

Health related quality of life of children and adolescents with Type 1 diabetes

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Abstract

Type 1 diabetes mellitus is a chronic health condition which affects approximately 750 thousand diabetics in the Czech Republic out of whom 3300 are children at the age of 8–18 years. The effects of illness and treatment go beyond medical control therefore evaluation of quality of life (QOL) is vital for children and adolescents with diabetes in order to examine how diabetes and its complicated and demanding treatment regimen affects their various life domains – family relationships, school, social activities, etc. Health related quality of life has been recognized as an important pediatric outcome measure in the past years and therefore health related quality of life of these children and adolescents was evaluated. The Pediatric Quality of Life Inventory 4.0 (PedsQL) and PedsQL 3.0 Module Diabetes were translated into the Czech language and administered to 79 children with diabetes and 79 parents. The objective of this study was to examine general and health related quality of life of children with diabetes at the age of 8–18. Results showed, that children endorse greater QOL in both general and diabetes related scales compared to their parents. Also, the concordance in reports of parents and children of QOL in children was variable. With regard to the aim of the research to determine whether QOL outcomes are predicted by duration of diabetes, results show that the duration of diabetes is a significant predictor of QOL in children. These results of QOL in children in the Czech Republic are then compared with the outcomes available from abroad.

INTRODUCTION

According to the Institute of Health Information and Statistics of the Czech Republic, type 1 diabetes (T1DM) is a chronic illness that has affected approximately 750 thousand inhabitants in the Czech Republic in 2006 (Health statistics, 2006). Out of this number, more than 3300 children and adolescents in the age 8–18 years are treated for T1DM. Each year there are approximately 200 new cases of T1DM in children.

T1DM is a chronic condition in which the body is unable to utilize glucose, an essential source of energy, caused by malfunction of insulin production in the pancreas. At the same time it affects the management of other important nutrients and

therefore influences the general transformation of nutrients in the body. While there is no cure, T1DM can be managed with a complex treatment regimen that includes frequent blood glucose checks and insulin injections, as well as monitoring of food intake and exercise. Medically, the goal for children is to maintain blood glucose at “near normal” levels (metabolic control), that is, levels that are as close as individuals without T1DM (Kasalová-Daňková, 2006).

In the past, medical outcomes have been the primary measure of successful treatment of T1DM. However nowadays, health-related quality of life (QOL) has received increased attention as an important outcome measure for individuals with chronic illness (Golden, 1998). Evaluation of

Abbreviations:

PedsQL – Pediatric Quality of Life Inventory;
QOL – quality of life

QOL is vital for children for children with T1DM in order to examine how diabetes and its complicated and demanding treatment regimen affect various life domains (family relationship, school, social activities, etc.) of the developing child (Varni, 1999; Eiser, 2001). Diabetes management not only involves numerous daily diabetes-specific tasks such as insulin injections and blood glucose checks, but also interferes with activities of daily functioning such as eating, sleeping, exercising, and socializing with friends, all of which may impact QOL.

Researches that have been conducted in the Czech Republic focused on the adult population (Petr, 2004; Krivohlavý, 2004). Data on the health-related quality of life of children with diabetes mellitus for the Czech Republic were unknown up till today. Even though T1DM is diagnosed predominantly in childhood, most of the researches on QOL of diabetics were realized abroad and with adults and adolescents and these are the only available data for comparison (Lloyd, 1999). Important information has been provided by these studies yet there are significant developmental differences between the two age groups and QOL issues that may be uniquely relevant for younger children.

Thanks to present development of QOL measures, general and diabetes specific measures are available for specific age groups.

The purpose of this dissertation thesis was to evaluate general quality of life and diabetes related quality of life in children and adolescents from 8–18 years of age with Type 1 diabetes and their caregivers. The aim of this work was to find out the quality of life of children and adolescents with type 1 diabetes mellitus as well as to find out the level of concordance in answers of children and caregivers in general and diabetes related questionnaires.

MATERIAL AND METHODS

The object of the research was to find out general and diabetes specific QOL of children and adolescents with T1DM in the age 8–18 years. Children and adolescents with T1DM in the age group 8–18 years were the subject of this research. Research was conducted on children and adolescents, who are on file in diabetes centers in the Czech Republic in towns Ceske Budejovice, Pisek, Pribram, Pardubice, Strakonice and Tabor. The method used to gather data was a questionnaire. The original intention to carry out an international comparison of outcomes of HRQOL in children and adolescents in the age group 8–18 years from the Czech Republic and Canada was not possible to carry out, due to the unavailability of patient data and inaccessibility of health organizations in Canada.

