



REVIEW ARTICLE

Adolescents with IBD: The importance of structured transition care

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Abstract

Children and adolescents with inflammatory bowel disease (IBD) tend to have more extensive and severe disease than adults. IBD presenting in childhood interferes with growth, education and employment as well as psychosocial and sexual development, frequently delaying adolescent developmental milestones. Transition, in the context of healthcare, is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions to adult-orientated healthcare systems. Although no single model has been widely adopted and despite a paucity of data, recent guidelines from Europe and the USA propose the formation of specialist transition clinics for adolescent patients with IBD. In order to develop a successful transition service, the barriers that arise because of differences between paediatric and adult IBD services need to be identified. In this article, we review the concept of transitional care for adolescents with IBD, highlighting the important differences in not only, paediatric and adult IBD, but also paediatric and adult IBD services. We consider the consequences of failed transition, and describe the limited published data reporting different approaches to transition in IBD, before outlining our own approach. © 2011 European Crohn's and Colitis Organisation. Published by Elsevier B.V. All rights reserved.

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1. Introduction

The incidence of IBD presenting in children is increasing, more than 25% cases are now diagnosed under the age of 16.^{1–4} Inflammatory bowel disease (IBD) presenting at this age is more extensive and severe than in adults.^{5–9} It interferes with growth, education and employment as well as psychosocial and sexual development.¹⁰ Adolescents have traditionally been transferred from paediatric to adult care at the age of 16 regardless of their maturity, pubertal stage or growth velocity. However, following political directives stating that the transfer of care must be clearly defined and planned for all childhood illnesses,¹¹ and in response to lobbying by patient organisations, recent guidelines from Europe¹² and the USA^{13,14} recommend the formation of specialist adolescent transition clinics.

Although well developed in other chronic childhood diseases such as diabetes and cystic fibrosis, adolescent clinics in IBD are in their infancy. Here we review the concept of transitional care for adolescents highlighting the important differences both between paediatric and adult IBD, and also paediatric and adult IBD services. We discuss the barriers to seamless transfer and both our own and alternative models for transition care.

2. Adolescence and transition

2.1. Adolescence

Adolescence literally means to grow up and describes the period of pubertal, emotional and cognitive development

that occurs between the onset of puberty and adulthood.¹⁵ Physiologically, adulthood is defined by the acquisition of secondary sexually characteristics and fecundity, usually occurring between 11 and 15 years of age. Psychologically the onset of adulthood is more difficult to define and probably differs according to gender: girls typically mature at a younger age than boys. Early adolescence (10–12 years) is characterised by pubertal development, middle adolescence (13–15 years) by psychosocial independence and late adolescence (16–18 years) by the development of personal identity, life aspirations and goals, as well as ethical and moral values.^{16,17} In everyday terms, though, there is no age cut-off and different adolescent developmental milestones may be reached at different times.

2.2. Age-adjusted expectations in chronic disease

In early adolescence, individuals can be expected to describe their condition, to name medications and doses, to discuss the role of their family, teachers, peer groups and themselves in their care, as well as consider the impact of their disease on school attendance and academic aspirations. By the end of adolescence individuals should be capable of making informed therapeutic decisions; to be able to book and attend appointments and investigations; to maintain an awareness of their sexual fecundity and the need for contraception; and to plan ahead and use the service in a flexible way.¹⁶ In addition they are expected to take on the administrative roles previously carried out by their parents, which may include organising their own healthcare insurance¹⁸ (Fig. 1).

