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Status of transition care in inflammatory bowel disease in Spain. Different medical perspectives

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ABSTRACT

Introduction: transition is important for a successful follow-up of adolescents with inflammatory bowel disease (IBD). The objectives of the study were to establish the situation of transition in Spain and to identify needs, requirements and barriers to transition from pediatric and adult gastroenterologist perspectives.

Methods: a structured survey for self-completion using the REDCap platform was distributed via the Spanish Society for Pediatric Gastroenterology, Hepatology and Nutrition (SEGHNP) and the Spanish Working Group on Crohn's Disease and Ulcerative Colitis (GETECCU). The questionnaire contained closed and ranked questions concerning transition, perceived needs, organizational, clinician and patient related barriers to transition.

Results: one hundred and forty surveys were answered, 53% in pediatrics (PG) and 47% from adult gastroenterologists (AG) among 90 hospitals; 66% of them were reference centers**.** There was a higher response from pediatricians (18.2%) *versus* adult gastroenterologists (8.3%) (p = 0.03). A structured transition program is adequate in 42.2% centers. A well-structured transition was perceived as very important by 79.5% of PG and 63% of AG (p = 0.03). A higher proportion of both groups identified inadequacies in the preparation of adolescents for transfer (43% and 38%, p = ns). The main deficit areas were the lack of knowledge about disease and treatment as well as the lack of self-advocacy and care coordination. Lack of resources, time and critical mass of patients were the highest ranked barriers by both groups. AG and PG (54% and 55%) highlighted suboptimal training in adolescent medicine.

Conclusions: in Spain, nearly half of the centers have developed a structured transition program. Lack of training, time and insufficient resources are the main barriers for a successful transition.

Key words: Inflammatory bowel disease. Adolescent. Pediatric. Adult gastroenterologist. Transition. Spain.

INTRODUCTION

Inflammatory bowel disease (IBD) has an incidence of 2.8/100,000 in our environment and a third of cases occur before the age of 20 years (1). With regard to pediatric IBD, adolescence is a critical moment of physical and psychological changes that influence its evolution (2).

Blum et al. defined transition as the planned movement of adolescents with chronic diseases to adult healthcare systems (3). Transition care programs require preparation, anticipation and planning. Their implementation has demonstrated a better disease control, adherence and continuity of care (4-8). For all these reasons, structured transition is a fundamental part of the clinical care of adolescents (9).

Currently, there is no ideal care transition model for IBD. Such programs often depend on factors related to the patient, pediatric and adult services involved, as well as health care organizations in each country. Due to these differences, a comparison of programs becomes more difficult to make across countries.

The main objectives of the study were to determine the current situation of the centers with IBD transition care programs in Spain and to analyze their development and the tools used in their application and evaluation. Other objectives were to identify the needs, requirements and barriers detected in the process by pediatric and adult gastroenterologists and to establish measures to improve transition in Spain.

METHODS

A descriptive, cross sectional study was performed using a survey distributed among pediatric gastroenterologists (PG) and adult gastroenterologists (AG). The contents of the questionnaire were developed based on the extensive literature of the standard practice in transition care in chronic diseases (10-12).

The 21-item survey contained five questions of categorical variables and the responses were ranked on the Likert-Scale of 1 to 5, defined as “5 = very important” and “1 = not important”. Furthermore, there were five closed multiple answer questions and eleven single answer questions. This survey addressed three main areas: the current status of transition care in Spain, perceived needs for effective transition care in IBD and perceived barriers to a successful transition in organizational, clinician, patient-related and professional terms. Likewise, the responses were analyzed and compared in block and separately between both medical groups.

The study was approved by the Ethics Committee of the Hospital Gregorio Marañón in Madrid, Spain. The survey was distributed via the REDCap platform, with a monthly automatic reminder by email, from October to December 2017. Study data were collected and managed using the REDCap electronic data capture tools (13) hosted at the Spanish Society for Pediatric Gastroenterology, Hepatology and Nutrition (SEGHNP) (www.recap.seghnp.org) with technical support by AEGREDCap (14). The survey was distributed to the SEPGHNP and the Spanish Working Group on Crohn’s Disease and Ulcerative Colitis (GETECCU).

