



Health related quality of life of diabetic children and factors affecting it in Sohag University Hospital, Sohag, Egypt

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Abstract:

Introduction: DM is the most common endocrine disease in children with increase in global incidence by 3% annually. Diabetes mellitus as chronic illness and its management negatively affect the quality of life of the diseased children. Health-related quality of life aspects are increasingly becoming an important concerns and outcome of diabetic patients management. Health-care professionals are becoming increasingly aware of the need to asses and monitor the QOL as an important outcome of diabetes care.

Aim of work: to assess the health related (QOL) and factors affecting it among children with type I diabetes.

Patients & methods: a hospital based cross sectional study that enrolled all diabetic children (80) in the Pediatric department from 1st of May 2013 till the end 30th Of April 2014. Pediatric Quality Of Life Inventory Scale (PedsQL) was used.

Results: A total of 80 diabetetic children were enrolled in this study 60% of them were males. The mean age was 10.08 ± 2.1 . 50% of the patients were diabetic for 1-3 years range and had follow up visits every 1-2 months and 45% of them had HbA1C level more than 10. A mean (Qol) total percent score of $70.2\% \pm 9.8$ was found indicating a low life quality. Significant association was found between (Qol) and intensive insulin therapy, compliance to treatment and low level of HB1C (below 7.5) while no significant association was found for duration of illness, No of follow up visits, No of blood sugar monitoring per day, No of hospital admission. Significant negative correlation was found between level of HB1C and high quality of life. No correlation was found between quality of life and other variables.

Conclusion: Measures for improving quality of life of diabetic children are needed with special emphasis on improving glycemetic control.

Keywords: type I diabetes, insulin regimen, pediatric quality of life.

Introduction

Diabetes Mellitus is one of the most common endocrine diseases in children. It can occur at any age, but tends to develop in childhood, so it has long been called 'juvenile diabetes. As of 2014, an estimated 387 million people have diabetes worldwide ⁽¹⁾, of which T1D accounts for between 5% and 10%. ⁽²⁾ Worldwide, an estimated 65000 children under 15 years old develop the disease each year, and the global incidence in children continues to increase at a rate of 3% a year ⁽³⁾. Diabetic complications continue to be a major cause of morbidity and mortality in persons with T1D.

Management of type I diabetes mellitus (DM) is lifelong and challenging. It is considered an over whelming demanding disease thus can negatively affect mental and physical health of the diseased children.

Quality of life (QOL) has been defined by the world health organization (WHO) as 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 ⁽⁴⁾. Health-related quality of life (HRQoL) is an assessment of how the individual's well-being may be affected over time by a disease, disability, or disorder ⁽⁵⁾. Health-care professionals are becoming increasingly aware of the need to asses and monitor the QOL as an important outcome of diabetes care. QOL is an important outcome in its own psychological and mental health, but also because it may influence the patient's self-care activities, which may consequently impact their diabetes control and management ⁽⁶⁾.

QOL consists of two components: The first component is a physical aspect which includes such things as general health, diet, body built, as well as pain and disease. The second component is psychological in nature and includes such things as stress, worry, pleasure and other positive or negative emotional states ⁽⁷⁾ and ⁽⁸⁾.

Methodology

This is hospital based cross sectional study assessing (HRQoL) of children with type I diabetes mellitus and factors affecting it. The study was conducted in the Pediatric Department (diabetes outpatient clinic, pediatric emergency unit and inpatient sector) of Sohag University Hospital, Sohag governorate, Egypt. The study was conducted during one year period that extended from 1st of May 2013 till the end 30th of April 2014.

Inclusion criteria included: every Infant & children under 12 years who was diagnosed as type I diabetes mellitus presented to the pediatric emergency department, visited the intermediate care unit or outpatient diabetes clinic.

Exclusion criteria included; neonates, patients presented with hyperglycemia only, patients suffered from other co-morbidities.

