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LIFE QUALITY OF THE CHILD WITH DIABETES MELLITUS

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Abstract

Background and Aims. *The intensive treatment in diabetes mellitus disturbs the common activities of the child, requiring a focus on the disease both from the part of the child and of the family, having an impact on the life quality. Therefore, the general assessment of the life quality of the child with diabetes mellitus becomes important.* ***Materials and Methods.*** *The study comprised 153 children known with type 1 diabetes mellitus, recorded with the Centers of Diabetes, Nutrition and Metabolic Diseases of Iasi and Suceava, aged between 8 – 18 years old, with a duration of diabetes mellitus of 1 – 10 years. For comparison, we employed a control group of 30 non-diabetic children. Each child and parent filled-in two questionnaires: Pediatric Quality of Life Inventory (PedsQL) and Diabetes Family Conflict Scale.* ***Results.*** *The direct analysis showed that child life quality decreases slightly in the case of a great number of insulin injections, but not significant. The multivariate analysis regarding PedsQL assessment score highlighted the fact that only the family conflict condition reported to diabetes mellitus of the child and the number of insulin administrations a day, influence in a significant manner their life quality.* ***Conclusions.*** *Family involvement in the management of diabetes mellitus of the child represents a fertile field for conflict appearance in family and we propose the intensive and correct involvement of the family in the management of diabetes mellitus of the child in order to maintain a high level of child life quality.*

key words: *diabetes mellitus, child, life quality*

Background and Aims

The increase of the number of children with diabetes mellitus requires intensive care programs in order to reduce the risk of specific chronic complications. The intensive management determines increases of the charges imposed to life routine and of the relationships between children and their families [1]. The care of the child with diabetes mellitus can raise particular problems to the medical staff. The management of the disease involves both the child and his family. Therefore, we understand how both diabetes mellitus and its treatment influence child life quality [2]. The intensive care in diabetes mellitus disturbs the common activities of the child, requiring the focus on the disease both from the part of the child and of the family, with an impact on the life quality [3]

The management of diabetes mellitus in children imposes the fulfillment of certain standards different from the ones for adults,

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because children and the young diabetics have characteristics and needs which involve special norms. Little children, including school children, do not have appropriate abilities of controlling in an optimal manner their diabetes mellitus, so the participation of an adult is essential. Adult monitoring must be permanent; the education in family should focus on the characteristics of each age, on the appropriate level of understanding and it must always be present over the entire duration of the transition process towards the total independence of the adult. Nowadays, the increasing responsibility of the family of the child and teenager with diabetes is given a great importance, the essence of the optimal control being in fact the supervision from the part of the parents and their active involvement in the treatment of their own children [4]. In the context of these interactions, the family conflict generated by diabetes mellitus can occur and can disturb the adherence to the treatment and attainment of the glycemic targets [5,6]. We often assist at the very early "transfer" of responsibility, when the young person with diabetes is not able to make the most accurate decisions, in different situations. Behavioral and psycho-educational interventions meant to improve communication or to solve the problems related to diabetes mellitus management show promising results for the diminution of the conflict level between the *caregiver* and the child with diabetes mellitus [7-9].

In the context of these aspects, the aim of the study was to examine life quality of the children with diabetes mellitus, as compared to the non-diabetic children. The analysis also examines the relationship between the burden of diabetes mellitus management and the family behavior with an influence on life quality.

Material and methods

The study comprised 153 children known with type 1 diabetes mellitus, registered in the Centers of Diabetes, Nutrition and Metabolic Diseases of Iaşi and Suceava. They were aged 8 – 18 years old and had a diabetes duration of 1 – 10 years. For comparison we employed a control group of 30 healthy children. We selected patients with a relatively short duration of the disease in order to catch any major impact on the life quality. Each child and parent filled in two questionnaires: PedsQL (Pediatric Quality of Life Inventory) [10] and Diabetes Family Conflict Scale (DFCS) [11].

