# Investigation of the quality of life in adolescents with type 1 diabetes and their parents in Al-Najaf City hospitals, Iraq

**Abstract:**

**Background:** Diabetes is a common chronic disease in childhood. This condition negatively affects healthcare and child development, potentially endangering lives and impacting the quality of life (QoL) of both adolescents and their parents. This study aimed to determine the QoL of parents and adolescents with type 1 diabetes (T1DM).

**Method**: This descriptive study involved 376 participants (188 adolescents with T1DM and 188 of their parents) who were hospitalized or visited outpatient clinics in hospitals in Najaf City, Iraq. Ethical approval was obtained from Iran University of Medical Sciences and the Najaf Hospitals Directorate. All participants provided informed consent. The researcher visited pediatric wards and clinics at various times, and a convenience sampling method was employed based on inclusion criteria. When available, parents and adolescents were asked to complete a demographic/disease information questionnaire and the Pediatric Quality of Life Inventory (PedsQL) Diabetes Module. Data were analyzed using descriptive statistics (frequency, mean, standard deviation) and inferential statistics (Chi-square, correlation coefficient) with SPSS version 22 software (SPSS, Chicago, IL, USA), considering a significance level of $P < 0.005$.

**Result:** Among participating parents, 121 (64.4%) were fathers and 67 (35.6%) were mothers. The mean (SD) age of mothers was 32 ± 6.41 years, and 32.4% of mothers had no formal education. Of the adolescents, 52.4% were boys, with a mean (SD) age of 9.8 ± 3.4 years. The mean (SD) QoL score for adolescents was 50.22 ± 6.90, while for parents it was 67.48 ± 5.1. Adolescent sex, age, illness duration, residency, and educational level showed no correlation with their QoL. However, adolescent weight was correlated with their QoL. Parental socioeconomic level was not correlated with their QoL, but their employment status was. Unemployed parents had a lower mean QoL (65.40 ± 4.60) compared to employed parents (67.68 ± 5.021). Parental educational level was also correlated with their QoL.

**Conclusion**: This study revealed that parents of adolescents with diabetes have an acceptable QoL level, while adolescents reported lower QoL. These discrepancies highlight the importance of not relying solely on parental reports when inquiring about adolescent health. Healthcare providers should be aware of these differences, as parental perceptions undeniably influence adolescents' utilization of healthcare services and overall diabetes management.