Doctors in the mentioned diabetes centers were addressed and they agreed to participate in the research. Some doctors and nurses distributed the questionnaires after being thoroughly educated on how to distribute the questionnaire and in other cases I have personally distributed the questionnaires and gathered the data. Each time the child and parent had received one set of questionnaire, which contained the basic information on the research, background variable questions, the PedsQL 4.0 and PedsQL 3.0. The parent version also included parent's informed consent, where the parents agreed for their child to participate in the research by signing the consent. If the consent was not signed, the child was excluded from the research. The sample consisted of 79 children in the age range 8–18 years and one of their parents.

Apart from the background variables respondents were also asked to indicate the level of their last measured HbA1c. This value determines average glycaemic levels within the last 8–10 weeks and through this value the level of compensation is determined. Former studies showed that the HbA1c levels are reliable for determining the level of compensation in children. The level of HbA1c is considered as more reliable in comparison to the measured levels of glycaemia in the past week, which can be influenced by the daily activities (Dane-man, 1981). The levels of compensation that the respondents indicated were the level obtained during their last visit to the diabetes centre. The level of compensation is according to the Czech Diabetes Association and the Czech Association of Clinical the following levels of HbA1c: excellent (< 4.5 %), satisfactory (4.5–6.0 %) and unsatisfactory (> 6.0 %) (CDA, 2007).

PedsQL 4.0 Generic Core Scales. After initial review of available questionnaires on QOL for the given age group and focused on chronic illness T1DM it was decided to use the only suitable questionnaire for Quality of life of children and adolescent diabetics – the PedsQL – Pediatric Quality of Life Inventory (Varni, 2004; 1999). It is a measure, which evaluates the general and diabetes related QOL.

Namely the PedsQL 4.0 Generic Core Scale was used. This evaluates the general quality of life in children and adolescents. In accordance to the WHO definition of health the PedsQL 4.0 evaluates social functioning, emotional functioning and the physical functioning of the respondent.

The PedsQL 4.0 Generic Core Scales is a commonly used measure of general QOL of children. Among the existing instruments in this field, the PedsQL 4.0 Generic Core Scales is the only empirically validated measure that has demonstrated item scale construct consistency, is available in child self-report and parent-proxy form, and can be used with a broad age range (2–4 years, 5–7 years, 8–12 years, 13–18 years) and in several world languages including Czech. In the version for children in the age group 2–4 years the questionnaire is filled out by parents only. The version for the

age group 5–7 years the respondents evaluate QOL on three point Likert scale 0=never, 1=sometimes, 2=often with appropriate „happy faces“. In the version for the age group 8–12 years and 13–18 years the respondents evaluate on a five point Likert scale „how big of a problem was the following for you in the past ONE month“ 0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always. Results in the end are converted on a scale 0–100, where it applies, that the higher the score, the higher the HRQOL (Varni, 2002; 2003).

Since this instrument is a measure of general QOL it can be used with samples of healthy children as well as children with acute or chronic illness. Research has shown that the core scales successfully distinguish these two groups. Additionally, there are disease specific modules of the PedsQL Generic Core Scales that provide detailed information about health-related QOL in various illnesses.

PedsQL 3.0 Type 1 Diabetes Module. The recently developed PedsQL 3.0 Type 1 Diabetes Module (Varni, 2003) is a disease specific measure of diabetes related QOL. The scales within this measure examine various treatment and adjustment issues related to T1DM. The PedsQL 3.0 Type 1 Diabetes Module has a version for child and the parent and can be also used among large age groups and is also available in several world languages (Varni, 2001). The questionnaire has 28 questions divided into the following categories: difficulties with diabetes symptoms, barriers to treatment, treatment adherence and diabetes related worries and communication. Division of age and evaluation of the PedsQL 3.0 Type 1 Diabetes Module is the same as in the PedsQL 4.0 Generic Core Scale.

