Optimization of the Transition of Pediatric Patients with Chronic Digestive Diseases to Adult-Oriented Healthcare Services

PhD Candidate: Silvia Cristina Poamăneagră (Strat)
Scientific Coordinator: Professor Smaranda Diaconescu

With the increasing survival rates of children and adolescents with chronic conditions such as congenital heart diseases, cystic fibrosis, congenital hepato-biliary disorders, and neoplasms, the prevalence of adolescents requiring transition from pediatric to adult healthcare services has risen considerably. Over the past decade, international scientific interest has focused on this topic, and transition service models have been implemented for various chronic pathologies.

Currently, in Romania, the prevalence of chronic digestive diseases among children is increasing, primarily due to early diagnosis facilitated by continuous technological advancement, the training of specialists in pediatric gastroenterology, and improved access to modern diagnostic and therapeutic modalities. Nevertheless, at the national level, there is no systematized protocol for transitioning these patients to adult-oriented healthcare services. In practice, the transfer to an adult gastroenterologist is typically based on a simple transmission of medical information through the patient, rather than on a structured and coordinated transition process.

Therefore, the present research aims to identify an optimal transition protocol for adolescents with chronic digestive disorders to adult-oriented healthcare services, ensuring the success of the transition process, the maintenance of disease stability, and optimal control of associated risk factors.

This work comprises retrospective studies (Study 1), cross-sectional studies based on questionnaire methodology (Studies 2, 3, and 4), and a prospective randomized interventional study (Study 5).

The first study was a retrospective observational study that evaluated patients aged 14 to 16 years with chronic digestive diseases who had attended at least one consultation at the Pediatric Gastroenterology Clinic between 2019–2020. A total of 223 patients were retrospectively analyzed. The patients were registered in the clinic with the following conditions: inflammatory bowel diseases (IBD), namely ulcerative colitis (UC) and Crohn's disease (CD); celiac disease; cystic fibrosis; chronic viral hepatitis B and C; liver cirrhosis; rare diseases (Pompe disease, portal cavernoma, autoimmune hepatitis); and chronic gastritis. The diagnosis of IBD was established, in most cases, at the onset of adolescence, with a mean disease duration at the time of analysis of 27.56 months for UC and 22.33 months for CD. In patients with UC, the average number of medical visits was three per year, whereas in CD it exceeded four visits annually. Patients with cystic fibrosis were diagnosed at the youngest age (2 years and 11 months), had the longest disease duration (over 10 years), and required the most intensive monitoring (up to 12 visits per year).

The second study was a cross-sectional investigation employing a questionnaire-based methodology to evaluate the practices used by a group of specialists from the North-Eastern region of Romania in the transition process of pediatric patients with chronic digestive diseases. A total of 70 respondents participated in the study, of whom 90% reported not having access to structured transition protocols. The ideal age for initiating the transition process was considered to be 16–17 years (51.4%), while transfer to adult services was recommended at 19–20 years by 42.9% of participants and at 18 years by 45.7%.

Regarding necessary resources, 78.55% of respondents expressed the need for an online platform, 58.55% requested transition readiness assessment tools, 51.41% identified online forms distributed via social media networks, and 48.55% selected informational brochures for patients and families, as well as a guideline for healthcare professionals. The identified barriers included the absence of a transition specialist (65.7%), lack of time to implement individualized transition programs (61.41%), patients' psycho-emotional attachment to the pediatric care team (52.84%), and insufficient knowledge among adolescents regarding their chronic disease (57.13%).

The third study was a cross-sectional investigation that assessed the needs and perceptions of legal guardians regarding the transition process, as well as the socio-demographic and financial characteristics that could contribute to defining the particular profile of families with children suffering from chronic digestive diseases who are approaching the transition stage and reside in the North-Eastern region of Romania. A total of 124 participants were included, of whom 73.4% lived in rural areas and 81.5% were the patients' mothers.

Positive correlations were identified between parents' perception of their child's readiness to make health-related decisions and overall transition preparedness ($r = 0.544$; $p = 0.000$); between encouraging the organization of medical records and parents' perception of their child's disease-related knowledge ($r = 0.67$; $p = 0.000$); between fear of therapeutic interruptions during transition and the perceived need for transition-related education ($r = 0.704$; $p = 0.000$); between fear of inappropriate health-related choices made by their children and fear of therapeutic interruptions ($r = 0.573$; $p = 0.000$), as well as parents' perception that adult healthcare providers would be more patient-oriented and less family-centered ($r = 0.453$; $p < 0.000$); and between parents' confidence in their children's self-management abilities and encouragement of independent decision-making ($r = 0.673$; $p < 0.000$).

The fourth study was a cross-sectional investigation assessing transition readiness among a cohort of adolescents with chronic digestive diseases from the North-Eastern region of Romania. A total of 124 patients were evaluated: 73.38% resided in rural areas and 26.62% in urban areas; 59.67% were female and 40.33% male. Most participants (91.93%) were enrolled in school, and 73.4% reported their intention to pursue university studies after the age of 18. Adolescents from urban areas demonstrated significantly better medication management skills ($p < 0.01$) and improved ability to monitor changes in their health status. Significant correlations were identified between medication management and appointment scheduling, health status monitoring, and communication skills. All investigated domains were positively correlated with overall transition readiness scores, highlighting the potential impact of targeted, active interventions during the transition process.

The final study was a prospective randomized interventional study that analyzed three models of transition. Patients were randomized into three groups: two intervention groups and one control group. The first intervention group benefited from transition assessment and counseling during the 11th and 12th grades, while the second group received two counseling sessions exclusively during the 12th grade. The control group did not undergo evaluation or active intervention and was automatically transferred to adult healthcare services at the age of 18. All patient groups were prospectively evaluated following transfer to adult-oriented medical services.

The comparative analysis of the three groups revealed significant differences between the two proposed intervention models and the traditional transfer approach. Treatment adherence was maximal in both intervention groups, whereas in the control group, 42% of participants experienced therapeutic interruptions. Regarding the level of knowledge about the chronic disease and the complications associated with treatment discontinuation, responses were relatively homogeneous in the intervention groups. In

contrast, in the control group, 58% of respondents self-assessed their knowledge as “limited,” and 42% as “very limited.”

The results indicate maximal therapeutic adherence in both intervention groups, compared to the control group, in which 42% of patients experienced therapeutic interruptions. The level of knowledge regarding the chronic disease was homogeneous and superior in the intervention groups, whereas the majority of patients in the control group reported limited or very limited knowledge. Communication with the physician and collaboration in developing the care plan were significantly more effective in the intervention groups, particularly in Group 1.

Post-transition clinical indicators revealed lower rates of hospitalization and emergency service utilization in the intervention groups compared to the control group. Regarding self-management of medical appointments, Group 2 demonstrated the highest level of autonomy, followed by Group 1, while the control group showed minimal involvement.

In conclusion, the findings support the relevance of implementing formal transition programs, even when concentrated within a shorter timeframe, demonstrating that well-targeted interventions can have a transformative impact on preparing young individuals with chronic diseases for integration into adult-oriented healthcare services.