UNIL | Université de Lausanne
Faculté de biologie
et de médecine

Département médico-chirurgical
de pédiatrie - DMCP
Hôpital de l'Enfance de Lausanne
Ch. Montétan 16
CH-1004 Lausanne

Mémoire de Maîtrise en médecine No 2601

Impact of a novel transition program on patient satisfaction and follow up of young adults with type 1 diabetes mellitus

Etudiante
Alessia Regusci

Tuteur
Prof. Nelly Pitteloud
Service d’Endocrinologie, Diabétologie et Métabolisme
CHUV

Co-tuteur
Dr. Michael Hauschild
DMCP - HEL

Expert
Dr. Mario Gehri
DMCP - HEL

Lausanne, 15.01.2016

UNIL | Université de Lausanne
Faculté de biologie
et de médecine

Département médico-chirurgical
de pédiatrie - DMCP
Hôpital de l'Enfance de Lausanne
Ch. Montétan 16
CH-1004 Lausanne

Impact of a novel transition program on patient satisfaction and follow up of young adults with type 1 diabetes mellitus

Type 1 diabetes mellitus is a chronic disease with increasing prevalence (1) The incidence of diabetes mellitus type 1 varies among regions and is estimated to be between 14-25/100000 inhabitants in middle Europe(2) (3) and > 40 /100000 inhabitants in northern European countries (4). Due to an auto-immune-mediated destruction of pancreatic beta cells, patients are required to regular insulin substitution. Type 1 diabetes mellitus is associated to short (hypo-and hyperglycaemia) and long term (retinopathy, nephropathy, peripheral and autonomic neuropathy) complications. Long term complications are clearly associated to metabolic stability of diabetes (5). Metabolic stability itself depends on insulin treatment strategy, individual insulin needs, general health status, and treatment adherence. Studies show a specially poor prognosis in young adults with type 1 diabetes mellitus (6) (7) (8)

Chronic disease in adolescence

Adolescence is defined in the medical literature as the age group between 10 and 19 years (9). It is a very sensitive period of life marked by rapid somatic and psychological transformations that might result in some fragility and insecurity feelings.

In patients with type 1 diabetes, physical changes related to puberty and psychosocial transformations typical of adolescence can have a major impact in disease control (10). For example, increasing activity of the gonadal axis and increased growth hormone secretion during puberty cause insulin resistance needing adjustment in insulin therapy (11). At the same time, social challenges, the search of independence, the role of self-image and the trend to take some risk seem to have a major impact in the quality of therapeutic compliance (12). Young patients with a chronic disorder not only have to deal with adolescence changes, but they have to face an additional challenge : gain of autonomy in the management of their chronic disease.

Transition from pediatric to adult care

In 1993 Blum and al. defined the transition as “ the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (13). This transition includes health management (for type 1 diabetes patients: self-control, insulin and nutrition management), psychosocial aspects, and the complex process of gain of responsibility, gaining complete autonomy of treatment and health care(14). This process includes to accept the disease as an integral part of life, to find the courage to share their own feelings about disease and to be able to ask for support from parents, friends and medical team during difficult moments. In most cases it takes place between 14-25 years (15). Even if the biological age is a good indicator, the most important element in the timing of transition,the maturation, and the patient’s capacity to understand his own disease. A recent study underlined that the most criticized aspect of some transition program was the fixed age at 18 years by one national legislation (16).

The severity of complications which can occur with uncontrolled diabetes must encourage us to act to set up a structured patient care (17)., Therefore, during the last fifteen years, impact of structured transition in the management of diabetes mellitus type 1 has been extensively studied (18) (19).

Transition models in the literature

Different approaches of structured transition models have been used (20): 1) models based on an intra-hospital transition with a strict collaboration between pediatric team care and the adult one 2) transition models including transition to a private practice or another hospital.

In 2007 Holmes-Walker and al. evaluated , a program including evening consultations and telephonic support by a specialist coordinator which aim to improve compliance. This study showed a moderate decrease of HbA1c and of acido-ketosis admissions (21).

In 2008 Van Wallenghem and al. evaluated a transition program, called "The Maestro Project" used in Manitoba, Canada. This models is based on an administrative coordinator consisting in telephonic and email support system for young patients aged between 18 and 30 years with diabetes mellitus type 1 also including newsletter, webside and group support events. The study showed that this models improved the medical follow-up, but had no impact on court term metabolic results (22).

In 2009 Cadario and al. evaluated a structured intra-hospital transition program. Compared to control group, patients benefiting from the structure transition intervention demonstrate an improvement in consult regularity, in satisfaction and decrease of HbA1c after one years of program's start (23).

In 2010 Mulvaney and al. evaluated a transition program named "YourWay", an internet-based self-management intervention which aims to improve adolescent problem-solving, coping with diabetes and glycemic control. The webside content included approach to problem solving, adolescent typical questions, social forum and comparison and motivational email. This study affirmed that the self-management adherence improved in the interventional group compared with the control group (24).

In 2011 Prince and al. evaluated a transition model named "Transition Pathway" which was implemented in 2006 and consisted in three-four sessions during their final year in pediatrics to plan their move into an adult service and ended with their first session in the adult diabetes service. This study underlined the importance given by young patients to the quality of their interaction with the medical team and the major impact that a flexible approach and an adolescent needs focused management could have in the transition process (25).

