

Type I Diabetes Patient Experiences Before and After Transfer from a Paediatric to an Adult Hospital

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Introduction: The management of type 1 diabetes (T1D) is especially complex during adolescence when youths are transferred to adult care centres. The objectives of this qualitative study were to: a) determine the expectations of young T1D patients prior to transfer, b) evaluate the transfer process between the 2 centres, and c) evaluate the therapeutic education and care programme (TECP) in the adult centre from their point of view.

Material and Methods: Opinion sampling of adolescents from 2018–2019 was performed: Phase 1: adolescents with T1D prior to transfer to the adult hospital; Phase 2: adolescents with T1D one or two years after transfer and having undergone TECP. A focus group (1.5h) and semi-structured interviews (45 min) were performed and taped, transcribed, and sent to the participants for confirmation. Data analysis was performed of the transcriptions of the focus group and interviews. Fragments were selected and meta-categories created.

Results: Eleven youths accepted to participate: 7 in Phase 1, 4 repeated in Phase 2 and 4 more transferred 2 years previously were added. The meta-categories obtained were: 1) perception of the quality of care and therapeutic education in the paediatric hospital. 2) transfer to the adult hospital. 3) experience of the youths 1–2 years after transfer and having undergone TECP. The data are presented in narrative form and are supported with text fragments of the participants' discussions.

Discussion and conclusions: Analysis of patients' experience complemented by clinical-educational evaluation of TECP provides understanding of the perspectives of youths on the complexity of living with a chronic disease since childhood. It also provides information regarding the factors favouring quality care and therapeutic education, the complexity of transfer from paediatric to adult care, determination of the strong and weak points and the establishment of strategies to improve the programme.

Keywords: Type 1 diabetes, adolescents, transition to adult care, qualitative research, patient experience, therapeutic patient education

Introduction

Diabetes is a complex chronic disease that requires continuous medical care with multifactorial strategies for the reduction of risk beyond glycaemic control. Continuous education and support for self-control of diabetes are fundamental to prevent acute complications and reduce the risk of complications in the long-term.¹

Follow-up and adherence to treatment of type 1 diabetes (T1D) is especially challenging during adolescence. In “emerging adults” from 18 to 30 years of age, a series of educational, social, and economic needs arise and must be met to achieve satisfactory adaption to adulthood.² In this stage of life, people with T1D also have other specific needs related to the disease, such as transfer from paediatric to adult care and the need to increase self-management of treatment and control of the disease due to less family participation.³ Several studies have shown that this transition may worsen the quality of life,⁴ adherence to treatment and metabolic control, increasing the risk of acute, chronic microvascular complications and early mortality^{5,6} as well as reducing attendance to clinical visits.⁸ According to the Autonomous

Community in Spain, the transfer from paediatric to adult care is undertaken at between 16 to 18 years of age. The consensus document of the working group of the Spanish Society of Diabetes (SED in Spanish) recommends that the transition of a paediatric patient to an adult Diabetes Unit is far from optimal, having adverse effects on health during both adolescence and adulthood.⁹ At present, the transition of patients to adult Diabetes Units is recognised as a key component of the care of adolescents with chronic disease. Most authors and several scientific societies coincide in recognising the need for specific, structured and coordinated programmes to enable adequate transition.⁷

In this context, in 2000, a therapeutic education and care programme (TECP) was developed aimed at youths transferred from the paediatric *Hospital Sant Joan de Déu* (HSJD) to the adult centre of the *Hospital Clínic de Barcelona* (HCB). Evaluations of the impact of this programme on the clinical and educational results of these patients were performed in 2004, 2013 and 2017. The main results showed that the TECP for youths transferred from paediatric care is effective for improving some aspects of metabolic control and competences for self-control without modifying the perception of quality of life, especially among those who completed the programme. Although the use of the specific TECP improves the metabolic outcomes in the medium term, the reduction of episodes of hypoglycaemia, especially severe episodes, continues to be a problem that is difficult to solve. Several recent studies have shown that at both the initiation and finalisation of the programme, patients with high adherence to self-management of treatment present fewer years of evolution, better control, lower insulin doses, perform more self-testing, and have better knowledge of diabetes and improved perception of quality of life.^{10–12}

To complement the evaluation of clinical and educational aspects and quality of life of the TECP, this qualitative study was carried out with the aim of evaluating the experience of patients prior to and after transfer and understand the complexity of this experience as well as determine the strong and weak points and establish strategies to improve the programme.

Since transfer to an adult hospital may be influenced by multiple factors associated with youths with T1D or their families,¹³ the objectives of this study were: 1) to determine the expectations of youths prior to transfer to the adult centre; 2) to evaluate the transfer process between the paediatric and the adult hospital; and 3) to evaluate the TECP from the perspective of the youths involved.

Method

The study population included adolescents with T1D who were transferred from a paediatric to an adult hospital and youths with T1D one and two years after having been transferred. Opinion sampling was performed. Cases were selected for their knowledge of the situation which would help to understand more in depth the process of transfer to an adult hospital and evaluate the TECP carried out in the adult hospital. The study settings were the HSJD and the HCB, and the study was carried out in two phases over a two-year period (2018–2019).

Phase 1: Prior to transfer. The inclusion criteria were: diagnosis of T1D one or more years previously; receiving care in the Paediatric Endocrinology Unit of the HSJD; being 18 years of age; need for transfer to an adult hospital and providing signed informed consent.

In the paediatric hospital, the team professionals informed all the youths who fulfilled these criteria of the objectives of the project and invited them to participate.

Phase 2. 1–2 years after transfer. The inclusion criteria were: having been transferred to the adult hospital from the HSJD one or two year previously, having participated in the TECP as shown in [Table 1](#)¹² and providing signed informed consent to participate.

In the adult hospital the same was done with the youths who had been transferred one year previously. Thus, to increase the number of participants and determine whether similar results were achieved, youths who fulfilled the inclusion criteria and had been transferred two years previously were invited to participate.

The exclusion criteria for both phases were: having cognitive, sensorial or other clinical problems making communication difficult, idiomatic barriers (not being able to speak Spanish or Catalan) and refusal to participate.

