

# Integrating Adolescents and Young Adults into Adult-Centered Care for IBD

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**Abstract** Planned healthcare transition, initiated in pediatric care, is a gradual process aimed at fostering the adolescent patient's disease knowledge and skills with the ultimate objective of preparing patients and families for adult-centered care. The process is critical in inflammatory bowel diseases (IBD) where there is an increased risk of non-adherence, hospitalizations, and emergency department use as young adult patients graduate from pediatric to adult-centered care. While evidence for healthcare transition in IBD is mounting, important gaps remain in the understanding of this process from the perspective of the adult gastroenterologist. This paper summarizes what is known about healthcare transition in IBD and explores the unanswered questions—a conceptual and methodological framework for transition interventions, relevant outcomes that define successful transition, and key stakeholder perspectives. For the adult gastroenterologist managing the

young adult patient population, this paper presents the paradigm of “care integration”—a process of ongoing, multi-modality support for the patient, initiated in the adult care setting, with the goal of improving self-management skills and active participation in medical decision-making.

**Keywords** Adolescents · Young adults · Emerging adults · Inflammatory bowel disease · Pediatric to adult transition · Healthcare transition · Adult-centered care

## Introduction

Inflammatory bowel diseases (IBD), including Crohn's disease and ulcerative colitis, are chronic illnesses that affect over 1.4 million people in the USA [1]. Peak age of IBD diagnosis, especially for Crohn's disease, coincides with the young adulthood stage of human development (18–25 years old) [2], with about a fourth of new IBD diagnoses made in individuals before age 20 [3]. The incidence of IBD, particularly pediatric IBD, is rising with about 10,000 new cases diagnosed annually [3]. Notably, childhood-onset IBD is associated with greater disease severity and complexity [4]. With current prevalence estimates of 100–200 IBD cases per 100,000 children in the USA, combined with low mortality of IBD, 10-year forecasts predict that the typical adult gastroenterology practice will be caring for a growing number of adolescents and young adults (AYA) with IBD [5]. In parallel with the changing epidemiology of IBD, treatment has moved away from surgical management and inpatient hospitalizations towards new and costly biologic therapies, with a resultant shift in direct healthcare costs of IBD now approaching \$6 billion annually in the USA [6].

Given the increasing numbers of young adults with IBD and the high cost of care for these individuals over the lifespan, there has been a growing national and international

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emphasis on healthcare transition (HCT), a step-wise, planned movement of patients with chronic illnesses from pediatric to adult health services [7]. However, HCT is a process that continues well after the physical transfer of a patient to adult-centered care (ACC) and adult IBD providers are in need of more education and information in order to effectively build upon this HCT process. In this article, we discuss, from the perspective of an adult IBD provider, existing knowledge about HCT (including its definition and key elements, disease-specific considerations for IBD, and existing evidence for planned HCT in IBD) as well as gaps in knowledge that present an opportunity for future research. Table 1 summarizes the frequently used abbreviations for this paper.

### Planned HCT: Definition, Elements, and Outcomes

The current expert consensus from the Society for Adolescent Medicine defines pediatric-to-adult healthcare transition, using a broad developmental perspective, as “a gradual, multi-dimensional and family-oriented process with focus on the anticipated developmental stage of an individual and with the ultimate goal of transfer to adult healthcare settings by empowering patients with disease knowledge and self-management skills and by preparing healthcare providers with adequate knowledge” [8]. Planned HCT for AYA has been identified as a health services priority area by the Department of Health and Human Service’s Healthy People 2020 report [9]. To improve the quality of care delivered to AYA, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians released a Consensus Report on Transition from Adolescence to Adulthood in 2011. This report is a collection of best practice guidelines that are derived from expert opinion and recommend that transition planning should be part of clinical care for all AYA. The statement recommends beginning HCT planning around age 12 with transfer to ACC completed between ages 18 and 21 years [10••].

