

The effect of medical and socioeconomic factors on health-related quality of life of children and families with type 1 diabetes mellitus: A research article

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Abstract

Background

The aim of our study was to evaluate health-related quality of life (HRQL) in type 1 diabetes mellitus (T1DM) children and their families in Hungary. Parallely our goal was to identify the effect of multiple factors (gender, age, diabetes specific factors). We examined effect of socioeconomic factors on perceptions of HRQL.

Methods

Between June and December 2024, a total of 130 children aged 2-17 and their parents completed PedsQL™ 4.0 Generic Core Scales (GCS), 2.0 Family Impact Module (FIM) and a socioeconomic questionnaire edited by our working group. To explore the HRQL score differences between the groups we used Mann-Whitney U and Kruskal Wallis test after normality testing.

Results

The results demonstrated that T1DM children and their families have slightly lower HRQL scores than the international and Hungarian general population. We found the lowest scores in the emotional functioning dimension (self-report (SR) 67.86 ± 19.33 , parent proxy-report (PPR) 69.00 ± 19.33) in GCS and in physical (61.27 ± 20.61), emotional functioning (61.80 ± 21.80), worry (62.25 ± 22.19) and daily activities (63.22 ± 26.22) dimensions in FIM. The results indicated that female gender, older age, usage of insulin pump and good glycemic control were associated with better general and family HRQL scores. Significant difference was proved between usage of insulin pump compared with pen in PPR (pump: 81.12 ± 14.48 , pen: 76.48 ± 13.59 , $p=0.035$). Family HRQL scores were significantly reduced in younger ages (2-4y: 45.14 ± 6.38 , 5-7y: 58.57 ± 18.51 , 8-12y: 68.85 ± 15.83 , 13-17y: 72.72 ± 15.38 , $p<0.001$). Socioeconomic factors had a strong effect on both general and family HRQL scores. We found significantly lower general HRQL scores among parents with lower levels of education, in case of maternal unemployment, with overcrowded housing and with lack of own car.

Conclusions

Our findings confirm the previously described positive effect of the usage of insulin pump on HRQL. We find strong negative effect of the chronic disease on families with young children and poor socioeconomic status. Our findings highlight the need for comprehensive support—from medical and psychological services as well as civil society and government organizations—for young people and those living in adverse social conditions.

Trial Registration

retrospectively registered in 08.06. in 2026

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Background

Type 1 diabetes mellitus (T1DM) is one of the most common chronic diseases in pediatric population and it shows a continuously rising incidence with modernization and changes in environmental factors [1,2].

According to the World Health Organization's (WHO) definition from 1946, health is not merely the absence of disease or disability, but a state of complete physical, mental and social well-being [3]. Health-related quality of life (HRQL) examines the objective and subjective impact of disease, injury, dysfunction, therapeutic or other health interventions on individuals [4]. The assessment of HRQL in pediatrics utilizes parallel child self-report and parent proxy questionnaires capturing the unique perspectives of caregivers [5]. In Hungarian population Berkes et al. studied HRQL in children aged 8–18 years with chronic cardiac disease compared to general population [6,7], and Lukács et al. examined T1DM population in the same age group [8]. Considering this fact, Lukács examined the HRQL and psychological well-being of families and mothers raising T1DM children aged 2–7 years [9]. The social determinants of HRQL have been confirmed in Hungarian child population [6].

The aim of this study was to conduct a parallel analysis of the HRQL scores of families raising T1DM children and that of the patients across a wide age range taking socioeconomic factors into account in Hungarian population. With this unique construction we sought to identify previously unexplored associations regarding HRQL. We planned to evaluate differences in several groups: gender, age, duration of T1DM, usage of insulin pen or pump, glucose sensor, hemoglobin A1c level, comorbid coeliac disease, diabetic community event.

T1DM is a unique condition where in addition to the guidance and recommendations provided by physicians, the implementation of the treatment and the ultimate success rest primarily in the hands of the patients and their caregivers [8,10,11]. Consequently, T1DM represents an excellent model for research focusing on patient self-management and adaptation to chronic illness.

Methods

Participants and procedures

Children and adolescents aged 2-17 years with T1DM, diagnosed at least 3 months previously, and one parent participated in our study. Participants were recruited from the Pediatric Diabetes Outpatient Clinic at the University of Debrecen Clinical Centre Pediatric Department between June and December 2024. We offered participation to 197 patients who attended to the regular visit during the study period. A total of 135 patients agreed to participate. During data

processing, we excluded 5 patients according to Pediatric Quality of Life Inventory (PedsQL) Scaling and Scoring Instructions, because more than 50% of the questions were incomplete. Parents were informed in written form about the purpose, method and voluntary nature of the study and written consent from parents and assent from adolescents were obtained before the study procedure according to the hospital's regulation. Participants filled in the questionnaire in the waiting room at the regularly scheduled appointment with the help of the health assistant and the attending physician. It required approximately 15 minutes to complete the questionnaire which consisted of 3 parts: PedsQL Generic Core Scales -self-report for children aged 5-17 years and parent proxy-report for children aged 2-17 years-, PedsQL Family Impact Module and socioeconomic survey.

The Ethics Committee of the University of Debrecen Clinical Centre (no. DE RKEB/IKEB: 6798-2024) approved this research protocol. The study was carried out in accordance with guidelines of the Declaration of Helsinki and Good Clinical Practice.

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Measures

The PedsQL Generic Core Scale (GCS) is a modular, multidimensional instrument designed to measure HRQL in children and adolescents [12]. It encompasses 23 items across four key dimensions of HRQL -physical, emotional, social, and school functioning- with developmentally appropriate versions for toddlers (2–4 years), young children (5–7 years), children (8–12 years), and adolescents (13–17 years). The scale is widely utilized due to its validated parallel versions for child self-report (SR) and parent proxy-report (PPR) [13]. It was developed and translated to Hungarian language by Varni et al. The psychometric properties of the Hungarian version were evaluated by Berkes et al. in 2010 [6].

The PedsQL Family Impact Module (FIM) assesses family functioning and measures the impact of chronic pediatric health conditions on parents and family [14]. The instrument consists of 36 items measuring parents' self-reported functioning on six subscales. The development and translation of this questionnaire is also attributed to J. Varni et al. The instrument on its original and on many other languages has already been clinically validated but not yet on Hungarian.