Group discussion was the preferred method for information collection, but semi-structured interviews were also used in four cases who had difficulty in participating in the group discussion due to the times these were scheduled. To coordinate the discussion groups and interviews, two people with experience in this area and unknown to the participants

Table 1 Healthcare Process During the First Year After the Transfer of T1D Patients from a Paediatric to an Adult Centre (Therapeutic Education and Care Programme TECP-Transferred)

Previous to Phase 1	1. Coordination paediatric/adult centre appointment	<ul style="list-style-type: none"> • Before paediatric discharge a visit is requested to facilitate the administrative work to the patient and/or family. <ul style="list-style-type: none"> -Clinical-educational discharge report -Presentation of pamphlet with information about the new centre and contact telephone numbers -Explanation of the new care process at the adult hospital.
Phase 1	2. Initial joint visit. Endocrinologist and nurse in adult centre	<ul style="list-style-type: none"> • Perception and expectations of the patient • Clinical and educational anamnesis: The following variables are collected: HbA_{1c}, ISF, I/CH ratio, alimentation, hypoglycaemias, injection technique and zone, BMI. • The following questionnaires are given: Knowledge (DKQ2), Quality of life (DQOL and SF12), Perception of symptoms of hypoglycaemia (Clarke), Adherence to treatment self-management (SCI-R.es) and Eating behaviour (EAT26). • Clinical and educational objectives are agreed upon.
Phase 2	3. Homogenous group course. Participants: 8–12 youths 1 Day 9–18h	<p>Introduction of participants to educators (members of the healthcare team).</p> <p>METHODOLOGY:</p> <ul style="list-style-type: none"> -Metaplan for asking questions anonymously: • Difficulties in the follow-up of diabetes • Expectations related to the course <ul style="list-style-type: none"> -Case method to potentiate active participation and discussion in small groups. <p>CONTENT: Adapt and prioritize based on the metaplan. Usually the following are covered:</p> <ul style="list-style-type: none"> -Night outs, action towards alcohol and other toxic substances, smoking, acute decompensations, food, and CH counting for meals, sports, sexual relations and pregnancy, future perspectives related to treatment. -At the end an experiential workshop is performed in which the following are described through magazine cuttings: how they perceive diabetes, how they see themselves in 3 years, how they believe a cure for diabetes will be achieved, and life motto. EVALUATION of the course.
Phase 3	4. Individual visit with nurse at 3 months	<p>Revision and reevaluation of objectives AGEED UPON in the initial visit. Difficulties and proposals for improvement.</p> <ul style="list-style-type: none"> -Evaluation of adherence to treatment. -Need to programme more telematic or presential visits, if necessary.
	5. Individual visit with nurse at 6 months T6 evaluation	<p>Adaptation schedule and education reinforcement for treatment self-management.</p> <ul style="list-style-type: none"> -Evaluation of the initial variables and questionnaires
	6. Individual visit with the endocrinologist at 9 months	<ul style="list-style-type: none"> - Revision of clinical and laboratory results. - Reinforcement of treatment self-management. - Perception of follow-up.
Phase 4	7. Individual visit with the nurse. T12 evaluation Discharge from TECP at 12 months.	<p>Adaptation schedule and education reinforcement for treatment self-management.</p> <ul style="list-style-type: none"> -Evaluation of the initial variables and questionnaires
Usual follow-up of the visits in the OPC with the endocrinologist according to the frequency of the tertiary level hospital (3 annual visits, although the frequency may be increased, or a new care and therapeutic education programme may be planned if necessary).		
Possibility of telephone contact with the Day Hospital, educators, or mobile endocrinology emergencies 24 hours/day, 365 days/year.		

Abbreviations: HbA_{1c}, glycated haemoglobin; CH, carbohydrates; ISF, insulin sensitivity factor; I/CH ratio, insulin/carbohydrate ratio; BMI, body mass index; DKQ2, Diabetes Knowledge Questionnaire 2; DQOL, specific type 1 diabetes quality of life questionnaire; SF12, general health-related quality of life questionnaire; Clarke, questionnaire on the perception of symptoms of hypoglycaemia; SCI-R.es, questionnaire on adherence to treatment self-management; EAT26, eating behaviour questionnaire; OPC, outpatient consultation.

were brought in from outside the two hospitals with the aim of favouring the neutrality of information and increasing scientific rigor.

Before carrying out the group discussions and the semi-structured interviews, a script of open questions was elaborated based on the objectives of the study. The script was not strictly followed but rather was adapted to the subjects that arose during the group and individual interviews. In addition to the coordinator, all the group discussion sessions included an observer who described the observations made and the reflections which arose in a report. The coordinator and observer noted the context, non-verbal communication, moments of tension or confrontation and strong points to remember as well as ideas and feelings experienced. The coordinator also made notes referring to each activity at the end of the sessions. The duration of the group discussions was approximately 1h 30 minutes and the interviews were 45 minutes in length. Each session was taped after having obtained consent from the participants. Information collection was completed when data saturation was achieved,¹⁴ that is, when the information collected from different persons or groups was redundant.

The transcriptions of each group discussion or interview were made immediately and a copy was sent to each participant for their reading and to give their opinion on the clarity and veracity. This procedure is one of the methods which the investigators used to validate the study data.¹⁵ An analysis of subject content was made following the steps proposed by Miles and Huberman:¹⁶ 1) reduction of data; 2) disposition and transformation of data; and 3) obtainment of results and verification of conclusions.

Data Analysis

Data analysis was performed manually from the literal transcriptions of the discussion groups and the interviews. Data analysis began by repeated readings of each transcription. Text fragments or units of significance were selected, and each fragment was assigned a code, and codes sharing the same significance were grouped. Afterwards, relationships between the coded data were sought and categories were created. Finally, the categories were synthesized and grouped and meta-categories or emerging topics corresponding to the explanation of the results and conclusions of the study were created. A previously constructed system of categories was not used, but rather an open construction process of the categories was carried out.

To ensure qualitative study rigour, the Lincoln and Guba trustworthiness criteria were used¹⁵ 1) Credibility: this criterion was achieved by the saturation of the results, data triangulation and revision of the discussion group and interview transcriptions by the participants. 2) Transferability: the context and the characteristics of the participants were described. 3) Dependability or consistency: To fulfil this criterion, the context was delimited, the type of participants and the field work techniques and the analyses were described, and a mixed study was performed by data triangulation. 4) Confirmability: In this study the coordinators of the discussion groups and interviews were experts external to the hospitals involved and were unknown to the participants.

Ethical Aspects

The Declaration of Helsinki was followed to establish the ethical framework of this study. This Project was approved by the Ethics Committee of Clinical Investigation of the *Hospital Clínic de Barcelona*. The participation of all the participants was voluntary and informed consent included publication of anonymized responses and was signed by the parents of the youths in phase 1 and only by the youths in phase 2 because they were over the age of 18. Data confidentiality and the anonymity of the participants was ensured, replacing the real names by fictitious names. All informants were assured of the confidentiality and anonymised responses. The transcriptions of the discussion groups and interviews were given to the participants, and they were given the opportunity to modify the content or suggest clarifications regarding the information provided. In addition, the recommendations on ethical aspects in qualitative investigation described by Emanuel¹⁷ (scientific validity, favourable risk-benefit ratio, and equitable subject selection) were taken into account.

