Assessment of health-related quality of life among adolescents with type 1 diabetes mellitus in Saudi Arabia

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ABSTRACT

الأهداف: تهدف هذه الدراسة إلى تقييم نوعية الحياة(HRQoL) المرتبطة بالصحة للمراهقين المصابين بداء السكري من النوع الأول.

الطريقة: أجريت الدراسة المستعرضة على 214 مراهق تتراوح أعمارهم من 18–13 سنة يعانون من مرض السكري من النوع الأول (T1DM)في مدينة الأمير سلطان الطبية العسكرية في المملكة العربية السعودية من يونيو إلى سبتمبر 2013م. وقد تم اختيار المشاركين بحسب تواجدهم أثناء الزيارات الروتينية إلى العيادات الخارجية و إجراء المقابلات باستخدام النسخة العربية من استبيان جودة الحياة للأطفال المصابين بالسكري (PedsQL3.0 DM).

النتائج: أظهرت النتائج أن الإناث اللاتي يعانين من مستويات أقل فيما يتعلق ب (PedsQL 3.0 DM) ومنها : أعراض مرض السكري ، وعوائق العلاج ، والالتزام بالعلاج ، والقلق ، وضعف التواصل الإجتماعي .مقارنة مع أولئك الذين يتلقون العلاج عن طريق عدة حقن يومية (MDI) والذين يستخدمون مضخة الأنسولين يعانون من ارتفاع عالي من (PedsQL 3.0 DM) باستثناء التواصل الإجتماعي. ومقارنة أيضاً مع المراهقين المصابين بمرض السكري من النوع الاول طويل المدى(7 years TIDM<) ظهرت تغيرات ايجابية في أعراض مرض السكري و لوحظ التواصل الإجتماعي في مرض السكري قصير المدى (7–1 years).وأظهرت الدراسة بأن المصابين بالحماض الكيتوني السكري (DKA) لديهم مستوى من (PedsQL 3.0 DM) أقل بكثير من الذين لا يعانون من (DKA) باستثناء التواصل الإجتماعي . مقارنة مع المراهقين الذين يعانون من نسبة السكر التراكمي HbA1c <7 استجابوا بشكل ايجابي لأعراض السكر للمراهقين HbA1c ≤7 .
وأظهر تحليل الإنحدار بان العمر ونوع العلاج (MDI) و المصابين بالحماض الكيتوني السكري DKA و نسبة السكر التراكمي HbA1c <7 هي عوامل مؤثرة مستقلة لمستوى أعراض السكر ، في حين نسبة السكر التراكمي HbA1c <7 له عامل مؤثر مستقل لعوائق العلاج ويشمل HRQ oL . الحمض الكيتوني السكري DKA له عامل مؤثر مستقل لمستوى القلق و للإناث عامل مؤثر مستقل لمستوى التواصل الإجتماعي .

الخاتمة: أشارت النتائج الى أن العمر و الإناث و نوع العلاج و نسبة السكر التراكمي و الحمض الكيتوني السكري هي عوامل مؤثرة على انخفاض HRQoL لمستوى واحد على الأقل من PedsQL 3.0 DM .

Objective: To evaluate the health-related quality of life (HRQoL) for adolescents with type 1 diabetes mellitus (T1DM).

Methods: A cross-sectional study was conducted among 214 adolescents (13-18 years) with T1DM at the Diabetes Treatment Center, Prince Sultan Military Medical City, Riyadh, Saudi Arabia from June to September 2013. Respondents were selected by their availability during routine visits to outpatient clinics, and interviewed using the Arabic translated version of the Pediatric Quality of Life Inventory 3.0 Diabetes Module (PedsQL 3.0 DM) independently.

Results: Female gender, multiple daily injection (MDI), longer duration of T1DM (>7 years), diabetic ketoacidosis (DKA) and adolescents with >7 HbA1c level had at least one poor HRQoL outcome. Multivariate linear regression analysis showed that age, treatment type (MDI), DKA, and >7 HbA1c were independent influencing factors for subscale diabetes symptoms, whereas >7 HbA1c was the independent influencing factor for treatment barriers and overall HRQoL. The DKA was the independent influencing factor for the subscale of worry, and female gender was the independent influencing factor for the subscale of communication.

Conclusion: Female gender, age, treatment type, >7 HbA1c, and DKA are the strongest determinants for lower HRQoL for at least one subscale of the PedsQL 3.0 DM.

