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ECCO Topical Review

European Crohn's and Colitis Organisation Topical Review on Transitional Care in Inflammatory Bowel Disease

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Abstract

Background: This European Crohn's and Colitis Organisation [ECCO] topical review focuses on the transition of adolescents with inflammatory bowel disease [IBD] from child-centred to adult-oriented care. The aim was to provide evidence-supported, expert consensus for health professionals taking part in the transition.

Methods: An online survey determined the areas of importance for health professionals involved in the transition of adolescents with IBD. Thereafter an expert panel of nine paediatric and five adult gastroenterologists was formed to identify the critical elements of the transition programme, and to prepare core messages defined as 'current practice points'. There is limited literature about transition, therefore this review is mainly based on expert opinion and consensus, rather than on specific evidence.

Results: A total of 21 practice points were generated before the first [online] voting round. Practice points that reached >80% agreement were accepted, while those that did not reach 80% agreement

were refined during a consensus meeting and subjected to voting. Ultimately, 14 practice points were retained by this review.

Conclusion: We present a consensus-based framework for transitional care in IBD that provides a guidance for clinical practice.

Key Words: Transition to adult care; inflammatory bowel diseases; ulcerative colitis; Crohn's disease

Terminology

“Transition” is defined as the purposeful, planned movement of adolescents with chronic medical conditions into adult-orientated health-care systems.¹ “Transfer” is defined as the point of handover of care to the adult health-care team, and should be considered part of [and not necessarily the end of] transition.²

1. Introduction

In late 2015 the Paediatric Committee of the European Crohn's and Colitis Organisation [P-ECCO] performed an online survey among ECCO members to examine current practices in transition. The survey was completed by 96 health professionals, of which 61% were working in paediatric care. Almost 40% of respondents did not perform a formalized transition process, merely writing a detailed summary letter to the adult gastroenterologist [see supplementary material 1].

It is not a surprise that transition from paediatric to adult-centred services is often poorly prepared, which can result in negative consequences for those involved [see clinical vignette]. There is no uniform model for successful transition, despite experts believing that a transition programme enabling an increasing responsibility for health management is important. Many papers have been published on transition in inflammatory bowel disease [IBD], but none has transcended beyond the evidence level of a single centre. There is currently no standard that can guide clinicians how to organize and run a transition clinic. This led ECCO to commission a topical review consensus group on transitional care in IBD. Following an open call among ECCO members in January 2016, 14 participants were selected, including 5 adult gastroenterologists and 9 paediatricians. The aim of the Consensus Group was to identify critical elements for the transition programme and to prepare core messages as “Current Practice Points”.

ECCO Current Practice Position 1A

Participation in a transition programme empowers adolescents by equipping them with knowledge and skills to manage their own IBD

Five working groups were formed, with each focused on a topic—current attitudes to transition, skills needed for successful transition, models and timing of transition, professionals to be involved, and continuing care after transition. The working groups searched for studies with appropriate keywords, published in Medline, Embase, and the Cochrane Library, and they restricted their search to studies published in English. A total of 21 provisional practice points were generated initially. Practice points that reached >80% agreement during online voting were then considered as final. The others were refined during a face-to-face consensus meeting in Vienna on October 15, 2016 and then subjected to a vote. Seven provisional practice points were ultimately rejected. The remaining 14 practice points appear in this document.

Clinical vignette

An 18-year-old adolescent visits the adult gastroenterology department for the first time accompanied by his mother. His paediatrician last saw him 5 months previously, when his Crohn's disease was in remission [with a Paediatric Crohn's Disease Activity Index score of 5]. He was diagnosed aged 16, since which time he has had two disease flares. Each flare was successfully treated with exclusive enteral nutrition for 6 weeks, followed by a return to a normal diet. According to the paediatrician's notes, the patient is receiving thiopurine maintenance therapy.