Statistical analyses were performed using SPSS version 21 (SPSS, Chicago, IL, USA) and the Chi-squared test was used for the comparison of proportions. The non-parametric Mann-Whitney U test was used for categorical variables. The Likert scale was used as a validated test for the scaled psychometrics questions about interest. The threshold for statistical significance was set at $p < 0.05$.

RESULTS

Demographic of responses

According to the latest records of both medical societies, 140 surveys were returned from 803 AG and 402 PG. The response rate was 11.6%, which was significantly higher among pediatricians (18.2% PG [73/402] *versus* 8.3% AG [67/803], p = 0.03). One hundred and thirty-eight surveys were completed, 53% from PG.

The gastroenterologist responders belonged to 90 institutions of the 275 hospitals (32.7%) within the Spanish National Health System (SNHS) (15); there was no more than one response per medical service. Madrid, Andalucía and Cataluña were the areas with the highest response rate as the highest number of hospital areas (35%). Among the 90 centers involved, 66.7% were tertiary/reference hospitals (Table 1). However, 38 (42.2%) of the responding centers had developed transition programs and there were no significant differences between heath care level. At least one center belonging to each autonomous community (CCAA) had developed transition programs, except for three.

In our study, 41.1% of PG care patients were up to 16 years and 34.2% were up to 18 years of age, while only 26.2% of the AG surveyed care patients were between 14 and 16 years, and 73.8% were over 16 years of age. Nevertheless, both medical groups thought there were insufficient training to deal with adolescents with chronic diseases (AG 58.6% and 41.4% of PG, p = ns). The median number of patients transited per year in Spanish hospitals was three (IQR: 7, range: 1-30) and 70% of centers had fewer than five patients per year and more frequently less than two (34%).

Perceived importance of structured transition

With regard to the importance of structured transition, 98.6% of the surveys showed an interest in the care transition process rated as "very important" (72.3%) or "moderately important" (26.3%). The transition program was valued as "very important" by 80.6% of PG and 63.1% of AG (p = 0.03). No statistically significant differences were found depending on the healthcare level.

The tools most used in programs were the joint session to introduce patients (72.1%), common visits of members of both services (67.2%) and alternate visits and a written program (27.9%). Regarding the program coordinator (27.9% of the centers), 47% corresponded to the PG, 30% to AG and in 23% to nurses.

The most frequent difficulties for transition by the centers without programs were a lack of time (41.6%), lack of cooperation between services (19.5%) and a lack of personnel and organization support (24.7%).

Timing of transition

The ideal age suggested for the initiation of transition was 14-16 years (52.7%), followed by 16-18 years (29.0%); 61.1% of participants selected this as the ideal age range to complete transition. With regard to patients-related criteria for the beginning of the transition (age over 14, leaving school, marriage or pregnancy, clinical remission and maturity), PG gave a greater importance to clinical remission and maturity (p = 0.03 and p = 0.012, respectively).

Perceived barriers to adequate transition

In relation to the perceived barriers to adequate transition, 48.1% of participants did not consider the patients' understanding of the disease adequate at the beginning of transition and there were no significant differences between medical groups. The areas with a lower preparation were self-care strategies (77.8%), maturity (65.1%), understanding of treatment and disease (41.3%) and the knowledge of the National Health System (35%). PG suggested that the lack of maturity and self-care was significantly more important (p = 0.006 and p = 0.03, respectively). Both groups considered the lack of patient independence and lack of self-care, the limited understanding of disease, parental reluctance to transition, the dependence on the pediatric service and the lack of clinic space/time of adult consultations as important barriers. AG considered the lack of trust from patients and their families in adult services as significantly greater (Table 2).

