

Relationship Between Metabolic Control and Quality of Life in Adolescents with Type 1 Diabetes

Report from two Italian Centres for the management of Diabetes in childhood

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Abstract. This study is aimed at answering the question whether the demands of the intensified diabetes management and good metabolic control may influence the Quality of Life (QOL) of adolescents with Type 1 Diabetes (T1D), and that of their parents. Overall, 153 adolescents were involved (78 males, mean age 15.0±2.3 median age 14.6 years; average diabetes duration 6.5±3.5 years) from the Regional Centres of the Universities of Chieti and Parma. HbA1c determination was centralized and the adolescents were tested according to the adolescent version of the questionnaire developed by Ingersoll and Marrero on the impact of diabetes, worries about diabetes, satisfaction with life, and health perception. The burden on the family was assessed following a newly constructed questionnaire. The average HbA1c value was 7.7±1.4% (boys 8.0±1.4 and girls 7.5±1.2%). The impact of diabetes was similar for both boys and girls (average scores: 44.68 vs 45.00) with no effect regarding age or the duration of diabetes, but the influence of HbA1c values was significant ($p<0.001$). Compared with boys, girls had an earlier (at about 12 years of age) and more significant increase in worries ($p<0.01$). Lower HbA1c values were associated with fewer worries ($p<0.02$). Satisfaction deterioration appeared earlier in girls than in boys and was associated with high levels of HbA1c ($p<0.01$). Health perception was poorer in girls than in boys and was influenced by HbA1c values ($p<0.005$) in both girls and boys. The burden on the family with diabetes decreased with the age of the adolescent. In conclusion, in our group of adolescents with T1D, lower HbA1c was also associated with better QOL and with a lower perception of a burden on the family. These findings justify the efforts to assess QOL perception in adolescents in order to facilitate achieving better metabolic control.

Key words: Quality of life, Type 1 diabetes, insulin therapy, metabolic control, adolescence

Both DCCT (Diabetes Control and Complications Trial) results and ISPAD (International Society of Pediatric and Adolescent Diabetes) guidelines stress the effectiveness of an intensified diabetes management in order to reach a satisfactory glycemic control and to prevent micro-vascular complications (1, 2). These targets usually come at a high price for a child with Type 1 diabetes (T1D): within a year he has to undergo at least 1500 insulin injections, 1000 capillary blood glucose measurements, 7 to 15 days of absence from school for clinical evaluations at hospital,

several calls to diabetes staff and a continuous control on his diet. Faced with this situation, a spontaneous question arises: how much may the demands of the intensified diabetes management and good metabolic control influence the Quality of Life (QOL) of adolescents with T1D, and their parents?

The relationship between QOL, diabetes treatment regimens and metabolic control is controversial. Some Authors report a link between QOL and HbA1c levels (3,) whereas others find no association (4, 5), but these results are affected by the small size of

the groups investigated. An exhaustive answer to the above-mentioned question has recently been given by the first large international multi-language study promoted by the Hvidore Study Group on the relationship between metabolic control and QOL in adolescents with T1D (6). According to these investigators, lower HbA1c levels are significantly associated with better adolescent QOL and with a lower perception of the burden on the family, as assessed by parents.

The present study reports the results obtained from 153 adolescents with T1D investigated in the two Italian Centres for the management of diabetes in childhood which perform the same treatment regimens and achieve similar good metabolic control in their patients, as proved in a previous study (7).

Patients and Methods

The study was conducted in the Regional Centres for the management of diabetes in childhood at the Universities of Chieti and Parma, located in southern and northern Italy respectively. The Centres were asked to enrol in the study children with Type 1 Diabetes seen in outpatient clinics fulfilling the following criteria: chronological age ranging from 11 to 18 years, more than 6 months duration of diabetes, no chronic disease associated with diabetes (i.e. celiac disease, autoimmune endocrinopathies, cystic fibrosis, etc.). Written informed consent was obtained from the parents and the children, when appropriate.

Overall, 153 patients (78 males, mean age 15.0 ± 2.3 , median age 14.6 years) consented and finally entered the study. The average diabetes duration was 6.5 ± 3.5 years (range: 1-15 years). The patients herein enrolled are the same subjects who participated in the Hvidore study (6).

