



Transition from pediatric to adult health services: A survey of challenges, needs, and preferences of youths and parents

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ABSTRACT

Aim: Transition from pediatric to adult healthcare is a critical period. Recommendations have pointed to greater preparation of youths and families and better coordination. Considerations such as patient values and preferences may – if not taken into consideration – impede uptake of clinical recommendations. This survey-based study aimed to better understand challenges, needs, and intervention preferences of youths and parents during transition.

Methods: Two online surveys were designed to investigate challenges, needs, and intervention preferences of youths with a chronic or rare condition and parents during transition. The youth survey included the French translation of the Transition Readiness Assessment Questionnaire (TRAQ). Additional questions were derived from an interview-based study and aimed to grasp issues related to human flourishing in addition to more conventional clinical issues related to the transition process. Descriptive statistics were used and ANOVAs to detect differences between the groups when applicable.

Results: 86 youths and 94 parents completed the survey. Average scores for TRAQ subscales were high except for “Tracking health issues” and “Appointment keeping”. Youths and parents reported being able to give their opinion. Parents were judged to be slightly over-involved. Ongoing involvement of parents in health management was desired. Awareness of differences between pediatric and adult healthcare was high, but a source of notable concern (e.g., accessibility of different medical and professional services). Information on transition was lacking. Installing a pivot-person, visits to the adult hospital, meeting other youths, and accessing transition videos were supported interventions.

Conclusion: Transition readiness can be high, but significant challenges can still be present and salient. Youths and adults want to be involved and informed to prepare actively for transition through meetings or adapted materials.

1. Introduction

The transition from pediatric to adult healthcare is a crucial period for youths with chronic health conditions. The abrupt change of healthcare settings is frequently experienced as a great source of anxiety, notably because healthcare systems have been found to be lacking in

coordination, sharing of information, and progressive engagement of youths.¹ Moreover, this transition occurs at a time when youths are living their adolescence, a period of significant physiological, psychological, and social changes.² In recent years, healthcare transitions have therefore been investigated and made the target of policies and clinical recommendations to ensure that youths face fewer daunting

Abbreviations: Y, Youths; P, Parents; X, Mean score; TRAQ, Transition Readiness Assessment Questionnaire; SD, Standard Deviation of the mean score.

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challenges.^{1,3,4}

Within transition care research, a focus on the values and preferences of youths and a broader appreciation of the factors underlying their wellbeing and their flourishing is emerging.^{5–8} Flourishing is a concept used in psychology and health literature to describe holistic wellbeing in ways that grasp the meaning-making ability of human beings in face of life and its adversities. Flourishing is often divided into specific dimensions such as – following Caroly Ryff’s influential account – positive relationships, purpose in life, autonomy, self-acceptance, mastery of the environment, and personal growth.⁹ Evidence points to an interrelationship between youth flourishing and health such that core dimensions of flourishing are not only psychologically valuable, but they also contribute to physical health in various ways.^{10–14} Indeed, integrating the challenges posed by transition and chronic conditions (e.g., experiencing positive relationships with others during the transition, accepting oneself with a chronic health condition, having a purpose in life during the period of transition) into one’s sense of purpose and meaning-making narratives could reduce existential fears and promote a more positive outlook on life. Most importantly, such a positive orientation can help youths engage in the self-care they need, in exercising autonomy and taking greater control over their condition.^{10,15}

Building on the literature on the transition with an eye to human flourishing, we embarked on a multi-stage mixed method (mostly qualitative) and participatory action research project where youths with chronic health conditions, parents of youths with such conditions, and healthcare professionals were asked to report and reflect on how the transition affects different dimensions of health and human flourishing (see explanatory [Box 1](#)). This publication reports the results of a survey with youths and parents on their challenges, needs, and preferences.

2. Methodology and materials

2.1. Ethics approval

Ethics approval from the Research Ethics committee of the Centre hospitalier universitaire Sainte-Justine (CHUSJ) and of the Institut de recherches cliniques de Montréal (IRCM) was sought and granted. This study conforms to Canadian and Quebec research ethics guidelines as well as international research guidelines such as the Declaration of Helsinki.

2.2. Participants and recruitment

The population were youths with chronic conditions receiving care at the participating pediatric hospital and parents of youths in this situation. Eligibility criteria for the youth population were: 1) aged between 14 and 20; 2) having one or more chronic condition; 3) receiving care at the participating pediatric hospital (CHUSJ); 4) not having transitioned to adult care; and 5) ability to read French given the

language of the survey. Parents were eligible if they had one or more youths who fulfilled the eligibility criteria and were able to complete the survey in French. The target sample size was 150 (N = 75 youths, N = 75 parents).

Recruitment followed two main strategies: 1) a large-scale recruitment effort targeting the general population followed at the pediatric hospital and 2) additional recruitment efforts to enroll participants susceptible of responding to the eligibility criteria. For the first strategy, recruitment was done in collaboration with the communication department of the pediatric hospital and included digital (through the official social networks of the hospital) and physical (through brochure distribution and poster displays in common areas) approaches. For the second strategy, recruitment was performed in collaboration with specific organizations (such as chronic disease foundations) and targeted clinics at the pediatric hospital. In these clinics, recruitment posters and brochures were distributed by receptionists, nurses and doctors. Additionally, two team members (FO and RGGR) approached directly staff and prospective participants in the different clinics to recruit eligible participants, with the approval of the clinic directors.

2.3. Survey development, organization and content

A homegrown survey was developed in two versions (youths and parents): a “youth” version with 57 items, including a French translation of the Transition Readiness Assessment Questionnaire (TRAQ) accounting for 20 items, and a “parent” version with 40 items. The survey – especially its original sections – was designed through an interdisciplinary research approach involving clinicians, research coordinators, patients, and parents. A first draft version of the survey was developed by the research assistant (FO) in charge of the project and revised by the principal investigator (ER). Initial questions (especially for [Sections 5 and 6](#) of the survey described below) were derived from the results of a previous phase of an ongoing research project on transition and human flourishing in which issues and important transition themes were identified through 54 semi-structured interviews with youths (N = 24), parents (N = 16), and healthcare professionals (N = 14).⁵ This first version was then revised by other researchers and clinicians involved in the project through an iterative process. Once this first version was finalized, the survey was shared with stakeholders (N = 4 youths, N = 3 parents) for cognitive pre-testing by using a think-aloud technique and probing questions on understandability, relevance, and completeness. Following this testing, the survey was revised, and the last version of the survey was shared with the research team members for final review. Following further changes, the final version was then introduced on the online LimeSurvey platform, tested for technical functionality with other members of the research team, and published.

The survey included 8 Section (7 for the parent version): 1) consent form; 2) context of the research project and the survey and definitions of the terms used (an explanatory section); 3) eligibility criteria (3

Box 1 Parachute Study.