Ethical approval was obtained from (SUEC) Sohag University ethical committee for conducting this research. Informed consents were obtained from their mother before conducting the study. Accordingly among 100 diabetic children visited the hospital during the study period only 80 diabetic children met the previous criteria.

Sociodemographic and background clinical data about the patients course of disease was conducted through interviewing both diabetic children and their mothers. These data included: age and sex and residence of the patients, duration of illness, number of follow up visit, regularity on treatment, insulin regimen, number of blood sugar monitoring per day, Hemoglobin A1C level and number of visits to the hospital in the previous year due to diabetic ketoacidosis or hypoglycemia. HbA1c was measured by high-performance liquid chromatography (ref. range 4.0–6.0%, Tosoh 2.2; Tosoh, Foster City, CA).

Qol was assessed by the PedsQL, (8) which measures the child's and parent's perceptions of the child's comprehensive quality of life, with two subscales of physical and psychosocial functioning. The 23-item

PedsQL 4.0 Generic Core Scale includes a child self-report and a parent proxy-report. It has 4 subscales: (1) physical function, (2) emotional function, (3) social function and (4) school function. The PedsQL 23 items scored using a five-point Likert scale (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, and 4 = almost always a problem). For easy interpretation, items were reversed and scored and then linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL as follows: 0 scored as 100, 1 as 75, 2 as 50, 3 as 25, and 4 as 0. Total Qol score results from averaging all items. The physical functioning score is the average of eight items and the psychosocial functioning score is the average of 15 items encompassing emotional, school, and social functioning areas. Therefore, all scale and subscale scores range from 0 to 100 (highest quality of life).

Statistical analysis

Statistical Package for the Social Science (SPSS) program (version 20) was used for grouping, tabulation and statistical analysis of the data. Normally distributed data were presented as mean and standard Deviation and T test was used to determine the difference. Abnormally distributed data are presented as median and range.

Results

A total of 80 diabetic children were enrolled in this study 60% of them were males. 60% of the studied diabetic children were residing in rural areas. The mean age of this studied group was 10.08 ± 2.1 . Table (1) presented clinical features of the studied diabetic children, 50% of them were diabetic for 1-3 years range. 80% of the patients had three doses of insulin per day while only 55% of them were regular in treatment. 40 out of the 80 studied diabetic children did not monitor their blood sugar regularly. The majority of the studied diabetic children showed uncontrolled diabetic as 45% of them had HbA1C level more than 10.

Results of Pediatric Quality Of Life Inventory Scale (PedsQL) reported by the studied children were compared by that reported by their mothers and presented in figure 1.

Association between quality of life and clinical findings are shown in tables (3-4). Significant association was found between high quality of life and both regularity on treatment (p value=0.01) and being on intensive insulin regimen (p value=0.04). Very high statistically significant association was found between high quality of life and both irregular blood sugar monitoring per day and HbA1c less than 7 (p value=0.0001).

Results of correlation between quality of life and the selected clinical variables are presented in table (5) significant negative correlation was found between quality of life and only the level of HbA1c (p value=0.0000). While no significant correlation was found for other clinical variables.

Table (1) Clinical features of the studied 80 diabetic children

Clinical features	Summary statistics
Duration of illness	
Less than 1 year	4 (5.00%)
1-3 years	40 (50.00%)
3-5 years	28 (35.00%)
More than 5 years	8 (10.00%)
Number of follow up visit	
Monthly	8 (10.00%)
Every 1-2 month	60 (75.00%)
Every 6 month	12 (15.00%)
Regularity on treatment	
Regular	44 (55.00%)

Not Regular	36 (45.00%)
Insulin regimen	
Conventional	16 (20.00%)
Intensive	64 (80.00%)
Number of injections	
Once	4 (5.00%)
Twice	12 (15.00%)
Three times	64 (80.00%)
Number of blood sugar monitoring/day	
Three times	8 (10.00%)
Twice	12 (15.00%)
Once	20 (25.00%)
Not regular	40 (50.00%)
HbA1C level	
Less than 7	4 (5.00%)
7-10	40 (50.00%)
More than 10	36 (45.00%)
Number of admission to hospital last year	
None	56 (70.00%)
Once	16 (20.00%)
Twice	8 (10.00%)

Figure (1): Child Vs parent perception of QoL using pedsQl .