This questionnaire was not unfortunately available in the Czech language; however Dr. Varni, the author of these questionnaires makes it possible for research purposes for the researchers to translate the questionnaires according to language validation process. Therefore the questionnaires were translated into Czech language. The Czech version of the questionnaire originated at the Faculty of Health and Social Studies at the University of South Bohemia in Ceske Budejovice, Czech Republic.

The translated version has undergone a linguistic validation process, which the author requires before using the questionnaire in the field. In 2007 a pilot study was conducted on a sample of 10 respondents according to the protocol requirements and later in the beginning of 2008 we have received the author's resolution that our translation can be used and are on the list of validated translations (Varni, 2008).

DATA ANALYSIS – RESULTS

Statistical data analysis was done in the statistical programme SPSS (Statistical Package for the Social Sciences).

Table 1 shows descriptive statistics of the sample. Here the identification data, level of compensation and means of general QOL and diabetes specific QOL are shown. The sample consisted of 79 children – 45 boys (57% of the sample) and 34 girls (43% of the sample). One parent always responded with one child. The average age of the sample was 13.5 years, the youngest was 8 years old and the oldest was 18 years old. Average duration of diabetes was 3.9 years and the average level of HbA1c was 6.8% which indicates, that the sample's compensation was rather unsatisfactory.

Table 2 informs about the Pearson correlation among the PedsQL 3.0 and the PedsQL 4.0. The outcomes show, that the variables are statistically significant. The most significant relation was proven between the duration of diabetes and compensation in both children and parent answers.

Main aim:

Analysis of the main aim of the research – find out the level of general QOL and diabetes related QOL in children and adolescent diabetics – was done by calculating the mean and standard deviation. According to the author, Dr. Varni, this value will determine the level of general QOL and diabetes specific QOL. According to the directions of the author the general QOL and the diabetes specific QOL is evaluated on a scale of 0 – 100, but the lower or higher rate level, which determines the

Table 1: Descriptive statistics of the group of respondents.

DESCRIPTIVE STATISTICS						
	% (number)	Mean	Std. deviation	N	Min.	Max.
Age		13.56	2.92	79	8	18
Duration of diabetes		3.85	1.42	79	1	8 years and more
Insulin application		2.16	0.37	79	pen	Pump
HbA1c		6.83	0.75	79	5.2	8.9
PedsQL 4.0		83.26	10.68	79	55.4	96.7
PedsQL 3.0		75.23	10.34	79	47.3	98.2
Boy	56.96 (45)					
Girl	43.03 (34)					

Note: N = total number of respondents;

Source: own research

Table 2: Correlation coefficient in descriptive statistics and compensation in relation to the values of PedsQL 4.0 and PedsQL 3.0

CORRELATIONS										
		Age	Sex	Duration of diabetes	Insulin application	Compensation	PedsQL 4.0 -child	PedsQL 4.0 - parent	PedsQL 3.0 - child	PedsQL 3.0 - parent
Age	Pearson correlation									
Sex	Pearson correlation	-.246*								
Duration of diabetes	Pearson correlation	.376**	-.069							
Insulin application	Pearson correlation	.044	.304**	.144						
Compensation	Pearson correlation	-.054	.038	-.315**	-.043					
	Pearson correlation	.222*	-.037	.223*	.060	-.030				
PedsQL 4.0 – parent	Pearson correlation	.285*	-.102	.138	-.023	-.065	.852**			
PedsQL 3.0 –child	Pearson correlation	.210	-.172	.284*	-.025	-.120	.655**	.557**		
PedsQL 3.0 –parent	Pearson correlation	.171	-.157	.150	-.198	-.057	.467**	.583**	.685**	

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed). Source: own research

Table 3: Means and standard deviations of answers of children and parents in PedsQL 4.0 and PedsQL 3.0.

