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# Adherence to diabetes management among school-aged children and adolescents living with type 1 diabetes in Jordan

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ABSTRACT

*Aims:* To measure the level of adherence to diabetes management among children and adolescents living with type 1 diabetes, and to explore socio-demographic factors associated with better diabetes management using both child and parent proxy reports.
*Background:* Worldwide, type 1 diabetes mellitus is one of the most widespread chronic diseases in children and adults. In Jordan, it is estimated that 10,000 children and adolescents are living with this disease. Management of diabetes is challenging for both children and their parents.
*Methods:* A cross-sectional study was performed using a convenience sample of 109 children and adolescents and 100 parents attending a major diabetes center in Amman.
*Results:* The mean scores of Diabetes Management Questionnaire (DMQ) for children/adolescents was low compared to other studies. There was moderate to good agreement between children/adolescents and their parents' report of adherence to diabetes questionnaire (Inter Class Correlation = 0.78). The study revealed that children/adolescents with poor glycemic control reported lower adherence to diabetes management ($p < 0.05$). Duration of diabetes and family income associated negatively with adherence to diabetes management scores.
*Conclusion:* Although the participants achieved an acceptable degree of adherence, collaboration between healthcare services and education sectors is needed to support those children to diabetes self-management at school. Demographic and management-related variables should be considered when designing health education.
*Practice implications:* The government of Jordan, along with nurses and other healthcare providers, can utilize the current findings to develop standardized and supportive strategies to support children/adolescents and their caregivers.



## Introduction

Type 1 diabetes mellitus (T1DM), commonly known as autoimmune diabetes, is caused by the pancreas inability to produce insulin, therefore requiring exogenous insulin to meet both basal and prandial insulin needs (Katsarou et al., 2017). As it is incurable, supportive care is recommended through daily insulin injections or the use of the insulin pump that can hugely impact children and adolescent's life (Bialo, 2018).

The Clinical Practice Consensus Guidelines of International Society for Pediatric and Adolescent Diabetes (ISPAD) call for routine screening and referral to evidence-based diabetes health therapies as a component of clinical care for children and adolescents with diabetes (Besser et al., 2022). It is well documented that adherence to recommended health guidelines required by complex diabetes care regimens is central to diabetes management (Bakir & Sezer, 2023). Management of T1DM demands constant attention to a variety of aspects, including insulin delivery, blood glucose monitoring, meal planning, screening for comorbid conditions and diabetes-related complications, all of which are best handled by a multidisciplinary health team (Arabiat et al., 2020). The goal of T1DM management is to achieve blood glucose values that are as close to healthy ranges as possible (Mistry et al., 2022).

However, suboptimal adherence to diabetes management is common and has a substantial impact on health outcomes among children living with T1DM (Besser et al., 2022). Given the need for good diabetes education of children and their families to understand health behaviors in multiple contexts, such as home, school and community settings, nurses are well-suited to support the needs of children with T1DM and their families to promote adherence to the demanding diabetes

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care regimen (Gomber et al., 2023), in particular with the increased risk of severe hypoglycemia or hyperglycemia (Yau et al., 2021). It is well suggested that children and adolescents living with T1DM should be able to control their diabetes within their school's environment as well as within their home and other community settings (Almeida et al., 2023; Gomber et al., 2023).

Jordan is a middle-income country that lies in the heart of the Middle East (AL Jabery & Arabiat, 2019). According to Odeh et al. (2022), children and adolescents living with T1DM in Jordan are often managed by general practitioner or a pediatrician with a lesser extent by a specialised endocrinologist. This is an addition to the fact that diabetes care of this population is often challenged by the limited access to specialised T1DM services, unavailability of insulin injection that is covered by patients' insurance, and unaffordability of glucose monitoring strips (Odeh et al., 2022). Related to limited financial resources and paucity of dieticians with experience in T1DM, educational programs of advanced carbohydrates counting, which often needed for diabetes management, are also missing or not applied in Jordan (Alassaf et al., 2023). The Jordanian culture, which is shaped by the families' beliefs could also influence diabetes management practice and hence diabetes adherence in children and adolescents (Momani et al., 2022).

