ABSTRACT

Introduction: Type 1 Diabetes Mellitus is one of the most significant and serious chronic diseases targeting children and adolescents worldwide. Improving or at least maintaining health-related quality of life in children and adolescents with chronic disease is one of the main objectives of healthcare. Methods: The article presents qualitative research or a scientific review of the published literature. The databases were reviewed using the following keywords: adolescents, children, diabetes mellitus type 1, and health-related quality of life. We used the PubMed database in the preparation of this article. Results: The results include a review and analysis of 12 published scientific articles in the period from 2019 to 2021. Conclusion: Healthcare professionals must include children, adolescents and their family members as part of the team to achieve better results in treating Type 1 Diabetes Mellitus. Education of children, adolescents and their family members is essential in treating type 1 Diabetes Mellitus in children and adolescents. In addition, assessing the quality of life and satisfaction with health care reported by patients can improve the holistic approach to treating Type 1 Diabetes Mellitus in children and adolescents to help patients and their families overcome problems in treatment and thereby improve the quality of their lives.

KEYWORDS

health-related quality of life, diabetes mellitus type 1, children, adolescents.
Although traditionally biomedical, not qualitative outcomes, have been the main endpoints in medical and health research, during the past decades, the use of quality of life (QoL) assessment has increased, and more research focuses on the quality of life of patients (9). Improving or at least maintaining the health-related quality of life (HRQoL) in children and adolescents with chronic disease is one of the main objectives of healthcare (10). Treatment of DM1 has demands reducing acute and long-term complications related to diabetes may occur. Frequent insulin injections, daily blood glucose monitoring, diet plan, and regular physical activity can affect family relationships and a burden on children, as they limit the daily activity of children and affect the behaviour of children and family members in a way that focuses on disease, which can negatively affect QoL (11). There is a linear relationship between QoL and glycolysing haemoglobin (HbA1c), which may present a two-way relationship between HbA1c and QoL and are interconnected (12).

DM1 is a condition that cannot be easily controlled by medication. Children and adolescents with DM1 can only have a long and full-filling life if they have appropriate care and support (6). Holistic healthcare is a medical model that stresses the need for correct and dignified rehabilitation and support during illness. Medical circles have returned to a holistic view after many reflections and reviews, emphasizing that complete medical care must cover a person’s physical, mental, and spiritual needs (13). Unfortunately, the efforts of health care professionals are sometimes insufficient because they may assume that they know what is best for patients. The first step toward success is involving patients in their treatment, together with their family members (14).

Methods
The article presents qualitative research or a scientific review of the published literature limited to papers published in English. The study included: original full-text articles that investigated the quality of life, factors that affect metabolic control, or satisfaction with treating children and adolescents with type 1 diabetes mellitus. The databases were rapidly reviewed using the following keywords: adolescents, children, diabetes mellitus type 1, and health-related quality of life. We used the PubMed database in the preparation of this article.

Results
The results include a review and analysis of 12 published scientific articles from 2019 to 2021 (Table 1). The studies published in these articles were conducted in Brazil, Poland, Spain, India, Wisconsin, Jordan, Germany, Saudi Arabia, USA, Romania, United Arab Emirates and Iran.

Discussion
DM1 brings many challenges in the lives of children and adolescents, as they must follow a complex and lifelong treatment regimen that is not flexible and pervades almost all children’s activities (26). In addition, a treatment regimen implies dietary control, adherence to an insulin regime and close glucose monitoring, which is difficult to comply with, particularly in children and adolescents undergoing major physical, cognitive and psychological changes and risk-taking behaviour (24).

Adequate glycaemia control in children with T1DM reduces the risk of future complications (26). Preventing comorbidity can significantly reduce the clinical and economic burden on the health system and improve patients’ quality of life (27). Identifying factors affecting HbA1c levels is crucial for managing metabolic control (20).