In all PedsQL questionnaires each item is scored using a 5-point Likert scale from 0 (never a problem) to 4 (always a problem), which is then transformed to a 0 to 100 scale with higher scores indicating better functioning.

Study design

We performed analyses of total PedsQL scores and subgroup analyses according to gender and age using the age categories of the questionnaire. The study population was divided into two groups according to the duration of diabetes. A cut-off of two years was used to compare newly diagnosed participants with those who had been living with diabetes for a longer period. According to the treatment of the T1DM we compared groups using continuous insulin injection system (pump) or pen and using continuous glucose monitoring system (sensor) or casual blood glucose tests. We also created comparison groups based on the mean of the last three hemoglobin A1c measurements obtained during 9-month preceding the study. The groups were: <6.5%, 6.5-7.5%, 7.5-8.5%, >8.5%. Since coeliac disease is one of the most common comorbidities in T1DM (4-10%) and has a great impact on daily life [15], we compared the scores with or without this comorbidity. We also examined whether we could find an effect of T1DM community events on HRQL.

To assess socioeconomic state of the families, we did not find an internationally used questionnaire, probably due to the very different social conditions in several countries. Therefore, we compiled our list of questions applying the factors of area-based deprivation index used in Hungary and the most significant ones described in the international literature [16,17]. The newly developed list consists of 10 questions and covers the parents' education, occupation, large or single-parent family, car ownership, density of housing and financial situation.

Parental education was categorized using a scoring system where elementary education was assigned 1-point, secondary education 2 points, and a college or university degree 3 points for both parents. The combined scores were then divided into two categories: low (1-3 points) and high (4–6 points). Regarding employment status, both parents were classified as either having a permanent job or being unemployed, including those engaged in occasional work. A 'large family' was defined as a household with three or more children. Housing density was calculated as the number of persons per room; a ratio ≥ 2 defined as crowded, while <2 was considered not crowded. Finally, the financial situation was assessed based on the total net monthly household income, categorized into three levels: <500,000 HUF, 500,000–1,000,000 HUF, and >1,000,000 HUF.

Statistical analysis

The analysis of the variables was performed by calculating the mean and the standard deviation. To explore the HRQL score differences between the groups we used independent t-test or Mann-Whitney U-test according to the results of normality test (Shapiro-Wilk test) in case of 2 data groups and Kruskal-Wallis test in case of more than 2 data groups. We defined a significance level $p < 0.05$. We examined the parent-child agreement with Pearson correlation coefficient which ranges from -1 to +1, with -1 indicating perfect inverse linear correlation, +1 perfect linear correlation, and 0 no linear correlation. All analyses were performed using the Statistical Package for Social Sciences (SPSS) software program, version 29.0 (SPSS Inc., Chicago, IL, USA).

Results

A total of 130 patients were included in the study. The mean age of the patients was 11.4 ± 4.17 years, and 74 (56.9%) were male. The distribution of the participants in terms of gender and age group is shown in Tables 1, 2 and 3.