Therefore, insight into the daily hassles encountered by children living with T1DM and their parents is needed. Nurses, as part of the health professional team, must explore and understand the limitations associated with adhering to an optimal regime of diabetes management at home and school. This will help in developing resources that can assist not only patients but also guide caregivers, and healthcare professionals when delivering interventions to improve glycemic control. This study is the first in Jordan to shed light on children's and adolescents' adherence to diabetes management. It helps in documenting the adherence to standard guidelines of diabetes care and highlights the level of agreement between children and their parents in rating their adherence to those guidelines. The findings of this study will assist healthcare professionals to identify measures to support children/ adolescents and their parents in achieving glycemic control. This may in turn reduce the risk of long-term complications and assist future studies in developing resources to help children to cope and adapt to diabetes.

## Aims

The aim of this study is to measure the adherence to diabetes management from both child and parents' point of view using child and parent proxy reports and to explore socio-demographic correlates of adherence to diabetes management.

## Methods

### *Study design*

A descriptive correlational design was adopted to measure adherence to diabetes management among children and adolescents living with T1DM in Jordan.

### *Setting*

This research was conducted at one large hospital in Amman. This hospital is specialised in diabetes and serves Jordanian patients with all type of diabetes at the national level.

### *Participants*

The population of this study was limited to children and adolescents aged between 8 and 18 years, and living with T1DM for >6 months. Participants included both children/adolescents and their parents or primary care givers. Unstable children or those with impaired cognitive abilities or unable to communicate were excluded. Children with critical conditions or comorbidities were also excluded.

The minimum required sample size calculated for this study was 87 participants. This was determined based on G-power software, after selecting a multiple linear regression, power set at 0.08 with alpha level 0.05 and medium effect size. An additional 25% was added to the sample size count, so the total sample included was 109 children/ adolescents and their parents.

### *Tools of the study*

The tool used for data collection included two sections:

1) The Socio-demographic questionnaire: provided a description of the sample demographic data of child's age, gender, weight, length, duration of diabetes, type of treatment (Insulin injection vs. Insulin pump), place of residence, comorbidities, type of school (public vs. governmental). The parent's demographic data included age of parents, the number of children, education level, employment status, insurance status, total income).
2) The Diabetes Management Questionnaire (DMQ) developed by (Mehta et al., 2015) was used in this study for children/adolescents and their parents. It includes 21-items measuring the level of adherence to T1DM. Of the 21 items, 20 items are based on 5-points Likert scale, ranging from 0 to 4 (0 = almost never-4 almost always). Before calculating the total score of DMQ, 6 items should be reversed (8,9,10,14,18 and 20). The mean score of the 20 items can be computed then multiplied by 25 to normalize the total score to a 0–100 scale. A higher DMQ score reflect higher adherence level and better diabetes management.

The DMQ is a valid and reliable tool for evaluating adherence to diabetes management and display high internal consistency (Cronbach's alpha) for parents (0.83) and for children (0.79) (Mehta et al., 2015). Permission to use and translate the DMQ into Arabic was taken from the original tool's author as attached appendix A. The Arabic version of the DMQ was developed using the World Health Organisation (WHO) guidelines for translation (2009). First, the study questionnaire was translated to Arabic and then back translated to English. There was a bilingual expert who translates the questionnaire from English to Arabic, and then the questionnaire was reviewed by one of the researchers (D. A) to ensure clarity and translation accuracy. An Arabic language professor double-checked the back translation to ensure that all spelling and grammatical errors had been addressed. Before starting the current study and to ensure that there were no problems with the study tools, a pilot study was carried out and included a sample of 20 children and 20 parents. A good internal reliability was obtained for the items of this study with a Cronbach alpha ($\alpha$) 0.772 for children and 0.742 for parents. All items were rated clear and easy to answer by the participants.

### *Ethical considerations*

The approval of the Ethics Committee of the diabetes centre included in this study was obtained after discussing the proposal with the Scientific Research Ethics Committee (IRB approval on 29/9/2021). Consent was also obtained from all children participants and their parents.

The researcher explained the purpose, procedures, as well as patients' rights to voluntary participation or withdrawal from participation. Those who agreed to participate were asked to sign a consent form. Children/adolescents and their caregivers were interviewed by the same researcher (M.S) in separate rooms to prevent their responses from influencing each other. Participants were assured their data would be anonymous and confidential, and that no one other than the research team would have access to their responses.

*Procedure of data collection*

Data was collected between October 2021 and January 2022. Participants were invited to take part in this study and an information sheet was given for interested participants. The questionnaires were completed by a convenience sample of 109 children and adolescents, aged between 8 and 18 years, and 100 parents. Both children and their parents completed the questionnaire during the waiting time at the clinic and before seeing their doctor. Of the 109 completed questionnaires, 100 questionnaires were completed by a proxy-report, and 109 were completed by children/adolescents themselves.

