



ORIGINAL ARTICLE

Transition of patients with inflammatory bowel disease from pediatric to adult care

Transition vers le gastroentérologue d'adultes des enfants suivis pour une maladie inflammatoire chronique intestinale

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Summary

Aim. – This study was designed to ascertain the perception of patients (and their parents) followed-up for inflammatory bowel disease (IBD) concerning the transition from pediatric to adult care.

Patients and methods. – Forty-eight youths with IBD who had transited from pediatric to adult care were surveyed. Their age at transition was 17.9 ± 0.9 years. Thirty-four patients (71%) had been referred to a gastroenterologist working in the same hospital and, in 27 cases, after having attended a joint pediatric–adult care visit.

Results. – The response rate was 71%. Twenty-nine patients (85%) and 25 parents (74%) felt they were ready to transit into adult care. Seven patients (22%) and 10 parents (32%) were apprehensive about transition to adult gastroenterology. All patients considered the joint medical visit beneficial in terms of transmitting information from their medical records and 93% considered it beneficial for building confidence in the new gastroenterologist. All parents considered the joint medical visit helpful for building the children's confidence in their new doctor. At the time of the survey, 29 patients (85%) were continuing to be followed-up by the same gastroenterologist.

Conclusion. – Effective planning, including a joint medical visit, enabled successful, well-coordinated transition to adult medical-care follow-up.

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Résumé

Objectif. – Évaluer le vécu des patients suivis pour maladie inflammatoire chronique intestinale, ainsi que de leurs parents, lors de la transition entre pédiatrie et médecine d'adultes.

Patients et méthodes. – Quarante-huit enfants devenus adultes et désormais suivis par un gastroentérologue d'adultes ont été inclus. L'âge lors de la transition était de $17,9 \pm 0,9$ ans. Trente-quatre patients (71 %) ont été confiés aux gastroentérologues du même hôpital, 27 fois au cours d'une consultation commune pédiatre–gastroentérologue.

Résultats. – Le taux de réponses était de 71 %. Vingt-neuf patients (85 %) et 25 parents (74 %) se sentaient prêts pour le passage en médecine d'adultes. Sept patients (22 %) et dix parents (32 %) l'appréhendaient. Tous les patients ont jugé la consultation commune bénéfique pour la connaissance du dossier et dans 93 % des cas bénéfique pour la confiance accordée au nouveau référent. Tous les parents ont jugé la consultation commune bénéfique pour la confiance accordée par leur enfant au nouveau référent. Vingt-neuf patients (85 %) étaient toujours suivis par le même gastroentérologue d'adultes. L'organisation de la transition et en particulier la consultation commune pédiatre–gastroentérologue ont permis d'assurer la poursuite de soins de façon coordonnée et sans rupture.

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Introduction

In Brittany, the annual incidence of inflammatory bowel disease (IBD) in the pediatric population is 1.6 per 100,000 for Crohn's disease and 0.5 per 100,000 for ulcerative colitis. IBD had begun before 17 years of age in 6.7% of these children [1]. Since IBD is a chronic illness, these patients will eventually move from pediatric to adult care, requiring the involvement of 'referring' pediatric and 'referral' adult-care physicians, as well as the adolescents themselves and their families. All of these healthcare partners have to participate in a careful examination of both the risks of the transition and the practical procedures involved. The extensive body of literature devoted to this problematical issue includes reviews and guidelines proposed by various learned societies [2–6], but no 'real-life' survey of adult patients who made the transition from pediatric to adult care.

Since 1992, the pediatric gastroenterology unit at the Rennes University Hospital Center has arranged for a joint medical visit for pediatric patients with IBD scheduled for transition to adult care within the center. The patients and their parents (on their request) are invited to attend a joint visit with the pediatric and adult gastroenterologists before making the transition. The purpose of the present study was to learn more about the way patients and their parents perceived this experience as a function of transition to adult-care gastroenterology.

