

“A study to assess the quality of life of children with Diabetes Mellitus as perceived by the Parent and Child”.

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Abstract

Background: Diabetes Mellitus (DM) is a chronic metabolic disorder with a heterogeneous etiology and risk factors at the social, behavioral, environmental levels with predominant genetic susceptibility. Health-related quality of life (HRQOL) has been progressively acknowledged as an essential outcome measure in clinical trials and health service research and evaluation.

Materials and methods: A descriptive study was conducted involving 70 children with Diabetes mellitus and their parents. Consecutive sampling method was used to select the samples for the study. The quality of the child and parent were assessed using the PedsQL 4.0 Generic Core Scale and Peds QL Diabetes Module 3.0 scale and analysis done.

Results: The findings revealed that both children(86.31) and parents(83.32) generally reported high quality of life both in general and diabetic related domains. There was significant relationship between their attendance in school with their generic and diabetic score of the child (76.59) and parent (76.67). A significant relationship was found between the child age and HbA1c value. There was no significance between the HbA1c and the QOL of children with diabetes.

Conclusion: It is hoped that the findings from the study will assist both families and clinicians working with children with T1DM to promote their quality of life.

Key word: quality of life, perception, diabetes, child, parent

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I. Introduction

Diabetes Mellitus is a chronic metabolic disorder with a heterogeneous etiology and risk factors at the social, behavioral, environmental and genetic susceptibility. When a child is diagnosed with type 1 diabetes, it becomes a complex and challenging situation for the whole family. According to WHO the QOL is a term that refers to “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. (WHO¹, 1993).

Parent seem to report more stress in the area of social disruption, emotional strain, and financial strain when the child's condition is associated with unpredictable symptoms.(Dodgson 2000)². Health-related quality of life (HRQoL) has been progressively acknowledged as an essential outcome measure in clinical trials and health service research and evaluation (Varni et al³, 2007). It is now well established that enhancing HRQoL in children with diabetes is as important as metabolic control and prevention of long-term complications (Emmanouilidou et al⁴, 2008). Health professionals need to be sensitive to address these major modifications that a family needs to make on the event of child being diagnosed with DM.

II. Materials and methods

Study Design: A descriptive design

Study Location: Apollo Children's hospital, Chennai, Tamil Nadu.

Study Duration: January- March 2021

Sample size: Sample size calculation: Based on the study done by Nurcanetal (2017) which looked at QOL in Children and adolescents with type I diabetes and their parents the sample size is calculated for this study. Require a sample size of 68 pairs of child and parent

Subjects & selection method: Total enumerative sampling.

Inclusion criteria:

Child :

- Children between 8 to 18 years of age diagnosed with Diabetes Mellitus and their parents.
- Children with a diagnosis of diabetes and is on treatment for more than six months.

- Children who speak and write English, Tamil or Hindi.

Parent:

- Parents who know to read and write Tamil, English, Hindi and accompanied the child

Exclusion criteria:

Child:

- Children with other co-morbidities/chronic conditions such as seizures, mental illness, developmental disorders.
- Children with diabetes who are acutely ill
- Children who are not accompanied by parent.

Parent:

- If either parent or child is unable fulfill the inclusion criteria both will be excluded from the study.

Procedure methodology

Samples will be collected in the endocrinology OP department for a period of 3 months. The investigator collected the information regarding the children between 8 to 18years of age who are diagnosed with Diabetes Mellitus from the Medical Records Officer (MRO). On the non-clinic days the investigator collected data from children who were admitted in the wards. The list of the children visiting the OPD were collected by the investigator. The investigator collected the samples after they met the diabetic educators. They were made to sit comfortably in a room in the OPD. Rapport was established with child and parent, the purpose of the study was explained and written informed consent from parents and an assent from children was obtained. Information on socio demographics and related to clinical variables was collected from parents and from the patient record. Age appropriate PedsQL Generic Core Questionnaire and the PedsQL Inventory 3.0 Diabetes Module were administered to the children which was developed by James W Varni et al in 2003. Parents were given the parent proxy version of the PedsQL generic version and the PedsQL Inventory 3.0 Diabetes Module⁵. Approximately 20 to 30 minutes were taken by the subjects to complete the inventories.