Information about the study along with the study paper-based questionnaires were distributed to the participants. The 1st author of this paper (M.S) performed the data collection and approached participants at the clinic after the ethics approval was obtained from the clinical setting and the University of Jordan.

*Statistical analysis*

SPSS IBM software version 28 was used to analyze the data. Descriptive frequencies were used to investigate the mean and Standard deviation of the MMQ scores in relation to the socio-demographic and clinical features of the children/adolescents on a scale of almost never (0) to almost always (4).

Inferential statistics were used to investigate if demographics of the respondents in terms of age, gender, educational level of the parents, duration of diabetes and income had a significant influence on the child/adolescent's adherence to diabetes management. The examination followed a principle that if $\rho \leq \alpha$ (0.05), then the demographic feature in question has significant influence on children' adherence to diabetes management; and if $\rho \geq \alpha$ (0.05), then the socio-demographic features have no significance influence on children'/adolescent's adherence to diabetes management. Multiple Regression was used to see the impact of predictors on criterion. We performed preliminary analysis to check for the assumptions such as normality, multicollinearity and homoscedasticity before further inferential analyses were generated.

Finally, we used Interclass Correlation Coefficient (ICC) for measure agreement between child and parent's report. An ICC can theoretically vary between 0 and 1.0, where an ICC of 0 indicates no agreement, and an ICC of 1.0 indicates perfect agreement (Bobak et al., 2018).

## Results

*Participants characteristics*

A total of 109 children and 100 parents completed the study. As shown in Table 1, the percentage of girls were slightly higher than boys (57.8% and 42.2%, respectively). More than half of the participants (53.2%) were aged between 8 and 12 years of age. Most participants lived in Amman ($n = 75$, 68.8%) with less percentages living in the northern or southern region.

Most parents had secondary education or less (54% for mother and 58% for father). The median family number was 6 people. About half (56%) of the participants did not have any health insurance and one third (37%) had governmental or other private health insurance (see Table 2).

*Adherence Diabetes Management Scale*

Table 3 shows the descriptive statistics of the MDQ scores. The mean score of DMQ for children and adolescents participating in this study was 61.45 (SD = 15.75), while the mean score of proxy reports was 64.21 (SD = 14.88).

**Table 1**
Characteristics and clinical background for children/adolescents ($N = 109$).

| Variables | N | % |
|---|---|---|
| Age | | |
| 8–12 years old | 58 | 53.2 |
| 13–18 years old | 51 | 46.8 |
| Gender | | |
| Boys | 46 | 42.2 |
| Girls | 63 | 57.8 |
| Weight | | |
| 25–40 kg | 44 | 40.4 |
| 41–55 kg | 42 | 38.5 |
| 56 kg and more | 23 | 21.1 |
| Length | | |
| 116–130 cm | 18 | 16.5 |
| 131–145 cm | 25 | 22.9 |
| 146–160 cm | 48 | 44.0 |
| 161 and more | 18 | 16.5 |
| Place of living | | |
| Central region | 90 | 82.4 |
| Southern region | 10 | 9.2 |
| Northern region | 9 | 8.3 |
| Time since diagnosis | | |
| 6monthes −1 year | 18 | 16.5 |
| 1–3 years | 36 | 33.0 |
| 3–5 years | 18 | 16.5 |
| >5 years | 37 | 33.9 |
| Comorbidities | | |
| Yes | 19 | 17.4 |
| None | 90 | 82.6 |
| Type of school | | |
| Governmental/ public | 75 | 68.8 |
| Private | 26 | 23.9 |
| Agency | 8 | 7.3 |
| Type of treatment | | |
| Insulin injection | 109 | 100.0 |
| Insulin pump | 0 | 0.0 |

**Table 2**
The demographic characteristics of parents ($N = 100$).

| Variables | N | % |
|---|---|---|
| Mother age | | |
| ≤40 years | 59 | 59.0 |
| 41–50 years old | 34 | 34.0 |
| ≥51 years old | 7 | 7.0 |
| Mother education level | | |
| Secondary and less | 54 | 54.0 |
| Diploma | 24 | 24.0 |
| University | 22 | 22.0 |
| Mother occupation | | |
| Worker | 24 | 24.0 |
| Housewife | 76 | 76.0 |
| Father age | | |
| ≤40 years | 25 | 25.0 |
| 40–50 years old | 61 | 61.0 |
| ≥51 years old | 14 | 14.0 |
| Father education level | | |
| Secondary and less | 58 | 58.0 |
| Diploma | 17 | 17.0 |
| University | 25 | 25.0 |
| Father occupation | | |
| Worker | 90 | 90.0 |
| Retired or unemployed | 10 | 10.0 |
| Family income | | |
| Less than 300JD | 19 | 19.0 |
| 301–400JD | 24 | 24.0 |
| 401–500JD | 22 | 22.0 |
| 501–600 | 11 | 11.0 |
| More than 600Jd | 24 | 24.0 |
| Health insurance | | |
| Governmental | 37 | 37.0 |
| Private | 7 | 7.0 |
| None (exemption from civil service bureau) | 56 | 56.0 |
| Family member (Md) | 6 | |

Md = Median.

