



HAL
open science

Pediatric-Adult Care Transition: Perceptions of Adolescent and Young Adult Patients with Sickle Cell Disease and Their Healthcare Providers

Delphine Hoegy, Ronald Guilloux, Nathalie Bleyzac, Alexandra Gauthier-Vasserot, Giovanna Cannas, Yves Bertrand, Claude Dussart, Audrey Janoly-Dumenil

► To cite this version:

Delphine Hoegy, Ronald Guilloux, Nathalie Bleyzac, Alexandra Gauthier-Vasserot, Giovanna Cannas, et al.. Pediatric-Adult Care Transition: Perceptions of Adolescent and Young Adult Patients with Sickle Cell Disease and Their Healthcare Providers. *Patient Preference and Adherence*, 2022, Volume 16, pp.2727-2737. 10.2147/PPA.S377236 . hal-03794939

HAL Id: hal-03794939

<https://hal.science/hal-03794939>

Submitted on 18 Jun 2024

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Pediatric-Adult Care Transition: Perceptions of Adolescent and Young Adult Patients with Sickle Cell Disease and Their Healthcare Providers

Delphine Hoegy¹⁻³, Ronald Guilloux^{3,4}, Nathalie Bleyzac⁵⁻⁷, Alexandra Gauthier-Vasserot⁷⁻⁹, Giovanna Cannas^{7,9,10}, Yves Bertrand⁷⁻⁹, Claude Dussart^{1,3,11}, Audrey Janoly-Dumenil^{1,3,12}

¹University of Lyon, University Claude Bernard Lyon I, Health, Systemic, Process (P2S), Research Unit 4129, Lyon, France; ²Pharmacie, Groupement Hospitalier Est, Hospices civils de Lyon, Lyon, France; ³Institut des Sciences Pharmaceutiques et Biologiques, Univ Claude Bernard Lyon I, Univ Lyon I, Lyon, France; ⁴Unité de recherche (UR) Sciences, Société, Historicité, Éducation et Pratiques (S2HEP), Univ Claude Bernard Lyon I, Univ Lyon I, Lyon, France; ⁵Equipe Mixte de Recherche (EMR) 3738, PK/PD Modeling in Oncology, Univ Claude Bernard Lyon I, Univ Lyon I, Lyon, France; ⁶Pharmacie, Hôpital Pierre Garraud, Hospices Civils de Lyon, Lyon, France; ⁷Centre de Référence Constitutif Syndromes Drépanocytaires Majeurs, Thalassémies et Autres Pathologies Rares du Globule Rouge et de l'Erythroïde, Hospices Civils de Lyon, Lyon, France; ⁸Institut d'Hématologie et d'Oncologie Pédiatrique de Lyon, Hospices civils de Lyon, Lyon, France; ⁹Laboratoire d'Excellence du Globule Rouge (Labex GR-Ex), PRES Sorbonne, Paris, France; ¹⁰Médecine Interne, Hôpital Edouard Herriot, Hospices civils de Lyon, Lyon, France; ¹¹Pharmacie centrale, Hospices Civils de Lyon, Lyon, France; ¹²Pharmacie, Hôpital Edouard Herriot, Hospices Civils de Lyon, Lyon, France

Correspondence: Delphine Hoegy, Pharmacy, Groupement Hospitalier Est, 59 boulevard Pinel, Bron, 69500, France, Tel +334 26 73 97 80, Fax +334 72 35 73 31, Email delphine.hoegy@chu-lyon.fr

Introduction: The pediatric-adult care transition, which takes place during adolescence, is a high-risk period for medical care adherence in chronic diseases, this encompasses treatment adherence, attending medical consultations and following healthcare advice. Studying perceptions is needed to get a more comprehensive picture of this care transition and to propose interventions to address the gaps. The authors analyzed perceptions from patients and caregivers in adolescents with sickle cell disease. Although this is the first step to improving the actual care management, to our knowledge, no study has explored perceptions from healthcare providers and compared it to patients' perceptions. The purpose of this study was to provide an insight on the experience of adolescent and adult patients, pediatric and adult healthcare providers in the context of pediatric to adult care transition, and analyze those concerns in order to better understand medical care adherence and improve patient care.

Material and Methods: Semi-structured interviews were conducted with adolescent and adult patients, as well as healthcare professionals (HCPs) in pediatric and adult departments. These interviews were audiotaped and transcribed before manual inductive content analysis.

Results: A total of 15 adolescent patients, 10 adult patients, 9 pediatric HCPs and 13 adult HCPs - including 12 nurses - were interviewed. Patients and healthcare providers all agreed that the pediatric-adult care transition was poorly experienced. This was mainly due to various changes in habits, physicians, and care organization. Anticipating this transition and acquiring new skills both for patients and HCPs are essential steps for improving medical care adherence during this challenging pediatric-adult care transition.