Several studies in this review have proven a link between HbA1c and the QoL of patients (11,15,16,17,21), and more effort is needed to help patients and their families achieve better metabolic control. A review of research studies identified different factors associated with metabolic control. Some of them include socio-demographic variables (15,28), family structure (20), such as the duration of development, following recommendations (21), and the involvement of mothers in the care of the child (20). Parents’ stress levels could also affect diabetes control in children and adolescents (22). Increased number of insulin injections per day and patients who were non-compliant with the dietary and drug regimen were related to psychosocial distress (18). Patients’ satisfaction and health perception in children and adolescents with type 1 diabetes mellitus may depend on the method used for diabetes treatment. Higher treatment satisfaction and better health perception have insulin pump users than those on multiple daily injections (24).

HRQoL is an important indicator for the overall measurement of health conditions (28). Diabetes is often associated with significant damage to HRQoL, imposing functional constraints, emotional discomfort and depression (11). QoL specific to diabetes differs among children and adolescents. It can be influenced by factors associated with the disease and its management, such as family conflicts and interactions, the emotional burden from DMT1 or progress in treatment regimens (29). It is an increasingly important outcome in healthcare to assess physical and social functioning, mental health and well-being among children and adolescents with chronic disease (30). Socioeconomic status is considered an important factor in determining an individual’s quality of life (28). QoL assessment after diagnosis of diabetes can be used to detect and solve problems that children, adolescents and their families may encounter early (31).

Families need additional support, particularly concerning nutrition and physical activity, to achieve health improvement goals (32). A healthy component of optimal treatment of type 1 diabetes and consultation on the overall healthy diet (33). A balanced diet is essential because post-meal glycaemia levels are one of the most important predictors of long-term health (32). It is important to find strategies to improve a healthy diet in the context of medical nutrition therapy to care for children and adolescents with type 1 diabetes (33). Nutrition is essential to diabetes management, and dietary counselling is necessary (34). Constant training and education are needed on using diabetes technologies for young people and their families as technologies are improving and updated. Outstanding progress in diabetes technologies can improve metabolic control and reduce some self-help burdens for young people with T1D, especially if implemented and maintained with education and support for people with diabetes and family (35).

As DM represents a significant economic burden for society, the evaluation of new technologies and interventions increasingly brings potential clinical benefits, long-term consumer efficiency, and patient satisfaction (28).

Family-centred tailoring of type 1 diabetes self-management resources may benefit specific youth and teens with low glycaemic control (19). Health care professionals must emphasise on psychosocial needs of the family (36). Involving a patient in their treatment of DMT1 is particularly important, as DMT1 management mainly falls on the individual and their family.
members (34). The holistic approach highlights patient vigour to improve health, experience, procedures, behaviour and patient decision-making (37).

A personalised healthcare treatment plan is a detailed approach to health care goals tailored to the patient’s needs in order to achieve health care goals, patient engagement and activation in self-care, patient health care, support for self-management and joint decision-making (38). In addition, early interdisciplinary healthcare increases the efficiency of T1DM management and the children’s QoL (4).

Adapting clinical resources aimed at the patient and his family to remove identifiable barriers to self-management of diabetes can benefit (19). Also, adapting recommendations in a clinical environment related to QoL for children and adolescents with T1DM and their family members can improve the experience for children with T1DM and their families (29).

Health professionals, institutions in the health system, as well as policymakers provide information on the health outcomes reported by patients, as well as aspects of their health that are relevant to their quality of life, including their symptoms, functioning, physical, mental and social health, can be used to assess the effectiveness of healthcare from a patient’s perspective (39). In addition, to a subjective assessment of patient health, patient-focused health institutions should also know how their patients perceive the quality of health care they receive(40). In addition to the outcomes of healthcare and treatment reported by patients, patient measures are increasingly used to assess healthcare quality (41). The outcomes reported by the patient may complement clinical metrics to assess the quality of healthcare and facilitate patient-oriented access (40).

Conclusion

Healthcare professionals must include children, adolescents and their family members as part of the team to achieve better results in treating type 1 diabetes mellitus. The education of children, adolescents and their family members are essential in treating type 1 diabetes mellitus in children and adolescents. In addition, assessing the quality of life and satisfaction with health care reported by patients can improve the holistic approach to treating type 1 diabetes mellitus in children and adolescents, to help patients and their families overcome problems in treatment and thereby improve the quality of their lives.