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According to a recent publication of the International Diabetes Federation, worldwide, the estimated number of adults living with diabetes has soared to 366 million in 2011, representing 8.3% of the global adult population. This number is expected increase to 552 million people by 2030, or 9.9% of adults.[1,2] Also, Saudi Arabia is listed as third among the top 10 countries with the highest prevalence rates of diabetes.[1] While type 2 diabetes dominates in sheer numbers, type 1 diabetes mellitus (T1DM) remains an important issue. With 70,000 newly identified young people every year, the prevalence of T1DM is rising globally.[3] Also, studies reported that the incidence of T1DM is rising over the last 30 years in Saudi Arabia,[4] and the prevalence of T1DM in Saudi Arabian children and adolescents is 109.5 per 100,000, which is higher than many developed countries.[5] Adolescents diagnosed with T1DM, face major lifestyle changes and the risk of facing debilitating and life-threatening complications.[6] The daily management of diabetes presents numerous challenges to reach adequate metabolic control; from multiple daily injections (MDI) and frequent blood glucose monitoring to routine laboratory work, frequent healthcare visits, and careful regulation of exercise and meal schedules.[6] Although in adolescents these tasks are implemented initially by the care givers, in the teenage years the burden of diabetes management falls on the adolescents themselves.[7] Research has confirmed that diabetes has an impact on many aspects of life and intensive treatment of T1DM frequently disrupts adolescents' usual activities, requires disease-focused behaviors from the teens and family, and potentially impacts overall health related quality of life (HRQoL).[8,9] Therefore, it becomes important to assess overall HRQoL of the adolescents with diabetes, considering disease management, physical symptoms, and normal developmental milestones, including school performance and social-emotional development. In Saudi Arabia, limited evidence exists on the determinants of HRQoL specific to adolescent with T1DM, which is very important for this population. Therefore, the present study aimed to evaluate the HRQoL among Saudi adolescents with T1DM using the Pediatric Quality of Life Inventory 3.0 Diabetes Module (PedsQL 3.0 DM).

Methods.

Study design and setting. This was a cross-sectional study conducted among 214 T1DM patients (aged 13-18 years) who had diabetes for more than one year at the Diabetes Treatment Center, Prince Sultan Military Medical City (PSMMC), Riyadh, Saudi Arabia between June and September 2013. The respondents were purposively and conveniently selected according to their availability during their routine visit to the outpatient clinics. The study was conducted in accordance with the Declaration of Helsinki, and the protocol of the study was approved by the research ethics committee of PSMCC. Parents and their adolescents were informed of the purpose and methods of the research both verbally and in written form. Written consent was obtained from the parents and verbal consent from adolescents before the completion of study measurement. Study participants were free to withdraw from the study at any time without giving a reason. The inclusion criteria of the study were: adolescents aged 13-18 years, who had been followed-up for at least 12 months, who did not have any other concomitant chronic disease, and who were able to read and write Arabic independently. Adolescents who had history of psychopathology, medical instability, visual, hearing, or cognitive impairment were excluded from the study. During the routine follow-up visits, socio-demographic data, and clinical data was gathered, and they were asked to complete the Arabic translated version of the PedsQL 3.0 DM questionnaire independently by self-administered data collection technique after providing instructions in the diabetes education room.

Measures. The HRQoL measurement. The PedsQL 3.0 DM is a modular instrument designed to measure HRQoL in children and adolescents.[10] The questionnaire takes 5-8 minutes to complete. The 28-item multidimensional PedsQL 3.0 DM encompasses 5 scales: diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence (7 items), worry (3 items), and communication (3 items). The instructions ask how much of a problem each item has been during the past one month. The format, instructions, Likert-type response scale, and scoring method are: 0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, and 4 = almost always a problem. Items are reverse scored and linearly transformed to a 0-100 scale (0 = 100, 1= 75, 2 = 50, 3 = 25, and 4 = 0), so the higher scores indicate better HRQoL or fewer symptoms/problems. The PedsQL 3.0 DM has been validated for Arabian usage.[11,12]

Body mass index. Body mass index (BMI) was computed by dividing the weight in kilograms by the square of height in meters (BMI; kg/m^2) and BMI z score (adjusted for child age and gender). The z score (or SD score) was calculated as per the formula (Xi-Mx)/SD, where Xi is the actual measurement, Mx is the mean value for that age and gender, and SD is the standard deviation corresponding to that age and gender.[13]

Exercise. Adolescents were considered active if engaged for at least 30 minutes for 3 days/week or more in structured and planned physical activities and sports such as jogging, swimming, water sports, and ball games, and so forth.

