

# Pre-Transition Consultations for Adolescents With Chronic Conditions in a General Pediatric Hospital: Lessons Learned

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## Research Article

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# Abstract

The objective of the study was to assess the clinically relevant features of the pre-transition consultation (PTC) offered in *AD'venir* transition unit (R.Debré hospital, Paris) to all adolescents with a chronic condition.

PTCs include a face-to-face interview with pediatricians trained in adolescent medicine, exploring the past (disease history), present (daily life, *Treatment Burden Questionnaire*, family/peer relationships, school, hobbies, sexuality, drugs) and future (global life project, transition, *Good2Go questionnaire*). Twenty-seven PTC recordings were qualitatively analyzed (girls=56%/median age=17.7yrs) within a multidisciplinary group (clinicians/sociologists/psychologist/public health researchers). Respectively 6-months and 2-years after PTC, benefits of PTC were assessed in referent healthcare providers (questionnaire) and in adolescents (phone interview).

PTCs were a form of training for adult care, adolescents meeting a practitioner alone often for the first time. Naming their chronic condition was frequently difficult. All complained of limitations experienced in their social life (notably diet, tiredness, laboratory/medical appointments), but not treatment itself. Most were willing to talk about sexuality. Feelings concerning transition were various, with poor representations of adult healthcare. Transfer was often unplanned, but this did not influence transition readiness. After PTC, healthcare providers often changed their practices. Two years later, transition was successful for most of adolescents.

## ***Conclusion***

The PTC is a relevant, easily implemented tool to help empower adolescents and customize their transition preparation within a holistic approach. A dedicated and long consultation, with an external/non-prescriber practitioner, including a physical examination are key factors promoting the establishment of trust, sharing of intimate issues and the assessment of potential barriers to transition.

## **Introduction**

Since the first definition of transition from pediatric to adult healthcare in adolescents with chronic condition (CC)[1], various guidelines have been published [2–5], based on growing evidence of the relevance of a structured and personalized healthcare transition process [6–10]. Health self-efficacy is associated with better long-term wellbeing, participation, satisfaction with services and condition-specific measures [11]. Key part of the learning process, aspects related to psychosocial development, including how to approach the self-concept, social life and the future with the illness, should also be considered [12]. However, the most effective ways to evaluate and promote adolescents' confidence in managing their CC remain unclear. Despite their relevance [2], the readiness questionnaires focus on skills and knowledge without exploring in depth the adolescent's global approach to adulthood with a CC. Indeed, transition of care is one of many changes from childhood to adulthood [13], that presupposes the need to adopt a developmentally appropriate approach to healthcare [11].

Developing personalized and structured transition support nevertheless remains a challenge in many clinical units, because of time or funding restrictions or limited interactions with adult healthcare providers (HCPs)[9, 14, 15].

To pool resources and provide more opportunities for care units without any transition program, the dedicated transition unit *AD'venir* was created in 2017 at the Robert Debré pediatric hospital (Paris, France). *AD'venir* aims to deliver patient-centered care to all adolescents with a CC, to enhance their quality-of-life through sustained high-quality healthcare and ongoing social participation in adulthood. To this end, we implemented individual pre-transition consultations (PTCs) to assess adolescents' readiness and tailor their preparation to transition.

Here, we report the clinically relevant features of the PTC.

## Materials And Methods

This research was mainly based on qualitative methods, and included quantitative methods.

## Population

PTCs were proposed by the referring HCPs (RHCPs) to adolescents (15–25 years), with any CC or disability managed at the R.Debré hospital, due to be transferred to adult healthcare within the following 2 years. Adolescents were informed about the research through an information letter. We recruited the first adolescents attending a PTC from May 2017 (launch of *AD'venir*), including participants until data saturation achievement, meaning that patients' discourses had become redundant and no new theme would arise with supplemental inclusions [16]. We also recruited each adolescent's RHCP.

## Content of the PTC

The PTC is a special medical appointment during transition preparation (Table 1). During almost 1 hour, a transition pediatrician (TP) receives each adolescent alone to explore chronologically their perceived experience and view of their CC: past, present, future. It includes: an interview structured according to the HEADSS checklist [17]; the Treatment Burden Questionnaire (TBQ, 15 items)[18] and the Good2Go questionnaire (25 items)[19]; and a physical examination. At the end, the TP and the adolescent each highlight the points requiring further transition support. This debriefing serves as a basis for the PTC report.

Table 1  
Process of a pre-transition consultation (PTC)

Step	Who (provider)	What	Why	How
BEFORE PTC	Referring Health Care Provider (RHCP)	<p>Gives an information letter to eligible adolescents (or parents, in the case of minors)</p> <p>Transmits their contact details (name, date of birth, gender, mail/e-mail/phone number) to the <i>AD'venir</i> coordinator</p>	<p>Inform about the research project</p> <p>No information about the nature of the CC, so as not to influence the Transition Pediatrician (TP)</p>	<p>Information letter</p> <p>E-mail or phone call</p>
	<i>AD'venir</i> coordinator	<p>Is full-time on the <i>AD'venir</i> unit, holds a diploma in health promotion and is a patient expert.</p> <p>Explains the purpose of the PTC and plans it:</p> <ul style="list-style-type: none"> <li>• paired with another appointment planned for usual medical follow-up in hospital (when possible)</li> <li>• not in an emergency setting</li> <li>• the parental presence is desirable at the beginning and end of the PTC, but not compulsory</li> </ul>	<p>Appropriate time</p> <ul style="list-style-type: none"> <li>• avoiding overloading the adolescent's agenda</li> <li>• adolescent's psychological availability to address their future</li> </ul>	<p>Phone call to parents or to adolescent at parents' request</p>
PTC				