Results

A total of 11 youths accepted to participate: Phase 1: 7 adolescents. Phase 2: 8 adolescents (4 were the same as those in Phase 1, and 4 who had been transferred two years before). Three patients from phase 1 could not participate in

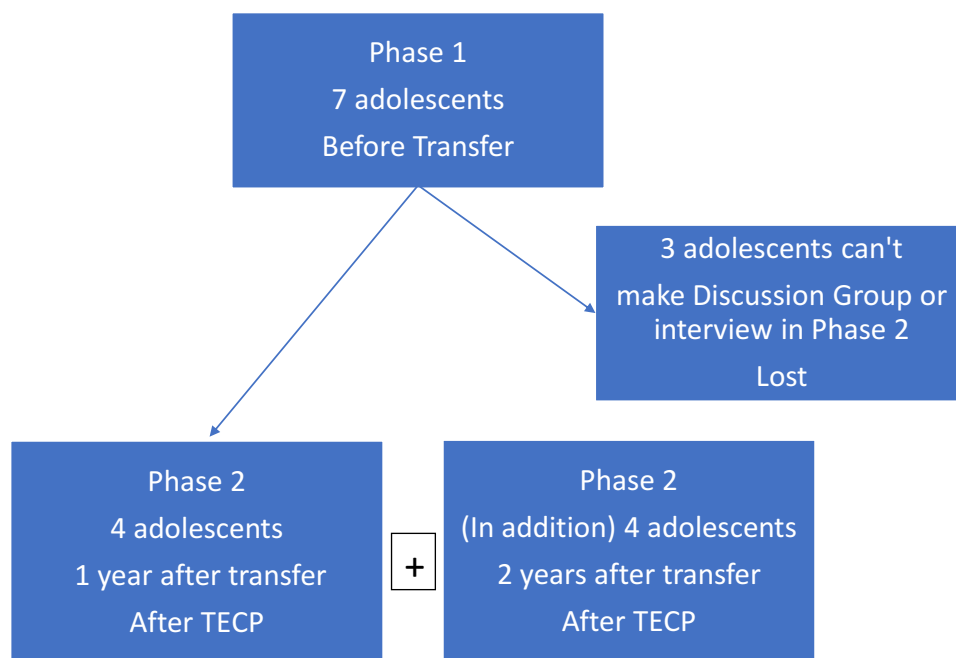


Figure 1 Flow Chart of the participants' study.

the second phase due to work or studies that did not allow time to attend the discussion group or the interviews, as we show in [Figure 1](#).

Characteristics: Phase 1: 7 adolescents (3 females and 4 males) aged between 17–18 years with a T1D evolution of between 4 and 14 years; Phase 2: 4 youths (2 males and 2 females) between 18–19 years of age who had transferred one year previously and had participated in Phase 1, and 4 youths (3 males and 1 female) 20 years of age who had been transferred two years previously. The characteristics of the participants are shown in [Table 2](#). The names are fictitious to maintain anonymity.

The categories obtained in the data analysis were grouped into 3 topics or meta-categories: Topic 1: Perception of the quality of care and therapeutic education in the paediatric hospital; corresponding to Phase 1; Topic 2) Transfer to the adult hospital, and Topic 3) Experience the youths with T1D had obtained with the transfer to the adult hospital 1 or 2 years previously and had had with TECP, both of which correspond to Phase 2.

The data were presented as a narrative and were reinforced by textual fragments of the discussion among the participants to illustrate and confirm the relationship between the theoretical concepts and the data.

Topic I. Perception of the Quality of Care and Therapeutic Education in the Paediatric Hospital

All the adolescents participating in the study were very satisfied with the care they received from the healthcare professionals, physicians, and nurses, although in their narratives they mainly mention the nursing professionals possibly because they are largely responsible for the therapeutic education (TE) in diabetes and have a closer and longer relationship with them over time. What the adolescents evaluated most highly of the healthcare professionals was their empathy, accessibility, comprehension, friendliness, listening ability and that they considered their perspectives and existential circumstances. They also positively evaluated the hospital installations.

So when I arrived at the hospital I liked it a lot because I was a relatively small kid and I was afraid of ...the needles, I was afraid of the finger prick, and I liked the way you treated me here; I mean, you calmed me down and everything, you know ... the way you looked at diabetes. that helped me. (Ramon)

Table 2 Characteristics of the Youths Transferred from the Hospital Sant Joan de Déu (HSJD) Who Participated in the Discussion Groups and/or Interviews

1st Discussion Group Carried Out by T1D Youths in the HSJD. November 2017							2nd Hospital Clínic February 2019
Name	Year of Birth	Years of T1D Evolution	Activity	CVRF	Type of Treatment	Living with Parents	
Ricardo	1999	8	Studying	No	IP	Yes	DG
Jaume	1999	7	Studying	Tobacco	MID	Yes	DG
Carla	1999	14	Studying	No	MID	No	Interview
Natalia	1999	9	Studying	Tobacco	IP	Yes	Interview
Joaquín	1999	6	Studying	No	MID	Yes	
Valentina	2000	4	Studying	No	MID	Yes	
Montse	1999	15	Studying	Alcohol	MID	Yes	
Discussion Group Performed by T1D youths in the Hospital Clínic 2 Years After transfer. November 2017							
Ramon	1998	7	Studying	No	MID	Yes	DG
Joana	1996	8	Studying	No	MID	Yes	DG
Mario	1996	8	Studying	No	MID	Yes	DG
Roger	1997	3	Studying	Tobacco	MID	Yes	DG

Note: The name of the participants is fictitious to maintain anonymity, although the sex has been maintained.

Abbreviations: T1D, type 1 diabetes; CVRF, cardiovascular risk factors; MID, multiple insulin doses; IP, insulin pump; DG, discussion group.

In the narratives they described the impact of the diagnosis of T1D and the importance the type of information given by the professionals, and mainly the way of expressing it, has in initial and posterior coping. The participants differentiated between the adult and the paediatric hospitals and other centres where they were diagnosed or received previous care.

In the first hospital I remember that I started to feel really scared and also my parents because we didn't know anything, the doctors took a long time to come and tell me what was happening and around three in the morning they took me here, and that was when they told me everything and when I started to calm down a little. (Jaume, pre-transfer interview)

The psychological aspects and the relationship with the healthcare professionals appeared as priority topics of concern because they perceived that the quality of care reduces the impact of T1D on the life of the patient and the family.

