

# **A Qualitative Study on the Educational Needs of Youth with Chronic Conditions Transitioning from Pediatric to Adult Care**

**Maxime Morsa<sup>1</sup>, Pierre Lombrail<sup>1,2</sup>, Bernard Boudailliez<sup>3,4</sup>, Cécile Godot<sup>5</sup>, Vincent Jeantils<sup>6</sup>, Rémi Gagnayre<sup>1</sup>**

## **Affiliations**

<sup>1</sup> Université Sorbonne Paris Nord, Laboratoire Éducatifs et Promotion de la Santé (LEPS UR3412), Bobigny, France

<sup>2</sup> Department of Public Health, Paris Seine St-Denis hospital, AP-HP, France

<sup>3</sup> Amiens University Hospital Center, France

<sup>4</sup> University Jules Verne Picardie, France

<sup>5</sup> Necker Hospital, AP-HP, France

<sup>6</sup> Jean Verdier Hospital, AP-HP, France

## **Corresponding Author**

Mr. Maxime Morsa

[maximemorsa@hotmail.com](mailto:maximemorsa@hotmail.com)

+33(0)148387641

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## **Abbreviations**

None.

## **Abstract**

**Objective** This study explores the experience of youth as they transition from pediatric to adult care, with the aim of identifying their educational needs during this period.

**Design and setting** A qualitative study was undertaken with youth suffering from various chronic conditions. Participants were recruited in 3 hospitals in France.

**Method** 17 adolescents and young adults (aged between 15 and 22 years) were interviewed face-to-face on their needs in 3 main skill-set categories: self-care, lifestyle management, and psychosocial skills. A qualitative content analysis was conducted to process the data.

**Results** Changes during the transition call for the development of specific skills, such as building an identity that isn't determined by the illness, learning about new topics related to lifestyle (addictions, stress, sexuality...), mastering the customs of consultation in adult medical care, etc. Maintaining a dual relationship with pediatric and adult units during a significant period of time has appeared useful for youth to feel more secure.

**Conclusion** A shift in perspective takes place when the transition is examined through the words of the adolescents themselves: the passage from the pediatric unit to adult care is no longer seen as being the heart of the process. It is instead a change among other changes, all of which impose themselves on youth during this period. In order to encourage a transition that answers the needs of adolescents, educational measures could focus on the acquisition of broad skills and be personalized.

## **Keywords**

Transition, Adolescence, Patient Education, Pediatric, Chronic Disease.

## **1. Introduction**

The transition from the pediatric unit to adult care is a key step in the health process of youth. Several changes take place over this short period of time: somatic and mental developmental upheavals, reaching the age of majority with its ensuing responsibilities, and changing healthcare services (Sawicki et al., 2014; Meleis, 2010). Some risks exist during this period: increased behavior patterns related to the non-adherence to treatment (Yeung et al., 2008; Watson, 2000) and cases of overall health deterioration (Ferro, 2013; Pacaud & Yale, 2005; Watson, 2000) have been observed.

There is, to this day, a lack of evidence to guide the development of transitional care (Campbell et al., 2016). The need to educate patients has, however, been highlighted by the literature, irrespective of the person's pathology (Schmidt et al., 2016a; Dovey-Pearce & Christie, 2013; Crowley et al., 2011; Rosen et al., 2003). Some authors call for the need to define a generic educational framework for all pathologies (Schmidt et al., 2016a; Stein, 2011). Such a framework is understood as a process that allows youth to acquire and/or maintain abilities and skills which could help them lead their lives with their conditions (WHO, 1998). These skills are wide-ranging: understanding one's illness and its treatments, performing technical gestures, making decisions in an emergency, etc. (Bravo et al., 2015; WHO, 1998). However, the specific skills that would make transitions more conducive to facilitating the life plans and health of youth are still poorly understood (Schmidt et al., 2016a; Fegran et al., 2014).

The needs of youth must be assessed to remedy this situation (Schmidt et al., 2016b). A recent review of the literature showed that studies mainly focused on organizational needs and did not often focus on the youth's lived experiences. Two reasons explain this: either the samples were only composed of experts and/or health professionals, or quantitative methods were used (Morsa et al., 2017). Studying the internal logics of the patients and their health-

related behaviors could shed further light on the needs of youth during the transition period, based on their experiences and feelings regarding health and life events associated to this period. Qualitative methods are preferred in such cases (Rich & Ginsburg, 1999; Pope & Mays, 1995).