Before the visit, adolescents and parents were invited to complete a questionnaire concerning their perception of QOL. The questionnaire for adolescents contained 52 items in four sections: impact of diabetes, worries about diabetes, satisfaction with life, and health perception. Questions were scored from 1 to 5. A lower score indicated better QOL. For each adolescent, one parent completed a five-item questionnaire about their perception of the burden on the

family related to the adolescent's diabetes. Questions were scored from 1 to 5. A lower score indicated less burden.

Patients clinical data was collected during the visit by a joint protocol between centres concerning: year of birth, sex, year of diabetes onset, height and weight, body mass index (BMI), and insulin regimen. At the end of the visit, a blood sample was taken from each patient and sent to the Steno Diabetes Centre (Gentofte, Denmark) for the determination of HbA1c.

QOL in adolescents was assessed by the adolescent version of the Diabetes Quality of Life questionnaire developed by Ingersoll and Marrero (4). The original questionnaire was translated into Italian and validated by the originators according to the procedures established by the steering committee of the Hvidore Study Group (6).

The completion rates of the questionnaires were high for both adolescents (95%) and parents (91%). Cronbach's α coefficient values for the questionnaires were: adolescent DQOL impact 0.77, worries 0.80 and satisfaction 0.86; parents 0.71. These values indicate a satisfactory internal validity and consistency.

Samples for HbA1c determination were collected using the Bio-rad HbA1c sample preparation kit (Bio-Rad Laboratories, Munich, Germany) and mailed to the Steno Diabetes Centre. The analyses were performed by automatic high-pressure liquid chromatography (Bio-Rad Variant, Bio-Rad Laboratories, Hercules, CA). Normal average HbA1c was 5.4% (range 4.4-6.3). Details of this assay and transport of specimens have been published previously (8).

Summary statistics were expressed as average \pm SD. ANOVA and linear regression tests were used for statistical analysis.

Results

The two groups of adolescents with T1D enrolled in the study were matched for sex, age, duration of disease, criteria for diabetes management, HbA1c values, daily insulin doses and number of insulin injections.

The average HbA1c value was $7.7 \pm 1.4\%$ (boys 8.0 ± 1.4 and girls $7.5 \pm 1.2\%$; $p=0.15$). The distribution

of HbA1c values according to age and sex showed HbA1c values higher in girls than in boys ($p < 0.001$) from the age of 16 years (Fig. 1/A). The average daily insulin dose was higher in girls (1.03 ± 0.23 IU/kg/day) than in boys (0.89 ± 0.24 IU/kg/day; $t = 3.68$, $p < 0.001$) and increased significantly with chronological age in both boys ($p < 0.04$) and girls ($p < 0.02$). Ninety-eight per cent of adolescents took 3 (26.8%) or 4 (73.2%) insulin injections per day. BMI increased with age in both girls ($r = 0.51$; $p < 0.01$) and boys ($r = 0.30$; $p < 0.01$), but the average of BMI was higher in girls (22.2 ± 2.4) than in boys (20.2 ± 2.8 ; $t = 4.75$, $p < 0.001$).

Figure 1/B shows the average of the total QOL scores in function of age and sex, and highlights that girls had a poorer QOL and perceived its deterioration earlier than boys. QOL was in general associated ($r = 0.51$; $p < 0.01$) with HbA1c values (Fig. 2/A) and this was particularly true in girls (Fig. 2/B). The impact of diabetes was similar for boys and girls (average scores: 44.68 vs 45) with no effect of age or the duration of diabetes and was significantly influenced ($r = 0.61$; $p < 0.001$) by HbA1c values (Fig. 3/A). Compared with boys, girls had an earlier (at about 12 years

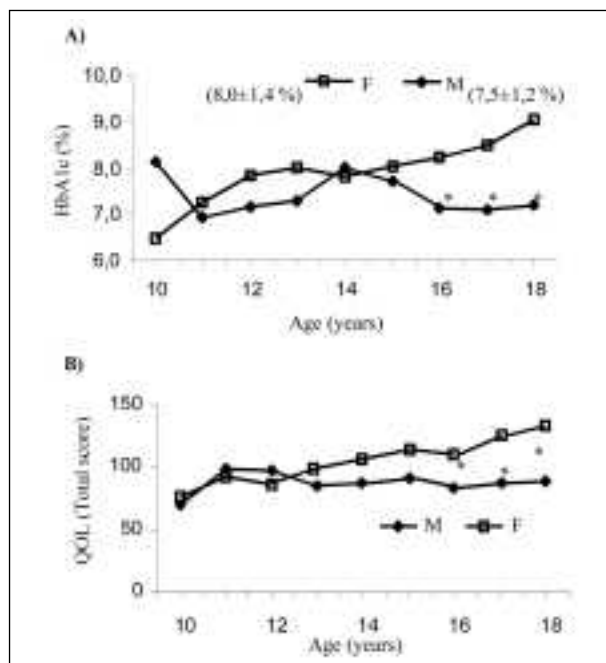


Figure 1. The association of HbA1c values (A) and QOL total score (B) with age and sex of patients