#### *Elements and Outcomes of Successful HCT*

While there remains a dearth of evidence-based elements and outcomes for successful HCT, a recent Delphi study, comprised of a panel of international transition experts including physicians, psychologists, and transition program managers, reached full consensus on the importance of assuring good

coordination between pediatric and adult providers and high consensus on tailoring transition plans to the needs of patients and families and on identifying a transition manager or coordinator. Panelists unanimously endorsed patient continuity of care with an adult provider (in contrast to ‘lost to follow-up’ or ‘no missed consultant appointments’) as a key indicator of successful HCT [11]. Open and easy communication between adult and pediatric teams and flexibility and adaptability in planned HCT were considered to be important as well. In a recent study of adult providers caring for AYA with sickle-cell disease, health care utilization (e.g., keeping medical appointments, preventing hospitalizations), quality of life outcomes (e.g., meeting developmental and life milestones), and clinical outcomes (e.g., stable or improved disease trajectory) were determined to be the chief outcomes of a successful planned HCT [12]. Despite this knowledge about the goals and elements of planned HCT, little attention has been paid, nationally or internationally, to creating systems-level solutions or policies for transition, as revealed by a comprehensive, international, cross-jurisdictional, policy scoping review of nine member countries of the Organization for Economic Cooperation and Development (OECD) [13].

#### *Transition Readiness*

Transition readiness, a construct reflecting skills in the realms of disease knowledge, information gathering, self-management, and decision-making, is expected in a patient who is ready to transfer to ACC. The objective of achieving transition readiness in a patient is to foster sustained self-efficacy and motivation for active participation in health and self-care behaviors. Since age of transfer of AYA to adult care is not standardized in the USA, individuals of varying developmental capacities are transferred to adult care, which can be a potential barrier to success of HCT. Therefore, measures of transition readiness are used to (1) decide whether a patient is ready to be transferred to adult care and (2) assess progress of the individual during a planned HCT program. For IBD, transition readiness is being used as a metric to track success of planned HCT and to set institutional benchmarks for transition programs. In a national survey of pediatric gastroenterologists who care for AYA with IBD, 76 % reported using objective assessments of patient transition readiness to decide timing of transfer to adult care [14••]. Despite 56 different generic and disease-specific transition readiness measures, a recent comprehensive meta-analysis demonstrated that none have been tested for predictive validity in terms of transition outcomes [15]. Additionally, it is unclear what cut-offs should be used for the purpose of institutional benchmarking, since there is no parallel body of research into what constitutes “gold standard” score on such measures in the adult population. In IBD, the most commonly used transition readiness assessment tool is the Transition Readiness Assessment Questionnaire, a self-

**Table 1** Frequently used abbreviations

IBD	Inflammatory bowel disease
AYA	Adolescents and Young Adults
HCT	Health care transition
ACC	Adult-centered care

report questionnaire regarding disease self-management skills [16]. This tool, however, does not take provider and/or family perspectives into account. Moreover, the exact self-management competencies needed for successful IBD management are not captured in this type of generic transition tool. In this regard, a disease-specific, self-efficacy scale for AYA with IBD may be a complementary tool to identify skills deficits among these patients [17].

#### *AYA Transition in the USA*

In the US, AYA do not currently receive adequate planned HCT services [18]. Only 22–47 % AYA with chronic illnesses receive any pediatric-to-adult transition planning [9]. While the number of AYA who received planning for HCT improved between 2001 and 2010, less than half of parents, interviewed as part of the National Survey of Children with Special Health Needs, report having a transition preparation plan in place with their pediatrician [19]. A 2009 American Academy of Pediatrics national survey of transition services demonstrated that less than half of pediatricians offer AYA and their families any transition support [20]. Given these data, many AYA, including those with IBD, will present to adult sub-specialty providers with unaddressed challenges in self-management skills and disease knowledge. Furthermore, regardless of whether an AYA has been engaged in a formal HCT program, the process cannot simply end with the transfer to ACC. Adult providers must build upon this process by integrating youth into ACC and addressing their unique needs. With the increasing incidence of pediatric IBD and low mortality of IBD, adult gastroenterologists will be increasingly tasked with managing AYA with IBD and, hence, it is critical to address the challenges faced by them in the management of AYA with IBD. Adult gastroenterologists consistently report that their limited training in adolescent medicine and in issues related to AYA is a persistent barrier in post-transfer care provision [21, 22]. Such barriers are not unique to the field of adult gastroenterology. Many other adult sub-specialties, including endocrinology, rheumatology, and cardiology, have similarly expressed a need for additional training in adolescent medicine [23, 24].