Statistical analysis

Data was entered using Excel and screened for outliers and extreme values using Box-Cox plot and histogram (for shape of the distribution). Summary statistics was used for reporting demographic and clinical characteristics. All categorical variables were reported using number and percentages and continuous variables were expressed in terms of Mean \pm SD.

III. Result

Table 1 Distribution of children according to their demographic variables

Demographic variables	n	%
Age		
8-11yrs	28	40
12-14 yrs	26	37.14
15-18yrs	16	22.86
Gender		
Male	36	51.4
female	34	48.6
Attendance in educational institution		
Yes		
no	65	92.9
	5	7.1
Type of family		
Nuclear	53	75.7
joint	17	24.3
Place of residence		
Urban	34	48.6
rural	36	51.4
Religion		
Christian	7	10
Hindu	58	82.9
muslim	5	7.1

Table 1 shows that among the children 36 (51.4%) of them were males and 34(48.6) were females, with regard to the institutional attendance 65(92.9%) of them attended schools regularly and 5(7.1%) of them did not go to school. Majority of them, that is 53 (75.7%) of them belonged to a nuclear family and 17(24.3%) were from joint families. 34(48.6%) of them resides in urban area and 36(51.4%) resides in rural area. Majority 58(82.9%) of them were Hindus and 5(7.1%) were Muslims.

Table 2
Distribution of parents according to their demographic variables

N = 70

Demographic variable	n	%
Parent		
Father	28	40
mother	42	60
Monthly income		
>10,000	39	55.7
10,001-30,000	22	31.4
>30,000	9	12.9

Table 2 shows that among the parent who filled the questionnaire 42(60%) were mothers and 28(40%) were fathers. Majority, 39(55.7%) of the family’s monthly income were less than Rs.10,000 .

Table 3
Distribution of children according to their clinical variables
N = 70

Clinical Variable	n	%
Age of Diagnosis in Children in years	70	100
Latest HbA1C Value (%)		
Administration of Insulin	70	100
Person-who-administers-insulin	N	
Self		
Parent	35	50
Others	34	48.57
Place where insulin is bought	1	
ACH		
Medical shop		
How often do you change syringe/needle		
Daily	35	50
Every week	35	50
	12	17.14
	58	82.86

Table 3 shows the mean age of diagnosis of DM was 7.5 years and average latest HbA1C value was 10 %. Half the proportion (50%) took insulin by self and a similar proportion (50%) bought insulin in the study hospital. Most of them, 58(82.9%) changed the needle once a week and only 12 of them (17.1%) changed the needle daily.

The overall mean scores of the generic PedsQL scale of the child and parent are represented using box plot.

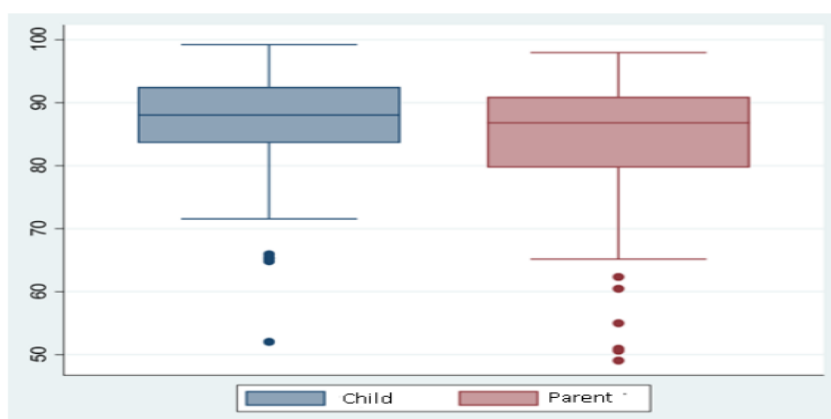


Figure 1. Overall mean scores of parent and child reports on the generic PedsQL scale Figure 2 shows the overall mean generic score of the child was higher (86.31) than that of the parent score (83.32).