Table 1
Comparison of dimensions of the PedsQL GCS self-report by study groups

Categories		Total Scale Score	Physical functioning	Psychosocial functioning	Emotional functioning	Social functioning	School functioning
Total mean $\pm$ SD (n = 124)		78.45 $\pm$ 11.99	85.07 $\pm$ 12.64	74.91 $\pm$ 13.74	67.86 $\pm$ 19.33	85.93 $\pm$ 14.77	70.77 $\pm$ 17.98
Gender	female mean $\pm$ SD (n = 53)	79.96 $\pm$ 11.24	85.73 $\pm$ 12.34	76.89 $\pm$ 12.50	66.32 $\pm$ 18.27	88.96 $\pm$ 13.02	75.38 $\pm$ 15.81
	male mean $\pm$ SD (n = 71)	77.31 $\pm$ 12.48	84.59 $\pm$ 12.93	73.43 $\pm$ 14.51	69.01 $\pm$ 20.14	83.66 $\pm$ 15.65	67.33 $\pm$ 18.82
	p ^a	0.199	0.664	0.148	0.490	0.083	0.011
Age groups	young child 5-7y mean $\pm$ SD (n = 25)	73.72 $\pm$ 13.97	80.11 $\pm$ 17.05	70.36 $\pm$ 15.19	65.00 $\pm$ 24.15	79.40 $\pm$ 14.02	66.60 $\pm$ 22.39
	child 8-12y mean $\pm$ SD (n = 40)	79.94 $\pm$ 12.12	86.56 $\pm$ 11.93	76.38 $\pm$ 13.83	68.88 $\pm$ 17.92	86.25 $\pm$ 15.72	73.84 $\pm$ 16.98
	adolescent 13-18y mean $\pm$ SD (n = 59)	79.43 $\pm$ 10.64	86.18 $\pm$ 10.46	75.83 $\pm$ 12.84	68.39 $\pm$ 18.18	88.47 $\pm$ 13.78	70.45 $\pm$ 16.43
	p ^b	0.187	0.290	0.264	0.920	0.016	0.532
Duration of T1DM	<2 years mean $\pm$ SD (n = 14)	78.26 $\pm$ 10.39	81.25 $\pm$ 13.70	76.67 $\pm$ 10.64	69.29 $\pm$ 11.41	86.79 $\pm$ 14.49	73.93 $\pm$ 17.12
	>2 years mean $\pm$ SD (n = 110)	78.47 $\pm$ 12.22	85.56 $\pm$ 12.48	74.68 $\pm$ 14.11	67.68 $\pm$ 20.14	85.82 $\pm$ 14.86	70.37 $\pm$ 18.12
	p ^a	0.853	0.215	0.749	0.689	0.749	0.579
Insulin pump or pen	pump mean $\pm$ SD (n = 47)	79.95 $\pm$ 11.81	87.70 $\pm$ 9.52	75.82 $\pm$ 14.94	67.55 $\pm$ 20.37	87.55 $\pm$ 13.71	72.34 $\pm$ 17.99
	pen mean $\pm$ SD (n = 77)	77.53 $\pm$ 12.08	83.45 $\pm$ 14.03	74.35 $\pm$ 13.02	68.05 $\pm$ 18.80	84.94 $\pm$ 15.38	69.81 $\pm$ 18.02
	p ^a	0.220	0.207	0.344	0.963	0.427	0.317
Use of glucose sensor	no mean $\pm$ SD (n = 35)	80.33 $\pm$ 8.72	86.61 $\pm$ 8.04	76.96 $\pm$ 11.18	70.14 $\pm$ 16.60	86.71 $\pm$ 14.65	73.96 $\pm$ 15.87
	yes mean $\pm$ SD (n = 89)	77.71 $\pm$ 13.02	84.48 $\pm$ 14.04	74.10 $\pm$ 14.61	66.97 $\pm$ 20.32	85.62 $\pm$ 14.88	69.51 $\pm$ 18.67
	p ^a	0.462	0.958	0.370	0.385	0.661	0.272
Hemoglobin A1c level (mean of last 3 measures)	<6.5 mean $\pm$ SD (n = 17)	76.85 $\pm$ 11.70	82.17 $\pm$ 14.69	74.02 $\pm$ 13.06	61.76 $\pm$ 22.91	86.18 $\pm$ 12.81	74.12 $\pm$ 17.79
	6.5–7.5 mean $\pm$ SD (n = 44)	81.93 $\pm$ 10.33	88.42 $\pm$ 9.50	78.45 $\pm$ 12.73	71.48 $\pm$ 18.94	88.18 $\pm$ 13.47	75.57 $\pm$ 17.76
	7.5–8.5 mean $\pm$ SD (n = 39)	74.75 $\pm$ 13.41	80.76 $\pm$ 14.71	71.56 $\pm$ 14.70	66.28 $\pm$ 16.85	81.79 $\pm$ 17.57	66.51 $\pm$ 18.29
	>8.5 mean $\pm$ SD (n = 23)	78.29 $\pm$ 10.64	87.50 $\pm$ 10.41	73.36 $\pm$ 12.83	66.74 $\pm$ 20.20	87.83 $\pm$ 12.60	65.07 $\pm$ 14.93
	p ^b	0.070	0.056	0.140	0.392	0.393	0.024
Comorbid coeliac disease	no mean $\pm$ SD (n = 106)	78.41 $\pm$ 12.39	85.20 $\pm$ 13.02	74.78 $\pm$ 14.35	67.88 $\pm$ 20.38	85.38 $\pm$ 15.38	70.90 $\pm$ 17.64
	yes mean $\pm$ SD (n = 18)	78.68 $\pm$ 9.59	84.38 $\pm$ 10.45	75.65 $\pm$ 9.70	67.78 $\pm$ 11.79	89.17 $\pm$ 10.18	70.00 $\pm$ 20.36
	p ^a	0.873	0.525	0.966	0.994	0.614	0.921
Psychosocial Health Summary Score: the mean of items of Emotional, Social and School functioning scores							
Missing values: There are 6 missing values in all groups, because children in the smallest age group (2–4 years) do not fill self-report questionnaire.							
a-statistical analysis with Mann-Whitney U test							
b- statistical analysis with Kruskal-Wallis test							
We defined a significance level p < 0.05 and highlighted in bold.							

Categories		Total Scale Score	Physical functioning	Psychosocial functioning	Emotional functioning	Social functioning	School functioning
Participation in diabetic camp	no mean $\pm$ SD (n = 82)	78.78 $\pm$ 12.11	85.90 $\pm$ 12.98	74.97 $\pm$ 13.80	67.93 $\pm$ 19.16	85.67 $\pm$ 15.29	71.20 $\pm$ 18.36
	yes mean $\pm$ SD (n = 42)	77.80 $\pm$ 11.88	83.47 $\pm$ 11.95	74.78 $\pm$ 13.78	67.74 $\pm$ 19.88	86.43 $\pm$ 13.85	69.92 $\pm$ 17.40
	p ^a	0.447	0.117	0.696	0.580	0.875	0.594
Psychosocial Health Summary Score: the mean of items of Emotional, Social and School functioning scores							
Missing values: There are 6 missing values in all groups, because children in the smallest age group (2–4 years) do not fill self-report questionnaire.							
a-statistical analysis with Mann-Whitney U test							
b- statistical analysis with Kruskal-Wallis test							
We defined a significance level $p < 0.05$ and highlighted in bold.							

Table 2
Comparison of dimensions for the PedsQL GCS parent proxy-report by study groups

