patient survey of outcomes Patients: 34			Hospitalizations	Therapy escalation; disease exacerbations			
Cole et al (24)	<b>Intervention:</b> Review of patient records Patients: 44 <b>Control:</b> Patients: 28			Surgery; diagnostic imaging	Medication adherence			
Moulton et al (27)	<b>Intervention:</b> Randomized to progressive or standard transition Patients: 13 <b>Control:</b> Patients: 19			Hospitalizations	Therapy escalation	Medication; insurance information		
Eros et al (17)	Patients: 160 randomized into intervention and control	Randomized controlled 2-arm multicentre trial	CACHE (IBD specific questionnaire)	Hospitalizations; surgery; diagnostic imaging; endoscopies; ED visits	Perianal CDAI; disease activity (biomarkers); therapy escalation; not lost to follow up; medication adherence		IMPACT-III questionnaire	IBDSES-A

Continued

TABLE 1. Continued

		Themes and measured outcomes						
Author (year)	Sample size	Method	Comfort in adult care	Health care utilization	Disease management	Knowledge	Quality of life	Self-efficacy
Shaikh et al (31)	<b>Intervention:</b> Patients: 33 <b>Control:</b> Patients: 24	Evaluation of treatment requirement and service engagement		Surgery	Therapy escalation			
Sattoo et al (16)	<b>Intervention:</b> Health care providers: 5 Patients: 80 <b>Control:</b> Health care providers: 3 Patients: 81	Controlled mixed-methods evaluation		ED visits	Disease exacerbations; medication adherence		Pediatric Quality of Life Inventory Young Adult	On Your Own Feet Self-Efficacy Scale; appointment attendance & independence
Schutz et al (29)	<b>Intervention:</b> Patients: 24 <b>Control:</b> Patients: 11	Evaluation of patients with and without structured transition		Costs of medications, hospitalizations, and surgery; diagnostic imaging; endoscopies	Disease exacerbations		IBDQ-32	
<b>Studies that measured outcomes after implementation of a transition program</b>								
Yadav et al (19)	Patients: 19	Cross-sectional study	Questionnaire					Questionnaire
Picardo et al (36)	Patients: 59	Interviews & questionnaire						
Avni-Biron et al (20)	Patients: 50	Retrospective review of patient files			Disease activity – clinical disease		IBD-DI	
Yerushalmy-Feler et al (37)	Patients: 27	Evaluation of transition clinic		Hospitalizations; surgery	Therapy escalation	Diagnosis; disease location; medications		IBD Yourself
Mollah and Giles (18)	Patients : 71	Medical records; questionnaire	IBD-PSQ	ED Visits				
Williams et al (38)	Patients: 28	Evaluation of IBD transition clinic						Appointment attendance
<b>Studies that measured outcomes following transition</b>								
Zhao et al (34)	Patients: 536	Population-based cohort		Hospitalizations; ED visits; laboratory use				
Szanto et al (32)	Patients: 59	Retrospective evaluation of transfer		Surgery; endoscopies	Therapy escalation			
Edwards et al (39)	Patients: 4 Parents: 10	Phone survey						

Continued

TABLE 1. Continued

Author (year)	Sample size	Method	Comfort in adult care		Themes and measured outcomes				
			Health care utilization	Disease management	Knowledge	Quality of life	Self-efficacy		
Testa et al (33)	Patients: 106	Evaluation before and after transition	Hospitalizations; surgery; number of outpatient visits	Partial mayo; CDAL; disease exacerbations					
Bollegala et al (23)	Patients: 95	Retrospective chart review	Hospitalizations; surgery; endoscopies; ED visits; outpatient clinic visits	Medication adherence					
Pamela et al (35)	Patients: 9	Review of patient records		Disease exacerbations; medication adherence				Appointment attendance	
Setya et al (30)	Patients: 7381	Retrospective cohort	Hospitalizations; diagnostic imaging; ED visits						
Bollegala et al (22)	Patients: 2043	Population-based retrospective cohort	Hospitalizations; surgery; diagnostic imaging; endoscopies; ED visits						

(29); Pediatric Quality of Life Inventory Young Adult (16). The remaining 2 studies sought to define transition success. Van den brink et al found that providers and patients included health-related QoL 1 year after transfer as an important outcome (7). Paine et al found providers indicated that health-related QoL was important and was defined as patients meeting the demands of daily life in terms of school, work, and family (21).