**Keywords:** Diabetes Mellitus; quality of life**,** parent, adolescents, Iraq

## Introduction

Type 1 diabetes mellitus (T1DM) is a heterogeneous disease often manifesting in childhood and adolescence, characterized by insulin deficiency due to pancreatic beta-cell destruction. T1DM is one of the most common chronic childhood diseases. While exact figures are unavailable, estimates suggest T1DM accounts for about 5% of all diabetes cases, with a prevalence of approximately 0.25%. Its incidence is increasing by 3-5% annually in most studied populations (1)Although predisposing factors for DM are defined, its incidence in the South East Asia Region is projected to rise from 30 million in 2025 to 80 million in 2030 (2) The Middle East has seen an epidemic increase in DM. In Basrah, Iraq, DM prevalence is extremely high, with at least one in five adults affected, placing significant strain on the healthcare system and fiscal resources(3) The total number of cases across Iraqi provinces from 2018 to 2022 was 2,933,397, consistent with the International Diabetes Federation's 2021 report stating 9.4% of Iraqi adults (approximately 2,011,400 individuals) have diabetes(4). Poor knowledge, low educational level, bad healthcare provider practices, and inadequate policymaker role-play directly affect the prevalence of DM in Iraq(5) Adolescents with T1DM must adapt to a lifestyle requiring self-management of diet, exercise, and insulin adjustment while developing autonomy and self-identity. The rapid biological changes of adolescence combined with chronic illness management can place adolescents at risk for poor metabolic control and life adjustment difficulties, potentially interfering with developmental tasks, psychological adjustment, and overall quality of life (QoL). Lower QoL scores have been associated with older age, poor glycemic control, increased hypoglycemic episodes, complications, lower education levels, self-reported depression, and female gender (6). QoL is a significant patient-reported outcome reflecting subjective assessments of general well-being, daily life satisfaction, work and leisure capacity, emotional state, and social participation. Youth QoL encompass developmentally appropriate social, emotional, and physical functioning(7). Poor adolescent glycemic control has been linked to inadequate self-management, leading to high family conflict and distress. Literature suggests metabolic control and health-related QoL (HRQoL) for parents of adolescents with T1DM are negatively correlated with low affectionate sensitivity, overly reactive discipline, low family income, and high parental distress. While HRQoL in T1DM adolescents has been studied in several countries, only one hospital-based study in Saudi Arabia has reported HRQoL solely from the adolescent perspective (8). Quality of life in children with diabetes is a complex and multidimensional phenomenon influenced by physical health, emotional well-being, social relationships, and familial support. Understanding the factors affecting QoL and implementing strategies to enhance it can lead to better health outcomes and improved overall well-being for children living with diabetes. A collaborative approach involving healthcare providers, families, schools, and communities is essential in promoting a supportive environment that nurtures the quality of life for these young patients (9-11). The stress of raising a child with T1D can be overwhelming. Parental coping with the stress of diabetes is likely to have an essential influence in how well children and families adjust to the disease. Parents mention the need for constant monitoring and a sense of ongoing obligation to maintain metabolic control and prevent episodes of hypoglycemia. Maternal distress and children's reported quality of life (QOL) in school-age and older children have both been linked to how much mothers find managing diabetes disturbing(12). Parents of children with diabetes often experience a significant emotional and psychological burden due to the demands of managing their child's chronic condition. This burden can affect their overall quality of life, including their mental, emotional, physical, and social well-being. Understanding these challenges and enhancing the QoL for parents is essential in the context of pediatric diabetes management (13). Understanding and improving the quality of life for parents of adolescents with diabetes is essential for fostering a supportive environment for both the child and the family as a whole. By addressing the emotional, financial, and social challenges parents face, healthcare providers and advocates can implement strategies that enhance their well-being and resilience. Nurses play a crucial role in diabetes management, which depends on patient health status. A solid educational foundation for competent self-care is essential for all patients with diabetes to manage long-term care and avoid complications affecting QoL, making it a central focus of nursing care. This study was conducted to determine the QoL of adolescents with T1DM and their parents in Al-Najaf City hospitals, Iraq 2024.

## Methods

This was a descriptive study using convenience sampling. The minimum required sample size for estimating QoL at a 95% confidence level, with an accuracy estimate of d=1 and a standard deviation of 9.89, was calculated to be 376 participants (188 parents + 188 adolescents).

Inclusion criteria were: adolescents aged 13-18 years, no other chronic diseases, adolescents and their parent residing in Al-Najaf, no hearing or speech problems, Arabic-speaking, and at least six months since T1DM diagnosis. In this study, Data were collected using a demographic questionnaire and the PedsQL Diabetes Module for adolescents and the PedsQL Family Impact Module for parents. The PedsQL Diabetes Module is a widely used, internationally validated instrument assessing diabetes-specific HRQoL in children, adolescents, and young adults from patient and parent perspectives. The demographic questionnaire included gender, age, educational level, residence, illness duration, and weight. The PedsQL 3.0 Diabetes Module comprises 28 items across five subdomains: Treatment Barriers (4 items), Treatment Adherence (7 items), Diabetes Symptoms (11 items), Communication (3 items), and Worry (3 items). It uses a five-point Likert scale (0=never to 4=almost always), except for the child report version for ages 5–7 years, which uses a three-point scale with visual aids. Items are reverse-scored and linearly transformed to a 0–100 scale, with higher scores indicating better HRQoL. The PedsQL Family Impact Module for parents consists of 36 items across eight scales: Physical Functioning (6 items), Emotional Functioning (5 items), Social Functioning (4 items), Cognitive Functioning (5 items), Communication (3 items), Worry (5 items), Daily Activities (3 items), and Family Relationships (5 items). It also uses a five-point Likert scale, reverse-scored and transformed to a 0–100 scale, with higher scores indicating better functioning. Both instruments have demonstrated reliability and validity (14). Ethical approval (code: IR.IUMS.REC.1403.215) was obtained from the ethics committee of Iran University of Medical Sciences and the Najaf Hospitals Directorate. Written informed consent was obtained from all study participants after explaining the data collection method and study procedures. It was explained to the parents and adolescents that the questionnaires are anonymous and the results was published without mentioning the names of participants. For this purpose, the researcher, according to the pre-determined schedule, went to the research site in different shifts, and then introduce herself to the head nurses and obtain their permission. First, the researcher was introducing herself and provide sufficient information about the research objectives. and the stages of the questionnaire was explained before presenting it to people, while providing sufficient time for the person to fill out and answer all the questions in the questionnaire. Its importance for parents and adolescents. Then each participant was given enough time to do so carefully read the informed consent form. Convenience sampling method was used from June to October 2024. Data were analyzed using descriptive and inferential statistics with SPSS version 22, with significance set at P < 0.005.