The Parachute Study is a participatory action research study on transition care. A working group of youths, parents, and healthcare professionals was constituted to advise on the development of the study conducted in a major Canadian pediatric hospital. A literature review identified how transition programs and the transition literature are often implicitly addressing – although rarely explicitly – human flourishing.⁶ This prompted and structured an interview-based study with stakeholders. Results show that, for example, a dimension of flourishing such as “mastery of the environment”⁹ – the ability to effectively change one’s situation and environment – is impacted by numerous challenges during transition (e.g., lack of continuity in care, gaps in knowledge and information about the transition) which undermines the ability to be a prepared and efficacious adult health service user.⁹ Another dimension of flourishing such as autonomy is impacted by parental involvement in healthcare and different desires to exercise autonomy in youths.⁵ To further broaden these findings, we undertook a survey study with youths and parents to adopt a quantitative outlook on some of their experiences. This was done to prepare for the next phase of the action-research study. The latter builds on the involvement of youths to develop video-based material addressing challenges encountered by youths during their transition.

questions, single choice answers); 4) TRAQ questionnaire (20 items for youths only; five-point Likert-type scales); 5) validation and assessment of issues and needs (17 questions for youths; 20 questions for parents; five-point Likert-type scales); 6) validation of preferences and recommendations for transition (9 questions; five-point Likert-type scales); 7) demographics (5 questions; combination of single answer choices, open-ended answers, and scrolling lists), and 8) information on the draw for participants (participants could enter a draw for five 100\$ gift certificates) and express interest in the next phase of the study (3 questions; combination of check boxes and open response). In the presentation of the results (see text and tables below), the original survey questions reported in this paper are numbered Q1-Q24 in the table entries while TRAQ questions are numbered T1 to T20. TRAQ questions afford answers with values ranging from 1 to 5 where “No, I do not know how” has a value of 1, and “Yes, I always do this when I need to” has a value of 5. All Q1-Q24 questions followed a five-point scoring system akin to the TRAQ formulated as: “do not agree at all” (value of 1); “do not agree” (value of 2); “neutral” (value of 3); “agree” (value of 4), and “completely agree” (value of 5). Q2 used the same scoring but with different linguistic formulations (“way too involved” (value of 1); “too involved” (value of 2); “just enough involved” (value of 3); “not enough involved” (value of 4), and “way not enough involved” (value of 5).

The youth version included a French version of the Transition Readiness Assessment Questionnaire (TRAQ)¹⁶ (available at https://www.etsu.edu/com/pediatrics/traq/documents/traq_french.pdf). This translation of the TRAQ consists of 20 short questions and has a reported Cronbach’s alpha of 0.91. It measures transition readiness with respect to 5 domains: 1) managing medications; 2) appointment keeping; 3) tracking health issues; 4) talking with providers and 5) managing daily activities. The official French translation we used is based on the 2014 English version of the TRAQ questionnaire.¹⁶ The English version of the TRAQ on which the French version is based¹⁶ has now been revised¹⁷ (e.g., the managing daily activities subscale has been removed¹⁸) but there is no current corresponding French translation of this new revised version.

Questions for Section 5 of the survey (i.e., validation and assessment of issues and needs) were derived from previous interview-based research on transition on human flourishing.⁵ In this research, 14 salient issues were identified (e.g., relational continuity with healthcare professionals [during transition], knowledge and information about the transition, navigating life with chronic illness [during transition]) and analyzed for their impact on six dimensions of human flourishing.⁹ These key issues were used to develop questions for Section 5 to assess whether these were also upheld by survey participants. These questions – building on the concept of human flourishing – loom broader than more clinical (but important) questions grasped in the TRAQ (e.g., “Q9 I have negative feelings (e.g., fear, stress, anxiety) about having to separate from my current healthcare team during the transition to adult healthcare”; “Q11 My health condition makes me feel different from others”). Reconciliation and rationalization in the questions occurred to avoid overlap with content of the TRAQ. Some questions (e.g., “Q4 Awareness of the differences between pediatric and adult healthcare systems”) were formulated to assess perspectives with respect to oneself (e.g., as a parent) and with respect to one’s child for parent respondents. Questions for Section 6 (i.e., validation of preferences and recommendations for transition) surveyed an array of potential scenarios for clinical management and for the development of resources which corresponded to options documented in the literature supplemented (e.g., transition coordinators) and the local resources available through this research project and the ongoing transition program of the participating pediatric institution. Other sections of the survey (e.g., consent, eligibility criteria) were developed with in mind compliance with existing research ethics guidelines and the purpose of the project. Demographics were kept simple given the lack of *a priori* hypothesis on the relationships between certain categories and the answers to the questions.

2.4. Statistical analysis

Descriptive statistics such as frequencies, and means and standard deviations, when applicable, were first computed for each question. On questions answered by both youths and parents, univariate analysis of variance (ANOVAs) was conducted to detect mean differences between the groups. Significance threshold was set at $p = .05$. All analyses were conducted using IBM SPSS Version 21.

3. Results

3.1. Demographics

Eighty-six (86) youths completed screening questions and consent of the survey and were included in the descriptive statistics. All reported living with a chronic or rare condition and were followed at CHUSJ in 26 different clinics, although many reported being seen in more than one clinic and living with several health conditions. Sixty-three (63; 73.3 %) had not started their transition, while 23 (26.7 %) were transitioning. Ninety-four (94) parents completed screening questions and consent. All declared themselves parents of a child followed at CHUSJ with a chronic or rare condition. Most of the parents’ children had not undertaken their transition ($n = 78, 83\%$), while 16 (17 %) were transitioning.

3.2. Transition readiness

Youths reported an average total TRAQ score of 3.71 (SD = .83) ranging from 1.95 to 4.95 (see Table 1). Average score for the “Talking with providers” subscale was very high (4.70) and for the “Managing daily activities” (4.18) and “Managing medications” (4.06) subscales were high. Scores for the “Tracking health issues” (3.15) and “Appointment keeping” (3.35) were lower.

Table 2 presents the frequencies and averages on all 20 individual questions contained in the TRAQ. In general, youths reported high averages on questions about answering questions from healthcare professionals (T17; 4.92), taking their medications by themselves (T3; 4.71), frequenting stores and services in their neighborhoods (T20; 4.58), telling physicians and nurses about how they feel (T16; 4.48), and about keeping their home or room clean and cleaning after meals (T19; 4.21). Lower scores were reported for items related to knowing whether they received financial support for school or work (T15; 1.93) and for knowing what is covered by their health insurance (T10; 2.73). Scores for all other questions fell between the “No, but I am learning to do this” and “Yes, I have started doing this” values.

Table 1
TRAQ scores.

TRAQ subscales	Cronbach’s alpha	minimum	maximum	mean	Standard-deviation
Managing medications	0.71	1.00	5.00	4.06	.96
Appointment keeping	0.90	1.00	5.00	3.35	1.28
Tracking health issues	0.71	1.00	5.00	3.15	1.11
Talking with providers*#	0.25	2.50	5.00	4.70	.55
Managing daily activities#	0.48	2.00	5.00	4.18	.69

N varied between 85 and 86.

* This subscale is only constituted of 2 questions in the Track and their correlation is .28

Low Cronbach’s alpha for these two subscales should prevent any strong conclusion based on these subscales.

