

## Review Article



# Transitioning Pediatric Patients with Inflammatory Bowel Disease: Key Considerations for Adult Gastroenterologists

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## GRAPHICAL ABSTRACT



### Optimize growth

Growth should be included as one of the targets to treat for, use of biologics and optimizing nutrition will achieve that target



### Optimize transition timing

Envision transition as a gradual planned process, rather than a point shift



### Screening first degree relatives (FDRs) for IBD

Owing the unique genetic and environmental factors in paediatric IBD, screening of FDRs for early IBD would be advised



### Psychiatric support

Implications of IBD on growth, body image and scholastic performance demands timely involvement of behavioral therapists



### Management strategy

Adopt multidisciplinary team approach with early involvement of dietitian



### Vaccination history

Reassess immunogenicity to childhood vaccination and re-vaccinate if needed

## ABSTRACT

The transition of young patients with inflammatory bowel disease (IBD) from pediatric to adult-centered healthcare presents a significant challenge, particularly in regions like Oman, where transfer occurs as early as 14 years old. Although both pediatric and adult patients require multidisciplinary management, key differences in disease characteristics, vaccination needs, growth considerations, and treatment approaches necessitate a carefully structured transition process. Effective communication between pediatric and adult gastroenterologists is crucial for ensuring optimal management for these young patients. This mini-review explores the complexities involved in transitioning young patients with IBD to adult healthcare services.

**Keywords:** Inflammatory bowel diseases; Transition to adult care; Adolescent; Colitis, ulcerative; Continuity of patient care; Pediatrics

**Conflict of Interest**

The authors have no financial conflicts of interest.

**INTRODUCTION**

Patients with inflammatory bowel disease (IBD) require ongoing, multidisciplinary care and long-term follow-up from a team of specialists, including gastroenterologists, nutritionists, surgeons, specialist nurses, and stoma nurses. The primary responsibility of disease management falls on the gastroenterologist, who acts as the central coordinator, ensuring a seamless integration of various specialists. Patient involvement in healthcare decision-making varies with age and maturity, with children typically requiring more support, while adults often take a more active role. However, individual preferences and circumstances may differ within both groups. Pediatric patients, in particular, rely heavily on trust and a strong personal connection with their physicians to adhere to treatment plans. Therefore, the transition from pediatric to adult healthcare is a crucial process that requires careful planning to ensure a smooth shift from a pediatric-centered to an adult-centered approach.

Multiple studies have shown that transitioning from pediatric to adult healthcare can be challenging, particularly due to the varying transition age, which ranges from 14 to 19 years [1-3]. Significant differences exist between pediatric and adult IBD regarding pathogenesis, epidemiology, and management. Understanding these differences is crucial for adult gastroenterologists to develop effective treatment plans. Considering these variations, it is essential for gastroenterologists to tailor their management approach, taking into account factors such as disease epidemiology, vaccination needs, and the importance of supporting continued growth.

**AGE-SPECIFIC CONSIDERATION WITH EPIDEMIOLOGY**

Approximately 25% of individuals with IBD develop the condition during childhood, often experiencing a more severe and disabling form of the disease [4-6]. Epidemiologically, approximately one-third of patients with pediatric IBD have a first-degree relative with IBD, highlighting the role of genetics in the pathogenesis of the condition [7]. Furthermore, monogenic defects have been identified exclusively in pediatric patients and are typically associated with refractory disease [8]. Family history is considered the most critical risk for IBD, with an even greater impact in childhood-onset cases [9,10]. Therefore, careful assessment of first-degree relatives of patients with childhood-onset IBD is crucial. Moreover, several reports suggest that IBD may follow a subclinical course for up to 5 years, during which laboratory findings may appear nearly normal, highlighting the need for a comprehensive counseling protocol to facilitate early detection of IBD in first-degree relatives.

**AGE-SPECIFIC CONSIDERATION WITH VACCINATION**

The standard care for patients with IBD, particularly in pediatric IBD cases, includes preventive vaccinations. Research indicates that the pediatric population responds poorly to many vaccines, including influenza, pneumococcus, hepatitis B, and diphtheria-tetanus-acellular pertussis vaccines [11]. Therefore, evaluating their immunogenicity to these vaccines after transitioning to adult care would be beneficial. Inactivated vaccines, including parenteral typhoid, polio, meningococcal, hepatitis A and B, rabies, and cholera, can be safely administered to pediatric patients with IBD in accordance with local guidelines [12].