For the adolescents interviewed, the meaning of TE is identified as self-control of glycaemia. From this point of view, they were very satisfied with the TE they had received in the paediatric hospital and mainly with the way it was presented, since the visits were not only focused on improving control but also on discussing the results with a process of problem resolution using simple language that facilitates analysis and reflection and increases the perception of confidence and self-efficacy of the adolescents. Another valued aspect was accessibility in that any doubt or problem with visits could be consulted by telephone or email.

I liked it a lot because always, I mean, what they told me was that "diabetes should not force you to stop doing something that you did before" you know? It was like at the time of changing you don't have to adapt to it but it has to adapt to you and you have to keep doing what you did before ... thanks to them I know everything I know, afterwards I have gone on to learn by myself but based on what they gave me here. (Montse)

The principal source of TE that they received was from the hospital, mainly by educational nurses. Although the healthcare professionals advise the families and children to attend summer camps for children with T1D, only 50% of the study participants had gone once or more. The adolescents who went to the summer camps valued the learning in TE,

feeling part of a group, sharing experiences and emotions and the leisure activities. Those who did not wish to go perceived that summer camps of children or adolescents with diabetes labelled them as a differentiated group and refused to spend vacation days focused on the disease.

There in the summer camp you are always remembering that you are a diabetic and I don't like this, I mean, I don't care about being one, I don't pay attention, that's it, but it's, having to thinkand even less go there with everyone, like if someone has a hypo, another a hyperit's like weird. I have enough ... (Montse, pre-transfer interview)

Another source of information that adolescents use is the Internet and, to a lesser extent, social networks. A recurrent topic of consultation is the consumption of alcohol before going out. Other topics of interest are investigation on the cure of T1D and in some cases the follow-up of people with diabetes through social networks.

I was looking for things on alcohol and overall, in the beginning I looked for diabetic people in Instagram which I use a lot to see if there were normal persons who were diabetics, but of course they said "are you diabetic" and I thought "hmmm, I must be fat" excuse the expression but ... I thought that all diabetics were fat and it's not like that. (Montse, pre-transfer interview)

Most adolescents consider that their metabolic control is good, although they recognise that it could improve. All reported having knowledge and abilities of self-control and knew what they had to do to avoid complications but were not always able to do so either due to laziness or low perception of self-efficacy and lack of confidence in the results.

Me, for example, more than being afraid of not doing it, it's confidence, I might not do it right and it might not work or if I inject too often I might end up with hypoglycaemia and ... (Jaume, pre-transfer interview)

The youths place great importance on hypoglycaemia and its physical, emotional, and social repercussions. They associate the risk of hypoglycaemia with the practice of physical exercise, night outs and the consumption of alcohol. Their narratives demonstrate that they have generic basic knowledge on the preventive measures they should take, but some do not know specific methods adapted to their individual needs and the mechanisms of action leading to hypoglycaemias.

I had a severe hypoglycaemic around 3 months ago. So, I thought "and when I have to go home?" its overwhelming because I say "and if something happens to me? And if I have a sugar low and something happens to me? ...I don't know, this really makes me afraid (Nadia, pre-transfer interview)

They also reported not fearing chronic complications. Their narratives show that they have little information on this topic and that, in general, it is not something that worries them at present. Some express the belief that chronic complications are inherent to T2D and are produced in older persons and rarely occur in T1D.

Anyway, type 2 has more complications than type 1 ... In the beginning ... I mean, I don't know anybody who is type 1 who has had any very big complication due to diabetes. (Claudia)

The adolescents stated that the nursing professionals promote their autonomy, although they perceive that the significance that nurses give to autonomy refers to self-control and management of treatment with insulin. They interpret this as a restrictive view of autonomy and personal freedom that they wish to conquer. In this study, all the youths wanted a greater degree of autonomy and rebelled against the control by the family, although they understood the difficulties of the family in delegating the responsibility of diabetes care.

Yeh, sometimes at home my parents get on me, you know? I would like to be more autonomous but because of the insecurity they are more on me and like. they don't let me ... they make you feel like a little kid. (Ricardo, pre-transfer interview)

Most considered that they had achieved adapting to T1D, although this does not temporarily preclude the appearance of feelings of anger, rebellion, and rejection of the disease. The narratives demonstrate that the problems the adolescents have are multifactorial and many are common to those of other friends without diabetes. The difference is that, when there is a problem, T1D reappears and is like a heavy weight that makes everyday problems seem worse.

Diabetes is like a big block, I don't have it constantly ... knowing that you have to drag diabetes along, I don't have how to explain it. Sometimes it's because of my period, sometimes exams, and sometimes if I have had a fight with a friend or boyfriend and I think about it (diabetes). (Claudia)

The adolescents expressed the need for family, social, and professional support as well as specialised psychological support to achieve adaptation to the disease. In the case of children and adolescents, in the beginning, the main source of support is the family, and secondly, the healthcare professionals. When they become adolescents, they consider the support and complicity of their friends and the exchange of experiences with other youths with diabetes as important.

The main difficulties identified by the adolescents are related to the hypoglycaemias, the needle pricks for both the administration of insulin and glycaemia determination, less food intake, technical problems derived from technology (glycaemia sensors, infusion pumps), the perception of a lack of control of the disease, tiredness and demotivation, special situations such as parties or nights out and a certain degree of stigmatization.

For me, the worst ... is injecting myself and ... being aware: "I feel dizzy, I don't know if I'm high or low, go inject myself, now take sugar and it doesn't go up much, you have to wait ... " (Nadia)

The adolescents consider the need to perform a visit or visit time with the physician or the nurses without the presence of the family. Many youths had started to drink alcohol or smoke and saw it as a normal activity that almost all adolescents do at some time. Their narratives indicate that the information they have on these subjects is very variable, but the variability depends on whether the adolescent dares to consult or not in the presence of the family or have had the opportunity to have a lone encounter with the professionals.

Let's see, the thing is that it would also be good if the parents didn't enter because now my parents come so that in this way they can find out about my things, but there should also be consultations alone, you know? ...but also have, like a space alone for the person and the child, you know? Giving 10 minutes with the parents outside and asking a few things would be more sincere than with the parents in front of you. (Montse)

Topic 2. Transfer to the Adult Hospital

The adolescents interpret the transfer to an adult hospital as an inevitable process in which they are no longer children and cannot continue in a paediatric hospital in which everything (structure, care, relationships) is prepared for children. This, however, does not impede them from expressing feelings of missing the healthcare professionals, especially their nurse educators.