#### **AYA with IBD: Special Management Issues for the Adult Gastroenterologists**

For the adult IBD provider, there are several unique, disease-related, and socio-demographic factors that should be considered in AYA with IBD. First, compared with adult-onset IBD, disease phenotype and evolution in pediatric-onset IBD is more aggressive with higher rates of associated complications. The multicenter EUROKIDS inception cohort study of children with IBD demonstrated that 60–80 % of pediatric-onset ulcerative colitis presented with pancolitis compared with

only 20–30 % in adult-onset ulcerative colitis [25, 26]. The incidence of acute severe colitis is higher in children and 10-year colectomy rates are over 40 % compared to less than 20 % in adults [26]. In Crohn's disease, greater upper gastrointestinal involvement, more penetrating disease, and higher rates of perianal disease are noted among individuals with childhood onset disease [26]. When disease characteristics were compared between 100 AYA with IBD presenting to a HCT clinic in Canada versus 100 adults with IBD matched for disease duration, more severe disease phenotype with disease-related complications and higher requirement for biologic agents was noted in the transitioning AYA population [27]. In addition, a third of children with Crohn's disease experience linear growth retardation prior to gastrointestinal manifestations secondary to under-nutrition and inflammation, which can lead to delayed puberty and related complications [28, 29].

AYA with childhood-onset IBD are also at greater risk of ionizing radiation exposure and radiation-related malignancies, given the recently documented rise in diagnostic imaging performed for pediatric IBD patients and the trend towards increased cumulative lifetime radiation exposure [30, 31]. Treatment-related concerns, especially the risk of lymphoma from immunomodulator therapies are also particularly relevant for this young population [32].

Sexual and reproductive health is another area of focus for AYA with IBD. Adverse pregnancy and outcomes, including preterm birth and low birth weight, are associated with active disease at time of conception and during pregnancy [33]. Induction and maintenance agents can affect fertility, another important issue for this young patient population. Therefore, for optimal management of IBD during and after pregnancy, preconception planning under specialist care is essential [34•]. However, counseling on issues of sexual health, birth control, and pregnancy remains very low among AYA with chronic illnesses including IBD [35, 36]. This is despite a greater prevalence of high-risk lifestyle behaviors in most young adults with chronic illnesses compared to their peers [37]. IBD symptoms and treatment, including surgical therapies, can significantly affect self-image and sexual functioning [38], and AYA with IBD tend to have more depressive disorders compared to other chronically ill youth [39].

Similar to youth with other chronic illnesses who achieve fewer lifetime milestones, AYA with IBD tend to receive more public assistance and have lower income levels [40]. They face a future of reduced employment opportunities, higher levels of disability, and lower work productivity. In the USA, the burden of work-related opportunity loss in active IBD is estimated at \$3.6 billion (\$5228 per person) annually, excluding the costs of poor quality of life and its effect on productivity [41]. Among AYA with IBD, a concerning trend of increasing emergency health services utilization is noted which appears to coincide with the transition to adult-

centered care. Using national and administrative claims databases, several studies have demonstrated an increase in emergency department use for acute care needs, for immunosuppressive therapy and lower ambulatory care use among AYA compared to other age groups and non-IBD patients [42, 43]. A recent Canadian study assessed healthcare utilization among AYA with IBD 1 year before and 1 year after transfer to adult care and found more missed ambulatory visits and more treatment non-compliance after transfer to adult care [44]. In addition, there is evidence of major financial burden for families and substantial out of pocket costs associated with pediatric-onset IBD of which adult IBD providers should be cognizant [45].