At the appointment, the patient says he is well and active. He claims to have no abdominal pain and a normal bowel habit. At this point, his mother interjects and claims this is not true. She states that her son is often in bed and she is afraid that he will fail his final school exam. Physical examination reveals a pale teenager who appears younger than his chronological age. Laboratory evaluation reveals anaemia, a C-reactive protein of 65 mg/L and a faecal calprotectin of 2500 µg/g. Additional testing reveals undetectable levels of thiopurine metabolites. The boy admits that he has stopped taking his medication and that he feels major symptomatic benefit since he started smoking marijuana.

Possible therapeutic options to treat the current disease activity are discussed. The adult gastroenterologist recommends biologic therapy. The mother states that she wants an opinion from their former paediatric gastroenterologist.

2. Current Attitudes

Transition is recognized increasingly as an important part of the clinical care of adolescent IBD patients. The optimal way to organize transition and transfer patients to adult care is not defined. A good starting point is to focus on the attitudes of the participants involved in the transition process (i.e. patient, caregiver[s], and paediatric and adult health-care providers). Recent published reports of surveys, questionnaires and focus group interviews of those involved usually report low response rates [mostly <30%]. Attitudes towards knowledge, skill and transition readiness, towards age at start of transition and at transfer, and towards potential barriers to successful transfer were relatively similar across studies from North America, Australia and Europe.

ECCO Current Practice Position 2A

IBD patients taking part in a transition programme are likely to have better compliance and less adverse outcomes after transfer to adult care compared with those who do not take part

A retrospective study from Canada reviewed the charts of 95 patients with IBD, a year before until a year after transfer to adult care. None of the study cohort took part in a formal transition programme. The researchers reported that after their transfer, patients had less outpatient visits and higher rates of non-compliance compared with their time in paediatric care. No difference in rates of surgery, emergency visits, or hospitalization were observed.³ A research group in England compared a cohort that took part in a transition programme with a historical cohort without formal transition arrangements, and found higher rates of non-compliance, hospitalization, clinic non-attendance, growth failure, opiate use and surgery in the historical cohort.⁴ These two studies indicate that taking part in a transition programme before transfer to adult care has the potential to impact positively on subsequent health-care resource utilization.

ECCO Current Practice Position 2B

Transition in IBD is a continuous process involving the patient, parents, and paediatric and adult health-care providers

ECCO Current Practice Position 2C

Patients, parents, and paediatric and adult health-care providers may have different attitudes towards transition. It is important to identify and harmonize these attitudes in advance

The various participants in transition may have differing views on the process.⁵ Adult as well as paediatric gastroenterologists report inadequacies in their knowledge, yet most agree that the process is important.^{6,7} Gastroenterologists focus on the reliable transfer of medical information.⁷⁻⁹ Patients fear changing to a new medical team and report that issues such as psycho-social aspects of care are easily neglected.¹⁰⁻¹² All participants involved in transition feel that a structured approach is the best way to harmonize divergent attitudes.¹²

3. Towards a Skills-based Transition Plan

Previous studies have shown that adolescents and young adults with IBD lack important knowledge of their condition [including disease extent and duration, medication regimen, side effects of medication, surgical history] and lack experience in self-care [including filling prescriptions and scheduling appointments].¹³⁻¹⁶ Paediatric and adult gastroenterologists have identified this lack of self-management as a barrier to successful transition.⁸ Without appropriately validated tools to assess “health literacy”, paediatric gastroenterologists may overestimate the readiness of their patients to transfer their care to adult gastroenterologists.¹⁶ In addition, parents can be reluctant to relinquish responsibility for decision-making as their child matures, despite the adolescent becoming more independent.¹² Despite this, parents are also likely to overestimate their child’s health-related knowledge. Patients’ self-reported health efficacy appears to improve with age, but not necessarily with disease duration.¹³ Despite the fact that any transition programme is by definition targeted at young patients with IBD, there has been limited involvement of these patients and their parents in the design and development of such programmes. Thus, there is a strong mandate to conduct needs assessments with these populations to learn about their concerns and expectations.¹²

There is widespread agreement that as part of the transition process adolescents need to acquire the self-management skills necessary