Categories		Total Scale Score (n = 130)	Physical functioning (n = 130)	Psychosocial functioning (n = 130)	Emotional functioning (n = 129)	Social functioning (n = 130)	School functioning (n = 120)
Total mean $\pm$ SD (n = 130)		78.19 $\pm$ 14.05	81.63 $\pm$ 17.01	76.37 $\pm$ 14.42	69.00 $\pm$ 19.33	87.54 $\pm$ 14.55	72.56 $\pm$ 18.24
Gender	female mean $\pm$ SD (n = 56)	79.98 $\pm$ 13.51	83.86 $\pm$ 16.70	78.00 $\pm$ 13.64	68.09 $\pm$ 18.35	90.00 $\pm$ 13.38	75.88 $\pm$ 17.11
	male mean $\pm$ SD (n = 74)	76.83 $\pm$ 14.38	79.94 $\pm$ 17.16	75.13 $\pm$ 14.95	69.68 $\pm$ 20.13	85.68 $\pm$ 15.20	69.93 $\pm$ 18.80
	p ^a	0.180	0.139	0.235	0.614	0.090	0.080
Age groups	toddler 2-4y mean $\pm$ SD (n = 6)	81.45 $\pm$ 12.38	82.29 $\pm$ 15.14	80.38 $\pm$ 11.62	70.00 $\pm$ 18.03	91.67 $\pm$ 12.11	72.22 $\pm$ 24.06
	young child 5-7y mean $\pm$ SD (n = 25)	70.70 $\pm$ 15.75	71.88 $\pm$ 19.78	70.37 $\pm$ 15.66	63.20 $\pm$ 20.86	81.60 $\pm$ 13.67	68.16 $\pm$ 22.74
	child 8-12y mean $\pm$ SD (n = 40)	79.41 $\pm$ 13.17	81.81 $\pm$ 16.61	78.13 $\pm$ 13.25	70.50 $\pm$ 18.04	87.25 $\pm$ 15.56	76.63 $\pm$ 15.21
	adolescent 13-18y mean $\pm$ SD (n = 59)	80.20 $\pm$ 13.27	85.5714.81	77.31 $\pm$ 14.52	70.36 $\pm$ 19.63	89.83 $\pm$ 13.99	71.21 $\pm$ 18.24
	p ^b	0.065	0.020	0.215	0.644	0.029	0.407
Duration of T1DM	<2 years mean $\pm$ SD (n = 19)	77.49 $\pm$ 13.66	76.15 $\pm$ 18.73	78.20 $\pm$ 11.64	69.17 $\pm$ 15.17	90.00 $\pm$ 12.25	73.44 $\pm$ 17.77
	>2 years mean $\pm$ SD (n = 111)	78.31 $\pm$ 14.17	82.57 $\pm$ 16.61	76.05 $\pm$ 14.86	68.98 $\pm$ 19.98	87.12 $\pm$ 14.92	72.43 $\pm$ 18.39
	p ^a	0.764	0.154	0.787	0.870	0.584	0.905
Insulin pump or pen	pump mean $\pm$ SD (n = 48)	81.12 $\pm$ 14.48	86.20 $\pm$ 14.57	78.34 $\pm$ 16.50	70.32 $\pm$ 22.97	89.58 $\pm$ 14.51	75.28 $\pm$ 17.52
	pen mean $\pm$ SD (n = 82)	76.48 $\pm$ 13.59	78.95 $\pm$ 17.83	75.22 $\pm$ 13.01	68.25 $\pm$ 17.01	86.34 $\pm$ 14.53	70.80 $\pm$ 18.59
	p ^a	0.035	0.020	0.086	0.352	0.108	0.192
Use of glucose sensor	no mean $\pm$ SD (n = 37)	78.82 $\pm$ 11.83	80.24 $\pm$ 16.24	78.26 $\pm$ 11.39	70.00 $\pm$ 15.18	89.73 $\pm$ 12.85	75.10 $\pm$ 15.84
	yes mean $\pm$ SD (n = 93)	77.94 $\pm$ 14.89	82.18 $\pm$ 17.36	75.62 $\pm$ 15.45	68.60 $\pm$ 20.83	86.67 $\pm$ 15.15	71.59 $\pm$ 19.07
	p ^a	0.961	0.312	0.546	0.841	0.401	0.348
Hemoglobin A1c level (mean of last 3 measures)	<6.5 mean $\pm$ SD (n = 17)	77.83 $\pm$ 14.59	79.96 $\pm$ 18.46	76.81 $\pm$ 15.22	66.18 $\pm$ 24.66	88.53 $\pm$ 12.22	77.50 $\pm$ 17.51
	6.5–7.5 mean $\pm$ SD (n = 46)	82.44 $\pm$ 11.79	86.69 $\pm$ 12.72	80.16 $\pm$ 13.19	72.33 $\pm$ 18.51	91.20 $\pm$ 12.03	76.63 $\pm$ 19.01
	7.5–8.5 mean $\pm$ SD (n = 42)	74.10 $\pm$ 15.58	77.68 $\pm$ 18.50	72.19 $\pm$ 15.56	65.51 $\pm$ 18.32	82.62 $\pm$ 17.85	68.87 $\pm$ 18.40
	>8.5 mean $\pm$ SD (n = 24)	76.65 $\pm$ 12.97	79.24 $\pm$ 18.87	75.24 $\pm$ 12.34	69.58 $\pm$ 17.63	87.92 $\pm$ 12.42	65.71 $\pm$ 14.08
	p ^b	0.080	0.126	0.081	0.385	0.150	0.044
Psychosocial Health Summary Score: the mean of items of Emotional, Social and School functioning scales							
Missing values caused by unanswered questions. School functioning was only relevant if the child attended to community.							
a-statistical analysis with Mann-Whitney U test							
b-statistical analysis with Kruskal-Wallis test							
We defined a significance level p < 0.05 and highlighted in bold.							

Categories		Total Scale Score (n = 130)	Physical functioning (n = 130)	Psychosocial functioning (n = 130)	Emotional functioning (n = 129)	Social functioning (n = 130)	School functioning (n = 120)
Comorbid coeliac disease	no mean ± SD (n = 112)	78.63 ± 14.47	82.39 ± 16.54	76.60 ± 15.18	69.47 ± 20.47	87.19 ± 15.23	73.24 ± 17.76
	yes mean ± SD (n = 18)	75.45 ± 11.05	76.91 ± 19.53	74.95 ± 8.37	66.11 ± 9.63	89.72 ± 9.31	68.13 ± 21.20
	p ^a	0.249	0.249	0.361	0.386	0.927	0.344
Participation in diabetic community camp	no mean ± SD (n = 88)	77.86 ± 13.99	81.39 ± 17.58	75.95 ± 14.14	67.95 ± 18.55	87.27 ± 14.40	72.92 ± 18.55
	yes mean ± SD (n = 42)	78.88 ± 14.31	82.12 ± 15.94	77.24 ± 15.10	71.19 ± 20.92	88.10 ± 15.02	71.79 ± 17.79
	p ^a	0.668	0.948	0.624	0.515	0.634	0.617
Psychosocial Health Summary Score: the mean of items of Emotional, Social and School functioning scales							
Missing values caused by unanswered questions. School functioning was only relevant if the child attended to community.							
a-statistical analysis with Mann-Whitney U test							
b-statistical analysis with Kruskal-Wallis test							
We defined a significance level p < 0.05 and highlighted in bold.							

