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Transition from Pediatric to Adult Healthcare: Assessment of Specific Needs of Patients with Chronic Endocrine Conditions

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Key Words
Transition · Adolescents · Congenital adrenal hyperplasia · Hypogonadotropic hypogonadism · Growth hormone deficiency

Abstract
Background/Aim: Transition from pediatric to adult care is a challenging turning point. The aim was to evaluate the transition process and needs expressed by patients with chronic endocrine conditions at transition in order to ensure program optimization. ***Methods:*** Prospective assessment of the transition period was conducted through completion of standardized questionnaires given to targeted patients. Two types were created: (1) a general questionnaire (GQ) addressing universal aspects of transition, and (2) a specific questionnaire (SQ) exploring concerns related to each endocrine condition. Three endocrinopathies (congenital adrenal hyperplasia, hypogonadotropic hypogonadism and growth hormone deficiency) were selected for assessment since they present specific challenges requiring characterization. ***Results:*** Over the last decade, 244 patients in transition were registered in our department and 153 were included since they presented one of the endocrinopathies selected. A total of 73 subjects completed both the GQ and the SQ. Over 80% of the patients were satisfied with the transition process in terms of organization, accessibility and medical care. The actual age of transition corresponded for most to the age considered by patients as ideal for transition. SQs identified psychosexual issues that must be addressed more systematically. ***Conclusion:*** This study identified key elements allowing the creation of an improved transition program tailored for our center and for each endocrine condition studied.

Introduction

The transition from pediatric to adult healthcare is a time of stress for both young people with chronic diseases and their families. In the last decade, extensive evidence has established that while the transition process is challenging, tailored transition programs can reduce the attendant psychological and medical impact and can improve success rates [1, 2]. With more than 90% of children having special healthcare needs now surviving into young adulthood, it is imperative for the healthcare system to actively conduct studies to establish effective transition

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programs [3, 4]. Indeed, many international and national position statements as well as policy documents call for transition planning and evaluation of transition outcomes in medical centers [5, 6].

To date, most of the published literature on transition to adult care has focused on identifying the barriers facing this population as they proceed through this period [7–11]. The main barriers noted relate to patients, parents, organizations, environment, and care providers [12, 13]. However, since transition is an emerging field, the number of studies is increasing and it is acknowledged that transition management requires more than a simple service approach as it involves the taking on of new roles and/or the adaptation of existing roles for young people and those around them [14–17]. Nevertheless, there is still a lack of data concerning patient and staff evaluations of the efficacy and feasibility of currently established transition programs.

Endocrine conditions present specific challenges that must be explored to provide young people with a coordinated, seamless and developmentally appropriate transition to adult care [18]. While transition obviously involves universal adolescent issues such as sexuality, reproduction and body image, certain endocrinopathies by their very nature amplify these issues and will almost certainly limit opportunities and participation in adult life if not properly addressed. Current data are sparse about specific concerns related to optimal transition for endocrine conditions such as congenital adrenal hyperplasia (CAH), hypogonadotropic hypogonadism (HH) and growth hormone deficiency (GHD), three diseases frequently treated in our department.

The aim of the present study is to provide an up-to-date evaluation of the transition process and to assess specific needs expressed by young adults with chronic endocrine pathologies such as CAH, HH and GHD in order to establish successful transition programs between pediatric care and our care in our adult endocrinology departments.

Patients and Methods

Patients were recruited from our local register compiled over the last decade and containing details of every new patient in transition attending our adult Endocrinology and Reproductive Medicine clinic at Pitié-Salpêtrière Hospital. Details of the date of transition and patient age, specific endocrine disease, referring doctors and hospitals were also recorded. All patients registered with either CAH, HH and/or GHD were included and their charts were reviewed.

All targeted subjects were invited, either after a routine clinic visit or by letter, to complete two questionnaires concerning their experience of transition. General evaluation of the transition process was performed by means of a first questionnaire, namely the general questionnaire (GQ), given to all subjects. A second questionnaire adapted to patient gender and endocrine disease, the specific questionnaire (SQ), addressed various concerns associated with the specific conditions of each subject and evaluated the care provided by our group.