In 2013 Garvey and al. analyzed barriers to establishment of adult diabetes care. Young post-transition adults were questioned about specific barriers to the transition, like *lack of adult provider name, difficulty getting appointment* or *competing like priorities*. 4 out of 5 patients reported at least one specific barrier to successful transition. Garvey and al.'s study demonstrated that the more important the number of barriers is, the longer the gap between last pediatric diabetes visit and first adult visit is (26).

In 2014 Steinbeck and al, evaluated the role of a coordinator providing comprehensive transition program (CTP) which consist in standardized telephone support at week 1 and 3-6-12 months after de transition from pediatric to adult care. Because of the low number of responders, it hadn't been possible for them to show a significant difference in clinical outcome between patients who benefited by CTP and those who didn't (27)

A comprehensive review of different transition programs has been published recently (28).

To our knowledge, the most recent structured transition program (Lets Empower and Prepare (LEAP) published in 2015 included 51 participants and 30 controls. The participants received tailored diabetes education, case management and access to a young adult diabetes clinic and transition website. The transition program allowed to improve glycemic control, hypoglycemia, and psychosocial well-being (29).

<u>Research Design and Methods</u>

The Lausanne Diabetes Transition Project (LDTP) and the role of the Transition Nurse

A study of an historical cohort followed in our tertiary care center revealed a high dissatisfaction of young adults with the unstructured transition process. Most of the young adult patient did not receive adequate planning and coordination in the transition process, and reported decreased medical follow-up , with subsequent risk of discontinuity in the medical follow (30).

A structured transition program, the Lausanne Diabetes Transition Project (LDTP), was therefore developed in collaboration with pediatric and adult dialetologist, specialized nurses, and the public health service, building on three phases:

1) The preparation phase: preparation of transition starts around age 14, with adapted diabetes training focusing on treatment autonomy including management of nutrition, sport, insulin treatment, treatment surveillance, adaptation of treatment in special conditions, and focus group. The individually tailored consultations are progressively done without the presence of the parents. At around 16 years of age the introduction of a specialized outpatient transition nurse (TN) with experience managing T1D is planned. The TN transition nurse encounters the patients and their families at the diabetes center or in the family home, the following appointments take place following the adolescent's preferences. All patients are given a "transition passport" ensuring that key health and diabetes education issues relevant for adolescents are addressed. Furthermore, practical issues of diabetes treatment and individual need (piercing, tattoos, sexuality, alcohol) are individually addressed by the TN, and further discussed during the transition process with the health care team if needed.

2) The actual transfer phase: The TN accompanies the patient through the transition process, guiding the patient and the family, ensuring timely communication and continuity of care. The TN is present during the first visit to the adult care-givers. The transition pass, in addition to the medical transfer reports, ensures the communication of key health related issues.

3) The engagement phase: The TN provides ongoing comprehensive case management and stays in close contact with the young adult patients on an outpatient basis, in close collaboration with the adult care givers. Partners and friends of the patient are welcomed during these encounters. During

this engagement phase, patients have the opportunity to gain news competences, to share insecurity feelings and to develop autonomy. There isn't any strict rule about parents' presence during consultations. Parental' presence varies from one family to another, according to the parents' concern and the relationship between the patient and his parents. The TN integrates the health care models of Jean Watson « Human caring » and Cox, providing affective support, decisional control, information about health issues, integrating technical and professional competences (31).

Transition Passport

Patients receive the "transition passport" at their first meeting with the TN. This passport allows for a better communication between health partners. This notebook also promotes empowerment of the young patients. The *Transition Passport* goes beyond the simply collection of laboratory data, like HbA1c and cholesterol value, and therapy data, like the type of therapy, units of insulin and number of hypoglycemia. A large part of the passport is dedicated to therapeutic education; there is a list of specific goals which will be reviewed during following meetings with the nurse. Among the objectives there is the capacity to recognize hyper/hypoglycemic signs, the management of nutrition, the self-confidence and well-being evaluation, the autonomy development, the role of physical activity, questions about sexual sphere, the risk of smoke and others teenager risk taking.

DATA collection

1) Control group

In a preliminary study, we analyzed the transition experience of young diabetic patients who transitioned from pediatric to adult care before the development of LDTP. The sample of this preliminary study included patients with type 1 diabetes mellitus who had been followed-up at the Pediatric Diabetes Unit of the University Hospital between 1990 and 2010 (n = 101). Medical records were revised, including number of medical visits, HbA1c, incidence of secondary health problems.).

For the evaluation of their transition experience a validated questionnaire has been used, addressing general health condition, the impact of their disease in everyday life, satisfaction with the preparation and experience of transition phase, and the role of the transition nurse. (32). 39 patients (38%) responded to our questionnaire.

2) Intervention group

All patients (N= 69) eligible for transition were enrolled in the structured program. Participants were transferred either to the adult university diabetes center or to an adult diabetologists practice. Pediatric medical records were revised, including number of medical visits, HbA1c, incidence of secondary health problems . All patients were asked to answer to the same study questionnaire utilized for the control group. In addition, the patients were requested to answer to the WHOQOL-BREF quality of life questionnaire, standardized and validated by the world health organization (33)

The questionnaires were been sent by post or e-mail with an explanatory letter. Patients were contacted in order to motivate them to fill up the questionnaires. 30 of the 69 patients in the intervention group (43.5%) answered to the study questionnaires. Out of the questionnaires received, 86.6% were complete and 13.3% incomplete.