This study therefore aims to explore the experience of youth with various chronic conditions and to identify their common needs during the transition period, by way of a qualitative method.

## **2. Method**

### *2.1. Participants and Recruitment*

The people participating in the study were teenagers and young adults with chronic conditions. To be included in the study, youth needed to be cared for in a hospital. Their transfer to the adult healthcare unit needed to take place within less than a year (“pre-passage” patients) or had already occurred less than five years ago (“post-passage”), so that they are concerned with the transition process.

Youth were recruited in three teaching hospitals in France (Amiens University Hospital Center, Necker Hospital, Jean Verdier Hospital).

Youth who had cognitive impairment, who were less than 14 years old and/or who did not master the French language enough to participate in interviews were excluded from the study.

Thanks to these selection conditions, we were able to gain a pluralistic view of the process like recommended in the standards of qualitative research (Green & Thorogood, 2014; Pope & Mays, 1995). The sample of patients was diversified: diverse pathologies (prevalent and rare diseases), diverse steps of the process (pre-passage and post-passage) and distinct environments were represented. A heterogeneous sample is recommended for qualitative

methods, as it allows for *diversity*, without purporting to be *representative* in the way quantitative methods are (Green & Thorogood, 2014).

Heads of pediatric healthcare units and adult units in the hospitals mentioned above were contacted and asked to notify the youth who fit the study's inclusion conditions for a period of 6 weeks. Meetings were then organized with the main investigator (MM) once the patients and the parents of under-age patients had consented to participate in the study.

The sample was targeted and non-randomized, with a selection strategy that was based on specific criteria.

The study received favorable opinions from the *Advisory Committee on the Treatment of Information in the field of Research* (n°16-311), the *National Commission on Computer Technology and Freedom* (n°1984766v0) and the *Ethics Evaluation Board for Health Research* (n°201713), in France.

## 2.2. Qualitative Interviews

Semi-structured interviews were conducted using an interview guide as a base (Table 1). This guide referred to the three categories of educational needs for adolescent patients, needs which are identified in the literature (Bell et al., 2008; Court et al., 2008; Sawyer et al., 2007): (1) needs related to skills in managing the illness and its treatments (*self-care skills*); (2) informational needs linked to broader health considerations: sexuality, smoking, alcohol, drugs, etc. (*lifestyle management skills*); (3) psychosocial and relational needs linked to the experience patients have with the disease (*psychosocial skills*).

These needs can be defined as the divide between the person's current situation and his/her desired situation. Such a gap is either identified by the patients themselves or based on a norm (Robinson, 1996). In our case, we aim to see whether such a divide can be bridged through learning processes to determine the needs related to education. Each item was explored

through the lens of the youth's experience during the transition period. We also made sure to let certain themes emerge, depending on the adolescents' comments.

Interviews took place in the hospital in which youth were cared for and were led by the main investigator (MM). One interview took place as a teleconference and another one was done by telephone, for reasons linked to the patients being geographically far from their hospitals. Interviews lasted between 30 minutes and an hour.

### 2.3. *Thematic Analysis*

Our data analysis respected the process recommended by Pope et al. (Pope et al., 2000) for qualitative research. Interviews were transcribed verbatim and the analysis was verified by a researcher who was not familiar with the study's objectives.

A directed approach to content analysis was used (Hsieh & Shannon, 2005) in order to understand the ways in which expressed needs could correspond to educational needs. Directed content analysis is a structured approach in which the primary constructs of a theory (e.g., patient education) guide the creation of the codebook (Schaefer et al., 2017). The three categories of skills cited above (skills related to self-care, lifestyle management and psychosocial) were identified as the initial coding categories. Each code was then made operational in a codebook.

According to De Ketele & Roegiers (2015), to achieve a skill the subject mobilizes knowledge, know-how, know-how-to-be or know-how-to-become. The coding of interviews was done based on the definitions of these types of knowledge (Table 2). This allowed us to associate a type of knowledge with a need expressed by the subject and, therefore, to have an interpretative framework for the needs of youth.

The *meaning saturation* principle (Hennink et al., 2016) was used to decide when to stop the research. This principle consists in determining whether the questions brought about in the

research are sufficiently and relevantly asked in the interviews, to the point where a new interview would not provide a renewed understanding of the phenomenon.