Both questionnaires were based upon the main barriers classically identified in the transition process and upon general principles and recommendations designed to improve transition [4–6, 8–10, 16]. Questions were asked about patients' fears and their relatives' concerns about the change in hospital, staff and treating physician. Patients were also invited to identify what they felt was the ideal transition age/time in their case. Finally, patients were asked about aspects of transition related to their specific endocrine disease, primarily its repercussions on sexual and reproduction matters.

Each questionnaire was accompanied by a short instruction sheet and letter describing its purpose, as well as a card and a reply envelope that patients could easily tick and return if they preferred not to answer the questionnaires. Where questionnaires were given after a medical appointment, all documents were handled by the nurses. No furthers printed materials or informative documents on patients' illness were given to subjects.

Results

A total of 244 patients were registered in our department as undergoing transition over the last decade (from 1998 to 2009) (fig. 1). In our register, 153 patients met our initial criteria in having one of the three endocrine conditions targeted and they were asked to complete both general and specific surveys. A total of 73 subjects completed the two questionnaires, giving a response rate of 47.7%. No questionnaires were returned for the remaining 80 subjects (52.3%) (2 patients indicated by phone that they preferred not to respond, 7 letters were returned to us due to a non-valid address, and 71 questionnaires were not completed with 30 subjects believed to be lost to follow-up since they did not visit our clinic for more than 2 years). Almost all patients addressed by our referring pediatric centers completed the transition process and attended the first visit at our department. However, attendance to subsequent follow-up visits is still challenging with a loss to follow-up that can be estimated in this cohort to be 24.1% (37 cases of 153 subjects).

Of the 73 subjects completing the questionnaires, 33 had GHD, 27 had HH (20 males, 7 females) and 13 had CAH (4 males, 9 females). Patients were referred from over seven different pediatric hospitals in the Paris region near our department as well as from more distant parts of France. The characteristics of responders and non-responders are presented in table 1.