The Overall mean scores of the diabetic pedSQL of the child and parent are represented using box plot.

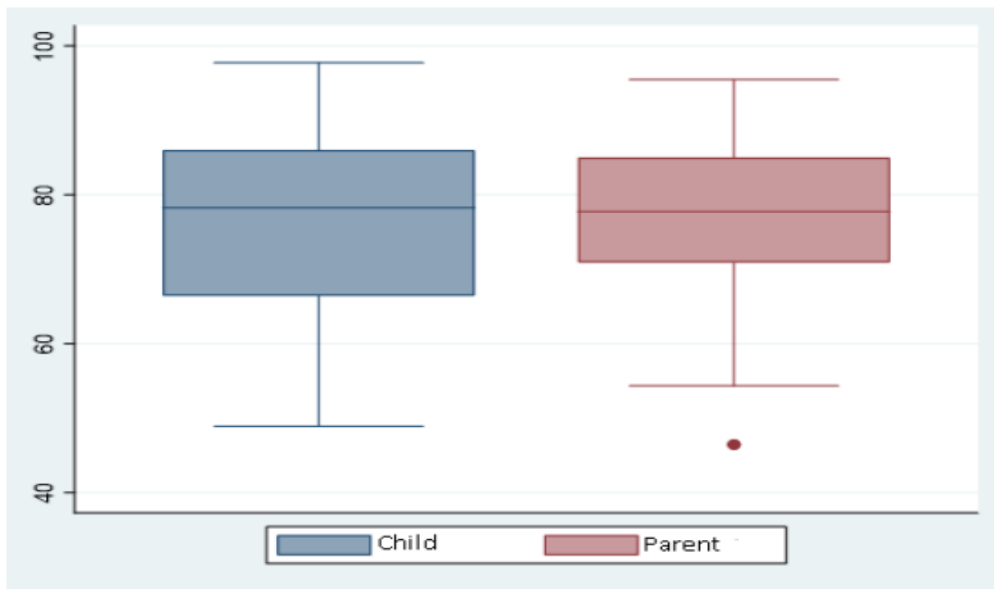


Figure 2. Overall mean scores of child and parent on the Diabetic PedsQL scale Figure 3 shows the overall mean diabetic score of the child (76.59) and parent (76.67) were almost the same.

Mean \pm SD of Generic Peds QL score in children and Parent

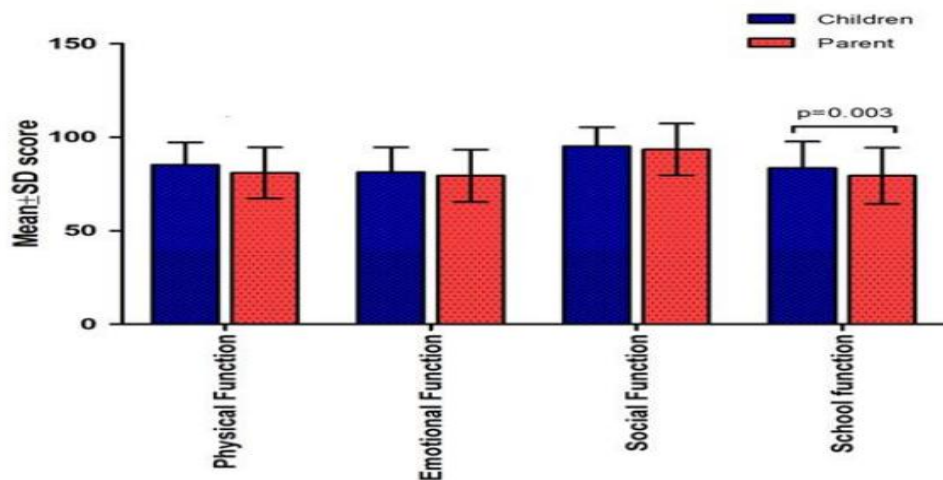


Figure 3. Mean scores in domains of Generic PedsQL in children and Parent There was a significant difference in the scores of school function between the child and parent reports in the generic PedsQL measure.