DESCRIPTIVE STATISTICS							
Child	Mean	Std. deviation	N	Parent	Mean	Std. deviation	N
Physical functioning	87.540	13.0152	79	Physical functioning	85.206	13.8197	79
Emotional functioning	78.481	15.9798	79	Emotional functioning	77.405	15.8693	79
Social functioning	93.734	11.5044	79	Social functioning	92.215	14.0454	79
School functioning	70.696	16.2854	79	School functioning	68.354	17.8261	79
Difficulties with Diabetes symptoms	71.030	12.7762	79	Difficulties with Diabetes symptoms	66.830	11.7167	79
Barriers to treatment	72.468	17.3494	79	Barriers to treatment	67.642	18.0077	79
Treatment adherence	84.629	11.3134	79	Treatment adherence	81.736	13.3261	79
Diabetes-related worry	71.308	18.1864	79	Diabetes-related worry	51.160	24.4503	79
Diabetes-related communication	76.266	20.1087	79	Diabetes-related communication	79.641	21.5061	79
PedsQL 4.0	83.255	10.6805	79	PedsQL 4.0	81.370	11.5986	79
PedsQL 3.0	75.226	10.3400	79	PedsQL 3.0	70.366	10.4654	79

Source: own research

good or bad QOL, is not determined. But generally it applies that the higher the mean the higher the QOL (Varni, 1999).

Table 3 shows means and standard deviations of the answers of children and parents in PedsQL 4.0 and PedsQL 3.0. In this sample the children showed higher general QOL – 83.3, as well as diabetes specific QOL – 75.2. On the other hand parents evaluated their general QOL – 81.4 and diabetes specific QOL – 70.4. Children evaluated the lowest levels in the region of school functioning – 70.7, and parents evaluated the lowest diabetes related worries – 51.2. The second lowest levels both groups evaluated in the area of difficulties with Diabetes symptoms – children 71.1 and parents 66.8.

Table 4 shows the correlation coefficients of general QOL (PedsQL 4.0) and diabetes specific QOL (Ped-

sQL 3.0). The results show that individual scales of both general and diabetes specific QOL closely correlate.

First component aim:

Analysis of first component aim – find out the level of concordance of answers of children and parents in general QOL and diabetes specific QOL – was calculated by Paired Sample Test. This test compares two means of children and parents in both the PedsQL 3.0 and PedsQL 4.0. Through the Pearson correlation in Table 5 we determine the significance for individual variables of children and parents. The results show that all variables in both general and diabetes specific QOL are statistically significant.

Based on the significance of the Paired Sample Test (Table 6) and on the correlation level of 0.05 we negate the determined zero hypothesis that there is no differ-

Table 4: Correlation coefficients in PedsQL 4.0 and PedsQL 3.0 of children and parents

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	
PedsQL 4.0 – child																							
1. Physical functioning	1																						
2. Emotional functioning	.214	1																					
3. Social functioning	.564**	.448**	1																				
4. School functioning	.396**	.512**	.574**	1																			
5. PedsQL 4.0	.757**	.690**	.809**	.800**	1																		
PedsQL 4.0 – parent																							
6. Physical functioning	.869**	.202	.522**	.357**	.675**	1																	
7. Emotional functioning	.122	.726**	.368**	.497**	.539**	.245*	1																
8. Social functioning	.398**	.348**	.757**	.519**	.631**	.448**	.450**	1															
9. School functioning	.400**	.486**	.585**	.818**	.736**	.424**	.547**	.593**	1														
10. PedsQL 4.0	.635**	.554**	.721**	.705**	.852**	.747**	.700**	.781**	.828**	1													
PedsQL 3.0 – child																							
11. Difficulties with Diabetes symptoms	.470**	.521**	.438**	.490**	.634**	.388**	.515**	.279*	.431**	.531**	1												
12. Barriers to treatment	.230*	.499**	.287*	.433**	.471**	.151	.526**	.359**	.331**	.424**	.426**	1											
13. Treatment adherence	.058	.442**	.315*	.323**	.349**	-.016	.427**	.234*	.269*	.272*	.377**	.554**	1										
14. Diabetes-related worry	.177	.438**	.325**	.346**	.408**	.123	.383**	.196	.314**	.321**	.222*	.366**	.442**	1									
15. Diabetes-related communication	.353**	.109	.132	.244*	.297**	.292**	.206	.098	.273*	.299**	.264*	.405**	.427**	.247*	1								
16. PedsQL 3.0	.406**	.599**	.456**	.546**	.655**	.304**	.608**	.343**	.478**	.557**	.788**	.752**	.762**	.556**	.597**	1							
PedsQL 3.0 – parent																							
17. Difficulties with Diabetes symptoms	.148	.429**	.379**	.306**	.392*	.174	.603**	.335**	.382**	.467**	.662**	.226*	.297**	.180	.097	.511**	1						
18. Barriers to treatment	.163	.317**	.231*	.419**	.365**	.203	.468**	.401**	.386**	.458**	.248*	.674**	.352**	.150	.327**	.475**	.200	1					
19. Treatment adherence	.092	.488**	.303**	.279*	.361**	.160	.515**	.323**	.261**	.391**	.389**	.449**	.650**	.339**	.378**	.617**	.378**	.549**	1				
20. Diabetes-related worry	-.007	.352**	.174	.392**	.282*	.119	.499**	.204	.321**	.359**	.191	.375**	.163	.418**	-.072	.291**	.256*	.435**	.331**	1			
21. Diabetes-related communication	.166	.032	-.010	.026	.087	.235*	.294**	.073	.076	.230*	.165	.341**	.126	.119	.579**	.340**	.123	.401**	.381**	.142	1		
22. PedsQL 3.0	.169	.517**	.361**	.430**	.467**	.259*	.734**	.416**	.443**	.583**	.560**	.577**	.493**	.355**	.353**	.685**	.700**	.706**	.786**	.606**	.530**	1	

