



# Impact of a special therapeutic education programme in patients transferred from a paediatric to an adult diabetes unit

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## Introduction

Type 1 diabetes mellitus (T1D) is a chronic auto-immune disease resulting from progressive destruction of the pancreatic beta-cells that occurs more frequently in childhood and adolescence.<sup>1</sup> In Catalonia, Spain, at least half of the newly diagnosed T1D patients are under 15 years of age and the vast majority are seen in paediatric health care departments after diagnosis.<sup>2</sup> Whatever the age of transition from the paediatric diabetes unit, it is always a very troublesome period for young people. The success of this transition will condition the future control of the disease, and when the transfer fails it will be a major obstacle in the adequate provision of medical care.<sup>3</sup>

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## Abstract

The control of type 1 diabetes (T1D) in young subjects is especially troublesome in adolescence. In this period, young T1D subjects are usually transferred to adult diabetes units. Transfer conditions could be a determinant factor to achieve adequate treatment compliance and optimal metabolic control.

The aim of this study was to evaluate the impact of a specifically designed transition therapeutic education programme (TEP) on glycaemic control, self-management and quality of life, 12 months after the transfer of young subjects with T1D from a paediatric to an adult diabetes unit.

The study included 80 young T1D subjects (aged  $19.0 \pm 1.3$  years, 39 females, T1D duration  $7.3 \pm 1.5$  years) transferred from a paediatric to an adult diabetes unit during 2000–2002. The transition TEP included the following. (1) Co-ordinated transfer between the paediatric and adult diabetes unit. (2) Initial evaluation of the patient/family regarding: (a) insulin schedule; (b) metabolic control; (c) self-management abilities and knowledge (DKQ2 test); (d) weight; and (e) quality of life score. (3) Pact about the insulin therapy schedule and goal-setting. (4) Group sessions: four sessions (two hours each). (5) Follow up: three to six visits during three to six months. (6) Evaluation: initially and 12 months after the transfer.

In all, 72 out of 80 subjects completed the TEP. We observed an improvement in metabolic control ( $HbA_{1c}$   $8.5 \pm 1.7$  vs  $7.4 \pm 1.5$ ,  $p < 0.001$ ) with a decrease in the number of hypoglycaemic episodes (severe: 0.39 vs 0.14 episodes/patient/year,  $p < 0.001$ ; >5 non-severe/weak: 15% vs 0% patients,  $p < 0.005$ ). There were no differences in terms of total daily insulin dose. However, an increase was observed in the proportion of rapid-acting insulin (23% vs 52%,  $p < 0.001$ ). After 12 months of TEP, a higher proportion of subjects were able to perform self-adjustment of insulin doses (13% vs 48%,  $p < 0.001$ ). Likewise, TEP improved their knowledge in T1D management (DKQ2 25/35 vs 29/35,  $p < 0.001$ ) without worsening the quality of life score.

In conclusion, the use of a special transition TEP achieves an improvement in metabolic control and self-management abilities without worsening the quality of life of young T1D subjects transferred from a paediatric to an adult diabetes unit.

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## Key words

type 1 diabetes mellitus; young adults and adolescence; transition to adult diabetes units

Ideally, the transition from a paediatric clinic to an adult diabetes unit should be a continuous, active and well co-ordinated process which should take into account that adolescence and young adulthood are critical and vulnerable periods.<sup>4</sup> Although the change from a paediatrician- and family-based care to an adult dia-

betes clinic may initiate a period of independence, it can also induce negligence and a lack of attendance to health care facilities.<sup>5</sup>

In spite of the well-recognised importance of an effective transfer from paediatric diabetes care, information and research concerning different approaches undertaking this transfer are still very scarce.



In this context, the aim of this study was to evaluate the impact of a specifically designed therapeutic education programme (TEP) on metabolic control, self-management of diabetes and quality of life, 12 months after the transfer from a paediatric to an adult diabetes clinic.

### Subjects and methods

Eighty young adult T1D patients (39 female) were transferred from a paediatric diabetes unit (Hospital de Sant Joan de Déu) to an adult diabetes clinic (Hospital Clínic i Universitari de Barcelona) during the years 2000–2002. At the time of discharge from the paediatric unit they were  $19.0 \pm 1.3$  years old with  $7.3 \pm 1.5$  years since diagnosis.

All young people transferred from paediatric centres were included in the programme. Dropouts from the study were not followed up in the adult hospital clinics due to, for example, change of address, and personal factors. (Initial average details of the young dropouts were: age 18 years;  $HbA_{1c}$  10%; and knowledge test score 23/35.)