Mean ± SD of Diabetic Peds QL score in children and Parent

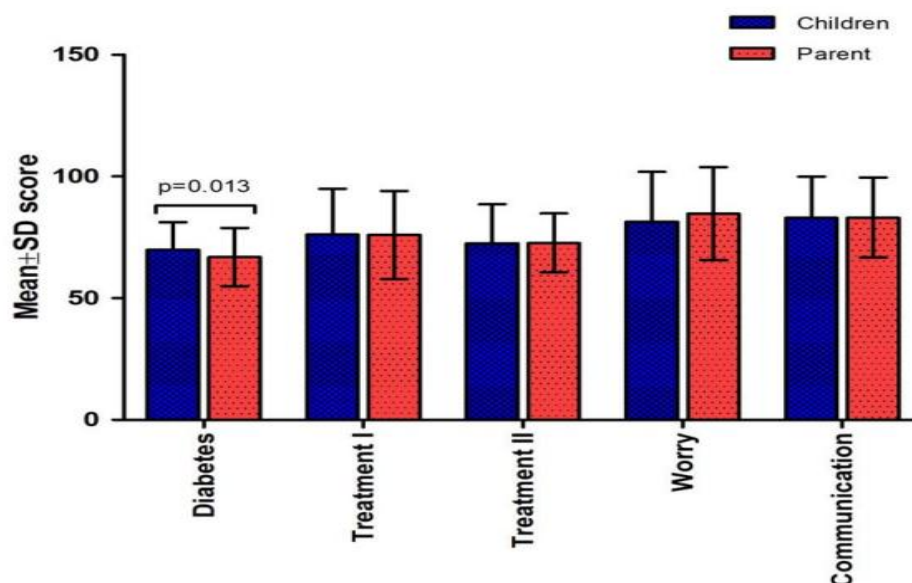


Figure 4. Mean scores in domains of Diabetic Peds QL in children and Parent There was a significant difference in the scores of diabetes domain between the child and parent reports in the diabetic Peds QL measure

Table 6 Relationship between the demographic variables of the child and the parent with the generic and diabetic PedsQL scores.

variable	Generic scale			Diabetic scale		
	Mean(SD)	t-value	p-value	Mean(SD)	t-value	p-value
Child age			0.823		--	0.787
8-11yrs	84.80(11.32)			77.44(12.37)		
12-14yrs	85.39(9.15)	---		76.20(10.35)		
15-18yrs	83.90(11.51)			75.90(11.62)		
Gender		1.845	0.069		-0.014	0.98
Male	88.26(7.31)			76.57(12.35)		
Female	84.23(10.73)			76.61(12.26)		
Attendance in school		2.43	0.017		1.68	0.09
Yes	87.03(8.83)			77.26(12.12)		
No	76.88(11.0)			67.86(9.95)		
Type of family		-0.283	0.777		-0.208	0.83
Nuclear						
Joint	86.13(9.20)			76.42(12.36)		
	86.37(9.83)			77.13(11.86)		
Place of residence		-0.208	0.835		-1.176	0.24
Urban						
Rural	86.07(8.36)			74.84(11.03)		
	86.53(10.21)			78.25(13.08)		
Religion		0.548	0.585		1.128	0.26
Hindu	86.58(9.19)			77.33(11.88)		
Christian & muslim	84.96(10.07)			72.99(13.41)		
Monthly income		0.893	0.374		0.400	0.690
<10,000						
>10,000	87.19(8.38)			77.11(12.79)		
	85.19(10.36)			75.93(11.50)		

Table 6 shows the relationship between the demographic variables of the child and parent with their mean generic and diabetic scores. There is a significant relationship between their attendance in school (p 0.01) and their generic quality of life. The mean scores of QOL was higher 87.03(8.83) in children who were attending school. There is no significant relationship between the demographic variables and their diabetic Peds QL score.