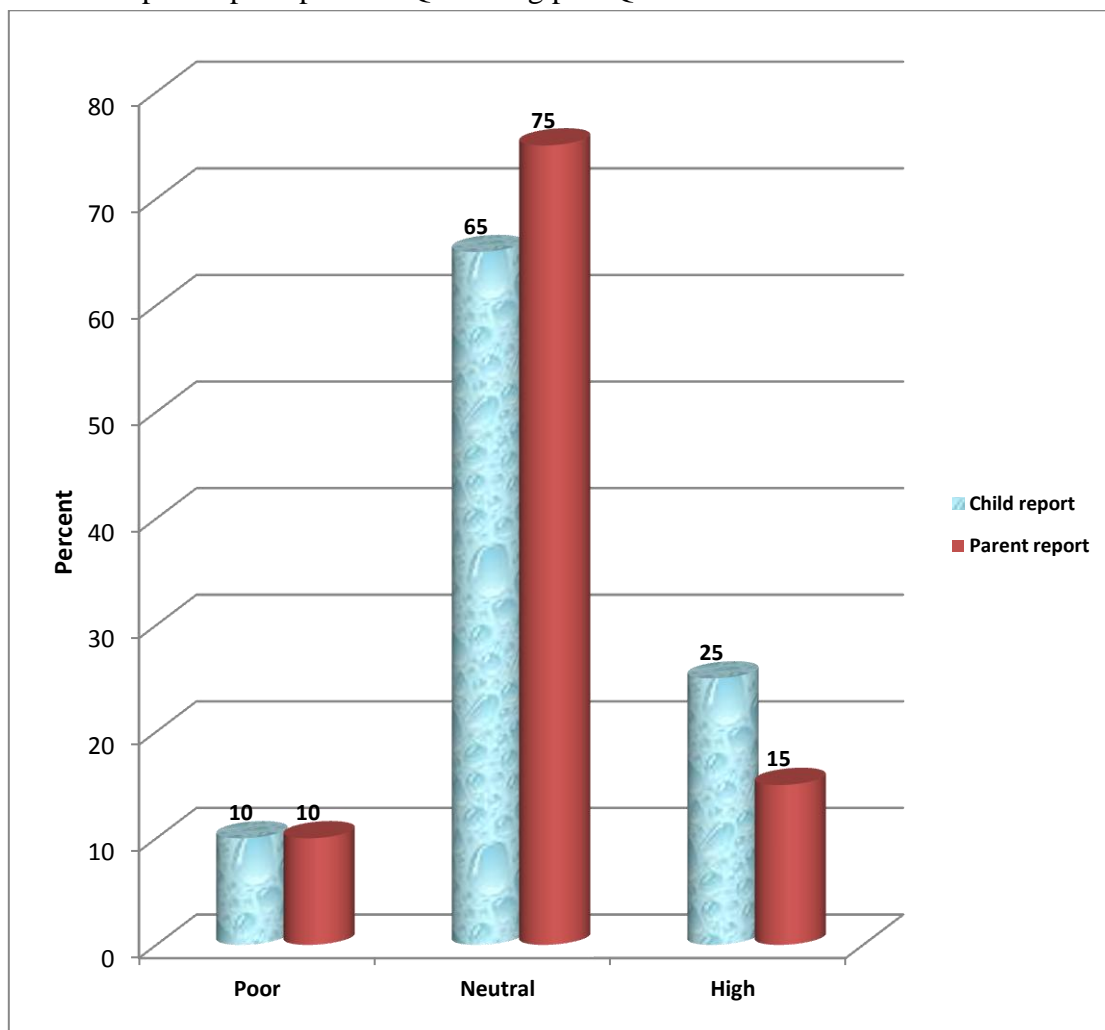


Table (2): Distribution of PedsQL of the studied 80 diabetic children in Sohag University Hospital, 2014 by their clinical features:

