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Position Paper

Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology

Italian Society of Paediatric Gastroenterology, Hepatology and Nutrition (SIGENP), Italian Association of Hospital Gastroenterologists and Endoscopists (AIGO), Italian Society of Endoscopy (SIED), Italian Society of Gastroenterology (SIGE)

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ABSTRACT

In 2013, four Italian Gastroenterological Societies (the Italian Society of Paediatric Gastroenterology, Hepatology and Nutrition, the Italian Society of Hospital Gastroenterologists and Endoscopists, the Italian Society of Endoscopy, and the Italian Society of Gastroenterology) formed a joint panel of experts with the aim of preparing an official statement on transition medicine in Gastroenterology.

The transition of adolescents from paediatric to adult care is a crucial moment in managing chronic diseases such as celiac disease, inflammatory bowel disease, liver disease and liver transplantation. Improved medical treatment and availability of new drugs and surgical techniques have improved the prognosis of many paediatric disorders, prolonging survival, thus making the transition to adulthood possible and necessary. An inappropriate transition or the incomplete transmission of data from the paediatrician to the adult Gastroenterologist can dramatically decrease compliance to treatment and prognosis of a young patient, particularly in the case of severe disorders. For these reasons, the Italian gastroenterological societies decided to develop an official shared transition protocol. The resulting document discusses the factors influencing the transition process and highlights the main points to accomplish to optimize compliance and prognosis of gastroenterological patients during the difficult transition from childhood to adolescence and adulthood.

1. Introduction

"*Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centred to an adult-centred healthcare system*" (Blum et al., 1993) [1]. Transition is not just a simple 'transfer' of patients from a paediatric service to an adult care one: transition medicine (TM) actually represents a complex scheduled process, which starts early with paediatric specialists, and aims to make patients independent in managing their own health (and disease) [2].

TM deals with critical aspects of care for patients with a chronic disease of childhood onset, when and as they move from child-oriented to adult-oriented services [3].

It is a very delicate phase of care provision and management, influenced by the particular degree of vulnerability of adolescents when they are faced with the difficulties arising from their age and disease [4].

The organization of TM is a dynamic process, aiming at ensuring continuity, coordination, flexibility and sensitivity in a multidisciplinary context, to meet the adolescent's clinical, psycho-social and educational needs as well as enhance his/her abilities [5].

Although widely discussed in the scientific literature, a smooth transition may encounter obstacles linked to the experience of the patients and their families (caregivers), as well as of the paediatric and adult health care providers. These obstacles challenge the adoption of a single preferred model as TM should take into account a wide range of specific needs [6]. A specific TM program has a complex structure and should include: setting up disease-oriented

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working groups at the hospital level including paediatric and adult gastroenterologists, internists, psychologists, developmental psychiatrists and other specialists; adopting a shared diagnostic and therapeutic work-up; identifying medical and paramedical staff to involve and the development of specific training for all operators; involving health care providers and institutions (e.g. scientific societies, voluntary sector associations and local government authorities); creating a centralized digital database (Regional Registry of Pathologies).

For chronic gastrointestinal conditions such as inflammatory bowel disease, celiac disease, chronic liver diseases with a paediatric onset, patients should undergo a transition process during adolescence. That is of paramount relevance for all disorders managed in dedicated centres (e.g. cystic fibrosis, Rendu-Osler disease etc.) [7]. Present, there are no specific transition programs endorsed by the gastroenterological scientific societies in Italy: this negatively affects both current clinical practice as well as future research in the field.

The above considerations have led the Italian Society of Paediatric Gastroenterology, Hepatology and Nutrition (SIGENP), the Italian Association of Hospital Gastroenterologists and Endoscopists (AIGO), the Italian Society of Endoscopy (SIED), and the Italian Society of Gastroenterology (SIGE) to call upon a panel of experts to develop a set of practical recommendations towards an appropriate roadmap for TM in Gastroenterology.

2. Methods

In May 2013 a panel of expert Gastroenterologists and Paediatricians members of SIGENP, AIGO, SIGE and SIED, was established to prepare a position statement on TM for gastroenterological disorders. The panel initially met on June 4th 2013 in Milan to define the timeline and milestones of the document. Regular conference calls followed with Web-based data exchange organized by a dedicated secretariat (Area Qualità). The document included the definition of the levels of evidence with a >90% agreement among operators.