Step	Who (provider)	What	Why	How
General framework	Transition Pediatrician (TP)	<p>In <i>AD'venir</i> premises</p> <p>Duration ≥ 1 hour</p> <p>Adolescent alone (confidentiality statement), parental presence at beginning and end of the PTC</p> <p>TP:</p> <ul style="list-style-type: none"> <li>• external to the referring team</li> <li>• trained in adolescent medicine</li> <li>• use of the polite “<i>vous</i>” (usual for adults)</li> </ul> <p>Chronological and multidimensional exploration of both the experience of CC and the needs of adolescence</p>	<p>Place dedicated to transition and external to the referring units</p> <p>Sufficient time to make adolescent feel comfortable and confident</p> <p>Respect of adolescent’s intimacy, training for adult care</p> <p>TP’s position:</p> <ul style="list-style-type: none"> <li>• new point of view, adolescent/parents’ freedom of expression</li> <li>• adolescent’s global health approach</li> <li>• training for adult care</li> </ul> <p>Contextualization of transition issue, identifying adolescent’s care needs</p>	<p>Premises external to but adjoining both the hospital and an adolescents’ clinic</p> <p>Flexibility in time planning</p> <p>Clear mention to adolescent and parent(s) of the confidential nature of the discussion</p> <p>Informal (body language, choice of clothing) and appreciative attitude, interest in the adolescent’s expert knowledge, use of concrete examples, humor, courtesy</p> <p>Semi-directive interview following a chronological sequence: past, present, future</p>
Past		<p>Adolescent’s own presentation of the CC: perceived origin, beliefs and representations</p> <p>Circumstances of the initial diagnosis, including diagnostic wandering or delay</p>	<p>Identifying misunderstanding or lack of knowledge</p> <p>Exploring the experience of the diagnosis announcement for the adolescent and their family, confidence level with healthcare system</p>	<p>Face-to-face interview</p> <p>Face-to-face interview</p>
Present		<p>Current medical and paramedical follow-up:</p> <ul style="list-style-type: none"> <li>• type and frequency of planned and unplanned</li> </ul>	<p>Identifying the points that are hardest to cope with and assessing</p>	<p>Face-to-face interview</p> <p>Treatment Burden Questionnaire (15</p>

Step	Who (provider)	What	Why	How
		<p>appointments</p> <ul style="list-style-type: none"> <li>• treatments: type, modalities, observance, burden</li> <li>• relationship with HCP</li> <li>• physical health: symptoms, comorbidities, growth, fatigue, pain, limitations</li> </ul> <p>Everyday life with the CC:</p> <ul style="list-style-type: none"> <li>• Home: family relationships, events and perceived support</li> <li>•</li> <li>Education/employment: school grade and attendance, relationships with teachers and peers</li> <li>• Activities: physical activity, hobbies, relationships with friends, use of social media, risky behaviors</li> <li>• Diet, eating disorders</li> <li>• Substance use (tobacco, alcohol, drugs)</li> <li>• Sexuality: pubertal development, sexual experience, contraception, knowledge about sexually transmitted infections, fertility and in relation to their disease</li> <li>• Sleep disorders</li> <li>• Body image, self-esteem</li> <li>• Psychological well-being, anxiety,</li> </ul>	<p>the complexity of coping with CC</p> <p>Knowing the cultural, developmental, organizational and contingency-related concerns</p> <p>Identifying needs for support concerning mental health, risky behaviors or intimate issues</p> <p>Assessment of pubertal development, and if necessary, reassurance of their own normality</p>	<p>items)<sup>a</sup></p> <p>Face-to-face interview based on HEADSS guide (17)</p> <p>Genealogical tree</p> <p>Physical examination</p>

Step	Who (provider)	What	Why	How
		depression or suicide ideation/attempt		
Future		<p>Global life project: professional aims, autonomy from parents, leaving home, having a family</p> <p>Progress of the transition process: planning of transfer (if known), hospital and HCP to be referred to, participation in a transition program</p> <p>Transition readiness</p> <p>Feelings about transfer to adults' healthcare, representations of adult health care units,</p>	<p>Help to project themselves in the future, with proper awareness of limitations and possibilities despite the CC context</p> <p>Assessing the level of transfer planning</p> <p>Identifying the points needing to be worked on before transfer</p> <p>Addressing the differences between pediatric and adult healthcare</p>	<p>Face-to-face interview</p> <p>Face-to-face interview</p> <p>Good2Go questionnaire (25 items) <sup>b</sup></p> <p>Tips on how adult healthcare functions</p>