HbA1c were measured using the DCA 200 analyzer (Bayer Health Care) until 2011, and with the Afinion AS100 Axis-Shield since 2011. In the literature we find that Afinion AS100 Axis-Shield and DCA 200 analyzer have comparable outcome and that they are analytical quality comparable to hospital laboratory instruments (34). Graphs statistical analyses have been managed using Graph Pad Prisme program.

3) Topics addressed at the structured transition questionnaire

Prospective data acquisition thanks the validated transition questionnaire (32) : health care utilization including number of medical visits, history of the chronic disease, acute complications (hypoglycemia, acidocetosis), number of hospitalizations, HbA1c, incidence of secondary health problems, evaluation of quality of life, impact of the chronic condition on work / school (absenteeism), psychological outcome, survey of transition, impact and satisfaction of NT.

Data acquisition thanks the WOQOOL-BREF questionnaire: the WOOQOL-BREF questionnaire investigates four domains of patient’s life: 1) physical health 2) psychological health 3) social relationships and 4) environment. Each question receives a point ranging from 1 to 5 and for each domain a final score could be calculated. The higher the score is, the better the quality of life is.

4) Adult care giver questionnaire

All the adult diabetes care providers were received an explanation letter with copy of research protocol of the study and the informed consent of the patient. They were asked to answer to a simple questionnaire evaluating the collaboration with the TN.

The research protocol was accepted from the Ethical Commission of the University of Lausanne.
The implementation of the LDTP and the transition nurse was supported by the public health service through the “Programme Cantonal Diabete” of the Canton Vaud, Switzerland.

Results

Baseline results:

As showed in *table 1. and 2.*, the two groups of patients present similar characteristic : difference of age at study questionnaire, of age at transition, of diabetes duration and of HbA1c are no significant.

Among patients who answered, 23.3% suffered from a comorbidity : mainly thyroiditis, coeliakie, thalassemia and epilepsy. 60% of the responders accepted that we contact their adult diabetes care provider to obtain some additional clinical and para-clinical information (last point of the questionnaire). Among the adult diabetes care providers contacted, three didn't answered and two weren't reachable.

Transition experience questionnaire:

This questionnaire gives us a larger vision of the transition phase, the preparation of pre-transition, the follow-up post-transition and the impact of diabetes mellitus on patients' life.

The most relevant impact of this project is on the support feeling during the transition (*Graph 1*). Patients who lived the transition from pediatric care to adult care before the development of the LDTP denoted a lack of support during that delicate phase, 34.2% of them affirm to not to be supported at all and only 21.05 % of them felt to be very well accompanied. On the contrary, 53.6% of the patients who lived this step under the Transition Project affirm to be very well supported and the proportion of them who felt not support at all fell to 7.1%.

The second interesting point concern age at transition. Even if in both groups the majority of patient were transferred at an median age of 18 years, after the development of the LDTP the age of transition has been slightly pushed up. On the whole, patients who taken part on LDTP faced the transition step few years later: no one pass to the adult care before 16 years, only 7.4 % at 16 years and 29.6% of them made the step at 19 years or more.
89.74% of historical group's patients and 92.9% of transition group's patients estimate that the more appropriate age to made the step is set between 16 and 19 years, only 7.6% of historical control group's patients and 3.6 % of intervention group's patients affirm that the best age to leave the pediatric care is before 16 years.

Transition Project seems to have a significant impact on the way to find and contact the adult diabetes care provider for the first time. As visible on *Graph 2*, 35.5 % of historical group's patients received no option about the way to contact their future adult diabetes care provider and 40% of them are suggested to find it by their own means.
Since the creation of LDTP, young patients seem to be better supported in the research and choice of their future adult care provider, 84.2 % them benefited of the TN help to organize the first appointment with the adult specialist : in two-thirds of the cases she was present and in one-thirds of the cases she helped the young patient to fix the appointment . Only 15.8% of transition group's patient had to find a new adult doctor by their own means and no one had received no option about the way to contact him.

There are some difference in the follow-up post transition distribution, in hospital or at private practice. Patients of LDTP intervention group prefer the hospital settings and patient of control group foster the private practice.
Not only the way to plan and organize the follow-up post transition have been influenced by the development of LDTP. Even the conduct of pediatric medical consultations have been greatly modified by the creation of transition nurse post. Before the development of LDTP, 31.5% of young patients had always

the opportunity to pass some time with the pediatric team without the parents, while the proportion rises at 51.9% after the creation of LDTP.

WHOQOL-BREF questionnaire :

The answers to the WHOQOL-BREF questionnaire shows a positive trend in quality of life of young with diabetes mellitus. 62% of answering patients estimates their quality of life as *good* and 24% of them estimates it as *very good* . Those numbers underlines that, although their chronic disorders, people with well controlled diabetes mellitus can have a high quality life.