Conclusion: Propositions emerged from patients and healthcare providers to improve care and subsequently to improve medical care adherence in patients with sickle cell disease during and after the pediatric to adult care transition.

Keywords: sickle cell disease, qualitative research, pediatric to adult care transition

Introduction

Sickle cell disease (SCD) is the most common genetic blood disorder worldwide.¹ SCD is a group of disorders that affects hemoglobin. People with this disorder have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle, or crescent, shape. Common complications include vaso-occlusive crisis, acute chest syndrome and stroke.¹ As soon as the disease is diagnosed, proper medical care is essential to manage the disease and its complications. In this framework, medical care adherence is essential to the patient's prognosis² and for improving health

outcomes.³ In developed countries, SCD diagnosis is generally made during the neonatal period and medical advances in past decades have classified SCD as a long-term chronic condition. In some healthcare settings patients transition from pediatric to adult care at the age of 18.

As reported by many authors, adolescence is a critical period: treatment adherence is suboptimal and medical consultation absenteeism is high;⁴ patient's health status decreases during this period,^{2,5} resulting in increased acute care (emergency and hospitalizations),⁶ and healthcare costs.^{7,8} For these reasons, "there is often greater availability of support and ancillary services in the pediatric world, such as social work and nurse coordinators".⁵ Switching to the adult care world is even more challenging for adolescent patients and their families, because they have lost their familiar care-related landmarks.⁵ The pediatric-adult transition is indeed a high-risk period for medical care adherence, which is the standard term encompassing medication adherence, medical consultations and healthcare advice.

With the objective of improving medical care adherence during this transition to adult care for adolescents with SCD, most authors analyzed perceptions on pediatric to adult care transition from adolescents and young adults (AYAs)^{9–11} with SCD and caregivers.^{10,12} Yet, to date, no study has explored perceptions from healthcare providers (HCPs). In France, some interventions were implemented to improve this difficult period, such as a transition-specific consultation with both pediatric and adult care physicians.¹³

Furthermore, better refining HCP perceptions is an important step in improving medical care adherence. Different points of views (AYAs' and HCPs' perceptions) are necessary to understand medical care adherence and improve it in a systemic approach. In other words, if transition "is the entire process of teaching health care independence for young adults, preparing for the transfer, and ensuring its completion",⁵ it is first essential to fully understand the experience of this transition from pediatric to adult care from the perspectives of patients, caregivers and HCPs.

The purpose of this study was to provide an insight on the experience of adolescent and adult patients with SCD as well as their pediatric and adult care HCPs in the context of pediatric to adult care transition; but also, to analyze those concerns in order to better understand medical care adherence and to improve patient care.

Materials and Methods

Design

A qualitative exploratory research was conducted using cross-sectional data from one center, in the hematology pediatric and internal medicine departments of the University Hospitals of Lyon.

Semi-structured interviews with patients and HCPs were conducted by a researcher (DH, female), dedicated to this research and with prior training in the methodology, and then analyzed via the "inductive content analysis" method^{14–16} by two researchers (DH, female; RG, male).

The used method abides by the COREQ (consolidated criteria for reporting qualitative research) and SRQR (Standards for Reporting Qualitative Research) checklists.

Data Collection

Participants

Four groups were differentiated. Inclusion criteria for Group 1 (adolescent patients) were: > 15 and < 18 years of age with SCD (SS, SC, Sβ+ and Sβ0 forms). Inclusion criteria for Group 2 (adult patients) were: ≥ 18 years of age with SCD (SS, SC, Sβ+ and Sβ0 forms). Inclusion criteria for HCPs (Group 3 and 4) were: being a medical doctor (physician or resident) or healthcare staff (nurse or pediatric nursing auxiliary) in the study center – pediatric (Group 3) or adult (Group 4) sector- and being involved in the direct care of SCD patients (inpatient or outpatient care).

The exclusion criterion was having a level of understanding of French that was incompatible with a semi-structured interview.

Prior to inclusion, three guides were designed: one guide was used for adolescent patients, another for adult patients and another for pediatric and adult HCPs. They were designed by two researchers and a sociologist, and validated by a multidisciplinary team (pharmacists, hematologists, psychiatrists and nurses). The three topics discussed were: the

disease (SCD), therapeutics, and the healthcare system, based on the 5 dimensions influencing medical care adherence (condition, patient, therapy, socioeconomics, healthcare system).