**Self-Efficacy**

Seven studies measured self-efficacy (7,16,17,21,35,37,40). Van den brink et al identified that outcomes important for transition success include appointment attendance within 3–6 months after transfer, ability for patients to contact and communicate with their physicians/nurses independently, and ability to make their own medical decisions (7). Attending or missing the initial appointment in adult care and regular clinic appointments were measured (16,35,40). Sattoe et al examined patients’ independence during consultations using self-reported measures and Partners in Health Scale to assess self-management skills; to assess self-efficacy, the study used On Your Own Feet Self-Efficacy scale (16). Four studies utilized questionnaires to measure self-efficacy. One questionnaire assessed independence with visits and within transition in general (19). To measure general coping with IBD, self-efficacy in medication use, and patient’s independence and behaviors at appointments, the questionnaire “IBD Yourself” was used (37). Eros et al used an IBD Self-Efficacy Scale for Adolescents and Young Adults, which assesses patients’ confidence in their ability to manage the demands of IBD (17).

Above describes the 6 themes in the literature on IBD transition outcomes. The following paragraphs discuss study results based on their focus.

**Studies With Controlled Implementation of a Transition Program**

In the 9 studies that compared the outcomes of patients who attended a transition program with those who did not, most involved joint consultations with adult and pediatric gastroenterologists prior to transitioning (16,17,27,29). These studies mainly measured outcomes at 1 year (17,26–28) or within 2 years (16,24,29) after transfer. These studies found that compared to patients who did not attend a transition clinic, those who did had lower hospital admissions (29% vs 61%; mean of 0.16 vs 0.51; 20% vs 50%), fewer appointment no-shows (29% vs 78%; mean of 0.36 vs 0.89), and were less likely to require surgical intervention (25% vs 46%; 13% vs 46%) (16,24,25,28,29). Patients in non-clinic groups were also less likely to be steroid free (vs 41% vs 71%), more likely to require steroid initiation (mean dose of 0.88 vs 0.50), develop intestinal complications (21% vs 64%), use biologics [6.7% (year 1), 10% (year 2) vs 50% (year 1), 47.8% (year 2)], and have less disease knowledge (e.g., medication names, doses, and side effects) (16,25–27,29). Cole et al found that 46% of patients who did not attend a transition clinic fully adhered to their medication, whereas this was 89% in patients who attended a clinic (24).

**Studies With Implementation of a Transition Program**

In the 6 studies that implemented a structured transition program, most administered a patient questionnaire to assess patient outcomes (18,19,36,37). Studies that used self-efficacy questionnaires found that after the implementation of a transition program, patient’s scores increased in the domains of coping with IBD and knowledge of disease, tests, and medications (average score of 1.85±0.3 before and 1.41±0.21 after) (19,37). Picardo et al measured IBD disability index at 12 months after program completion

and found that scores of transitioned patients ( $20.69 \pm 13.19$ ) did not differ significantly from adult patients ( $24.90 \pm 14.18$ ) (36). Additionally, 75% of patients had stable disease activity throughout the 12 months posttransfer. Avni-Biron et al implemented joint consultations and found that within the first year, 94% of patients had continuous care, 74% required medication modification, and 20% required hospitalization (20). Williams et al found an 80% retention rate in adult care and a 0% no-show rate, which was compared with 33% and 46% before the implementation of a transition clinic (40). Mollah and Giles found IBD-related ED visits decreased by 24% over a 1-year period after transition clinic attendance (18).