Table 3
Comparison of dimensions of the PedsQL Family Impact questionnaire by study groups

Categories		Total Scale Score (n = 129)	Parent HRQL Summary (n = 129)	Physical functioning (n = 129)	Emotional functioning (n = 129)	Social functioning (n = 129)	Cognitive Functioning (n = 128)	Communication (n = 129)	Worry (n = 127)	Family Summary (n = 128)
Total mean $\pm$ SD (n = 130)		67.98 $\pm$ 17.46	68.01 $\pm$ 18.38	61.27 $\pm$ 20.61	61.80 $\pm$ 21.80	74.71 $\pm$ 25.18	76.80 $\pm$ 20.43	73.61 $\pm$ 22.08	62.25 $\pm$ 22.19	68.95 $\pm$ 21.87
Gender	female mean $\pm$ SD (n = 55)	68.88 $\pm$ 17.20	68.94 $\pm$ 18.26	60.38 $\pm$ 21.38	62.84 $\pm$ 21.68	76.36 $\pm$ 22.91	79.36 $\pm$ 19.37	75.15 $\pm$ 19.74	66.93 $\pm$ 20.75	67.61 $\pm$ 22.67
	male mean $\pm$ SD (n = 70)	66.22 $\pm$ 17.49	66.43 $\pm$ 18.51	61.13 $\pm$ 20.16	59.88 $\pm$ 21.88	72.41 $\pm$ 27.14	74.29 $\pm$ 21.27	71.43 $\pm$ 23.68	57.57 $\pm$ 22.05	69.11 $\pm$ 21.34
	p ^a	0.443	0.501	0.941	0.592	0.520	0.189	0.489	0.038	0.539
Age groups	toddler mean $\pm$ SD (n = 6)	45.14 $\pm$ 6.38	41.25 $\pm$ 11.29	39.58 $\pm$ 5.74	35.83 $\pm$ 10.69	45.83 $\pm$ 29.23	45.00 $\pm$ 17.89	54.17 $\pm$ 15.59	47.50 $\pm$ 12.94	50.00 $\pm$ 10.46
	young child mean $\pm$ SD (n = 25)	58.57 $\pm$ 18.51	58.66 $\pm$ 19.94	53.83 $\pm$ 21.18	52.25 $\pm$ 20.32	61.00 $\pm$ 30.31	68.20 $\pm$ 22.63	61.67 $\pm$ 21.52	53.00 $\pm$ 23.05	60.63 $\pm$ 24.59
	child mean $\pm$ SD (n = 38)	68.85 $\pm$ 15.83	68.44 $\pm$ 17.00	59.98 $\pm$ 20.97	62.67 $\pm$ 18.54	75.66 $\pm$ 24.86	78.55 $\pm$ 17.70	74.78 $\pm$ 21.96	66.97 $\pm$ 19.12	68.83 $\pm$ 20.98
	adolescent mean $\pm$ SD (n = 56)	72.72 $\pm$ 15.38	73.71 $\pm$ 15.20	66.74 $\pm$ 9.0	66.88 $\pm$ 22.45	82.03 $\pm$ 17.96	82.23 $\pm$ 17.63	79.02 $\pm$ 20.23	63.50 $\pm$ 22.58	73.66 $\pm$ 20.36
	p ^b	<0.001	<0.001	<0.001	<0.001	0.002	<0.001	0.001	0.031	0.009
Duration of T1DM	<2 years mean $\pm$ SD (n = 19)	62.21 $\pm$ 19.14	60.07 $\pm$ 20.17	55.26 $\pm$ 19.39	55.26 $\pm$ 21.11	63.49 $\pm$ 30.78	67.90 $\pm$ 23.35	70.61 $\pm$ 18.92	59.74 $\pm$ 21.83	65.95 $\pm$ 22.27
	>2 years mean $\pm$ SD (n = 106)	68.32 $\pm$ 16.93	68.88 $\pm$ 17.80	61.79 $\pm$ 20.77	62.24 $\pm$ 21.79	76.06 $\pm$ 23.91	78.07 $\pm$ 19.71	73.51 $\pm$ 22.59	62.04 $\pm$ 22.00	68.90 $\pm$ 21.86
	p ^a	0.089	0.039	0.066	0.110	0.083	0.050	0.393	0.462	0.458
Insulin pump or pen	pump mean $\pm$ SD (n = 46)	70.67 $\pm$ 19.93	70.33 $\pm$ 20.66	63.13 $\pm$ 22.86	64.89 $\pm$ 25.81	77.72 $\pm$ 26.28	78.48 $\pm$ 22.48	77.36 $\pm$ 23.22	68.26 $\pm$ 23.43	70.52 $\pm$ 24.70
	pen mean $\pm$ SD (n = 79)	65.48 $\pm$ 15.46	65.91 $\pm$ 16.82	59.44 $\pm$ 19.23	59.02 $\pm$ 18.85	72.07 $\pm$ 24.72	75.38 $\pm$ 19.36	70.56 $\pm$ 21.05	57.86 $\pm$ 20.14	62.25 $\pm$ 20.08
	p ^a	0.090	0.131	0.251	0.153	0.142	0.195	0.055	0.008	0.355
Use of glucose sensor	no mean $\pm$ SD (n = 36)	69.29 $\pm$ 13.53	68.82 $\pm$ 15.62	61.00 $\pm$ 17.26	61.39 $\pm$ 17.95	76.56 $\pm$ 22.68	79.44 $\pm$ 16.51	73.38 $\pm$ 20.69	61.42 $\pm$ 19.26	73.87 $\pm$ 14.37
	yes mean $\pm$ SD (n = 89)	66.62 $\pm$ 18.68	67.02 $\pm$ 19.43	60.72 $\pm$ 21.93	61.10 $\pm$ 23.21	73.17 $\pm$ 26.40	75.34 $\pm$ 21.92	72.94 $\pm$ 22.66	61.80 $\pm$ 22.99	66.26 $\pm$ 23.96
	p ^a	0.546	0.658	0.839	0.944	0.610	0.572	0.996	0.912	0.155
Parent HRQL Summary Score: the mean of item of Physical, Emotional, Social, and Cognitive Functioning scales										
Family Functioning Summary Score: the mean of Daily Activities and family Relationships scales										
Age groups: toddler 2–4 years old, young child 5–7 years old, child 8–12 years old, adolescent 13–18 years old										
a-statistical analysis with Mann-Whitney U test										
b-statistical analysis with Kruskal-Wallis test										
We defined a significance level $p < 0.05$ and highlighted in bold.										