Patients and methods

Since 1992, IBD pediatric patients who reach adulthood have been invited to transfer their subsequent care to the adult gastroenterology unit of the same University Hospital Center or to another practitioner. When patients express their desire to stay within the same center, a one-hour joint visit is scheduled in the adult-care gastroenterology unit to plan for further follow-up. This consultation is conducted by both the pediatric physician currently in charge of the patient and the adult-care gastroenterologist proposed for the subsequent

follow-up. Patients may attend the visit with or without their parents, as they wish. The objective is to enable a discussion among the participating partners to detail the patient's medical situation. The pediatric physician summarizes the patient's record for the new physician and the patient and/or parents contribute whatever further information they feel is necessary. The current treatment is then discussed along with any future considerations (need for further examinations, control endoscopy procedures, treatment changes). Then, with the patient's agreement, the pediatric and adult gastroenterologists establish a treatment and follow-up schedule. For patients who request referral to another, outside specialist rather than staying within the same center (for example, for personal reasons related to occupational or educational needs), a complete summary of the patient's record is sent to the referral physician.

The present study included all patients with IBD, followed regularly by the pediatric gastroenterology unit of the Rennes University Hospital Center from 1988 to 2005, who became adults during this period and who were followed for at least one year by an adult-care gastroenterologist. Of the 48 patients (37 male, 11 female) who were included, 38 had Crohn's disease (28 male, 10 female) and 10 had ulcerative or non-classifiable colitis (nine male, one female). Given the small number of patients with ulcerative or non-classifiable colitis, all 48 patients were considered as one group with IBD. Mean age at diagnosis was 12 ± 2.2 years (median: 12 years, range: 6–16.5). Regular follow-up was defined as more than three visits per year for more than two years. The duration of pediatric follow-up was 5.8 ± 2.2 years (median: six years, range: 2–12).

Patients' data were collected from their pediatric medical charts and included age at diagnosis, duration of follow-up, age at transition, type of disease (Crohn's disease, ulcerative colitis, non-classifiable colitis), disease localization (cumulative over the entire follow-up period), medical and surgical treatments delivered and the presence or not of a mixed follow-up (pediatric and adult-care gastroenterologists) up to the time of transition (particularly

Table 1 The cumulative gastrointestinal localizations and treatments during pediatric assessment of the 48 patients involved in the survey.*Descriptif des localisations digestives cumulées et des traitements reçus au cours de la prise en charge pédiatrique des 48 patients inclus.*

	Crohn's disease (n = 38)	Ulcerative and non-classifiable colitis (n = 10)
Small bowel involvement	32 (84%)	0
Large bowel involvement	33 (87%)	10 (9 pancolitis)
Anal involvement	14 (41%)	
5-ASA	33 (87%)	10
Corticosteroids	32 (84%)	8
Azathioprine	23 (60%)	4
Infliximab	8 (21%)	2
Methotrexate	7 (18%)	0
Enteral nutrition	27 (71%)	1
Surgery	12 (31%) (1–5 procedures)	0

as regards proctological care). Data related to the transition included patient age, stage of puberty, educational or occupational situation, ongoing treatment, any indication for referral other than patient age, name of gastroenterologist chosen for follow-up and procedures of the joint visit, if any. To simplify the analysis, three categories were used to define disease activity at the time of transition: remission; treatment-controlled active disease; acute episode or complications requiring hospital admission to an adult-care unit because of age over 18 years. The characteristics of the study population are presented in [Table 1](#).

In June 2006, a questionnaire was mailed to patients and parents to collect data concerning their perception of the transition to adult-care gastroenterology. The questionnaire was accompanied by a covering letter explaining the study and a stamped return envelope. For the patients, the questionnaire was divided into three parts, covering the patient's current medical situation, the patient's adult opinion of the transition procedures and, if relevant, the patient's opinion of the joint visit with the pediatric and adult-care gastroenterologists. For the parents, the questionnaire included only the last two parts, concerning the procedures of the transition and the joint visit. The self-administered questionnaire had multiple-choice questions with spaces for additional remarks and could be completed and returned anonymously.

The study was designed as a retrospective evaluation of the patients' and parents' experience of the preparation for transition and the transition itself (with or without a joint visit). The patients and parents were also invited to offer any suggestions for improvements. The questionnaires, however, did not allow detailed 'discussion' of any other procedures that the patients or parents might have preferred, nor did they address the possibility of a joint visit for those patients who had not attended such a meeting.

Chi-square and Fisher's exact tests were used for statistical analyses where appropriate. $P < 0.05$ was considered statistically significant. Results are expressed as means \pm standard deviation (median, range). In the event of missing data, percentages were calculated per number of responses obtained, item by item.

Results

Circumstances of the transition

The mean patient age at transition was 17.9 ± 0.9 years (median: 18; range: 15.5–20.5). The transition was later in one patient (aged 20.5 years at transition) because of disease-related retardation of growth and puberty. Forty-six patients had completed puberty by the time of transition. These data were missing for two patients.