In order to determine the life quality of the children with diabetes mellitus regarding the social-emotional condition and the physical development, we used a *generic* questionnaire – PedsQL – developed by Varni et al. [12,10]. The PedsQL score measures the perception of the child and of the parent on the life quality, with two subscales: one regarding the physical aspects (item 1-8) and the second regarding the psycho-social aspects of the child (item (9-23)). PedsQL distinguishes between healthy children and the pediatric patients with acute or chronic disorders, if these conditions influence in a significant manner the children life quality. PedsQL is the only pediatric instrument empirically validated with elements and the scale built in the coherence child – parent, reported in several groups of age [2]. It consists of 23 coded items by means of a Likert 5 points scale: 0 – never a problem; 1 – almost never a problem; 2 – sometimes a problem; 3 – often a problem; 4 – almost always a problem. The questionnaire presents a range of aspects which can represent a problem for the child. The answer quantifies the measure in which each aspect represented a problem for the child in the last month. The answers were scored as follows: 0 – 100, 1 – 75, 2 – 50, 3 – 25, 4 – 0. The total score was calculated as an average of these items (8 for physical activities, 15 for emotional, school and social aspects).

Each child also filled in a revised version of the Diabetes-specific family conflict scale in order to report the family conflict on a 19 items scale [11]. The family conflict scale of the children with type 1 diabetes mellitus provided data regarding parents' involvement in the management of diabetes mellitus. On this scale, the family conflict level reported in the child with diabetes mellitus was codified as follows: 1 – never a conflict; 2 – sometimes a conflict; 3 – always a conflict. The final score was obtained by gathering all the answers, with a variation between 0 and 19.

The score was considered 0 for the answer „almost never". Therefore, the final score of the family conflict level could vary from 0 to 19, a maximum score of 19 showing the conflict on all the elements.

We also assessed: the age, diabetes duration, patients' gender, glycemia and HbA1c, insulin therapy and conflict presence in family regarding the child with diabetes mellitus. The assessment took into consideration the age of the children, therefore, two groups of study were created: children (8-12 years old) and teenagers (13-18 years old).

Statistical analysis. Data analysis was carried out in SPSS version 18 and included comparison tests (analysis in pair, T test, ANOVA) enforced for the scores regarding the life quality among the created groups (study group, control group, age groups, parents-children etc.). Moreover, correlation tests were used (parametric – Pearson and non-parametric – Spearman, Gamma correlation).

Results

Demographic and diabetes related data

Detailed information regarding the demographic and diabetes related data of the study group are given in Table 1. A total of 41.83% of the participants in the study were children and 58.17% teenagers. The average age in the study group was of 13.2 ±2.93 years, with minimum values of 8 years old and maximum values of 18 years old. The mean duration of type 1 diabetes mellitus was 3.22±2.5 years in children and of 6.25±4.05 years in teenagers, the differences between the two groups of patients being significantly statistic ($F=27.8$, $p<0.05$). The two analyzed groups (study, control) were homogenous from the point of view of patients' gender (Table 1).

Table 1. Demographic aspects and aspects specific to type 1diabetes mellitus vs. age groups.

	Age group		Total
	Child (8-12years old)	Teenager (13-18ani)	
Number of cases	64	89	153
DEMOGRAPHIC DATA			
Age	10.31±1.45	15.4±1.55	13.27±2.93
Length of diabetes	3.22±2.56	6.25±4.05	4.98±3.8
Gender (% male)	51.56%	51.69%	51.63%
Body mass index	17.06±2.22	21.36±2.79	19.9±3.33
One parent family	17.19% (n=11/64)	16.85% (n=15/89)	16.99%
DATA SPECIFIC TO DIABETES			
Insulin IU/kg	1.03±0.43	1.01±0.32	1.02±0.37
No. of injections a day			
Two	39.06%	38.20%	38.56%
Three	9.38%	7.87%	8.50%
Four	48.44%	52.81%	50.98%
HbA_{1C} (%)	8.73±2.11	9±2.02	8.89±2.05

Assessment of the life quality of the child with type 1 diabetes mellitus

PedsQL – Pediatric Life quality Inventory study group vs. control group

The analysis of the number of daily insulin injections highlighted the fact that most of the patients receive four injections a day (50.98%) - 52.81% of teenagers and 48.44% of children, while 38.56% receive two injections a day (38.2% of teenagers and 39.06% of children). HbA_{1C} values presented an average of 8.89% with minimum values of 5.11% and maximum values of 14.7% (Table 1). There were no

significant differences between HbA_{1C} values in children as compared to the ones obtained in teenagers (F=0.49, p=0481).