Table 2
Frequencies and proportions of the TRAQ questionnaire: Youth participants only.

	No, I do not know how (1) N (%)	No, but I want to learn (2) N (%)	No, but I am learning to do this (3) N (%)	Yes, I have started doing this (4) N (%)	Yes, I always do this when I need to (5) N (%)	Mean (SD)
Managing Medications						
1. Do you fill a prescription if you need to?	N = 10 (11.6 %)	N = 10 (11.6 %)	N = 8 (9.3 %)	N = 8 (9.3 %)	N = 50 (58.1 %)	3.91 (1.48)
2. Do you know what to do if you are having a bad reaction to your medications?	N = 8 (9.3 %)	N = 19 (22.1 %)	N = 8 (9.3 %)	N = 10 (11.6 %)	N = 41 (47.7 %)	3.66 (1.48)
3. Do you take medications correctly and on your own?	N = 1 (1.2 %)	N = 2 (2.3 %)	N = 2 (2.3 %)	N = 11 (12.8 %)	N = 70 (81.4 %)	4.71 (.73)
4. Do you reorder medications before they run out?	N = 8 (9.3 %)	N = 8 (9.3 %)	N = 13 (15.1 %)	N = 9 (10.5 %)	N = 48 (55.8 %)	3.94 (1.39)
Appointment Keeping						
5. Do you call the doctor's office to make an appointment?	N = 13 (15.1 %)	N = 17 (19.8 %)	N = 12 (14.0 %)	N = 10 (11.6 %)	N = 34 (39.5 %)	3.41 (1.54)
6. Do you follow up on any referral for tests or check-ups or labs?	N = 14 (16.3 %)	N = 16 (18.6 %)	N = 8 (9.3 %)	N = 10 (11.6 %)	N = 38 (44.2 %)	3.49 (1.59)
7. Do you arrange for your ride to medical appointments?	N = 11 (12.9 %)	N = 12 (14.1 %)	N = 9 (10.6 %)	N = 3 (3.5 %)	N = 50 (58.8 %)	3.81 (1.56)
8. Do you call the doctor about unusual changes in your health (e.g., allergic reactions)?	N = 13 (15.3 %)	N = 13 (15.3 %)	N = 10 (11.8 %)	N = 14 (16.5 %)	N = 35 (41.2 %)	3.53 (1.52)
9. Do you apply for health insurance if you lose your current coverage?	N = 26 (31.3 %)	N = 9 (10.8 %)	N = 6 (7.2 %)	N = 3 (3.6 %)	N = 39 (47 %)	3.24 (1.81)
10. Do you know what your health insurance covers?	N = 28 (33.7 %)	N = 17 (20.5 %)	N = 10 (12.0 %)	N = 5 (6.0 %)	N = 23 (27.7 %)	2.73 (1.64)
11. Do you manage your money and budget household expenses (eg, use checking/debit card)?	N = 17 (20.0 %)	N = 13 (15.3 %)	N = 9 (10.6 %)	N = 21 (24.7 %)	N = 25 (29.4 %)	3.28 (1.52)
Tracking Health Issues						
12. Do you fill out the medical history form, including a list of your allergies?	N = 17 (20.5 %)	N = 11 (13.3 %)	N = 5 (6.0 %)	N = 12 (14.5 %)	N = 38 (45.8 %)	3.52 (1.64)

(continued on next page)

Table 2 (continued)

	No, I do not know how (1) N (%)	No, but I want to learn (2) N (%)	No, but I am learning to do this (3) N (%)	Yes, I have started doing this (4) N (%)	Yes, I always do this when I need to (5) N (%)	Mean (SD)
13. Do you keep a calendar or list of medical and other appointments?	N = 10 (11.8 %)	N = 11 (12.9 %)	N = 8 (9.4 %)	N = 19 (22.4 %)	N = 37 (43.5 %)	3.73 (1.43)
14. Do you make a list of questions before the doctor's visit?	N = 15 (17.6 %)	N = 10 (11.8 %)	N = 11 (12.9 %)	N = 28 (32.9 %)	N = 21 (24.7 %)	3.35 (1.43)
15. Do you get financial help with school or work?	N = 55 (65.5 %)	N = 7 (8.3 %)	N = 5 (6.0 %)	N = 7 (8.3 %)	N = 10 (11.9 %)	1.93 (1.46)
Talking With Providers						
16. Do you tell the doctor or nurse what you are feeling?	N = 4 (4.7 %)	N = 1 (1.2 %)	N = 4 (4.7 %)	N = 17 (20 %)	N = 59 (69.4 %)	4.48 (1.00)
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?	N = 0	N = 0	N = 0	N = 7 (8.2 %)	N = 78 (91.8 %)	4.92 (0.28)
Managing Daily Activities						
18. Do you help plan or prepare meals/food?	N = 6 (7.1 %)	N = 8 (9.4 %)	N = 15 (17.6 %)	N = 29 (34.1 %)	N = 27 (31.8 %)	3.74 (1.21)
19. Do you keep home/room clean or clean up after meals?	N = 2 (2.4 %)	N = 2 (2.4 %)	N = 14 (16.5 %)	N = 25 (29.4 %)	N = 42 (49.4 %)	4.21 (0.97)
20. Do you use neighborhood stores and services (eg, grocery stores and pharmacy stores)?	N = 0	N = 3 (3.5 %)	N = 2 (2.4 %)	N = 23 (27.1 %)	N = 57 (67.1 %)	4.58 (0.71)

3.3. Issues associated with the transition

In terms of voicing their opinions and preferences at CHUSJ, youths and parents tended to agree about being able to give their opinion, but youths significantly more so (Q1; 4.43 and 3.76). In terms of the various aspects of their health management, youths and parents tended to consider parents, being “just enough involved” for all aspects surveyed (Q2a-Q2e). However, significant differences were detected between youths and parents with respect to the distribution of answers for “decision on treatments” (Q2e).

Both youths and parents agreed that they desired the ongoing involvement of parents in the management of their condition. However, parents agreed significantly more than youths (Q3; 3.97 and 4.59). Both groups were cognizant of the differences between pediatric and adult healthcare (Q4, 4.28 and 4.64). Parents considered their child to be significantly less aware of these differences, even more so than the youths themselves (Q4; 4.64 and 3.47). With respect to these differences, there were several sources of concern: changes of attitudes of healthcare professionals (Q5a); accessibility of different medical and professional services (Q5b); lower levels of supervision in the management of the condition (Q5c); and changing hospitals (Q5d). Respondents tended to disagree that they had sufficient information on the transition (Q5e, 3.63 and 2.28 with parents ranking lower than youths at 2.12).

Both groups reported that healthcare professionals encouraged them to participate in the management of their condition, with youths reporting this more (Q6; 3.89 and 3.44).

3.4. Means of supporting the transition

Both youths and parents reported a strong desire to meet the new physician responsible for adult healthcare before the transition, with parents being even more adamant about this (Q17, 4.15 and 4.45). Parents reporting being more in favor of including parents when this option was offered (Q18c and Q18d).

