A determination of the quality of life of children and adolescents with type 1 diabetes and their parents☆

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ABSTRACT

Objective: Type 1 diabetes is a chronic illness which can have a negative effect on the health care and development of children and can put their lives in danger. This descriptive study aimed to determine the quality of life and the factors affecting it of children and adolescents with type 1 diabetes using the Pediatric Quality of Life Inventory (PedsQL).
Methods: The study was conducted in the Child Endocrinology Unit of a University Hospital in Bursa, Turkey. Totally 64 children eight-12 years and 85 adolescents aged 13–18 with type 1 diabetes and their parents were recruited. HbA1c measurements were obtained from the records of the endocrinology clinicare, which were made once every three months, and the average of the last three measurements was taken in the study. The PedsQL was used to measure quality of life of the children and adolescents. The data was analyzed using SPSS version 20.0 and $P < 0.05$ was considered significant. The demographic data of the children and parents were analyzed using means and percentiles. Pearson's correlation analysis was used to assess the relationship between two averages.
Results: Of the sub-groups on the scale, affective and school function scores were somewhat low, and social function scores were high. The quality of life scores of the children and adolescents were found to correlate with those of their parents. A negative correlation was found between HbA1c levels and adolescent quality of life, a positive correlation was found between the child's age and the quality of life of the child and parents, and a negative correlation was found between the number of children in the family and the quality of life of the child and parents.
Conclusions: An evaluation of the quality of life after a diagnosis of diabetes can be used to assess the problems which may be faced by children and adolescents and to combat these problems.

1. Introduction

Type 1 diabetes is one of the most widely seen chronic childhood diseases, and approximately 0.25%, around 208,000 children and adolescents under the age of 20 in the world today are affected by it [1]. Children have to face the short and long term effects of the illness. The treatment for type 1 diabetes, its evaluation and the approach to the disease are different between children and adolescents. In the adolescent period in particular, developmental and emotional problems are encountered and it has been said that HbA1c levels must be kept below 7.5% in order to reduce the long term health problems of diabetes [1,2]. For this reason, the main aim of diabetic care must be to keep the social and psychological development of children and adolescents, along with glycemic control, at optimum levels [3–5].

The concept of quality of life formed from the physical environment and a combination of social, emotional and school-related functions [5–10], can be affected by factors such as the age of onset of diabetes [7,11], and the child's age and sex [12]. The parents' views on illness, achieving glycemic control, and the lifestyle of their children is also very important [7,11,14–16]. For this reason, child-family-illness-focused approaches are necessary in order to

make decisions on the management of type 1 diabetes [4,17].

This research was planned as a descriptive study with the aim of determining the quality of life of children eight-12 years and adolescents aged 13–18 with type 1 diabetes and that of their parents, and the factors affecting it.

2. Methods

2.1. Sample

The universe of the study consisted of children and adolescents with type 1 diabetes registered at the Child Endocrinology Clinic and Outpatients Department of the Medical Faculty Hospital of Uludağ University in Bursa, Turkey, and their parents. Criteria for inclusion in the study were a years of between eight and 12 for children and 13 and 18 for adolescents, a diagnosis of type 1 diabetes made at least six months previously, having started treatment, and having parents with them. Totally 64 children eight-12 years and 85 adolescents aged 13–18 with type 1 diabetes and their parents were recruited.

2.2. Data collection

This cross-sectional study was conducted between October and December 2012. The study data was drawn from the retrospective medical records of the clinic and the results of the personal questionnaire of the diabetic patients or their parents. Personal questionnaire was performed by the researchers by one-to-one interviews with the children/adolescent with type 1 diabetes and their parents in the hospital. Completing the questionnaires took approximately 15–20 min. The researchers used a personal characteristics form, quality of life measurement forms for the eight –12 and 13–18 years groups, and a quality of life form for the parents. The personal characteristics forms were developed by the researchers in line with the literature [3–5].

2.2.1. The personal characteristics form

The form for use with children contained questions dealing with demographic and illness-related topics such as the child's sex, weight, height, age, how many years they had had diabetes and the age at which it had started, HbA1c levels, the number of times per day that their blood glucose was measured, and how they took insulin.

The parents' form had questions on marital status, educational level and family income. There were also questions on whether the children had had hypoglycemic attacks, and how many, how many times they had been taken to hospital because of diabetes, and how many days they had stayed in hospital.