Blood glucose. During the study, the participants' most recent insulin dose and hemoglobin A1c (HbA1c) values for the blood glucose control were taken from the medical records. The HbA1c test is the most reliable measure of glycemic control and diagnostic test for diabetes.[14]

Diabetic ketoacidosis. Diabetic ketoacidosis (DKA) was defined as a blood glucose >250 mg/dL, and 2 of the following 3 criteria: serum bicarbonate <8 mEq/L; serum β-hydroxybutyrate >3 mmol/L; and pH <7.30.

Statistical analysis. Data analysis was carried out using Microsoft Excel 2002 (Microsoft Corporation, Seattle, WA, USA) and the Statistical Package for Social Sciences version 16 (SPSS Inc., Chicago, IL, USA). The Kolmogorov-Smirnov test was performed for equal variances across the groups. In addition to the descriptive analysis, "t" test was used to look at differences among the groups. Multivariate linear regression analysis was carried out to find out the variables associated with HRQoL. A *p*-value of <0.05 was considered statistically significant.

Results. The demographic data are presented in Table 1. The mean age of the study participants was 15.27±1.61 (mean±SD) years. One hundred and twenty-three were males (57.5%), and 91 were females (42.5%). The mean duration of diagnosis of DM

Table 1 - Demographic and history of 214 type 1 diabetes mellitus patients who had diabetes for more than one year included in a study at the Diabetes Treatment Center, Prince Sultan Military Medical City, Riyadh, Saudi Arabia.

Variable(s)	n	(%)
Male	123	(57.5)
Female	91	(42.5)
Age (years)		
13-15	126	(58.9)
16-18	88	(41.1)
Exercise		
Yes	136	(63.5)
No	78	(36.5)
Treatment type		
Multiple daily injections	161	(75.2)
Insulin Pump	53	(24.8)
Duration of DM (years)		
1-7	147	(68.7)
>7	67	(31.3)
Diabetic ketoacidosis		
Yes	25	(11.7)
No	189	(88.3)
Hemoglobin A1c		
≤7	43	(20.1)
>7	171	(79.9)

Table 2 - The scores of the Pediatric Quality of Life Inventory 3.0 Diabetes Module (PedsQL 3.0 DM) subscales among adolescents with type 1 diabetes mellitus.

Variables	Diabetes symptoms	Treatment barriers	Treatment adherence	Worry	Communication	Total
Gender						
Male	60±20	46.8±30	59.2±28.1	49.7±30.4	66.7±29.3	56.4±23.1
Female	56.7±20.4	41±28.3	52.9±25.4	47.7±26.9	56.8±27.8*	51±21.7
Age (years)						
13-15	61.5±17.4	43.8±24.5	55.3±21.8	51.3±22.5	63.4±23.1	51.2±23.7
16-18	55.8±18.6	44.3±19.6	54.2±23.1	45.3±23.5	62.5±31.7	52.3±24.1
Exercise						
Yes	59.6±20.5	46±29.1	58.8±27.3	52.4±28.7	65.5±28.1	56.4±22.6
No	56.7±19.7	41.4±30.3	52.4±26.3	42.5±28.2	57.1±30	50±22.3
Treatment						
Multiple daily injections	54.5±20.9	40.4±29.2	53.8±29.6	44.5±28.3	63.4±29.3	51.3±22.9
Insulin pump	66.7±16*	52.1±28.7*	61.9±20.5*	57.3±28.4*	60.7±28.4	59.7±21.2*
Duration						
1-7	58.4±21.1	44.2±28.3	55.3±27.3	48.3±29.1	72.8±32.2	53.7±21.4
>7	51±20.6 *	46.1±26.5	51.1±25.9	50.7±27.7	61.2±27.5*	51.7±20.1
Diabetic ketoacidosis						
Yes	42.5±21.1	35.8±31.2	48.5±31.9	30.6±23.9	62.2±34.3	43.7±23.1
No	61.5±18.8*	46.2±28.9*	58.3±25.7*	52.2±28.5*	62.6±28.2	56.2±22*
Hemoglobin A1c						
≤7	63.2±21.3	51.4±22.3	49.4±19.5	45.6±16.4	57.4±18.3	51.4±23.1
>7	39.5±19.3*	32.5±93.4	45.5±21.4	42.4±17.5	55.2±21.3	41.3±21.7