In the advent of a pivot-person during the transition, there was support for the current physician (Q20a, 3.62 and 3.60), a nurse (Q20b, 3.24 and 3.88), and a new person specialized in transition care (Q20e, 3.20 and 3.43) to play this role. There was less agreement for a psychologist (Q20c, 2.96 and 3.19), a social worker (Q20d, 2.92 and 3.19), and a peer having completed transition (Q20f, 2.99 and 2.83) to serve as this pivot-person.

Both youths and parents wanted to visit the adult hospital before transition (Q21, 3.90 and 3.91), meet other youths with similar conditions (Q22, 3.25 and 3.52) and have access to videos about the transition (Q23, 3.52 and 3.89) with parents supporting more strongly this latter option than the youths. In terms of information contained in such short

videos, there was agreement and sometimes strong agreement with all proposed topics (e.g., Q24a-Q24g).

4. Discussion

This survey-based study investigated the transition readiness of youths as well as the challenges associated with the transition. It tapped into the attitudes and preferences of youths and parents with an eye to human flourishing and with respect to remediation strategies such as the involvement of healthcare professionals, the instalment of a transition coordinator, and the use of informational short videos.

The TRAQ results show that this diversified cohort of youths felt rather prepared for the more medical aspects of their condition but less so for the financial and health insurance-related questions. Although insurance and finance-related questions hold a peculiar meaning in the socioeconomic context of Canada's healthcare systems, youths do have to prepare for complementary private health insurance (e.g., in Québec) when they lose coverage offered by their parents' insurance, which is a concern that has been voiced before in pediatric settings.¹⁹ The TRAQ, including its various recent translations, has a high reported internal consistency supported by subsequent studies reporting Cronbach's alpha values between 0.78 and 0.94.^{16,17,20–22} However, in our study, two subscales had particularly low alpha values ("Talking with providers" (TWP) subscale = 0.25 and "Managing daily activities" (MDA) subscale = 0.48) although this is partly due to the low number of items for these subscales. Ideally, French translation should be updated to match newer versions of the TRAQ. It is now a four-subscale questionnaire without the TWP subscale¹⁸ but still with low internal consistency for the fourth (MDA) subscale.²³

Transition readiness assessments like the TRAQ are important instruments and should be integrated into formulated transition plans, but they do not provide a comprehensive overview of all the factors that might determine the success of youth transitions.²⁴ The use of flourishing as a conceptual framework to broaden the understanding of "transition readiness" previously showed that many difficulties experienced by youths and parents are not captured by questionnaires focused on autonomy and functional independence.⁵ Likewise, our current results show that transitioning youths face difficulties engaging with their favorite activities, enacting their life goals, or feeling like they belong with their peers (see Q10-Q14, Table 3). These issues touch upon dimensions of human flourishing such as positive relationships, purpose in life, and self-acceptance such that they might translate into a lack of motivation and sense of purpose necessary to tackle the health-related challenges exacerbated by the transition. Envisioning youths as people who face these broader issues within their lives helps situate transition care within a holistic scheme personally and socially.

Our results also suggest that youths tend to negatively apprehend the change of healthcare team, notably, because they expect to be treated differently by adult care providers. Both issues were slightly underappreciated by parents, who tend to view pediatric and adult healthcare providers in a more positive light. Furthermore, our results indicate that generally, youths tend to think that their parents are adequately involved in the management of their condition, although there is some discrepancy concerning treatment decisions and involvement once the transition has occurred.

Regarding remediation strategies, both youths and parents reported a desire to meet the adult physician beforehand and be accompanied by parents or by their current physician. This aligns well with recommendations suggesting more consolidated communication and better coordination between pediatric and adult healthcare providers.²⁴ Meeting the adult physician alone was not as strongly preferred and parents also wanted to be included or wanted to avoid youths meeting alone with the adult physician. Various strategies to prepare for the transition (e.g., visiting the adult hospital, meeting peers with transition experience, having access to videos) were supported, including video options on a wide array of topics. If there were to be a pivotal person, either a

physician or nurse would be welcomed.

Transition is a critical moment in the care of young patients with chronic illness. This study shows that transition readiness can be high in terms of scores measured by standardized instruments (such as the TRAQ), but youths and parents can nevertheless experience considerable distress and perplexity. Youths and adults want to be involved and informed to prepare for transition through meetings or adapted materials. Our study suggests that more conventional clinical approaches would gain from extended considerations beyond biomedical aspects of care and continued development of accessible and approachable resources to support transition.

5. Limitations

First, participant numbers are small despite numerous energetic attempts to bolster recruitment. This could be due to the post-Covid context of the study, limited knowledge about transition, and restrictions to recruitment posed by clinical gatekeeping. This small size prevents us from stratifying answers across age groups. Second, convenience sampling prevents establishing a participation rate or assessing the representativeness of the samples. It is possible that participants have higher interest in transition than average. Also, the survey did not include youths with learning disabilities (i.e., those who could not read the surveys at a certain reading level) or intellectual disabilities and does not represent a full depiction of youths with chronic illness. Third, youths and parents are not matched as dyads. This can also be seen as a strength to test for differences. For example, many answers are not statistically different across the two separate groups of respondents although this conclusion warrants further testing because the sample sizes are small. Fourth, the majority of youths (and parents) had not transitioned or been engaged in transition. Completing the transition could allow confirmation or dissipation of certain worries and apprehensions reported in this study, although grasping what worries youths and parents have prior to the transition also has value. Fifth, observed tendencies should be further validated in a larger sample and different settings to strengthen the evidence base. Furthermore, demographic and clinical information collected on the condition of participants was scant and difficult to use (e.g., imprecise and informal language, several conditions reported, voluntary nature of the answer) because of the survey nature of the study, but further research could now move on to more complex data gathering (e.g., coupled with clinical charts) and data analyses now that the survey has been deployed once and has offered an initial set of data. For example, it could be the case that older patients might be more aware of financial and health insurance than younger patients.

6. Conclusion

This survey study showed that, although transition readiness can be rather high, significant challenges (e.g., lack of information and preparation) as reported more openly by youths and parents may nevertheless be present and salient. Areas touching upon human flourishing such as leisure activities and feelings of belonging with peers need consideration within a more holistic understanding of health. Both youths and adults wanted to be involved and informed to prepare actively for transition, whether through meetings or by consulting materials such as videos. The next steps of the project will involve moving in this direction to co-develop such resources.

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Table 3
Issues related to the transition*.