The satisfaction degree of patients about their own personality, their general health status, their relationship and the access to health system are shown in *(Graph 3).* Also in this case, positive answer overtake negative answers. Concerning self-satisfaction, health satisfaction and relationship satisfaction more than 60%, 40% and 50% respectively of patients estimate their situations as *satisfactory*, concerning their health system access nearly 60% of the patients affirm they are *very satisfied*.

Six of the 26 questions of the questionnaire are centered on psychological evaluation: frequency of negative feelings, bodily image and appearance, self-esteem, concentration, sense of life and love for life. Concerning the question “Have you often negative feelings like melancholy, anxiety, depression or despair?” 65.4% of the patients affirm having rarely negative feelings, 23% of them say never have it, 7.7% quite often and 3.8% all the time. The mean score for psychological domain of intervention group is 74.4%. In the literature we can find that the psychological mean health score for the general population of the same age (20-29) is 74.3%. (35)

Adult diabetes care providers’ satisfaction about transition nurse :

A questionnaire to 22 adult diabetes care provider was send to evaluate the role and collaboration with the TN. 59% of physicians answered to the questionnaire, 61.5% female and 38.5% male.

84.6% of the responders affirm to know the TN, the majority of them know it thanks to an individual presentation and a minority of them thanks to the Diabetes l Program Forum.

About them, 92.2 % are clear about the nurse transition role . Number of patients aged between 16 and 25 is 5 - 20 per adult diabetes care provider. 75% of them have benefited from the presence of TN at first appointment with a new young patients. All physicians agree that the presence of the TN is reassuring for the patient and that it allow a better transition. The majority of the physicians affirm to be *satisfied* (23%) or *really satisfied* (38.5%) of her presence, 30.8% doesn’t answer and no one says to be unsatisfied of TN. 70% of adult care providers report additional TN collaboration for a part of their young patients. They appreciate the impact of teamwork, the global view of the TN about patient’s life and the exchange of information allowing a better comprehension on patient’s situation and to become aware of his transition process and of any possible difficulties that can have an impact on the medical care.

Concerning the Transition Passport, 76.9 % of the responders affirms to know it : among them, 70% judge it as a useful summary of the medical condition and a motivation tool for the patient while 30% evaluated it as “not very useful” because of its complexity and, according to some physicians, there isn’t enough time during the medical consultation to go through all of the items.

Secondary end points:

1) HbA1c

   Although not statistically significant, we saw a clear trend towards lower HbA1c between the control and the intervention group at their last pediatric visit, reaching near statistically significant when compared with the HbA1c at adult visit (*Graph 4*). This trend towards lower HbA1c mean a significant decrease in the mortality and morbidity factors.

2) Post- transition hospitalization

   Low rate of diabetes hospitalization in the last 12 months is an additional positive result. 80% of intervention group’s responders had never been hospitalized during the last 12 months because of diabetes complications, 16.6% of them had been hospitalized between one and two time during the last years and only 1 patient had to be hospitalized more than 5 times.

Discussion

We successfully implemented a structured transition program with the collaboration of pediatric and adult diabetologists, nurses and the public health system with a clear impact on somatic and psychological outcome on patients with type 1 diabetes.

Quality of the study:

In 2015, Findley and al. (28) published a systematic review in order to evaluate the quality assessment of 31 research articles focusing on transitional diabetes care. They used three modified scales of assessment criteria based on the JBI (36) permitting to assess cross-sectional studies, intervention - group comparison studies and qualitative studies. Each scale is based on 10 questions concerning multiple aspects of quality study and the final score ranging from 1 to 10. In addition to quality assessment, Findley and al. applied the American Diabetes Association (37) evidence grading system of levels A, B, C and E to each article. Considering these criteria, we would consider the study as level B (supportive evidence from a well conducted cohort study or case-control study).

Evaluation of satisfaction with the transition project:

Response rates are slightly above the response rate observed in the literature which are around 25-30% (38) probably due to the chronic condition and the reminders.

Three questionnaires have been used in order to evaluate three different issues of the transition program.

- We showed a significant improvement of accompanying feeling of patient in the intervention group compared to control group and this improvement is clearly associated to the presence of a TN. The TN is a point of reference for the huge majority of the patients. Not only she follows the medical aspects of the disease and she helps in the contact with adult diabetes care providers, but the psycho-social situation of young patients is a central element of her support and that, during the fragile time of adolescence, is a basic ingredient allowing a more solid therapeutic alliance and, consequently, a better follow-up with valuable decrease of drop-out. We observed a higher proportion of patients followed in an ambulatory setting of the adult tertiary care center, which could be explained by the smoother transition thanks to the easier collaboration between pediatric and adult health care providers.

- The WOQOOL-BREF questionnaire allowed us to investigate patients' quality of life and satisfaction degree. Data collected thank to this questionnaire are very encouraging. Despite an important number of studies showing a high prevalence of depression and negative feelings in young patient with chronic disease, the large majority of the patients in the intervention group seem to have a good quality of life and psychological well-being, comparable to the general population aged of 20-29 years (35).
  Our data suggest that people with well supported and accompanied patients with diabetes mellitus can have a high quality life. The supportive role of the transition nurse seems primordial. Transition is not only about blood sugar control and insulin dose adjustment. Transition is also about insecurity, school, sexuality, physical change and autonomy development, this is the reason why young patients must have the opportunity to share their fears and ask their questions to a professional person they trust.