This study complied with the COREQ guidelines for qualitative research (Tong et al., 2007).

### **3. Results**

#### *3.1. Characteristics of Participants*

Seventeen adolescents were interviewed (10 women and 7 men). The average age was of 18.2 years (SD  $\pm$  1.8). Seven patients were in pre-passage and 10 patients were in post-passage. Eight patients suffered from common pathologies (type I diabetes, HIV, epilepsy) and 9 patients had rare disorders (mastocytosis, multiple sclerosis, sickle-cell anemia,  $\beta$ -thalassemia, liver transplantation, cystic fibrosis). Seven patients came from Necker Hospital, 6 patients came from Amiens University Hospital and 4 patients were from Jean Verdier Hospital (Table 3).

#### *3.2. The Youth Experience of Transition*

The content analysis of verbatim revealed that the needs expressed by the young interviewees came as a result of changes that were taking place in their lives during the transition period.

##### 3.2.1. A New Role

- ***As a human being***: Some young people expressed a negative attitude towards their illness: it was seen as preventing them from being who they wanted to be or who they would want to be in the future (weariness of treatments, of consultations, etc.).

*(Patient 5) "I don't like hospitals. I'm fed up because I've been coming here since I was very little. I'm fed up with the medicine. I've been traumatized by the capsules."*

The illness was seen as taking up too much space in some of the respondents' lives and in the ways they perceived themselves (cognitive load due to the attention paid to the illness, being "sick" first and "young" second). A fear of being categorized was also expressed (being perceived by others as only being "sick").

*(Patient 1) "When I was younger, I didn't think about my illness. But now that I'm older, I think about the fact that this disease is really going to ruin my life. Because I know that I'll always have problems. I'll never be like everyone else."*

*(Patient 9) "I'm always afraid of the way people will react if I talk about my illness. I feel like I expose myself any time I talk about it. After that, people know my weaknesses."*

*(Patient 10) "It's not that I don't want people to know I'm sick, I'm not ashamed. But I don't want people to see me like this."*

In such cases, youth could feel excluded from various communities because of their health (why me? Why is my life more complicated than the life of my peers?).

*(Patient 17) "Sometimes I'm sad when I see my friends doing things I can't do."*

*(Patient 3) "Being diabetic was difficult to accept. Actually, I still don't accept it and I never will. We always ask ourselves: why me, etc."*

*(Patient 14) "Even though I can continue to live... it's the fact that it landed on me that I don't accept."*

*(Patient 11) "I sometimes tell myself: why me? Why am I the one with the illness and not someone else? Why does this illness exist?"*

**- Being responsible for the illness and its treatment:** While self-care tasks don't change in adulthood, adolescent patients realize that they must become autonomous to manage their illness. Some interviewees expressed the need to feel more confident in order to take on such a responsibility. They viewed the fact that their parent(s) transferred skills to them as their main source of training in self-care. Youth expressed more worry about their future autonomy when their parents omitted to transfer skills.



*(Patient 10) "I became autonomous with my treatment quite early (12 years old) to feel calm right away. My parents taught me. They did quite a few trainings (to manage the illness) when I was younger"*

*(Patient 12) "Until 13-14 my mother took care of my treatment. And from there, my mother made me more responsible by telling me to think about it too."*

*(Patient 1) "I know how to prepare the injection for myself. But I can't do the shot because I'm a little scared. So my mother injects it. I'm afraid of doing things wrong."*

Some individuals were also keen to know more about the illness. While they had a procedural knowledge of the management of the illness and its treatments (a knowledge shared with the parents), they sometimes lacked a deeper understanding of the illness and its treatment.

*(Patient 2) "I really want to understand, even the biological mechanisms and everything... It would interest me to know very exactly what happens and how it happens."*

- **As a patient:** Certain young people said that, while they were required to have greater autonomy in the way they managed their illness as they grew up, they didn't always feel more autonomous when it came to medical decision making. In those cases, patients felt like they were passively enduring their care and that their opinions were not taken into account, when they actually felt capable of participating in decisions (planning the transition, deciding on the number of necessary consultations, etc.).