	Do not agree at all (1)	Do not agree (2)	Neutral (3)	Agree (4)	Completely agree (5)	Averages (and SD)	Variance and p
Q1: I feel comfortable expressing my opinions and preferences to healthcare professionals CHUSJ in discussions concerning the management of my health condition (medication, appointment scheduling, communication with the doctor, treatment decisions).							
	Y N = 1 (1.3 %)	Y N = 2 (2.6 %)	Y N = 8 (10.5 %)	Y N = 21 (27.6 %)	Y N = 44 (57.9 %)	Y X = 4.43 (0.79)	F(1, 167) = 18.72, p < .001
	P N = 3 (3.2 %)	P N = 14 (14.9 %)	P N = 15 (16.0 %)	P N = 33 (35.1 %)	P N = 29 (30.9 %)	P X = 3.76 (1.14)	
Q2: In the various aspects of managing my health condition (medication, appointment scheduling, communication with the doctor, treatment decisions), I consider that my Parents are:							
	Way too involved (1)	Too involved (2)	Just enough involved (3)	Not enough involved (4)	Way not enough involved (5)	Averages (and SD)	Variance and p
Q2a: Medication	Y N = 7 (9.2 %)	Y N = 8 (10.5 %)	Y N = 56 (73.7 %)	Y N = 2 (2.6 %)	Y N = 3 (3.9 %)	Y X = 2.82 (0.80)	F(1, 168) = 0.001, p = .98
	P N = 8 (8.5 %)	P N = 12 (12.8 %)	P N = 67 (71.3 %)	P N = 3 (3.2 %)	P N = 4 (4.3 %)	P X = 2.82 (0.80)	
Q2b: Appointment scheduling	Y N = 5 (6.7 %)	Y N = 5 (6.7 %)	Y N = 58 (77.3 %)	Y N = 5 (6.7 %)	Y N = 2 (2.7 %)	Y X = 2.92 (0.71)	F(1, 168) = 0.001, p = .14
	P N = 11 (11.7 %)	P N = 16 (17 %)	P N = 57 (60.6 %)	P N = 7 (7.4 %)	P N = 3 (3.2 %)	P X = 2.73 (0.88)	
Q2c: Accompaniment to appointments	Y N = 7 (9.3 %)	Y N = 13 (17.3 %)	Y N = 53 (70.7 %)	Y N = 0	Y N = 2 (2.7 %)	Y X = 2.69 (0.75)	F(1, 166) = 2.791, p = .10
	P N = 8 (8.6 %)	P N = 4 (4.3 %)	P N = 73 (78.5 %)	P N = 7 (7.5 %)	P N = 1 (1.2 %)	P X = 2.88 (0.71)	
Q2d: Communication with the doctor	Y N = 7 (9.3 %)	Y N = 14 (18.7 %)	Y N = 49 (65.3 %)	Y N = 4 (5.3 %)	Y N = 1 (1.3 %)	Y X = 2.71 (0.77)	F(1, 166) = 0.756, p = .39
	P N = 11 (11.8 %)	P N = 9 (9.7 %)	P N = 61 (65.6 %)	P N = 10 (10.8 %)	P N = 2 (2.2 %)	P X = 2.82 (0.86)	
Q2e: Treatment decisions	Y N = 11 (14.5 %)	Y N = 6 (7.9 %)	Y N = 57 (75 %)	Y N = 0	Y N = 2 (2.6 %)	Y X = 2.68 (0.82)	F(1, 167) = 4.54, p < .05
	P N = 7 (7.4 %)	P N = 7 (7.4 %)	P N = 67 (71.3 %)	P N = 10 (10.6 %)	P N = 3 (3.2 %)	P X = 2.95 (0.78)	
	Do not agree at all (1)	Do not agree (2)	Neutral (3)	Agree (4)	Completely agree (5)	Averages (and SD)	Variance and p
Q3: I would like my parents to continue to be involved in the management of my health condition (medication, appointment scheduling, communication with the doctor, treatment decisions) after the transition.							
	Y N = 1 (1.3 %)	Y N = 5 (6.6 %)	Y N = 16 (21.1 %)	Y N = 27 (35.5 %)	Y N = 27 (35.5 %)	Y X = 3.97 (0.98)	F(1, 168) = 2427, p < .001
	P N = 0	P N = 1 (1.1 %)	P N = 4 (4.3 %)	P N = 28 (29.8 %)	P N = 61 (64.9 %)	P X = 4.59 (0.63)	
Q4: Awareness of the differences between pediatric and adult healthcare systems.							
	Y N = 0	Y N = 4 (5.3 %)	Y N = 10 (13.5 %)	Y N = 23 (30.3 %)	Y N = 39 (51.3 %)	Y X = 4.28 (0.89)	P - self F(1, 168) = 10.18, p < .01
	P - self N = 0	P - self N = 1 (1.1 %)	P - self N = 2 (2.1 %)	P - self N = 27 (28.7 %)	P - my child N = 64 (68.1 %)	P - self X = 4.64 (0.58)	P - my child = 23.95, p < .001
	P - my child N = 7 (7.4 %)	P - my child N = 13 (13.8 %)	P - my child N = 24 (25.5 %)	P - my child N = 29 (30.9 %)	P - my child N = 21 (22.3 %)	P - my child X = 3.47 (1.20)	
Q5: The following differences between pediatric and adult healthcare services concern or worry me:							
Q5a: Change of attitude among healthcare professionals							
	Y N = 4 (5.3 %)	Y N = 5 (6.7 %)	Y N = 20 (26.7 %)	Y N = 32 (42.7 %)	Y N = 14 (18.7 %)	Y X = 3.63 (1.04)	F(1, 167) = 0.06, p = .809
	P N = 7 (7.4 %)	P N = 10 (10.6 %)	P N = 19 (20.1 %)	P N = 37 (39.4 %)	P N = 21 (22.3 %)	P X = 3.59 (1.17)	
Q5b: Accessibility of medical services							
	Y N = 2 (2.7 %)	Y N = 9 (12 %)	Y N = 20 (26.7 %)	Y N = 23 (30.7 %)	Y N = 21 (28 %)	Y X = 3.69 (1.09)	F(1, 167) = 3.95, p < .05
	P N = 3 (3.2 %)	P N = 6 (6.4 %)	P N = 14 (14.8 %)	P N = 34 (36.2 %)	P N = 37 (39.4 %)	P X = 4.02 (1.05)	
Q5c: Lower levels of supervision in managing my health condition							
	Y N = 2 (2.7 %)	Y N = 9 (12 %)	Y N = 15 (20.0 %)	Y N = 26 (34.7 %)	Y N = 23 (30.7 %)	Y X = 3.79 (1.09)	F(1, 167) = 1.14, p = .288
	P N = 4 (4.3 %)	P N = 7 (7.4 %)	P N = 13 (13.8 %)	P N = 34 (36.2 %)	P N = 36 (38.3 %)	P X = 3.97 (1.10)	
Q5d: Changing hospital							
	Y N = 3 (3.9 %)	Y N = 5 (6.5 %)	Y N = 23 (30.3 %)	Y N = 25 (32.9 %)	Y N = 20 (26.3 %)	Y X = 3.71 (1.06)	F(1, 168) = 0.213, p = .645
	P N = 4 (4.3 %)	P N = 9 (9.6 %)	P N = 17 (18.1 %)	P N = 37 (39.4 %)	P N = 27 (28.7 %)	P X = 3.79 (1.10)	
Q5e: Information about the transition[±]							
	Y N = 12 (15.8 %)	Y N = 25 (32.9 %)	Y N = 22 (28.9 %)	Y N = 13 (17.1 %)	Y N = 4 (5.3 %)	Y X = 3.63 (1.11)	P - self F(1, 167) = 3.72, p = .055
	P - self N = 31 (33.3 %)	P - self N = 28 (30.1 %)	P - self N = 18 (19.4 %)	P - self N = 9 (9.7 %)	P - my child N = 7 (7.5 %)	P - self X = 2.28 (1.24)	P - my child F(1, 167) = 11.02, p < .01
	P - my child N = 34 (36.6 %)	P - my child N = 28 (30.1 %)	P - my child N = 20 (21.5 %)	P - my child N = 8 (8.6 %)	P - my child N = 3 (3.2 %)	P - my child X = 2.12 (1.10)	
Q6: Healthcare professionals of CHUSJ encourage me to take responsibility for managing my health condition (medication, making appointments, communication with the doctor, making treatment decisions).							