Categories		Total Scale Score (n = 129)	Parent HRQL Summary (n = 129)	Physical functioning (n = 129)	Emotional functioning (n = 129)	Social functioning (n = 129)	Cognitive Functioning (n = 128)	Communication (n = 129)	Worry (n = 127)	Family Summary (n = 128)
Hemoglobin A1c level (mean of last 3 measures)	<6.5 mean $\pm$ SD (n = 16)	66.02 $\pm$ 15.82	67.34 $\pm$ 19.49	61.20 $\pm$ 19.82	60.31 $\pm$ 23.06	76.56 $\pm$ 24.31	74.38 $\pm$ 22.28	69.79 $\pm$ 22.34	59.38 $\pm$ 23.30	65.43 $\pm$ 18.56
	6.5–7.5 mean $\pm$ SD (n = 44)	69.40 $\pm$ 19.19	68.49 $\pm$ 20.02	60.13 $\pm$ 22.69	63.86 $\pm$ 23.50	74.86 $\pm$ 26.19	78.07 $\pm$ 22.24	75.57 $\pm$ 22.83	67.87 $\pm$ 20.91	70.31 $\pm$ 24.95
	7.5–8.5 mean $\pm$ SD (n = 42)	65.45 $\pm$ 15.73	65.22 $\pm$ 15.58	60.52 $\pm$ 17.05	56.82 $\pm$ 18.77	71.73 $\pm$ 24.63	74.05 $\pm$ 19.04	71.63 $\pm$ 21.78	57.98 $\pm$ 22.79	68.38 $\pm$ 21.40
	>8.5 mean $\pm$ SD (n = 23)	68.04 $\pm$ 18.07	70.07 $\pm$ 19.71	62.32 $\pm$ 24.05	64.62 $\pm$ 22.49	75.54 $\pm$ 26.98	79.57 $\pm$ 19.12	73.19 $\pm$ 21.61	58.26 $\pm$ 19.81	67.12 $\pm$ 19.28
	p ^b	0.759	0.735	0.986	0.502	0.695	0.470	0.720	0.113	0.736
Comorbid coeliac disease	no mean $\pm$ SD (n = 107)	67.95 $\pm$ 17.38	68.15 $\pm$ 18.54	62.07 $\pm$ 20.78	61.29 $\pm$ 22.34	75.47 $\pm$ 25.17	76.26 $\pm$ 20.71	73.13 $\pm$ 22.67	61.83 $\pm$ 21.99	69.33 $\pm$ 21.71
	yes mean $\pm$ SD (n = 18)	64.04 $\pm$ 17.18	63.89 $\pm$ 17.39	53.24 $\pm$ 18.44	60.56 $\pm$ 18.46	66.32 $\pm$ 25.65	78.06 $\pm$ 19.94	72.69 $\pm$ 18.26	60.83 $\pm$ 21.98	63.19 $\pm$ 22.63
	p ^a	0.313	0.345	0.100	0.978	0.101	0.836	0.718	0.774	0.246
Participation in diabetic camp	no mean $\pm$ SD (n = 87)	66.53 $\pm$ 17.75	66.45 $\pm$ 18.83	59.77 $\pm$ 20.83	59.97 $\pm$ 22.03	73.13 $\pm$ 26.23	75.35 $\pm$ 21.09	72.61 $\pm$ 22.30	60.93 $\pm$ 22.87	67.96 $\pm$ 22.45
	yes mean $\pm$ SD (n = 38)	69.35 $\pm$ 16.44	70.03 $\pm$ 17.25	63.16 $\pm$ 20.22	63.95 $\pm$ 21.12	76.48 $\pm$ 23.36	79.21 $\pm$ 19.19	74.12 $\pm$ 21.64	63.42 $\pm$ 19.70	69.57 $\pm$ 20.67
	p ^a	0.371	0.281	0.247	0.221	0.533	0.300	0.546	0.440	0.553
Parent HRQL Summary Score: the mean of item of Physical, Emotional, Social, and Cognitive Functioning scales										
Family Functioning Summary Score: the mean of Daily Activities and family Relationships scales										
Age groups: toddler 2–4 years old, young child 5–7 years old, child 8–12 years old, adolescent 13–18 years old										
a-statistical analysis with Mann-Whitney U test										
b-statistical analysis with Kruskal-Wallis test										
We defined a significance level $p < 0.05$ and highlighted in bold.										

Missing values were found in GCS SR ranging 0.0–26.3%, in GCS PPR ranging 0.0–50.0% with highest values in the school functioning domain, and for FIM ranging 0.0–5.9% with the highest values in the cognitive functioning and the worry domains.

Table 1 shows the results of GCS self-reports. The total mean score of this questionnaire was 78.45 ± 11.99 , with the highest scores in the physical (85.07 ± 12.64) and social functioning (85.93 ± 14.77) dimensions and the lowest in the emotional functioning (67.86 ± 19.33) dimension. We found higher scores among females. In the age category we found that GCS scores of the 5–7-year-old age group were lower than those of other age groups in every dimension. We found a significant difference in the social functioning dimension (5-7y: 79.40 ± 14.02 , 8-12y: 86.25 ± 15.72 , 13-17y: 88.47 ± 13.78 , $p_{\text{Kruskal Wallis}} = 0.016$). With the use of pump compared to pen, we measured higher but not statistically significant values across all dimensions except the emotional one. In the HbA1c category, we observed the highest HRQL scores in the range of 6.5–7.5%. The comparison according to duration of T1DM, usage of glucose sensor, comorbid coeliac disease and participation in diabetic camp categories did not reveal any differences.