Evaluation for revaccination or booster shots should be regularly performed based on factors such as declining immunity and individual risk profiles.

## AGE-SPECIFIC CONSIDERATIONS WITH GROWTH OPTIMIZATION

Every adult gastroenterologist should consider growth milestones when managing adolescents with IBD. For a 14-year-old patient, growth is a major concern for both the individual and their family. Adolescents are preoccupied with physical and emotional development, including body image, puberty, peer recognition, and career aspirations. Additionally, up to 50% of adolescents with IBD exhibit lower bone density, which aggravates their risk of osteoporosis and fractures as they engage in physical activities [13]. Growth failure at diagnosis occurs in 15-40% of pediatric-onset Crohn's disease cases, compared to 3-10% in ulcerative colitis [14]. Studies have shown that this impairment can affect the final height of these patients as they grow older than 20 years [15-18]. The primary causes of delayed growth milestones are chronic inflammation and malnutrition [19]. Pro-inflammatory cytokines, such as tumor necrosis factor (TNF)-alpha and interleukin-6, directly inhibit growth by suppressing appetite and blocking insulin growth factor 1 [19,20]. Additionally, malnutrition, resulting from inadequate nutrient intake, maldigestion, and fecal nutrient losses, contributes to growth delays. Both inflammation and malnutrition can lead to hypogonadism, which exacerbates growth impairment [20]. The use of glucocorticoids can also contribute to growth failure [21]. Strategies to optimize growth include nutritional management, with the involvement of a dietitian to initiate enteral nutrition therapy [22,23]. Interventions such as percutaneous endoscopic gastrostomy for supplemental nutrition have proven to improve growth over 2 years [24]. Moreover, controlling inflammation with anti-TNF agents can help normalize height when administered during the pre-pubertal phase [22,25,26]. Avoiding corticosteroids is also essential for maintaining optimal growth and preserving bone density in these patients [27]. Regular monitoring of growth and nutrition, including assessments of bone age, bone densitometry, and serum levels of calcium, phosphorus, magnesium, parathyroid hormone, ionized calcium, vitamin D, and tissue transglutaminase immunoglobulin, is essential [28].

## AGE-SPECIFIC CONSIDERATIONS WITH MANAGEMENT STRATEGY

Pediatric-onset IBD typically follows a more aggressive course than adult-onset disease. Despite receiving more intensive immunosuppressive therapies, patients with pediatric-onset IBD often experience a more aggressive disease course characterized by extensive anatomical involvement, rapid disease progression, and increased disease activity [29]. Certain therapeutic approaches for pediatric IBD may not be appropriate for adults, necessitating careful reevaluation and potential discontinuation of transitioning into adult healthcare. In lieu of this, while Exclusive Enteral Nutrition is recommended as an initial therapeutic option to induce remission in pediatric Crohn's disease [30], it has proven ineffective with adults [5]. Recent guidelines for IBD management recommend a treat-to-target strategy, which should be carefully adapted for pediatric patients. This is particularly important given that up to 50% of children with IBD show normal laboratory findings, including serum inflammatory markers [31]. Unfortunately, limited data are available regarding optimal indications, biomarkers, and treatment strategies in pediatric patients [32].

A practical therapeutic approach to managing IBD can be categorized into three distinct phases. The initial phase aims to alleviate symptoms and improve the patient's quality of life. In the intermediate phase, the focus shifts to achieving better disease control and supporting intestinal healing. The long-term objective is to prevent complications, including growth failure, strictures, fistulas, surgical interventions, and hospitalizations. Notably, in pediatric patients with IBD, growth is a primary goal of intervention, distinguishing their management from that of adults [33].

Given the increased susceptibility of children to infections, guidelines recommend initiating prophylaxis for *Pneumocystis jirovecii* pneumonia in those requiring triple immunosuppressive therapy, including corticosteroids [34].