*(Patient 3) "The dietitians are super strict, so I don't actually ask them how to adapt my food habits. Because if I listen to them, I don't eat anything."*

*(Patient 10) "In pediatrics, I was viewed as a baby. In adults, people ask me what's wrong and try to solve it. Whereas in pediatrics, it's 'We're the ones who will find out what's wrong'. I feel better about the present situation."*

*(Patient 17) "I prefer it in the adults (unit). It's more mature. There are more people my age. I'm left alone more, too."*

### 3.2.2. A New Lifestyle

The youth being interviewed were encountering new situations, and they did not always feel like they were presented with the right information to make decisions based on their pathologies. Some of these situations included fatigue, health-risk behaviors (smoking, alcohol, drugs), stress and sexuality. Although youth were sometimes aware of the general recommendations linked to their conditions, they nevertheless did not always understand the reasons behind such recommendations.

*(Patient 3) "I know that it's not good to smoke when you have diabetes, but I don't see the connection."*

Similarly, they expressed interrogations regarding new experiences (fatigue, stress), as they could not tell whether these sensations were linked to their illness, to their lifestyle or to their own personal development.

*(Patient 8) "I'm often tired, but I don't know why. I don't know if it's because of my illness or not."*

*(Patient 6) "I never understand if drinking alcohol can lower blood sugar levels."*

It seemed difficult for these patients to discuss such situations with healthcare professionals since such conversations did not fit within the strict framework of the medical exam. Members of the healthcare staff were not viewed as advisers in this regard.

*(Patient 10) "It's hard to talk about sexuality with someone we don't know very well or that we see as being 'higher up' (talking about healthcare staff), a little bit like parents. If we're given documents first, it goes a lot better."*

*(Patient 13) "We never talked about all of that (sexuality, alcohol, etc.) with the healthcare staff."*

### 3.2.3. A New Healthcare Service

According to the youth who were consulted, the transition did not automatically imply feelings of stress or anxiety, nor did it necessarily lead to sadness upon leaving the pediatric unit and its health-care staff. It was not necessarily a time of questioning either. The passage from the pediatric unit to adult care could therefore be perceived as a normal event that was to be expected.

*(Patient 2) "Moving to the adult services isn't going to change anything at all."*

*(Patient 4) "I'm not afraid of going to the adults' (unit)."*

*(Patient 11) "The transition isn't going to change anything in my life."*

*(Patient 12) "I didn't have the impression that it was hard to pass to the adults' (unit). For me, it was in the continuation."*

Youth were, however, sensitive to their parents' fears of losing quality healthcare and relational ties in the pediatric unit.

*(Patient 12) "For me, the transition is a small change. But for my mother, it's a big change."*

Findings also showed (from "post-passage" patients) that feelings of stress could emerge once patients had discovered the adult unit (shorter consultations, different ways of making appointments, etc.).

*(Patient 9) "I don't feel as close to the doctors now that I'm with the adults. There are fewer exchanges. I don't feel as confident with a doctor in adult care: since he doesn't know me as well, I'm more afraid of his choices. Afraid that he'll take things lightly and make a mistake."*

The administrative procedures (being reimbursed for treatments, dealing with social security, etc.) could also be perceived by youth as complicated to manage.

*(Patient 7) "It would be nice if there was a training session for young adults to help them manage the papers that need to be filled out, handed in... health insurance... explain how to manage those papers. Managing the medicine, that's well explained, but not the papers..."*

### 3.2.4. Maintaining a Dual Relationship with Pediatric and Adult Care Units

According to certain young people, maintaining a relationship with the pediatric team for a specific amount of time while the adult unit was first being explored allowed them to experience a “true” transition instead of a simple transfer. Patients sometimes engaged in this type of behavior informally by continuing to talk (by phone) to the pediatric doctor for questions they considered urgent, personal or important. Since the relationship with the doctor in the adult service was still new, trust had not yet been fully established. The patient could therefore prefer to ask certain questions to his pediatric doctor at first.