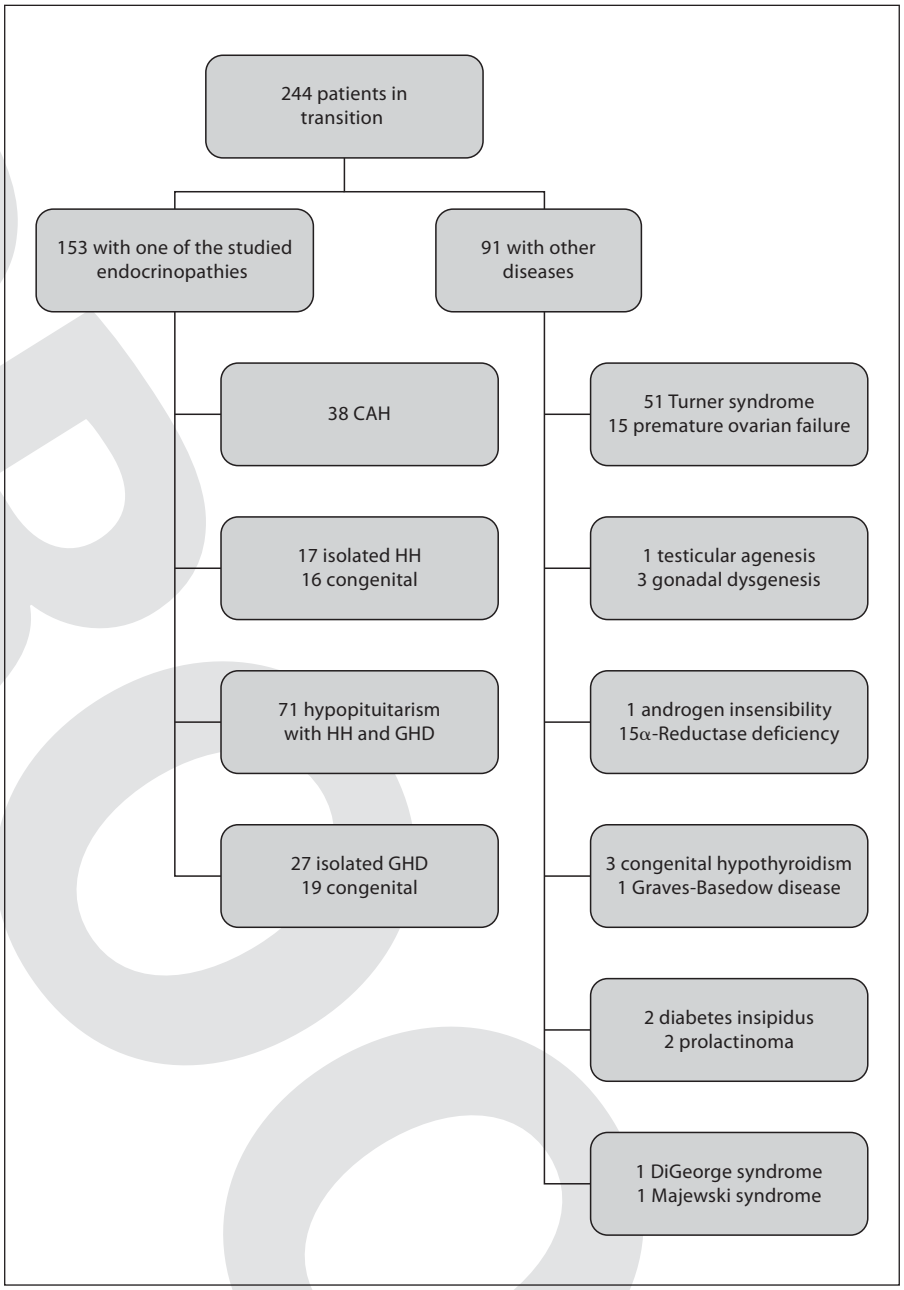

Fig. 1. Description of patients registered in transition at our center from 1998 to 2009.

General Survey: Breakdown of Responses

A total of 18 questions were asked in the general survey, divided into five subsections (table 2).

Organization and Accessibility

Transition to an adult service was organized predominantly by the pediatricians and their staff (69% of cases). Patients' relatives, mainly their mothers, were the second most prevalent organizer of transition (20%). However, 8% of young adults had to conduct their transition themselves (fig. 2). A summary was prepared by the pediatrician and transmitted to the new adult physician in 96% of cases. It mainly contained medical information about the patient's condition, medication and latest laboratory results, and in some cases, details were included about the patient's situation (e.g. student, employed, unemployed), psychological well-being and therapeutic compliance. A total of 17% of patients had to change city for adult follow-

Table 1. Characteristics of our study cohort – responders versus non-responders

	Survey responders (n = 73)	Non-responders (n = 80)	Total (n = 153)
Mean age at survey, years	24.7 ± 4.5	26.8 ± 6.5	
Median age at survey, years	23.3	25.7	
Endocrine condition			
CAH	13	25	38
HH	6	11	17
GHD	16	11	27
HH + GHD	38	33	71
Women	24	40	64
Men	49	40	89
Year of transition			
Before 2000	9	10	19
2000–2004	7	30	37
2005–2009	57	40	97

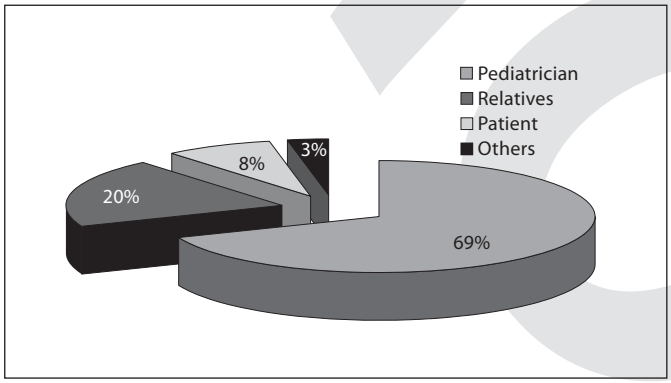

Fig. 2. Distribution of persons in charge of organizing transition.