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed). Source: own research

Table 5: Concordance in answers of children and parents in PedsQL 4.0 and PedsQL 3.0 expressed in Pearson correlation

		N	Correlation	Sig.
Pair 1	C Physical functioning & P Physical functioning	79	.869	.000
Pair 2	C Emotional functioning & P Emotional functioning	79	.726	.000
Pair 3	C Social functioning & P Social functioning	79	.757	.000
Pair 4	C School functioning & P School functioning	79	.818	.000
Pair 5	C Difficulties with diabetes symptoms & P Difficulties with diabetes symptoms	79	.662	.000
Pair 6	C Barriers to treatment & P Barriers to treatment	79	.674	.000
Pair 7	C Treatment adherence & P Treatment adherence	79	.650	.000
Pair 8	C Diabetes-related worry & P Diabetes-related worry	79	.418	.000
Pair 9	C Diabetes related communication & P Diabetes related communication	79	.579	.000
Pair 10	C PedsQL 4.0 & P PedsQL 4.0	79	.852	.000
Pair 11	C PedsQL 3.0 & P PedsQL 3.0	79	.685	.000

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed).
 Note: C – children’s answers; P – parent’s answers; Source: own research

Table 6: Paired sample test – concordance in answers of children and parents in PedsQL 4.0 and PedsQL 3.0

		PAIRED SAMPLES TEST			Paired differences		t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean				
					Lower Bound	Upper Bound			
Pair 1	C Physical functioning & P Physical functioning	2.3339	6.9060	.7770	.7870	3.8807	3.004	78	.004
Pair 2	C Emotional functioning & P Emotional functioning	1.0759	11.7852	1.3259	-1.5638	3.7157	.811	78	.420
Pair 3	C Social functioning & P Social functioning	1.5190	9.2110	1.0363	-.5442	3.5821	1.466	78	.147
Pair 4	C School functioning & P School functioning	2.3418	10.4033	1.1705	.0116	4.6720	2.001	78	.049
Pair 5	C Difficulties with diabetes symptoms & P Difficulties with diabetes symptoms	4.2002	10.1188	1.1385	1.9337	6.4667	3.689	78	.000
Pair 6	C Barriers to treatment & P Barriers to treatment	4.8259	14.2925	1.6080	1.6246	8.0273	3.001	78	.004
Pair 7	C Treatment adherence & P Treatment adherence	2.8933	10.4684	1.1778	.5485	5.2381	2.457	78	.016
Pair 8	C Diabetes-related worry & P Diabetes-related worry	20.1477	23.5932	2.6544	14.8631	25.4323	7.590	78	.000
Pair 9	C Diabetes related communication & P Diabetes related communication	-3.3755	19.1299	2.1523	-7.6604	.9093	-1.568	78	.121
Pair 10	C PedsQL 4.0 – P PedsQL 4.0	1.8850	6.1283	.6895	.5123	3.2576	2.734	78	.008
Pair 11	C PedsQL 3.0 – P PedsQL 3.0	4.8599	8.2537	.9286	3.0111	6.7086	5.233	78	.000

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed).
 Note: C – children’s answers; P – parent’s answers; Source: own research

Table 7: Analysis of Variance (ANOVA) of children and parents background variables and compensation in relation to PedsQL 4.0 and PedsQL 3.0