The global life quality was assessed by the children with type 1 diabetes mellitus and by their parents and compared to that of the control group. Based on the two sub scores, we could assess both the physical activities and the psycho-social aspects in the study group (Table 2).

Table 2. Average of PedsQL score in children with type 1 diabetes mellitus vs. control group.

	Type 1 diabetes mellitus	Control group	p 95%CI	
Subscale: Physical activities (item 1-8)				
Children	90.6±5.56*	91.56±6.57	0.403845	ns
Parents	90.4±5.51	90.52±6.79	0.916277	ns
Subscale: psycho-social aspects (item 9-23)				
Children	78.80±4.82	76.82±5.4	0.974366	ns
Parents	77.03±5.32	77.72±8.09	0.551881	ns
Total score				
Children	82.91±3.92	83.26±5.09	0.668451	ns
Parents	81.68±4.23	82.17±6.85	0.601909	ns

ns – not significant

Table 3. Average of PedsQL score for children with type 1 diabetes mellitus vs. age group.

	Child (8-12 years old)	Teenager (13-18 years old)	p 95%CI	
Subscale: physical aspects (item 1-8)				
Children	90.19±6.2	90.91±5.07	0.430956	ns
Parents	90.04±6.1	90.66±5.06	0.493278	ns
Subscale: Psycho-social aspects (item 9-23)				
Children	78.57±5.59	78.97±4.21	0.612105	ns
Parents	76.41±6.38	77.47±4.38	0.222353	ns
Total score				
Children	82.61±4.85	83.12±3.11	0.426622	ns
Parents	81.15±5.30	82.06±3.24	0.190211	ns

Comparing the life quality of the child with type 1 diabetes mellitus to the one of the children in the control group, we can notice that there was any significant difference neither for the total score nor among PedsQL sub scores regarding the physical activities and the psycho-social aspects (Table 2).

PedsQL score according to children age

We analyzed the PedsQL score assessed by the children and by their parents on the two study groups formed according to the age of participants (child – 8-12 years old, teenager – 13-18 years old). In all the analyzed situations, the life quality assessed by PedsQL score presented comparable values, there being any difference neither between the groups (child/teenager), nor between parents and children (Table 3).

The results of the correlational analysis highlighted the fact that there is no significant correlation among the score regarding the life quality of the child with diabetes mellitus (PedsQL) and the age of the child (r=0.0593, p=0.466), type of family (F=0.499, p=0.3017), length of diabetes mellitus (r=0.0263, p=0.747), number of daily injections (F=1.99, p=0.1178) or the total daily dose of insulin (units/ kg) (r=0.0497, p=0.591). Moreover, neither children assessments nor those of the parents presented a significant correlation with the gender of the

children with type 1 diabetes mellitus (F=1.129, p=0.289).

We noticed the presence of a significant opposite correlation between the total PedsQL score and HbA_{1C} (r= - 0.57, p=0.00536) in the sense that for high values of the score there are low values of HbA_{1C}. The significant correlation is also maintained in the case of PedsQL sub score for physical activities (r= - 0.4562, p=0.00422). Another significant correlation was established between the body mass index and PesdQL (r=0.311, p=0.0254).

The life quality reported by the children was in compliance with the life quality reported by the parents (r=0.9455, p<0.05), with no significant differences between these results.

Family conflict level reported by the child with diabetes mellitus

DFCS - Diabetes Family Conflict Scale

Family conflict level specific to the child with diabetes mellitus was assessed by DFCS - Diabetes Family Conflict Scale, the results of the study highlighting the absence of certain significant differences (F=0.426, p=0.514) between the two groups of participants (children vs. teenagers).