2.2.2. HbA1c

HbA1c measurements are made once every three months, and the average of the last three measurements (taken over nine months) was taken in the study. HbA1c measurements were obtained from the records of the endocrinology clinic.

2.2.3. Pediatric Quality of Life Inventory (PedsQL)

The Quality of Life Scale was devised by Varni et al. [18] to measure the quality of life in relation to illness of children and adolescents between the years of two and 18. The forms for children and adolescents were similar, but the children's form used simpler language because of the difference in cognitive development.

The inventories are forms for child self-report and parent proxy-report scales. Child and adolescent self-reports include ages 8–12 and 13–18 yr. Parent proxy-report includes ages 8–12 (child),

13–18 (adolescent) and assesses parent's perceptions of their child's fatigue. The items for each form are essentially identical. The parent proxy-report forms are parallel to the child self-report forms and are designed to assess the parent's perceptions of the child's health-related quality of life.

The quality of life inventory for children consists of 23 items. The total score on the inventory are made up from the fields of total psychosocial health score derived from the calculation of the scores of the three subscales evaluating affective, social and school functions [19]. The items are scored between 0 and 100. Total scores are obtained by totaling the scores and dividing them by the number of items completed. The result is that the higher the total score, the higher perceived quality of life. The inventory is short and can be completed in five to 10 min, so that one of its most important characteristics is that it is easy for the researcher to apply and score. Validity and reliability of the Turkish version of the Quality of Life Inventory for Children was tested by Memik N.Ç. et al. This is an inventory applied to children aged eight –12, adolescents aged 13–18 and to parents [20]. A five-point response inventory is used for child/parent self-report (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). The Pediatric Quality of Life Inventory (PedsQL) is an inventory measuring general quality of life and is suitable for use with large populations such as schools and hospitals, as well as with healthy and sick children and adolescents.

2.3. Evaluation of data

Evaluation of data was carried out by computer using SPSS 20.0 for Windows. The demographic data of the children and parents were analyzed using means and percentiles. Pearson's correlation analysis was used to assess the relationship between the HbA1c, age, number of children and PedsQL. For all the analyses, $P < 0.05$ was considered to be statistically significant.

2.4. Ethical permission

Ethical permission for the study was obtained from the Ethics Committee of Uludağ University Medical Faculty (2012-14/15). Participants were provided with information about the study, and they took part voluntarily after oral and written approval had been obtained. Permission to use the child-adolescent-parent version of PedsQL was obtained from Memik [20].

3. Results

The mean age of the children was 10.20 ± 1.53 years, and that of the adolescents was 14.96 ± 1.5 years. The mean HbA1c levels were 9.65 ± 2.39 in the children and 9.53 ± 2.57 in the adolescents (Table 1).

Total scores on the PedsQL inventory were found to be 79.91 ± 13.60 for the eight-12 year-olds and 79.89 ± 14.87 for the 13-18 year-olds. When the total scores on the inventory of the children, adolescents and parents were compared, it was seen that they correlated with each other (Table 2).

It was observed that the views on quality of life of the children, adolescents and parents coincided to a large extent (Table 3).

A statistically significant negative relationship was found between HbA1c level and total PedsQL score ($P < 0.05$) in the adolescent group. A significant relationship ($P < 0.05$) was also observed between the children's ages and the directly related PedsQL scores of the children and their parents. A significant negative relationship was determined between the number of children in the family and the PedsQL scores ($P < 0.05$) of both the children and their parents, and a rise in the number of children

Table 1
Demographic characteristics of individuals with Type 1 Diabetes ($n = 149$).

Demographic characteristics	Children (age 8–12, $n = 64$)	Adolescents (age 13–18, $n = 85$)
Sex		
Female	26 (40.6%)	38 (44.7%)
Male	38 (59.4%)	47 (55.3%)
Age	10.20 ± 1.53	14.96 ± 1.5
How many years diabetic?	3.47 ± 2.94	5.05 ± 3.51
HbA1c	9.65 ± 2.39	9.53 ± 2.57
How often is blood sugar measured?(presume per day)	4.30 ± 1.44	3.85 ± 1.22
How is insulin taken?		
Injection	62 (96.9%)	83 (97.6%)
Pump	2 (3.1%)	2 (2.4%)
Ever hospitalized?		
Yes	23 (35.9%)	32 (37.6%)
No	41 (64.1%)	53 (62.4%)

Table 2
Mean PedsQL scores for the children (age 8–12, $n = 64$), adolescents (age 13–18, $n = 85$) and their parents ($n = 149$).