ANOVA of variable Age in relation to PedsQL 4.0 and PedsQL 3.0 – child and parent					
Respondent		Sum of Squares	Mean Square	F	Sig.
Child	PedsQL 4.0 * Age	222.492	222.492	1.975	.164
	PedsQL 3.0 * Age	110.742	110.742	1.036	.312
Parent	PedsQL 4.0 * Age	310.143	310.143	2.345	.130
	PedsQL 3.0 * Age	113.944	113.944	1.041	.311
ANOVA of variable Duration of diabetes in relation to PedsQL 4.0 and PedsQL 3.0 – child and parent					
Respondent		Sum of Squares	Mean Square	F	Sig.
Child	PedsQL 4.0 * Duration of diabetes	763.623	152.725	1.371	.245
	PedsQL 3.0 * Duration of diabetes	1385.678	277.136	2.909	.019*
Parent	PedsQL 4.0 * Duration of diabetes	645.254	129.051	.957	.450
	PedsQL 3.0 * Duration of diabetes	932.515	186.503	1.789	.126
ANOVA of variable Insulin application in relation to PedsQL 4.0 and PedsQL 3.0 – child and parent					
Respondent		Sum of Squares	Mean Square	F	Sig.
Child	PedsQL 4.0 * Insulin application	32.429	32.429	.282	.597
	PedsQL 3.0 * Insulin application	5.046	5.046	.047	.830
Parent	PedsQL 4.0 * Insulin application	5.623	5.623	.041	.840
	PedsQL 3.0 * Insulin application	334.748	334.748	3.140	.080
ANOVA of variable Compensation in relation to PedsQL 4.0 and PedsQL 3.0 – child and parent					
Respondent		Sum of Squares	Mean Square	F	Sig.
Child	PedsQL 4.0 * Compensation	35.141	35.141	.305	.582
	PedsQL 3.0 * Compensation	72.010	72.010	.671	.415
Parent	PedsQL 4.0 * Compensation	54.353	54.353	.401	.528
	PedsQL 3.0 * Compensation	52.682	52.682	.478	.492
ANOVA of variable Gender in relation to PedsQL 4.0 and PedsQL 3.0 – child and parent					
Respondent		Sum of Squares	Mean Square	F	Sig.
Child	PedsQL 4.0 * Gender	12.349	12.349	.107	.744
	PedsQL 3.0 * Gender	247.918	247.918	2.359	.129
Parent	PedsQL 4.0 * Gender	108.978	108.978	.808	.371
	PedsQL 3.0 * Gender	210.693	210.693	1.947	.167

** . Correlation is significant at the 0.01 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed). Source: own research

ence in the answers of children and parents in the following fields: physical functioning, school functioning, difficulties with diabetes symptoms, barriers to treatment, treatment adherence, diabetes related worry and PedsQL 3.0 and PedsQL 4.0. The given very low levels of significance indicate that the differences in answers are statistically significant. Other fields did not prove to be statistically significant.

Generally the respondents – children and parents did not significantly agree on the answers of general QOL of physical functioning and more statistically significant responses were in the diabetes specific QOL.

Second component aim:

Analysis of second component aim – find out if age, gender, duration of diabetes and compensation influence the levels of general QOL and diabetes specific QOL – was calculated through the ANOVA – Analysis of Variance.

Table 7 shows the levels of significance, which determine the variance. According to the outcomes the duration of diabetes was statistically significant in the PedsQL3.0 in children.

Table 8: Comparison of general QOL (PedsQL 4.0) and diabetes related QOL (PedsQL 3.0) in children and parents in Czech and American sample

Child	CZE	USA	Parent	CZE	USA
	Mean	Mean		Mean	Mean
Physical functioning	87.540	90.44	Physical functioning	85.206	84.62
Emotional functioning	78.481	81.15	Emotional functioning	77.405	74.80
Social functioning	93.734	87.40	Social functioning	92.215	86.57
School functioning	70.696	80.00	School functioning	68.354	75.20
PedsQL 4.0	83.255	80.05	PedsQL 4.0	81.370	80.68
Difficulties with diabetes symptoms	71.030	68.76	Difficulties with diabetes symptoms	66.830	58.22
Barriers to treatment	72.468	84.40	Barriers to treatment	67.642	68.99
Treatment adherence	84.629	86.93	Treatment adherence	81.736	78.50
Diabetes-related worry	71.308	79.17	Diabetes-related worry	51.160	62.98
Diabetes-related communication	76.266	82.21	Diabetes-related communication	79.641	74.36
PedsQL 3.0	75.226	84.92	PedsQL 3.0	70.366	68.55

DISCUSSION

Nowadays the number of diabetics rises throughout the whole world.