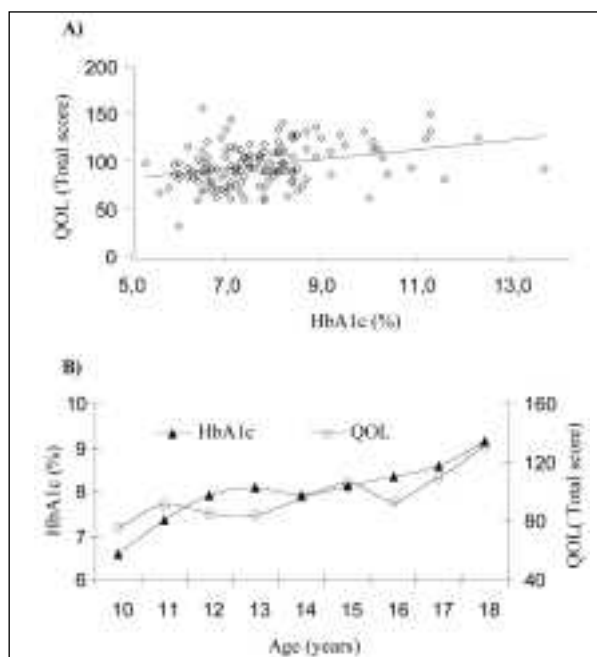


Figure 2. Relationship between total scores of QOL and HbA1c values in all patients (A) and association of QOL scores and HbA1c values with age in girls (B)

of age), more significant and more progressive increase in worries about diabetes (19 ± 4.3 vs 17 ± 4.9 ; $t = 2.80$, $p = 0.002$) and in satisfaction with life (35 ± 8.6 vs 31 ± 6.9 ; $t = 3.18$, $p = 0.006$). Total scores for worries and satisfaction were associated with HbA1c values (Fig. 3/B-C). HbA1c values influenced health perception in both girls and boys ($r = 0.42$; $p < 0.05$).

There was no significant relationship between the number of insulin injections per day and adolescent QOL. There was no association between BMI with impact of diabetes, worries about diabetes, satisfaction with life and health perception in both sexes.

Family burden for diabetes was not influenced by age of children and did not decrease during puberty (Fig. 4). The difference by sex was not statistically significant although it was more pronounced in the parents of girls.

Conclusions

This is the first study evaluating QOL in adolescents with T1D in Italy and was part of the Hvidore