Potential barriers in the health care organization that were considered as very important were the lack of time and clinic space, lack of support from the health care organization, lack of organizational structures in each center and a lack of common protocols. However, AG also considered the lack of communication between services and a lack of support from pediatric services as significantly very important (p = 0.045 and p = 0.017, respectively) (Table 3).

Transition protocols at present

In the clinical practice, the time most frequently chosen to introduce the transition program was two years before the transfer (37.0%). Communication of the transition at first pediatric visit (16.7%) or at an obligatory administrative age (13.0%) were considered as less important.

The tools more frequently used to develop transition protocols were training material on IBD (57.3%), a program coordinator (29.5%), written programs (24.6%), check-list of transition documents (23.0%) and written chronograms including visits and final transference (21.3%). Virtual connections were facilitated during the process in only 21% of cases.

To evaluate the programs, the most used tools were the improvement of healthcare objectives (32.8%), scheduled satisfaction surveys by patients after the transition (14.8%) and quality of life questionnaires (6.6%). In centers with a transition program, 49.2% reviewed the protocol periodically (40% annually, 30% every two years, and 26.7% beyond five years).

DISCUSSION

In Spain, there are no specific clinical guidelines for transition care in IBD, unlike other countries (16-21). Thus, each center designs its own transition programs adapted to the characteristics of patients, families and the services involved. Our study is the first one that describes the distribution of centers with transition programs and the tools used for their development in Spain. Furthermore, it also allows us to know different perceptions from the physicians involved, requirements and barriers and also to establish measures that will improve the process of transition in Spain.

The response rate by pediatric and adult gastroenterologists in our study was lower than that published in the United Kingdom (10) (51%) and outside Europe (26% in Saudi Arabia [22], 28.2% in the Quebec area [23], and 41% in Australia and New Zealand [5]). It was slightly higher than that reported in the United States (8.5%) (11,14). However, when the distribution of the survey in these studies was analyzed, this did not specify the degree of experience with IBD nor their participation in transition programs. Thus the state of transition is likely to be overestimated. In our study, the response rate of physicians with an established transition program was significantly higher among pediatricians than in previous studies.

Furthermore, the number of participating hospitals throughout Spain is high, especially reference centers, which implies an adequate representation of the transition situation in our country. The percentage of centers with transition programs is higher than that reported in other countries (27% in UK [10], 26% in Saudi Arabia [22], and 25.4% in the United States [11]) but lower than in France (60%) (24). In addition, there are no differences in Spain in the application of the transition programs in relation to the hospital level. The autonomous communities with the highest percentage of transition programs are the most populated and have the highest number of hospitals in the SNHS. The most important barriers for the absence of programs cited were the lack of time, lack of cooperation between services and lack of patients with IBD, which is similar to other studies (10,11,24,25). In order to solve these problems, it would be necessary to increase the interest of health care organizations, the involvement of professionals and continuous training on transition (23).

Despite the fact that there is no single model of transition, a greater number of programs in our country include joint patient exposure sessions and common visits with both services. This model follows the recommendations of the European Crohn's and Colitis Organization (ECCO) (26) like

France (24), Israel and Italy (27), due to the similarity of their health care structure. However, in countries with a greater territorial dispersion, this model is less useful and other tools are used (e-mail or alternating visits between services) (11,22,28). In Spain, tools such as the delivery of written programs, transition checklists, or maturity scales are used to a minor extent (23). The program coordinators are used in less than half of the programs, mostly by pediatricians, unlike other countries where nurses are responsible. Currently, in Spain, multidisciplinary IBD units are being accredited and it is expected that the involvement of specialized nursing personnel in the transition process will increase.

In our study, the timing of transition was shown to be flexible between the initiation time at 14 and completion at 18 years, as in the United States, Canada and the United Kingdom, whereas in other studies the limit is 16-18 years (9,23,24). The time of transition should ideally happen in relation to maturity for optimal adult care, especially for pediatricians (10,23,28). This contrasts with the scarce use of maturity scale tools during the process. The importance of disease remission scored higher among pediatricians, as in other studies (10). Furthermore, pediatricians consider the understanding of the disease and the clinical conditions as important factors of the transition (8,29).