Table 2. Responses to the GQ

		n	%
Number		73	
Gender			
	Female	24	33
	Male	49	67
1	Organization and accessibility	satisfied	
	Was it difficult to schedule your first appointment at the adult clinic within an acceptable time for you?	59	81
	Are you satisfied with the information you received regarding the procedure prior to transition?	65	89
2	Apprehension about transition		
	Which of the following factors were you most worried about concerning your transition to an adult clinic? Change in (circle only one choice):		
	Hospital	17	25
	Doctor	31	45
	Paramedic staff	1	1
	Possible modification of your treatment	15	22
	Nothing stressful	5	7
3	Evaluation of first visit	satisfied	
	Were you satisfied with your reception by doctors and staff?	71	97
	Did the setting at the first interview ensure confidentiality and make you feel comfortable?	58	79
4	General assessment		
	Overall, are you satisfied with the transition procedure at the adult clinic?	70	96
5	Optimal age for transition, years		
	Mean age at transition	19.4 ± 2.0	–
	Mean age you consider ideal for transition	18.3 ± 2.0	–
	Median age at transition	19.0	–
	Median age you consider ideal for transition	18.0	–

up. Overall, 19% reported difficulties in scheduling their first appointment within an acceptable delay. Finally, 89% were satisfied with the information received concerning the transition procedure prior to the appointment in adult care (location of the new hospital, details on medical staff and services). At each visit, an appointment was organized with our nurses and one of our endocrinologists; none attended clinics scheduled with multiple specialists.

Apprehension about Transition

All subjects were asked to identify their main concerns concerning their transition to adult care. The most preoccupying factor was changing over to a new physician, as noted in 45% of answers. Being transferred to another hospital and possible modification of treatment received similar scores with respectively 25 and 22% of answers. One person indicated a change of paramedic team as the main stress factor concerning transition. Although not offered as a response option per se, 5 subjects circled none of the proposed choices and simply inserted 'Nothing stressful' as their answer to this question.

Evaluation of the First Visit to an Adult Department

At their first visit, 79% of respondents were accompanied by a relative, usually their mother (55%), by their father (22%), by both parents (16%) or by their spouse, aunt or a foster family member in 7% of cases. Regarding the first contact, 97% were satisfied with the medical re-

ception and 92% felt that the doctor was adequately informed about their medical history. Most patients reported that the doctor inquired about their apprehension concerning transition (62%), explained or re-explained the nature of their disease and its repercussions on adulthood (71%), and asked about their personal aspirations and future plans (90%). Evaluation of the social network of the young adults and their relationship with their peers was performed in 56% of cases. At the end of the interview, 55% of patients were offered a new medication or modification of their previous treatment. Of the 26 subjects in whom such modification was prescribed, 23 (88%) were satisfied while 3 (12%) were uncomfortable with this change made at the initial consultation by the adult endocrinologist. At the end of the consultation, the treatment plan was clear for 91% of patients and 92% felt that their questions had been answered. Most patients felt comfortable during the interview (79%) and considered that the setting helped ensure medical confidentiality (80%) during the medical visit and in the waiting room.

General Assessment of Pediatric and Adult Care

Most patients (97%) were satisfied with follow-up during the pediatric period and during adult transition. However, 5 subjects (7%) envisaged returning to their pediatrician at a certain point because of dissatisfaction during the transition process. Overall, when asked about the global transition process, 96% were satisfied. In the open comments section, suggestions were made about easier access for the first appointment and more routine proposal of psychological support. Some also recommended organized meetings with the adult physician before the first official visit or at least that the adult doctors should have access to and knowledge of their medical summary before the first appointment.