At the time of transition, 26 patients were in secondary school and 11 in higher education; failing in school was noted in two patients and was disease-related in one case. Five patients were in an occupational apprenticeship and data were missing for four others.

A total of 34 patients (71%) transferred their care to adult-care gastroenterologists within the same center (Rennes University Hospital Center), while 14 patients (29%) transferred their care to a private gastroenterologist chosen by the patients themselves and/or their parents; in these cases, the gastroenterologist chosen had either initially referred the patient to the pediatric unit ($n = 8$) or practised in a hospital center near the patient's residence ($n = 5$ in a teaching hospital, $n = 1$ in a general hospital).

The patients' characteristics at the time of transition are summarized in [Table 2](#) according to type of transition. There was no difference in disease activity at the time of transition, as this was deliberately undertaken during a period of disease quiescence. It was noted, however, that the disease course had been less severe, as reflected by the cumulative therapeutic regimens undertaken during pediatric care, among patients who transferred their care to a practitioner outside of the university center. The differences between the two patient groups were significant for all treatments other than salicylates (corticosteroids, immunosuppressants, enteral nutrition) ([Table 2](#)).

Organization of the transition

Among patients followed-up at the Rennes University Hospital Center, 27 (79%) attended a joint visit before their

Table 2 Comparison of patients according to the type of transition.
Comparaison des patients selon le type de transition.

	Transition within the same center (n = 34)	Other transitions (n = 14)	P
Age at diagnosis (years; range)	11.8 ± 2.4 (6–16.5)	12.5 ± 1.5 (11–16)	NS
Duration of follow-up (years; range)	6.2 ± 2.4 (2–12)	4.8 ± 1.4 (2–6.5)	< 0.05
Age at transition (years; range)	18 ± 0.8 (15.5–20.5)	17.4 ± 0.8 (16–18.5)	NS
Inflammatory bowel disease	28 Crohn's/6 colitis	10 Crohn's/4 colitis	NS
Disease activity at transition: remission/active/complications	23/6/5	13/0/1	NS
Cumulative treatments			
Corticosteroids	32	8	< 0.01
Enteral nutrition	23	5	< 0.05
Azathioprine	22	5	< 0.05
Infliximab	10	0	< 0.05
Surgery	12	1	< 0.05

definitive transition to adult care and constituted 'group A'. Five of these patients (15%) had been followed conjointly by pediatric and adult-care gastroenterologists for proctological care: three had a 'formal' joint visit and the two others declined such a visit as they had already attended several joint consultations and were familiar with adult gastroenterology care.

Group B (n = 21) comprised those patients followed at the Rennes University Hospital Center who did not attend a joint visit (either because of emergency hospital admission or because logistical problems prevented a joint consultation involving the patient, parents and physicians) together with those who transferred their follow-up to someone outside of the university center.

The characteristics of the patients in groups A and B and those who responded to the questionnaires are presented in Table 3. It should be borne in mind that the patients who attended a joint visit had more active disease during the pediatric follow-up, as evidenced by the cumulative therapeutic regimens they received. Anal involvement in Crohn's

disease was more frequent in group A patients and the transition was also less likely to have been organized for a period of complete remission in the A patients. Both of these differences were significant.

Perception of the transition

Responses were received from 34 patients and 34 parents (71%) (including one patient alone, one set of parents alone and 33 other patients and their parents). Although questionnaires could have been returned anonymously, all were returned with patient identification. The transition was further in the past for non-responders. It is worth noting that all non-responders had quiescent disease or were in remission at the time of transition. Comparative data for responders and non-responders are shown in Table 4.

At the time of the survey, most of the patients (29/34, 85%) were still being followed-up by the gastroenterologist designated at the time of transition. They had attended

Table 3 Characteristics of responding patients according to attendance or not at a joint consultation (responders only).
Caractéristiques des patients suivant l'organisation (groupe A) ou non (groupe B) d'une consultation commune pédiatre–gastroentérologue d'adultes (patients répondeurs uniquement).