## Result

### Demographic characteristics parents and adolescents with type 1 diabetes

Results showed Of the adolescents, 129 (68.6%) were female, 42 (22.3%) were intermediate school graduates, and 99 (52.7%) lived in rural areas. The mean (SD) age was 15.16 ± 1.59 years, and the mean (SD) illness duration was 5.16 ± 2.98 years. Weight for 74 (39.4%) adolescents was between 50-60 kg, with a mean (SD) of 54.97 ± 14.88 kg. Among parents, 121 (64.4%) were male, 85 (45.2%) had a middle economic status, 127 (67.6%) were married, 149 (79.3%) were employed, and 42 (22.3%) were primary school graduates. The mean (SD) parental age was 45.53 ± 8.41 years.

Tabel 1: **Quality of Life and Its Domains in Adolescents with Type 1 Diabetes**

| **Quality of life and its domains** | **min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|
| About my diabetes | 20.45 | 77.27 | 50.84 | 11.28 |
| Treatment - i | 6.25 | 93.75 | 50.96 | 17.18 |
| Treatment - ii | 7.14 | 89.29 | 49.84 | 13.77 |
| Worry (problems with…) | 0 | 100.00 | 48.75 | 21.66 |
| Communication (problems with…) | 8.33 | 100.00 | 49.29 | 20.59 |
| Total | 33.93 | 71.43 | 50.22 | 6.90 |

Frequency and Mean and standard deviation of items of each domain of quality of life in adolescents with type 1 diabetes showed in Table 2.

**Table 2:** Frequency and mean and standard deviation of items of each domain of quality of life in adolescents with type 1 diabetes in Al-Najaf City hospitals, Iraq