The panel members carried out a comprehensive PubMed research for English-written articles, without time limits, using the following Mesh terms: transition medicine, adolescence medicine, gastroenterology, gastrointestinal diseases, inflammatory bowel disease, IBD, Crohn's disease, ulcerative colitis, celiac disease, gluten-related enteropathy, celiac sprue, dermatitis herpetiformis, gluten free diet, Barrett oesophagus, liver transplantation, cholestasis, biliary atresia, Alagille's syndrome, viral hepatitis, HCV, HBV, alpha-1 antitrypsin deficiency, Wilson's disease, progressive familial intra-hepatic cholestasis, immunosuppressive therapy, therapy compliance. Whenever possible the level of evidence and recommendations were defined for each statement. The criteria used for evidence and recommendations were in accordance with the Oxford Center of Evidence-based Medicine, March 2009 edition (www.cebm.net/oxford-centre-evidence-based-medicine-levels-evidence-march-2009/) and were reported in parentheses at the end of each statement.

The manuscript was structured bearing in mind that inflammatory bowel disease, celiac disease, and chronic liver diseases represent the majority of chronic gastroenterological disorders with a paediatric onset. For other diseases, such as eosinophilic esophagitis, one should consider a specific transition pathway following the indications of the literature [8].

3. Common aspects of transition during adolescence

Any chronic disease can negatively affect infancy and adolescence, deeply influencing a patient's physical and mental development. Both patients and their families should be fully informed of these issues. From a young patient's point of view, he/she has to deal with the responsibility of balancing social life, school attendance and health management, while possibly lacking the cognitive and emotional capabilities needed to comply with a therapeutic regimen. As a consequence, the rate of adherence to treatment during adolescence is lower than in other age groups or other developmental life stages. Limited life experience and a sense of adolescent 'invincibility' may prevent young patients from fully understanding their actual state of health. Some young adults may also show an apparent reluctance to abandon their paediatric medical staff and to refuse the support of their own families [1,2].

As widely reported, the crucial issue of switching from a family-centred (paediatric) care model, with direct involvement of parents in the diagnostic and therapeutic decision-making process, to self-managed (adult) care, may cause a young patient to experience a sense of exclusion and fear [9].

Even the attitude of the specialists involved can represent an obstacle to the transition process: paediatric gastroenterologists and their staff (e.g. nurses, nutritionists, psychologists) potentially contribute to an unbalanced relationship that bonds them to the young patients and their families, possibly due to a feeling of 'exclusivity' in care ("I know the patient better than anyone else"). Conversely, it is possible that a physician caring for adult patients may lack the experience to manage an adolescent with a childhood-onset disease [6].

Other potential factors that lead to inadequate TM, are: insufficient knowledge by the 'new' gastroenterologist of a patient's clinical history, adolescent's resistance to change, family anxiety, reluctance by the paediatric gastroenterologist to "lose the patient" or even the difficulty to identify a dedicated specialist.

Based on these considerations, it is clear how difficult it is to define an ideal age for a patient's transition, even if it is expected to occur at the age of 18 years. The patient's physical and emotional maturity, the level of disease activity, 'compliance' to treatment, the degree of autonomy in disease management, all represent key factors influencing the ideal transition age [10].

Despite the current availability of general recommendations concerning transition from paediatric to adult Gastroenterologists, pertinent guidelines or statements for the most appropriate methodology are still lacking. Patients must be aware of the course of their chronic disease and the possibility that it would negatively affect their everyday life or lead to the development of other associated diseases. Accordingly, an adult Gastroenterologist should establish the most appropriate transition time together with the patient's family [11]. Moreover, all available support resources should be taken into account when planning the transition process: need for referral to a dedicated service for the underlying disease with both in-house facilities and access to specialized staff (physicians, nurses, etc.) near the patient's home, and the availability of an accessible Gastroenterology Unit [12].

Ideally, at the beginning of adolescence, the paediatric Gastroenterologist should start to educate both the patient and their family about transition, with the goal of making the patient gradually autonomous in the management of his/her chronic disease, therefore preparing him/her for the later transfer to an adult facility. This initial induction should desirably involve a developmental psychologist. As a result, both patients and their families will become able to recognize the onset of symptoms, the disease characteristics, any related complications, the appropriate medications and any drug-related side effects [12].

Within the healthcare provider unit, regular meetings should be held during the transition process with all professionals involved. In particular, the most relevant treatment decisions should be discussed and shared (i.e., consultation by phone or computer) between the adult and paediatric Gastroenterologists at the beginning of the transition period; ideally one would create a specific 'patient-centric' network within the regional healthcare facilities.

The second transition phase should begin when the paediatric Gastroenterologist believes the young patient is ready to move on, i.e. he/she has become independent in disease management and/or has reached maturity within the age range of 16–20 years. At this point, a reassessment should be performed by all involved professionals to agree on the specific transition program. The paediatric Gastroenterologist should provide the adult counterpart all medical records; ideally, medical records should be easily to allow the effective transfer of patient information between specialists. Medical records should be translated if the patient spends a significant periods abroad for study or family reasons.