	Group A (n = 20/27)	Group B (n = 14/21)	P
Age at diagnosis (years; range)	11.4 ± 12 (6–16)	12.4 ± 12.3 (9.5–14.5)	NS
Duration of follow-up (years; range)	6.3 ± 6 (2–12)	5.3 ± 5 (3–9)	NS
Age at transition (years; range)	17.7 ± 18 (15.5–19)	17.7 ± 18 (16–20)	NS
Inflammatory bowel disease	16 Crohn's/4 colitis	11 Crohn's/3 colitis	NS
Crohn's: small bowel	15/16	10/11	NS
Crohn's: large bowel	13/16	9/11	NS
Crohn's: anal	10/16	2/11	< 0.05
Disease activity at transition: remission/active/complications	9/6/5	13/0/1	< 0.05
Cumulative treatments			
Corticosteroids	19	9	< 0.05
Enteral nutrition	14	5	< 0.05
Azathioprine	15	4	< 0.01
Infliximab	8	0	< 0.01
Surgery	8	2	NS

Table 4 Comparison of patients responding and not responding to the survey questionnaire.
Comparaison des patients «répondeurs» et «non-répondeurs».

	Non-responders (n = 14)	Responders (n = 34)	P
Duration of pediatric follow-up (years; range)	5.6 ± 2 (2–8.5)	5.9 ± 2.3 (2–12)	NS
Age at diagnosis of IBD (years; range)	12.6 ± 2 (10–16.5)	11.8 ± 2.2 (6–16)	NS
Age at transition (years; range)	18.2 ± 0.9 (16.5–20.5)	17.7 ± 0.8 (15.5–20)	NS
Patients who attended a joint visit (%)	7 (50%)	20 (59%)	NS
Disease activity at transition: remission/active/complications	14/0/0	22/6/6	< 0.05
Time elapsed since transition (years; range)	4 ± 3.2 (1–11.5)	3.2 ± 2.5 (1–11.5)	< 0.05

3 ± 2.8 visits (median: 2; range: 1–12) per year. Of the remainder, two patients had discontinued their medical follow-up, one had moved to another area, one was followed within the same hospital, but by another gastroenterologist, and one gave no reason for changing physicians.

As nearly all of the responses (33/34) were provided by both patients and parents, the results are reported here comparatively. All patients remembered that their pediatric gastroenterologist had discussed the importance of transition to adult-care gastroenterology. All considered that this information had been delivered 'early enough' and all considered that their medical records had been transferred satisfactorily. Two patients contacted their pediatric physician once after the transition. Of 24 responders, 21 attended follow-up visits alone, within a mean period of one year.

All parents felt that they had received sufficient information about the transition. Those parents who felt they were not ready for the transition to adult-care gastroenterology gave the following reasons: it is difficult to change physicians; they had a good confidential relationship with the pediatric gastroenterologist; transition took place at the time of a surgical procedure; the child was too young (the parents wanted to delay the transition till after age 20). Two parents who felt unprepared for the transition and whose child did not attend a joint visit stated that they regretted not attending such a visit. The parents of 26 patients (79%)

visited the adult-care gastroenterologist with their child. The parents of four patients (13%) contacted the pediatric gastroenterologist once after the transition. The parents of 23 patients (77%) stated that they felt involved or totally involved in the new management scheme, whereas the parents of seven patients (23%) felt they were excluded from the new management scheme. The responses of all patients and parents are compared in Table 5.

The joint visit

This visit was a key element of the transition. The responses of patients with and without a joint visit are compared in Table 6. Although there was no significant difference between them, the patients who had a joint visit stated more often that the choice of which adult-care gastroenterologist had been imposed on them (9/20 totally or partially imposed versus 3/14 who felt the decision had been shared). These patients also were slightly more frequently apprehensive (6/13 versus 1/13) about the transition.

The responses of patients and parents concerning the joint visit are presented in Table 7. Out of 20 patients, 16 responded to this part of the questionnaire. Two patients considered that the duration of the joint visit was insufficient and six felt that having only one joint visit was not

Table 5 Comparison of patients' and parents' responses regarding medical transition to adult care.
Comparaison des réponses des patients et des parents au questionnaire sur la transition en gastroentérologie «d'adultes».