The specifically designed TEP included:

- Co-ordinated transfer visits. After preparation and advice from the paediatric diabetes care providers (nurses and physicians), the transition was co-ordinated including a simultaneous first visit by the endocrinologist and the nurse.
- Initial evaluation by the diabetes adult centre staff. The first visit was scheduled and included physician and nurse evaluation. This visit included subject and family assessment. The time planned for each first visit was 90 minutes. After the presentation, we explained what we were going to do during the visit and asked patients what aspects they wanted to cover. The test com-

	Initial	12 months later
<b>Diabetes meal plan†</b>		
Carbohydrate (%)	42.2	43.9
Protein (%)	20.6	19.8
Fat (%)	37.3	36.3
<b>Insulin modification</b>		
NPH/day (iu)	42	27
Rapid-acting/day (iu)	23	52‡
<b>Self-adjustment</b>		
Pre-prandially (%)	77	93
Basal adjustment (%)	13	48‡
<b>Weight (kg)</b>	65.4	67.3‡
<b>Test of diabetes knowledge (DKQ2)</b> (maximum score 35)	25/35	29/35‡
<b>Quality of life (DQOL) scores</b>		
Satisfaction	32	30
Impact	42	42
Social preoccupation	13	16
Diabetes preoccupation	8	8
†There were no changes in nutritional percentages, but the daily management of carbohydrate counting was improved. ‡ $p < 0.001$ .		

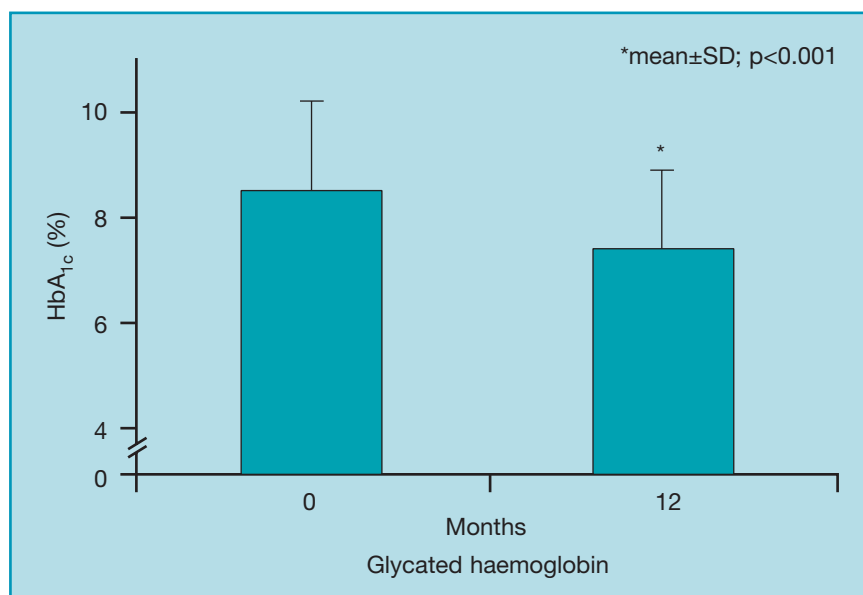
**Table 1.** Data obtained at the initial evaluation and after 12 months of follow up

ponents of the visit were well accepted and quickly answered (taking around 10 minutes in all). From the patient we obtained information concerning: self-management abilities; self-perception and knowledge (DKQ2 test)<sup>6</sup> related to diabetes; weight and body mass index; metabolic control; insulin schedule; meal planning/composition and quality of life score (DQOL test).<sup>7</sup> Information was also obtained about vocational planning, lifestyle (including drugs and alcohol), sexual health, psychosocial support and other health care behaviours. Likewise, the content of the TEP was explained and a leaflet was given to each subject.

- After the first visit a pact was established to adapt the insulin therapy programme and set the goals to be achieved. In order to quantify hypoglycaemic episodes, these were classed as severe or non-

severe and estimated from the subjects' diaries of self-capillary blood glucose monitoring. Non-severe hypoglycaemic events were defined as symptoms or signs associated with hypoglycaemia experienced by the patient and self-treated without the need of assistance from a third party, or as a blood glucose measurement of  $<3.3$  mmol/L. Severe hypoglycaemic events were defined as those associated with neuroglycopenia severe enough to require treatment from a third party.

- The follow up of the subject also included group sessions (four sessions, two hours each) with T1D patients and relatives included in the TEP. The sessions covered the usual topics in diabetes management, as well as aspects of general interest in the daily life of young adults and adolescents. All subjects were asked to participate actively, especially during the case report



**Figure 1.** Glycated haemoglobin values initially and after 12 months of follow up

discussion.