| | **No.** | **Item** | **Never** | **Almost Never** | **Some-Times** | **Often** | **Almost Always** | **Mean (s.d)** |
|---|---|---|---|---|---|---|---|---|
| ABOUT MY DIABETES (problems with…) | 1. | I feel hungry | 38(2/20) | 36(19.1) | 36(19.1) | 33(17.6) | 45(23.9) | 2.06(1.4) |
| | 2. | I feel thirsty | 41(21.8) | 39(20.7) | 40(21.3) | 37(19.7) | 31(16.5) | 1.88(1.3) |
| | 3. | I have to go to the bathroom too often | 31(16.5) | 34(18.1) | 45(23.9) | 43(22.9) | 35(18.6) | 2.09(1.3) |
| | 4. | I have stomachaches | 38(20.2) | 45(22.9) | 38(20.2) | 25(13.3) | 42(22.3) | 1.94(1.4) |
| | 5. | have headaches | 43(22.9) | 38(20.2) | 35(18.6) | 36(19.1) | 36(19.1) | 1.91(1.4) |
| | 6. | I go "low" | 30(16.1) | 53(28.2) | 41(21.8) | 37(19.7) | 26(14.4) | 1.88(1.2) |
| | 7. | I feel tired or fatigued | 32(17) | 44(33.4) | 38(20.2) | 26(13.8) | 48(25.5) | 2.07(1.4) |
| | 8. | I get shaky | 37(19.7) | 43(22.9) | 36(19.1) | 38(20.2) | 34(18.1) | 1.94(1.3) |
| | 9. | I get sweaty | 32(17) | 44(23.4) | 32(17) | 44(23.4) | 36(19.1) | 2.04(1.3) |
| | 10. | I have trouble sleeping | 37(19.7) | 37(19.7) | 49(26.1) | 32(17) | 33(17.6) | 1.93(1.3) |
| | 11. | I get irritable | 41(21.8) | 42(23.3) | 39(20.7) | 32(17) | 34(18.1) | 1.87(1.4) |
| TREATMENT - I (problems with…) | 12. | It hurts to prick my finger or give insulin shots | 32(17) | 29(15.4) | 47(25) | 40(21.3) | 40(21.3) | 2.14(2.4) |
| | 13. | I am embarrassed about having diabetes | 48(25.5) | 36(19.1) | 40(21.3) | 31(16.5) | 23(17.6) | 1.81(1.8) |
| | 14. | My parents and I argue about my diabetes care | 34(18.1) | 37(19.7) | 42(22.3) | 39(20.7) | 36(19.1) | 2.03(2.0) |
| | 15. | It is hard for me to stick to my diabetes care plan | 49(26.1) | 35(18.6) | 31(16.5) | 40(21.3) | 33(17.6) | 1.86(1.8) |
| TREATMENT – II (problems with…) | 16. | It is hard for me to take blood glucose tests | 31(16.5) | 39(20.7) | 45(23.9) | 38(20.2) | (18.6) | 1.81(1.3) |
| | 17. | It is hard for me to take insulin shots | 43(22.9) | 37(19.7) | 48(25.5) | 32(17) | 28(14.9) | 2.03(1.3) |
| | 18. | It is hard for me to exercise | 50(26.6) | 28(14.9) | 41(21.8) | 35(18.6) | 34(18.1) | 1.87 (1.4) |
| | 19. | It is hard for me to keep track of carbohydrates or Exchanges | 31(16.5) | 40(21.3) | 44(23.4) | 39(20.7) | 34(18.1) | 2.03(1.45) |
| | 20. | It is hard for me to wear my id bracelet | 31(16.5) | 34(18.1) | 36(19.1) | 44(23.4) | 43(22.9) | 2.18 (1.4) |
| | 21. | It is hard for me to carry a test - acting carbohydrates | 35(18.6) | 32(17) | 44(23.4) | 35(18.6) | 42(22.3) | 2.06(1.3) |
| | 22. | It is hard for me to eat snakes | 30(16) | 50 (26.6) | 31(16.5) | 39(20.7) | 38(20.2) | 2.03 (1.3) |
| WORRY (problems with…) | 23. | I worry about " going low" | 38(20.2) | 40(21.3) | 31(16.5) | 44(23.4) | 35(18.6) | 1.99(1.4) |
| | 24. | I worry about whether or not my medical treatments are working | 34(18.1) | 39(20.7) | 40(21.3) | 32(17) | 43(22.9) | 2.06(1.4) |
| | 25. | I worry about long-term complications from diabetes | 30(19.1) | 39(20.7) | 31(16.5) | 34(18.1) | 48(25.5) | 2.10 (1.4) |
| COMMUNICATION (problems with…) | 26. | It is hard for me to tell the doctors and nurses how I feel | 39(20.7) | 37(19.7) | 41(21.8) | 35(18.6) | 36(19.1) | 1.96 (1.4) |
| | 27. | It is hard for me to ask the doctors and nurses questions | 34(18.1) | 35(18.6) | 31(16.5) | 34(18.1) | 54(28.7) | 2.21 (1.4) |
| | 28. | It is hard for me to explain my illness to other people | 38(20.2) | 41(21.8) | 40(21.3) | 36(19.1) | 33(17.6) | 1.92(1.3) |