- An important step of the LDTP was the integration of adult diabetologist in the planning and structure of the project. The positive satisfaction degree with the collaboration with the TN underlines the need for good communication with health care providers. . The relative bad acceptance of the *Transition Passport* hints at the complexity of the transmission of data and the need to smoothen this process. In academic literature, the need of a better communication between pediatric and adult care providers and the access for adult diabetes providers to summaries of diabetes control and mental health issues of young adult patients are strongly underlined as well as the comprehension of divergent care approaches by pediatric and adult diabetes providers (36). One more time, here we find the relevant interest of TN: her personal presence at the first adult visit could partly compensate the lack of communication between pediatric and adult diabetes providers and could ensure a smoother transition for the patient and to allow them to adapt to adult care approach. Intra-hospital transition programs with common pediatric and adult consultations seem another viable option.

What differentiates our transition program from others:

Diabetes, as well as other chronic disease, has multiple repercussions on patients' life. The human factor provided by the TN, integrating affective, ongoing support, decisional control, and information about health issues seem primordial. Our results show that any transition phase should include a standardized and, at the same time, flexible approach.

Contact with NT aren't limited to phone call or email, but she starts a trusting relationship with patients, meeting patients at the hospital, at home or at the café corner, adapting to patient needs. The presence of TN seems to have somatic and psychosocial positive impact, allowing to increasing chances of a successful outcome of the transition and to decrease court term and long term complications.

We are convinced that the successful transition rate of 98% with ongoing is due to the presence of a dedicated transition nurse.

Changes between the control and the intervention group :

Since the development of LDPT, not only the follow-up during and after the transition have been greatly improved, but young patients could benefit from an structured and individual focused preparation to the transition.

The lack of a structured transition in the control group causes a relevant rate of insecurity and abandonment feeling during the transition phase. More than 70% of patients had to search and contact the new adult diabetologist by their own means which obviously cause a great number of drop out and expose patients to court and long term risks of an uncontrolled diabetes mellitus. Furthermore, psychological sphere risks to me affected too. TN plays a major role in moral support and in her absence patients are alone to face the multiple psychosocial issues of transition. In 2015, Garvey and al. proved that an easier access for mental health referral has a relevant impact on barriers to diabetes management, reporting the need for additional resources (39).

HbA1c :

Compared to recent publications (29), our results of clinical end-points like HbA1c are very encouraging.

Comparing HbA1c value of control and intervention group, we find that even before the transition HbA1c of control group is slightly higher than HbA1c of intervention group. The decrease of HbA1c in the intervention group show that the first phase of LDTP, starting around age 14 (*preparation phase*), has a significant impact of disease progression. To achieve a successful transition, bases for the pass from pediatric to adult care team must be prepared several years before the actual transfer phase.

Comparison of intervention group's value before and after the transition show a decrease of HbA1c. An active and supportive follow-up during and after the *actual transfer phase* and the *engagement phase* permit a satisfactory decrease, or at least a good stabilization, of HbA1c.

Decrease of drop-out : what does this mean for short and long term complications :

The active support by the TN helped young patients to improve the comprehension and the management of their chronic disease. Consequence of the acceptance of the disease, of the comprehension of court and long term consequences, of the emotional support, of the easier access to adult specialist and of the patient empowerment is decrease of drop out. Continuity of medical follow-up permit, amongst others, good stabilization of HbA1c and, consequently, a successful health care. On the contrary, drop-out lead to uncontrolled HbA1c which, in turn, will have important negative consequences in court and long term on patient’s health. Decrease of drop-out number during the transition must be a central aim of transition programs.

In summary, we developed a successful transition program for patients with type 1 diabetes mellitus, including a dedicated transition nurse with successful transition in 100% , and continuous care after 2 years of 98% of patients in the program. Satisfaction indices with the transition phase are clearly better than in the historical control group. We saw a positive trend of metabolic control as suggested by the decreased HbA1c. Our data show that effective transition programs have significant impact on health-quality of young persons with type 1 diabetes mellitus. Young patients suffering from diabetes have important resources and margins for improvement, but need assistance in sensitive moment of their life. Our transition program should allow for a better control of the diabetes and an important reduction of diabetes short-term and long-term complications.

Key words : type 1 diabetes mellitus, transition, follow-up, quality of life, outcome

References

1. Patterson CC, Dahlquist GG, Gyürüs E, Green A, Soltész G, EURODIAB Study Group. Incidence trends for childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicentre prospective registration study. Lancet. 2009 Jun 13;373(9680):2027–33.

2. Wojcik M, Sudacka M, Wasyl B, Ciechanowska M, Nazim J, Stelmach M, et al. Incidence of type 1 diabetes mellitus during 26 years of observation and prevalence of diabetic ketoacidosis in the later years. Eur J Pediatr. 2015 Oct;174(10):1319–24.

3. Fazeli Farsani S, Souverein PC, van der Vorst MMJ, Knibbe CAJ, Herings RMC, de Boer A, et al. Increasing trends in the incidence and prevalence rates of type 1 diabetes among children and adolescents in the Netherlands. Pediatr Diabetes. 2016 Feb;17(1):44–52.