*(Patient 9) “I’ve continued to contact staff from pediatrics since I’ve been in adult (care). I know that if I have questions I better talk to a doctor in pediatrics.”*

*(Patient 4) “The doctor (in pediatrics) told me that I could come back for a consultation, even after passing to the adult unit... If I have a question or a difficulty, I think that I would contact my new adult healthcare team, but I would also keep my pediatrics doctor up to date.”*

*(Patient 14) “I think that I’ll continue to contact the pediatrics healthcare staff during my first weeks/months in adult (care).”*

*(Patient 12) “I reached out to the pediatrician doctor for a few questions even after having been with the adults. He made me understand that I needed to talk to the adults’ doctor, but he answered my questions. Actually, I didn’t have the adult doctor’s contact information...”*

*(Patient 16) “I know that if I need to one day, I can call my pediatrics care team.”*

### 3.2.5. Encouraging Exchanges with Peers

Some adolescents expressed the fact that talking to other youth with chronic conditions could help them, and made them progress when learning to live with the illness, whether in managing self-care or in understanding the illness’s psychosocial dimension. Peers can become a resource for youth when the relationship with health-care professionals is difficult. Youth find support in their peers who have lived through similar experiences and who can

share self-care strategies or tips on adapting, all of which are perceived as useful and effective.

*(Patient 3) “I understood that I could eat other things because I went to a camp for young diabetic patients. I met other young people... And sharing experiences, that helped me. They were the ones who taught me that I could eat differently. Because the dietitians, they’re not very cool.”*

*(Patient 11) “The camps help a lot. We had lots of training sessions on smoking, alcohol, drugs, eating habits, physical activity... We also talked with others who also have diabetes, we talked how we did...”*

*(Patient 9) “I’m in a couple with someone who also has an illness. It helped me to take a step back towards my illness. She has a reaction towards my illness that is “honest”. And it also allows me to realize that it’s not because we have an illness that we’re necessarily unhappy.”*

### *3.3. The Educational Needs of Youth During the Transition*

The needs identified from the youth experience of transition correspond to the thematic skill-set categories that had been pre-defined (self-care, lifestyle management, psychosocial). A fourth category of skills emerged over the course of the interviews: understand and use the healthcare system.

For each skill-set category, we deduced from these results, which types of knowledge contributive to the skill (knowledge, know-how, know-how-to-be, know-how-to-become) were concerned by the youth’s comments, by analyzing verbatim. We could then associate their needs with pedagogical objectives (Table 4). The educational needs of youth during the transition correspond to broad skills relating to identity building, managing one’s way of life, using the healthcare system... not automatically relating to managing illness or treatment. The educational needs concern to *growing up with a chronic condition*.

## **4. Discussion and conclusion**

### *4.1 Discussion*

So far, patient education has been recommended to optimize transition. However, the skills that the patient needs to acquire are not well documented (Schmidt et al., 2016a; Fegran et al., 2014; Morsa et al., 2017). Regarding the transition process, four main types of skill-sets were identified in this study. Three of these categories had been defined before reaching the interview stage. They were based on international recommendations for the education of adolescent patients (Bell et al., 2008; Court et al., 2008; Sawyer et al., 2007): self-care skills, lifestyle management and psychosocial adjustment to the illness. A fourth category emerged during the interviews: skills related to understanding and using the healthcare system. This category refers to the youth's capacity to use and understand a new health-care service which does not share the same culture as the pediatric unit. For each skill-set category, we have argued for the learning needs of youth by exploring the ways in which they experienced the transition. This work has allowed us to determine the skills that needed to be acquired or that needed to be implemented by youth, so that the transition would be most favorable to their lives and health projects (Table 4).

The interviews showed that one of the major skills that the patient needed to acquire during this period related to his/her psychosocial adjustment to the illness. However, works relating to the transition did not often highlight the need for this skill (Morsa et al., 2017). This skill consists in the adolescent's ability to give a balanced and dynamic place to the illness within his/her conception of him/herself. The interviews showed that youth who exhibited strong non-adherence behaviors were also those who expressed having more difficulties in mastering this psychosocial skill. This is confirmed by the works of several authors in psychology (Ferro & Boyle, 2013; Luyckx et al., 2008; Helgeson & Novak, 2007) showing that the more youth with chronic conditions define themselves as "sick", the more they risk lowering their

adherence to treatment or developing a high level of unhappiness. The attitude towards the illness is also decisive: giving a central place to the illness when defining one's self is problematic if the adolescent considers the illness to be ruining his/her life, to be painful, to rob him/her of the future he/she wants, etc. But this isn't automatically the case. The development of a satisfactory identity for the adolescent could be an explicit goal in educational programs, given the importance of identity during the transition – as expressed by youth – and its impact on health behaviors (Schwartz & Petrova 2017). It does indeed consist in a psychosocial *skill* in that it calls for different types of knowledge (knowing one's self, understanding one's emotions, communicating) in daily life and with the illness. Such a skill can therefore be fostered through learning (Bandura, 1986) by addressing the elements summarized in Table 4.