Step	Who (provider)	What	Why	How
Conclusion		<p>Oral debriefing with adolescent alone:</p> <ul style="list-style-type: none"> <li>• highlighting facilitators and barriers to a successful transition, setting the priorities: medical, psychosocial issues for transition</li> <li>• list of what the adolescent considers as confidential (i.e. not to be mentioned in the PTC report)</li> </ul> <p>Oral debriefing with adolescent and their parent(s) (if present):</p> <ul style="list-style-type: none"> <li>• assessment of their parents' own transition preparedness and their specific support needs</li> <li>• comparison of the Good2Go questionnaire responses of the adolescent with those of their parents</li> <li>• discussion about the key points of the PTC (except if judged as confidential), the facilitators and the barriers to a successful transition</li> </ul> <p>Co-constructed recommendations about what to work on and how to support the adolescent and their parents to prepare the transfer</p>	<p>Stepping forward on their personal care- and life-pathway</p> <p>Respect of the adolescent's intimacy</p> <p>Assessment of the parental point of view, to be able to specifically support the parents and help them find the right position to adopt</p> <p>Addressing with parents what is different between pediatric and adult healthcare</p> <p>Tailoring the transition support to ensure a successful transition with realistic goals</p>	<p>Oral debriefing including the listing of confidential points not to be mentioned in the medical record</p> <p>Parental version of Good2Go questionnaire (25 items) <sup>b</sup></p> <p>Tips on how adult healthcare functions</p> <p>Listing of practical and customized guidelines concerning transition preparation and general health</p>



Step	Who (provider)	What	Why	How
AFTER PTC	TP	<p>Writing the PTC report:</p> <ul style="list-style-type: none"> <li>• reviewed within the <i>AD'venir</i> team (TP and <i>AD'venir</i> coordinator)</li> <li>• sent to both the adolescent and their parents, the RHCP, the future adult HCP (if already chosen) and all the medical correspondents (primary care doctor, sub-specialists practitioners)</li> </ul>	<p>Process of PTC report writing:</p> <ul style="list-style-type: none"> <li>• confronting different points of view, enhancing the practical, customized guidelines concerning transition preparation and general health matters</li> <li>• involving both adolescent and parents in the transition process, empowering the adolescent</li> <li>• no mention of the confidential points which were pointed out by the adolescent</li> </ul>	<p>Written PTC report including scores of Treatment Burden and Good2Go questionnaires and customized guidelines, within:</p> <ul style="list-style-type: none"> <li>• need for supplemental information delivered by RHCP:</li> <li>• about the CC's nature and mechanisms, long-term consequences (fertility, risk of transmission, etc.)</li> <li>• about transfer: HCP/hospital for adults to be referred to, timing</li> <li>• actions offered by <i>AD'venir</i>.</li> <li>• putting in place specific support by a psychologist and/or a guidance counselor</li> <li>• referral to specific HCPs: nutritionist, gynecologist, addiction doctor</li> <li>• referral to patients' association</li> <li>• working groups within young people with different CC: learning about administrative tasks, sharing their experience with the CC</li> </ul>

Step	Who (provider)	What	Why	How
	<i>AD'venir</i> coordinator	Systematic invitation of the adolescent to attend <i>AD'venir</i> workshops until their transfer to adult healthcare		E-mails, newsletter, website
	RHCP	Assessment of RHCP's experience 6 months after the PTC		Anonymous on-line satisfaction questionnaire

In our study, PTCs were delivered by one of the 4 *AD'venir* TPs (3 females = HM, MG, SGN; 1 male = PJ), external to the referring team, using youth-friendly communication [20], based on HCPs' positioning and linguistic tools inspired by motivational interviewing, interview techniques and their adolescent medicine training. A central component was the negotiating of power.

## Data analysis

The qualitative approach was developed to gain insight into the conduct of the PTC, because they are relevant methods to understand how health services work and to provide detailed understandings of intervention functioning on a small scale [21]. PTCs were audio-recorded, transcribed by a professional, and contextualized by a form stating the schedule and the adolescent's psychological condition. A two-step qualitative analysis was performed. As a first step, two parallel analyses consisting in an inductive identification of themes [22] were performed by two *AD'venir* TPs (HM, PJ) and two sociologists (AD, CG), respectively. Emerging themes and the analytical framework were discussed together to present a report to a dedicated multidisciplinary working group, including the two sociologists, the four *AD'venir* TPs, one researcher in public health (ELR) and one psychologist (MM). In a second step, the working group held regular meetings to discuss different views on the analysis of transcriptions and reach a consensus on the key results to be developed in the present paper. Two years after the PTC, an independent male HCP (LP), trained in adolescent medicine, conducted semi-structured phone interviews to explore adolescents' perceived support and transition progress. Data are reported according to the COREQ checklist [23].

The quantitative methods consisted in: 1-an analysis of responses given to the TBQ and the Good2Go (continuous variables expressed as median (quartiles) or mean (standard deviation, SD) as appropriate; categorical variables as frequencies (percentages)); 2-an anonymous questionnaire sent to RHCP 6 months after the PTC, to assess the perceived benefits of the PTC (Google-forms®, 8 items).

## Ethics

The R.Debré Ethics Committee approved the protocol (No.2016/268), subject to written approval being obtained from the heads of all hospital units. All data were anonymized.