Ideally, patients should be in remission from their disease at the time of transfer. Otherwise, the involved specialists should cooperate to achieve remission during the transition period.

The paediatric Gastroenterologist will provide the information concerning the recommended adult Gastroenterology Unit(s), based on the specific disease to be treated, geographic location, patient's life projects (e.g. relocation for study or work) and any possible preferences. The recommendations are then discussed and shared with the patient and the family.

Common aspects of the transition program are its duration, the meeting schedule between paediatric and adult Gastroenterologists, providing an adequate amount of time for first visits, and helping raise the patient's awareness and understanding of his/her condition by providing printed materials.

During the final phase, the transfer is completed and whenever possible the paediatric Gastroenterologist would remain available for approximately one year, should the need for further case discussion or patient review occur.

For patients suffering from chronic gastroenterological diseases and other disabilities and/or cognitive deficits, additional support should be provided as required.

3.1. The panel's recommendations

- **Adolescent patients are generally characterized by low levels of compliance to therapy and should be strictly monitored before starting the transition (2c-B).**
- **Although difficult to establish, the ideal age for transition is between 16 and 20 years, depending on physical and emotional maturity, disease activity, compliance to treatment, autonomy in disease management (2c-B).**
- **Paediatricians should decide when their young patients are ready to start the transition program, by taking into account the above reported factors and with the help of psychologists when needed (3b-C).**
- **Paediatricians should start the transition program by informing patients and families or caregivers about the purpose of transfer to an adult setting; they should be informed on the disease characteristics, treatments (including side effects) and how to recognize alarm symptoms. They should also be informed on the location of available adult centres, taking into consideration the patient's wishes and needs (5-D).**
- **The transition process should include a period of overlap between paediatric and adult care providers; the length of this period depends on disease severity (5-D).**
- **Regular meetings or suitable Web-based interaction between paediatric and adult Gastroenterologists should be scheduled to improve the effectiveness of the transition program (5-D).**

4. Transition medicine for specific gastroenterological diseases

4.1. Inflammatory bowel disease

The course of inflammatory bowel disease (IBD) is mainly chronic-relapsing, characterized by alternate periods of remission and exacerbation. IBDs include Crohn's disease (CrD), ulcerative colitis (UC) and indeterminate colitis. Up to 25% of IBDs have an onset in childhood with a peak in adolescence, showing a rising incidence rate in recent years, especially with regard to CrD [13,14,15]. The increasing number of adolescents with IBD makes it necessary for both paediatric and adult gastroenterologists to know about the problems the disease poses in adolescence [16]. Therefore the initial diagnostic work-up and treatment of paediatric patients (<16 years of age) should be performed in a Paediatric Department (within a network of paediatric gastroenterology clinics) with regard to the specific problems of paediatric-onset IBD. The current literature highlights the difficulties in managing chronic diseases during adolescence, such as reduced compliance or even non-adherence to therapy and follow-up programs. This can lead to worsening disease control and overall reduction of patient's quality of life, potentially leading to a dramatic increase in IBD management costs [17–19]. As with other chronic diseases, the transition of paediatric IBD patients to adulthood represents a period of vulnerability, further increased by the serious disease-related growth obstacles to physiological development, psychological sexual maturity and acquisition of social skills [18,20].

Importantly, the transition from paediatric to adult care facilities also implies a cultural switch, which is linked to the changes of the patient's "care habits"; in fact, the family-centred relationship system including direct parental involvement in decision-making and a multi-disciplinary approach, changes to a direct contact model [21,22]. The patient should be informed that the diagnostic approach could also be different. For instance, endoscopic examinations may no longer be performed under heavy sedation and surveillance colonoscopy would be planned at ten-year intervals or more frequently when dealing with the most severe forms of IBD [23]. A shared transition program between paediatric and adult Gastroenterologists reportedly improves both patient's prognosis and psycho-social well-being. In this context, different studies reported that, after childhood ends, patients prefer to be treated at an adult care centre and to be directly responsible for their own health [24]. There are some distinctive aspects of IBD in the transition period: they concern the acquisition of specific knowledge and skills by both patients and their healthcare providers [25,26]. In detail, educating patients on their transition should start early and aim at acquiring skills such as understanding disease characteristics and evolution; understanding complications, infection risk, neoplastic risk, effects on fertility and pregnancy resulting from both the disease and its treatment; knowing the names of medications, their indications, dosing, side effects, how to obtain repeat prescriptions, and the risks of non-adherence to treatment; knowing how to schedule their own appointments and who to contact in case of relapse; learning about exemptions and legal rights resulting from chronic/disabling diseases; being aware of the available services dedicated to IBD (e.g. information on the closest adult centre); learning to ask questions directly to the physician, and the possibility that a medical examination may be take place without parental supervision [27].