First, the researcher looked at the medical consultation schedule, then the physician in charge of the patient's care gave her the "go/no go" to meet with the patient. Second, on the consultation patients were asked to participate in the study. At that time, the researcher explained to future participants the objective of the research and that interviews would be audiotaped. The interviews were then conducted, before or after the medical consultation.

HCPs were asked to participate to the study during their workdays and interviews were conducted at the hospital in a private room and were audiotaped. HCPs were randomly selected in the care center independently from patients' selection.

Data Analysis

Audiotapes were manually transcribed without rephrasing content. Study materials were separated into the four groups.

This material was analyzed manually by an "inductive content analysis" method.^{14–16} No software was used. Two analysts performed the three steps of the analysis separately for the 4 different study groups. First the raw text was read; second the analyst created categories by identifying specific text segments. This categorization method was itself divided into two steps: first a vertical categorization, consisting in analyzing the interviews one by one and focusing on recurrences and contradictions; second a horizontal categorization, consisting in comparing similarities, differences and oppositions between categories.^{17,18}

Finally, each analyst reduced and organized the different categories. Both analysts pooled their analyses and resolved differences in opinion via a consensus. The name of categories and subcategories were chosen jointly by the two analysts. After those analytic steps, the main researcher pooled the patient groups and HCP groups separately, and condensed data for a synthetic analysis. For instance, only one quote was chosen when different groups strictly expressed the same idea.

The three topics discussed were: the disease (SCD), therapeutics and the healthcare system. During the analysis of the latter, "pediatric to adult care transition" appeared to be a salient subtopic, not present in the interview guide and revealed by our study; this is why data saturation was not reached for this subtopic.

Ethics Approval and Informed Consent

The ethics committee of the Hospices Civils of Lyon (University Hospital) approved this research on December 6, 2016, it abides by the Declaration of Helsinki and related ethics rules and regulations. All patients volunteered for the study. They were informed orally. All adult participants signed an informed consent form for audiotaping their interview. For patients under 18 years old, their parents or legal guardian signed consent. This informed consent form included the aim of the study, the right to request additional information, and a notice that the patient could withdraw from the study at any stage, that the audiotape would remain confidential and that it would have no impact on the quality of healthcare.

Results

Participant Characteristics

Patients' interviews were conducted from December 2016 to March 2017. HCP interviews were conducted from May to June 2017.

Adolescent patients (A): Fifteen interviews with adolescent patients were conducted, but only 5 talked about the pediatric to adult care transition. Their characteristics are presented in [Table 1](#). Mean age of adolescent patients was 16.4 years old (R: 15–17.5). Three of these patients had the SS-form, one the Sβ+ and Sβ0 forms and one the SC-form. Mean interview duration was 17.5 minutes (R: 9–24.8).

Adult patients (ADU): Ten interviews with adult patients were conducted, and 4 talked about the pediatric to adult care transition. Their characteristics are presented in [Table 1](#). Mean age of adult patients was 22 years (R: 19–25). The pediatric-adult transition was performed at age 18. Three of those adult patients had the SS-form and one the Sβ+ and Sβ0 forms. Mean interview duration was 25.5 minutes (R: 16.5–33.5).

Table 1 Demographic Data and SCD Types of Interviewed Adolescent and Adult Patients

	n	Patient's Gender	Patient's Age (Years Old)	SCD Form
Adolescent patients	A7	F	17	SS
	A9	F	16.5	SC
	A10	M	15	SS
	A11	F	16	SS
	A13	M	17.5	Sβ
Adult patients	ADU1	M	23	Sβ
	ADU8	M	21	SS
	ADU9	M	19	SS
	ADU10	M	25	SS

Pediatric healthcare providers (PH): Nine interviews with pediatric healthcare providers of patients were conducted, and 5 talked about the pediatric to adult care transition (PH4 to PH8). Their characteristics are presented in Table 2. All participants were women. Mean age was 40.4 years (R: 28–58). They were: three nurses, two pediatric nursing auxiliaries and four physicians. Three worked in the hospitalization unit, two in the consultation unit, and four (physicians) divided their activities between both services. Mean interview duration was 21 minutes (R: 15.5–30).