The result of the family conflict score was normalized according to the quintiles of the series (Q20, Q40, Q60, Q80) of values obtained. This method was useful in order to obtain an assessment scale of the conflict condition level. Therefore, we obtained 5 conflict levels: minimum (minimum value - Q20), low (Q20-Q40), moderate (Q40-Q60), high (Q60-Q80) and increased (Q80-maximum value) as detailed in Figure 1.

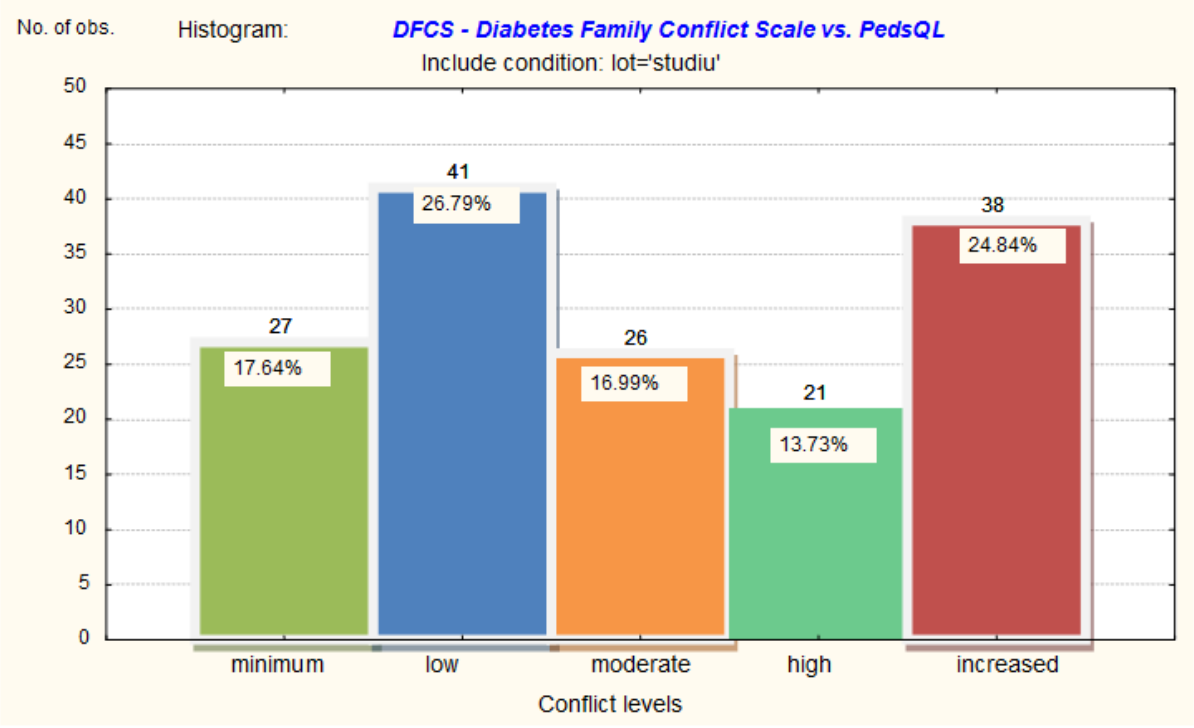

Figure 1. *Cases distribution according to the level of family conflict condition specific to the child with diabetes mellitus.*

The assessment of the family conflict condition in the child with type 1 diabetes mellitus highlighted the fact that 38.56% of the cases preset an increased and high conflict condition, while 61.44% present a minimum to a moderate conflict condition (Fig. 1).

The relationship between the life quality expressed by PedsQL and family conflict level

reported to the child with type 1 diabetes mellitus proves the presence of certain significant opposite correlations both in the case of PedsQL assessment by the children in the study group (r=-0.4251, p=0.0079) and in the case of PedsQL assessment by their parents (r=–0.509, p=0.00241). The average values of the total PedsQL score according to the DFCS scale group is given in Figure 2.

