

Mistakes in transitional care for children and young adults and how to avoid them

Jorge Amil-Dias, Hans Törnblom, Moriam Mustapha and Patrizia Burra

Children and adolescents diagnosed with chronic diseases that may require life-long awareness and treatment have special needs that may impact their daily lives and those of their families. Paediatric diagnosis and management are usually provided in specialist facilities where parents are central in discussing therapeutic options, risks, and benefits. However, there comes a time when children must be transferred to adult healthcare facilities where the environment and guidelines are different. The awareness of transitioning to an adult healthcare setting was recognized years ago as a relevant process in managing paediatric patients. It can be defined as a "purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult-oriented health care".¹ There are different rules about the age limit of paediatric patients, but a transition program may be implemented according to these specific requirements. Some conditions are rare, and there may be fewer centres with expertise in adult care than in paediatric settings, e.g., intestinal failure. Finding the right reference centre to promote patients' transition when they reach adulthood may be challenging. Therefore, the transition process that ideally would be in the same institution may need cooperation between centres or even across countries, given the frequent mobility of young adults.

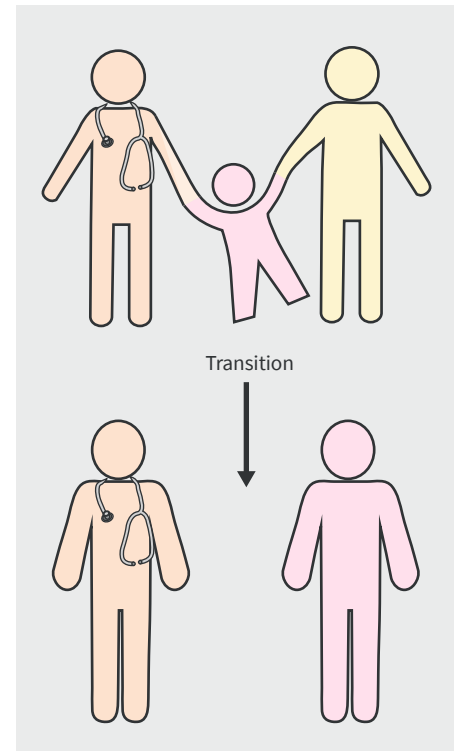
It has been well documented that the transition phase from paediatric to adult health care may be a moment of loss for follow-up, suspension of treatment or monitoring, and subject to risks of unnecessary complications or disease relapse.²⁻⁴ Several factors beyond specific medical management may significantly impact chronic conditions' long-term prognosis and outcome.^{5,6} Therefore, organizing a proper adolescent transition program is very important.² Several models have been implemented in many hospitals with varying results regarding satisfaction, control of the disease, and adherence to follow-up.^{4,7-9} Frequently, some things need to be corrected in this process.¹⁰ Here, we present eight mistakes made during the transition from paediatric to adult care, with evidence from literature and professional experience where possible.

Mistake 1 Starting the transition process too late

The age of starting the transition process varies depending on the healthcare setting and the disease to be handled. However, a general principle should be to start the transition from paediatric to adult care early and involve a wider multidisciplinary team. Abrupt transfer at 18 may lead to dissatisfaction and frustration among all involved; the patient, the parents, and the health care professionals.¹¹ Therefore, healthcare professionals must alert parents and patients to the need to prepare for this process so that they are fully aware of it.

It is common for adult healthcare to meet with the adolescents whose disease/illness

mainly has been managed through the parents, without responsibilities entrusted to the patient. Letting this situation linger on reinforces a passive patient attitude and accommodates patients and parents to the perception of being crucial for their child's continued care. An open discussion ahead of the transition about the plan reassures the patient and family that the multidisciplinary healthcare team will be globally engaged in providing a stable process and promoting the patient's progressive integration of autonomy. Planning the transition process along an expected path will help to comply and reassure them about the new healthcare team being able to meet their expectations.^{8,12} This is also an essential role for the transition coordinator.



Setting occasional appointments with or without limited time for the parents provides a direct opportunity for the patient to improve their knowledge and take responsibility for treatment and follow-up. It is also an opportunity for the patient to start talking about hidden concerns or fears related to the disease and its impact on life. It is also an opportunity to ask questions they would otherwise not dare to ask, e.g., about alcohol, smoking, and contraceptives. Adherence to diets, medication, and sexual issues may be discussed during these initial appointments, allowing the patient to bring up all the relevant topics. If additional involvement of other health professionals is needed at this point, a proper counselling or specific referral may then be agreed upon.