Adult healthcare providers (AH): Thirteen interviews with adult healthcare providers were conducted, and 5 talked about the pediatric to adult care transition (AH9 to AH13). Their characteristics are presented in Table 2. Eleven

Table 2 Demographic Data of Interviewed Adult and Pediatric Healthcare Providers (HCPs)

	n	HCP's Gender	HCP's Age (Years Old)	Profession	Worked Service
Adult HCPs	AD1	M	25	Nurse	Consultation
	AD2	F	51	Nurse	Consultation
	AD3	F	47	Nurse	Consultation
	AD4	F	39	Nurse	Consultation
	AD5	F	36	Nurse	Hospitalization
	AD6	F	28	Nurse	Hospitalization
	AD7	F	58	Nurse	Hospitalization
	AD8	F	24	Nurse	Consultation & Hospitalization
	AD9	F	46	Nurse	Consultation
	AD10	F	45	Physician	Consultation & Hospitalization
	AD11	M	31	Physician	Consultation & Hospitalization
	AD12	F	36	Physician	Consultation & Hospitalization
	AD13	F	31	Physician	Hospitalization
Pediatric HCPs	E1	F	27	Pediatric nurse auxiliary	Hospitalization
	E2	F	58	Pediatric nurse auxiliary	Hospitalization
	E3	F	56	Nurse	Consultation
	E4	F	33	Nurse	Consultation
	E5	F	33	Nurse	Hospitalization
	E6	F	31	Physician	Consultation & Hospitalization
	E7	F	39	Physician	Consultation & Hospitalization
	E8	F	36	Physician	Consultation & Hospitalization
	E9	F	51	Physician	Consultation & Hospitalization

participants were women and two were men. Mean age was 38.2 years (R: 24–58). They were nine nurses and four physicians. Four worked in the hospitalization unit, five in the consultation unit, and four divided their activities between both services. Mean interview duration was 15.7 minutes (R: 9.5–27.5).

Perceptions on the Subtopic “Pediatric-Adult Care Transition”

Perceptions presented below were synthesized in Table 3.

Subjectives Experiences

Difficult Experience

Two adolescent girls reported apprehending this transition: “I don’t want to! (...) I wouldn’t like sleeping there (A11)”. Two adult patients, two adult HCPs and three pediatric HCPs reported a difficult transition from pediatric to adult care experience: “it was a bit difficult to come here (ADU8)”; “it must be quite a shock to be in adult care (PH5)”. To explain this difficult experience, two adolescents and three pediatric HCPs talked about changes in habits and new healthcare providers (physicians and other HCPs): “it’s a bit difficult to come here, because you need to change unit, you leave people behind, switching from one unit to another (ADU8)”; “they are a bit stressed to switch teams. Some of them actually try to negotiate (...) one more consultation, please just one more” (PH8). An adult care physician brought up another explanation, the different psychosocial support: “I think the offer is very large in the other sector (pediatric), whereas we just started having a sophrologist to help them a bit” (AH13). Furthermore, an adult patient, a pediatric nurse

Table 3 Compared Perceptions of Pediatric-Adult Transition Between Adolescent and Adult Patients and (Pediatric and Adult) Healthcare Providers

	Perceptions			
	Adolescents	Adults	Pediatric HCPs	Adult HCPs
SUBJECTIVE EXPERIENCES	Apprehending	Difficult transition experience		
	Changes in habits and new healthcare providers	- Different psychosocial support - “Pampered/like in a cocoon” in pediatric care	- Changes in habits and new healthcare providers - “Pampered/like in a cocoon” in pediatric care	- “Pampered/like in a cocoon” in pediatric care
		Different physician-patient relationship, regarding caregivers		Different physician-patient relationship, regarding caregivers
		Longer for adult HCPs to take patients’ pain into account than in pediatric units		
CHANGES IN CARE ORGANIZATION			Source of patients lost to follow-up	
	Follow-up being similar in both care units	Follow-up being similar in both care units but different organization of the medical consultations	Difference in scheduling appointments	Follow-up being similar in both care units
	Differences in leisure activities during hospitalizations		Different waking-up times	
NEEDS AND PROPOSITIONS	Doubts regarding the time and location	Need for more explanations	Lack of knowledge on the organization	
		Need time to adapt to the new care management	Not really anticipated Other improvement axes	Wish to anticipate some explanations

and an adult care physician told us that the patient is “pampered/like in a cocoon” in pediatric care but it is not the case in adult care: “Because I think that during their hospital stay, they are not pampered like in our unit (PH5)”; “Now, I no longer care, but when I was 18, I was used to being pampered (ADU10)”.

A Different Relationship Between Patient-Caregiver-HCP

One young adult and two adult care physicians reported a different place for caregivers in the patient-caregiver-HCP relationship in adult care vs pediatric care:

this is the main principle of pediatric care: we have parents, a family environment, but here in adult care, they are older, they do not need their parents to come. (AH12)

One adult patient expressed a feeling of exclusion in pediatric care: “there was more interaction with my mom. Physicians were asking more questions to my mom than me (...) in fact, there weren’t interacting with me (ADU9)”. In adult care, caregivers are excluded, as expressed by one adult physician, and this change makes the physician-patient relationship in adult care centered on the patient: “Me, when parents come, I say hello but I do not consider them (...) The relation needs to be created between the doctor and patient” (AH10). Healthcare professionals also bring up the facts that caregivers (parents) are always “behind” patients in pediatrics but “as adults they [patients] no longer live with their parents, sometimes they are not even in the same city, so they come alone to the consultation” (AH11).