	Patients (n = 34)	Parents (n = 34)
From memory, at what age did you learn about transition to adult-care medicine?	16.9 ± 1.5 (17; 11–18)	16.8 ± 1.5 (17; 1–19)
Were you informed 'early enough' about this transition?	33 yes; 1 no response	33 yes; 1 no response
In your opinion, the choice of the new gastroenterologist was		
A shared decision	21	21
Partially imposed	8	6
Completely imposed	4	6
Did you feel 'ready' for the change to adult-care medicine?	29 yes; 4 no	25 yes; 9 no
Were you apprehensive about changing to adult-care medicine?	25 no; 7 yes	21 no; 10 yes
Did you feel more self-reliant?	13 yes; 20 no	
Did you think your child was sufficiently self-reliant?		27 yes; 6 no
After how long did you attend medical visits alone? (years; range)	3 'not yet'; 21 yes after 1 ± 1 year (0–3.5 years)	

Table 6 Comparison of patients' responses according to attendance or not at a joint medical visit.
Comparaison des réponses des patients suivant l'organisation (groupe A) ou non (groupe B) d'une consultation commune pédiatre–gastroentérologue d'adultes.

	Group A (n = 20)	Group B (n = 14)	P
From memory, at what age did you learn about transition to adult-care medicine?	16.8 ± 1.8 (17; 11–18)	17 ± 1 (17; 15–18)	NS
Were you informed 'early enough' about this transition?	20 yes	14 yes	NS
In your opinion, the choice of the new gastroenterologist was			
A shared decision	11	11	NS
Partially imposed	5	3	
Completely imposed	4	0	
Did you feel 'ready' for the change to adult-care medicine?	17 yes; 3 no	13 yes; 1 no	NS
Were you apprehensive about changing to adult-care medicine?	13 no; 6 yes	12 no; 1 yes	NS
Did you feel more self-reliant?	9 yes; 11 no	4 yes; 9 no	NS
After how long did you attend medical visits alone? (years; range)	3 'not yet'; 13 yes after 1 ± 1 year (0–3.5 years)	8 yes after 0.9 ± 0.9 year (0–2 years)	NS

enough. There were no suggestions on how to improve the joint visit. Looking back, four patients (but none of the parents) felt that the joint visit was of 'little use'. Of the parents, 14 responded to this portion of the questionnaire and three did not respond because they had not attended a joint visit. The parents of three patients felt the visit was too short and the parents of four patients felt that one visit was not enough.

During the planning period for the transition, all of the parents of patients who chose to continue their follow-

up within the same hospital center were informed of a possible joint visit. None of the patients who had attended a joint visit regretted their participation. However, among the patients who continued their follow-up in another town, the parents of two patients regretted the lack of a joint visit. For the transitions that took place in the 'unexpected' setting of admission to an adult hospital ward, two patients regretted that the transition had not taken place during a quiescent period.

Table 7 Patients' and parents' opinions of the joint medical visit.
Opinion des patients et des parents sur la consultation commune (CC).

	Patients (n = 20)	Parents (n = 20)	P
Is one joint medical visit enough?	6 no; 10 yes	4 no; 10 yes	NS
The time spend during the joint visit was			
Very insufficient	0	0	NS
Insufficient	0	2	
Sufficient	15	11	
Very sufficient	1	1	
The decision to have a joint visit was			
A shared decision	11	9	NS
Partially imposed	3	2	
Completely imposed	2	3	
What effect did the joint visit have on subsequent care?			
Very beneficial effect/beneficial effect/no effect	3/9/4	4/9/0	NS
What effect did the joint visit have on the new gastroenterologist's knowledge of your case?			
Very beneficial effect/beneficial effect/no effect	3/13/0	4/10/0	NS
What effect did the joint visit have on your confidence in the new gastroenterologist?			
very beneficial effect/beneficial effect/no effect	5/10/1	5/9/0	NS
What effect did the joint visit have on your child's confidence in the new gastroenterologist?			
Very beneficial effect/beneficial effect/no effect		5/9/0	

Sixteen patients responded. Six sets of parents did not respond (including three couples who had not attended a joint visit).

Seize patients ont répondu. Six couples de parents n'ont pas répondu (dont trois couples de parents n'ayant pas assisté à la consultation commune).

Discussion

Like other chronic diseases beginning in childhood, IBD eventually requires transition from pediatric to adult care [2–6]. ‘Successful’ transition enables uninterrupted coordinated care that is well-adapted to the patient’s development and maturity both before and during the transition and probably contributes to better patient compliance to medical care in adulthood. The guidelines proposed by expert societies increasingly urge pediatric gastroenterologists to develop a transition strategy in coordination with their adult-care colleagues [3,4], similar to the approach of pediatric physicians who provide care for children with other chronic diseases [7–11].