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Conflict of interest

There are no conflicts of interest to declare by any of the authors of this study.

References


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<td>Maria Amélia de Souza et al. (15) 2019 Brazil</td>
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<td>“To evaluate the health-related quality of life of adolescents with type 1 diabetes mellitus, associating it with sociodemographic, clinical and biochemical variables”.</td>
<td>“Cross-sectional study with 92 adolescents with type 1 diabetes mellitus. A form containing socio-demographic, clinical and biochemical variables was used, as well as the Diabetes Quality of Life for Youths questionnaire. Descriptive statistics and logistic regression were used for analysis”</td>
<td>“Regarding socio-demographic variables, the economic class showed statistically significant differences concerning total Health-Related Quality of Life (p-value =0.02) and the impact domain (p-value =0.009). However, the impact domain was more compromised. Diabetes-related complications (p-value =0.004), number of hospitalizations (p-value =0.01), number of daily insulin injections (p-value =0.02), glyced hemoglobin (p-value =0.002) and triglycerides (p-value =0.03) were associated with greater impairment of quality of life related to total health and greater dissatisfaction”.</td>
<td>“Regarding socio-demographic variables, adolescents with T1DM belonging to the economic class D presented greater impairment in HRQoL. Adolescents who evaluated their health as poor showed greater impairment of total HRQoL. In the logistic regression analysis, single male adolescents, with a lower level of education and with high HbA1c levels were more likely to have low HRQoL”.</td>
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<td>Karolina Dlużniak-Golaska et al. (16) 2019 Poland</td>
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<td>“To assess HRQOL and identify factors that may be affected, with particular emphasis on gender”.</td>
<td>“The study group included 197 girls and boys (13.9±2.33 years old) with a history of type 1 diabetes (&gt;1 year) treated with the use of insulin pumps. PedsQL Diabetes Module 3.0 questionnaire was used in the assessment of HRQOL. Multivariate linear regression with gender as a covariate was used to investigate the relationship between total PedsQL score and selected variables associated with patient characteristics, insulin dosage and the control of glycemia. Moreover, the presence of gender differences was verified in terms of variables which significantly affected HRQOL”</td>
<td>“Significantly higher results were observed in boys as regards the total PedsQL score (70.8±11.91 vs 62.4±13.91; P&lt;0.001) and individual subscales of the questionnaire (except “Worry”). In addition, regression analysis demonstrated a significant negative relationship between HRQOL assessment and HbA1c concentrations, WHtR value and the frequency of hypoglycemic episodes. However, it was noted that better HRQOL was observed in boys than in girls, regardless of the quality of the metabolic control of diabetes, regular pattern of adipose tissue distribution and experiencing hyperglycemic episodes”.</td>
<td>“Female gender was an independent factor which adversely affected HRQOL. Other factors which negatively influenced HRQOL included poor metabolic control of diabetes, central distribution of adipose tissue and frequent episodes of hyperglycemia. Therefore, it seems necessary to focus also on other factors that may potentially influence HRQOL of patients with type 1 diabetes”.</td>
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<td>Julio López-Bastida et al. (17) 2019 Spain</td>
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<td>“To assess health-related quality of life (HRQOL) of pediatric patients with type 1 diabetes mellitus (T1DM) and their caregivers”.</td>
<td>“CHRYSAL was an observational cross-sectional study conducted in Spain in 2014 on 275 patients under 18 years old diagnosed with T1DM. Patient/caregiver pairs were stratified by patients’ HbA1c level (≥ 7.5% versus &lt;7.5%) and by the presence or absence of T1DM complications and/or comorbidities. In addition, EQ-5D and PedsQL questionnaires were administered to patients and caregivers”.</td>