- The diabetes staff of each subject performed a total of three to six individual visits during a three to six month period. The pact and goals previously established were revised. The number of visits varied from individual to individual. A higher number of visits was related to the greater necessity of the patient – and/or their family – to improve their self-management (e.g. perform three or more glycaemic controls/day, modify the insulin doses, and have their insulin schedule well adapted to their daily activities).

- When the TEP was completed, transferred T1D subjects were discharged and included in the usual follow up for outpatients with T1D, maintaining the same medical specialist. A complete educative and clinical report was written and included in the clinical files. Twelve months after initiating the transition, all of the parameters evaluated at the beginning of the TEP were reassessed.

#### Statistical analysis

All values are expressed as mean±SD or as a percentage.

Changes from baseline values at the end of the study were compared with a paired t-test. Categorical variables were compared using the chi-square test and Fisher exact test. A p value <0.05 was considered statistically significant. All statistical calculations were performed by the Statistical Package for Social Science (SPSS) for personal computers v. 10.0.

#### Results

A usual TEP lasted from three to six months of follow up on average. Globally, 12–15 hours were dedicated to each subject, 50% of which were group sessions. In all, 72 out of 80 subjects completed the TEP. Seven abandoned the follow up due to personal reasons and one subject died, the cause not being related to diabetes.

At the end of the follow up, there were no changes in meal plan composition in terms of percentage of carbohydrates, protein and fat. However, there was a tendency towards an improvement in carbohydrate counting and interchange in the vast majority of subjects. Table 1 presents data obtained at the initial evaluation and after 12

months of follow up.

There were no differences in terms of total daily insulin dose. Nevertheless, we observed an increase in the proportion of rapid-acting insulin at the end of the follow up compared to the beginning, 52% vs 23%, respectively (p<0.001). There was an increase in the proportion of subjects who performed readjustments of insulin doses considering self-measurement of capillary blood glucose after three or more days of monitoring (13% vs 48%, initially and after 12 months of follow up, respectively; p<0.001).

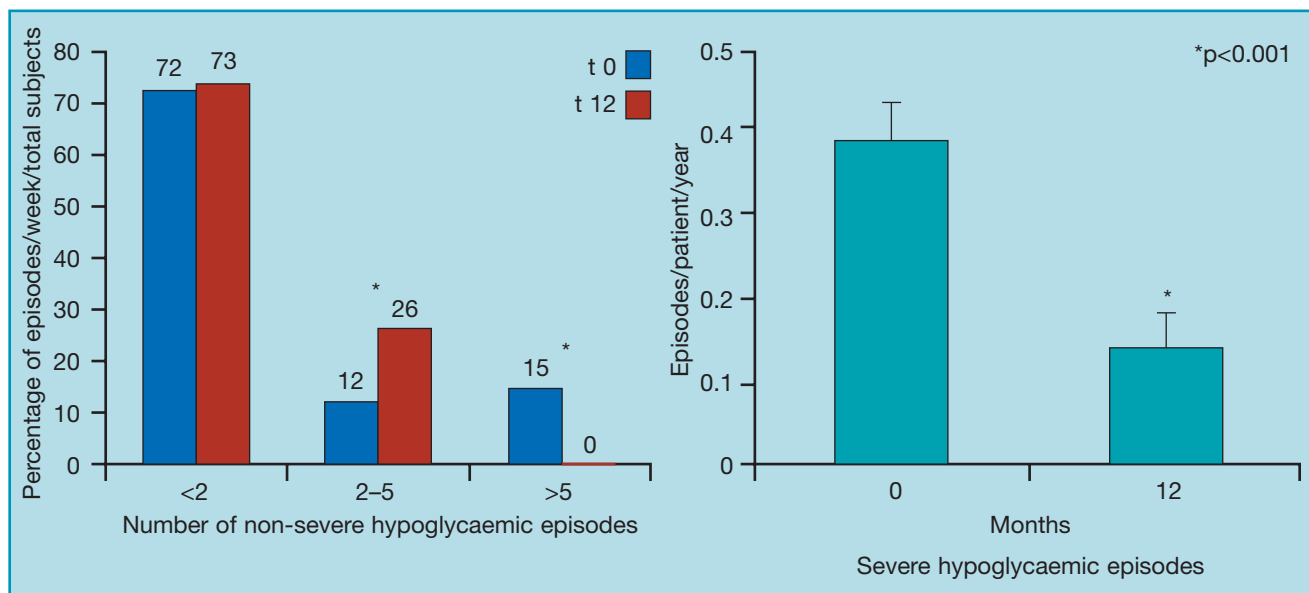
As is shown in Figure 1, there was a significant decrease in glycated haemoglobin at the end of the study. In addition, we observed a decrease in the number of hypoglycaemic episodes (severe and non-severe) as is shown in Figure 2. As expected, there was also a significant increase in body weight at the end of the follow up (65.4±9.3kg vs 67.3±7.4kg, initially and after 12 months, respectively; p<0.001). It should be pointed out that the whole improvement in metabolism was achieved without any deterioration in DQOL scores.