The aim of the dissertation was to find out the general and diabetes specific QOL of children and adolescents in the age 8–18 years. The data was collected through the PedsQL questionnaires PedsQL 3.0 and PedsQL 4.0. The results showed the children evaluated their general QOL (PedsQL 4.0) 83.26 in comparison with their parents, who evaluate their QOL 81.38. It is obvious that children from the Czech sample evaluate their QOL very well. In comparison with parents, who evaluate the QOL worse, we confirm the hypothesis of the research, that parents will evaluate the QOL of children as worse in comparison to the children's evaluation.

In evaluation of diabetes specific QOL (PedsQL 3.0) children evaluated their QOL better than their parents. The levels of QOL of children were 75.23, in comparison to the parents 70.37. These outcomes are similar to the outcomes of foreign outcomes of researches of QOL of children with chronic illness such as diabetes, asthma or cystic fibrosis (Sawyer, 2005; Rye, 2006). The only exception is diabetes related communication, which the children evaluated 76.27 and parents 79.64. This category determined how are children able to communicate with doctors and nurses about their illness. But statistically there was no significance – see Table 7.

From the total comparison children evaluated the worse school functioning (70.67). This can be due to the fact, that the Czech schooling system is one of the most demanding among the European systems. Therefore the level of Hb1Ac could be influenced by these demands. On the other hand parents evaluated the worse diabetes related worry (51.16). This category evalu-

ated if the children are worried about being hypoglycemic, if they worry for late complication. The results of the parents might have shown that the parents have not understood the question well and answered their worries. But this has not been statistically proven. As the best children and parents evaluated accordingly the social functioning (children 93.73 and parents 92.21). This category evaluated how the children *get along* with their friends.

The children evaluated their QOL better than their parents did. This state is not surprising, as to the role the parents play in the life and management of diabetes of the child's life. Good diabetes management requires good team work of the parent and the child, because many children are not ready to deal with their life, not to mention the demanding disease such as diabetes (La Greca, 1990).

Outcomes can be compared with results of research of Rye, 2006. Outcomes are shown in Table 8. This research was conducted on a sample of American children and focused on general and diabetes specific QOL. The American sample is not identical to the Czech sample, but it is the closest comparison available. In comparison with the American sample the Czech sample evaluated their general QOL better. On the other hand the Americans evaluate diabetes specific QOL better than the Czech sample. From the study of Rye the duration of diabetes was not statistically significant but in the Czech sample this was significant.

CONCLUSION

This work dealt with the QOL of children and adolescent in the age of 8–18 years with T1DM. It dealt with the diabetes specific and general QOL and the instru-

ments used to evaluate QOL.

The aim of the work was to find out the general and diabetes specific QOL and to compare the results with the answers of the children's parents. Also the aim of the work was to determine the concordance of the answers and to find out if variables were significant in the answers of the respondents in both general and diabetes specific QOL.

The data were collected by using the PedsQL 4.0 and PedsQL 3.0 questionnaires, which had to be translated into Czech language before start of the research.

From the elaborated research data on the QOL of children with diabetes are now available for the Czech Republic sample as well. Similar research was not conducted before and therefore is considered as groundbreaking in the quality of life data for the Czech Republic. From the research it is evident that the answered of parents and children differ, but the same results were described in the foreign studies as well.

The most significant for the research was the outcome, that the duration of diabetes is significant in the answers of children in the diabetes specific questionnaires. Nonetheless the future research should be focused on two age groups – the younger children and adolescents, as different variables of their life domains could influence their answers.

The biggest benefit of this research as not only the available data on QOL of children with diabetes, but also the Czech version of instruments on health related quality of life. Within this research the PedsQL 3.0 was translated but as well as the PedsQL – influence of chronic illness on the family was translated as well. These instruments will serve in the field as a valid instrument for determining QOL of children and adolescents as well as the influence of a chronic illness on the family as a whole.

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