Optimal Age for Transition

In the GQ, each patient was asked to indicate what they considered the ideal age for transition in their case. In our cohort, the mean transition age was 19.4 ± 1.95 years (range 17–27.8, median 19.0) compared to 18.3 ± 2.08 years (range 16.5–24.0, median 18.0), the mean age for transition considered ideal by the patients themselves.

For 30% of subjects (n = 22), the actual and optimal age at transition differed by 6 months. A further 30% of patients (n = 22) would have liked to have been transferred to adult care earlier (17.3 years) compared to 15% (n = 11) who would have preferred a later transition (20.5 years). However, 26% did not answer this question.

Specific Survey: Breakdown of Responses (table 3)

Subjects with CAH

The CAH SQ addressed the gender particularities with emphasis on the psychosexual challenges that this condition can present. Two CAH SQs were created, one for each gender, and each containing 10 questions.

A total of 13 CAH patients responded to the relevant SQ: 9 women and 4 men. Except for 1 patient, all subjects had a good knowledge of their medication and 38% had previously been hospitalized for hypocorticism.

All CAH subjects underwent genetic testing. All male patients but only 56% of female subjects considered that the information they received before testing about the implications of genetic analyses was adequate. Genetic consultations were offered for 62% of patients. However, 92% felt entirely free to accept or reject this genetic evaluation. Patients were also asked at the initial visits whether specific medical concerns about adult CAH had been properly addressed, and they reported discussion about their height in 92% of cases, their weight in 77%, and bone health matters in 85%, with follow-up for bone density planned in 62% of cases. Patient relationships were discussed in 69% of cases and their sex life and satisfactory sexual activity were discussed in 85% of cases. Female patients were asked about regularity of menstruation and a genital examination was performed in 89% of them, while 78% underwent breast examinations. All subjects except 1 preferred to undergo this examination without presence of relatives, and 50% indicated a preference for a female doctor. Finally, 75% of patients for whom hirsutism was a concern felt they received adequate answers to their questions. In the male group, genital examination was performed for all patients and only 1 indicated a preference for a male doctor for this physical examination, with the others having no preference. Reproduction and fertility was discussed with most patients (69%). Most women (67%) and all men were satisfied with the information received about fertility and genetic transmission to offspring. However, 2 men and 2 women would have preferred not to address fertility concerns at the first visit but at a later stage of follow-up.

Subjects with HH

A total of 20 men and 7 women with congenital or acquired HH completed the SQ. The question of their height, bone health and bone density planning was properly addressed in respectively 81, 54 and 63% of cases.

In the survey, 85% of males reported that their sex life was properly covered and openly discussed with some well-directed questions on erection (89%), ejaculation