The GCS PPR results can be seen in Table 2. The total mean score was 78.19 ± 14.05 , with the highest scores in the social (87.54 ± 14.55) and the lowest in the emotional functioning (69.00 ± 19.33) dimension. We found higher scores among females. In the age category, we found that PPR scores of the 5–7-year-old age group was lower than that of the younger or older age groups. We found statistically significant difference in physical (2-4y: 82.29 ± 15.14 , 5-7y: 71.88 ± 19.78 , 8-12y: 81.81 ± 16.61 , 13-17y: 85.57 ± 14.81 , $p_{\text{Kruskal Wallis}} = 0.020$) and social functioning (2-4y: 91.67 ± 12.11 , 5-7y: 81.60 ± 13.67 , 8-12y: 87.25 ± 15.56 , 13-17y: 89.83 ± 13.99 , $p_{\text{Kruskal Wallis}} = 0.029$). With the use of pump compared to pen, we measured higher results (Total: pump: 81.12 ± 14.48 , pen: 76.48 ± 13.59 , $p = 0.035$). In the HbA1c category, we observed the highest HRQL scores in the range of 6.5–7.5%. Patients with comorbid coeliac disease showed lower scores without statistical significance. The comparison according to gender, duration of T1DM, usage of glucose sensor and participation in diabetic camp categories did not reveal any differences.

Results of FIM are presented in Table 3. We found the highest scores in cognitive (76.80 ± 20.43) and social functioning (74.71 ± 25.18), and the lowest scores in physical (61.27 ± 20.61), emotional functioning (61.80 ± 21.80), worry (62.25 ± 22.19) and daily activities (63.22 ± 26.22) dimensions. In younger ages the scores were significantly lower in all dimensions (total: 2-4y: 45.14 ± 6.38 , 5-7y: 58.57 ± 18.51 , 8-12y: 68.85 ± 15.83 , 13-17y: 72.72 ± 15.38 , $p_{\text{Kruskal Wallis}} < 0.001$). Duration of T1DM ≥ 2 years resulted in higher scores, which reached a significant level in the parental HRQL dimensions, which is summed of physical, emotional, social, and cognitive functioning scales ($< 2y$: 60.07 ± 20.17 , $> 2y$: 68.88 ± 17.80 , $p = 0.039$). The use of insulin pump resulted in higher values compared to pen in all dimensions. Families raising children with comorbid coeliac disease showed lower scores without statistical significance. We measured higher values in families of children who had participated in diabetic community events except family relationships dimension. The comparison according to gender, usage of glucose sensor and HbA1c level categories did not reveal any differences.

To observe the agreement between the perceptions of children and their parents we used Pearson correlation coefficient. It was between 0.735–0.859 in all dimension groups, which means strong positive correlation.

Table 4 presents the effects of social factors on HRQL indices. We found significantly higher GCS total scale scores with higher level of parental education (SR low: 71.98 ± 12.42 , high: 79.59 ± 11.66 , $p = 0.026$, ppr low: 70.34 ± 14.84 , high: 79.44 ± 13.66 , $p = 0.016$). Both GCS and FIM total scale scores were significantly higher in case of permanent maternal employment group compared to unemployment group (SR unemployed: 71.27 ± 11.04 , permanent job: 81.29 ± 10.97 , $p < 0.001$, PPR unemployed: 67.62 ± 12.07 , permanent job: 82.05 ± 12.53 , $p < 0.001$, FIM unemployed: 59.05 ± 15.49 , permanent job: 72.51 ± 16.24 , $p < 0.001$). Paternal unemployment involved only 4 persons among 111, so statistical analysis was not performed in these groups. Examining large families and one-parent families we did not find differences between groups. Individuals living in overcrowded housing had significantly lower scores compared to those living in non-overcrowded housing (SR crowded: 77.15 ± 12.89 , not crowded: 79.95 ± 11.81 , $p < 0.001$, PPR crowded: 75.76 ± 14.40 , not crowded: 81.12 ± 14.48 , $p = 0.01$, FIM crowded: 65.89 ± 15.67 , not crowded: 70.45 ± 20.00 , $p < 0.001$). We found higher scores among those who owned their own car. The highest scores were found in the highest income group based on the family's net monthly income.

Table 4
Comparison of study groups by PedsQL questionnaires Total Mean Scores

	Generic Core Scales Self-report			Generic Core Scales Parent-proxy report			Family Impact		
	N	Mean ± SD	p	N	Mean ± SD	p	N	Mean ± SD	p
Education*									
low	15	71.98 ± 12.42	0.026^a	15	70.34 ± 14.84	0.016^a	15	61.33 ± 16.26	0.12 ^a
high	107	79.59 ± 11.66		107	79.44 ± 13.66		107	70.22 ± 17.04	
Work of mother									
unemployed/occasional work	29	71.27 ± 11.04	<0.001^a	29	67.62 ± 12.07	<0.001^a	29	59.05 ± 15.49	<0.001^a
permanent job	92	81.29 ± 10.97		92	82.05 ± 12.53		92	72.51 ± 16.24	
Single parent									
no	99	78.11 ± 12.58	0.61 ^a	99	77.85 ± 14.64	0.72 ^a	99	67.98 ± 17.54	0.19 ^a
yes	23	79.02 ± 11.37		23	77.41 ± 13.95		23	72.23 ± 15.76	
Large family (3 or more children)									
no	86	78.90 ± 12.87	0.08 ^a	86	78.62 ± 14.81	0.10 ^a	86	67.88 ± 18.01	0.29 ^a
yes	36	76.80 ± 10.91		36	75.72 ± 13.56		36	70.94 ± 15.26	
Density of housing**									
crowded	80	77.15 ± 12.89	<0.001^a	84	75.76 ± 14.40	0.01^a	86	65.89 ± 15.67	<0.001^a
not crowded	47	79.95 ± 11.81		48	81.12 ± 14.48		48	70.45 ± 20.00	
Own car									
no	11	75.40 ± 6.53	0.19 ^a	11	67.74 ± 10.91	0.008^a	11	62.08 ± 10.98	0.07 ^a
yes	111	78.56 ± 12.73		111	78.76 ± 14.42		111	69.45 ± 17.63	
Family income per month									
<500.000 Ft	34	79.32 ± 11.67	0.44 ^b	34	77.33 ± 15.28	0.8 ^b	34	70.69 ± 15.48	0.04^b
500.000 Ft-1.000.000 Ft	69	76.83 ± 13.10		69	77.49 ± 14.45		69	66.76 ± 17.81	
>1.000.000 Ft	8	85.05 ± 8.49		8	81.52 ± 13.00		8	80.90 ± 14.38	
* We made 2 education groups by scoring: We give 1 point for elementary school, 2 for high school and 3 for college or university both mother and father, 1–3 points get low, 4–6 points get high class in education groups.									
** The participants declared density of housing by person/room. We determined ≥2 crowded and <2 not crowded.									
a-statistical analysis with Mann-Whitney U test									
b-statistical analysis with Kruskal-Wallis test									
We defined a significance level p < 0.05 and highlighted in bold.									