<td>“On the EQ-5D, according to caregivers’ perception, 17.7% of children experienced moderate pain or discomfort, 9.7% suffered problems performing usual activities, and 13.2% demonstrated moderate anxiety or depression. The mean EQ-5D index score was 0.95, and the mean visual analogue scale (VAS) score was 86.1. By HbA1c level (≥ 7.5% versus &lt;7.5%), mean index scores were 0.94 and 0.95, and mean VAS scores were 82.8 and 89.2, respectively. Mean index scores were 0.91 for children with complications and/or comorbidities and 0.96 for children without. Mean VAS scores were 83.7 and 87.2, respectively. HRQOL per the PedsQL tool ranged from 68.1 (ages 2–4) to 73.1 (ages 13–18). EQ-5D index and VAS scores were significantly correlated (rho = 0.29–0.43) with several age groups of the PedsQL. EQ-5D scales showed a significant moderate correlation between EQ-5D-Y and EQ-5D-3L proxy VAS score (rho = 0.45; p &lt;.001)”.</td>
<td>“The results of this study provide baseline information about HRQOL in pediatric T1DM in Spain. Patients with few DCC and well-controlled HbA1c reported a relatively high HRQOL. This information will help evaluate the effectiveness of further intervention focused on improving HRQOL in T1DM pediatric patients and their caregivers. Patients with few complications and controlled HbA1c reported a relatively high HRQOL”.</td>
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<td>Subhankar Chatterjee et al. (18) 2020 India</td>
<td>To determine the prevalence and spectrum of psychosocial morbidities among pediatric T1DM patients and factors associated with psychosocial distress</td>
<td>“Among 39 pediatric T1DM patients, a cross-sectional questionnaire-based study was carried out. Psychological distress was measured by applying a childhood psychopathological measurement schedule (CPMS) questionnaire. Psychosocial distress was analyzed across various sociodemographic factors and disease-specific variables by applying the Chi-square test using the statistical package for social sciences (SPSS) version 16”.</td>
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<td>Rosanna Fiallo-Scharer et al. (19) 2019</td>
<td>To assess an intervention that tailored delivery of self-management resources to families’ specific self-management barriers.</td>
<td>“At two sites, 214 children 8-16 years old with type 1 diabetes and their parent(s) were randomized to receive tailored self-management resources (intervention, n = 106) or usual care (n = 108). Our intervention (1) identified families’ self-management barriers with a validated survey, (2) tailored self-management resources to identified barriers, and (3) delivered the resources as four group sessions coordinated with diabetes visits. Mixed-effects models with repeated measures were fit to A1c as well as parent and child QOL during the intervention and 1 year thereafter”.</td>
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<td>Abeer Allassaf et al. (20) 2019 Jordan</td>
<td>To identify possible socioeconomic predictors of poor metabolic control this patient group in Jordan, a developing country with limited resources.</td>
<td>“Medical charts of children with type 1 diabetes attending the pediatric endocrine clinics in two major diabetes centres were reviewed. HbA1c ≥ 7.5% (58 mmol/mol) was considered to reflect poor metabolic control. Logistic regression analysis was performed to identify predictors of poor glycemic control. The association between socioeconomic characteristics and metabolic control was evaluated using multiple correspondence analysis (MCA)”.</td>
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<td>Two hundred and fifty-nine children were enrolled in the study. One-fifth of the patients (20.5%) achieved HbA1c &lt; 7.5%. Patients with dietary non-compliance (odds ratio (OR): 3.333, confidence interval (CI): 1.803 - 6.926; p&lt;0.001), and those who were overweight (OR: 3.869, CI: 1.218 - 12.294; p=0.022) were more likely to have poor metabolic control. Children whose mothers had a bachelor’s degree or higher were less likely to have poor metabolic control than children whose mothers only had elementary education (OR: 0.241, CI: 0.079 - 0.734; p=0.012). MCA revealed an association between low socioeconomic status and poor metabolic control. Children with deceased mothers had significantly higher HbA1c of 10.6±1.86% compared to an average of 8.7±1.45% for the rest of the participants (p=0.005)”.</td>
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<td>Low socioeconomic status, lower levels of maternal education and maternal death were associated with poor metabolic control. Identifying children with these risk factors might be important in optimizing metabolic control and providing better diabetes care”.</td>
<td>“The present study revealed a very high prevalence (53.85%) of psychosocial morbidity among T1DM patients. Psychosocial distress was significantly more among patients taking an increased number of insulin injections per day and patients who were non-compliant with the dietary and drug regimen. Greater awareness among parents, primary caregivers, paediatricians, and endocrinologists are needed for early diagnosis and subsequent intervention”.</td>