ECCO Current Practice Position 3A

The skills for successful transition comprise disease-specific knowledge, self-efficacy and decision-making

to function independently of their parents in order to be ready to transfer to an adult health-care system.¹³ First, patients should possess appropriate disease-specific knowledge. This is likely to include an understanding of their diagnosis and previous medical history; knowledge of their current medication and response; side effects from previous medications; an understanding of the value and role of procedures for monitoring their disease; an appreciation of the concept of a disease flare; and knowledge as to how to obtain further information about IBD. Thus, it is critically important for health-care professionals to educate patients about their disease and health-care needs. In addition to being supported to undertake self-directed learning, the patient should be encouraged to ask questions such that they participate actively in their care. As well as acquiring appropriate disease-specific knowledge, it is essential that patients develop self-efficacy, which is the ability to organize and implement a pattern of behaviour necessary for health promotion. Self-efficacy skills are likely to include the ability to monitor symptoms and report them to a health-care professional, to manage their medication and maintain adherence to the prescribed regime, to recognize and understand how to handle a disease flare, and to work in partnership with health-care providers. The patient needs to be able to demonstrate the skills necessary to navigate and communicate with the health-care system, such as making appointments and filling prescriptions. Self-efficacy skills may also include handling financial issues and arranging transportation to and from hospital. Finally, the patient should be involved in decision-making to learn making informed and ideally healthy choices and to act with self-advocacy.¹⁷⁻²⁰ Acquisition of these skills is not likely to occur in a single encounter, but rather should be a step-wise program, facilitated by an age-appropriate checklist of tasks by which the patient and the medical team can monitor progress.²¹

ECCO Current Practice Position 3B

The education of patients should be age-appropriate and addressed from at least 1 year before transfer

Awareness around transition for providers of paediatric health care alone is not sufficient for increasing patients’ disease knowledge.²² Educating patients is as important as educating providers, and this should be addressed throughout the period of transition [from age 12 onwards]. Education of patients is particularly important in the year preceding transfer to adult care. Developmental maturity has been identified as a key component of transition success; thus psycho-social difficulties, communication challenges with health-care providers, and motivational problems may present barriers to successfully achieving the requisite educational objectives.²³ Hence, the focus of education should be adapted so that it is appropriate for the patient’s age as well as for their emotional and cognitive maturity. This should promote self-reliance and independent behaviour.^{21,24,25}

IBD-related education must be reinforced by repetition, with concrete examples provided to emphasize particular issues. It is important to establish an environment in which adolescents feel comfortable posing questions and revealing their knowledge gaps. A supportive environment for education throughout transition is essential if crucial issues such as the influence of smoking, alcohol, and drugs, the consequences of non-adherence, and issues related to sexuality and reproduction are to be covered.¹⁷

Sexual development and maturation may be delayed in adolescents with IBD. It is important for the patient and their families to understand the alterations in normal physiological sexual development that may be caused by their chronic disease. Parents should be encouraged to discuss the topic.²⁶ Issues around sexuality are very important at a time when individuals are commonly transitioned to adult care. Counselling is important to avoid unintended pregnancy, reduce pregnancy-related complications, and to optimize disease control for any planned pregnancy.²⁷

There is no approved template that details how to deliver the education required for successful optimized transition of a young IBD patient to an adult clinic. Transition workshops may provide aspects of this information,²⁸ but several alternative approaches to enhancing disease knowledge and self-management skills have been assessed. The use of technology to inform patients about their disease and involve them in ongoing disease assessment is a common theme from these studies.^{29,30} For example, a transition intervention for chronic disease [MD2Me] has been tested in a number of chronic diseases, including IBD.²⁹ This intervention uses technology-based communication between the health-care team and patient [web- and text message-based intervention] to enhance access to the health-care team and to provide disease management and skills-based interventions. In a randomized controlled trial, this has been shown to improve health-related self-efficacy, enhance disease self-management and increase patient-initiated communication. However, no beneficial impact was demonstrated in measures of quality of life, functional performance or disease status.