Table 7
Relationship between the clinical variables of the child with the generic and diabetic PedsQL scores.

variables	Generic scale			Diabetic scale		
	Mean(SD)	t-value	p-value	Mean(SD)	t-value	p-value
Age of diagnosis						
<6yrs			0.452			
7-9yrs	83.53(11.54)	0.80		75.18(12.03)	0.95	0.389
>9yrs	86.21(8.65)			78.46(10.49)		
	85.33(10.62)			77.01(11.33)		
HbA1c						
5-8.9yrs	86.65(10.03)		0.933	79.05(13.32)	0.57	0.568
9-11.9yrs	85.87(8.19)	0.06		75.79(11.69)		
12 & above	86.77(10.99)			75.83(11.96)		
Insulin administration						
Self						
Parent	87.12(9.37)	0.738	0.462	77.07(11.71)	0.365	0.715
	85.45(9.41)			75.99(12.62)		
Change of syringe						
Daily		-0.885				
Every week	84.14(7.73)		0.378	76.98(11.44)	0.120	0.904
	86.76(9.58)			76.51(12.40)		

Table 7 shows that there is no significant relationship between the clinical variables and the generic and diabetic PedsQL scores. On comparing the HbA1c with the child age, the highest was found in the children between 12 – 14yrs of age with the mean of 86.77(10.99). It also showed a significant relationship with the p value of 0.001.

IV. Discussion

The purpose of this study was to assess the child and parent perception of Quality of life of child with Diabetes Mellitus, visiting the Pediatric Endocrinology Unit, Apollo Childrens hospital. A total of 140 participants were selected for the study. A total of 70 children with Diabetes and their parents who fulfilled the inclusion criteria were included in the study. The data were collected using Generic PedsQL scale and Diabetic PedsQL module which was filled by both the child and their parent.

The collected data were analyzed using statistical package for social sciences (SPSS) version 25.0 for windows. Descriptive statistics was used to assess the distribution of subjects based on demographic variables and clinical variables. Frequencies and percentages, mean and standard deviation, median and interquartile range were used to present the data on quality of life. Paired t test was used to show the comparison between the child and parent perception on the generic and diabetic PedsQL. Chi square and independent t test were used to show the relationship between the demographic and clinical variables of the child and parent with their generic and diabetic scores. One way ANOVA was used for comparison of child's age, their age of diagnosis and HbA1c values. A p value of <0.05 was considered statistically significant in all analyses.

With regard to education a majority of children (92.9%) were attending school in classes appropriate for age. The findings show that the diagnosis of a chronic condition such as diabetes did not divert their interest or need to pursue formal education. Similar result was seen in another study from North India where majority of children with diabetes had either completed high school (65.2%) or went ahead with college level education (17%) (Kumar et al., 2020). It was also found that the disease or its increased care demands in these children did not deter them from doing excellently (24.3%) or well (54%) in school compared to nondiabetic children in another study done in Kuwait by Abdul-Rasoul, Alotaibi, Abdulla, Rahme and Alshawaf⁵ (2013).

The present study revealed that the mean age of diagnosis for the children were found to be 7.5years. In this study the mean age falls a little above the mean years reported from other similar studies from other countries but lower than another study from India. An another Indian study reported the mean age of diagnosis as 9.9 (±2.8years) (Kumar et al.,2020). Studies from other countries like Abdul-Rasoul et al(2013) in Kuwait and Nansel, Weisberg-Benchell, Wysocki, Laffel and Anderson⁶ (2009) in USA reported mean age at diagnosis as 6.1 and 6.7 years. The finding point to a probable delay in identifying diabetes in children in India. Further studies are needed to explore the factors related to disease identification and diagnosis. HbA1c levels are an important indicator of the extent to which the diabetes is controlled. Serum HbA1c assay is done for children attending this tertiary care center regularly at three months interval.