Ideally, the transition period should also involve a developmental psychologist, possibly dedicated to IBD. The initial work-up should be shared between the paediatric and the adult Gastroenterologist to facilitate both homogeneity and continuity of care [28]. During the transfer period it is advisable that the disease be in remission and the transfer organization should consider in detail the actual availability of local resources, mainly IBD dedicated services with adequately trained medical and nursing staff [29,30].

Overall, the transition program will last from six to twelve months, giving priority to the collegial visits (at least once or twice during this period) by the two lead professionals and to alternative delivery modes (e.g. alternate visits at the two care service sites)

subject to resources and needs. The involvement of both parents and patients is advisable at the beginning. It is useful to start the transition gradually, and to ensure that the patient has been given the most complete information regarding available services and physicians.

4.1.1. The panel's recommendations

- **The transition program in IBD patients should start at 16 years of age (2c-B).**
- **Transition in IBD should be carried out gradually, taking into account physical and emotional maturity, disease activity, compliance to treatment, autonomy in disease management (2c-B).**
- **Transition should start during disease remission (2c-B).**
- **The paediatrician should start informing the patient about the transition program; this phase should be followed by at least one combined visit (paediatric and adult Gastroenterologist) to be held at the adult centre (the number of combined visits can be increased depending on the patient's status) (5-D).**

4.2. Coeliac disease

Coeliac disease (CD) is a frequent chronic autoimmune enteropathy with a prevalence of approximately 1:100, a male: female ratio of 1:2, and a bi-modal peak of onset (during paediatric age and in the IV decade) [7,31].

Currently, the only available treatment for CD is a lifelong gluten-free diet (GFD). Given its chronic nature and the possible development of co-morbid disorders (i.e. autoimmune and/or neoplastic diseases, disorders secondary to chronic inflammation or atrophy of the small intestine, such as anaemia and osteoporosis), CD requires on-going medical support, which has shown to improve the disease outcome and patients' compliance to GFD [32–37].

The transition phase for young CD patients is pivotal in maintaining optimal quality of life and a long-term prognosis comparable to the general population. To date, there is no data concerning the transition in CD, although O'Leary et al. [38] have reported that patients with discountinuous follow-up after the paediatric stage, frequently (50%) abandon GFD. Medical follow-up therefore is a motivational factor to maintain good dietary compliance in about 25% of cases. Poor compliance to GFD among teenagers can negatively affect both quality of life and clinical course. In fact, a coeliac patient's quality of life might depend on whether diagnosis was based on symptoms or obtained after family screening. At diagnosis, patients presenting with a typical CD have a relatively low quality of life, which improves with GFD; conversely, the better quality of life of asymptomatic patients before the exclusion diet, worsens later owing to the limitations and constraints imposed by GFD, in turn reducing the patient's motivation to adhere to the prescribed dietary treatment. Paradoxically, asymptomatic patients diagnosed by screening are at greater risk of non-adherence to GFD, thus requiring a more strict follow-up [39]. Differently from other diseases discussed in this report, CD transition is peculiar in that it is characterized by a high number of affected subjects and a relatively low incidence of complications. To effectively enable the transition of paediatric CD patients, it is essential to ensure continuity of care. The transition can be simply performed via a joint visit by the paediatric and the adult Gastroenterologist, during which the patient's needs are identified with respect to his/her expectations and the modalities for follow-up. 'Simple' patients would require both psychological and nutritional support. Otherwise, when facing patients with particular co-morbidities (e.g. other autoimmune diseases requiring chronic therapy or showing an incomplete response to GFD), the evaluation could change over time depending on the equipment and the specialists required [40]. Also in these cases, psychological consultation may be needed and thus the opportunity for two combined visits should be considered. For the subset of CD patients with optimal clinical response but some difficulties in adherence to GFD during adolescence, consultation with a psychologist is advisable.

4.2.1. The panel's recommendations

- **The transition program in CD patients should start at 16 years of age (4-C).**
- **Transition in CD should be started by a paediatrician taking into account the patient's physical and emotional maturity and can include a combined visit (paediatric and adult Gastroenterologist) to reduce GFD drop-out rates (2c-B).**
- **Only in cases of a complicated disease and particular comorbidities (i.e., multiple autoimmune diseases), an IBD-type transition program should be considered (5-D).**

4.3. Chronic liver diseases

The aetiology of chronic liver diseases (CLDs) during childhood varies significantly when compared to CLDs in adulthood. Many children with complicated CLD can now survive into adulthood thanks to specialized medical care. As paediatric CLD patients receiving treatment of both hepatic and extra-hepatic complications reach adulthood, the transition to adult care requires a comprehensive knowledge of paediatric CLD [41].