On evaluating the results concerning knowledge of diabetes, we observed a significant increase in the scores used for this purpose (DKQ2 score 25±3 vs 29±4, p<0.001).

#### Discussion

Our study has attempted to evaluate the efficacy of a specifically designed transition programme for young adults and adolescents with T1D in transition to adult diabetes care units. We confirm that the implementation of a specific TEP could be useful in order to maintain or improve metabolic control without impairment in either clinic attendance or DQOL scores.

Transition from paediatric dia-



**Figure 2.** Number of severe and non-severe hypoglycaemic episodes initially and after 12 months of follow up

betes clinics to adult diabetes units is a major milestone in the natural history of T1D affecting childhood. Although it is a well-recognised difficulty, there is a lack of information and research about different forms of transitional procedures. There are many possible contributing factors to the lack of success of this transition process.<sup>8</sup> Some are related to the potential differences in the kind of care provided by paediatricians and adult specialists in diabetes. However, the most outstanding fact is that the transfer from paediatric care occurs at a particularly vulnerable period for young people with diabetes. We performed the transfer in subjects 17–19 years of age. In agreement with other authors,<sup>5–8</sup> we believe that it is better to delay the transition until the young person has almost completed the developmental tasks of adolescence, avoiding transitions before 16 years of age. In our opinion, the transfer should also preferably be performed before the age of 20, in order to start an adult-oriented care and to promote a smooth and continuous transfer to an independent self-management of the disease.

In the absence of a 'joint clinic' with paediatricians and adult specialists involved in diabetes care, we designed our TEP to introduce young T1D patients in our adult unit. We tried to build up a co-ordinated process with very active involvement of not only the subject but also the staff members. In this context, the reduced compliance and clinical attendance observed in the transfer from paediatric care was not observed in our programme and less than 10% of the subjects did not complete the planned follow up. This period of diabetes care is also a big challenge to the prognosis of the disease and could preclude good metabolic control. In this context, the fact that the application of our TEP improved metabolic control by reducing both glycated haemoglobin and hypoglycaemic episodes is outstanding. Moreover, the amelioration in the metabolic profile was obtained without deterioration in the quality of life perception. Although we did not include a control group for comparisons with other alternative approaches, we think that our results are still of interest considering the paucity of data in this field.

Furthermore, in view of our previous unsuccessful experience with non-specific transfer for young people with T1D in terms of metabolic control and compliance with treatment (data not published), we did not consider a control group with the current method of transfer to be appropriate.

In 1995 we evaluated an educative programme directed to young people transferred from paediatric centres. We observed few changes in improvement of control ( $HbA_{1c}$  8.5% initially *vs* 8.8% one year after the transfer), although knowledge was improved (26/35 *vs* 31/35). These results prompted us to change our programme, and it did not seem ethical to include some young people in the conventional, previous programme. Another concern relates to the handling of other young people transferred from paediatric to other adult centres – which is an aspect we have not been able to evaluate.

A possible drawback of our specific TEP is the fact that we needed around one visit per month in order to complete the whole programme. Considering the age of the subjects included in the



transition programmes from paediatric clinics, it is mandatory to minimise the number of physical visits in order to avoid absences from high school, college or university or from first employment. Performance of TEP including virtual visits using online facilities may become a challenge in the very near future.<sup>9</sup>

In summary, the use of a special transition TEP achieves improvement in metabolic control and self-management abilities without deterioration in the quality of life of young T1D subjects transferred from paediatric to adult diabetes units.

### Acknowledgments

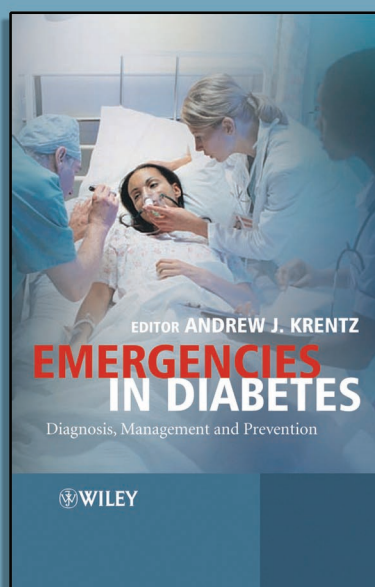
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