Transition must be recognized as a process of change and not as a distinct event in an often already long period of pediatric care [2,4,10–13]. The idea of a transition to adult care should be mentioned well in advance to allow the idea to take shape in the patient’s mind; some authors even suggest discussing it as early as at the time of diagnosis [3,4,10,11]. In their survey of transition among American children aged 13 to 17 years with special healthcare needs, Lotstein et al. [12] noted that 50% of the parents had already brought the subject up. It is important to present the transition as a positive event, detailing the benefits (independence, maturity) and the various other aspects considered in adult-care medicine (such as sexuality, fertility, occupational considerations, risk of cancer and long-term course) [3,13]. The process of transition from pediatric to adult care occurs at a critical time in the life of the patient, involving transformation from childhood to adulthood along with its attendant psychoaffective remodeling. In certain adolescents, fear of the unknown and fear of losing a privileged relationship may lead to feelings of being abandoned [3,11,13]. The transition process can also be a source of anxiety and distress for parents who have spent years helping their child to manage the disease [13]. Although the lack of statistical significance in the present study was probably due to the small sample size, our findings do illustrate that the opinions of the parents and the patients themselves can differ when it comes to feeling apprehensive about the transition (7/32 patients expressed concern compared with 10/31 parents). This difference in perception is probably an exacerbated reflection of the difference in opinion between an adolescent and his parents concerning the transition from childhood to adulthood. For this reason, the pediatric team should encourage families to progressively develop their children’s autonomy and self-reliance in making health-related decisions [3,11,13]. Parents should learn to accept the idea of the physician dealing directly with the patient, while keeping in mind the importance of maintaining family support [8]. The pediatric physician should gradually establish an independent relationship with the patient (for example, conducting visits with the patient on his own, foreshadowing the future situation in adult care) [3,11].

In our study, both patients and their parents remembered that the issue of transition had been mentioned at least a year, on average, before it actually took place. All felt that this time lag was sufficient. Two patients remembered specifically that they had been aware of the idea since their diagnosis. The study by Scal and Ireland [14], conducted in

2000–2001 among American adolescents aged 14–17 with chronic diseases, showed that, while 50.2% of the patients had already talked about transition to adult care with their pediatric physician, only 16.4% had discussed the practical aspects of the transition process itself.

The legal age limit for pediatric medical care in France is 18 years (21 years in the United States). It is not, however, the official age that must be taken into consideration, but rather the physical and psychological maturity of the patient. This is determined largely by the pediatric physician and will have a major impact on the decision to initiate transition to adult care. The retarded puberty often observed in Crohn’s disease has to be taken into consideration [3,4,15], as was the case for one of our patients, whose transition took place at the age of 20.5 years. For many patients, being 18 coincides with the end of secondary schooling and the transition to higher education or an occupational activity. This change in the social context from adolescence to youth offers an opportunity to make additional changes in medical care [3,11]. The adolescent needs to gradually acquire a certain degree of autonomy and, finally, independence from the support of the family, which was for so many years part of the disease-management scheme [13]. The fact that the opinions of patients and parents may well differ on the issue of maturity is no surprise. Only four of our 33 patients stated that they were not ready for the transition, while this was the response of nine of the 34 parents; 6/33 parents felt their child was not sufficiently self-reliant and approximately 40% of the patients stated that the transition made them feel more responsible for the management of their disease. It is the role of the pediatric physician to strike a three-way balance between the wishes of the patient, those of the parents and his own opinion as to the best time to make the transition.

For the patients and parents, the question becomes one of deciding who is to be in charge of the subsequent care. In their study of transitional procedures among diabetic adolescents, Crosnier and Tubiana-Rufi [16] noted that this decision was made during a dialogue between the adolescent and the pediatric physician, but with the latter more often having the greater influence. In our experience, patients and parents have generally discussed the choice of the future gastroenterologist with the pediatric physician, with the final choice being generally considered to be a ‘shared decision’.