Taking into Account Patients’ Pain

Two adult patients reported that in the adult hospitalization unit or in the adult ER, it took longer for HCPs to take patients’ pain into account than in pediatric units: “when I have crises, sometimes I press the call button. In pediatrics I noticed that they came right away! Here they take more time (ADU9)”. Two adults offered some explanations: “I think they now see us as adults, no longer as kids! So maybe they think we can handle the pain, that they have time! (ADU9)”. A pediatric nurse brought up the difference in therapeutics: “maybe they won’t have the Kalinox[®] (anesthetic gas for pain)” (PH4).

Changes in Care Organization

Changes in Follow-Up

This follow-up was reported by two adolescents, at least one adult patient and one adult care physician, as being similar in both care units: “in regards to follow-up visits, it doesn’t change, only the location does (ADU8)”. However, a young adult spoke of the different organization of the medical consultations:

regardless of everything, I was always seeing Dr Z in pediatric care. (...) when I arrived in the adult sector, the first time I was introduced to Dr X, then the next time to another doctor, and then the following time yet another doctor. (ADU7)

One pediatrician talked about the difference in scheduling appointments:

in pediatrics we are used to dealing with everything: consultation appointments, we call them if they do not show up, we give them a new appointment, we reschedule the dopplers or any other exams if they can’t come. (PH7)

Furthermore, 4 pediatric HCPs talked about the transition to adult care as a source of patients lost to follow-up, no longer coming to consultations: “Generally, they no longer come to consultations” (PH7).

Changes During Hospitalizations

Two adolescents and two young adults largely reported differences in leisure activities during hospitalizations, with less options in adult care: “what is different, there are fewer distractions when we are hospitalized (...) When you are in pediatrics, you can have a game console in you room (ADU7)”. A pediatric nurse talked about different wake-up times from one sector to the next:

in the adult care unit, generally, I know how it works, blood test at 7am, breakfast at the same time and nobody asks your opinion. In the pediatric care unit, we let them sleep until 10 am. (PH5)

Needs and Proposals

Need for Explanations

Three adolescents spontaneously expressed their doubts regarding the time when they will leave the pediatric care but also about the location of the adult care unit: “I think that X (pediatric hospital) is only until you are 18, I am not sure but ...after I don’t know (A9)” “I will be at the hospital, I will be at Y (adult care hospital), I think. I don’t know but I think it is Y (A13)”. Two young adults talked about the need for more explanations on their care management: “when you are a child, you really want to know what the medicines are for! (ADU9)”.

In fact, three nurses talked about their lack of knowledge on the organization of the transition: “I don’t know if there is a difference in care management. I believe the follow-up is every year in adult care? (PH4)”.

Need for Anticipation

For three out of the 4 adult patients time is needed to adapt to the new care management: “we had a hard time getting used to it (ADU8)”. And three pediatric HCPs spontaneously said that the transition was not really anticipated: “For us, adult care is a totally different world. It’s true that in one instant, POOF, they’re gone we no longer see them (PH5)”. And one adult physician expressed her wish to anticipate some of the information shared with the patient, especially regarding adolescence-specific topics:

I think that we could change a bit the attitude by addressing certain topics such as sexuality, birth control, from the age of 15: because I believe that some kids only hear about it in adult care (AH10)

Areas of Improvement

Four pediatric healthcare professionals brought up areas for improvement:

- “Peer-Mentoring”: “The mentoring by another patient” (PH8)
- Medical transition: “transition managed by your pediatric physician, whom you have known for a long time, who takes you to the adult care unit and introduces you to your new healthcare team. It is in my opinion a necessary step, in order for the trust to be passed on to the adult care service. In my sense it is more serene. I really believe that this symbolic step is essential for them ... like in any chronic disease” (PH6)
- Transition to other healthcare professionals: “We really did not hear a thing about it, (...) we would need a transition period to communicate [with fellow nurses from the adult care unit] about the crises, because we know our patients very well” (PH5)
- Alternation of pediatric and adult consultations: “Maybe alternate for two years? (...) this way we will have feedback on how it went, and we could make sure they went to the consultations, because I know they would come to our consultations” (PH8)
- Similar organization for medical appointments: “there no longer was someone taking care of them. They had to manage their disease by themselves, doctors were no longer doing it for them. It is a major change and it could be quite upsetting for some. I believe it could be the reason why some patients were lost to follow-up” (PH7)
- Good communication between physicians of both units: “I communicate well with X (adult care physician), so every time we call each other and I tell him: one of my patients just turned 18, I am sending you the letter, can you see him?” (PH7)

Comparison of Perceptions in Different Populations

Perceptions according to the different populations are synthesized in [Table 3](#).