The transition from paediatric to adult care remains a difficult process for both patients and their families. Particular attention must be paid to the nutritional aspects, vaccination status, degree of sexual development, the presence of extra-hepatic manifestations and psycho-social implications [42].

A transition program should be considered for the following CLDs.

4.3.1. Biliary atresia

Biliary atresia (BA) is the result of a destructive inflammatory process of the bile ducts inside and outside the liver with resulting fibrosis and progression to cirrhosis. With an incidence of 1:5000–12,000 newborns, BA is the most common cause of chronic cholestasis in infants and the most frequent indication for liver transplantation in children. A timely diagnosis is crucial as appropriate treatment ensures a better long-term prognosis. The Kasai procedure to drain bile flow represents the standard of care. Children with BA have a variable prognosis; moreover, both short and long-term complications are common. Approximately 80% of BA patients will require an orthotopic liver transplant (OLT) and those reaching adulthood will require strict follow-up. In particular, women are at increased risk of portal hypertension during pregnancy [43].

4.3.2. Alagille's syndrome

This autosomal dominant disorder caused by a defect in the JAG1 gene, affects the liver (paucity of bile ducts and portal fibrosis), heart, eyes, skeleton, kidneys, causes delayed puberty as well as a characteristic facies. OLT is performed in approximately 15% of all patients due to risk of liver failure, for intractable pruritus or osteodystrophy, and may be necessary at any age [44].

4.3.3. Alpha-1 antitrypsin deficiency

This is an autosomal recessive disease characterized by CLD and early development of pulmonary emphysema, when severe phenotypic expression is present. Neonatal jaundice and cholestasis represent key factors and liver damage evolves to fibrosis and cirrhosis, occurring during childhood or adulthood, possibly progressing to hepatocellular carcinoma and cholangiocarcinoma. OLT is currently the only treatment in case of end-stage disease [45].

4.3.4. Progressive familial intra-hepatic cholestasis

This is a heterogeneous group of autosomal recessive disorders of bile acid transport, with an incidence of 1:50,000 to 1:100,000. Three distinctive genotypes have been identified with various phenotypes. Patients with PFIC1 and PFIC2 may present with early onset of progressive cholestasis, poor growth, intractable pruritus and progression to liver failure. Some PFIC1 gene mutations may be associated with benign recurrent intra-hepatic cholestatic forms (BRIC1). In some patients, cholestatic jaundice crises are associated with use of oral contraceptives or pregnancy. In patients with PFIC3, the onset of cholestasis is late, sometimes during adolescence. These disorders can be initially treated pharmacologically; however, their progression can lead to surgical biliary drainage. OLT is necessary in advanced stages with liver failure and in severe forms [46].

4.3.5. Wilson's disease

This is an autosomal recessive disease resulting in an accumulation of copper in the liver, central nervous system, cornea and other organs. The incidence is 15–30:1 million (heterozygote frequency 1:100). WD presentation is highly variable even in members of the same family. Liver involvement, always present, may be clinically silent or lead to acute to fulminant hepatitis. In most cases, lifelong chelation therapy can control WD progression. However, non-response to drug therapy and progression to cirrhosis may require OLT [47].

4.3.6. Autoimmune hepatitis

Many patients with autoimmune hepatitis (AH) are diagnosed before the age of 18 years, 75% are females and there is a peak incidence before puberty. Type-1 AH is present in two thirds of all cases and occurs in adolescence; type-2 AH occurs in younger children and can present as acute liver failure. Lifelong immuno-suppressive therapies require strict laboratory and imaging follow-up. OLT is required when hepatic failure ensues (0.5% to 8% of patients after 8–14 years from diagnosis). AH can recur after transplantation in 20% of cases, even several years later [48].

4.3.7. Chronic viral hepatitis

Hepatitis C virus (HCV) infection in children is usually transmitted from their HCV-RNA positive mothers in the neonatal period and becomes chronic in 80% of cases although often with an uneventful course. Viral replication may persist until adulthood, often with cytolysis. An adequate antiviral regimen including pegylated interferon and ribavirin or, more recently, protease inhibitors, is standard therapy with a high success rate. OLT may be required. Hepatitis B virus (HBV) infection is frequent among immigrant or adopted children: 90% of infants and 25–50% of children infected in early childhood become chronically infected. The infection is often asymptomatic; treatment of chronically infected children or adolescents should be based on their individual immunological status [49,50].