The severity of the disease during pediatric care (reflected by the treatment regimens, as shown in Tables 2 and 3) clearly influenced the choice of the referral gastroenterologist by the pediatric physician, the patient and the parents. There was no attempt to randomize referral practices, so the more ‘serious’ cases were, in fact, referred to gastroenterologists within the same hospital center. Most of these patients attended joint visits. It was deemed reasonable to refer patients who had more active, complex and complicated disease to a hospital gastroenterologist (which, in our study, generally meant attending a joint visit). Such a decision may, in certain cases, have appeared to have been imposed (as was reported by 9/20 patients in group A and 3/14 in group B). The greater level of fear regarding transition to adult care among patients in group A (6/19 versus 1/13 in group B) was very likely related to disease severity. The chances that the transition to adult care might

be a source of misunderstanding of the patient's particular situation were greater for patients who had more active disease. In addition, in comparison to cases of uncomplicated disease, the patient–(parent)–physician relationship is probably stronger in a presence of more severe disease (as reflected by the greater number of visits).

Whenever possible, patients should nevertheless be referred to the private practice or hospital gastroenterologist who had initially made the diagnosis. Initial agreement on objectives between the pediatric and adult gastroenterologists is essential. Also, another advantage of referring patients to a gastroenterologist working within the same hospital center, which may appear to be a decision imposed upon the patient and parents, is to introduce the patients to the fact that these physicians are used to working together and have common (including scientific) objectives. Moreover, the presence of an ongoing collaboration favors transition by having less of a risk of misunderstandings [10,11].

The current guidelines emphasize the importance of organizing alternating or joint visits before completing the transition [2,6,11]. In France in 2007, however, more than 60% of the pediatric gastroenterology centers lacked an organized system for alternating or joint visits with their adult-care colleagues [17]. For the young adult patient and his family, such consultations are the concrete manifestation of a coordinated collaboration between the pediatric and adult-care gastroenterologists that will help them to face the new future situation with confidence [3,10,11]. There is, nevertheless, the problem of availability of the two physicians and the patients (and parents) at the same time. Arranging for more than one joint visit becomes even more complex, especially if the referral physician also practices at another center. We decided to favor joint, rather than alternating, visits. Even though for certain patients a single visit may not be enough, it does allow for a formal hand-over of the decision-making process. For the patient attending alternating visits, it may be difficult to ascertain who is making the final decisions [11]. Irrespective of the referral procedure, the pediatric physician needs to draft a summary document for the adult-care physician. It is imperative that this document remain confidential as it concerns the privacy of the patient, who ultimately has the right to release such information or not [11].

Preferably, the transition should not take place during a period of disease aggravation [3,4,11]. However, the unpredictable course of IBD can make this difficult to achieve. Two of the six patients, who were admitted to an adult-care ward (medicine or surgery) without having gone through a planned transitional process, regretted this manner of transition. However, such feelings of regret were not shared by patients whose disease was more severe and active, but effectively controlled by treatment (for example, repeated infusions of anti-TNF). Anoperineal localizations, highly specific of Crohn's disease, are particularly difficult to accept during puberty and may contribute to a patient's reluctance to change physicians. In such cases, longer joint follow-up, rather than a single joint visit, facilitated later transition.

It would have been useful, though extremely difficult, to conduct a randomized study of the benefits of joint visits, but our research nonetheless reveals the genuine contribution of this type of consultation. The joint situation allows

the new practitioner to establish a personal relationship with the young patient and his parents, thus removing any fears related to the unknown and reducing the risk of any interruption to the medical follow-up. Nearly all of the patients and all of the parents, felt that the joint visit was beneficial in terms of subsequent care, the adult-care physician's knowledge of the individual case and the patient's confidence in the new physician. A few patients and parents felt that a single joint visit was insufficient and some patients who had not attended such a visit later regretted the lost opportunity.

Young patients and their parents are acutely aware that good medical care requires coordination among physicians and that any abrupt change in management can only have a negative impact on therapeutic compliance [3,13,16]. Although this aspect of treatment in itself cannot predict the degree of patients' compliance, it is worth emphasizing that most of our now adult patients are followed regularly by an adult-care physician and are still consulting the gastroenterologist chosen during their transition.

Conclusion

For pediatric patients at the Rennes University Hospital Center with IBD, transition from pediatric to adult care appears to have been a successful experience, allowing them to continue their coordinated care without interruption. Careful consideration of the developmental and growth phases of each individual patient, discussions among the pediatric physician, the patient and his family that anticipate the transition several years ahead of time, the development of joint visits since 1992 and the use of joint visits during the pediatric follow-up, especially for patients with anoperineal involvement appear to have been the key elements making for successful transition.

In addition, it may be useful to organize a few supplementary joint visits to respond to patients' and parents' questions concerning disease management and to further reinforce the confidential relationship with the new physician.

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