## Results

Twenty-seven adolescents were included (15 girls [56%]; median age = 17.7 years [17.0;18.6]; 13 from a low socioeconomic background [48%]; 14 with birth-onset CC [52%])(Table 2). PTCs' median duration was 63.0 min (54.5;76.5). Five participants were accompanied, mostly by their parent(s)(Table 2). Many met a doctor alone for the first time. Two 18-year-old girls with inflammatory bowel disease decided to come alone: *"Now I'm responsible, I'm autonomous; I can do this without my parents."*; *"When I received the e-mail, it was written 'parents if possible but not mandatory', I didn't even think of asking my mother."*

Table 2

Characteristics of the 27 participants and responses to the Treatment Burden Questionnaire and the Good2Go questionnaire

Variable	Participants (n = 27)
Gender: Girls – <i>n</i> (%)	15 (56)
Age at pre-transition consultation, in years – <i>median</i> (Q1,Q3; <i>min</i> , <i>max</i> )	17.7 (17.0, 18.6; 14.4, 23.2)
Age at diagnosis of the chronic condition	1.8 (0.0, 8.8; 0.0, 16.0)
Age in years – <i>median</i> (Q1,Q3; <i>min</i> , <i>max</i> )	
Period of diagnosis – <i>n</i> (%)	14 (52)
<i>Birth</i>	7 (26)
<i>Infancy</i>	6 (22)
<i>Adolescence</i>	
Chronic condition – <i>n</i> (%)	8 (30)
Chronic diarrhea (Crohn's disease, hemorrhagic rectocolitis, non-labeled chronic diarrhea)	5 (19)
Cystic fibrosis	4 (14)
Type 1 diabetes	3 (11)
Anorectal malformation (VACTERL syndrome with hypospadias, anorectal and esophageal malformations, malformation without uropathy)	2 (7)
Rheumatic musculoskeletal diseases (spondyloarthritis, connective tissue disease)	
Hirschsprung disease	1 (4)
Craniopharyngioma	1 (4)
Nephrotic syndrome	1 (4)
Asthma with respiratory allergy	1 (4)
Chronic intestinal pseudo-obstruction	1 (4)
Cognitive retardation – <i>n</i> (%)	2 (7)
Yes	25 (93)
No	

Variable	Participants (n = 27)
Education (in the absence of cognitive retardation) – <i>n (%)</i>	18 (72)
Normal school career	6 (24)
Educational difficulties	1 (4)
De-schooling	
Socioeconomic background* – <i>n (%)</i>	5 (19)
High	9 (33)
Middle	13 (48)
Low	
Alone or accompanied to pre-transition consultation – <i>n (%)</i>	22 (81)
Alone	4 (15)
With mother	1 (4)
With brother	
Duration of the pre-transition consultation, in minutes – <i>median (Q1,Q3; min, max)</i>	73 (65, 87; 50, 118)
Planning of transfer to adult healthcare – <i>n (%)</i>	12 (44)
No information	7 (26)
Vague information about the adults' hospital and/or timing of transfer	8 (30)
Planned transfer	
Feeling of being ready for transfer – <i>n (%)</i>	13 (48)
Yes	14 (52)
No	
Good2Go domain scores – <i>median (Q1,Q3; min, max)</i>	40 (24, 50; 13, 75)
Health self-advocacy	70 (48, 78; 5, 100)
Knowledge about chronic condition	43 (27, 73; 0, 100)
Practical skills	43 (27, 73; 0, 100)

## Clinical features of the PTC

### Past

Adolescents were first asked to describe their CC, from the start and up to the present. Most could say the exact name, but some had great difficulty in naming their CC and mentioned their treatment or medical device (central catheter, insulin, etc.), or the symptom that revealed the CC (e.g. *"I did not eat"*, *"I kept vomiting"*). Six adolescents, four with cystic fibrosis (CF) used periphrases such as *"the same disease as Gregory Lemarchal"* (a famous French singer who died from CF aged 24). One 18-year-old girl never said 'cystic fibrosis' for fear of being stigmatized: *"I don't want people to say 'Oh, she's going to die soon...'"*.

The terms *"digestive ostomy"* and *"incontinence"* were also avoided. Sometimes, difficulties reflected a lack of knowledge or scientific terminology, especially in cases of cognitive impairment: *"When I say 'nephrotic syndrome' I don't see what that's got to do with the kidneys."* (18-year-old girl, early-childhood-onset nephropathy).

Two boys did not know the names of their CC, respectively laparoschisis and VACTERL syndrome, despite a history of multiple surgical interventions and, in one case, incontinence. The absence of an explicit link between the CC and the tests could also be confusing, such as a hand X-ray for growth retardation exploration in a girl with chronic diarrhea syndrome.

## Present

Concerning TBQ, laboratory tests, diet, doctor appointments and administrative tasks emerged as impacting daily life (Fig. 1, Table 2). If laboratory tests were often synonymous with pain or stress, the loss of time and the constraints of appointments underlined the differences from healthy peers. Other items were scored low, even when treatment was constraining. Only 3 adolescents had a low TBQ global score. No effect of age, age at diagnosis, gender or type of CC was observed on global score (Fig. 2). Treatment observance was most often good, but talking about treatment frequently led to sharing their distress at living with a CC: *"I don't like the thought of having to go on being treated, I just feel I want to be left alone"* (19-year-old boy, VACTERL syndrome).

All adolescents complained of the limitations experienced in social life, notably diet, tiredness or having to renounce physical activity (Table 3). Intimate concerns were shared increasingly easily as the PTC progressed, sometimes only after 45 minutes. Even some refused the genital examination, the physical examination provided an opportunity to address their often-impaired body image and to go further in talking about intimate concerns (Table 3). Mostly, adolescents were willing to discuss their sexual concerns. However, as for tobacco, drugs and alcohol, Good2Go showed that a minority talked about sexuality with HCP. One 19-year-old boy with a penile malformation multiplied his sexual partners out of a need to be reassured, but he did not discuss this with his surgeon. This taboo made them feel quite ashamed. A boy (23-year-old, urogenital malformation) who was about to get married, declared: *"Is it OK if I ask you?[...] I'm a bit paranoid about...not having children, you see, and stuff like that"*. Many were poorly informed about impact of CC on fertility or course of pregnancy. Parental presence during appointments with their RHCP was cited as a barrier.