4.3.8. Liver transplantation

As mentioned earlier, many CLDs eventually require OLT as therapy of end-stage liver disease. Adolescents who are paediatric liver transplant recipients show an increased risk (17–50%) of non-adherence to immuno-suppressive therapy [51], which increases risk of chronic rejection, graft loss and other complications of long-term care [52]. This is of paramount importance for planning the outpatient transition and its appropriate timing, which should not be based on a standard procedure but tailored to the specific situation and developmental maturity of the individual patient. Paediatric and adult Gastroenterologists in collaboration with other specialists, including specialized paediatric Psychiatrists and Hepatologists should perform the assessment, along with the corresponding adult specialists in the joint assessment clinic. This synergistic approach is of relevance also for the adult specialists, to guide the adult healthcare provider gradually into the peculiarities of each case, while the patients learn to independently manage their condition, and are gradually released from the support of their families and former paediatric services.

The results of OLT are usually reported in terms of both organ and patient survival rates, medical and surgical complications, and quality of life. However, these conventional parameters are not always sufficient and appropriate to evaluate the results of OLT in the teenager population [53,54].

4.3.9. The panel's recommendations

- **The transition program in CLD patients should start between 16 and 18 years of age (2c-B).**
- **Transition in CLD should be performed gradually, taking into account the patient's physical and emotional maturity, disease activity, compliance to treatment, degree of autonomy in disease management (2c-B). Because of the severity of many CLDs and the potential for OLT, psychological support should be included (2c-B).**
- **Whenever possible, transition should start during a remission phase (2c-B).**
- **The paediatrician should inform the patient about the transition program; this phase should be followed by four combined visits (by the paediatric and adult Gastroenterologist) over a 12-month period, to be held, if possible, at a dedicated centre (Transition Unit), or alternating between the adult and the paediatric care centres (5-D).**
- **In this context, the establishment of a transition program is likely to improve prognosis and reduce costs (3b-B).**

5. Organizational issues

Child-to-adult transition projects are 'easy' to organize in hospital settings where both paediatric and adult specialties are in place. In such a scenario, an agreement should be made between the two units, endorsed by the health department and aimed at providing shared outpatient sessions to facilitate the patient's switch.

The situation is quite different in a paediatric centre, such as a children's hospital, lacking adult specialties. In this scenario, it is essential to refer patients to a pre-arranged service level agreement between the paediatric and adult hospitals to ensure "privileged access" during transition. An ideal arrangement would include two outpatient sessions between the paediatric facility and the adult referral hospital so that the patient may become accustomed and feel confident with the new physicians and services.

In the case of patients coming from a paediatric facility outside the region of the adult referral service, a pre-arranged shared program may not be easily accomplished. It is critical in these cases that appropriate psychological support be provided, with comprehensive communication, both verbal and written, between the paediatrician and the specialist/s of the receiving adult care facility. This should include forwarding of a detailed clinical report and all imaging studies carried out during paediatric care.

In the case of a transition between very geographically distant centres or from other logistical difficulties, resorting to internet-based interfaces can certainly improve contact and information exchange between paediatric and adult Gastroenterologists [55].

5.1. The panel's recommendations

- **When the paediatric and adult centres are not within the same hospital, a strong collaboration should be established with regional/remote adult referral services and a preferential pathway for patients in transition must be established (5-D).**

Table 1
Characteristics of transition for patients with inflammatory bowel disease, celiac disease and chronic liver diseases.

	IBD	CD	CLD
Suggested start age (years)	16	16	16–18
Duration of the transition process (months)	6–12 Specialists should stay in contact and/or schedule web conferences to maintain a uniform follow-up	1 IBD-like transition process to be considered when dealing with complicated cases	6 Specialists should stay in contact and/or schedule web conferences to maintain a uniform follow-up
Number of combined visits (minimum)	1 or 2 depending on the severity of the disease	1	4
Location of visits	Alternating between the paediatric and adult gastroenterological services	Adult gastroenterological service	Transitional clinic
Location of service	Secondary or tertiary referral centres	Secondary or tertiary referral centres	Secondary or tertiary referral centres

IBD, inflammatory bowel disease; CD, celiac disease; CLD, chronic liver diseases.

In this scenario alternative, (i.e., internet- based) systems of medical communication should be considered (5-D).

6. Conclusion: why create an outpatient transition?

In order to support patients and their families in the difficult switch from adolescence to adulthood, healthcare professionals can help bring paediatric and adult medicine together by promoting effective patient autonomy in disease management and fostering close patient-family-physician cooperation (see recommendations summarized in Table 1).

The transition team has the delicate task of assisting young adults and their families in understanding and appreciating the cultural and practical differences between paediatric and adult medicine. In fact, with regard to the psychological aspects involved, children and adolescents with chronic diseases are at greater risk of long-lasting psychological distress than the general patient population, resulting in non-adherence to their treatment and follow-up regimens. An effective transition can avoid gaps in medical care and ensure physical and mental well-being during this difficult time.