With regard to barriers, these can be grouped into two groups: patient-family communication and communication between services. Within the first group, the lack of understanding of the disease, self-care and the lack of maturity are the most important barriers. These were also highlighted in other studies abroad (10,12,23). Therefore, the promotion of training of patients about the disease with written medical material and scientific information on social networks and the internet will be important to improve the transition programs. We should stimulate the autonomy/independence of patients that attend the clinic unaccompanied by relatives, handling of appointments by the adolescent and the assessment of therapeutic adherence (30).

Our study raised the importance of communication barriers for adult gastroenterologists, such as the lack of trust in receiving services, lack of communication between services and lack of support from pediatricians, unlike other countries (10,11). This data highlights the need to improve communication with the application of common protocols and the use of updated modern communication tools (internet, telemedicine). Furthermore, common visits are required to introduce the future adult doctors, written references to adult services and an increased involvement of all professionals in the transition process (24).

Regarding the barriers of the health care organizations, lack of time, organizational support and space for joint visits were identified, as in previous studies (10,25). Thus, an appropriate care transition should be considered as a healthcare objective that requires the support of the health organization at all times (11,12).

In our study, a high percentage of gastroenterologists reported that they did not feel adequately prepared to deal with adolescents in transition, which is similar to that referred by European countries. In other countries such as Canada and the United States, health care professionals perceive a better training, probably thanks to guides, meetings and on-line training, etc. (11,12,23).

Transition is actually perceived by patients with a high satisfaction, improving the perceived quality of their follow-up and the services involved (31,32). Furthermore, transition programs are relatively recent in Spain, so their evaluation and review are a lower priority than their development. In our setting, we should work with professionals on the importance of the frequency of evaluation by patients and the review of programs (7,23).

Finally, this study has a number of limitations such as the low response rate of professionals, which may overestimate the importance given to transition in our country. Furthermore, a bias that improves with the wide geographical distribution, the importance of the responding hospitals and the number of centers by regions with a program should also be highlighted. In this study we focused on physicians, especially adult gastroenterologists involved in inflammatory bowel disease, and other health professionals such as nurses were not included. Even though we used a non-validated questionnaire, the use of the Likert scale as a validated tool to measure the trend towards median perceptions means that we can compare our results with similar studies abroad, despite the possible response bias of respondents (10,12).

CONCLUSIONS

In conclusion, nearly half of the Spanish responding centers have developed structured transition programs. However, all autonomous communities have a representative transitional care program. Similar models of transition programs developed include patient introduction sessions and joint visits by professionals.

The main barriers detected in transition were the lack of autonomy, lack of self-care and family reluctance, as well as a lack of trust in the receiving services. The most important barriers of health care organization were the lack of time and clinic space, the lack of interest and structures for its organization and the lack of communication between services. For all these reasons, the transition programs in Spain require a multidisciplinary approach, improving collaboration and communication, with a greater support from the Health Care Organization.

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Table 1. Regional representation of respondent centers in Spain