The literature on transition highlights how important it is for youth to be more autonomous in regards to self-care (Morsa et al., 2017). We have noticed, on this point, that youth engaged in vicarious learning: they observed and analyzed their parent(s)' care procedures in an effort to gradually apply them autonomously as they were growing up. They therefore do not automatically express needs for education nor do they view education programs to be a priority in this realm. However, the parent-child transfer of skills (in self-care) can be hindered in cases when parents are afraid of letting their children become autonomous in the management of their health. The healthcare team must therefore ensure that the transfer of skills does indeed take place, they must promote it or even dispense these skills themselves if needed. On the contrary, patients requested more information on general matters of health (risk behaviors, sexuality...) linked to their illnesses, which confirms the findings of previous studies (Fernandes et al., 2014; van Staa & Sattoe, 2014). Youth are led to question themselves when faced with issues such as fatigue or stress, since they are unable to determine the impact their illness has on their experiences and whether a healthcare

professional can help in these cases. These issues are common to all young people, since the latest HBSC report showed that the adolescent population was increasingly preoccupied by questions related to mental and physical well-being (WHO, 2016).

The acquisition of the skills needed to live with a chronic health condition cannot be reduced to a formal educational process. The patient's family and healthcare environments, as well as the health system as a whole, contribute to the acquisition of such skills (Walsch & McPhee, 1992). The patient's transition education must be designed systemically and must fit within an overall system that is patient-centered (WHO, 2015). For example, formalizing a dual relationship would allow youth to feel secure and not to abruptly sever the connections made in the pediatric unit. The patients could gradually create a relationship with the new caregivers; a coordination between the units could be set up. This formalized system can benefit from joint consultations, the designation of a coordinating nurse (Suris et al., 2008), or the visit of adult facilities by adolescents in the pre-passage phase (Malivoir et al., 2016).

Professionals and youth could co-decide on a time to end the dual relationship (based on a reasonable time-frame). At an age when adolescents ask for more autonomy and responsibility, giving them a more proactive role in the transition process could reinforce the therapeutic relationship and the adherence to treatment. Similarly, as they highlighted the progress they made after having learned from peers, this peer system could be formalized within the transition process by setting up educational programs in which patients in the post-passage phase could testify and talk about their experiences. Such examples of engagement from patients living with chronic illnesses are starting to take place within the health system. This comes as a response to the users' increasing demand to be more involved in the care they receive, or to be represented more satisfactorily (Karazivan et al., 2015; Pomey et al., 2015; Gross & Gagnayre, 2013).



#### *4.2. Limitations*

Since this was a qualitative study, we were able to better understand and highlight certain phenomena specific to the transition period among youth, but the proposals that were uncovered must be read as hypotheses that will need to be further verified with other studies. Similarly, the analytical framework used for the interviews was limited to an educational reading of the phenomena at hand. Although we aimed to pay attention to the “off-topic” elements that seemed meaningful to youth, our questioning approach may have led us to miss certain topics which would not have been spontaneously mentioned by the participants, given our interview model.

#### *4.3. Conclusion*

To answer the needs of youth, the patient’s transition education from pediatric to adult care could consist in an education focused on change. Youth are led to take on a new role (both responsible for their own health and as human beings), to make decisions regarding new lifestyles (emotional and sexual life, smoking, alcohol, etc.) and to use a new healthcare service. In order to succeed, youth must enlist skills related to self-care, lifestyle management, psychosocial aspects and an understanding of the healthcare system. This study provides a generic framework for educational programs which could be implemented regardless of the patient’s specific pathology and healthcare context. It seems like it would be possible to formalize a “transition process” that would take the patient’s situation into account and would engage the pediatric unit as much as it would adult services. The transition can, finally, be viewed as an opportunity for youth to participate and be engaged in the healthcare system more easily.