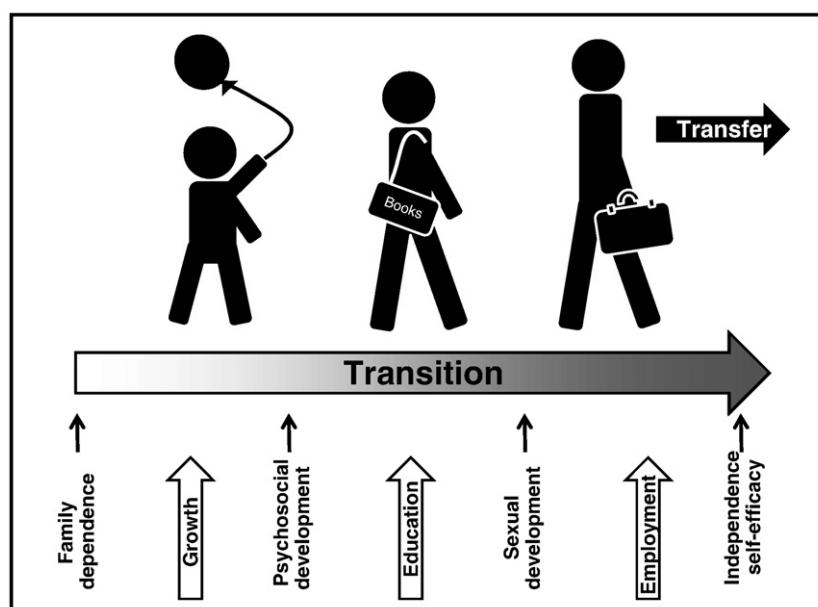


Figure 1 Adolescent milestones, transition and transfer of care. A schematic diagram that demonstrates the differences between transition and transfer with the milestones that patients may be expected to reach at each stage.

2.3. Defining transition and transfer of care

Transition, in the context of healthcare, can be defined as the purposeful, planned movement of adolescents with chronic physical and medical conditions to adult-orientated healthcare systems.¹⁹ Transition should be uninterrupted, coordinated and matched to the developmental abilities of the individual.¹⁷ Transfer is the point of handover to the adult healthcare team, and should be considered part of, and not necessarily the end of transition (see Fig. 1).

3. Childhood compared with adult onset IBD

Although beyond the scope of this review, there are important differences in the incidence, presentation, clinical phenotype and management of IBD between children and adults that need to be taken into account when planning an IBD transition service.

3.1. Incidence

The incidence of UC in the UK is 13.9/100 000 new diagnoses per year; Crohn's disease is less common with 8.3/100 000.²⁰ Overall more than 25% cases of IBD are now diagnosed under the age of 16.^{1,2} The paediatric incidence of UC in the UK is 1.3/100 000, and in contrast to adults, Crohn's disease is more common with 2.5/100 000 new diagnoses per year.²¹ However, more recent studies from Finland report a much higher incidence in paediatric clinics (CD 5/100 000, UC 9/100 000).³ Adult incidence rates in the UK appear to be stable,²² in contrast incidence rates in children are increasing,^{3,4,23} suggesting an increasing requirement for transition care in IBD in the future.

3.2. Phenotype

Data from well-designed adequately powered cohort studies confirm that children and adolescents with IBD are more likely to have Crohn's disease (CD) than ulcerative colitis (UC): both diseases tend to be more extensive and severe at diagnosis and more likely to extend in the first 3 years than in adults.^{5,6} Upper gastro-intestinal (GI) involvement is often cited as being more common in paediatric IBD than in adults.^{24–27} Unfortunately, little data is available for adults with IBD, as until recently upper GI endoscopy has not been routinely undertaken.

3.3. Presentation

Arguably the most important difference between adults and children with IBD is the potential for growth failure and/or pubertal delay. At presentation 10–40%^{28,29} of children have anthropomorphic evidence of growth failure in part due to anorexia and malabsorption but also resulting from a direct effect of intestinal inflammation.³⁰

3.4. Management

In view of the patients' age, disease extent at presentation and crucial relevance of growth and puberty in the adolescent with IBD, several management issues are specific to this patient population. Therapeutic strategies to induce remission which include corticosteroids can have a significant negative impact on growth velocity.²⁹ Therefore in Europe, an exclusive liquid diet is recommended as induction therapy for Crohn's disease to avoid the negative impact of steroids on growth.^{12,31} However, steroids remain the mainstay of induction therapy for 5-ASA refractory or severe, ulcerative colitis and for Crohn's disease in North America. In view of concerns regarding the impact of corticosteroids on body image, especially in teenage