Discussion

In our study we found that Hungarian children and adolescents with T1DM in our region present just slightly lower general HRQL than the Hungarian and international average of the general children population as reported in previous research [18,19]. The relatively good general HRQL results can be explained by the generally good physical functioning in T1DM patients in contrast to other chronic conditions in childhood [20] confirmed by our results. In contrast to general population among T1DM patients emotional and school related stress decreases HRQL according to our study and international literature [19]. Low

emotional functioning may reflect difficulty accepting the illness, fear of short- and long-term consequences, and a sense of being restricted due to numerous limitations [10]. School functioning may be impaired by frequent absences from school, neuropsychological deficits caused by poorly controlled T1DM, anxiety, social exclusion by peers [10].

Comparing the study groups, we found that females had slightly higher GCS scores in almost all dimensions, contrary to the findings of other studies [21]. GCS SR scores increased with age, which is contrary to the trend that adolescents have lower HRQL, described in the literature [21]. We did not find a clear trend in GCS scores with the duration of T1DM. Insulin pump-user patients achieved significantly higher GCS scores, consistently with other studies [22]. We found no positive effect of the use of glucose sensor on GCS scores; however, the literature notes that sensors can reduce the stress of hypoglycemia, enable more restful sleep at night, and improve metabolic control, but these positive effects can not necessarily translate into an improved HRQL [23,24]. GCS scores were highest in the group with near-normal HbA1C levels (6.5–7.5%), consistently with data in the literature, probably caused by more frequent hypoglycemic episodes or stricter lifestyle control at lower HbA1C levels and more complications, more frequent hospitalization at higher levels [25]. In cases of comorbid coeliac disease, we observed slightly lower scores in the PPR, however, the great difference in sample size may skew our results [15]. In the case of diabetes summer camps, we found higher indices in the GCS PPR, which may support their positive effect, also described in the literature [26]. The identified strong positive correlation in parent-child agreement supports that we got relevant information about the patients and their treatment [27].

The HRQL of families raising T1DM children is reduced compared to the general population [28]; furthermore, according to a Hungarian study, the mothers of T1DM preschool-aged children reported lower levels of resilience and more depressive symptoms than mothers of healthy peers [9]. Comparing our results with the only one larger-scale survey conducted in Hungary among 8- to 18-year-olds, we found lower scores regarding the family HRQL, particularly in the physical, emotional, worry, and daily activities dimensions [8].

We were unable to identify any gender differences. Surprisingly significant permanent decline was shown with decreasing age of patients in family HRQL total score and each dimension. A limitation is the small sample size in the youngest age group. Lukács [9] found no significantly lower scores in family HRQL in the 2-6-year-old T1DM population compared to healthy controls, suggesting that the results are at least partly age-related. However, she demonstrated that mothers' resilience and depressive symptoms were significantly higher and, overall, they assessed the vulnerability of families in this age group. The dramatically low FIM scores in our study among the younger age group highlight the potentially devastating impact of chronic illness on this already vulnerable segment of population. Therefore, it is crucial to prioritize support for this age group. When asked about their overall needs, 49% of patients requested psychological, 36% financial, and 26% educational support in the whole T1DM population. These high rates indicate their need for support and its necessity. The positive impact of T1DM duration on family HRQL is a documented finding in the literature [21], which supports the beneficial effect of establishing routines related to the illness. Usage of insulin pump apparently has positive effect on families' HRQL proved in our study as in the literature [22]. Among co-occurring chronic disease, we examined coeliac disease which showed negative impact on family HRQL. The beneficial impact of a one-week diabetes camp with professional supervision on family HRQL may be attributed in part to the temporary relief it provides parents from the constant pressure of being alert, and in part to the improvement in the patient's social and therapeutic skills.

Our study confirmed that socioeconomic background has a strong effect on HRQL of T1DM children and their families consistently with literature [29,30,31]. Higher educational attainment of parents improves patient and family HRQL, while maternal unemployment worsens it. People with lower financial status, expressed by density of housing, car ownership and family income has decrease on perceptions of HRQL.

Strengths of this study is simultaneous examination of HRQL of T1DM patient, family and socioeconomic factors, which have not been studied in Hungarian population yet. The limitations are (1) the lack of healthy control group and (2) the low number of cases. We used GCS questionnaire instead of the more specific Diabetes Module, because this study is part of a greater examination with various chronic conditions. The specialty of the chosen population is the great impact of patients family's self-management of disease under medical supervision.

I consider our most significant finding to be the demonstration of a correlation between Family HRQL and patient age. To further validate these findings, we believe it is warranted to conduct a multicenter survey of the 2–6-year T1DM population across all of Hungary, based on the Hungarian Diabetes Registry. It is important to draw the attention of government and civil society organizations to these disadvantaged families and to ensure they receive the psychological, financial, and educational support they need.

Abbreviations

T1DM -type 1 diabetes mellitus

WHO-World Health Organization

HRQL -health-related quality of life

PedsQL - Pediatric Quality of Life Inventory

GCS - PedsQL Generic Core Scale

SR - self-report

PPR - parent proxy-report

FIM - PedsQL Family Impact Module

Declarations

Ethics approval and consent to participate:

The Ethics Committee of the University of Debrecen Clinical Centre (no. DE RKEB/IKEB: 6798-2024) approved this research protocol. The study was carried out in accordance with guidelines of the Declaration of Helsinki and Good Clinical Practice.

Consent for publication:

Not applicable

Availability of data and materials:

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Competing interests:

The authors declare that they have no competing interests.

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Authors' contributions:

Flóra Ujhelyi participated in data collection, performed data entry and data processing, and wrote the manuscript. László Ujhelyi and Péter Juhász assisted with data processing and the writing of the manuscript. Andrea Berkes and Enikő Felszeghy designed the study, participated in data collection, assisted with data interpretation, and reviewed the manuscript. Tamás Szabó provided the conditions and institutional support.

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