4. Berhan Y, Waernbaum I, Lind T, Möllsten A, Dahlquist G, Swedish Childhood Diabetes Study Group. Thirty years of prospective nationwide incidence of childhood type 1 diabetes: the accelerating increase by time tends to level off in Sweden. Diabetes. 2011 Feb;60(2):577–81.

5. Skrivarhaug T, Bangstad H-J, Stene LC, Sandvik L, Hanssen KF, Joner G. Long-term mortality in a nationwide cohort of childhood-onset type 1 diabetic patients in Norway. Diabetologia. 2006 Feb;49(2):298–305.

6. Lind M, Svensson A-M, Kosiborod M, Gudbjörnsdottir S, Pivodic A, Wedel H, et al. Glycemic Control and Excess Mortality in Type 1 Diabetes. N Engl J Med. 2014 Nov 20;371(21):1972–82.

7. Writing Group for the DCCT/EDIC Research Group. ASsociation between 7 years of intensive treatment of type 1 diabetes and long-term mortality. JAMA. 2015 Jan 6;313(1):45–53.

8. Bryden KS, Dunger DB, Mayou RA, Peveler RC, Neil HAW. Poor prognosis of young adults with type 1 diabetes: a longitudinal study. Diabetes Care. 2003 Apr;26(4):1052–7.

9. WHO | Adolescent development [Internet]. WHO. [cited 2014 Nov 30]. Available from: http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/

10. WHO | The adolescent with a chronic condition [Internet]. WHO. [cited 2014 Dec 2]. Available from: http://www.who.int/maternal_child_adolescent/documents/9789241595704/en/

11. Casazza K, Higgins PB, Fernández JR, Goran MI, Gower BA. Longitudinal Analysis of the Insulin-Like Growth Factor System in African-American and European American Children and Adolescents. J Clin Endocrinol Metab. 2008 Dec;93(12):4917–23.

12. KyngÄs HA, Kroll T, Duffy ME. Compliance in adolescents with chronic diseases: a review1. J Adolesc Health. 2000 Jun 1;26(6):379–88.

13. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. J Adolesc Health. 1993 Nov 1;14(7):570–6.

14. Weissberg-Benchell J, Wolpert H, Anderson BJ. Transitioning From Pediatric to Adult Care A new approach to the post-adolescent young person with type 1 diabetes. Diabetes Care. 2007 Jan 10;30(10):2441–6.

15. de Beaufort C, Jarosz-Chobot P, Frank M, de Bart J, Deja G. Transition from pediatric to adult diabetes care: smooth or slippery? Pediatr Diabetes. 2010 Feb;11(1):24–7.

16. Busse FP, Hiermann P, Galler A, Stumvoll M, Wiessner T, Kiess W, et al. Evaluation of patients' opinion and metabolic control after transfer of young adults with type 1 diabetes from a pediatric diabetes clinic to adult care. Horm Res. 2007;67(3):132–8.

17. Spaic T, Mahon JL, Hramiak I, Byers N, Evans K, Robinson T, et al. Multicentre randomized controlled trial of structured transition on diabetes care management compared to standard diabetes care in adolescents and young adults with type 1 diabetes (Transition Trial). BMC Pediatr. 2013 Oct 9;13(1):163.

18. Lyons SK, Becker DJ, Helgeson VS. Transfer from pediatric to adult health care: effects on diabetes outcomes. Pediatr Diabetes. 2014 Feb 1;15(1):10–7.

19. Bowen ME, Henske JA, Potter A. Health Care Transition in Adolescents and Young Adults With Diabetes. Clin Diabetes. 2010 Jan 7;28(3):99–106.

20. Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT, et al. Current methods of transfer of young people with Type 1 diabetes to adult services. Diabet Med J Br Diabet Assoc. 2002 Aug;19(8):649–54.

21. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15-25 years. Diabet Med J Br Diabet Assoc. 2007 Jul;24(7):764–9.

22. Van Walleghem, Norma, A. M Catherine, Dean, Heather J. Evaluation of a Systems Navigator Model for Transition from Pediatric to Adult Care for Young Adults with Type 1 Diabetes. 2008;1529–30.

23. Cadario F, Prodam F, Bellone S, Trada M, Binotti M, Trada M, et al. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. Clin Endocrinol (Oxf). 2009 Sep;71(3):346–50.

24. Mulvaney SA, Rothman RL, Wallston KA, Lybarger C, Dietrich MS. An Internet-Based Program to Improve Self-Management in Adolescents With Type 1 Diabetes. Diabetes Care. 2010 Jan 3;33(3):602–4.

25. Price CS, Corbett S, Lewis-Barned N, Morgan J, Oliver LE, Dovey-Pearce G. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. Child Care Health Dev. 2011 Nov;37(6):852–60.

26. Garvey KC, Wolpert HA, Laffel LM, Rhodes ET, Wolfsdorf JI, Finkelstein JA. HEALTH CARE TRANSITION IN YOUNG ADULTS WITH TYPE 1 DIABETES: BARRIERS TO TIMELY ESTABLISHMENT OF ADULT DIABETES CARE. Endocr Pract Off J Am Coll Endocrinol Am Assoc Clin Endocrinol. 2013;19(6):946–52.