Table 3  
Topics reported as impacting social life

Topic	Comment	Example of verbatim
Physical tiredness	<ul style="list-style-type: none"> <li>• Main complaint spontaneously reported</li> <li>• Impacting several daily tasks: school life, use of public transport or participation in recreation activities</li> <li>• May be related to the chronic condition or to treatments</li> </ul>	<p><i>"You're just not like the others any more [...] you're so tired, [...] you can't feel OK when there's a disease inside you [...] eating up all your energy"</i> (Girl, aged 17, inflammatory bowel disease)</p> <p><i>"[sleep?] Well, at present... huh!...[...] not much. I'd say it's a bit mixed because of the new machine"</i> (Boy, aged 18, cystic fibrosis and type 1 diabetes, requiring parenteral nutrition)</p>
Pain	<ul style="list-style-type: none"> <li>• Frequently reported</li> <li>• In contrast to tiredness, did not systematically lead to adolescents having to give up to social activities (sport, class trips, etc.), even if severe</li> </ul>	<p><i>"I like playing football so [the pain] troubled me a lot [...] but I played anyway"</i> (Boy, aged 16, spondyloarthritis)</p>
Renouncement of physical activity	<ul style="list-style-type: none"> <li>• Source of sadness at being excluded from sports' clubs as place for socializing</li> </ul>	<p><i>"To be honest I'd rather watch football than play it... that's because... at the beginning it was great fun and I enjoyed it, I was really keen, but then, as I got more and more tired and so on... I just couldn't run any more, I was tired all the time during the games, it wasn't much fun, so in fact I preferred...er...supporting, and going to watch, rather than playing"</i> (Girl, 18 years, nephrotic syndrome)</p> <p><i>"Sport really helped me, [...] it helped me build relationships"</i> (Boy, aged 17, VACTERL syndrome, exclusively parenteral nutrition)</p>
Being forbidden to swim	<ul style="list-style-type: none"> <li>• In the case of central catheters</li> <li>• Requirement for an (expensive) Expect with an (expensive) wetsuit</li> </ul>	<p><i>"What's more, I think I've probably forgotten how to swim."</i> (Boy, aged 14, laparoschisis)</p>

Topic	Comment	Example of verbatim
Having a diet	<ul style="list-style-type: none"> <li>• During infancy, excess of care from the teaching staff in school increased the visibility of the CC and the social withdrawal</li> <li>• In adolescent, not being able to eat some adolescents' favorite food (sodas, fast-food) impair social integration in healthy peer groups</li> </ul>	<p><i>"[at school] I had a packed lunch so I used to eat on my own" (Girl aged 16, DT1)</i></p> <p><i>"Before, I never used to go out to eat with friends [...] I'd say to myself 'no, no, I'm not going to go, I'm not going to eat...er...in fact I'm not going to eat anything'" (Boy, aged 17, VACTERL syndrome, exclusively parenteral nutrition)</i></p>
Fear of taking a medication	<ul style="list-style-type: none"> <li>• Linked to the absence of knowledge about side effects</li> </ul>	<p><i>"I'm really afraid of medicines, I try to take as few as possible [...] Just imagine if there are side effects or something, I don't know how my body's going to take it, how it's going to react to that, and that's really what makes me...er...makes me really scared" (Girl, aged 18, Crohn's disease with joint damage)</i></p>
Growth delay and low weight	<ul style="list-style-type: none"> <li>• Frequent cause of dissatisfaction and impairment of body image (feeling of weakness), especially in boys</li> <li>• Reminder of the presence of the CC, in reference to the period of diagnosis during which a severe weight loss was frequent</li> </ul>	<p><i>"I've been the same height for the past 2 years, I'm really fed up!" (girl, 17 years, non-labelled chronic diarrhea)</i></p> <p><i>"Compared to the physical activities I can't do, what's really a constraint...er...[...] it's perhaps not having the same capacity as the others, well, when it comes to...[...] muscles" (Boy, aged 17, VACTERL syndrome)</i></p>
Scars	<ul style="list-style-type: none"> <li>• Increasing the visibility of CC</li> <li>• Need to develop strategies to cope with peers' questions</li> </ul>	<p><i>"Well, sometimes, when it [the scar] shows a lot, especially when I wear a bikini [at the swimming pool], and what's more, after I keep getting asked 'why have you got that' and then I have to go on and explain" (Girl, aged 18, nephrotic syndrome)</i></p>

## Future

Most were aware of the need to transfer. However, transfer was accepted with passivity as a natural process towards maturity, but with sadness at leaving the hospital they were used to and "their" RHCPs who were "allowed to know everything". Some were afraid of being forgotten. Some even refused to think about it, even when they felt ready to transfer: "Maybe I'm ready? But I don't want to." (17-year-old girl, Crohn's disease). None cited the non-physician HCP. Some were not ready and comfortable with being



dependent on their parents but confident they would be able to look after themselves when the time came: *"I know that when I have to look after myself, I'll be able to."* (16-year-old girl, inflammatory bowel disease).