For the youths, transfer to the adult hospital symbolically means recognition of their adulthood and the possibility of achieving full autonomy. The idea of undergoing medical and nursing visits without the family is attractive for most adolescents, although there are exceptions.

I think that for me this will be the culmination of the autonomy I have been waiting for for so long ... I think that now my needs may be simply medical because I have been assuming the others. (Joaquin)

The adolescents are satisfied with the information received regarding the transfer process and the new hospital. The perception that there is coordination and contact between the professionals of both centres reassures them, although they perceive the adult hospital as a cold and impersonal place where there are good professionals who focus their care on control of the disease. Only one participant hoped that the relationships were not as cold and distant as the rest of the participants believed.

I know that I will be seen in the Hospital Clinic, I mean, I imagine it as a hospital that is very ... very cold. (Joaquin)

The concerns with respect to the transfer to the adult hospital were mainly focused on resistance to change, living in a world of older patients and the level of participation in decision making. The adolescents perceived that their educational needs were now covered, and they could learn autonomously through their experience and thus, the care should be focused on therapeutic efficacy.

Maybe we are going to the Hospital Clinic, and they will explain the idea of using an artificial pancreas. I mean, like the learning door is never closed because maybe new things will appear in the future, but ... the process of learning to be a diabetic and self-control is pretty well achieved, we've been diabetics for some time. (Carla)

Transfer to the adult hospital makes them nervous about the first visit, but the adolescents are confident that they will adapt to the new hospital. They trust the experience of the professionals, and while they think that they will lose the affective relationship that they had with the professionals of the paediatric hospital, they interpret this as normal in adult relationships and this will facilitate their autonomy.

I think that in the beginning you will be very small within the hospital, don't you think?.because you know this place, you know the people, you know the faces of the people in reception, right?. you get to know most of the doctors, but there no, when you get there, you will fell little until you start to feel confident about the place, the doctors, the people, because in the end it's like everything, adapt and everything will go fine, well, I think it will go well and (Carla)

Although they were satisfied with the information received about the transfer process, the adolescents suggested that they should have more information about the adult hospital and make the first consultation together with the professionals of both hospitals or be accompanied by a healthcare professional of the paediatric hospital during the first visit in the adult hospital.

Topic 3. Experience of Adolescents with T1D Who Transferred to the Adult Hospital 1 or 2 Years Previously and Followed the Transfer Program During the First Year of the Transfer

The youths evaluated the process of transfer to the adult hospital positively. They believe that in the paediatric hospital they are prepared to be able to assume full autonomy in the adult hospital; that they received correct information regarding the transfer process, of the new hospital and of the professionals who will attend them in the future. They believe that the paediatric hospital facilitated the administrative and healthcare formalities and continue to perceive that there is good coordination between the two centres.

The truth is that the transfer went really well because nurses from the Clinic came to Sant Joan de Déu and gave a talk and it was good because, you know, when they say "You're going to the Clinic", you say: "Goodness, the Clinic and Sant Joan de Déu have nothing to do with each other" ... that was what I was afraid of, that it was an adult hospital, but the truth is that it went pretty well, because they gave the talk, I had a visit with the nurse and the doctor and afterwards we came here for the course, and the truth is that it went really well. (Natalia)

The adolescents interpret the transfer to the adult hospital as a recognition of their adulthood and achievement of full autonomy. Most of the youths feel that this has been accomplished, and now they feel my autonomous and free from parental control.

I think that the experience has been good. First, because going to a hospital for adults is like you go as you like, at your own speed, without your parents ... I mean, it's like another step towards being an adult, only without anybody, without depending on anybody and in my case, I felt really comfortable and with the nurse and the doctor I have ... well, also really good. (Carla)

In one case the reverse was perceived. The fact of being treated as an adult and being given greater autonomy by the family and the professionals, produced a low perception of self-efficacy and awareness of not feeling able to self-manage the treatment and control that the disease requires. In another case, the grade of autonomy in the hospital was considered positive, but also excessive and the adolescent felt that it should be done more progressively. Other youths expressed the difficulties of the family to give up the management of the treatment and control of T1D and allow the youths to go to the medical and nursing visits alone.

Too much, I mean, too much freedom, I mean a middle point, that the change should be so brusque from cold to hot in no time ... they let you be too free and sometimes that's not good, I don't know. (Roger)

With respect to the adaptation process after transfer to the adult hospital, some youths reported having long periods of concern and psychological stress due to the disease or by the demands of treatment and controls. However, most stated now having had good adaptation to the disease and that they do similar activities to those of their friends without diabetes, although occasional changes in their mood persist - mainly feelings of sadness. The differences with the results of the interview prior to transfer to the adult hospital is that now they are more aware of the problems that trigger these situations and are able to apply more coping strategies. In this second interview, no participant mentioned the need for a psychologist. Another difference compared to the first interview is that the youths were more sincere when expressing the relationship with their behaviour of self-care and their glycaemic control results. The narratives of the youths transferred to the adult hospital showed more expressions of resilience, but two youths continued to feel limited by diabetes and stigmatized, and they avoided injecting insulin or performing controls in public places, confirming their condition as a person with diabetes to people outside the family circle or close friends or in determined contexts and they disliked being asked questions about the disease or the treatment.

I have this fixation that is: I can't let anybody see me injecting myself, so whenever I have to do a test or prick or inject myself, I have to go somewhere else, this is the only problem like that, that I have (Roger, 2 years after transfer)

Another difference after transfer to the adult hospital is that most of the youths were less interested in internet and social networks for subjects related to diabetes than before the transfer. The greatest interest in using internet and social networks to search for subjects related to diabetes occurs at around the age of 16–17 years. In contrast to what the adolescents did before transfer, those who now continue to frequently use internet search for accredited webs or sources of scientific data, aspects which are worked on during the group course of the programme. The most recurrent search subject after transfer to the adult hospital is investigation in diabetes, and contrary to the initial group of adolescents, these youths tend to clarify doubts or news that they hear with healthcare professionals. This could be interpreted as the fact of being more mature persons, who are more confident in themselves, and thus, have more confidence and capacity to express their doubts to the team of professionals.

The narratives of the adolescents who were to be transferred to the adult hospital showed that many youths had begun to drink alcohol and smoke and had little knowledge about alcohol intake and its effects. They justified this by saying that they were afraid to ask the professionals about this because of the presence of the family. In this second interview we again asked about smoking and alcohol consumption and about the perception of risk youths with T1D have. From their responses it can be seen that approximately half smoke sometimes when they go out, and in some cases, between 3–4 cigarettes a day and have no perception of the risk of smoking. The reason for smoking is to not feel different from their friends.