### Table 1: Interview Guide

- Can you tell me how you manage your illness and your treatments now that you are becoming an adult? (Or, can you tell me how you manage your health and your treatments *now that you are an adult?*)
- How would you react if you had an incident in an adult unit? (Or, how have you reacted when you had an incident *since you have arrived in the adult unit?*)
- How would you describe the adult unit?
- Can you tell me what you think is important for adolescents to know before they leave the pediatric department?
- What are your feelings about leaving the pediatric department? (Or, what *were* your feelings about leaving the pediatric department?)
- How would you describe a young person with your condition who goes in an adult unit?
- How important is your illness in your life?
- Do you have specific interests in certain health topics?
- Who do you talk to if you have questions about alcohol, tobacco, drugs, sexuality, etc.?
- What is your life plan?
- Is there anything you consider important that we have not discussed today?

**Table 2: Thematic analysis coding principles based on the definitions of knowledge contributive to a skill, according to De Ketele & Roegiers (2015, p.21)**

Categories under study	Definition of the Skill	Types of knowledge contributive to the skill	Definitions used for the coding of the interviews
Self-care skills	The possibility for an individual to channel a range of resources (knowledge, know-how, know-how-to-be, know-how-to-become) in relevant, internalized and thoughtful ways, in order to solve a complicated situation or task belonging to a body of situations or tasks.	<b>Knowledge</b>	Knowledge designates what is <i>known</i> as evidence: facts, concepts, laws, models, formulas... these are already constituted, learnt or given.
Lifestyle management skills		<b>Know-how</b>	Know-hows designate the various <i>practical steps</i> that are needed to practice the know-how as an activity. An example consists in the procedure to dress a wound. Know-hows extend to socio-affective actions: for example, the ability to listen, to apologize, to communicate in a functional way...
Psychosocial skills		<b>Know-how-to-be</b>	Know-how-to-be designates <i>attitudes</i> , values, ways of apprehending reality, or representations.
		<b>Know-how-to-become</b>	Know-how-to become refers to <i>projects</i> as content.

**Table 3: Sample description**

<b>N = 17</b>	
<b>Average age</b>	18.2
<b>Gender (N =)</b>	
<i>Girl</i>	10
<i>Boy</i>	7
<b>Pathology (N =)</b>	
<i>Type 1 diabetes</i>	5
<i>Liver transplantation</i>	3
<i>HIV</i>	2
<i>Sickle-cell anemia</i>	2
<i>Epilepsy</i>	1
<i>Cystic fibrosis</i>	1
<i>Multiple sclerosis</i>	1
<i>β-thalassemia</i>	1
<i>Mastocytosis</i>	1
<b>Type of pathology (N =)</b>	
<i>Prevalent</i>	8
<i>Rare</i>	9
<b>Transition (N =)</b>	
<i>Pre-passage</i>	7
<i>Post-passage</i>	10
<b>Hospital Center (N =)</b>	
<i>Amiens University Hospital Center</i>	6
<i>Necker Hospital</i>	7
<i>Jean-Verdier Hospital</i>	4

**Table 4: Identifying specific skills to encourage the transition and making the connection with pedagogical aims**

<p><b>Psychosocial skills</b></p>	<p><b>Know-how-to-be:</b></p> <ul style="list-style-type: none"> <li>- to cultivate a non-negative attitude towards the illness</li> <li>- to give a dynamic place to the illness within the self-concept</li> <li>- not to compare one's self negatively to others</li> <li>- to develop a feeling of self-efficacy in order to manage self-care</li> </ul> <p><b>Know-how:</b></p> <ul style="list-style-type: none"> <li>- to talk about the illness to others</li> </ul> <p><b>Know-how-to-become:</b></p> <ul style="list-style-type: none"> <li>- to include the illness in one's life path</li> <li>- to formulate a short-term project</li> </ul>
<p><b>Skills related to understanding and using the healthcare system</b></p>	<p><b>Knowledge:</b></p> <ul style="list-style-type: none"> <li>- to project one's self in the adult service</li> </ul> <p><b>Know-how:</b></p> <ul style="list-style-type: none"> <li>- to master the codes of consultations in adult care</li> <li>- to manage administrative tasks</li> </ul>
<p><b>Self-care skills</b></p>	<p><b>Knowledge:</b></p> <ul style="list-style-type: none"> <li>- to understand the reasons for the illness's development.</li> </ul> <p><b>Know-how</b></p> <ul style="list-style-type: none"> <li>- To manage one's health and treatment autonomously.</li> </ul>
<p><b>Lifestyle management skills</b></p>	<p><b>Knowledge:</b></p> <ul style="list-style-type: none"> <li>- to know the impact a lifestyle has on the illness and vice-versa</li> </ul>

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