In contrast, some pointed out the pediatricians' inability to *"speak frankly"* or to deal with "adult" issues, such as vaginal mycoses in an 18-year-old girl with CF. The adolescents rarely had comprehensive information about transfer (timing, doctor/hospital to be transferred to). Some had been involved in the choice of their future HCP (several girls preferred a female doctor) or in transfer planning (*"after my baccalaureate exam"*). Representations of adult healthcare were globally poor, with a similarity to pediatric units.

Previous discussion facilitated completion of the Good2Go questionnaire. Scores were globally consistent with the TP's impression of transition readiness, without correlation with age at diagnosis of the CC, knowing the CC's exact name, having information about transfer, educational level or socioeconomic background. Scores of the 3 domains revealed intrapersonal heterogeneity (Fig. 2). Older adolescents had slightly higher scores in domains 1 (health advocacy) and 3 (practical skills), whereas gender did not seem to influence scores (Fig. 2). Non-scored items identified the mother as the main resource person, rather than siblings (one boy mentioned his brother, with CF too) or the father.

## **RHCPs' perceived benefits of the PTC**

Thirteen RHCPs (13/27) completed the questionnaire. All were satisfied with the PTCs and the PTC reports. RHCPs reviewed their practices with regard to talking about transition or the long-term outcomes for adolescents with CC (n = 12), supporting the parents (n = 10) or involving adolescents during appointments (n = 9). RHCPs noted behavioral improvements in adolescents and their parents in terms of looking ahead to transfer (n = 13) or more generally to the future (n = 12), self-management skills (n = 12), or participation during appointments (n = 11).

## **Adolescents' perceived benefits of the PTC**

All but one adolescents accepted the phone interview 2 years after PTC. None was lost of follow-up. Transfer in adults' care had occurred for 19, of whom 18 were satisfied and trusted their new HCP. One girl (19 years, Crohn's disease) returned in pediatric healthcare; during the PTC, the Good2Go indicated high scores of transition readiness, but transfer in adults' care was mainly perceived as an opportunity to leave the fusional relationship with their mother. All others adolescents (n = 7) were now informed about the transfer planning.

Concerning experience of PTC, some participants had appreciated this opportunity to have information about transition, how will it proceed, and to prepare adequately for the transfer. PTC was also a place to talk about social issues like insurance or pregnancy, and to share about their intimate experience of the CC: *"It allows me to have more information about the hospital, what was going to happen; I was maybe less anxious [...]. It helped me to have a deeper understanding about my CC; I used to think it was a pulmonary problem, diabetes, and that's all."* (18-year-old boy, CF).

## Discussion

The PTC relies on a holistic approach to care delivery for adolescents with CC and adopts most of the elements of the transition theoretical framework [24, 25], inspired by the Chronic Care Model [26]: youth-centered and strength-based focus, emphasis on self-determination and self-management, acknowledgment of individual differences and complexities, and recognition of vulnerabilities, cultural beliefs and socioeconomic disparities. This model of dedicated consultations, assessing transition readiness and identifying tailored and negotiated actions for transition preparation, irrespective of the adolescent's CC, is a first in France and, to our knowledge, very innovative internationally. The PTC is implemented by experts in adolescent medicine occupying an independent but complementary position with regard to the RHCP. One experience in neurodevelopmental conditions bears some similarities [27], but our research underlines the invariable points shared by all CC and highlights the relevance of a disease-neutral intervention.

First, the PTC offers adolescents an appreciated opportunity to step back, review and speak freely about their history with CC, how they have arrived at their present point and how they see themselves in the future. This helps them analyze their strengths and barriers to transition success [7]: CC self-management skills, feeling of self-efficacy, trust in adult healthcare and perceived social support. The PTC report gives the RHCP a comprehensive transition planning tool to tailor the transition preparation with a deeper overview of the day-to-day challenges facing the adolescent, such as fatigue, rarely explored despite its impact on their social life [28–31].

Second, the PTC is a place of training, positioning the adolescent as a direct interlocutor of a new practitioner, without their parents, and RHCPs pointed out a beneficial change in the adolescent-RHCP dynamic. Thus, it develops their self-advocacy, making them express their point of view, sometimes for the first time, concerning all relevant life issues, from CC self-management to intimate issues. In this exercise, putting their CC into words was sometimes difficult because of an insufficient knowledge, a discrepancy between their own representation and medical physiopathology [32] or coping strategies such as avoiding words perceived as too crude. While this was not an obstacle to self-management skills acquisition, using the exact wording of the CC was encouraged to empower adolescents in an adult healthcare setting. Adolescents were also given crucial information about health needs and functioning in adult care, to help them to take responsibility for their health and enhance their level of confidence in their future health services, both of which facilitate access to healthcare [11].

Finally, the RHCPs' high satisfaction rate of and changes introduced in their clinical practices following PTCs, as well as the favorable 2-years outcomes of participants show that implementing a dedicated consultation helped to develop a transition policy within the hospital and to enhance transition support of adolescents.