Yeh, I smoke. Well, how much do I smoke, well ... a rolling packet can last me a month, but you know, now that I'm in high school and such I might smoke 3 cigarettes a day, on the weekend I smoke another, but during the week 3 cigarettes a day. (Natalia)

They described consuming alcohol when at parties and, sometimes, in quantities of risk. The youths recognised the risk of hypoglycaemia, but many continued having insufficient knowledge of the mechanisms that originate hypoglycemia, the recommended consumption, and the preventive measures of hypoglycaemia, and therefore, on occasions, they continued to seek information on this subject on the Internet. Some youths had reduced their alcohol intake with respect to the previous interview by feeling more responsible, having to drive, or having experienced a severe hypoglycaemia episode.

Alcohol ... yeah When I was younger I was more likely to go and do a street party and now that we're older, we have a car and so we don't get drunk like before, but before it was ... I was more afraid because I got drunk and didn't know anything about diabetes the way I was because I wasn't conscious about being aware of the diabetes, but I was always, ... if there were four of us, one controlled and the others got drunk and now it's better because I don't get drunk like before. I have, I don't know, three rum and Cokes or something like that, more or less, two rum and Cokes and one beer, one beer with supper and three rum and Cokes, but not to the extent of being drunk, vomiting, that's in the past. (Carla)

All the youths described that the fears or possible anxiety that they felt about the transfer to the adult hospital immediately disappeared, and within a short time they created the same connection with the adult hospital that they had with the paediatric hospital. They perceived that, in most cases, this also happened with their families. Although they described differences in the personal treatment with the healthcare professionals from the adult hospital, they interpreted it as something that is normal among adults, and all except one youth preferred the type of relationship of the adult hospital given their age and current situation. Some used a numerical qualification for evaluating the care received in the adult hospital and the values ranged between 9 and 10, except for one who gave a 7.

I think that at 18 in Sant Joan de Déu you feel too old, and also because of the setting with all the colours and like that (everybody laughs) and very controlled and like that, and it's like you want them to give you a little more autonomy, but you get here and you feel smaller, like "ok, it was the change I wanted, but ..." Yeah, we're going little by little and not. the idea "from now on I am the one who has to control this", but the change is also positive. (Ramon)

The youths stated that, in the first year, the treatment that they followed and the regimen of visits every three months were similar to what they did in the paediatric hospital, although afterwards they went on to having two visits annually. What changed was the type of relationship with the professionals and the grade of autonomy demanded.

I think that the way we are treated is very different, they treat you with more ... like with much more autonomy ... and, for example, the consultations with the nurse, like they really surprised me because they gave me the controls and said: "what's going on here? You tell me, right?" and you know, the changing the chip and I think that I have changed quite a lot these last years, the way I look at it, but for the good, right? (Mario)

In their narratives, the youths expressed the high value they had of both the physicians and nursing professionals, and the difficulty of perceiving differences between the visits made by the endocrinologists and those with the specialised diabetes nurses. They expressed feeling closer to the nursing professionals to consult doubts or talk about personal subjects.

The care here is really good, with the doctors and with the nurses. You know, I am closer to the nurse ... If I have a consultation, well I don't know, for some personal problem, I would do it with the nurse. (Natalia)

Despite the positive evaluation that they gave in their narratives regarding the care received, certain aspects of depersonalization were observed.

I knew all the names of the doctors and nurses of the paediatric hospital, but I saw them more often and the names become known, but here, you know, you might not see them in three months ... uff, I don't know, the next time I see them I will remember their name. (Ramon)

They also expressed some criticisms related to administrative aspects and discontinuity of the care of the endocrinologist, although they recognised that they had access to professionals whenever a problem arose or when they needed to consult about something.

Well, I think that when you come here everything is really planned out in you know: "visit every three months, every six, I don't know what" you know, you just come in and they already have all the visits for the year planned out, and yeah, they could adapt a little more to the person, but apart from this ... (Ramon)

In this study, the narratives of the adolescents who were to be transferred to the adult hospital described that they all had the perception of not needing more TE for having acquired the competences for self-care and self-management of diabetes in the paediatric hospital. The adult hospital impacts the TE at an individual level in the follow-up visits and provides a specific group TE course of one day in length with a methodology of resolution of practical cases related to self-control and the specific needs of the youths (TECP). The narratives of the youths show that all were satisfied with the care and education received, although there were discrepancies in the evaluation of the results of the group course.

For most, the content of the course was similar to the educational content of the paediatric hospital or to that received in the summer camps for children with diabetes and did not provide new knowledge. For some youths, this course was unnecessary, although in general, the evaluation was positive because it was useful for remembering concepts.

It was a little bit of a pain because you spend all day talking about one thing that you already know, I think that what you need to know about the control of diabetes was already taught to me, but in the end it helped me a little to, you know, remember things that I didn't remember, and well, well, the truth is that I evaluated it positively. (Ramon)

Some youths believed that the methodology, the duration of the course and especially the content should be modified. They proposed working from the specific experiences of the participants instead of predefined cases, because they felt that in this way this would adapt better to their needs and increase interest. The most valued aspect was the group interaction since the TE received in the paediatric hospital was fundamentally individual.

I think it was really good because I realised that she or he might have the problems that I have, you know? I'm not a weirdo who is the only one who has this, who has drops in sugar, I saw that several persons were going through what I was going through, that they had periods of depression because of diabetes and I felt the same and said: "wow, I'm not the only person going through this" and I was happy about that, I left feeling really happy. (Natalia)

What they valued best were the educational interventions made in the individual visits since the discussion and reflection about their own results facilitates learning and change.

There the schedules are much more fixed, they measure a lot: "this is what you have to eat, this is what you have to inject" and they don't give you the opportunity to play with: "I inject less, I eat less". And what I think they do really well here is that you look at it yourself, you do the changes in your schedules yourself and they don't give you everything, because in that way you know, in other words, what happens to me, I have two weeks of stress, a thousand things to do, so I look back, I look at the controls and I know how to change my schedules so that this changes; before I didn't, if I had a visit at three months, well up to three months I was like this and that is positive. (Joana)

In the narratives of the adolescents some educational needs that persist among the youths after the transfer to the adult hospital were detected. These were mainly related to chronic complications, pregnancy, and risk factors such as smoking and alcohol consumption.