	AG (n = 65)	*PG (n = 73)*	*Answers per physicians (n = 138)*	*Answers per center (n = 90)*	*Centers with transition program*
Andalucía	9 (13.8%)	11 (15.1%)	20 (14.3%)	14 (15.6%)	5/14 (35.5%)
Aragón	-	2 (2.7%)	2 (1.4%)	2 (2.2%)	1/2 (50%)
Cantabria	1 (1.5%)	-	1 (0.7%)	1 (1.1%)	-
Castilla y León	2 (3.1%)	6 (8.2%)	8 (5.7%)	6 (6.6%)	1/6 (16.7%)
Castilla-La Mancha	3 (4.6%)	4 (5.5%)	7 (5%)	4 (4.4%)	1/4 (25%)
Cataluña	10 (15.4%)	9 (12.3%)	19 (13.6%)	11 (12.2%)	8/11 (72.3%)
Comunidad Foral de Navarra	2 (3.1%)	1 (1.4%)	2 (2.1%)	1 (1.11%)	1/1 (100%)
Comunidad Valenciana	8 (12.3%)	5 (6.8%)	13 (9.3%)	9 (9.99%)	1/9 (11.1%)
Extremadura		1 (1.4%)	1 (0.7%)	1 (1.11%)	-
Galicia	6 (9.2%)	7 (9.6%)	13 (9.3%)	6 (6.66%)	3/6 (50%)
Islas Baleares	1 (1.5%)	1 (1.4%)	2 (1.4%)	2 (2.2%)	1/2 (50%)
Islas Canarias	7 (10.8%)	2 (2.7%)	9 (6.4%)	4 (4.4%)	1/4 (25%)
La Rioja	1 (1.5%)	-	1 (0.7%)	1 (1.11%)	-
Madrid	9 (13.8%)	18 (24.7%)	27 (19.3%)	19 (21.1%)	12/19 (63.1%)
País Vasco	2 (3.1%)	4 (5.5%)	6 (4.3%)	4 (4.44%)	1/4 (25%)
Principado de Asturias	3 (4.6%)	1 (1.4%)	4 (2.9%)	3 (3.3%)	1/3 (33.3%)
Región de Murcia	1 (1.5%)	1 (1.4%)	2 (1.4%)	2 (2.22%)	1/2 (50%)

PG: pediatric gastroenterologist; AG: adult gastroenterologist.

Table 2. Perceived importance of competencies in transition

	AG (n = 59) Mean ± SD	*PG (n = 71) Mean ± SD*	*p value*
Understanding of disease	4.5 ± 0.5	4.5 ± 0.7	NS
Understanding of treatment	4.5 ± 0.5	4.7 ± 0.6	0.015
Understanding of impact of diet	3.4 ± 1	3.8 ± 1	0.003
Ability to attend clinics without parents	3.8 ± 1	4.1 ± 0.9	NS
Ability to take medicines independently	4.2 ± 0.8	4.6 ± 0.9	0.001
Disease remission	3.8 ± 0.9	4.1 ± 0.85	NS
Previous knowledge of teams	4.1 ± 0.8	4.1 ± 0.9	NS
Therapeutic adherence	4.3 ± 0.8	4.3 ± 0.8	NS

PG: pediatric gastroenterologist; AG: adult gastroenterologist. Range of response: 1 = not important – 5 = very important. Mann-Whitney U test.

Table 3. Patient/parent and health system organizational barriers

	AG (n = 55) Mean ± SD	*PG (n = 68) Mean ± SD*	*p value*
Patient/parent barrier			
Knowledge of disease	3.9 ± 0.9	3.7 ± 1	NS
Lack of independence	4.2 ± 0.8	4.2 ±1	NS
Lack of self-care	4.1 ± 0.7	4.2 ± 0.9	NS
Parental reluctance	3.98 ± 0.9	3.93 ± 0.77	NS
Lack of trust in receiving services	3.9 ± 1.1	3.4 ± 1.2	0.008
Dependence on the pediatric service	3.9 ± 0.9	4.1 ± 0.8	NS
Administrative problems	3.5 ± 1	3.8 ± 1	NS
Health system organization			
Lack of interest of pediatric service	3.3 ± 1.2	2.9 ± 1.5	NS
Lack of interest of adult service	3.4 ± 1.1	3.3 ± 1.4	NS
Lack of time and clinic space	4.2 ± 0.8	4.4 ± 0.9	NS
Lack of interest of Health Care System	4.3 ± 0.9	4.2 ± 1	NS
Lack of organizational structures	4.3 ± 0.77	4.25 ± 0.9	NS
Lack of defined protocols	4.3 ± 0.7	4.1 ± 0.8	NS
Lack of communication between services	3.9 ± 1.1	3.4 ± 1.5	0.045

PG: pediatric gastroenterologist; AG: adult gastroenterologist. Range of response: 1 = not important – 5 = very important. Mann-Whitney U test.