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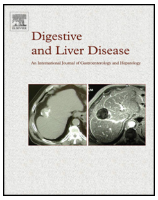

Position Paper

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.