I know the long-term complications, but I don't understand the why or the how they come about ... I haven't asked either, you know? I'm afraid to ask, but ... (Joan)

I smoke when I go to a party, well, and if I'm in a bar having a beer too, but I don't think that this is a risk for diabetes. I don't consider myself a smoker. (Joaquin)

The transferred youths made some suggestions for improving the care and TE in the adult hospital:

- Adapt the content of the group course. Work from the specific experiences of the participants instead of predefined cases.
- Adapt the administrative formalities and examinations (visits, diagnostic tests) to the needs of the persons with diabetes. Agree on day and time.
- Promote interaction among peers through activities or WhatsApp groups.
- At the beginning of the transfer, demand autonomy and responsibility progressively, adapting to individual needs and preferences.
- Provide information on the advances in investigation in diabetes.

Tables 3 and 4 summarise the experiences of the youths prior to and after transfer.

Table 5 summarises the strong and weak points and proposals of improvement according to the youths before and after transfer.

Table 3 Experience of the Youths Prior to Transfer

Living with diabetes	Negative event, especially during adolescence. Good adaptation, despite rage crises. Stigmatization/rejection to techniques being seen. Positive: better control of body, more mature.
Social aspects	Perception that their friends protect and support them. Summer camps, aspects ± Focused on the disease.
Quality of healthcare and therapeutic education	Positive evaluation despite claims for psychological support and more information on complications and investigation.
Transfer to adult hospital	Generates anxiety and missing paediatric centre but accept the change. False impression of reality. Educational needs covered. Want therapeutic efficacy.
Proposals for improvement	Make first visit with professionals from both centres. Visits with professionals without the presence of the family in order to discuss personal aspects.

Table 4 Experience of Youths with T1D Post Transfer

Coordination	Positive evaluation. Good coordination between centres.
Adult age and autonomy	More autonomous and free from parental control despite believing that it is too quick.
Visits, types and frequency	Similar to the paediatric hospital during the first year. Evaluate the discussion and reflection on their results well.
Group course	Believe reinforcement not necessary. Changes in methodology: less discussion of cases and more discussion of own experiences.
Social networks	Consume less. Clarify concepts with professional.
Proposals for improvement	Adapt group course content Agree on day and hour of consultation. Promote interaction with peers: Activities, WhatsApp, ...

Discussion

The present study explored the experiences of youths with T1D prior to and after the transfer of these youths from a paediatric to an adult hospital.

The aspects of healthcare best evaluated by the adolescents were related to the human quality of the professionals. As in other studies, trust was considered the central nucleus of the professional-patient relationship.^{18,19}

Trust in the professionals does not only refer to their professional competence but also to the capacity of creating scenarios of comprehension and acceptance. The creation of a context and setting of closeness and acceptance is a key variable in the development of trust between the professional and patient.²⁰

The problems of adaptation and episodes of psychological distress coincide with those described in other studies which have reported that adolescents with T1D have 2- to 3-fold more psychological type problems than their friends without diabetes,^{21,22} and some youths interpret the demand for control as T1D as a loss of control of their lives.^{22,23}

In the DAWN2 study psychological distress was recognised by 45% of the participants.²⁴ The American Society of Diabetes considers that suboptimal glycaemic management should not automatically be attributed to rebellion of the adolescent of a lack of preoccupation for health, and that it is necessary to perform an evaluation of psychosocial aspects and the therapeutic regimen and adapt it to the needs of the person with diabetes to facilitate self-management.²⁵

Table 5 Strong and Weak Points and Proposals for Programme Improvement. Youths with T1D Prior to and Following Transfer

Youths with T1D Prior to Transfer		
Strong Points	Weak Points	Proposals for Improvement
<ul style="list-style-type: none"> - Logical and irreversible. - Way to obtain complete autonomy. - Relationship of the adults with the professionals 	<ul style="list-style-type: none"> - Generates anxiety and missing of paediatric professionals. - False idea of cold hospital that does not focus attention on the person. - Perception of mass consultations with older people. 	<ul style="list-style-type: none"> - Visit without the presence of the family to consult emotional and personal aspects. - Be accompanied by the paediatric team in the first visit to the adult hospital.
Youth with T1D Following Transfer		
Strong Points	Weak Points	Proposals for Improvement
<ul style="list-style-type: none"> - Good coordination - More independent of parental control. - High evaluation of the professionals and reflection of results. - Interaction of the group in the course. Transfers. - Initial fears disappear. - Link with the adult professionals same as with the paediatric professionals. 	<ul style="list-style-type: none"> - Process too quick. - Barrier by families for allowing youths to self-manage treatment. - False perception of annual visits. - Difficulty to differentiate medical or nursing visits and remember names. - Long group course. 	<ul style="list-style-type: none"> - Able to choose day and time of visits. - Promote interaction with peers: WhatsApp. - Individualised autonomy and responsibility. - More information about pregnancy, tobacco, alcohol, chronic complications, and investigation in T1D.

The results of this study also coincide with others that have demonstrated that in children the main source of support is the family and the healthcare professionals, but when they become adolescents, support and acceptance by their peers²⁷, friends, and fellow students, is necessary to favour adaptation.^{7,33}

In a recent qualitative study, youths with chronic diseases demonstrated that exchange with peers who had lived similar experiences helped them to learn to live with the disease, for either managing the self-management tasks or to face the psychosocial dimensions of the disease, because they share advice and tricks and speak a common language.^{28,33} Other studies have described the importance of incorporating other youths who had been transferred years previously and describe their experiences in the programmes of transition to an adult hospital.^{29,30}

It is difficult to maintain good metabolic control during adolescence.^{28,31,32} Other studies have described the difficulties reported by adolescents to comprehend the mechanisms regulating the complications and the effects of treatment or preventive measures²⁶ and how to apply generic knowledge to the specific individual needs.^{26,33} The perception of self-efficacy and self-esteem are the main determinants for performing self-care behaviours,^{28,34,35} while the main negative determinants are stigmatization and low perception of self-efficacy to maintain perseverance in self-care.³⁶

The results related to the fear adolescents have of hypoglycaemia and the emotional and social repercussions that it generates coincide with those of other studies that have described that some adolescents prefer to eat more and maintain their blood glucose levels above the recommended levels than to suffer a hypoglycaemia episode, or they overtreat when they become aware of the first symptoms.^{26,37,38}

Hypoglycaemia is the most common and feared complication and can condition the perception of severity and vulnerability, life with the disease and the perception of self-esteem and self-efficacy.^{37,39,40} Some studies have reported the fear adolescents feel towards chronic complications, while others coincide with the results of this study, in which the youths reported their lack of worry about disease progression and the appearance of complications in the long term.⁴¹