Adult patients were the only ones who talked about the difference in pain management between pediatric and adult care. Adolescents were the sole ones who did not bring up the “cocoon” of pediatric care as an explanation for the difficult experience of the pediatric-adult care transition.

Regarding knowledge on pediatric-adult care organization, adolescents, adults and pediatric HCPs brought up some concerns and need for explanations. To improve this transition, adult patients, pediatric and adult HCPs underlined the

need to anticipate this transition, to give more information on the adult care unit and to give time to patients to adapt to the new setting.

Discussion

To our knowledge, this study is the first one in Europe to explore perceptions of both AYA patients and their HCPs regarding medical care adherence in the context of the pediatric to adult care transition.

This care transition is poorly experienced as expressed by SCD patients,²⁰ but also patients with other chronic diseases.²¹ Our study highlights multiple reasons for this poorly experienced transition: different habits and new physicians, but also changes in care organization. Pediatric patients have known their physician for many years; they almost grew up with him or her. However, in adult care, patients do not always see the same physician at each medical consult. The patient-physician relationship is an important factor associated to medical appointment adherence.²²

Also, in pediatric units, HCPs “pamper” their patients, which is definitely not the case in adult care, where patients need to be autonomous. These aspects, which were addressed in our study, were also reported in other chronic diseases.⁹ Another explanation for this poorly experienced transition is that the adult care unit is not as welcoming as the pediatrics unit. For instance, in adult care, pain is not taken into account as quickly as in pediatric care, as reported in our study but also by AYAs in Renedo et al¹¹ and Porter et al⁹ and HCPs.¹² Those two reasons for the poorly experienced transition, “pampered pediatric care” and difference in pain management, were not expressed by adolescents in our study, which underlined that they were not really expecting it.

In Porter et al,⁹ young adults expressed their fear but also their feelings of being abandoned by caregivers and HCPs alike. Caregiver support is an important factor associated to medical appointment adherence.²² During the pediatric to adult care transition, the roles of caregivers and patients change:²¹ in fact, caregivers must distance themselves (sometimes required by HCPs in adult care), and patients need to develop a more active role to become autonomous and in charge of their own health.⁹ Caregiver distancing in the patient-caregiver-HCP relationship can be appreciated by some young adult patients, as expressed in our study, because the relationship with the physician becomes more patient-centered. This is a major factor of medical care adherence.²³ Another major factor is that there is not enough time to transition from a pampered setting with the caregiver behind the patient to a more autonomous setting where the patient is alone; it happens too quickly. So, the pediatric to adult care transition needs to be anticipated, as requested by adult patients and HCPs in our study and in the literature.^{13,24} This anticipation allows HCPs to take time to facilitate this transition between pediatric and adult teams. That way, patients can gain autonomy by acquiring new skills and are able to put their trust into new physicians and healthcare teams.²¹ In parallel, good communication and care coordination between pediatric and adult teams is essential as brought up by one physician in our study and underlined in the literature.²⁵

The evaluation of chronic diseases needs to underline the importance of information given to AYA patients on general health-related matters, but also the relevance of their own experience, shared with peers, to improve the pediatric to adult care transition.²¹ The need for more information was expressed by HCPs and AYA patients in our study. In SCD literature, beyond receiving information, young adults expressed the need to acquire specific skills and prepare mentally before this pediatric to adult care transition: by meeting their future HCPs, getting hands-on training,⁹ improving SCD knowledge and self-management.²⁵ Different ones are needed to face up to the disease challenge: medical status, medication, crisis triggers, self-efficacy,⁹ activities limitations,^{9,10} healthcare navigation skills,¹² transmission, pain management,¹⁰ communication skills (to explain the disease in different contexts),^{10,12} parental skills on disease knowledge and therapeutics.¹² Some of these skills are similar in other chronic diseases: disease adaptation (identity construction, positive attitude development), self-management of the disease and treatment, lifestyle skills (emotional life, sexual life, etc.).²¹ For experiential teaching, one HCP in our study suggested “peer mentoring” between pediatric and adult patients, and AYAs with chronic diseases suggested increased sharing of experiences with peers.²¹

After setting out all these aspects, it is essential to propose an intervention to improve the currently poor experience of pediatric-adult care transition, which could also improve non-optimal patient adherence to medical care reported in literature.^{5,7,26} The obtention of new skills both for AYAs and HCPs is essential.