27. Steinbeck KS, Shrewsbury VA, Harvey V, Mikler K, Donaghue KC, Craig ME, et al. A pilot randomized controlled trial of a post-discharge program to support emerging adults with type 1 diabetes mellitus transition from pediatric to adult care. Pediatr Diabetes. 2015 Dec;16(8):634–9.

28. Findley MK, Cha E, Wong E, Faulkner MS. A Systematic Review of Transitional Care for Emerging Adults with Diabetes. J Pediatr Nurs. 2015 Sep;30(5):e47–62.

29. Sequeira PA, Pyatak EA, Weigensberg MJ, Vigen CP, Wood JR, Ruelas V, et al. Let's Empower and Prepare (LEAP): Evaluation of a Structured Transition Program for Young Adults With Type 1 Diabetes. Diabetes Care. 2015 Aug;38(8):1412–9.

30. Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, Khairy P, Melvin P, Sawicki GS, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. J Pediatr Rehabil Med. 2014;7(1):43–51.

31. Watson MJ. New Dimensions of Human Caring Theory. Nurs Sci Q. 1988 Jan 11;1(4):175–81.

32. Rutishauser C, Akré C, Surìs J-C. Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents. Eur J Pediatr. 2011 Jul;170(7):865–71.

33. WHO | WHO Quality of Life-BREF (WHOQOL-BREF) [Internet]. WHO. [cited 2016 Jan 10]. Available from: http://www.who.int/substance_abuse/research_tools/whoqolbref/en/

34. Sølvik UØ, Røraas T, Christensen NG, Sandberg S. Diagnosing diabetes mellitus: performance of hemoglobin A1c point-of-care instruments in general practice offices. Clin Chem. 2013 Dec;59(12):1790–801.

35. Hawthorne G, Herrman H, Murphy B. Interpreting the WHOQOL-Brèf: Preliminary Population Norms and Effect Sizes. Soc Indic Res. 2006 May;77(1):37–59.

36. Aromataris E, Pearson A. The systematic review: an overview. Am J Nurs. 2014 Mar;114(3):53–8.

37. American Diabetes Association. Standards of medical care in diabetes--2014. Diabetes Care. 2014 Jan;37 Suppl 1:S14–80.

38. Fincham JE. Response Rates and Responsiveness for Surveys, Standards, and the Journal. Am J Pharm Educ [Internet]. 2008 Apr 15 [cited 2016 Jan 16];72(2). Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2384218/

39. Garvey KC, Telo GH, Needleman JS, Forbes P, Finkelstein JA, Laffel LM. Health Care Transition in Young Adults With Type 1 Diabetes: Perspectives of Adult Endocrinologists in the United States. Diabetes Care. 2015 Dec 17;

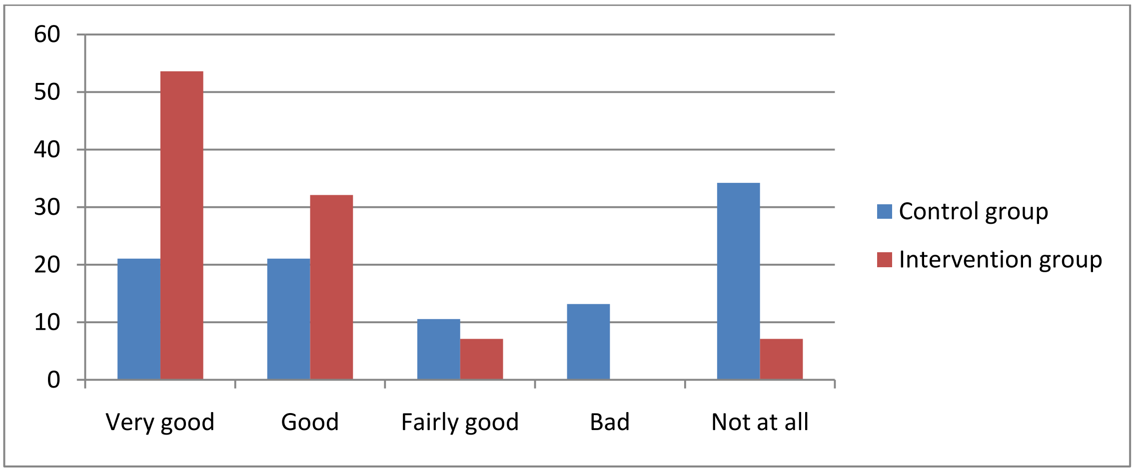
Table 1 : Comparison of responders to the questionnaire at transition

	Responders of historical group N=39 Median (range)	Responders of transition model N = 30 Median (range)	P-value
Age at study questionnaire (yr)	23 (17-31)	20 (16 -23)	
Female / male (%)	60.5 / 39.5	66.6/33.3	
Age at transition (yr)	17.3 (13.3-19.3)	18 (16 -20)	0.199181109
Diabetes duration (yr)	9 (1-14)	9 (3-20)	0.244411969
Insulin dose (U/kg/day)	0.98(0.54-1.33)	0.85 (0.36-0.95)	0.037904001
HbA1c (%)	*8.5 (6.8-13.5)*	8.2 (5.7-14)	0.181639156
Therapy			
Conventional(%)	*56*	10	
Basal-bolus (%)	*34*	70	
Pump (%)	*10*	20	
Informed about transition (%)	66.4	100	