**Table 3**: Mean and SD of quality of life and their domains in parents of adolescents with type 1 diabetes in Al-Najaf City hospitals, Iraq

| **Variable (N=188)** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|
| Physical functioning | 33.3 | 100 | 70.4 | 12.8 |
| Emotional functioning | 25.0 | 95 | 62.4 | 14.3 |
| Social functioning (problems with…) | 20.3 | 76.5 | **50.21** | **13.6** |
| Cognitive functioning (problems with…) | 35.0 | 100.00 | 69.81 | 13.4 |
| Communication (problems with…) | 25 | 100 | **71.01** | **16.4** |
| WORRY (problems with…) | 40.00 | 100.00 | 70.15 | 13.27 |
| DAILY ACTIVITIES | 25.00 | 100.00 | 68.70 | 16.7 |
| Family relationships | 25 | 95 | 62.47 | 15.3 |
| Total | 54 | 80.6 | 67.48 | 5.1 |

Item-level analysis revealed specific challenges lowered Mean (SD) in domain "About child diabetes (problems with…) "Was I feel physically weak (1.80±1.392), low Mean (SD) in domain "Emotional functioning" were I feel angry 1.9±1.4) and. Lower Mean (SD) in domain "Social functioning domain was" I feel isolated from others (1.88±1.3). Lower Mean (SD) in "cognitive functioning (problems with…)" domain was it is hard for me to keep my attention on things" (1.91±1.3)". Lower Mean (SD) in communication (problems with…) domain was "it is hard for me to talk about my child's health with others". Family (1.96±1.4). Lower Mean (SD) in domain WORRY (problems with…) was "I worry about how my child's illness is affecting other family members (1.81±1.3). Lower Mean ±SD in domain Daily activities domain was "I feel too tired to do the things I like to do (1.92(1.3)). Lower Mean in family relationship domain was Conflicts between family members (1.88 ±1.4).

## Correlational Analysis

No significant correlation was found between adolescent QoL and sex (t = -0.11, P = 0.907), age (r = -0.008, P = 0.913), illness duration (r = 0.004, P = 0.959), residency (t = 1.05, P = 0.293), or educational level (F = 0.145, P = 0.965). However, a significant negative correlation was found with adolescent weight (r = -0.163, P = 0.025).

Parental socioeconomic level was not correlated with their QoL (F = 0.430, P = 0.430), but employment status was (t = 2.57, P = 0.011). Unemployed parents had significantly lower QoL (65.40 ± 4.60) than employed parents (67.68 ± 5.021). Parental educational level also correlated with QoL, with a trend (p = 0.066) suggesting lower QoL among intermediate school graduates

## Discussion

This study involved 188 adolescents with T1DM and their parents. The first aim was to determine adolescent QoL. Results indicated a moderate QoL level (50.22), highlighting the balance these adolescents maintain between managing their condition and typical childhood experiences. A study conducted in Turkey found a mean quality of life score 65.3 among children with diabetes, indicating a significantly higher quality of life compared to our findings. Other studies in Ethiopia(15) and Kuwait also showed higher quality of life compared to our findings(16). This discrepancy may reflect differences in healthcare access, diabetes management education, and parental support systems in these counties versus Iraq (17). In a study from Egypt, researchers reported a mean QoL score of 56.4 for children with diabetes, which, while still higher than our findings, suggests a somewhat closer context (18). Differences in healthcare infrastructure and public health policies may also account for the observed variances between these populations Conversely, research conducted in lower-resource settings, such as Somalia, reported a mean QoL score of 45.0, closer to our findings (19). This highlights potential commonalities in challenges faced by children with diabetes in regions with limited resources and healthcare access. The observed differences in QoL scores between our study and others can likely be attributed to various factors, particularly the effectiveness of healthcare systems and diabetes education programs (20). In many higher-income countries, comprehensive diabetes management programs and education services are well-established, contributing to better health outcomes and enhanced quality of life for children (21). These gaps can directly impact how children perceive their quality of life, especially in managing the daily demands of diabetes.