girls,³² adult gastroenterologists may come across significant resistance to further courses of steroids, and patients who have already taken exclusive enteral nutrition may subsequently request it during relapse. The extensive disease at presentation and the potential long duration of IBD in adolescents often mandate early use of disease modifying immunosuppressive medications such as azathioprine and biologic therapy.¹² Furthermore, recent evidence in both CD and UC suggests that combination therapy with both a thiopurine and an anti TNF antibody is more effective than monotherapy with either agent alone (although these trials did not include patients under the age of 21).^{33,34} The potential side effects of this strategy such as opportunistic infections and malignancy need to be discussed with all patient groups. However, these risks are not equal in all age groups and the risk of opportunistic infections increases with age.³⁵ In contrast, the case reports of hepato-splenic T cell lymphoma in patients with CD receiving combination therapy suggest that this fatal complication is more common in young men.³⁶ In addition, medical and surgical strategies may impact on both fertility and fecundity which have particular relevance to adolescent patients.^{12,37} Thus both the benefits and the risks of individual therapeutic strategies are different in the adolescent compared to the adult patient.

3.5. Quality of life

IBD diagnosed during childhood leads to behavioural adaptations that interfere with psychosocial and sexual development, education and employment. Psychological adjustment not only to the diagnosis of a life-long disorder but also to the uncertainty of the relapse-remission cycle depends on an individual's coping resources.³⁸ Although the mechanisms underlying psychological distress and depression in IBD are complex,³⁹ longitudinal studies in adults,^{40,41} report a positive relationship with disease activity. The combination of intrusive gastrointestinal symptoms, corticosteroid exposure and the release of centrally active pro-inflammatory cytokines result in adolescents with IBD reporting poorer quality of life (QOL) scores and having a higher prevalence of psychological distress, in particular depression than unaffected peers.^{42,43} Unfortunately comparative studies between children and adults in IBD have not been undertaken, though it seems likely, given the extent and inflammatory nature of their disease, that adolescents will suffer more. Avoidant coping (where an individual distracts themselves with social diversion) to deal with stress, is more commonly employed by adolescents with IBD than their peers.⁴⁴ This behaviour may be associated with disease relapse in patients with quiescent disease.⁴⁵

Therefore, an adult gastroenterologist will inherit adolescent patients with complex and extensive disease, often with ongoing active inflammation that is refractory to medical treatments, not easily amenable to surgery, and frequently complicated by growth failure and significant psychological distress. The risks and benefits of individual therapeutic strategies differ for adolescent patients compared with the conventional adult population. Unfortunately traditional adult services are not well suited to serve this complex group of patients and when planning their care it is important to consider differences between paediatric and adult IBD services as they may lead to significant barriers to patient transfer (see Table 1).

4. Paediatric versus adult IBD services

4.1. Geographical constraints

Paediatric gastroenterologists caring for patients with IBD are usually clustered together in tertiary centres. In the UK, there are 26 such centres; 10 are linked to academic posts with access to novel drug treatments.⁴⁶ Traditional transition then, as well as being ideological is often geographical with adolescent frequently being discharged back to their local referral centre at 16.

4.2. Specialist skills

Adult gastroenterologists have different skill sets to paediatricians; few have been trained to assess growth velocity or to evaluate pubertal stage, and when questioned only about half felt competent to do so.⁴⁷ In non-academic centres, IBD patients are commonly seen in general gastroenterology clinics, and often by physicians without a sub-specialty interest in IBD. In a UK national questionnaire survey, paediatric gastroenterologists highlighted a lack of interest and specialist training in the receiving adult gastroenterologist as a significant barrier to transition.⁴⁸

4.3. Outpatient services

There are also marked differences between paediatric and adult outpatient clinics that children diagnosed with IBD need to adapt to during the transition to adult care. Paediatric clinics are typically family-focused; appointments are more frequent and typically longer than permitted in adult care. A multidisciplinary approach, including specialist nurses, dieticians, clinical psychologists, pharmacists and the medical team are usually available. Multidisciplinary clinics, by contrast, are less well established for adults, at least in the UK.⁴⁶

4.4. Inpatient and endoscopy services

Inpatient infrastructure is vastly different between paediatric services, where wards are age-specific, compared with adult services where the majority of patients are elderly. This is a serious issue for young patients admitted to the adult wards for the first time. In addition, their parents may not be allowed to stay overnight on the ward with them as they had been used to whilst in the paediatric service. Finally, most endoscopic investigations are performed under general anaesthetic in children. In contrast, the vast majority of adult procedures occur under conscious or no sedation, which may alarm many adolescents.