Our methodology enabled us to analyze the implementation and functioning of this new service, in particular in terms of participants' responses to CPT, and to adapt the PTC modalities in real time [21]. Because adolescents often minimized the treatment burden, the TBQ was abandoned to only assess the

most burdensome topics (tests, appointments, diet). Thus, to involve parents [4, 5, 15, 19] bearing in mind their organizational difficulties, we now offer them individual interviews with the *AD'venir* coordinator or a psychologist and specific information on-line (<https://advenir-robertdebre.aphp.fr/>). Raising adolescents' awareness of their own situation, the Good2Go is now completed at the very end of the PTC to give a more accurate indication of what to work before transfer [2]. However, the failure of transfer for one adolescent reminds that the predictive value of transition readiness questionnaires remains unclear in terms of transition success [19, 33]. Thus, we found no correlation between Good2Go scores and level of information regarding the transition or social context, which are nevertheless both key-points of transition success. Therefore transition readiness questionnaires must be seen as a complement to a global interview. Inversely, not assessed by Good2Go, lack of autonomy in daily life tasks was not considered sufficient to defer the transfer. Indeed, most adolescents become truly independent years later and holistic life-skills are not associated with transition outcome [11]. This reinforces our choice of the Good2Go among others validated questionnaires [19, 33].

Although recording might be intrusive, this research offers TPs a unique opportunity for self-reflexive and collective work on clinical practice. The external and non-prescriber TP's position facilitates a non-judgmental attitude and avoids focusing on compliance and inducing a feeling of 'good' or 'bad' patient. Our results also emphasize two arguments in favor of choosing physician rather than non-physician HCPs to deliver PTCs. First, PTCs require medical knowledge in multiple fields to understand the context of the CC. Second, the physical examination helps to build a bond of trust necessary to address intimate concerns [34]. However, as adults [35], adolescents feel embarrassed to talk with HCPs about sexuality or risky behaviors, which are nevertheless frequent in adolescents with CC [36, 37]. This emphasizes the need to develop adolescent medicine in pediatric settings [38].

The main strength is the multidisciplinary approach, crossing the viewpoints of both clinicians and researchers to allow a finer adjustment of the intervention. Well-accepted and less time- and cost-consuming than qualitative interviews, audio-recordings allowed a real-life analysis. Finally, including a panel of CC responded to a need to enlarge the recruitment in transition studies [10]. Concerning weaknesses, including the first adolescents attending a PTC may introduce a recruitment bias, leading to more positive results [39].

## Conclusion

Thanks to the study, the refined content of the PTC offers a comprehensive overview of transition and is now used in routine clinical practice in our hospital. Implementing the PTC represents an achievable prerequisite to improve other important aspects of transition preparation [38], such as the development of a transition policy, assessment of transition readiness in a global life perspective, planning of transfer and evaluation of progress in transition preparation. This intervention will need in the future to be backed up by a means of facilitating and tracking integration in adult care and evaluated in terms of cost-effectiveness [8].