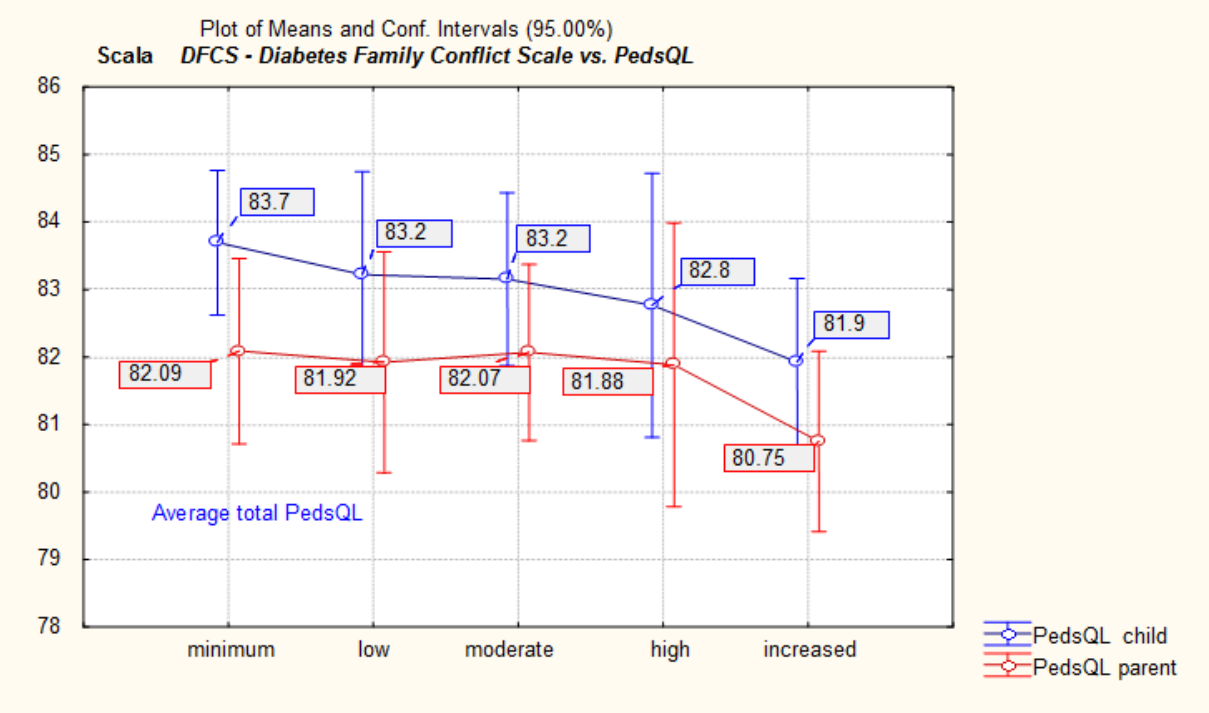

Figure 2. *Average values of PedsQL according to the DFCS scale group.*

Multivariate analysis of the association degree of the factors which influence the life quality (PedsQL life quality assessment score)

We performed a multivariate analysis regarding child life quality and the family conflict condition specific to diabetes (DFCS score), controlled according to age, length of diabetes, patients' gender, type of family (one parent), HbA_{1C} value, but also the number of insulin administrations a day and insulin dose.

I. The multivariate analysis of the predictive factors regarding PedsQL assessment score of life quality – assessed by the parents

Based on the results of PedsQL assessed by the parents, we found that DFCS score (r= -0.426, p=0.026014) is the most important predictive factor of the life quality of the child with type 1 diabetes mellitus, this one being followed by the daily number of insulin injections (r=-0.307, p=0.0365).

The daily insulin dose (r=-0.113, p=0.2351), but also the age of the participants in the study (r=0.095, p=0.361), HbA_{1C} value (r=-0.089, p=0.372), the type of family (r=-0.070, p=0.473), the length of diabetes (r=0.029, p=0.811) and their gender (r=-0.0102, p=0.915) do not influence in a significant manner the child life quality. The results of the multivariate analysis are given in Figure 3.