4.5. Diagnostic radiation

Since IBD runs a relapsing and remitting course and requires repeated endoscopic and radiological evaluations, patients are frequently exposed to high levels of diagnostic radiation. A retrospective cohort of 409 patients with Crohn's disease,⁴⁹ identified age at diagnosis under 17 years as a specific risk factor for exposure to more than 75 mSv of diagnostic radiation (equivalent to three abdominal CT scans), a level

Table 1 Differences between children and adults, and paediatric and adult services in disease type, ideology of care, service provision, approach to investigations, lifestyle and psychological distress that create barriers to successful transition and transfer in IBD.

	Children and paediatric services	Adults and adult services
IBD	More CD Extensive and severe UC and CD Limited disease duration (less than 5 years) Disease course modification Exclusive enteral diet main induction treatment in CD Body image concerns limit surgical options	UC = CD Frequently limited and 'burnt-out' disease Often longer disease duration Management of flares and complications Prednisolone main induction treatment in CD 80% patients undergo surgery by 10 years
Ideology	Family-focused Limited disease specific knowledge Parental decision making Passive role with little autonomy Lengthy appointments	Patient-focused Well-informed Individual decision making Autonomy allows self-directed appointment booking, nurse or telephone follow up Business like, short appointments
Service	Multidisciplinary approach Consultants with IBD subspecialty training Tertiary centres Access to research trial drug treatments High quality and age specific treatment areas	Consultant led Majority general gastroenterologists limited subspecialty training Local hospitals Variable access to drug trials Variable quality and not age specific treatment areas
Investigations	Diagnostic tests frequently conducted under GA High risk of radiation induced malignancy (USS/MRI) Ability to screen for pubertal delay and growth failure Oral and upper GI complications	Diagnostic tests with conscious or no sedation Radiation risk probably less Limited knowledge of developmental delay and or growth failure Surveillance for secondary conditions (cancer/osteoporosis/anaemia)
Lifestyle	Sexual experimentation Cigarette/alcohol/drug experimentation Exam pressures Employment/higher education demands	Awareness of fecundity, contraception and family planning Smoking cessation Career progression Becoming a parent
Psychological distress	Anxiety and depression common Suicide more common general population	Association with active disease

that reportedly increases the risk of a cancer related death by 7.3%.^{50,51} It is conceivable that seeing patients in a young adult clinic where physicians are used to re-investigating patients may reduce cumulative exposure to diagnostic radiation. In support of this, our own comparative study demonstrated that adolescents received no more diagnostic radiation than adults matched for disease duration, despite having more extensive and severe disease. In addition they were more likely to have been investigated with MRI than adults.⁷

4.6. Psychological support

Cognitive behavioural therapy (CBT) aims to modify coping strategies, improves mood and quality of life (QOL) scores and may improve the clinical course of IBD itself.^{52,53} About one third of adult IBD patients would like access to

psychological support⁵⁴ however this treatment is offered in only 2% of UK IBD centres.⁴⁶ This is partly because of a perceived lack of benefit by adult gastroenterologists, but also because CBT requires multiple, often inconvenient and not inexpensive visits to a therapist. In contrast child psychologists are an integral part of the paediatric multi-disciplinary team, and although not evidence based are recommended as part of the transition setup.

No studies have been designed to assess the experience of young people during transition in IBD. Extrapolations of results of studies using qualitative methods from other chronic medical disorders including; cystic fibrosis,⁵⁵ juvenile diabetes⁵⁶ congenital heart disease (CHD),^{57,58} sickle cell anaemia⁵⁹ and organ transplantation recipients^{60,61} need to be interpreted with care due to the differences in associated mortalities and disease course. However, the obstacles to transition identified in these studies are thought to be generic and likely to exist in IBD.¹⁷