### Planned HCT: Current Evidence for AYA with IBD

The North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) addressed the issue of HCT in IBD with a set of expert-opinion based consensus recommendations for both pediatric and adult gastroenterologists about HCT-related planning, preparing the patient and family, and continuing the process once the patient has physically transferred care to the adult healthcare environment [46–49]. However, to date, little has been published regarding the systematic development, implementation, and evaluation of planned HCT models in IBD. Joint pediatric and adult IBD clinics, of various durations and with different starting points, have been the most commonly recommended and studied models for planned HCT in IBD [50–52]. A recent retrospective study assessed disease-specific outcomes, over a 2-year period, of AYA with IBD who participated in a planned HCT program in the UK compared with patients who were transferred directly to an adult gastroenterology clinic with a referral letter. This transition clinic was a joint adult-pediatric clinic with support from IBD nurses, dietitian, and clinical psychologists where an individualized transition plan was made for each patient with emphasis on patient and parental disease-specific education. AYA attending the transition clinic had significantly enhanced continuity of care with improved clinic attendance, self-reported medication adherence, decreased surgery and hospitalization rates, higher rates of university education and employment, and a trend towards lower ionizing radiation exposure risk [53]. Results of a randomized clinical trial comparing different transition models being conducted in the United States are eagerly awaited [54].

### Gaps and Opportunities

In order to effectively develop HCT interventions that are generalizable to varied practice settings, some critical gaps need to be addressed including: (1) solidification of a conceptual and methodological framework for HCT interventions; (2) determination of relevant constructs and outcomes; (3) understanding of key stakeholders; (4) adaptation from other

childhood-onset chronic disease models, and (5) expansion of HCT to include integration of AYA in the adult care setting.

### *Conceptual and Methodological Frameworks for Healthcare Transition in IBD*

The existing approach to HCT places patient knowledge and self-management skills at the center of the entire process. However, this approach may be sub-optimal given that important contextual factors, including psychosocial, community, and economic factors, are minimally addressed or neglected in such an approach. The Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) model of transition readiness, informed by the social-ecological framework and validated among patients, families, and providers, offers a robust methodological framework to capture the important intersecting stakeholders, distinct phases of care, and specific contributions of each stakeholder to transition readiness. The SMART model also emphasizes the use of a healthcare utilization metric in assessing HCT success and has been validated for use in IBD [55–57].

Implementation of planned HCT can be considered a healthcare improvement initiative and, as such, meets the Agency for Healthcare Research and Quality and Institute of Healthcare Improvement “Triple Aim” framework of improving the individual experience of health care, health of the population, and reduction of healthcare costs [58]. In designing and implementing a planned HCT program, emphasis on measuring improvements in both individual and population health outcomes and healthcare utilization and costs are essential [59]. Additionally, there is a need to develop quality metrics to systematically evaluate planned HCT interventions for IBD. One novel program, sponsored by the Centers for Medicare and Medicaid (CMS) and AHRQ, the Pediatric Quality Measurement Program, is engaged in the development of evidence-based, quality, self-report measures for the pediatric- to adult-centered care transition [60]. These can be used to measure important elements such as patient-reported transition preparedness, and also serve as a benchmark for comparing transition programs [61]. Finally, it is essential to think about successful implementation of planned HCT interventions for IBD. Borrowing from implementation science, HCT interventions for IBD should include measurement of the fidelity, cost of implementation, penetration, and sustainability of the intervention, while being mindful of structural (e.g., infrastructure, public policy); organizational (e.g., leadership and employee involvement); patient-level (e.g., health-related beliefs, motivation); provider-level (e.g., knowledge of intervention); and innovation-level factors (e.g., quality of evidence supporting the efficacy of the intervention) [62, 63].