Firstly, a part of the intervention could be focused on HCPs: they should be informed on the organization of the pediatric to adult care transition. Furthermore, as reported by HCPs in our study and in the literature,⁹ HCPs need transition-related training, and training regarding the disease itself and adolescence-related issues, as well as specific pain management and communication skills. Secondly, part of the intervention should be focused on patients and caregivers in a global vision of the patient care management (biological, clinical, psychological and social aspects).^{9,28} The objective should be the development of their proactive role to master self-management.^{5,27} To achieve this multifactorial objective, it is essential to rely on a multidisciplinary team.²⁶ In fact, caregivers must be part of this intervention, because their roles change a lot during this crucial period as underlined above and, in the literature^{9,25,26}

Scientific Rigor, Credibility, Transferability, Trustworthiness

The scientific rigor of this research is based on the choice of a published analytic method (Thomas, 2006). The “inductive content analysis” was previously described,¹⁶ and two researchers conducted the analysis to increase its objectivity. Also study results were compared to those in the literature to assess plausibility. The objective of the “inductive content analysis” was to identify raw and fundamental data significant to the object of the research. This analysis was chosen because it is more explorative in nature: the knowledge is produced from data as opposed to “deductive analysis” for which theoretical knowledge precedes the reading of reality.

Our method was based on individual semi-structured interviews that allowed the exploration of participants’ experience around a framework and without a priori. An individual interview setting was chosen over a focus group for collecting each participant’s point of view in an equitable manner. There is a subjectivity bias inherent to the interviewer being an HCP: the interviewer may have induced a bias in participants who might have wanted to “please” the interviewer and not be critical of the hospital. Nevertheless, the interviewer was unknown to patients up to that point, and was not involved in their direct care.

Three months before the start of this work, the main researcher (interviewer and analyst) was positioned as a student observer in the study center, her knowledge of the research context allowed her to pay attention to data’s salient features. Conversely, the second researcher (analyst for triangulation data) did not have this background, which made his interpretation all the more interesting.

Another aspect regarding the credibility of this work was participants’ feedback, which was systematically encouraged. Only two participants accepted it.

Regarding inclusion criteria, patients were interviewed face-to-face when they came to the study center for a medical consultation or follow-up visit, without any pre-selection. Our study sample is not meant to be representative. Regarding inclusion criteria, healthcare providers were interviewed at their place of work. The sample size of participants was chosen so that recruitment could be completed within one year of inclusion while meeting the COREQ quality criteria of a qualitative study.¹⁹ It is an intrinsic limitation of this explorative study. This explains partly why data saturation was not reached but also since the study only reports one part of the 3-topic interview guide.

Because the context of this research can never be exactly the same, this work cannot pretend to be reproducible.

The study main limit was its focus on the subtopic of pediatric to adult care transition, not present in the interview guide. Nevertheless, this focus was all the more interesting as it emerged from the interviews. Consequently, only a small number of participants in each group talked about it. Other publications are needed to provide further insights on these topics. The first topic of the interviews, the disease (SCD), was previously published (BLINDED FOR PEER REVIEW).

Even if this study compares perceptions between adult and adolescent patients and also pediatric and adult HCPs, this study did not compare patient perceptions according to the different SCD forms (SS, SC, Sβ+ and Sβ0). It would indeed be interesting to compare patient experiences between the different SCD forms.

Another limitation is the intrinsic bias inherent to the one-year duration of data collection for this study. This was done out of convenience and it limited the sample size, and data saturation was difficult to achieve. If data collection had occurred over a longer period of time, it would have increased the study quality. Moreover this study would be even more relevant with more subjects from different study centers.

Conclusion

The transition from pediatric to adult care is poorly experienced by AYA patients with SCD as reported in this study. It was explained by the multiple changes in habits, physicians, care organization. This transition could be better experienced with more anticipation, which would increase medical care adherence. In that case, HCPs would have more time to introduce patients to the new adult team and patients would have time to acquire new skills. HCPs are aware of the difficult transition and provided some explanations.