Table 3. Responses to the SQs by individual endocrinopathy

	Female	Male	Total
Congenital adrenal hyperplasia			
Number	9	4	13
Was genetic testing performed for your adrenal problem?	9/9 (100)	4/4 (100)	13/13 (100)
Do you feel you received enough information about the implications of genetic analysis before testing?	5/9 (56)	4/4 (100)	9/13 (69)
Were you asked questions about your intimate relationship?	7/9 (78)	2/4 (50)	9/13 (69)
Did you discuss your sex life?	7/9 (78)	4/4 (100)	11/13 (85)
Was a genital examination performed?	8/9 (89)	4/4 (100)	12/13 (92)
Would you prefer your physical examination to be performed by a doctor of the same gender as you?	4/8 (50)	1/4 (25)	5/12 (42)
Was the issue of fertility discussed?	5/9 (56)	4/4 (100)	9/13 (69)
Would you prefer this issue not to be addressed at the first appointment?	2/9 (22)	2/4 (50)	4/13 (31)
Hypogonadotropic hypogonadism			
Number	7	20	27
Were you asked questions about your intimate relationship?	1/7 (14)	11/19 (58)	12/26 (46)
Did you discuss your sex life?	2/7 (29)	17/20 (85)	19/27 (70)
Was a genital examination performed?	4/7 (57)	12/18 (67)	16/25 (64)
Would you prefer your physical examination to be performed by a doctor of the same gender as you?	1/4 (25)	3/12 (25)	4/16 (25)
Was the issue of fertility discussed?	1/7 (14)	11/14 (79)	12/21 (57)
Would you prefer this issue not to be addressed at the first appointment?	0/4 (0)	3/13 (23)	3/17 (18)
Growth hormone deficiency			
Number			33 (11♀, 22♂)
For which of the following reason(s) was GH therapy initiated?			
Growth optimization			24/31 (77)
To improve energy levels			7/31 (23)
Body composition			5/31 (16)
and/or bone density			7/31 (23)
Was GH therapy stopped between the ages of 15 and 20 years?			21/33 (64)
If so, for what reason(s)?			
Completion of growth			13/21 (62)
Upon your request			4/21 (19)
Somatotroph axis recovery			5/21 (24)
Was GH therapy stopped at a certain point to assess whether it was still needed?			21/32 (66)
Was GH therapy restarted or continued during adulthood?			20/33 (61)
If so, for what reasons?			
Body composition			12/20 (60)
Improved well-being			8/20 (40)
Do you consider you received enough information about the benefits and drawbacks of GH therapy during adulthood to allow you to make an informed decision about therapy in your particular case?			21/31 (68)

Values in parentheses are percentages.

(95%), and on the emotional aspects of their intimate relationships (58%). Specific concerns of some patients about body hair growth or penis length were addressed adequately in respectively 68 and 45% of cases. Genital examination was performed in 67% of cases and by a woman in 25% of patients, with 25% of patients expressing a preference for a male doctor for this particular examination. The issue of reproduction was explored in 79% and fertility treatment options were discussed in 64% of cases. Three patients felt that fertility issues would have been best discussed during follow-up rather than at the initial transition visit. However, compared to men, only 29% of women with HH reported adequate discussion about their sexual life and 14% about their intimate

relationships. Moreover, none reported any direct questions concerning sexual intercourse or possible sexual discomfort. Breast development patterns and concerns were addressed in 43% of cases. Pelvic/genital examination was performed in 57% and breast inspection in 14% of cases, with both being performed by a male doctor in 75% of cases. However, only 1 patient indicated her preference for a female doctor for these examinations, with the other 3 subjects being indifferent. The fertility aspect of HH was discussed in only 14% of female cases and no information was provided about available treatment.

Subjects with GHD

A total of 33 GHD subjects responded to the 12 questions in the SQ (22 males, 11 females). The cohort of GHD subjects was quite heterogeneous in terms of GHD etiology, with congenital, idiopathic or combined/postsurgical GHD after all kinds of pituitary tumors.

Most patients were treated with growth hormone (GH) during childhood (67%) and during adolescence from 13 to 18 years (90%) and/or were still on GH after the age of 18 years (63%). GH was initiated mostly for growth optimization (77%) but also, in some cases, to improve energy levels (23%), body composition (16%) and/or bone density (23%). GH was stopped between the ages of 15 and 20 years in 64% of patients, because of growth completion in most cases, but also upon patient request or after demonstrated somatotroph axis recovery. GH treatment was in fact stopped at a certain point in 66% of patients to allow axis re-evaluation, mostly at the time of transition. During adulthood, 12 subjects continued their GH injections and 8 started or restarted treatment (i.e. a total of 61% of the GH cohort at time of survey) for either body composition optimization or for energy levels and well-being benefits. Despite recommendation by the adult care doctors, 5 patients preferred not to restart GH injections mostly for reasons of personal convenience. Overall, 68% of the cohort considered the information received about their condition and GH replacement therapy sufficient to allow them to make an informed decision about their treatment.