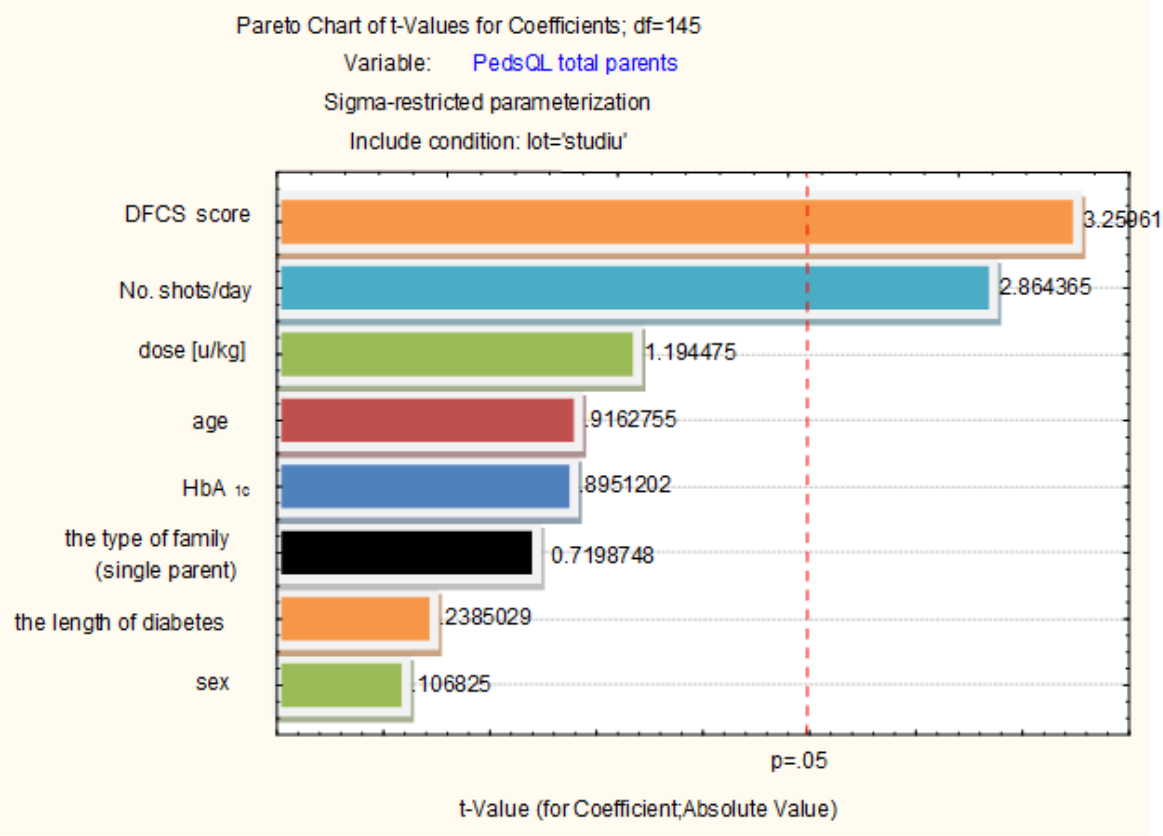

Figure 3. *Absolute value of "t" statistics in multivariate analysis assessment (parents perspective).*