Conflict of interest
None declared.

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References

[1] Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. Journal of Adolescent Health 1993;14:570–6.
[2] David TJ. Transition from the paediatric clinic to the adult service. Journal of the Royal Society of Medicine 2001;94:373–4.
[3] Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. Journal of Pediatric Rehabilitation Medicine 2014;7:43–51.
[4] Sanders RA. Adolescent psychosocial, social, and cognitive development. Pediatrics in Review 2013;34:354–8, quiz 8–9.
[5] Amaria K, Stinson J, Cullen-Dean G, et al. Tools for addressing systems issues in transition. Healthcare Quarterly 2011;14 Spec No 3:72–6.
[6] Salmon P, Young B. Dependence and caring in clinical communication: the relevance of attachment and other theories. Patient Education and Counseling 2009;74:331–8.
[7] Buscarini E, Conte D, Cannizzaro R, et al. White Paper of Italian Gastroenterology: delivery of services for digestive diseases in Italy: weaknesses and strengths. Digestive and Liver Disease 2014;46:579–89.
[8] Soon IS, Butzner JD, Kaplan GG, et al. Incidence and prevalence of eosinophilic esophagitis in children. Journal of Pediatric Gastroenterology and Nutrition 2013;57:72–80.
[9] van Staa A, van der Stege HA, Jedeloo S, et al. Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors. Journal of Adolescent Health 2011;48:295–302.
[10] Linebarger JS, Ajayi TA, Jones BL. Adolescents, young adults with life-threatening illness: special considerations, transitions in care, and the role of pediatric palliative care. Pediatric Clinics of North America 2014;61:785–96.
[11] Westwood A, Langerak N, Fieggen G. Transition from child- to adult-orientated care for children with long-term health conditions: a process, not an event. South African Medical Journal 2014;104:310–3.
[12] Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. Pediatrics 2014;133:e1639–46.
[13] Fakhoury M, Negrulj R, Mooranian A, et al. Inflammatory bowel disease: clinical aspects and treatments. Journal of Inflammation Research 2014;7:113–20.
[14] Ruel J, Ruane D, Mehandru S, et al. IBD across the age spectrum: is it the same disease. Nature Reviews Gastroenterology & Hepatology 2014;11:88–98.
[15] Sawczenko A, Sandhu BK, Logan RF, et al. Prospective survey of childhood inflammatory bowel disease in the British Isles. Lancet 2001;357:1093–4.
[16] Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. Inflammatory Bowel Diseases 2011;17:2169–73.
[17] Freed GL, Hudson EJ. Transitioning children with chronic diseases to adult care: current knowledge, practices, and directions. Journal of Pediatrics 2006;148:824–7.
[18] Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: the importance of structured transition care. Journal of Crohn's and Colitis 2011;5:509–19.
[19] Goodhand JR, Kamperidis N, Sirwan B, et al. Factors associated with thiopurine non-adherence in patients with inflammatory bowel disease. Alimentary Pharmacology and Therapeutics 2013;38:1097–108.