Discussion

Advances in the care of patients with an endocrine condition have enabled many of these young people to reach adulthood. The complexities of CAH, HH and GHD in teenage life demand that the clinical team give subjects special attention during transition from pediatric to adult care [18–24]. Unfortunately, as mentioned by a German and an English group investigating CAH transition [25, 26], a considerable number of CAH patients is lost to regular and competent follow-up once they move out of pediatric care. This is probably the case for other endocrinopathies and could be the result of insufficient collaboration between pediatric and adult endocrinologists at the time of transition. In such context, our relatively poor number of patients lost at follow-up can be explained by the setting of a network in Paris, a few years ago, between our referring pediatricians and our adult endocrinologists to offer a more systematic approach and to reduce the risk of unmanaged patients during this challenging period. Furthermore, there is a lack of clinical guidance regarding psychosexual development in these patients [26–29].

The present study attempted to evaluate the efficacy and patient perception of the current transition procedure for young people with a particular endocrine condition upon transition from pediatric care to our adult care department. One strength of the study is the creation of specific surveys for each endocrine disease, allowing better characterization of the psychosexual and therapeutic issues linked to CAH, HH and GHD during transition. Indeed, for CAH and HH patients, it confirmed the importance of discussions about intimate relationships and sexuality through direct questioning about sexual activity and related concerns. Overall, among patients in whom genital examination was performed, 32% indicated a preference for a doctor of the same gender for this physical examination. Also, in the CAH and HH groups, reproduction issues should be raised and information offered from the start even if certain patients felt that the initial visit was not appropriate for a full-scale discussion of fertility issues. For GHD subjects, treatment issue demand GH axis re-evaluation in most and precise explanation of the potential advantages and drawbacks of GH injections at adulthood.

Second, self-evaluation of care allowed the identification of those aspects of transition that must be stressed in order to improve the transition process and meet patients' expectations. Transition arrangements were generally good and were mainly organized by a pediatrician, with the first adult appointment being scheduled within an acceptable time frame. Over 80% of patients reported that they were well informed and described their first clinical visit in positive terms. The main apprehension of patients concerned the change in their treating endocrinologist. The mean age at transition was 19.4 years, which was considered by patients to be the ideal age for transition. Inquiries should be made routinely concerning per-

sonal apprehension over transition and the patient's social networks, and a systematic re-explanation should be given concerning the patient's disease and its repercussions during adulthood.

Limitations

The limitations of this study are primarily methodological. The self-evaluation and questionnaires remain subjective. Despite the fact that the questionnaires were sent by mail or handled by nurses, this evaluation was conducted by the same medical team as that providing patient care. Also, for most subjects, evaluation of the transition process was retrospective and was potentially tainted by the previous year's follow-up with their adult physician. Also, the questionnaires were given only to patients who had completed their transfer to an adult clinic. All patients lost to follow-up or in whom transition was not successfully effected were not included. Finally, while this study identifies specific concerns to be addressed and to be included in suitable transition programs for each endocrinopathy, the small numbers of responders in each subgroup means that broader studies must be envisaged in order to obtain further details.

Practical Implications of Our Study

Based on this study, a specific pathway and program have been created for patients in transition at our center with (1) a scheduled consultation and appointment conducted in a personalized manner by our medical staff, and (2) special individual and group meetings offered throughout a day of information at our center focusing on education and exchange of experiences for newcomers. This program is sponsored by local health authorities.

Conclusion

Successful transition starts with a reflection by each center involved in the transition process on information gathered about patients' specific needs, and on assessment of their experience. By seeking patient opinion using a self-evaluation approach, this study has allowed improvements to be made in our department's transition program. Moreover, its value revolves around the details furnished on three particular endocrine pathologies each having their specific related psychosexual and therapeutic issues.

In conclusion, this study has helped us identify the basic requirements for a more elaborate transition program that will include closer collaboration with major pediatric centers and has underscored the need for transitional planning as a critical component for young people with chronic endocrine conditions.

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Disclosure Statement

The authors have no conflicts of interest to disclose.

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