The second aim was to determine parental QoL. The mean score of 67.48 ±5.1 provides insights into the emotional and social complexities of parenting a child with a chronic illness. Research on the quality of life in parents of children with diabetes has yielded varying results, often reflecting differences in methodology, population demographics, and contextual factors. For instance, a study by Lloyd et al. (2013) reported a mean quality of life score of 75.9 among parents, significantly higher than our findings. This difference may be attributed to the study's focus on a more homogeneous group of parents with higher socioeconomic status and access to diabetes education resources, suggesting that socioeconomic factors play a critical role in parental well-being. Conversely, a study by Kovacs et al. (2015) found that parents of children with poorly controlled diabetes reported lower quality of life scores, averaging 61.2. This aligns more closely with our findings and reinforces the idea that if parents struggle with their child's diabetes management, their quality of life can significantly decline. Our findings, in line with this literature, indicate a potential avenue for intervention: enhancing educational initiatives and support networks may improve the psychosocial outcomes for parents of children with diabetes (9, 22).

" A significant correlation was found between adolescent QoL and weight, emphasizing the importance of weight management in diabetes care. When compared to other studies, several key themes and implications emerge regarding the implications of weight on the quality of life in pediatric diabetes patients. other study indicated that children with better glycemic control, often associated with maintaining a healthy weight, reported higher QoL scores (23, 24). Conversely, a study by Gonzalez et al. (2017) found that children who were overweight or obese not only had poorer quality of life but also faced additional complications related to diabetes management. The study suggested that excess weight can exacerbate physical limitations and emotional strain, leading to a notable decline in QoL (25). Our findings highlight the potential of proactive weight management in improving quality of life outcomes. Identifying children at risk of obesity and providing early interventions could be beneficial. Initiatives that promote awareness about healthy lifestyle choices and provide resources for families struggling with weight-related issues are crucial in this population.

Also, our findings indicate that unemployed parents had significantly lower QoL than employed parents. This result sheds light on the influence of employment status on parental well-being, particularly in the context of chronic illness management. Comparative analyses with existing literature further underline the implications of these findings. The significant difference in quality-of-life scores between unemployed and employed parents aligns with findings from zang et al. (2024), which reported that job-related factors play a critical role in the overall well-being of caregivers. Employed parents often experience a sense of structure, purpose, and social engagement that can contribute positively to their mental and emotional health. In contrast, unemployment can lead to feelings of inadequacy, low self-esteem, and increased stress, which negatively impacts quality of life (26). Some studies also highlighted that unemployed parents of children with chronic conditions, including diabetes, faced additional psychological burdens, including anxiety and depression, which can hinder their ability to provide effective care (27, 28). Peer support groups and community services aimed at families coping with chronic illness may help bridge this gap, providing unemployed parents with the necessary tools and emotional support to enhance their well-being (29). The cross-sectional design of our study in one hospital restricts our ability to infer causation. Future research should aim for multi-center studies that include diverse populations to strengthen the generalizability of findings. Additionally, other factors contributing to quality of life, such as psychosocial elements and family dynamics, may not have been fully explored in our analysis. According of results Future research efforts should focus on exploring the disparities in experiences and the development of effective interventions that solve to the diverse needs of parents. Future research should consider longitudinal studies to assess how weight changes over time influence the quality of life and how interventions can effectively target both weight management and psychosocial support. Expanding the scope of research to include diverse populations will also provide a more comprehensive understanding of the relationship between weight and quality of life in children with diabetes.

## Conclusion:

This study investigated the QoL of adolescents with T1DM and their parents in Al-Najaf City, Iraq. Parents reported an acceptable QoL level, while adolescents reported lower QoL. This discrepancy underscores the necessity of directly assessing adolescent health perceptions rather than relying solely on parental reports. Healthcare providers must recognize these differences, as parental perceptions significantly influence adolescent healthcare utilization and diabetes management.