### Age-specific respect of psychological needs

The aforementioned factors highlight the inherent complexities that adult gastroenterologists may encounter when managing this multiplex patient group. A recent study found that pediatric cases accounted for approximately 1.5% of newly diagnosed patients with IBD. This small proportion means that adult gastroenterologists have limited exposure to pediatric patients during the transition of care [35]. Moreover, the age at which this transition occurs varies across countries, influencing the experience of the specialists. For instance, in the United States, adult gastroenterologists typically begin seeing pediatric patients at 18-19 years old, while in Oman, the transition may occur as early as 14 years old [3,36].

Establishing trust and building rapport with pediatric patients during their initial consultation is crucial. These consultations typically take longer than those with newly counseled adult patients. One of the challenges in transitioning to adult care is persuading patients to modify their treatment regimen, such as discontinuing methotrexate as they approach the age of conception [27]. Counseling pediatric patients for colonoscopy can be particularly challenging, as pediatric IBD specialists tend to rely more on imaging studies. For patients experiencing challenges during the transition from pediatric to adult IBD care, a proactive approach involving pediatric IBD specialists is recommended [37]. Additionally, recent evidence suggests that individualized transfer timing may be beneficial, with the option to delay transfer for patients with active disease [38].

IBD has been linked to various skin conditions, which may result from malnutrition, medication side effects, or as extraintestinal manifestations of the disease. Despite their infrequent occurrence in the pediatric population, these extraintestinal dermatological manifestations can have a significant psychological impact on adolescents, particularly due to their disfiguring and occasionally painful nature [39]. Additionally, anti-TNF therapy, particularly infliximab, has been linked to the development of psoriasiform lesions [39,40]. The female sex [41] and perianal Crohn's disease [42] have also been identified as risk factors for this rare complication.

Moreover, nutritional deficiencies caused by malabsorption or malnutrition in patients with IBD can result in various skin conditions. These deficiencies may lead to skin lesions characterized by specific nutrient shortages, such as zinc deficiency (acrodermatitis enteropathica), niacin deficiency (pellagra), vitamin C deficiency (scurvy), vitamin K deficiency (purpura), and vitamin B deficiencies (glossitis, angular cheilitis). Iron deficiency anemia, which affects approximately two-thirds of pediatric patients with IBD, can also contribute to persistent hair loss. The psychological impact of these dermatological

manifestations can be significant, potentially affecting school performance as patients may withdraw from social interactions due to anxiety and depression [43].

When managing a child with any associated dermatological condition, it is crucial to consider all relevant factors and provide timely interventions, including referrals for behavioral therapy, to support their overall well-being and academic performance.

### Aspects related to the transition process

The transition from pediatric-centered to adult care for patients with IBD should be a gradual process, beginning at approximately 10-12 years old when children start to think more abstractly about the future. This process involves assessing the child's understanding of their condition, often uncovering gaps in knowledge regarding the disease's extent, location, severity, diagnostic tests, treatment goals, and management plans [44]. The primary objective of this transition is to help the child through this knowledge acquisition process, equipping them with the necessary skills for effective self-management. Despite these efforts, many adult and pediatric gastroenterologists report gaps in patient preparation for transition. To address this, adult gastroenterologists should employ a structured approach, incorporating digital tools such as smartphone applications designed for patients with IBD, like myColitis and myIBD+. These applications can help facilitate the transition and ensure optimal care for individuals with IBD [36]. Notably, recent studies indicate that a suboptimal transition process can lead to a substantial increase in disease burden [45].

## CONCLUSION

A successful transition of care for individuals with IBD from pediatric to adult settings requires seamless and well-coordinated collaboration between pediatric and adult specialists. This collaborative approach should focus on determining the optimal timing for transfer, considering both disease control and the patient's readiness. All transitioning patients should undergo a comprehensive evaluation encompassing growth and immunization status. Healthcare providers should also educate patients and caregivers about the increased familial risk of IBD, emphasizing the importance of early medical assessment for any suggestive symptoms. The transition process should begin gradually in early adolescence, emphasizing patient education and the development of self-management skills. Implementing a structured approach, supported by tools like smartphone applications, can facilitate this transition and improve patient outcomes.

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