Acknowledgments

We would like to acknowledge the caregivers and patients who agreed to participate in this study.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Rees DC, Williams TN, Gladwin MT. Sickle-cell disease. *Lancet*. 2010;376:2018–2031. doi:10.1016/S0140-6736(10)61029-X
2. Quinn CT, Rogers ZR, McCavit TL, et al. Improved survival of children and adolescents with sickle cell disease. *Blood*. 2010;115:3447–3452. doi:10.1182/blood-2009-07-233700
3. Atkin K, Ahmad WI. Living a ‘normal’ life: young people coping with thalassaemia major or sickle cell disorder. *Soc Sci Med*. 2001;53:615–626.
4. Sabaté E. Adherence to long-term therapies: evidence for action. Geneva: World Health Organization; 2003. Available from: http://www.who.int/chp/knowledge/publications/adherence_report/en/. Accessed June 20, 2016.
5. Berens JC, Jan S, Szalda D, et al. Young adults with chronic illness: how can we improve transitions to adult care? *Pediatrics*. 2017;139:pii:e20170410.
6. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA*. 2010;303:1288–1294. doi:10.1001/jama.2010.378
7. Candrilli SD, O’Brien SH, Ware RE, et al. Hydroxyurea adherence and associated outcomes among Medicaid enrollees with sickle cell disease. *Am J Hematol*. 2011;86:273–277. doi:10.1002/ajh.21968
8. Yang YM, Shah AK, Watson M, et al. Comparison of costs to the health sector for comprehensive and episodic health care for sickle cell disease patients. *Public Health Rep*. 1995;110:80–86.
9. Porter JS, Wesley KM, Zhao MS, et al. Pediatric to adult care transition: perspectives of young adults with sickle cell disease. *J Pediatr Psychol*. 2017;2:1016–1027. doi:10.1093/jpepsy/jsx088
10. Kulandaivelu Y, Laloo C, Ward R, et al. Exploring the needs of adolescents with sickle cell disease to inform a digital self-management and transitional care program: qualitative study. *JMIR Pediatr Parent*. 2018;25:e11058. doi:10.2196/11058
11. Renedo A, Miles S, Subarna Chakravorty S, et al. Not being heard: barriers to high quality unplanned hospital care during young people’s transition to adult services - evidence from ‘This Sickle Cell Life’ research. *BMC Health Serv Res*. 2019;19:876. doi:10.1186/s12913-019-4726-5
12. Stollon NB, Paine CW, Lucas MS, et al. Transitioning adolescents and young adults with sickle cell disease from pediatric to adult health care: provider perspectives. *J Pediatr Hematol Oncol*. 2015;37:577–583. doi:10.1097/MPH.0000000000000427
13. De Montalembert M, Guitton C. Transition from paediatric to adult care for patients with sickle cell disease. *Br J Haematol*. 2014;164:630–635.
14. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62:107–115. doi:10.1111/j.1365-2648.2007.04569.x
15. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis qualitative. *Health Res*. 2005;15:1277–1288. doi:10.1177/1049732305276687
16. Thomas DR, General Inductive A. Approach for analyzing qualitative evaluation data. *Am J Eval*. 2006;27:237–246.
17. Blanchet A, Gotman A. *L’entretien. [The Interview]*. 2nd ed. Paris: Armand Colin; 2007. French.
18. Kaufmann JC. *L’entretien Compréhensif. [The Comprehensive Interview]*. 4th ed. Paris: Armand Colin; 1996. French.
19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–357.
20. Smith WR, Sisler IY, Johnson S, et al. Lessons learned from building a pediatric-to-adult Sickle Cell transition program. *South Med J*. 2019;112(3):190–197. doi:10.14423/SMJ.0000000000000950
21. Morsa M, Lombrail P, Boudailliez B, et al. A qualitative study on the educational needs of young people with chronic conditions transitioning from pediatric to adult care. *Patient Prefer Adherence*. 2018;12:2649–2660. doi:10.2147/PPA.S184991
22. Crosby LE, Modi AC, Lemanek KL, Guilfoyle SM, Kalinyak KA, Mitchell MJ. Perceived barriers to clinic appointments for adolescents with sickle cell disease. *J Pediatr Hematol Oncol*. 2009;31:571–576. doi:10.1097/MPH.0b013e3181acd889
23. Stevenson FA, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expect*. 2004;7(3):235–245. doi:10.1111/j.1369-7625.2004.00281.x
24. Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128:182–200.
25. Calhoun CL, Abel RA, Pham HA, et al. Implementation of an educational intervention to optimize self-management and transition readiness in young adults with Sickle Cell disease. *Pediatr Blood Cancer*. 2019;66:e27722. doi:10.1002/pbc.27722
26. Treadwell M, Telfair J, Gibson RW, et al. Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. *Am J Hematol*. 2011;86:116–120.

27. Hibbard JH, Stockard J, Mahoney ER, et al. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004;39:1005–1026.
28. Speller-Brown B, Patterson KK, VanGraafeiland B, et al. Measuring transition readiness: a correlational study of perceptions of parents and adolescents and young adults with Sickle Cell disease. *J Pediatr Nurs.* 2015;30:788–796.

Patient Preference and Adherence

Dovepress

Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focusing on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize clinical outcomes for existing disease states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/patient-preference-and-adherence-journal>