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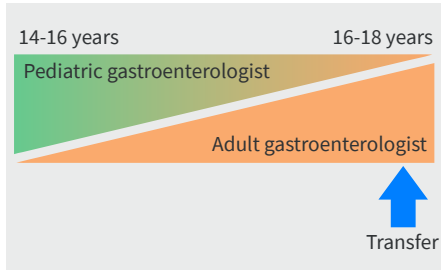


Figure 1 | Concept of a progressive process of smooth handover from the pediatric into adult health teams.

Transfer-related issues may be addressed at ages 14-16, providing progressive autonomy for the adolescent patient (figure 1).

Mistake 2 Not coordinating the transition process well enough

Identifying a healthcare professional that the patient and parents may reach to sort out emerging problems of the transition process may help with communication and coordination issues. Physicians managing the patients need to concentrate on the clinical evolution of the disease and decisions to be taken to keep it well controlled. This may overlook other relevant parallel aspects of the transition process, and the

role of a transition coordinator was mentioned above. As proposed by Dellon et al.¹³, the tasks of the transition coordinator start considerably before the transition is completed (figure 2), where a progressive understanding of the expected adaptation to the new environment in adult healthcare is needed. This is a relevant role of the transition coordinator, preparing the patient and parents for that moment and evaluating their readiness. The role of a transition coordinator usually fits a nurse or an allied healthcare professional (AHP) rather than an administrative clerk since there is more to it than just managing the appointments agenda. The transition coordinator is critical for the patient's and parents' smooth guidance to adult healthcare while monitoring the obstacles that require specific action.¹⁴

Mistake 3 Getting used to meeting adult healthcare professionals too late

There may be very different practices in institutions or countries, but the actual need to involve the adult multidisciplinary team may occur closer to the final handover. In all instances, it is appropriate to have joint appointments to gain advanced knowledge with the subsequent team. This can make bonding

easier and improve confidence in someone new in managing their disease. The parents often choose or approve the paediatrician (or paediatric subspecialist), but the paediatrician often identifies the new physician in adult healthcare. Therefore, a progressive approach is desirable.

All too often, paediatricians tolerate discussing the disease evolution and treatment plans with the patient's parents without involving the adolescent patient. Engaging the patient in the discussion about his/her disease and listening to their concerns and objections is vital in progressive and desirable empowerment. Adult physicians may be more aware of this risk as they interact primarily with their patients and less often with close relatives. The joint appointments make clear that the dialogue needs to be shifted to the patient, even if parental support and concerns are still welcomed in this phase.

Patients also transition between nursing teams and other allied health professionals, not only from one doctor to another. Due to capacity issues, young adults often have more contact with nurses and allied health professionals than medical staff in the adult setting. Having a team that is adequate for the type of diseases in the adult side of care provides confidence and facilitates the adaptation of patients.