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<td>Kathrin I Fischer et al. (2021) Germany</td>
<td>To investigate HRQL of children and adolescents with T1DM and its association with HbA1c values over the course of 6 months.</td>
<td>Patients aged 7-17 years (n = 203) with T1DM provided HRQL data on a monthly basis. HRQL was measured using the Kids-CAT, a computer-adaptive test (CAT) comprising five generic HRQL domains. HbA1c concentrations were assessed at baseline, at 3 and 6 months. We explored the trajectory of HRQL at the domain level using linear mixed-effects models. Further, we investigated the association between HRQL and HbA1c concentrations over time using path analysis models.</td>
<td>“Children and adolescents with T1DM reported high scores across all HRQL domains over time. However, those with an HbA1c concentration of &gt;9.0% reported significantly lower scores in physical well-being and parent relations than those with an HbA1c concentration of &lt;7.5%. In addition, path analysis models revealed a minimal temporal relationship between HbA1c and HRQL, with a small negative impact of HbA1c on physical well-being, psychological well-being and parent relations”.</td>
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<td>Mohammed Aldubayee et al. (2020) Saudi Arabia</td>
<td>Assessed the stress levels parents experience in caring for a child diagnosed with T1D in four different domains.</td>
<td>This cross-sectional study was conducted in two specialized diabetic centres in Riyadh, Saudi Arabia, from February to May 2015 (AlDubayee et al., Horm Res Paediatr 88:2019). We used an Arabic translation of the validated Pediatric Inventory for Parents (PIP) questionnaire. The frequency and perceived difficulty of stressful events were rated by interviewing parents caring for children with T1D using two 5-point Likert scales.</td>
<td>“Sample realized as 390 parents. The level of stress increased in separated and unemployed parents. The frequency (mean 64.9/210, SD 7.529) and difficulty (mean 65.3/210, SD 9.448) indices of the parental stress level were compared with variables possibly associated with stress. Both of the frequency difficulty indices correlated with the marital status, the father’s level of education and occupation, and HbA1c level (P-value &lt;0.05). In addition, the frequency index correlated with hypoglycemia and the difficulty index correlated with the number of children in the family (P-value &lt;0.05)”.</td>
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<td>Kathrin I Fischer et al. (2021) Germany</td>
<td>This study aimed to capture the experience of parents of youth with recent-onset Type 1 diabetes who initiated the use of continuous glucose monitoring (CGM) technology soon after diagnosis, which is a new practice.</td>
<td>Focus groups and individual interviews were conducted with parents of youth with Type 1 diabetes who had early initiation of CGM as part of a new clinical protocol. Interviewers used a semi-structured interview guide to elicit feedback and experiences with starting CGM within 30 days of diagnosis and the benefits and barriers they experienced when adjusting to this technology. Groups and interviews were audio-recorded, transcribed and analysed using content analysis.</td>
<td>“Participants were 16 parents (age 44.13 ± 8.43 years; 75% female; 56.25% non-Hispanic White) of youth (age 12.38 ± 4.15 years; 50% female; 50% non-Hispanic White; diabetes duration 10.35 ± 3.89 months) who initiated CGM 11.31 ± 7.33 days after diabetes diagnosis. Overall, parents reported high levels of satisfaction with starting CGM within a month of diagnosis and described a high level of reliance on the technology to help manage their child’s diabetes. All participants recommended early CGM initiation for future families and were committed to continuing using the technology for the foreseeable future, provided that insurance covered it”.</td>
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“Although observed HRQL of young patients with T1DM was comparable to age-related German-speaking reference population over 6 months, those with an HbA1c concentration >9.0% reported lower scores in selected HRQL domains. Thus, special attention should be drawn to the HRQL of children and adolescents with higher HbA1c concentrations. The minimal relationship between HbA1c and HRQL indicates that the two therapy goals, i.e., achievement and maintenance of glycemic targets and high HRQL, should be considered and evaluated independently in clinical routine”. |