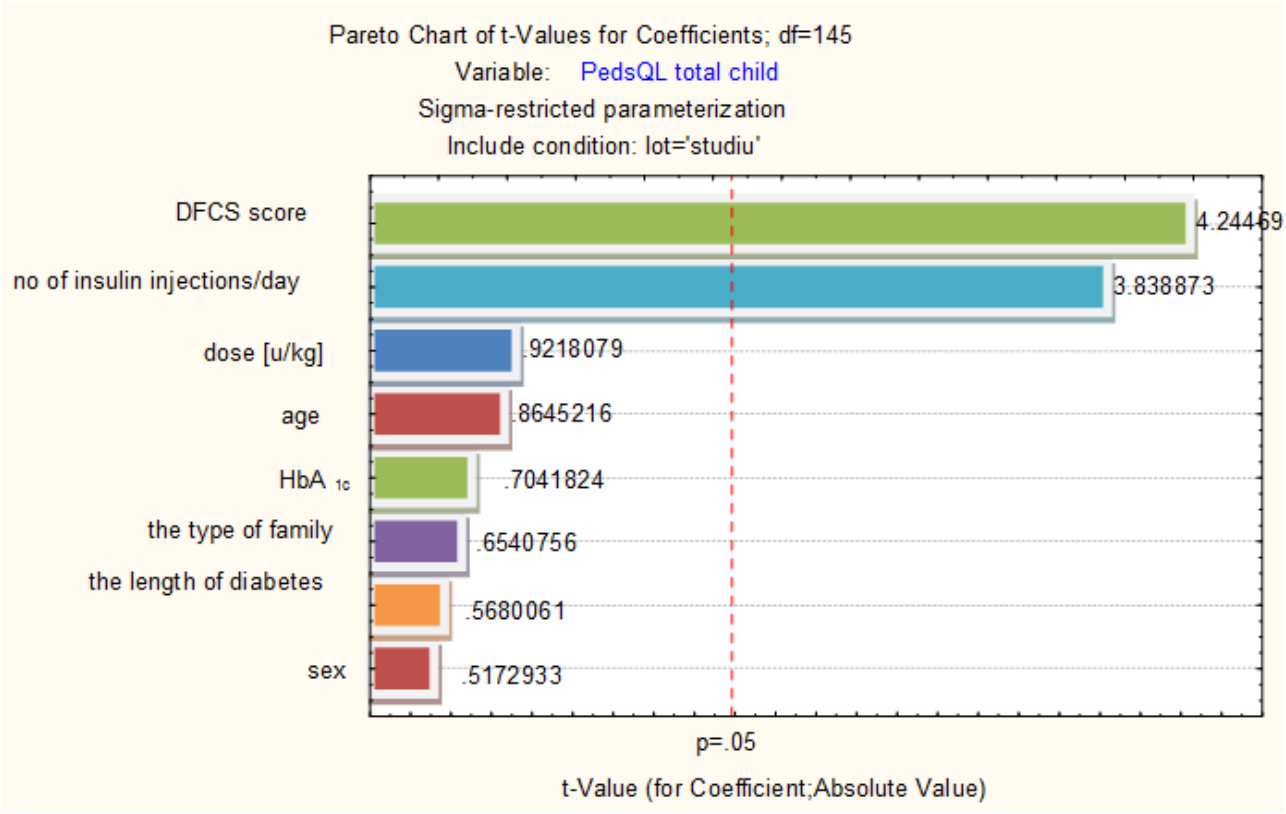

Figure 4. *The absolute value of "t" statistics in the assessment of the multivariate analysis (children perspective)*

II. The multivariate analysis of the predictive factors regarding PedsQL assessment score of the life quality – assessed by the children

We performed the same multivariate analysis regarding child life quality from child's perspective and the family conflict condition specific to diabetes (DFCS score), controlled according to age, length of diabetes, patients' gender, type of family (one parent), HbA_{1C} value, but also the number of insulin administrations a day.

The results were similar to the ones from the study of PedsQL score - parents and we can assess that DFCS score (family conflict specific to the child with diabetes) (r= - 0.422, p=0.02699) is the most important predictive factor of the life quality of the child with type 1 diabetes mellitus (child's perspective), this one being followed by the number of insulin injections a day (r=-0.317, p=0.0368) as shown in Figure 4.

Discussions

Diabetes mellitus appears in a child with his own history of life, an evolving personality, with his own anguishes, hopes and projects. We cannot talk about *the child with diabetes mellitus* generally speaking, because each child is unique in the manner in which he perceives his disease. The chronic evolution of diabetes can however impress other constant personality features, such as: passiveness, resistance, histrionism, suggestibility. Diabetes mellitus influences the development of the cognitive and emotional functions, the behavior of the child and teenager, marking his personality.