(continued on next page)

Table 3 (continued)

	Do not agree at all (1)	Do not agree (2)	Neutral (3)	Agree (4)	Completely agree (5)	Averages (and SD)	Variance and p
	Y N = 3 (3.9%) P N = 7 (7.5%)	Y N = 1 (1.3%) P N = 12 (12.9%)	Y N = 17 (22.4%) P N = 22 (23.7%)	Y N = 35 (46.1%) P N = 37 (39.8%)	Y N = 20 (26.3%) P N = 15 (16.1%)	Y X = 3.89 (0.95) P X = 3.44 (1.14)	F(1, 167) = 7.732, p < .01
Q7: I feel that the healthcare professionals at CHUSJ see me too much as a patient, and not enough as a human being.	Y N = 25 (32.9%) P N = 41 (44.1%)	Y N = 24 (31.6%) P N = 37 (39.8%)	Y N = 11 (14.5%) P N = 7 (7.5%)	Y N = 9 (11.8%) P N = 6 (6.5%)	Y N = 7 (9.2%) P N = 2 (2.2%)	Y X = 2.33 (1.30) P X = 1.83 (.97)	F(1, 167) = 8.191, p < .01
Q8: I feel that healthcare professionals in the adult healthcare system will see me too much as a patient, and not enough as a human being.	Y N = 4 (5.3%) P N = 6 (6.5%)	Y N = 9 (11.8%) P N = 22 (23.7%)	Y N = 26 (34.2%) P N = 26 (28.0%)	Y N = 24 (31.6%) P N = 25 (26.9%)	Y N = 13 (17.1%) P N = 14 (15.1%)	Y X = 3.43 (1.08) P X = 3.20 (1.16)	F(1, 167) = 1.760, p = .186
Q9: I have negative feelings (e.g., fear, stress, anxiety) about having to separate from my current healthcare team during the transition to adult healthcare.	Y N = 5 (6.6%) P N = 12 (12.9%)	Y N = 11 (14.5%) P N = 12 (12.9%)	Y N = 13 (17.1%) P N = 20 (21.5%)	Y N = 21 (27.6%) P N = 32 (34.4%)	Y N = 26 (34.2%) P N = 17 (18.3%)	Y X = 3.68 (1.27) P X = 3.32 (1.28)	F(1, 167) = 3.374, p = .068
Q10: I feel that those around me (e.g., friends, colleagues, teachers) understand the reality that I have to face with my health condition.	Y N = 7 (9.2%) P N = 11 (11.8%)	Y N = 17 (22.4%) P N = 30 (32.3%)	Y N = 16 (21.1%) P N = 17 (18.3%)	Y N = 21 (27.6%) P N = 25 (26.9%)	Y N = 15 (19.7%) P N = 10 (10.8%)	Y X = 3.26 (1.27) P X = 2.92 (1.23)	F(1, 167) = 3.086, p = .081
Q11: My health condition makes me feel different from others.	Y N = 8 (10.5%) P N = 8 (8.6%)	Y N = 10 (13.2%) P N = 19 (20.4%)	Y N = 14 (18.4%) P N = 92 (9.7%)	Y N = 26 (34.2%) P N = 33 (35.5%)	Y N = 18 (23.7%) P N = 24 (25.8%)	Y X = 3.47 (1.28) P X = 3.49 (1.31)	F(1, 167) = 0.011, p = .917
Q12: My health condition is an obstacle to the pursuit of my educational and/or professional goals.	Y N = 14 (18.4%) P N = 16 (17.2%)	Y N = 12 (15.8%) P N = 30 (32.2%)	Y N = 16 (21.1%) P N = 10 (10.8%)	Y N = 16 (21.1%) P N = 20 (21.5%)	Y N = 18 (23.7%) P N = 17 (18.3%)	Y X = 3.16 (1.43) P X = 2.91 (1.40)	F(1, 167) = 1.239, p = .267
Q13: My health condition prevents me from doing the activities I enjoy.	Y N = 12 (15.8%) P N = 15 (16.1%)	Y N = 17 (22.4%) P N = 29 (31.2%)	Y N = 18 (23.7%) P N = 7 (7.6%)	Y N = 8 (10.5%) P N = 27 (29%)	Y N = 21 (27.6%) P N = 15 (16.1%)	Y X = 3.12 (1.44) P X = 2.98 (1.38)	F(1, 167) = 0.414, p = 51
Q14: The difficulties I encounter in everyday life that are not directly related to my health condition (e.g., a bad day at school, an argument with friends) have a negative impact on the management of my health condition.	Y N = 11 (14.5%) P N = 11 (11.8%)	Y N = 18 (23.7%) P N = 31 (33.3%)	Y N = 13 (17.1%) P N = 16 (17.2%)	Y N = 22 (28.9%) P N = 26 (28.0%)	Y N = 12 (15.8%) P N = 9 (9.7%)	Y X = 3.08 (1.32) P X = 2.90 (1.22)	F(1, 167) = 0.806, p = .371
Q15: Having access to a psychologist and/or social worker is important for the psychological difficulties my health condition may cause.	Y N = 7 (9.2%) P N = 4 (4.3%)	Y N = 14 (18.4%) P N = 11 (11.8%)	Y N = 20 (26.3%) P N = 21 (22.6%)	Y N = 18 (23.7%) P N = 27 (29.0%)	Y N = 17 (22.4%) P N = 30 (32.3%)	Y X = 3.32 (1.27) P X = 3.73 (1.16)	F(1, 167) = 4.93, p < .05
Q16: I expect to have access to a psychologist and/or social worker when I come to adult healthcare.	Y N = 8 (10.5%) P N = 1 (1.1%)	Y N = 20 (26.3%) P N = 11 (11.8%)	Y N = 17 (22.4%) P N = 22 (23.7%)	Y N = 11 (14.5%) P N = 27 (29.0%)	Y N = 20 (26.3%) P N = 32 (34.4%)	Y X = 3.20 (1.37) P X = 3.84 (1.07)	F(1, 167) = 11.74, p < .001

X: = mean score

SD = Standard deviation of the mean score

Y = youths

P = parents

± Question asked to youths and parents regarding themselves (i.e., if they had sufficient information on the transition and also asked to parents with respect to their youths

* Questionnaire presented in French and translated for data presentation

Ethical statement

Ethics approval from the Research Ethics committee of the Centre hospitalier universitaire Sainte-Justine approval no. 2019-2133] and of Institut de recherches cliniques de Montréal was sought and granted (approval no. 2020-1064). This study conforms to Canadian and Quebec research ethics guidelines as well as international research guidelines such as the Declaration of Helsinki.