5. Generic barriers to transition

Paediatric caregivers are often reluctant to relinquish their patient's care: about a third of paediatric diabetes centres and cystic fibrosis units reportedly continuing to care for patients over the age of 25.^{62,63} Similarly, qualitative data suggest that children and their parents are frequently reluctant to break the familiar relationship with their paediatrician who they have often known since diagnosis,^{56,57,60,61} and report anxiety about joining a new healthcare team that are not appropriately informed of their history.^{55,60,64} In particular, patients with cystic fibrosis and their parents reported frustration at the inflexibility of the legislatively determined age of transfer.⁵⁶ Adolescents frequently criticised the lack of information provided,^{56,57,60} and suggested opportunities to meet new healthcare teams and visits to adult-oriented venues prior to transfer as a way of improving the transition process.⁶⁴ One qualitative theme identified in several studies was that teenagers like being treated as adults, and prefer healthcare staff to address them instead of their parents.^{60,61,64} In this young age group few adult or paediatric gastroenterologists directly address the issues of social drug use or safer sex relationships. Data from transplant recipients suggest that teenagers would value this information though do they not want to ask directly for it.⁶⁰

5.1. Disease specific knowledge

To pursue employment and fulfil education commitments adolescents with IBD, like those with other chronic illnesses⁵⁶ are often highly mobile and frequently change their address and treating physician. Adolescent patients have been criticised by adult gastroenterologists for not taking an interest in their disease or responsibility for their own care. Recent data from Toronto suggests that this pejorative opinion is justified.⁶⁵ Only 22% of adolescent patients could recall the location of their disease and only 55% could recall when they were diagnosed. Perhaps more surprisingly, their parent's knowledge was not significantly better, although they could recall which insurance company was paying for the care. Although little data suggests that disease specific knowledge influences disease activity or rates of relapse,³⁹ it is crucial for adult gastroenterologists who need to make treatment decisions based on previous history. In order to improve lines of communication between different treating physicians and as part of the 'The Good 2 Go Transition Program' established at the Hospital for Sick Children (SickKids) in Toronto,⁶⁶ a handheld synopsis of their condition, called the MyHealth passport⁶⁷ has been developed for adolescents. This simple card details the pertinent IBD history and fits into a wallet, it remains to be seen whether adolescents will use these or other, for example electronic reminders and whether they improve knowledge, drug adherence, or clinic attendance.

6. Consequences of failed transition

Transition aims to educate the patient and their parents so that they are ready for transfer to adult services and to ensure that the ongoing healthcare provider is sufficiently informed about the past and current problems so as to

provide continuity of care. An inadequate transition process results in delayed and inappropriate care, improper timing of transfer, and undue emotional and often financial stress for patients, their families, and the health care system.⁶⁸ Non-specific measures such as lost to follow-up, admission and medication non-adherence rates can be used as surrogate markers to assess the efficacy of transition services.

6.1. Lost to follow-up rates

More than 90% children born with congenital heart disease (CHD) survive to adulthood.⁶⁹ Surprisingly, 75% are not followed up in adult life, despite the increased risk of morbidity associated with endocarditis, secondary pulmonary hypertension, arrhythmias and cardiac failure.^{69,70} A study of 300 adolescents with CHD identified 'perceived importance of follow up', disease severity, older age, independent paediatric outpatient visits, a lack of substance abuse and adherence to antibiotic prophylaxis as factors predictive of successful transfer.⁷¹ To our knowledge there is no population data available to support a similar 'lost tribe' of young patients with IBD.⁷²

6.2. Admission rates

Further evidence that adolescence is a vulnerable time in patients with chronic diseases, comes from a study of patients with CHD using insurance database records demonstrating that the proportion of patients admitted via the emergency department nearly doubled at the time of transfer to adult care.⁷³ Similarly, in a recent study of adolescents with diabetes, hospitalisation rates increased from 7.6 to 9.5 cases per 100 patient-years in the 2 years after transfer to adult care. Previous DM-related hospitalisations, lower income, female gender, and living in areas with low physician supply were associated with higher admission rates. In support of stable transition care, individuals who were transferred to a new allied health care team with no change in physician were 20% less likely to be hospitalised after the transition than were those transferred to a new physician with either a new or no allied health care team.⁷⁴

In our own study of adolescents with IBD 'Did not attend' (DNA) rates and hospital admissions were significantly greater in the adolescent than matched adult group.⁷ School, university and employment commitments may make daytime clinic appointments inconvenient, and patients may not appreciate the need for regular follow up especially when their condition is inactive. What is not clear from our admission data is the extent to which the increased admission rate in adolescent patients reflects severity of disease versus difficulties in accessing adult care services.