Characteristics	Poor N=8	Neutral N=60	High N=12	P
Diabetes duration				
Less than 1 yr.	0 (0.00%)	4 (6.67%)	0 (0.00%)	0.50
1-3 years	4 (50.00%)	28 (46.67%)	8 (66.67%)	
3-5 years	4 (50.00%)	20 (33.33%)	4 (33.33%)	
More than 5 yrs.	0 (0.00%)	8 (13.33%)	0 (0.00%)	
Number of follow up visit				
Monthly				0.06
Every 1-2 month	0 (0.00%)	8 (13.33%)	0 (0.00%)	
Every 6 month	8 (100.00%)	40 (66.67%)	12 (100.0)	
	0 (0.00%)	12 (20.00%)	0 (0.00%)	
Regularity on treatment				
Regular	6(75.00%)	28 (46.67%)	8 (66.67%)	0.01
Not Regular	2 (25.00%)	32 (53.33%)	4 (33.33%)	
Insulin regimen				
Conventional	6 (75.00%)	16 (26.67%)	0 (0.00%)	0.04
Intensive	2(25.00%)	44 (73.33%)	12 (100.0%)	

Table (3): Distribution of PedsQL of the studied 80 diabetic children in Sohag University Hospital, 2014 by their clinical features

Characteristics	Poor N=8	Neutral N=60	High N=12	P
No. of blood sugar monitoring/ day				
Three times	4 (50.00%)	4 (6.67%)	0 (0.00%)	<0.0001
Twice	0 (0.00%)	8 (13.33%)	4 (33.33%)	
Once	0 (0.00%)	20 (33.33%)	0 (0.00%)	
Not regular	4 (50.00%)	28 (46.67%)	8 (66.67%)	
HBA1C level				
Less than 7	0 (0.00%)	4 (6.67%)	12 (0.00%)	<0.0001
7-10	8 (100.0%)	12 (20.00%)	0 (0.00%)	
More than 10	0 (0.00%)	44 (73.33%)	0 (100.0%)	
No. of admission to hospital last year				
None	2 (25.00%)	36 (60.00%)	12 (100.0%)	0.02
Once	2 (25.00%)	16 (26.67%)	0 (0.00%)	
Twice	4 (50.00%)	8 (13.33%)	0 (0.00%)	

Table (4): Correlation between quality of life and clinical features of the studied 80 diabetic children in Sohag University Hospital, 2014.

Clinical feature	r	P value
Diabetes duration	-0.067	0.554
Regularity on treatment	0.109	0.333
Insulin regimen	0.051	0.648
No. of blood sugar monitoring/day	0.182	0.105
HBA1C level	0.411	0.00000
No. of admissions to hospital last year	0.061	0.586

Discussion

Individuals with type 1 diabetes face major challenges on a daily basis by the demands of diabetes management and the fear of complication; hence, their health related quality of life can be easily and considerably affected especially in developing countries. This is a hospital based cross sectional study assessing health related quality of life of 80 diabetic children with type 1 diabetes mellitus and clinical factors affecting it in Sohag University Hospital, Sohag, Egypt.