Values are mean ± SD, *p<0.05. Higher scores indicate better HRQoL

was 8.7±6.5 (mean±SD) years. **Table 2** presents the scores of the PedsQL 3.0 domains/subscales among the adolescents with T1DM. The HRQOL was found to be lower among females on the subscales of diabetes symptoms, treatment barriers, treatment adherence, worry, and communication than their male counterparts. However, these differences were not found to be statistically significant expect for communication (p<0.03). Compared with adolescents practicing exercise, adolescents who were not practicing exercises showed insignificantly lower HRQoL in all domains. Compared with MDI treatment, significant positive differences were found in all domains of the HRQoL of insulin pump adolescents except communication. Compared with adolescents with longer duration (>7 years) of T1DM, significant positive differences were observed in diabetes symptoms and communication than shorter duration T1DM adolescents (1-7 years) (p<0.05). Adolescents with DKA showed significantly lower HRQoL than without DKA in all domains of HRQoL except communication. Compared with adolescents with >7 HbA1c, significant positive difference was observed in diabetes symptoms of ≤7 HbA1c adolescents. The results of regression analysis with β-coefficient and 95% confidence interval (CI) for PedsQL 3.0 DM dimensions adjusted for significant confounders' gender, age, treatment type, duration of T1DM, DKA, and HbA1c are demonstrated in **Table 3**. Multivariate linear regression analysis indicated that age, treatment type (MDI), DKA, and >HbA1c were independent influencing factors for subscale diabetes symptoms, whereas >HbA1c was the independent influencing factor for treatment barriers and overall HRQoL. The DKA was independent influencing factor for subscale of worry, and female gender was independent influencing factor for subscale of communication (**Table 3**).

Table 3 - Results of regression analyses with ß-coefficient and 95% confidence intervals (CI) for Pediatric Quality of Life Inventory 3.0 Diabetes Module (PedsQL 3.0 DM) subscales (n=214).

Variables	ß-coefficient	95% confidence intervals		*P*-value
		Lower	Upper	
Diabetes symptoms				
Female	-4.41	-4.47	-0.336	0.24
Age	-2.39	-4.45	-0.338	0.023
BMI	-4.93	-1.33	0.346	0.247
Exercise	0.805	-0.85	7.46	0.811
Insulin pump	10.68	3.69	17.67	0.003
Duration of DM	-2.68	-7.68	2.31	0.289
DKA	-10.02	-19.95	-0.094	0.048
HbA1c (>7)	-2.52	-4.91	-0.14	0.038
Treatment barriers				
Female	-6.97	-17.05	3.10	0.173
Age	0.833	-2.43	4.10	0.615
BMI	-1.08	-2.41	0.25	0.111
Exercise	-3.19	-13.76	7.38	0.552
Insulin pump	9.41	-1.69	20.52	0.096
Duration of DM	2.09	-5.85	10.02	0.603
DKA	2.26	-13.51	18.04	0.777
HbA1c >7)	-5.05	-8.84	-1.26	0.009
Treatment adherence				
Female	-6.65	-15.93	2.62	0.158
Age	-0.667	-3.67	2.34	0.662
BMI	-1.41	-2.64	-0.19	0.051
Exercise	-3.35	-13.09	6.38	0.496
Insulin pump	7.61	-2.60	17.84	0.143
Duration of DM	0.299	-7.01	7.60	0.936
DKA	-4.05	-18.5	10.4	0.581
HbA1c (>7)	-2.70	-6.18	0.785	0.128
Worry				
Female	-4.49	-14.1	5.14	0.358
Age	-2.99	-6.41	0.426	0.86
BMI	-1.08	-2.42	0.172	0.091
Exercise	-5.12	-15.0	4.82	0.310
Insulin pump	9.01	-1.43	19.4	0.90
Duration of DM	1.22	-1.11	3.56	0.302
DKA	-15.3	-30.2	-0.487	0.48
HbA1c (>7)	-2.00	-5.59	1.59	0.273
Communication				
Female	-9.66	-19.71	0.395	0.046
Age	-1.02	-4.28	2.24	0.537
BMI	-1.98	-2.51	0.149	0.081
Exercise	-6.16	-16.71	4.39	0.250
Insulin pump	-3.44	-14.52	7.64	0.540
Duration of DM	7.21	-.707	15.13	0.074
DKA	3.24	-12.50	18.9	0.684
HbA1c (>7)	-2.47	-6.25	1.30	0.198
Total HRQoL				
Female	-6.16	-13.74	1.41	0.110
Age	-1.43	-3.89	1.02	0.251
BMI	-0.96	-1.96	0.040	0.060
Exercise	-3.34	11.29	4.61	0.407
Insulin pump	6.69	-1.66	15.04	0.115
Duration of DM	2.34	-3.62	8.31	0.439
DKA	-5.25	-17.11	6.61	0.383
HbA1c (>7)	-2.82	-5.66	0.026	0.049