“Parents of children with T1D in Riyadh experience considerable stress, correlating with the child’s glycemic profile that could affect the diabetes control. Therefore, the parental level of stress should be periodically assessed, and to provide optimum care, psychosocial support should be incorporated as part of routine care for these patients and their families”. |

“To conclude, this study’s qualitative data demonstrate that the new practice of introducing CGM within the new-onset period of Type 1 diabetes is not only accepted but also viewed as essential by parents. Rather than add undue burden and distress during a significant life adjustment, CGM initiation appears to have contributed to reduced diabetes management burden and reduced distress and worry among parents in our study”. |
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<td>Constanta Urzeală et al.</td>
<td>2020</td>
<td>Romania</td>
<td>To assess the quality of life in Romanian type 1 diabetes mellitus (T1DM) children attending an early interdisciplinary healthcare intervention.</td>
<td>This research embeds a cross-sectional observational study, incorporating some clinical characteristics relevant for diabetes management. The Kidscreen 27 questionnaire was issued to 100 T1DM children aged between 7 and 17. Parents completed the questionnaire. All subjects received interdisciplinary healthcare in the previous year. Statistics were performed using SPSS v20. The required sample size of 100 subjects was obtained with confidence interval of 95% and a sampling error of 0.009. The tests were two-sided, with a type I error set at 0.05.</td>
<td>Subjects reached an increased level of physical well-being, psychological well-being, autonomy, parent relationships, peer and social support, and school inclusion. There was a significant difference (p &lt;0.05) between children who practiced leisure activities and children who only participated in physical education (PE) classes regarding their physical well-being (t = 2.123). ANOVA demonstrated significant differences between age groups regarding physical well-being. Early interdisciplinary healthcare increases the efficiency of T1DM management and the children’s quality of life. Medical education of both family and child must begin with the onset of the disease and be complemented by nutritional and psychological counselling, along with physical activities, as the main components of a complex healthcare intervention requiring an interdisciplinary team.</td>
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<td>Asma Deeb et al.</td>
<td>2019</td>
<td>UAE</td>
<td>This study aims at assessing the effects of advanced insulin pump system on patients with type 1 diabetes mellitus (T1DM).</td>
<td>The prospective, observational study in two centres addressed patients on multiple daily injections (MDI) switching to an integrated pump system (primary: adolescents and young adults, secondary: school-children). Treatment and patient satisfaction parameters were recorded at baseline and two visits at 12 and 24 weeks. Thirty-eight patients were analyzed; primary n = 24 (mean-age 16) and secondary n = 14 (mean-age 9). From baseline to visit2, the mean decrease of HbA1c was 1.09% (p = 0.00009) and 0.79% (p = 0.09) for the primary and secondary group, respectively. The patient satisfaction rate was favourable. Exploratory analyses revealed that patients favouring the remote control achieved the best reductions in HbA1c (p = 0.0174). Safety was encouraging with no adverse events in the period from visit1 to visit2.</td>
<td>Switching young T1DM patients from MDI to a remote control-integrated pump system reduced HbA1c and insulin dose. Positive attitude towards remote operating enhanced these effects. Patient satisfaction has markedly improved.</td>
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<td>Maryam Hashemipour-Zavareh et al.</td>
<td>2020</td>
<td>Iran</td>
<td>To compare family life quality of type 1 diabetic (T1DM) patients with healthy children from the perception of their mothers.</td>
<td>In this case-control study, mothers of children with T1DM, who referred to endocrine and metabolism clinics of Isfahan city, were enrolled. Demographic and familial characteristics of the studied population were recorded. Family life quality was evaluated using Retting and Leichtentritt questionnaire and compared between two groups. The questionnaire consists of 32 items, representing six resources including love, status, services, information, goods, and money.</td>
<td>This study evaluated 50 children with T1DM and 50 healthy children and their mothers. Mean total score of family life quality and its resource classes were significantly higher in mothers of T1DM patients than mothers of healthy children (P &lt;0.05) except for love (P = 0.05). The findings of this study indicated that the total family life quality score was significantly lower in families of diabetic patients than healthy children families from the perception of their mothers. In addition, our results indicated that most of the family-life-related dimensions, including attitude and service, services, information, goods, and money affected by the disease conditions and its related comorbidities.</td>
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