Similar to our results, other studies have described that adolescents consider the consumption of tobacco and alcohol as normal and have the need to not feel different from their peers without diabetes.^{41,42} Some do not know the mechanisms by which alcohol intake can reduce the levels of glycaemia²⁸ and tend to seek information about alcohol consumption and the prevention of hypoglycaemia from the Internet because they dare not consult the healthcare professionals.^{32,33,36,43}

Despite the recommendations of the healthcare professionals, only 50% of the participants had attended the summer camps for children with diabetes once or more. Those who did not wish to attend the camps considered that these camps for children or adolescents with diabetes labelled them as a differentiated group and refused to spend some vacation days focused on the disease. This can be interpreted as a rejection of the disease but also as an act of defence against self-stigmatization. The literature available suggests that it is unlikely that one or more summer camps will contribute to improving metabolic control,⁴⁴ but the results of this study and a recent qualitative study²⁸ demonstrate the satisfaction of the children and adolescents who went to summer camp, their perception of learning within an entertaining setting, the benefits of feeling part of a group and the opportunity of making friends and sharing experiences during the camps and afterwards.

The perception of autonomy by the adolescents and some youths oscillated between their desire for freedom and the need the family has to continue being responsible for the care. As stated by Bateman,⁴⁵ an adolescent with T1D has an additional fight in their struggle to achieve normal development of their autonomy similar to the rest of adolescents without the disease, since they must deal with the needs of self-care and control demanded by the disease.⁴⁶ Some studies have shown that to achieve greater autonomy the perception of self-efficacy and the support of other persons, especially stimulation by the parents, acceptance by their peers and the support of the healthcare team are necessary²⁶ and that peer groups should foster the abilities of problem resolution, decision making and trust in self-management of the disease.²⁶

Adolescents with T1D interpret transfer to the adult hospital as an inevitable and necessary process and as “a change among other changes”, although they go through it with deference and miss the paediatric professionals. Other studies report that the adolescents do not present negative emotions towards the transfer to the adult hospital,⁴⁷ although a minority are worried about the process⁴⁸ and think that they will miss their healthcare team.⁴⁸

Following transfer more expressions of resilience appeared, indicating that they conceive and deal with life in a more optimistic, enthusiastic, and energetic way and have high levels of positive emotionality. Nonetheless, similar to the results of previous studies, some youths felt limited by diabetes and having to maintain some stigmatizing situations such as injecting insulin or performing controls in public places.^{7,49,50}

The problems that the youths interviewed had before and after transferring to the adult hospital are multifactorial and many are common to other adolescents without diabetes. Di Battista⁵¹ reported that adolescents feel different from their peers without diabetes, but also normal since their problems, preoccupations, joys, and sadness are similar.

The behaviour towards alcohol varied before and after the transfer, with some youths having reduced the consumption for feeling more responsible, having to drive, or having experienced a severe hypoglycaemia. With regard to tobacco, they continued to have no perception of risk. These observations have also been described by other studies.^{7,28}

The results of a recent systematic review showed an association between transition of healthcare and a reduction in attendance to clinical visits and also some preliminary evidence of a positive impact of the structured transition programmes on attendance to clinical visits. In the present study, the results of the evaluation of the transfer programme showed that attendance to clinical visits did not diminish, especially in the initial visit and that the youths transferred one or two years previously perceived a continuity in care and TE. The results of a previous prospective, longitudinal, pre-test and post-test of a single cohort, showed that the TECP improved the metabolic control and self-control of treatment without deteriorating the quality of life of the youths.^{9,11}

Other studies have shown that the factors that facilitate care transition are receiving previous information of the transfer,⁴⁷ the information or knowledge of the professionals of the adult hospital⁵⁰ and the continuity and adherence to care,^{49,52} all of which were provided in the transfer programme evaluated.

The standards of quality of the American Diabetes Association⁵³ state that there are four critical times at which it is necessary for professionals to evaluate the educational needs and act accordingly: at the time of diagnosis, annually to evaluate the results and emotional needs, when complications or factors that influence self-control arise and transitions in care. The transfer of youths with T1D to adult centres continues to be a healthcare challenge for many professionals. We hope that collaborative work and evaluation of transfer programmes will benefit this collective, which is representative of the future of our society.

Study Limitations

The results obtained correspond to perceptions of adolescents and youths with T1D who were transferred from a paediatric to an adult hospital in Catalunya (Spain), thereby making extrapolation to different contexts difficult. Nonetheless, the results obtained transcend what is strictly particular of the cases studied and allows reflecting on the experiences of adolescents with T1D regarding their transfer to an adult hospital, the care and TE given in our context and also allows qualitative evaluation of the transfer programme undertaken between the paediatric and the adult hospital. Some changes in the attitudes and behaviours of the transferred youths could be influenced by the maturity acquired with age and the fact of having followed a structured programme of care and TE during the first year post-transfer, which has also demonstrated benefits at a clinical level.^{10–12}

It would have been interesting to include the healthcare professionals in the study to evaluate their perceptions and evaluation of the transfer programme.

Conclusions

The expectations of youths prior to transfer are realistic and they consider that it is a logical and irreversible process, although they experience it with deference.

The programme of transfer implemented between the paediatric and the adult hospital is effective, reasserting the idea that a structured programme has a positive impact on the transition process.

After the transfer the youths reported that the fears and nervousness prior to the transfer disappeared within a short time, and they created the same connection with the adult hospital as that which they had had in the paediatric hospital, although they described differences in the treatment of the professionals which they interpreted as normal among adult persons.

The transition to the adult hospital did not induce a reduction in attendance to clinical visits as suggested by some studies, it did not worsen metabolic control, it improved the grade of autonomy and adaptation, and the grade of satisfaction was very high, in agreement with data obtained over a decade of experience.¹²

The qualitative focus allowed evaluation of the internal logic of the youths regarding the transfer process to an adult hospital as well as their behaviour towards diabetes and health in general.

All the adolescents participating in the study were very satisfied with the care they received from the healthcare professionals, physicians, and nurses of both centres. They interpreted the transfer to an adult hospital as an inevitable process and evaluated the transfer process to the adult hospital positively.

It would be important to introduce in the program the changes proposed by the patients themselves and assess how they influence in future evaluations.

Analysis of the experience of a patient complementary to the evaluation of clinical care and educational and quality of life of the TECP provides understanding of the perspectives of youths regarding the complexity of living with a chronic disease since childhood, the factors favouring quality care and TE, the complexity of transfer to an adult hospital, determination of the strong and weak points and the establishment of strategies to improve the programme.

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