CRedit authorship contribution statement

Rojas Rocio Gissel Gutierrez: Writing – review & editing, Project administration, Investigation. **Ouimet François:** Writing – review & editing, Writing – original draft, Validation, Methodology, Data curation, Conceptualization. **Racine Eric:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Fournier Anne:** Writing – review & editing,

Table 4
Means of supporting the transition*.

	Do not agree at all (1)	Do not agree (2)	Neutral (3)	Agree (4)	Completely agree (5)	Averages (and SD)	Variance and p
Q17: I'd like to meet my new doctor before transitioning to adult healthcare.							
	Y N = 3 (4.2 %)	Y N = 3 (4.2 %)	Y N = 10 (14.1 %)	Y N = 19 (26.8 %)	Y N = 36 (50.7 %)	Y X = 4.15 (1.09)	F(1, 158) = 4.12, p < .044
	P N = 1 (1.1 %)	P N = 0	P N = 7 (7.9 %)	P N = 31 (34.8 %)	P N = 50 (56.2 %)	P X = 4.45 (0.74)	
Q18: I would like the first meeting with my new doctor to take place:							
Q18a: Alone with the doctor	Y N = 12 (16.9 %)	Y N = 15 (21.1 %)	Y N = 21 (29.6 %)	Y N = 18 (25.4 %)	Y N = 5 (7.0 %) P N = 1 (1.1 %)	Y X = 2.85 (1.19) P X = 2.09 (1.00)	F(1, 157) = 18.81, p < .001
	P N = 29 (33.0 %)	P N = 32 (36.4 %)	P N = 18 (20.5 %)	P N = 8 (9.1 %)			
Q18b: With my current doctor	Y N = 2 (2.8 %)	Y N = 9 (12.7 %)	Y N = 20 (28.2 %)	Y N = 20 (28.2 %)	Y N = 20 (28.2 %)	Y X = 3.66 (1.11) P X = 3.68 (1.13)	F(1, 157) = 0.01, p = .91
	P N = 4 (4.5 %)	P N = 8 (9.1 %)	P N = 26 (29.5 %)	P N = 24 (27.3 %)	P N = 26 (29.5 %)		
Q18c: With my parents	Y N = 3 (4.2 %)	Y N = 6 (8.5 %)	Y N = 12 (16.9 %)	Y N = 22 (31.0 %)	Y N = 28 (39.4 %)	Y X = 3.93 (1.14) P X = 4.36 (0.87)	F(1, 157) = 7.40, p < .01
	P N = 2 (2.3 %)	P N = 1 (1.1 %)	P N = 8 (9.1 %)	P N = 29 (33.0 %)	P N = 48 (54.5 %)		
Q18d: With my parents and my current doctor	Y N = 5 (7.0 %)	Y N = 9 (12.7 %)	Y N = 20 (28.2 %)	Y N = 16 (22.5 %)	Y N = 21 (29.6 %)	Y X = 3.55 (1.24) P X = 3.93 (1.11)	F(1, 158) = 4.20, p < .05
	P N = 4 (4.5 %)	P N = 5 (5.6 %)	P N = 18 (20.2 %)	P N = 28 (31.5 %)	P N = 34 (38.2 %)		
Q19: I'd like a pivot person to accompany me during the transition period							
Q19a: Before the hospital transfer	Y N = 2 (2.8 %)	Y N = 5 (7.0 %)	Y N = 23 (32.4 %)	Y N = 21 (29.6 %)	Y N = 20 (28.2 %)	Y X = 3.73 (1.04) P X = 4.07 (0.94)	F(1, 157) = 4.53, p < .05
	P N = 2 (2.3 %)	P N = 3 (3.4 %)	P N = 15 (17.0 %)	P N = 35 (39.8 %)	P N = 33 (37.5 %)		
Q19b: After the hospital transfer	Y N = 2 (2.8 %)	Y N = 9 (12.7 %)	Y N = 24 (33.8 %)	Y N = 22 (31.0 %)	Y N = 14 (19.7 %)	Y X = 3.52 (1.04) P X = 3.99 (0.88)	F(1, 157) = 9.45, p < .01
	P N = 1 (1.1 %)	P N = 2 (2.3 %)	P N = 22 (25.0 %)	P N = 35 (39.8 %)	P N = 28 (31.8 %)		
Q19c: Before and after the hospital transfer	Y N = 2 (2.8 %)	Y N = 8 (11.3 %)	Y N = 28 (39.4 %)	Y N = 16 (22.5 %)	Y N = 17 (23.9 %)	Y X = 3.54 (1.07) P X = 4.00 (0.94)	F(1, 158) = 8.55, p < .01
	P N = 1 (1.1 %)	P N = 5 (5.6 %)	P N = 18 (20.2 %)	P N = 34 (38.2 %)	P N = 31 (34.8 %)		
Q20: I would like this pivot person to be:							
Q20a: My current doctor	Y N = 3 (4.2 %)	Y N = 4 (5.6 %)	Y N = 25 (35.2 %)	Y N = 24 (33.8 %)	Y N = 15 (21.1 %)	Y X = 3.62 (1.02) P X = 3.60 (0.96)	F(1, 158) = 0.02, p = .878
	P N = 2 (2.2 %)	P N = 9 (10.1 %)	P N = 27 (30.3 %)	P N = 36 (40.4 %)	P N = 15 (16.9 %)		
Q20b: A nurse	Y N = 5 (7.0 %)	Y N = 8 (11.3 %)	Y N = 29 (40.8 %)	Y N = 23 (32.4 %)	Y N = 6 (8.5 %) P N = 24 (27.0 %)	Y X = 3.24 (1.01) P X = 3.88 (1.04)	F(1, 158) = 15.20, p < .001
	P N = 4 (1.1 %)	P N = 7 (5.6 %)	P N = 9 (20.2 %)	P N = 45 (38.2 %)			
Q20c: A psychologist	Y N = 9 (12.9 %)	Y N = 12 (17.1 %)	Y N = 28 (40.0 %)	Y N = 15 (21.4 %)	Y N = 6 (8.6 %) P N = 7 (7.9 %)	Y X = 2.96 (1.12) P X = 3.19 (1.08)	F(1, 158) = 1.784, p = .184
	P N = 7 (7.9 %)	P N = 16 (18.0 %)	P N = 26 (29.2 %)	P N = 33 (37.1 %)			
Q20d: A social worker	Y N = 9 (12.7 %)	Y N = 14 (19.7 %)	Y N = 30 (42.3 %)	Y N = 10 (14.1 %)	Y N = 8 (11.3 %)	Y X = 2.92 (1.14) P X = 3.19 (1.09)	F(1, 158) = 2.426, p = .121
	P N = 6 (6.7 %)	P N = 18 (20.2 %)	P N = 27 (30.3 %)	P N = 29 (32.6 %)	P N = 9 (10.1 %)		
Q20e: A new person specialized in the transition	Y N = 7 (9.9 %)	Y N = 11 (15.5 %)	Y N = 24 (33.8 %)	Y N = 19 (26.8 %)	Y N = 10 (14.1 %)	Y X = 3.20 (1.17) P X = 3.43 (1.09)	F(1, 158) = 1.656, p = .200
	P N = 6 (6.7 %)	P N = 11 (12.4 %)	P N = 23 (25.8 %)	P N = 37 (41.6 %)	P N = 12 (13.5 %)		
Q20f: A youth who has already experienced the transition	Y N = 9 (12.7 %)	Y N = 15 (21.1 %)	Y N = 23 (32.4 %)	Y N = 16 (22.5 %)	Y N = 8 (11.3 %)	Y X = 2.99 (1.19) P X = 2.83 (1.16)	F(1, 158) = 0.685, p = .409
	P N = 13 (14.6 %)	P N = 23 (25.1 %)	P N = 25 (28.1 %)	P N = 22 (24.7 %)	P N = 6 (6.7 %)		
Q21: I'd like to visit the adult hospital before the transition to adult healthcare.							
	Y N = 2 (2.8 %)	Y N = 4 (5.6 %)	Y N = 18 (25.4 %)	Y N = 22 (31.0 %)	Y N = 25 (35.5 %)	Y X = 3.90 (1.04) P X = 3.91 (1.07)	F(1, 158) = 0.003, p = .959
	P N = 2 (2.2 %)	P N = 6 (6.7 %)	P N = 25 (28.1 %)	P N = 21 (23.6 %)	P N = 35 (39.3 %)		
Q22: I'd like to be able to get in touch with other youths with similar health conditions who are going through or have already gone through the transition, to help me prepare for it.							
	Y N = 8 (11.3 %)	Y N = 9 (12.7 %)	Y N = 25 (35.2 %)	Y N = 15 (21.1 %)	Y N = 14 (19.7 %)	Y X = 3.25 (1.24) P X = 3.52 (1.09)	F(1, 158) = 2.044, p = .155
	P N = 3 (3.4 %)	P N = 11 (12.4 %)	P N = 33 (37.1 %)	P N = 21 (23.6 %)	P N = 21 (23.6 %)		
Q23: I'd like to have access to video clips containing information on transition.							