ECCO Current Practice Position 3C

Validated assessment of a patient's progress through transition, and the impact of targeted interventions, should occur throughout transition and be reassessed as required

The appropriate use of assessment tools can quantify progress through the educational goals of transition. For example, use of a transition readiness questionnaire can identify patients at risk of non-adherence, who may benefit from targeted specific educational and organizational interventions.³¹ The impact of any intervention should be reassessed throughout transition to confirm its effectiveness. Finally, the patient's health literacy and readiness to undergo transfer to adult care should be assessed using a validated tool.

Evidence-based tools have been designed to assess:

- (1) A patient's disease-specific knowledge: 'IBD-yourself',¹⁴ 'MyHealth Passport for IBD',¹⁵ the 'IBD-KID' questionnaire,³² and the interactive iPad™ quiz 'The Emma iPad Game'³³ [although this has not been validated];
- (2) A patient's generic self-efficacy for transition, including the 'Transition Readiness Assessment Questionnaire' [TRAQ]³⁴ and 'The Successful Transition to Adulthood with Therapeutics' [STARx]^{35,36};
- (3) A patient's self-efficacy around self-management, 'The IBD Self-Efficacy Scale' [IBD-SES].^{37,38}

Although many of these tools have been validated, adaptation may be needed according to differences in culture, language and health systems.

One aim of transition is to decrease the role of the parent[s] in disease management and to devolve those responsibilities over time to the patient, as their education and self-efficacy increases. Parents often feel insecure handing over responsibility for treatment decisions

ECCO Current Practice Position 3D

Education of parents to devolve responsibility for disease management to their child is desired

and may not trust the adult care team. Also, they may experience a profound sense of loss when asked to leave their familiar paediatric team, who have usually been a source of support and guidance over several years.²⁰ Parents need to be encouraged to have confidence in their child's expanding self-management skills, and to be reminded that any intervention designed to build independence should be supported and continued at home. Therefore, a crucial role for the transition team is to prepare the parents for handing over the management of the disease to their child and ensure that the parents are comfortable and secure with the process of transition.^{17-19,25} In practice, this can often be facilitated by seeing the patient alone for part or all of the clinic consultation, prior to transfer to adult services.

4. Models and Timing of Transition

Although the starting and end points of the physical transition are clearly demarcated, from the beginning of rapid growth to reaching final height, the boundaries for psychological transition are less clear. At the age of 18 years, adolescents vary greatly in their resolution of inner conflicts regarding autonomy and self-esteem. Most adolescents have not yet completed their own psychological transition to adult behaviour at the time of transfer to adult services. A step-wise training program [see section 3] will help the adolescent patient acquire the minimum set of skills needed to function effectively in the new, adult health-care setting.^{4,18,39-42}

ECCO Current Practice Position 4A

A joint paediatric-adult clinic, as part of a transition programme, is considered the ideal model

Although there is no evidence that one particular model of transitional care is more effective than others, certain components are considered essential, including opportunities to be seen independently from parents or caregivers. Rather than advocating a universal model, we recommend that each institution adapts a model that is optimal, including consideration for the geographical location of the paediatric and adult care teams. Limited data suggest that a single joint appointment with both teams present facilitates the transmission of information from the medical records to the new gastroenterologist, and enhances confidence in the new care team.⁴³ In situations with paediatric and adult services on the same site, a combined clinic throughout the transition process is usually undertaken [or at least one to two joint meetings occur shortly before the actual transfer]. In situations where IBD care is continued at a different location, at least one joint meeting in the familiar [paediatric] environment and a second in the new [adult] environment will probably improve transfer outcome. When this is not feasible, transfer will rely heavily on a written handover, with the transition process being exclusively monitored by the paediatric team. Even so, we consider it the joint responsibility of both the paediatric and adult team to specify a checklist of minimally required transition skills and to address any observed deficiencies to ensure they have been attained.