The medical problems of the child can be regarded by the parent and by the entourage as a negative reflection on the parent. The parents are concerned by the financial problems which affect their capacity of coping with the situation. Rejecting the disease, its negation, the feeling of guilt or fury can interfere with parents' ability of cooperating with the medical team.

As for the distance in the couple parent-child, it can increase by a mechanism of defense of the parent or can become too close, sometimes intrusive; it is possible to encounter sharp transitions which affect the model of the subsequent relationships. In certain families, there can appear conflicts with the elder brothers, given the fact that parents focus their attention on the child with diabetes mellitus.

The family conflict specific to diabetes mellitus can derive from the decrease of child life quality if the parents criticize the manner of managing the disease, such as the glycemic monitoring, insulin administration, dietetic aspects. Therefore, the possessive involvement of the parents can represent the premise of family conflict occurrence. On the other hand, family involvement does not generate conflicts when it includes positive communication aspects [7].

The aspects described in this study, as in the case of other authors [13,14], express potentially modifiable interactions that can represent therapeutic goals for improving the life quality of the young person with diabetes mellitus. Once with the general endeavors of the medical community for improving and intensifying the glycemic control, the interventions for family support must include struggles to reduce family conflict for the purpose of preserving child life quality.

It is well established that adherence rates decrease as children and adolescents get older and our results are similar. Although age was a significant covariate of adherence, it did not retain significance in the equations predicting the life quality, suggesting that other factors likely have a stronger direct association with biological outcomes. Specifically, medical factors, such as

the mode of insulin administration, and family characteristics, such as diabetes-specific family conflict, were associated with the life quality level. The key implication of this study is that early identification and treatment of diabetes-specific family conflict are critical to prevent a trajectory of declining adherence and glycemic control across the teenage years.

Another aspect which derives from the study is the fact that the parents of the children with type 1 diabetes mellitus perceive a degradation of their life quality both from a physical point of view and at social and emotional level. These values of the total score and of the sub score regarding the physical and the psycho-social condition of the child with type 1 diabetes mellitus is not however significantly smaller as compared to the non-diabetic patients (control group).

The multivariate analysis highlighted the fact that among all the analyzed factors (age, length of diabetes, patients' gender, type of family (one parent), HbA_{1C} value, but also the number of insulin administrations a day, the insulin dose and the family conflict score specific in the case of the child with diabetes mellitus (DFCS)), only the DFCS score and the number of insulin administrations a day influence in a significant manner their life quality. In this respect, the results were similar both in the assessment performed by the parents and in the assessment performed by the children. This result can be explained by the special and often exaggerated care of the parents with regard to the management of type 1 diabetes mellitus, which can significantly diminish the relationship parent – child. These results are similar with other studies [3,5], mentioning in addition the presence of a correlation between the life quality and the glycemic control.

As with all clinical research, this study has limitations. The sample consisted primarily of adolescents, but the number of patients has not been very big and has been not analyzed the quality of life in children under the age of 8 years. The findings of this study raise a number of important questions to be investigated in future research and would have implications for clinicians and researchers gathering data about the family environment from both parents and children, because the quality of family interactions plays an important role in how is achieved and maintained glycemic control.

Conclusions

Both the global life quality of the child with type 1 diabetes assessed by parents and children, and the aspects regarding the physical and psycho-social activities based on the two sub scores, could be assessed in comparison with the control group. The results did not highlight significant differences in the study group as compared to the control group, neither in the assessment performed by the children ($F=0.18402$, $p=0.66845$) nor in the assessment performed by the parents ($F=0.236085$, $p=0.6019$). Even though these children follow a treatment with insulin injections and are submitted to a strict regimen with regard to glycemia and meals control, etc., they do not perceive a major decrease of the life quality.

Our results highlight the fact that family involvement in the management of diabetes mellitus of the child represents a fertile field for the family conflicts if the involvement is not performed prudently and if it does not include a good communication. Therefore, we propose the enhancement of the glycemic control and the intensive and correct involvement of the family in the management of diabetes mellitus in the child, in order to reduce the conflicts specific to the disease and to maintain a high level of child life quality.

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