6.3. Adherence

Adherence is defined by the WHO as the extent to which a person's behaviour (taking a medication, following a diet, and/or executing life style changes) corresponds with agreed recommendations from a health care provider.⁷⁵ Evidence from other medical disciplines suggests that adherence to medications during transition is variable. Adolescent transplant patients have non-adherence rates (defined using

variability of serum immunosuppressant levels) of up to 70%.⁷⁶ Likewise adolescents with diabetes show a reduction in glycaemic control as assessed by glycosylated haemoglobin (HbA1c) levels at the point of transfer to adult care.^{77,78} The factors underpinning adherence to IBD medications are complex and poorly understood. Time constraints, medication side effects, poorly controlled disease activity and the perception that the drug is not working,⁷⁹ as well as simply forgetting have been cited by adolescents with IBD and their parents as reasons for non-adherence in IBD.⁸⁰ In contrast, factors that predict good adherence include shorter disease duration, greater maternal involvement in the medical regimen and higher perceived disease severity.⁸¹ In keeping with this we have reported better apparent adherence to thiopurine therapy in children and than adults in two different case-controlled studies.^{7,82}

7. Supportive evidence for structured transition

Whilst unproven, it is postulated that transition programmes that inform patients about the rationale for ongoing follow-up and teach them how to navigate the medical system may avoid unnecessary admissions and improve adherence.⁷² To date, no large scale prospective study has compared outcomes of transfer, with or without a structured transition programme in IBD.¹⁴ However, a pilot educational programme for adolescent liver transplant recipients reported a significant reduction in the previously documented variation of serum immunosuppressant levels in association with a reduction in elevated liver enzymes.⁸³ Likewise, structured transition in diabetes has been reported to improve glycaemic control.⁷⁸ In addition to a significant reduction in HbA1c, specialist nurse transition facilitators that coordinate outpatient visits and telephone based education reduced both the number and duration of admissions for diabetic keto-acidosis.⁸⁴ Finally, an age-adjusted structured transition programme improved QOL in both patients with juvenile arthritis and their parents.⁸⁵

8. Approaches to transition in IBD

In order to develop a successful model for transition in IBD, one must take account of differences in maturity, disease phenotype between childhood onset and adult onset IBD and the services provided for the different age groups.⁸⁶ Unfortunately the lack of comparative studies means that no specific model can yet be recommended.

8.1. Types of transition reported in IBD

The simplest method of transfer is the use of a detailed handover letter or discharge summary. Although inexpensive, anecdotal reports suggest that this form of abrupt transfer causes unnecessary harm, insufficient confidence in parents and frustration in the adult gastroenterologist.⁸⁷ Limited uncontrolled data suggest that a single one-hour joint clinic where paediatricians introduce the adolescent to the adult team and handover care in detail is sufficient with 85% patients and 74% parents reporting being ready to transfer.⁸⁸ Similar positive feedback has been reported by

patients attending several joint-run clinics.⁸⁹ However, there are relatively few paediatric gastroenterologists and most are clustered together in city teaching hospitals. One solution might be to create a managed clinical network ensuring that clinicians can have the appropriate training and facilities to care for this age group as close to home as is possible.

8.2. Timing of transfer

Not all patients psychologically adapt to IBD in the same way, some will be mature enough to transfer at 16, but others may need to stay in transition care much longer. The factors determining the timing of transfer are outlined in Table 2. Wherever possible the timing of transfer to adult services should be adjusted to the maturity of the individual. Unfortunately not all healthcare providers allow this flexibility and insist upon transfer at a predefined chronological age.⁹⁰ As in juvenile rheumatological disorders,⁹¹ independence/self-efficacy scales have been developed, but not yet validated in paediatric IBD ('IBD-yourself').⁹² In the future, these psychometric tools may allow an objective measurement of maturity to determine when transfer is most appropriate.

8.3. Transition at Barts and the London NHS Trust

Barts and the London NHS Trust in the East End of London is a tertiary centre for adult and paediatric IBD, providing care to about 2500 patients. In 2004, we instigated a weekly multidisciplinary meeting with adult and paediatric gastroenterologists, surgeons and allied health care professionals in attendance where complex cases are discussed to allow input from adult physicians into decisions on children who would shortly transfer to their care.⁹³ Alongside this 3 monthly stand alone transition clinics where adult IBD specialists sat in clinic with paediatric colleagues were initiated.