PedsQL	Children	Children's parents	Adolescents	Adolescents'parents	t	P
Physical health	81.54 ± 14.62	71.82 ± 22.43	85.52 ± 13.27	72.80 ± 25.19	−2.070	0.043
Affective function	74.29 ± 20.96	72.81 ± 22.14	74.05 ± 17.13	69.87 ± 20.50	0.323	0.748
Social function	90.85 ± 13.29	82.73 ± 22.39	91.77 ± 12.83	85.60 ± 19.37	−0.453	0.652
School function	74.52 ± 20.01	75.54 ± 15.76	73.79 ± 18.07	69.49 ± 22.79	−0.440	0.662
Total	79.91 ± 13.60	74.91 ± 15.24	79.89 ± 14.87	72.84 ± 18.03	0.056	0.956

Note: t values in the table mean the comparison between scores of children and adolescents.

Table 3
Correlation between child, adolescent and parental PedsQL scores ($r,n = 149$).

PedsQL	Parents				
	Physical health	Affective function	Social function	School function	Total
Children (age 8–12)	0.349[a]	0.865[b]	0.483[b]	0.489[b]	0.628[b]
Adolescents (age 13–18)	0.284[c]	0.438[b]	0.346[a]	0.532[b]	0.304[a]

Note: [a]$P < 0.01$, [b]$P < 0.001$, [c]$P < 0.05$.

lowered the quality of life of both children and parents (Table 4).

In conclusion, a negative correlation was found between HbA1c levels and quality of life. Also, as the number of children rose, the quality of life fell.

4. Discussion

It was found that the total scores on the quality of life scale of eight-12 year-olds, 79.91, and that of 13–18 year-olds, 79.89, were very close to each other (Table 2). Other studies had similar results on this topic 75.6 [7], 80.91 [5] and 77.78 [20]. Lukács et al. [12] found life quality scores in children and adolescents of 69.3 in females and 72.76 in males. In studies comparing the quality of life of children and adolescents with type 1 diabetes mellitus and healthy children and adolescents, it was found that the scores of the two groups were similar [5,10,20,21]. Other studies were encountered, however, in which the scores of healthy children and adolescents were higher than those of diabetics [11,22].

It was observed in the study that while the children's scores on the social function subscale were high, their scores on the subscales of affective function and school function were low. Emmanouilidou et al. [5] found that the best discriminator for quality of life was social function. Other studies had similar results: Lukács et al. [13] found that social function was the highest and affective and school

Table 4
Comparison of child, adolescent and parental HbA1c levels with PedsQL scores according to age and number of children ($r,n = 149$).

Characteristics			Physical health	Affective function	Social function	School function	PedsQL total
HbA1c	Age 8–12	Child	−0.053	−0.021	−0.050	0.078	0.007
		Parent	−0.110	0.026	−0.260[a]	−0.079	−0.191
	Age 13–18	Adolescent	−0.205	−0.245[a]	−0.317[b]	−0.224[a]	−0.266[a]
		Parent	−0.126	0.002	0.009	−0.280[a]	−0.141
Age	Age 8–12	Child	0.339[b]	0.309[a]	0.145	0.164	0.271[a]
		Parent	0.391[b]	0.262[a]	0.205	0.002	0.305[a]
	Age 13–18	Adolescent	−0.112	−0.072	0.029	−0.025	−0.086
		Parent	−0.018	−0.092	0.045	−0.145	−0.149
Number of children	Age 8–12	Child	−0.105	−0.301[a]	−0.129	−0.236	−0.253[a]
		Parent	−0.208	−0.209	−0.189	−0.283[a]	−0.256[a]
	Age 13–18	Adolescent	−0.115	−0.198	−0.049	−0.133	−0.088
		Parent	−0.253[a]	−0.315[b]	−0.086	0.014	−0.191

Note: [a]$P < 0.05$, [b]$P < 0.01$ based on Pearson Correlation analysis.

functions were low; Abdul-Rasoul et al. [7] found that the subscale of school function was the lowest. Although there is no restriction of physical space for children with type 1 diabetes, emotional problems such as anger and psychosocial problems can arise [23]. On the other hand, it is known that after children and adolescents are first diagnosed they have difficulty getting used to the new health condition caused by their illness, but that in time they adapt to their illness and their perceptions of quality of life improve, even though they were low at the beginning [15,24,25]. It has also been found in other studies that type 1 diabetes did not affect social life. In Turkish culture, such factors as the high regard for children and support from the extended family may help the child to face problems from outside the family. The findings of the study suggest that it is necessary to get help on topics which need sensitivity such as in the emotional field and in school life.