The overall mean score for general QOL (measured by generic Peds QOL scale) as reported by the children was 86.31±9.3. The maximum being 96% (The score ranges from 0- 100).The findings show that children with diabetes generally had a better QOL. It was observed in the study that while the children's generic

scores on the social function subscale were high (95.14 ± 10.28), their scores on the subscales of affective function (81.36 ± 13.38) and school function (83.50 ± 14.25) were low. The findings are supported with a study done by Samardzic, M., Tahirovic, H., Popovic, N⁹ (2016) in Montenegro on comparing children with T1DM and a healthy group which revealed that children and adolescents with T1DM had lower HRQOL on domain psychosocial health and school functioning when compared with healthy population ($p=0.008$; $p \leq 0.001$).

The diabetic related QOL was measured by PedsQL™ Diabetes Module . The overall score of the scale was 100 as high and 0 as lower score. The overall mean score was 76.59 ± 12.16 . The reports on the diabetic scale revealed that the children's score with regard to worry (81.43 ± 20.47) and communication (82.98 ± 16.93) were higher and it was the lowest on diabetes symptoms (69.84 ± 11.43) since most of the children felt difficulty in managing the symptoms as it interfered with their activities of daily living. The findings were supported by a similar study done by Emmanouilidou et al (2008), on the youth in the Northern Greek that showed lowest score on the diabetic symptoms and the highest in the communication domain as the children did not have any difficulty in communicating their problems related to the disease to their health care professionals. Kalyva et al.¹³ (2011), in their study, stated that children and adolescents with T1DM had lower general HRQoL compared with healthy matched children and adolescents.

The parents' reports showed similar perception as that of the child. The overall mean score as reported by the parent on general quality of life was 83.32 ± 11.6 revealing a perception of higher QOL. Parent's score on the social function (93.05 ± 13.81) of the child was high and their scores on affective (79.43 ± 13.98) and school function (79.43 ± 14.95) were low like that of their children. A similar study done by Özyazıcıoğlu, Avdal, & Sağlam¹⁴, (2017) also stated that parent reported high score on social functioning (82.73 ± 22.39) of the child compared to the other domains. This finding is also supported by the study done by AbdulRasoul et al¹⁵ (2013), where the parent reported higher score in the social function (76.2 ± 8.4) and lower scores in the affective and school function of the child. Parents reported that their child often showed anger and argued about their condition and it even affected their academic performance and absenteeism to school due to diabetic symptoms or OPD visits. The overall mean score in the diabetic scale as reported by the parents were 76.67 ± 10.72 . The parents in the study also reported higher scores in the worry (84.76 ± 19.09) and communication (83.10 ± 16.48) domains and lower scores on the diabetic symptoms domain (66.85 ± 11.94) of the disease specific QOL scale. This is supported by a similar study done in Kuwait by Abdul-Rasoul et al (2013) that showed lowest scores in the diabetic symptoms domain (59.3 ± 11.3) of the parent. Another comparative study done in USA by Nansel et al (2009), found that the diabetic symptoms domain shows lower score and the communication domain gives a higher score.

The paired samples t test showed that there was a statistically significant difference between the generic QOL scores calculated from reports by patients with T1DM compared to scores calculated from the parent reports. In Generic QOL, the total scores based on reports by child was (86.31 ± 9.3), compared to (83.32 ± 11.6) by their parents ($t = 2.797$, $p < 0.05$) showing a significant difference between parents and child perception. A similar study done in Turkey, the total scores based on reports by the children was 75.6 ± 11.6 , compared to 70.1 ± 10.2 by their parents ($t = 4.78$, $p < 0.001$). Children reported better QOL compared to their parents because parent reports reflect their anxiety for their chronically ill children and underestimate the children's quality of life. There was a significant difference in the school function with p value 0.003 in the current study. There was similar significant difference in mean scores in the Turkey study also ($p < 0.01$).