In 2005, following the publication of 'National Standards Framework (NSF) for Children, Young People and Maternity services' which stated that transition must be clearly defined for all children with chronic illnesses in the UK,¹¹ we set up a regular joint outpatient clinic. In brief, a paediatrician and

Table 2 Adolescent and disease specific milestones that determine the 'ideal' timing of transfer to adult care.

Determinant	Ideal
Chronological age	Between 16 and 25
Maturity	Mature (role self-efficacy scales)
Independent in health care	No longer reliant on parents
Self-advocacy	Ability to make informed decisions
Preparation	Knowledgeable
Readiness	Comfortable with adult care team
Availability of adult specialist	Specialist interest in adolescent IBD
Current medical status	Clinical remission
Adherence to treatment	Adherent even in remission

paediatric specialist IBD nurses attend a bi-weekly joint clinic for adolescents with IBD with an adult gastroenterologist. Our patients are seen by either an adult gastroenterologist or a paediatrician, with trainees from both specialties in attendance. The clinics run at the same time as our biologic infusion clinic and there is also access to a dietitian and psychologist (Fig. 2).

This approach yields benefits for the patient as well as the paediatric and adult gastroenterologist. For the patient, continuity of care is seamless: patients attend clinic albeit held in adult outpatients where they see familiar faces, including their paediatric IBD specialist nurse, who co-ordinates transition care. Furthermore as there are many other patients in clinic of a similar age, patients can appreciate that 'they are not alone' and mentors are easily identified. For the paediatric gastroenterologist, this extended period of transition care reduces the importance of transfer during a period of remission as they can continue the care of adolescents whilst gradually introducing them to the adult service. In addition, paediatricians are able to see the future impact of management decisions made in the paediatric clinic and can become more familiar with the decision making process in adult gastroenterology to inform the expectations of subsequent patients. The key advantages of this approach for the adult gastroenterologist is that it increases understanding of the paediatric approach to decision making and allows sufficient time to become familiar with several years of medical history during paediatric follow up. We have found too that it stimulates research and recruitment to clinical trials.

In the last 5 years during which we have cared for 500 adolescents in this clinic, feedback from the children and families has been very positive. Not all patients wished to be

seen in the transition clinic preferring to immediately attend a more local provider. In general these were patients with relatively mild and easily controlled disease, those with the more severe disease were reassured in attending a specialist adult IBD clinic at least until they had completed their education or had settled in work. In terms of the provider this is regarded as an adult clinic. What has made this most effective and achievable is the co-localisation of large paediatric and adult IBD services on one site, the IBD nurse specialist crossing the adult and paediatric settings and the very close working relationship of the adult and paediatric gastroenterologists. For young patients with chronic disease we would argue this is the ideal scenario. Many paediatric units are in standalone Children's Hospitals separate from adult services and so setting up of such clinics is much more difficult to achieve. In these circumstances managed clinical networks may ensure similar levels of care.

9. Conclusions

IBD diagnosed during childhood and adolescence is becoming increasingly common and the disease itself tends to be more extensive and severe than in adults. The adult gastroenterologist inherits a group of patients many of whom may have ongoing active inflammation, with extensive disease, that is frequently refractory to medical treatments and may not be amenable to surgery. High quality evidence guiding therapeutic decisions in this setting is often lacking as most studies in IBD are conducted in adults. Differences in paediatric and adult services create significant barriers to seamless transfer of care, which need to be taken into account when planning transition services. Although increasingly more approaches to transition are being described, cost-benefit analyses are required to determine the best model for transition care and its optimal timing. Extended transition clinics facilitated by a specialist IBD nurse, like the one we have devised, although not evidence-based are conceptually attractive, since they allow time for adolescent patients to adjust to their new adult gastroenterologists whilst concurrently seeing their paediatrician.

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Figure 2 Facilitators of extended transition in IBD. A schematic diagram that highlights the importance of multi-disciplinary care in adolescent patients with IBD undergoing transition. This can be used to explain the roles of members of the multidisciplinary team to patients and their parents in clinic.

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