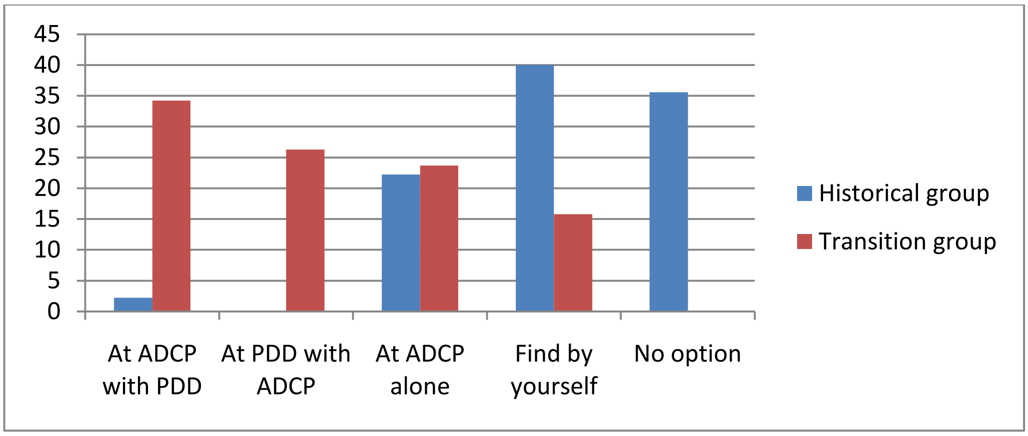
Table 2 : Patient characteristics at transition (responders and non responders)

	Historical group N=137 (1980-2010) Median (min-max)	Transition model N = 68 (2011-2014) Median (min-max)	P-value
Age at study questionnaire (yr)	-	21 (15-24)	
Female / male (%)	63.4/36.6	42.6/57.4	
Age at transition (yr)	17.6 (13.3-20.4)	17 (7-21)	0.041222903
Diabetes duration (yr)	-	10 (6-21)	
Insulin dose (U/kg/day)	0.97 (0.01-10.61)	0.9 (0.09-1.39)	0.065009078
HbA1c (%)	*8.7 (5.1-16.3)*	8.4 (5.5-15.2)	0.182532433
Therapy			
Conventional(%)	49	6	
Basal-bolus (%)	43	83.3	
Pump (%)	8	10.6	
Informed about transition(%)	-	100	
Nurse contact (total / patient)	3(0-37)	14 (0-59)	

Graph 1. Satisfaction of being accompanied during transition by TN



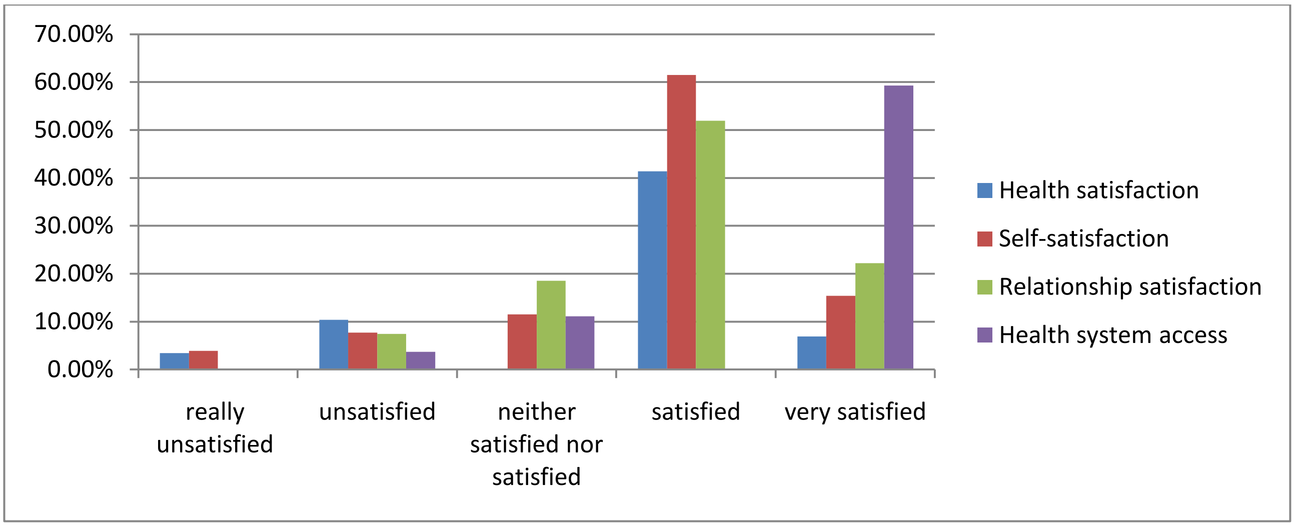
Graph 2 : Options offered to young patients by the pediatric team to meet the adult diabetes care provider for the first time.



Legend:

- ADCP : adult diabetes care provider
- PDD : pediatric diabetes doctor

Graph 3 : Intervention group's satisfaction degree about them-self, the health, heath system access and the relationships.



.

Graph 4 : Trend towards lower HbA1c between the control and the intervention group.