[20] Baldassano R, Ferry G, Griffiths A, et al. Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. Journal of Pediatric Gastroenterology and Nutrition 2002;34:245–8.
[21] Zeisler B, Hyams JS. Transition of management in adolescents with IBD. Nature Reviews Gastroenterology & Hepatology 2014;11:109–15.
[22] Mamula P, Markowitz JE, Baldassano RN. Inflammatory bowel disease in early childhood and adolescence: special considerations. Gastroenterology Clinics of North America 2003;32:967–95, viii.
[23] Sebastian S, Jenkins H, McCartney S, et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. Journal of Crohn's and Colitis 2012;6:830–44.
[24] Hait EJ, Barendse RM, Arnold JH, et al. Transition of adolescents with inflammatory bowel disease from pediatric to adult care: a survey of adult gastroenterologists. Journal of Pediatric Gastroenterology and Nutrition 2009;48:61–5.
[25] Dabadie A, Troadec F, Heresbach D, et al. Transition of patients with inflammatory bowel disease from pediatric to adult care. Gastroenterologie Clinique et Biologique 2008;32:451–9.
[26] Philpott JR. Transitional care in inflammatory bowel disease. Gastroenterology and Hepatology 2011;7:26–32.
[27] Escher JC. Transition from pediatric to adult health care in inflammatory bowel disease. Digestive Diseases 2009;27:382–6.
[28] El-Matary W. Transition of children with inflammatory bowel disease: big task, little evidence. World Journal of Gastroenterology 2009;15:3744–7.
[29] Paine CW, Stollon NB, Lucas MS, et al. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. Inflammatory Bowel Diseases 2014;20:2083–91.
[30] Whitfield EP, Fredericks EM, Eder SJ, et al. Transition readiness in pediatric patients with inflammatory bowel disease: a patient survey of self-management skills. Journal of Pediatric Gastroenterology and Nutrition 2014;60:36–41.
[31] Mooney PD, Hadjivassiliou M, Sanders DS. Coeliac disease. British Medical Journal 2014;348:g1561.
[32] Bardella MT, Elli L, De Matteis S, et al. Autoimmune disorders in patients affected by celiac sprue and inflammatory bowel disease. Annals of Medicine 2009;41:139–43.
[33] Bardella MT, Elli L, Velio P, et al. Silent celiac disease is frequent in the siblings of newly diagnosed celiac patients. Digestion 2007;75:182–7.
[34] Elli L, Discepolo V, Bardella MT, et al. Does gluten intake influence the development of celiac disease-associated complications. Journal of Clinical Gastroenterology 2014;48:13–20.
[35] Elli L, Contiero P, Tagliabue G, et al. Risk of intestinal lymphoma in undiagnosed coeliac disease: results from a registered population with different coeliac disease prevalence. Digestive and Liver Disease 2012;44:743–7.
[36] Elli L, Bonura A, Garavaglia D, et al. Immunological comorbity in coeliac disease: associations, risk factors and clinical implications. Journal of Clinical Immunology 2012;32:984–90.
[37] Olsson C, Hornell A, Ivarsson A, et al. The everyday life of adolescent coeliacs: issues of importance for compliance with the gluten-free diet. Journal of Human Nutrition and Dietetics 2008;21:359–67.
[38] O'Leary C, Wieneke P, Healy M, et al. Celiac disease and the transition from childhood to adulthood: a 28-year follow-up. American Journal of Gastroenterology 2004;99:2437–41.
[39] Lee A, Newman JM. Celiac diet: its impact on quality of life. Journal of the American Dietetic Association 2003;103:1533–5.
[40] Tjon JM, van Bergen J, Koning F. Celiac disease: how complicated can it get. Immunogenetics 2010;62:641–51.
[41] Vajro P, Ferrante L, Lenta S, et al. Management of adults with paediatric-onset chronic liver disease: strategic issues for transition care. Digestive and Liver Disease 2014;46:295–301.
[42] Rook M, Rosenthal P. Caring for adults with pediatric liver disease. Current Gastroenterology Reports 2009;11:83–9.
[43] Goldman M, Pranikoff T. Biliary disease in children. Current Gastroenterology Reports 2011;13:193–201.
[44] Hartley JL, Gissen P, Kelly DA. Alagille syndrome and other hereditary causes of cholestasis. Clinics in Liver Disease 2013;17:279–300.
[45] Stockley RA. Alpha1-antitrypsin review. Clinics in Chest Medicine 2014;35:39–50.
[46] Jacquemin E. Progressive familial intrahepatic cholestasis. Clinics and Research in Hepatology and Gastroenterology 2012;36(Suppl. 1):S26–35.
[47] Weiss KH, Stremmel W. Evolving perspectives in Wilson disease: diagnosis, treatment and monitoring. Current Gastroenterology Reports 2012;14:1–7.
[48] Maggiore G, Nastasio S, Sciveres M. Juvenile autoimmune hepatitis: spectrum of the disease. World Journal of Hepatology 2014;6:464–76.
[49] Niederau C. Chronic hepatitis B in 2014: great therapeutic progress, large diagnostic deficit. World Journal of Gastroenterology 2014;20:11595–617.
[50] Muir AJ. The rapid evolution of treatment strategies for hepatitis C. American Journal of Gastroenterology 2014;109:628–35, quiz 36.
[51] Dobbels F, Van Damme-Lombaert R, Vanhaecke J, et al. Growing pains: non-adherence with the immunosuppressive regimen in adolescent transplant recipients. Pediatric Transplantation 2005;9:381–90.
[52] Fredericks EM. Nonadherence and the transition to adulthood. Liver Transplantation 2009;15(Suppl. 2):S63–9.
[53] Guariso G, Visona Dalla Pozza L, Manea S, et al. Italian experience of pediatric liver transplantation. Pediatric Transplantation 2007;11:755–63.
[54] Neuberger JM. Transition of care between paediatric and adult gastroenterology. Liver transplantation. Best Practice and Research Clinical Gastroenterology 2003;17:277–89.
[55] Caffery LJ, Smith AC. A literature review of email-based telemedicine. Studies in Health Technology and Informatics 2010;161:20–34.