Transition is best initiated in early adolescence, ideally officially announced during a planned face-to-face encounter with a member of the paediatric IBD team. A formal, written transition checklist

specifying tasks for all those involved could form part of the patient’s medical record at the start of the transition process.

The ideal duration of a transition program has not been assessed. The sooner the program is started, the more likely the patient and his/her family will move through the process at an appropriate pace for both them and their health-care providers. Many authors agree that transition milestones should be assessed several times during the process, in order to recognize and repair knowledge and skills gaps.^{31,44–46} When a failure is observed in acquiring transition-readiness skills, re-evaluation of the initial transition checklist is warranted; it may be necessary to increase the frequency of visits to the IBD clinic or delay the time of the planned transfer to adult services until transition readiness is complete or is at a point beyond which improvement is not possible.

In many European countries and Canada, the transfer of care is at the age of 18 years, while in the USA this is frequently delayed till the age of 21 years or even up to 25 years.¹⁸ As explained already [Introduction section], the transition process does not necessarily end with transfer to adult care. Some patients and/or caregivers may need additional support to complete specific transition tasks, which should focus on optimization of the patient’s self-management skills. In addition, the paediatric team should be available to the adult team as a resource for information or assistance during the immediate post-transfer period.

ECCO Current Practice Position 4B

Transfer to adult-oriented care preferably occurs during stable remission

The transfer is preferably done during times of stable remission. For patients who are diagnosed with IBD during late adolescence, an accelerated transition programme should be offered. Adolescents with significant learning difficulties should also be prepared for adult services, as far as possible, while at the same time supporting their carers through the transition process, using the same transition plan.⁴⁷ These patients may require a longer period of transition.

ECCO Current Practice Position 4C

Transfer to adult services requires a handover letter written by the paediatric team

A detailed handover letter or discharge summary should be written by the paediatric team prior to the transfer to adult-oriented care. It is a means of communication between the paediatric and adult services, which is particularly important if joint clinics are not part of the transition process.⁴⁸ A handover document is distinct from the transition checklist in that it does not stipulate transition readiness but rather summarizes the patient’s disease type, drug and surgical history, and the current clinical situation. In addition, the handover letter can be used to document future care, including the infusion schedule for biologic therapies. Some hospitals have developed a patient passport, which contains similar information to the handover letter. Adolescents should be encouraged to complete the passport themselves, with the assistance of a transition coordinator [section 5]. This process should start early enough to form part of the discussions with the adolescent and their carers. Filling in the passport promotes patient-driven learning and empowers the patient to take on the care of their disease, and so complements the information passed over in a formal medical letter.¹⁵

5. Professionals to be Involved

ECCO Current Practice Position 5A

The most commonly recommended transition models in IBD are based on a collaborative approach between paediatric and adult IBD teams [including gastroenterologists and IBD nurse specialists]

ECCO Current Practice Position 5B

The transition process is best coordinated by a key accountable individual, usually a paediatric IBD nurse

ECCO Current Practice Position 5C

Individual requirements may necessitate the involvement of other professionals, e.g. psychologists, social workers, and surgeons

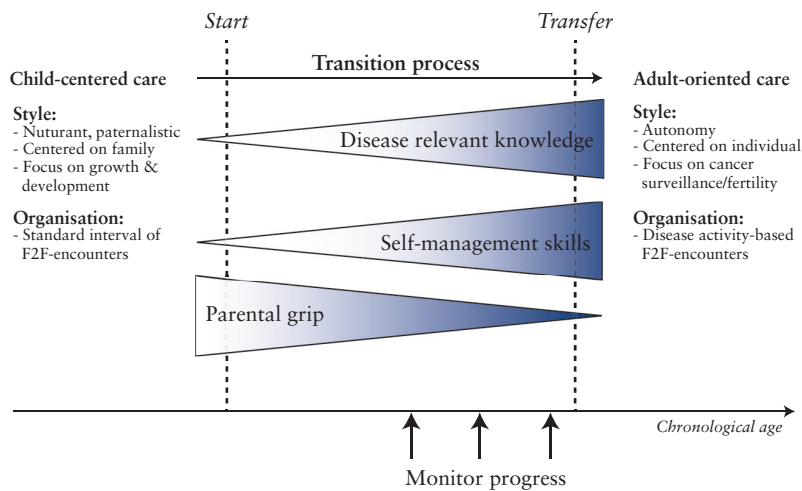


Figure 1. Conceptual model of transition from child-centred to adult-oriented care. The transition process should not end with transfer to adult care. F2F: face-to-face.