On comparing the child and parent perception on the Diabetic QOL in the present study the overall scores of the child (76.59 ± 12.16) and parent (76.67 ± 10.72) showed a similar perception without a difference. However there was significant difference ($p < 0.001$). The most significant difference was in the worry and treatment adherence scales ($p < 0.0001$ and $p < 0.001$, respectively).

In this study the mean scores of the QOL were compared in order to show the relationship between the demographic and clinical variables of the child and parent with their generic and diabetic QOL scores. A p value of ≤ 0.05 was considered statistically significant in all analyses. The study showed a higher mean generic scores in children between 12-14yrs of age with mean $85.39(9.15)$. This is supported with the findings of the study conducted by AlBuhairan et al¹⁶ (2016), that showed teens in early adolescence (13–15 years) had better QOL compared to teens in later years of adolescence (16–18 years). In this study there was no significant relationship was found between the demographic variables such as age ($p=0.82$), gender ($p=0.06$), type of family ($p=0.77$), religion ($p=0.58$), place of residence ($p=0.83$) and the monthly income of the family ($p=0.37$) with the generic scores of the child and parent. However there was a significant relationship ($P < 0.01$) between the attendance in educational institution and the generic score of the child with the mean value of $87.03(8.83)$. The mean generic QOL scores were higher in the school going children. The influence of school and the peer group at school could be a positive influencing factor. Although the scores were low in school functioning in QOL scale, school seems to have a positive effect on general QOL of children with diabetes which needs to be explored further. A study conducted by Cooper, McNamara, de Klerk, Davis & Jones¹⁷, (2014), stated that there was no significant

difference seen in the performance of the children with diabetes when compared with their peers, but an association was found between the poorer glycemic control and poorer school performance.

In this study, the mean scores on Diabetic PedsQL scale were compared in order to show the relationship between the demographic variables of the child and parent with their diabetic QOL scores. A p value of < 0.05 was considered statistically significant in all analyses. The study reveals that there was no significant relationship between the demographic variables of the child and parent with their diabetic QOL scores. Contrary to the findings in the present study study done in Saudi Arabia showed that gender and age were the statistically significant predictors impacting teens' quality of life. Females had lower QOL scores compared to males ($p < .0001$), and younger adolescents aged 13–15 years had higher QOL scores compared to older adolescents aged 16–18 years ($p < 0.0002$). Another similar study done in Kuwait by Abdul-Rasoul also supported that in most age groups, male sex was associated with better QOL ($p < 0.05$). Lukács A, Kiss-Tóth, Soós & Barkai, (2014) in her study included that on comparing the HRQOL of diabetic boys and girls with the PedsQL DM, it was observed that boys had significantly better quality of life than girls (boys ($n = 184$): 72.77 ± 12.95 vs. girls ($n = 171$): 69.89 ± 12.31 ; $p = 0.033$). This was confirmed by the parents' answers (boys ($n = 170$): 70.82 ± 11.24 vs. girls ($n = 158$) 66.86 ± 12.16 ; $p = 0.002$).

The mean scores of the QOL scales was compared in order to show the relationship between the clinical variables of the child and parent with their diabetic QOL scores. A p value of 9 years. On comparing the HbA1c with the child age, the highest value was found in the children between 12 – 14yrs of age with the mean of 10.89(2.55). It also showed a significant relationship with p value of 0.001. In this study, HbA1c shows no significant relationship on comparison with the generic and diabetic PedsQL scores. However the children with HbA1c in the range 5 -8.9 showed a higher mean score (79.05) in their diabetic scale when compared with the children with HbA1c value of >9 .

V. Conclusion

It is hoped that the findings from the study will assist both families and clinicians working with children with T1DM to promote the physical, psychological, social, educational and the disease specific and treatment adherence focused aspects. An evaluation of the quality of life after a diagnosis of diabetes and on a regular basis can be used to assess the problems which may be faced by children and the parent that will help finding solutions to their problems which may further enhance their perception about quality of life.

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