(continued on next page)

Table 4 (continued)

	Do not agree at all (1)	Do not agree (2)	Neutral (3)	Agree (4)	Completely agree (5)	Averages (and SD)	Variance and p
	Y N = 3 (4.2 %) P N = 0	Y N = 7 (9.9 %) P N = 5 (5.6 %)	Y N = 25 (35.2 %) P N = 19 (21.3 %)	Y N = 22 (31.0 %) P N = 46 (51.7 %)	Y N = 14 (19.7 %) P N = 19 (21.3 %)	Y X = 3.52 (1.05) P X = 3.89 (0.80)	F(1, 158) = 6.228, p < .05
Q24: The following information would be useful to have in these video clips:							
Q24a: Information on the differences between both healthcare systems	Y N = 1 (1.4 %) P N = 1 (1.1 %)	Y N = 2 (2.8 %) P N = 2 (2.2 %)	Y N = 11 (15.5 %) P N = 9 (10.1 %)	Y N = 30 (42.3 %) P N = 48 (53.9 %)	Y N = 27 (38.0 %) P N = 29 (32.6 %)	Y X = 4.13 (0.88) P X = 4.15 (0.78)	F(1, 158) = 0.022, p = .883
Q24b: Information on the new responsibilities in adult healthcare	Y N = 0 P N = 1 (1.1 %)	Y N = 2 (2.8 %) P N = 0	Y N = 12 (16.9 %) P N = 12 (13.5 %)	Y N = 29 (40.8 %) P N = 43 (48.3 %)	Y N = 28 (39.4 %) P N = 33 (37.1 %)	Y X = 4.17 (0.81) P X = 4.20 (0.76)	F(1, 158) = 0.72, p = .789
Q24c: Information on the stages of the transition	Y N = 0 P N = 1 (1.1 %)	Y N = 3 (4.2 %) P N = 0	Y N = 12 (16.9 %) P N = 9 (10.1 %)	Y N = 30 (42.3 %) P N = 46 (51.7 %)	Y N = 26 (36.6 %) P N = 33 (37.1 %)	Y X = 4.11 (0.84) P X = 4.24 (0.72)	F(1, 158) = 0.997, p = .320
Q24d: Information on resources available during the transition	Y N = 0 P N = 1 (1.1 %)	Y N = 5 (7.0 %) P N = 0	Y N = 11 (15.5 %) P N = 9 (10.1 %)	Y N = 29 (40.8 %) P N = 41 (46.1 %)	Y N = 26 (36.6 %) P N = 38 (42.7 %)	Y X = 4.07 (0.90) P X = 4.29 (0.74)	F(1, 158) = 2.920, p = .089
Q24e: Information on resources available in adult healthcare	Y N = 1 (1.4 %) P N = 1 (1.1 %)	Y N = 4 (5.6 %) P N = 0	Y N = 8 (11.3 %) P N = 8 (9.0 %)	Y N = 31 (43.7 %) P N = 43 (48.3 %)	Y N = 27 (38.0 %) P N = 37 (41.6 %)	Y X = 4.11 (0.92) P X = 4.29 (0.73)	F(1, 158) = 1.905, p = .169
Q24f: Testimonials from young people and Ps who already experienced the transition	Y N = 3 (4.2 %) P N = 2 (2.2 %)	Y N = 6 (8.5 %) P N = 5 (5.6 %)	Y N = 28 (39.4 %) P N = 26 (29.2 %)	Y N = 19 (26.8 %) P N = 33 (37.1 %)	Y N = 15 (21.1 %) P N = 23 (25.8 %)	Y X = 3.52 (1.05) P X = 3.79 (0.97)	F(1, 158) = 2.736, p = 1.00
Q24g: Testimonials from healthcare professionals for adults	Y N = 3 (4.2 %) P N = 2 (2.2 %)	Y N = 7 (9.9 %) P N = 3 (3.4 %)	Y N = 18 (25.4 %) P N = 18 (20.2 %)	Y N = 27 (38.0 %) P N = 43 (48.3 %)	Y N = 16 (22.5 %) P N = 23 (25.8 %)	Y X = 3.65 (1.07) P X = 3.92 (0.90)	F(1, 158) = 3.098, p = .08

X: = mean score

SD = Standard deviation of the mean score

Y = youths

P = parents

* Questionnaire presented in French and translated for data presentation

Resources, Investigation, Funding acquisition, Conceptualization. **Clermont Marie-José**: Writing – review & editing, Resources, Investigation, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

The authors do not have permission to share data.

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