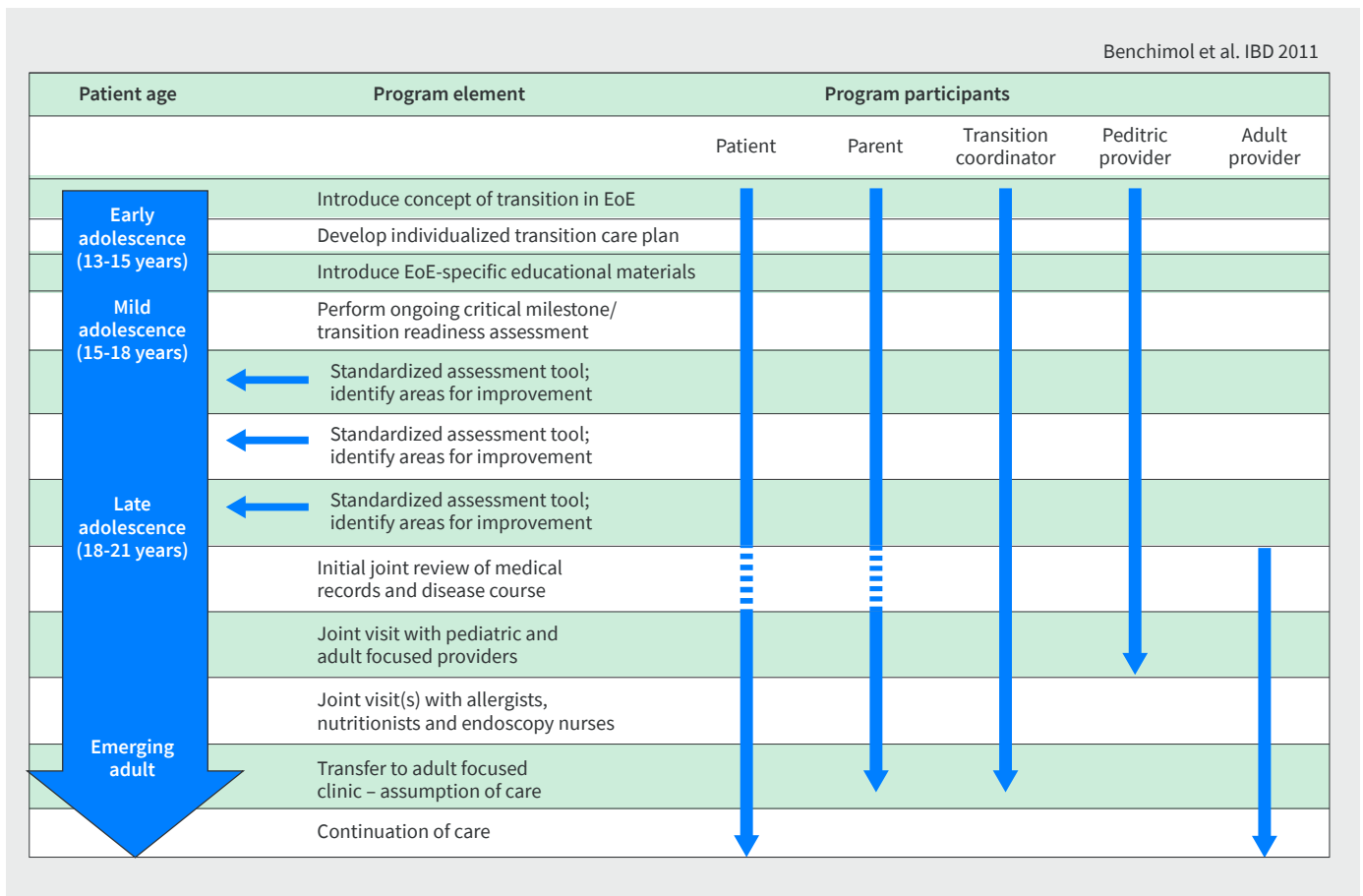


Figure 2 | Flowchart of the timeline and specific roles of the various healthcare team members in the transition process.

Mistake 4 Missing the identification of age-related factors increases the risk of poor adherence.

Adolescence and early adulthood are times of significant changes where adult social and working life is prepared. Some medical and non-medical factors associated with poor adherence in adolescents with chronic disease have been identified with a clear impact on the outcome^{15, 16}, like complications or associated diseases, education failure, or substance abuse. Close monitoring of the adolescent patient during the transition process may help identify essential aspects that can affect compliance.⁶

The multidisciplinary team, with a relevant role for the transition coordinator, must become aware of specific issues in each patient that

may limit their progressive autonomy and compliance with control of their disease. Missing out on relevant factors may dramatically impact the young adult's quality of life and health. An open discussion about plans regarding studies and work is also crucial since it might include a new geographic location for shorter and longer periods. Suppose the patient is moving to a different place later, and the joint contact between paediatric and adult physicians must be disrupted; in that case, the patient should be reassured that initial contact between health professionals and a detailed report on the condition, including relevant data, will be provided.⁸ Some healthcare providers use something similar to "MyHealth Passport" (figure 3), which may be a handy tool and ease the difficulties related to limited personal contact between past and future healthcare providers.¹⁷

As mentioned above, the emotional impact of some chronic diseases that require continued medical therapy may dramatically affect the long-term prognosis.^{6, 15, 18} Supporting integration into patient support/networking groups with similar conditions and providing a more optimistic view of everyday life despite some physical constraints may help patients to cope with their disease.¹⁹ Support from other patients with current or previous problems of similar nature is an integral part of growing up with health issues that impact daily activities and interaction with peers. The role of patient organizations and dedicated social media may help social integration and prevent feelings of loneliness, reinforcing the sense of being part of a community. Many of these associations promote open-air activities providing self-reassurance and much-needed adolescent interaction. Knowledge of these associations and providing information to the patient and parents is essential. The involvement of psychological professionals as part of the wider multidisciplinary team is also essential.

Mistake 5 Absence of active management of failed appointments

It is essential to provide efficient tools to keep the patient in contact with the health care team while keeping them informed on the risks of relapse or worsening of the chronic disease. Old-fashioned ways of communication may contribute to the risk of loss of follow-up. There is an absolute need for multiple ways to quickly contact healthcare providers, such as by smartphone apps, web-based solutions, telephone, and similar technologies that may facilitate contact and adherence. The role of a transition coordinator within the healthcare team is significant to spot problems related to young patients not showing up and to prompt the team for suitable action.

Paediatric settings tend to be more tolerant of unplanned contacts. Some transient tolerance or special availability may be welcome by the young adult. In this regard, the transition coordinator may help adapt to the rules of the future unit and provide reasonable ways to let the adult team be informed of any anticipation of incidental contact.