The mean total QoL score of the studied diabetic children was $70.2\% \pm 9.8$ which indicates a low life quality. Although variability in mean scores of quality of life of diabetic children was demonstrated among different studies most studies report worse quality of life for people with diabetes compared to the general population, especially regarding physical functioning and well-being. This was the case when quality of life of 94 diabetic Iranian children was compared to 200 normal Iranian children using Persian version of the PedsQL™ 4.0 Generic Core Scales and the PedsQL™ 3.0 Diabetes Module ⁽⁹⁾. Our results are consistent with ⁽¹⁰⁾ who conducted a retrospective, cross-sectional, multicenter study performed by the Brazilian Type 1 Diabetes Study Group that analyzed EuroQol scores from 3,005 participants with Type 1 DM, in 28 public clinics in Brazil. They reported an average score of 72. Our finding is slightly lower than both ⁽¹¹⁾ and ⁽¹²⁾ who reported a mean score of $76.36\% \pm 9.7$ and $75\% \pm 9.8$ respectively. The former conducted a quazi experimental study to assess self rated quality of life (QoL) and glycemic control in adolescents with type 1 diabetes in Alexandria, Egypt. While the second used the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scale and PedsQL 3.0 Diabetes Module to assess the quality of life and to identify the risk factors associated with it in 436 diabetic children through a case control study in Kwait. A higher mean score of $(81.3\% \pm 4.57\%)$ was reported among 100 youth with type 1 diabetes in USA ⁽¹³⁾. On the other hand our score is higher than that reported by ⁽¹⁴⁾ who conducted a case control study to evaluate quality of life of 117 children with type I diabetes compared to 128 healthy control using Pediatric Quality of Life Inventory (PedsQL) scale and reported a mean total score of $(61.07\% \pm 13.43)$ in Greece. Also ⁽¹⁵⁾ reported a mean score of 64.8 after conducting a cross sectional study of the quality of life of 315 adolescent diabetic patients in Saudia Arabia. Both can be explained by a higher mean age of their sample as the more age of the child the more awareness and fear of complications. This variability in quality of life score between different studies can be explained through two dimensions: the first is the facts that variable instruments are used to assess quality of life, different in sample size and age of the studied sample. The second is large number of factors that might be responsible for the negative impact of diabetes on quality of life (QoL), such as fear of hypoglycemia or of secondary complications, future worries on stigmatization, loss of flexibility, poor self-image, overprotection, age, economic class, health care system, education, ethnicity, knowledge regarding the disease and the daily demands of diabetes therapy (i. e. insulin therapy, blood glucose. Monitoring ⁽¹⁴⁻¹⁵⁾

Concerning the mean total QoL score reported by parents we found that it was (59.9%±11) which is significantly lower than that reported by the children themselves (70.2% ± 7.8) as (p < 0.0001) these findings are consistent with that reported by many studies^{(12), (14), (15)}. This significant difference can be explained by the parent's awareness and worry about the complication.

As mentioned early different factors play important rule in affecting and diminishing the life quality of diabetic children, we found that variables like diabetes duration, No of follow up visits and No of hospital admission during the last year showed no significant association with quality of life. Among studies that agree with our results a principle component analysis that was conducted to examine the associations between PedsQL-T1DM total score of 2602 indian diabetic person aged ≥ 5 years and demographic and clinical characteristics⁽¹⁶⁾ and⁽¹¹⁾ who reported poor correlation between diabetes duration and quality of life. Contrary to our results are that of Logistic regression analysis which was used to examine the association between SRH responses of 124 diabetic children and clinical variables. No significant association was found between follow up visit and hospital admission while significant association was reported on comparing good and poor quality of life and a better HRQoL with short duration⁽⁹⁾. The negative impact of diabetes duration on quality of life resulted from occurrence of long term diabetes complications that reduces person perception of well being and productivity. This is not the case in our study as we studied children in whom duration of diabetes ranged from 1-5 years only, while⁹ study a higher range of diabetes duration of 5.82 (±1.60) and average age of 13.08 (±3.19) and he used self rated health questionnaire (SRH) which depend on perception of the child of his health from very poor to excellent and he compared poor health to very good which is different from our approach.

We found that 80% of the studied diabetic children were on intensive insulin therapy (receiving from 3-4 injections per day) and only 20% receiving 1-2 injections per day .This is consistent with⁽⁹⁾ but not consistent with⁽¹²⁾.