## Studies Measuring Outcomes of Transition

Eight studies measured transition outcomes without an intervention. One study found no statistically significant differences in hospitalizations pre- and posttransfer demonstrated by a relative incidence (RI) of 0.70 (CI: 0.42–1.18) for CD patients and 2.41 (CI: 0.62–9.40) for UC patients (34). This study did find significant pre- and postdifferences in ED utilization, as demonstrated by a RI of 2.12 (CI: 1.53–2.93) for CD and 2.34 (CI: 1.18–2.01) for UC (34) and found CD patients had a RI of 1.43 (1.26–1.63), UC patients with RI of 1.38 (CI: 1.13–1.68), as it related to laboratory utilization. Another 2 studies found significant differences in ED use (20% vs 12%) and hospitalizations ( $0.1 \pm 0.3$  vs  $0.28 \pm 0.44$ ) compared with in pediatric care (30,33). Setya et al found females had a higher number of ED visits (18.7% vs 15.0%), opioid (63.5% vs 56.7%), and benzodiazepine prescriptions (41.0% vs 37.4%) compared with males (30). Bollegala et al found that although there were no differences in hospitalizations and ED visits when comparing academic versus community adult gastroenterologist, patients seeing a community gastroenterologist had less ED visits compared to in pediatric care (mean of  $-0.4$ ) (22). Two studies found that 67% and 88% of patients became established in adult care (35,41). Pamela et al reported 67% of patients in adult care regularly attended appointments, and adhered to medications, and lab tests (35). Bollegala et al documented 43% were nonadherent with medications compared with 29% in pediatric care (23). Szanto et al reported that within 9 months after transfer, 58% of patients required steroid initiation (32).

## DISCUSSION

This review is the first to summarize outcomes in the literature after a patient with IBD has transitioned from pediatric to adult care by characterizing outcomes into 6 themes. The 2 most common themes were health care utilization and disease management. Within these themes, health care utilization was commonly categorized by hospitalizations (63%), surgical intervention (53%), and ED visits (47%), whereas disease management was mainly in terms of therapy escalation (60%) and medication adherence (40%). Considering the wide use of these outcomes, we suggest these aspects of health care utilization and disease management be incorporated for future research on transition outcomes. Although these themes were commonly used to evaluate transition, we also believe that these factors may not fully represent transition outcomes, as they may be independent of transition and rather related to natural fluctuations of disease activity (42). Given the interplay in these outcomes, reliance should not be placed solely on the outcomes of health care utilization and disease management when evaluating transition. Rather, these outcomes should be used in conjunction with others outlined in this study.

The findings highlight the range of outcomes assessed after a patient has transitioned. There remains a need to fully understand the outcomes that providers should be assessing before determining that a transition has been successful. Of the 26 studies

included, 2 focused on defining transition success (7,39), whereas another 4 studies provided a definition of successful or unsuccessful transition (16,20,38,41). Where a definition was provided, attending appointments and avoiding return to pediatric care was thought to be successful. By solely defining success as regular follow up, we may miss out on patients lacking other important outcomes, such as medication nonadherence or an inability to communicate with their physician. We suggest that, for a process as collaborative, individualistic, and complex as transition, a definition be created that is equally as robust and multifactorial.

Sixteen studies used medical charts or health administrative data to assess outcomes with 5 of these 16 employing a survey or questionnaire to patients. As transition highly relies on patients taking control of their own disease management, we believe that patients should be involved in defining transition success. If providers are aware of how patients view transition success, which may differ from providers' perspectives, they would be able to provide patient-centered support and intervene with patients not likely to achieve success.

Studies that measured comfort in adult care as an outcome were all conducted in European countries—specifically the Netherlands where 75% of studies mentioning this theme originated. The emphasis on comfort in adult care in this region may reflect cultural attitudes and differences in managing transitioning patients. The Netherlands may place more value on ensuring that the patient is established and confident when navigating adult care. Future studies could focus on analyzing transition outcomes trends by region, which will allow for an understanding of the optimal approach to transition as reflected by the outcomes.

Survivor bias is a potential limitation to the studies included in this article. Patients who may have moved and transferred clinics or became lost to follow up and never attended adult care were often overlooked. By not including these patients, the impact of transition interventions may be overestimated. Most studies measured outcomes at 1 year or 2 years after transfer. As there exists no guidelines on when to assess outcomes, these studies could be missing the optimal timeframe; however, we hoped to minimize this limitation by including studies that measured outcomes up to 5 years after first adult appointment.

The strength of this scoping review is that it identifies overall themes of IBD transition outcomes in the literature. We recommend that future research focus on defining transition success according to both patients and providers. This will enable a consensus on transition success indicators, which can then be used to systematically evaluate studies implementing a transition program. We also suggest that once systematic evaluation is available, the focus is on addressing questions of an optimal transition program, such as “what should be covered in consultations?” and “how many visits are needed?” By identifying and outlining the key steps of a successful transition program, we can provide the best opportunity for patients to achieve success. This will be especially valuable in centers where implementation of a transition program is not feasible.

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