Mistake 6 A lack of mutually agreed guidelines between the paediatric and the adult multidisciplinary teams

The treatment guidelines can differ in paediatric and adult healthcare settings. Examples of this are that they aim at populations with different disease severity or different pharmacodynamics of recommended treatments. Moreover, new drugs are implemented in adult healthcare long before being approved for the same condition in children. Therefore, it is unsurprising that paediatric and adult healthcare may take different approaches

My health passport example	
Name	My health passport example
DOB	January 2, 1983
Diagnosis	Crohn's disease
Location	Esoph., terminal ileum, R colitis
Perianal	Skin tags, Fistulae
xtra intes	Pyoderma Gangrenosum, Arthritis
Family Hx	No family history or IBD
Medical problems	Asthma
#adm date last	2x, January 2010
Meds	MTX
Vitamins	Multivit, Calcium, Vit D
WARNING	THIS PERSON IS ON IMMUNOSUPPRESSANT MEDICATION. IF PRESENTS WITH FEVER, PLEASE CALL THEIR DOCTOR
Drug allergies	Penicillin
Immunization	Routine immunizations up-to-date
Chickenpox	I have had chickenpox
TB	Negative, 2008
Height	172 cm, linear height delay
Weight	72 kg
Scopes	Upper endoscopy, Colonoscopy 1x, January 1, 2010,
Imaging	Small bowel follow-through, January 1, 2010, ileal cobblestoning
Bloodwork	1x q2 months
Coverage	Insurance company name
Paediatrician	Dr Smith - (000)555-1111
Family doctor	Dr Jones - (000)555-1112
GI ped	Dr Singh - (000)555-1113
Pharmacy	Pharmacy - (000)555-1114
ICE	Mom - (000)555-1115
Date created	5/10/2010 www.sickkids.ca/MyHealthPassport

Figure 3 | Example of a MyHealth passport with detailed information that may be used to communicate relevant patient data with the adult healthcare team.

when treating similar conditions. However, sudden changes in therapy by the "new doctor" may raise concerns and doubts in the patient and parents. In this context, it is recommended that both physicians in the transition team agree on similar regimens before engaging in new treatment protocols. In the case of different approaches, changes should be implemented cautiously and explained clearly to avoid mistrust in the new healthcare team after years of adherence to different guidelines.

Mistake 7 Not being fully aware of the specifics of some conditions

Some diseases are more frequent or behave differently comparing paediatric and adult patients, with differing demands on their multidisciplinary teams. One typical example is the treatment of intestinal failure or metabolic diseases that until recently would not reach adult life. Adult patients with intestinal failure usually have it after an acute event (trauma, vascular disease, cancer), requiring surgery and adapting their lives to the new condition. However, most paediatric patients live with parenteral nutrition for many years after early life events that require surgical removal of most of their gut or because of severe congenital dysfunction despite having the gastrointestinal tract in situ. These patients depend mostly or entirely on parenteral nutrition and must adjust their lives, schooling, and growth to the circumstances of their disease. They need a multidisciplinary team (gastroenterologist, dietitian, specialist nurse, intervention radiologist, surgeon, stoma expert, pharmacist) to be familiar with the condition and to manage their disease and complications. The team receiving these patients in adult life must be familiar with the

specific needs and problems of these patients.²⁰ Attendance of adult healthcare professionals at paediatric outpatient clinics may help them to get acquainted with the specifics of these diseases that may be considerably different from their regular practice.

In some diseases, like inflammatory bowel disease, patients might reach adult life after several treatment adaptations or even surgery that limit future treatment options. Adult physicians taking further care of these patients need to be aware of the specific scenarios and options to move forward in health care, even in young adulthood.

Some chronic conditions, like intestinal failure, coeliac disease, eosinophilic oesophagitis, or inflammatory bowel diseases, require multidisciplinary approaches that are usually in place in paediatric settings. Similar arrangements are appropriate for adult patients.

Mistake 8 Handing over a patient with a flaring disease may require immediate treatment change during the adaptation to the new physician

Disease exacerbation often leads to treatment adjustments with potential side effects or complications. This may not be the ideal moment to change from one doctor to another.²⁴ Bringing the disease recurrence to remission before the final transition of medical care promotes a more stable process. Suppose the disease exacerbates and requires treatment modification. In that case, this should be conducted by the doctor most familiar with the patient, leading to some delay in the transition process until the situation is stable again. If this is difficult to achieve, then it should be apparent to the patient and family that both

doctors agree on the treatment protocol, thereby reducing the risk of discomfort.

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Your transitional care in children and young adults briefing

UEG week

- 'Benefits of paediatric to adult transition program in inflammatory bowel disease: the butterfly study of Geteccu' session at UEG Week 2022 [https://ueg.eu/library/benefits-of-paediatric-to-adult-transition-program-in-inflammatory-bowel-disease-the-butterfly-study-of-geteccu/564775d4-9363-11ed-a912-0242ac140004]

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