No effect of intensified treatment on quality of life of diabetic children was reported by some studies. Other work suggests that intensification may enhance quality of life by reducing the immediate and chronic effects of hyperglycemia. The current study found that being on intensive insulin therapy was significantly associated with better quality of life. These findings agree with results of a study of two patient cohorts, In cohort A, 77 patients deliberately intensified their traditional insulin injection therapy from up to two daily injections with syringe to multiple daily injections with insulin-pen; in cohort B, 55 patients changed from intensive therapy with pen to insulin pump-treatment (CSII). Both reported increased treatment satisfaction after intensification of insulin therapy mainly due to greater flexibility with leisure-time activities, and with the diet⁽¹⁷⁾. Also QoL was significantly associated with the number of insulin injections/day ($\chi^2 = 6.73$, P < 0.001) as reported by⁽¹¹⁾. On the other hand the use of multiple daily injections was found to be associated with worse QoL in a younger age group (2-4 years, p < 0.05) than that of older age⁽¹²⁾. Or no association was found⁹.This can be explained as very intensive regimens may reduce quality of life through highly demanding self-care regimens and increased incidence of hypoglycemia.

As regard other studied clinical variables, we found that the mean HbA1c level measured was 9.8±1.2.This figure indicates poor glycemic control which is consistent with¹³ who reported that about three-quarters (74.8%) of adolescents had uncontrolled glucose levels according to the HbA1c level, and only 25.2% were controlled. Although this figure is higher than that from other studies in Egypt, USA and Kuwait: (8.02±1.2), (8.0 ± 1.6) and (8.4 ±1.2) respectively.^{(9), (10), (12)}. This can be explained by the fact that 65% of mothers of the diabetic children in this study were illiterate in addition to about half the studied children reported irregularity in treatment.

Good glycemic control is very effective in delaying cardiovascular complications of diabetes so leads to better quality of life. Glycemic control can be assessed by both regularity in treatment and the level of

HbA1c. We found significant association between high quality of life and both regularity on treatment and level of HbA1c below 7.5. These findings agree with ⁽¹²⁾, ^{(14),(16)} and ⁽¹⁸⁾. Again health related quality of life of 68 children and adolescents from a tertiary care clinic of University of Lu'beck who completed the generic KI NDL-R questionnaire was assessed and Lower HbA1c (<8%) and intensified insulin therapy (>3 injections/ day) were associated with a better HRQOL in different domains ($P < 0.05$) ⁽¹⁹⁾. Furthermore evaluating over 2,000 adolescents with Type 1 DM, found that better HbA1c levels were associated with lower impact, fewer worries, greater satisfaction, and better health perception ⁽²⁰⁾. On the other hand no significant difference was found between the diabetic patients with good, moderate and poor metabolic control in terms of quality of life ⁽²¹⁾.

Among the studied clinical variables no significant correlation was found between high quality of life and any variable except for level of HB1C. This is consistent with many studies. ¹⁰⁾, ⁽¹⁸⁾ and ⁽²¹⁾ their results revealed no correlation between disease duration, number of daily insulin injections, frequency of blood sugar monitoring and quality of life. Concerning our findings of very strong significant correlation ($r=.$) this is consistent with ⁽¹²⁾ who reported that there was a significant correlation between total QoL scores and mean HbA1c ($r2 = -0.7$, $p = 0.001$). In all age groups, subjects with better metabolic control had better total (fig 3), emotional ($r2 = -0.4$, $p < 0.05$) and social ($r2 = 0.043$, $p < 0.05$) QoL scores. These results also agree with ⁽²³⁾ who reported that high mean HbA1c was negatively correlated with QOL ($r = -0.18$ to -0.29 , $p < 0.01$) across all subscales.

Conclusion & Recommendations

Diabetic children in Sohag governorate live a poor life quality due to irregular follow up of their illness in addition to low socioeconomic status and poor glycemc control. Measures for improving quality of life of diabetic children are needed with special emphasis on improving glycemc control.

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