HRQoL - health related quality of life, DM - diabetes mellitus, DKA - diabetic ketoacidosis, BMI - body mass index, HbA1c - hemoglobin A1c

Discussion. Studies reported that adolescents with T1DM, particularly females, have to deal with a multifaceted and demanding daily treatment regime, which can have a negative impact on the HRQoL.[14] In this present study, we found insignificant but lower HRQoL among females on the PedsQL 3.0 DM subscale of diabetes symptoms, treatment barriers, treatment adherence, and worry than their male counterparts. However, compared with male a significant difference was found in female gender on the subscale of communication. This lower level of HRQoL in females may be due to culture, as males have easier access to medical treatment than females. Also, previous studies reported that female adolescents in Saudi Arabia were

significantly prone to develop obesity compared with males. Similarly, lack of physical exercise in females is an important risk factor for adolescent obesity in Saudi Arabia. Most female adolescent obesity can be attributed to the prohibition of physical education in schools for girls for cultural reasons, and earlier hormonal and pubertal changes in teenage girls may decrease the HRQoL of female adolescents.[15] Several studies have shown that females denoted significantly poorer HRQoL perception than males.[16,17] In addition, studies have consistently found that girls endorse more diabetes-related worries, less satisfaction, and have poorer perceptions of their own health than boys.[18,19]

Multiple daily injection treatment is the most widely used method of insulin administration, and comprises intermediate or long acting insulin once or twice a day as a basal dose and rapid-acting insulin at each meal time, and patients are required to have at least 3 or more injections a day. A technological alternative to this method of insulin delivery is the continuous subcutaneous insulin infusion (CSII, or insulin pump therapy).[11] The insulin pump is a programmable medical device that offers the most physiologic way of insulin delivery and the amount of insulin delivered can be changed by the user. The present study found that when compared to MDI significant positive differences were found in all domains of the HRQoL of insulin pump users except communication. Previous studies reported that the insulin pump gives patients more flexibility in the timing of their meals and patients on the pump can adjust for snacks and meals, as well as for exercise and physical exertion. Also, the insulin pump reduces the occurrence of serious hypoglycemic episodes.[19-21] The regression analysis of our study showed that treatment type (MDI) was the independent influencing factor for the subscale diabetes symptoms of the HRQoL. However, studies reported that CSII is generally successful for patients with T1DM in improving glycemic control, alleviating the burden of hypoglycemia, and improving the HRQoL.[19,22-24] The present study also reported that compared with those receiving MDI, insulin pump adolescents had significantly higher levels for all domains of the PedsQL 3.0 DM.

The research findings have been mixed regarding the relationship between HRQoL in people with T1DM and duration of diabetes, with either no association,[25,26] or a high HRQoL with a shorter duration.[6,12,27,28] In this present study, we found that when compared with adolescents with a shorter duration of T1DM, significant negative differences were observed in the PedsQL 3.0 DM subscales of diabetes symptoms and communication of longer duration on T1DM adolescents. However, in the regression analysis, there were no significant differences between HRQoL and diabetes duration of T1DM.

The DKA is the most serious diabetic emergency in T1DM patients and it is the leading cause of mortality in young adults with T1DM. Also, many studies reported that DKA significantly reduced the HRQoL of young T1DM patients.[29,30] In this study, we found that adolescents with DKA had significantly lower HRQoL than without DKA in all domains of the PedsQL 3.0 DM except for communication. Also, the regression analysis of this study showed that DKA was the independent influencing factor of the subscale worry. Several studies reported that lower HbA1c, thus, better metabolic control, was associated with higher levels of HRQoL.[31-33] In the present study, we found when compared with adolescents with >7 HbA1c, positive differences were observed in diabetes symptoms, treatment barriers, treatment adherence, worry, communication and total HRQoL of ≤7 HbA1c adolescents. Regression analysis of our study also showed that >HbA1c was the independent influencing factor for diabetes symptoms, treatment barriers, and total HRQoL.

The major limitations of this study include: 1) the limited number of risk factors and limited socio-demographic factors examined, 2) performed at a single center, and 3) there was no control group to compare the study group. Further research is needed to address the limitations indicated in the study. Despite the limitations, the study delivers valuable data for HRQoL among adolescents with T1DM in Saudi Arabia.

In conclusion, the results of this study indicate that T1DM has significant association with the majority of diabetes-specific quality of life instrument domains. Female gender, duration of T1DM, and DKA are the most important predictors for lower HRQoL. Understanding the effect of diabetes on quality of life is important for day-to-day clinical management and also for public health policy initiatives in order to improve the quality of life and health outcomes of those with T1DM.

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