There are relatively few studies addressing the key professional stakeholders that need to be involved during a successful transition process. The consensus group agreed that representatives from both the paediatric and adult IBD teams [gastroenterologists as well as IBD nurse specialists] should participate in the transition programme. The paediatric team is primarily responsible for the assessment tools that identify progress through the educational goals of transition. Adult care providers often feel incompetent, having sub-optimal training in adolescent medicine.^{8,17,19} Several papers emphasize the key role of a named transition coordinator for a successful programme.^{2,42,49} The transition coordinator is commonly a specialist paediatric nurse, working during and also after the patient's transfer to adult-care centres, in order to address possible gaps in patient health care.⁵⁰

6. Defining Successful Transition

The first visit to the adult provider should not be viewed as the end of the transition process.¹⁸ Continuity of care with the same provider before and after a patient's transfer to adult care can be seen as a marker of successful transition.⁴¹ Without an established transition programme, a significant number of patients may be lost to follow-up during transfer, with consequently higher rates of non-adherence, and an increased number of visits to Accident & Emergency Departments, leading to higher rates of surgery.^{4,51}

Several other variables have been suggested as objective outcome measures for successful transition, including endoscopic remission rates, quality of life, and reduced attempts to return to child-centred care. So far, no prospective and quantitative evaluations of continuity of care have been published. In order to improve services, regular audits of the transition process should take place, taking opinions from all those involved.

ECCO Current Practice Position 6A

Patients, parents, and health-care providers should all be involved in the evaluation of the transition programme

7. Conclusion

The overall goals of this project were to identify critical elements for the transition protocol, to establish responsibilities for all those involved in the transition process, and to define successful transition. This topical review is summarized in a "Transition Toolkit", which is meant to serve as a checklist for clinicians who wish to set up a transition programme [see supplementary file 2].

Conflict of Interest

ECCO has diligently maintained a disclosure policy of potential conflicts of interests [CoIs]. The conflict of interest declaration is based on a form used by the International Committee of Medical Journal Editors. The CoI statement is not only stored at the ECCO Office and the editorial office of JCC but also open to public scrutiny on the ECCO website [<https://www.ecco-ibd.eu/about-ecco/ecco-disclosures.html>], providing a comprehensive overview of potential conflicts of interest of authors.

Disclaimer

The ECCO Topical Review Projects are based on an international consensus process. Any treatment decisions are a matter for the individual clinician and

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1. Current attitudes about transition: Johanna Escher, the Netherlands; Garret Cullen, Ireland
2. Education and skills needed before transition: James Lindsay, UK; Katrine Carlsen, Denmark; Eleftheria Roma, Greece
3. Models and timing of transition: Patrick van Rheenen, the Netherlands; Jaroslaw Kierkus, Poland; Rachel Cooney, UK
4. Professionals to be involved: Marina Aloï, Italy; Irit Avni Biron, Israel; Richard Russell, Scotland
5. Continuing care after transition: Salvatore Cucchiara, Italy; Joanna Sieczkowska-Golub, Poland.

Reviewer, on behalf of GuiCom: Marcus Harbord, UK.

Chair of the ECCO Transition Topical Review Group: Patrick van Rheenen, The Netherlands.

Author Contributions

This manuscript is a joint expert consensus activity. Hence all authors participated sufficiently, intellectually, and practically in the work, and take public responsibility for the content of the article, including the conception, design, data interpretation, and writing of the manuscript. All authors approved the final manuscript.

Supplementary Data

Supplementary data are available at *ECCO-JCC* online.

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