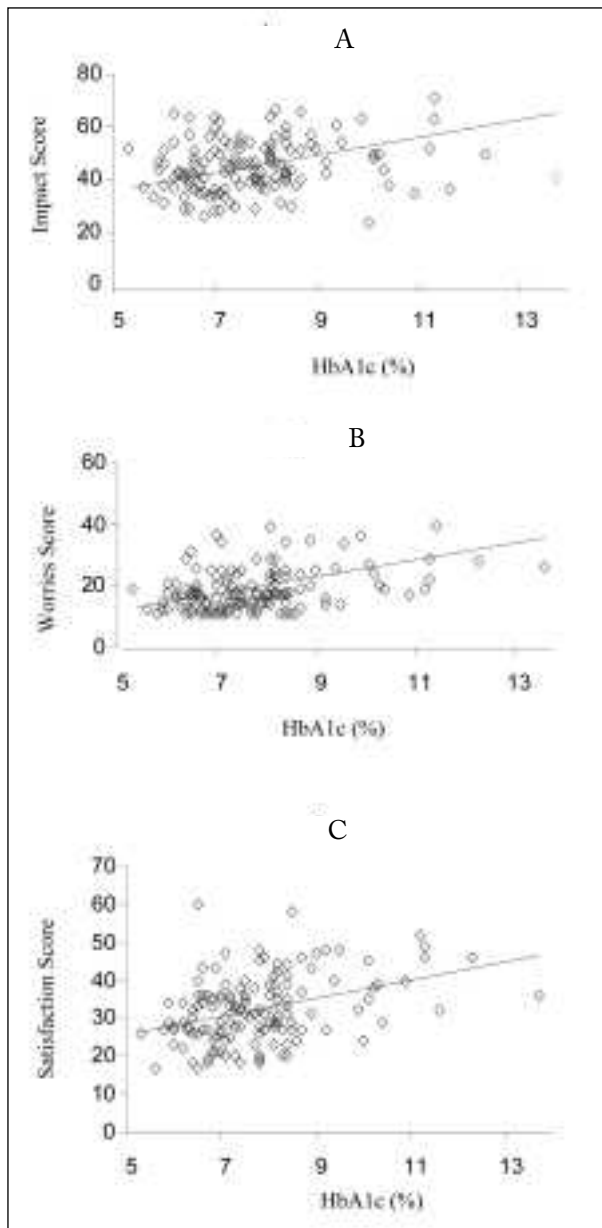


Figure 3. The association of total score in all adolescents on impact of diabetes (A), worries about diabetes (B) and satisfaction with life (C), with HbA1c values

study on metabolic control and QOL in adolescents with T1D (6). According to the report of Hoey et al. published in the core-paper (6), the results of this study confirm that better metabolic control is associated with a better QOL and with a lower burden perceived by parents. These conclusions are in conflict with those reported by other Authors (4, 5), but the

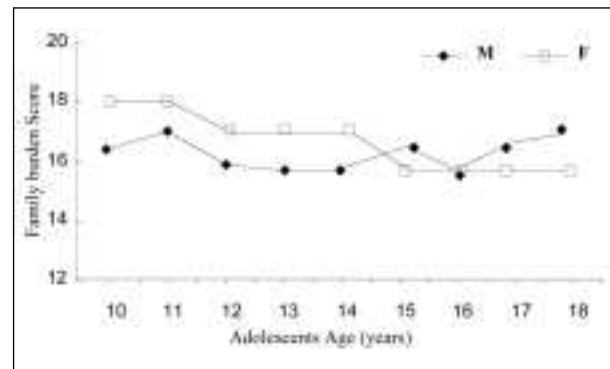


Figure 4. The decrease of the burden on the family with the age of adolescents

groups of adolescents investigated in these studies were smaller than those herein involved.

Based on these data, the efforts to achieve optimal metabolic control, stressed by both DCCT results (1) and ISPAD (International Society of Pediatric and Adolescent Diabetes) guidelines (2), appear at this time justified, as well as on the grounds of QOL.

Adolescents with a good QOL are certainly better equipped physically and psychologically than those with a poor QOL, to accept and manage the diabetes condition, and to have better self-esteem.

The adolescents with T1D enrolled in this study demonstrated some problems reaching good metabolic control with increasing age, and these critical periods affected their QOL. We found more worries, less satisfaction and poorer health perception in teenage girls than in boys associated with the difficulties of diabetes control. These findings could be related to higher incidence of psychological disturbances, earlier hormonal and pubertal changes, higher BMI, and more frequent abnormal eating disorders reported in adolescent girls than in boys with or without diabetes (8-11).

In contrast to the results of Hoey et al. (6), the burden about diabetes reported by the Italian families herein studied did not decrease with adolescent age. The difference could be due to the social-cultural characteristics of the Italian families which are inclined to manage teenagers' life for a longer period of time than the corresponding families of other countries. The lack of decrease in burden in the parents of adolescents with T1D was associated with a higher HbA1c, and resulted also in an increased worry about

diabetes. A slightly higher burden was found in the parents of girls compared with those of boys, and this could be ascribed to a sooner involvement of girls than boys in the self-management of diabetes, resulting from an earlier entry of the girls in to puberty.

In conclusion, lower HbA1c is associated with better QOL also in our cohort of adolescents with T1D. These findings agree with those reported by other Authors (3, 6) and justify the efforts to assess QOL perception in adolescents in order to facilitate achieving better metabolic control by individual strategies. We are convinced that it is easier to motivate an adolescent to reach optimal HbA1c levels for improving his/her QOL than for preventing long-term diabetes-related complications. In this perspective, periodical QOL assessment should be part of the clinical evaluation in adolescents with diabetes.

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