### *Relevant Constructs and Outcomes*

For adult gastroenterologists, challenges in caring for AYA with IBD can be best understood from the application of a “developmental lens.” AYA experience a short but unstable period between adolescence and full adulthood that is marked by changing roles (e.g., student, employee, parent), geographical and social flux (e.g., leaving home for higher education, starting work), and variable dependence on caregivers for financial and emotional support and decision-making [64•]. This period typically coincides with the time when most AYA with IBD need to integrate into ACC, either because of a new diagnosis or after transfer from pediatric care. This developmental paradigm, referred to as emerging adulthood, has been used as a conceptual basis to explain poor disease outcomes and patterns of healthcare utilization often seen among AYA with chronic illnesses like type 1 diabetes mellitus, mental illness and solid organ transplantation [65–68]. Disease self-management becomes especially challenging with gaps in adherence [69], follow-up, and insurance coverage [70]. These may partly explain the deterioration in clinical outcomes (e.g., poor HbA1c, organ graft loss), interrupted ambulatory care, and increased emergency department use and hospitalization seen during this developmental stage [71–77]. It is imperative that adult IBD providers be aware of the many unique needs and challenges of AYA with IBD, in order to provide developmentally appropriate post-transfer care to this at-risk sub-population.

### *Continuity of Care*

Continuity of care is a multi-dimensional, patient-oriented construct that is a composite of important health services domains including care coordination, care integration, and patient-provider communication [78]. Continuity of care includes management and relational continuity with the same provider over time (personal) and between different care settings (cross-boundary) [79]. Different instruments have been developed and validated for measuring continuity of care in the health services research literature and a recent systematic review highlights the strengths and weaknesses of each instrument [78]. The importance of continuity of care as an objective, measurable, and clinically relevant outcome for successful HCT has been echoed across chronic diseases. In type 1 diabetes mellitus, 34 % patients have a gap of >6 months in medical care following transfer to adult care [80]. Based on structured interviews with pediatric and adult gastroenterologists, a recent study demonstrated that continuity of care with an adult provider was the most commonly used indicator of successful HCT and considered even more important than previously used outcomes like hospitalization rates, quality

of life, and corticosteroid use [56]. While these studies underscore the importance of this construct to evaluate the success of planned HCT, to date, no continuity of care measure has been validated for use among AYA with IBD.

### *Stakeholder Input in Planned HCT for IBD*

Clearly identifying the main stakeholders in the process of planned HCT and focusing on their perceived barriers is essential for facilitating success of HCT. Several recent studies have assessed perspectives on HCT in IBD among patients, parents, pediatric, and adult health providers, outlining their importance as major stakeholders in the process with each group identifying perceived barriers in the process of HCT and transfer to ACC [21, 81, 82].

Pediatric GI providers, who are primarily responsible for transition preparedness among patients and parents, are an integral stakeholder group in the HCT process. A recent national survey of US pediatric gastroenterologists and allied health professionals caring for children and AYA with IBD identified major barriers in creating or maintaining planned HCT programs. Similar to the perceptions of the patient and caregiver group, nearly 94 % endorsed resistance from the patient or parent to transfer to ACC, in addition to lack of patient maturity and medication adherence [14••]. Hence, understanding the perspective of pediatric providers will allow for better alignment of common goals between adult and pediatric providers. Adult gastroenterologists, tasked with the integration of AYA with IBD into ACC, represent another vital, but historically neglected, stakeholder group. Adult GI providers have repeatedly expressed perceived challenges in caring for AYA with IBD population including inadequate patient disease knowledge and self-management skills and their own lack of training and knowledge about needed care for this population [21, 22]. However, it is known that simply increasing provider awareness towards HCT issues does not result in improvement in patient self-management behaviors [83]. Therefore, the perspectives of pediatric and adult providers are essential to address and incorporate in any HCT intervention.

There is a substantial body of literature focused on challenges faced by AYA with IBD including low disease-specific medical knowledge (about disease history, medication, and related side-effects) [84], low interactive health literacy needed for transition to adult care [85], evidence of poor participation in medical decision making. Up to 20 % of AYA cannot perform basic disease self-management skills, even by age 18 [86]. Despite these obvious challenges, patient and their families have had little involvement in HCT planning and development and only recently have patient and caregiver perspectives been highlighted in literature. A series of focus groups of patients and parents revealed important areas of concern surrounding HCT, including fear of loss of

relationship with the pediatric provider, perception of poorer quality of adult care, lack of a clear understanding of the process of transfer to ACC, and the lack of knowledge about healthcare insurance and finances [87••]. Further, in a survey-based study of post-transition AYA with IBD, despite “terrifying” first visits with adult IBD providers, patients reported overall positive relationships with their adult providers [88]. Therefore, understanding barriers and facilitators of successful HCT from the perspective of patients and caregivers and incorporating their suggestions into program design and implementation is crucial to HCT success.