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## Figures

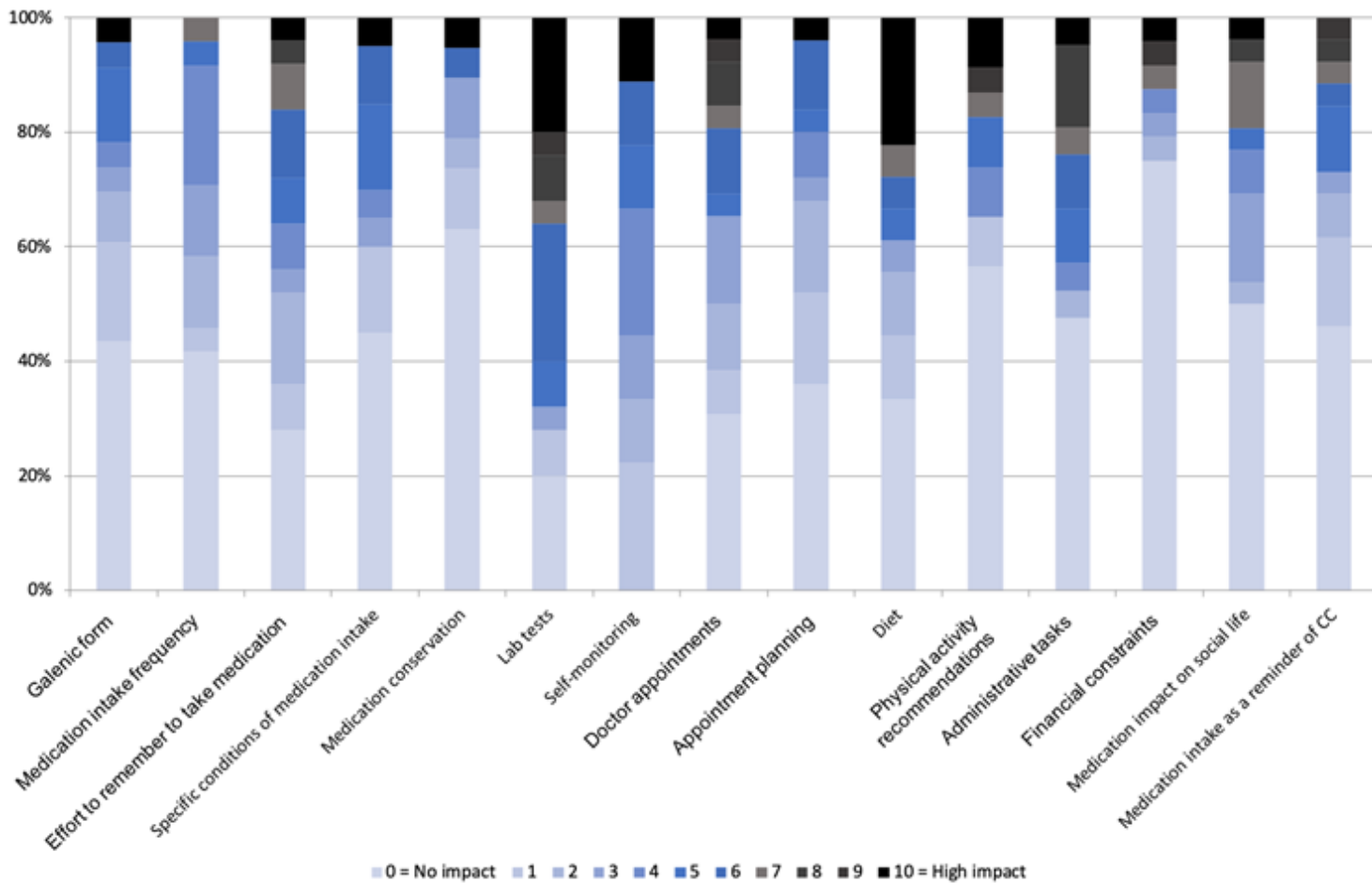
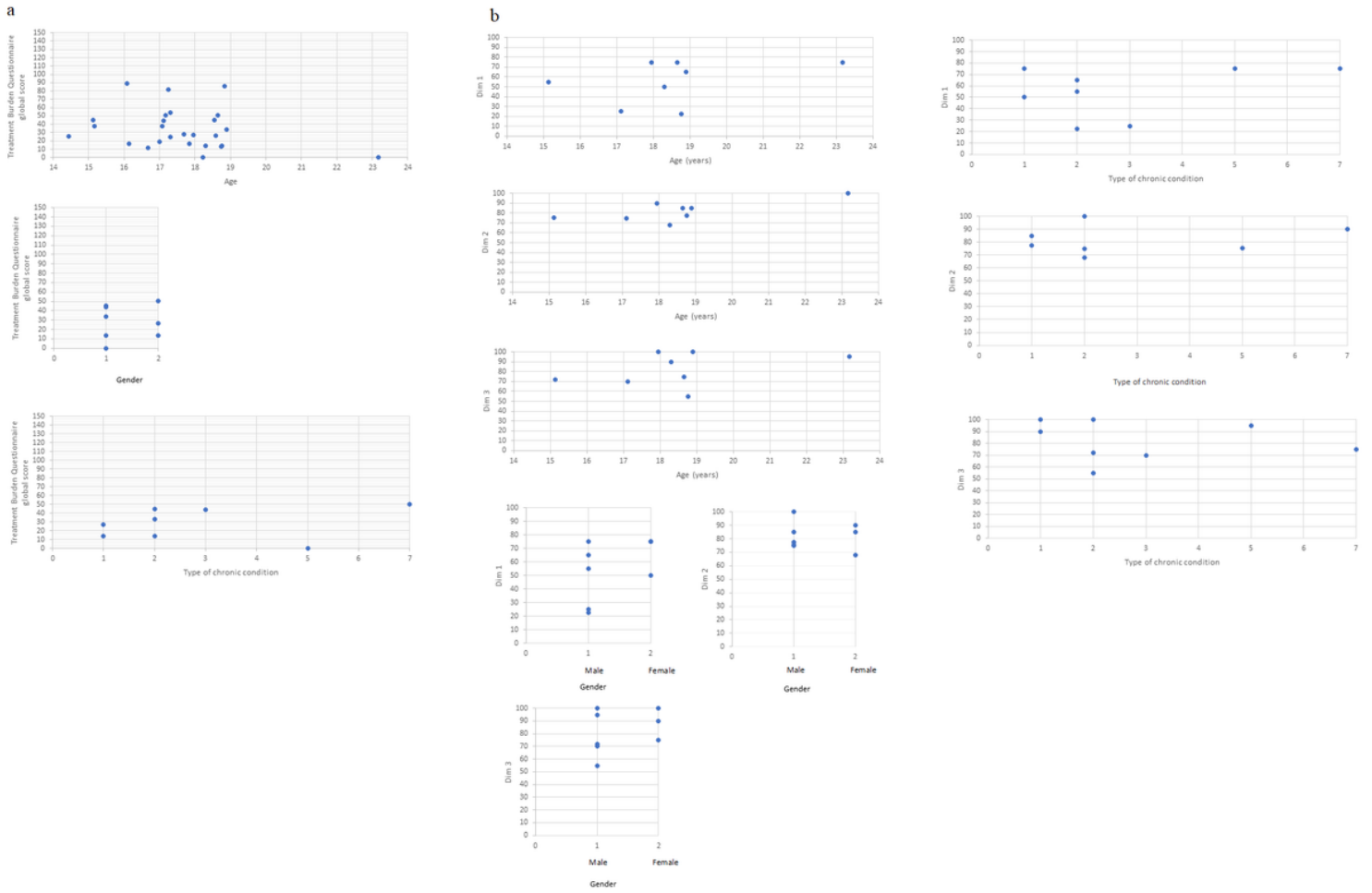


Figure 1

Participants' responses to the Treatment Burden Questionnaire (n=27)



**Figure 2**

Responses to the Treatment Burden Questionnaire and the Good2Go questionnaire. a. Scores of the Treatment Burden Questionnaire scores, by age, gender and type of chronic condition b. Scores for the 3 domains of the Good2Go questionnaire by age, gender and type of chronic condition