As can be seen in Table 2, the total quality of life scores of the parents were somewhat lower than the evaluation of the children, but in Table 3 the scores of the patients and their parents largely coincide.

In the assessment of quality of life, it was expected that the scale and subscale scores of the patients and their parents would coincide, and in fact the degree of fit between patient and parental scores was high in this study [11,16](Table 3). In studies by Emmanouilidou et al. [5], Reid et al. [6], and Lukács et al. [13], a significant relationship was found between the scale scores of the patients and their parents [5,6,13]. The parents may be more affected by the illness than the children themselves, and this illness may have great effects on their lives [11]. This significant correlation may be said to show that the parents closely monitor the children's physical, emotional, social and school functions, and that they take a close interest in their children.

Young people have an increased risk of psychosocial problems. The existence of diabetes can make a person feel different and alone [26], affect an adolescent's attempts at independence, reduce family control, and cause a deterioration in the metabolic control of an adolescent as a result of conflicts within the family [8,27]. A negative relationship was detected in the study between HbA1c levels in adolescents in the 13−18 years group and their total PedsQL scores (Table 4). This result is in accordance with the results of other studies on similar populations [6,7,10]. The participation of parents in the management of diabetes increases the child's compliance with achieving metabolic control and self management. However, the American Diabetes Association discusses the need for allowing a gradual progression to independence and the reduction of parental control in the middle and high school years in its advisory standards. A conflict between adolescents and their parents can worsen metabolic control [28].

Lawrence [8] found a negative correlation between the HbA1c levels of all children in the eight-17 years group and their total scale scores and psychosocial subscale of quality of life values.

The results of this study show that the factors which make up a child's psychosocial health − the child's feelings, social relationships and school success − are negatively affected by blood glucose control. This topic needs to be supported by further studies with a wider participation.

In the eight −12 years group, an increase in age and an increase in physical and affective functions also raised the general PedsQL score, but in the adolescent group there was no difference. Lawrence [8] reported that there was a very small effect of age on quality of life. In a report by Kalyva et al. [11], it was found that as the age of the onset of diabetes increased, blood HbA1c levels were lower and quality of life was higher than in the younger age group. In the present study it can be said that physical and emotional development of children in the eight-12 years group increased with age.

The number of siblings had a negative effect on the quality of children in the eight −12 years group and their parents. On this topic, the feelings of the children and their parents were similar. No study was found on the connection between the number of children in a family and quality of life in diabetics.

In addition to the research data, a relationship was found between quality of life and the duration of the diabetes, the sex of the child or adolescent, their age, and the educational level of the parents. Similar findings were seen in two other studies [5,14], and in a further study a relationship was found between quality of life and age, sex and the duration of the diabetes [29].

5. Conclusions

PedsQl scores were generally found to be at a good level in the study. Affective and school functions were somewhat low, while scores on the subscale of social function were higher. The PedsQL scores of the children, adolescents and their parents were similar. There was a negative relationship between HbA1c levels and adolescent quality of life, a positive relationship between the child's age and the quality of life of the child and parents, and a negative relationship between the number of children and the quality of life of the children and parents. An evaluation of the quality of life after a diagnosis of diabetes can be used to detect early and to combat problems which children and adolescents may encounter.

Nurses should talk especially to young people about blood sugar balance and the activities which they participate in. In order to raise affective and school function scores, which were found to be low in the study:

1. Intervention is recommended to strengthen quality of life when facing the problems specific to diabetes: education on adaptation to the illness, self-efficacy, psychological wellbeing, etc.
2. There must be support from schools in the process of adaptation to diabetes as it relates to school life. Measures such as providing a suitable environment for blood glucose monitoring and giving injections, education of the peer group on diabetes with the aim of reducing the child's feeling of being left out [26], and making school programs more flexible would reduce the problems encountered by children and adolescents to a minimum [7].
3. In families with a large number of children, it is necessary to involve the siblings in diabetes education and enable them to take responsibility, and to show the families where they can obtain social support.

Acknowledgments

Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.ijnss.2017.01.008.

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