#### *Other HCT Models in Chronic Illnesses*

Planned HCT efforts in other pediatric-onset chronic diseases have evolved further in comparison to IBD. Type 1DM is the second most common chronic illness in children and its incidence has increased particularly in the youngest age groups [89] with growing numbers of AYA needing to transition each year to ACC. Clinical attendance, continuity of ambulatory care and disease control are noted to worsen for patients with Type 1 DM in the post-transfer period [75]. Among planned HCT interventions across chronic childhood illnesses, a recent systematic review found most robust data among interventions focused on AYA with type 1 DM [90]. Four intervention studies demonstrated significant improvement in hemoglobin A1C levels, blood pressure control, improved ambulatory clinic attendance, and improved screening for nephropathy in AYA with type 1 DM who went through structured HCT interventions [91–94]. The interventions primarily focused on disease-specific patient education and self-management skills and the most commonly used model was a specific AYA or joint pediatric-adult clinic. Two of these studies identified the greatest gains in patients who had the poorest pre-intervention disease control. Therefore, HCT interventions in IBD can be informed by the program design, implementation methods and scaling of interventions in the field of Type 1 DM.

#### *Integration of AYA into Adult-Centered Care: Adoption of Expanded HCT*

Existing planned HCT interventions in IBD, though sparse, are based in the pediatric setting with an emphasis on patient transition preparedness primarily via improved patient education. However, none of these programs address care after the transfer to ACC is completed. While preparing AYA and their families for adult-centered care is certainly essential, integration of these AYA into ACC, is equally, if not more important for improved long-term outcomes. This is especially important because not all young adults who present to an adult IBD clinic have transitioned from pediatric care and many might have been only recently diagnosed, as adults. This paradigm shift, where adult providers actively participate in AYA patient education, counseling, and evaluation, that addresses the specific issues of AYA and seeks to improve self-management skills and active participation in medical decision-making, is known as “care integration.” The 2011 Consensus report emphasized the need for care integration of AYA into ACC, after transfer from pediatrics to adult healthcare has been completed, thereby expanding the definition of planned HCT. However, little research has focused on the integration into the ACC phase and no specific studies have been undertaken, specifically, to define the process, key elements, or outcomes of integration of AYA IBD patients into ACC. This new area remain open for future investigation.

#### **Conclusions**

The rising incidence of pediatric-onset IBD and its low mortality is contributing to a substantial increase in the number of AYA with IBD, with complex disease requiring treatment with biologics, who need to be cared for by adult providers. Hence, it is becoming essential for adult gastroenterologists to be trained and equipped with a nuanced understanding and specific management tools to manage the disease-specific, psychosocial, and developmental needs of this young population of IBD patients. While substantial research has focused

**Table 2** Planned Integration of Young Adults with IBD into Adult Care: Next Steps

A.	Continue evaluations of planned HCT interventions to assemble adequate evidence of the effectiveness of HCT on cost, quality, clinical, and patient-satisfaction outcomes.
B.	Evaluate the intersecting interests, needs, and barriers of key stakeholder groups (patient, family, provider, payer, education system, health system, and social services system).
C.	Create individualized and disease-specific processes for planned HCT.
D.	Define specific, measurable, validated, and broadly accepted measures of successful HCT and ACC integration.
E.	Raise national and international discourse about the importance of HCT and ACC integration to initiate systems level solutions (e.g., policy, funding models).
F.	Conduct rigorous implementation research about planned HCT and ACC integration.

*HCT* healthcare transition, *ACC* adult-centered care

on preparedness for HCT primarily guided by pediatric providers, there is a critical need to engage in focused research about the integration of these AYA in ACC. A developmental framework, based on the stage of emerging adulthood, is a potential conceptual model for this research. Table 2 presents a summary of recommendations for the next steps in integration of AYA with IBD into ACC.

### Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflicts of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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- Of major importance

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