**Table 3**
Mean and standard deviation for child and parents DMQ.

| DMQ Score | Children/adolescents | Parents |
|---|---|---|
| Mean ± SD | 61.45 ± 15.75 | 64.21 ± 14.88 |
| 8–12 years | 63.66 ± 15.22 | |
| 13–18 years | 58.92 ± 16.10 | |

SD = Standard Deviation, DMQ = Diabetes Management Questionnaire (Mehta et al., 2015).

*Agreement between child and parents' reports*

The Intraclass Correlation Coefficient (ICC) for adherence to diabetes management questionnaire was calculated and revealed good agreement between child and parent's report (ICC = 0.798) 95% CI (0.701–0.864). According to Bobak et al. (2018), an ICC (<0.5) is considered poor, 0.5–0.75 is moderate, 0.75–0.90 is good and ICC >0.90 is considered an excellent agreement.

*Socio-demographic correlates of diabetes management*

The socio-demographic variables that are associated with the children/adolescent's reports of adherence to diabetes management are presented in Table 4. Family income and diabetes duration were entered into the multiple linear regression and the final model was statistically significant ($F = 7.660$, $P < 0.001$) with both variables explaining at least $^{adj}R^2 = 28\%$ of variance in child adherence to diabetes management.

As shown in Table 4, monthly income of 301–400 JD and 401–500 JD negatively associated with child adherence to diabetes management when compared to families with income >600 JD (−14.65 and −7.384, $P < 0.001$, $P = 0.032$).

Duration of diabetes or time since diagnosis (6 months to 1 year) significantly associated with increase in child adherence by 12.343 ($P < 0.001$) compared to children/adolescent who had T1DM for >5 years. Similarly, duration of diabetes for 1 to 3 years significantly associated with increase in child adherence to diabetes management by 6.758 ($P = 0.018$) compared to those who had T1DM for >5 years.

Other socio-demographic variables, such as parents' age, education, occupation, health insurance, family size, anthropometric measure of BMI, comorbidities, place of living and school types were not included in the final regression model due to insignificant *p*-values.

## Discussion

In this study, our findings suggest lower adherence to diabetes management among children and adolescents living with T1DM when compared other studies. An earlier study conducted in the USA reported a mean score of 70.60 (SD = 12.90) for children aged 8–18 years during a routine clinic visit (Mehta et al., 2015), while our study showed a mean score of 62.45 (SD = 15.75) using the same questionnaire (DMQ) and the same age group. This may relate to the enhanced services primary care trusts had commissioned in the developed countries and the team approach to diabetes management between home, schools and clinical settings. For example, children and adolescents living with T1DM in the developed countries often have access to continuous monitoring equipment and insulin pumps (Charalampopoulos et al., 2018), which is not the case for other children in the developing countries. In Jordan, basic education is only provided at early diagnosis and this education is often limited to basic skills of insulin injection and the use of gluco-check monitoring devices. This is in addition to the lack of structured follow-up visits, which leave patients and their caregivers in need of more information and support.

Our findings also showed adolescents are at higher risk for poor diabetes management when compared to school-age children. The adherence to diabetes management scores in this study using the DMQ were significantly higher for children aged under 13 years compared to children older than 13 years (63.66, 58.92 respectively). This is consistent with Mehta et al. (2015)'s study which showed better DMQ mean scores (73.70) for children aged <13 years and lower mean score (68.0) for children aged 13 years and older. This could be partly explained by the greater parental support received by pre-adolescent children where families can be more involved in the daily diabetes responsibilities of younger children, as well as the limited capacity to recall diabetes control behaviors among children below 13 years (Mehta et al., 2015). The age effects here, refer to the developmental processes that may confound the interpretation of summary scores in children self-report of diabetes management. For example, in interpretating the DMQ scores, differences in child self-reported scores between children below and above 13 years may not be attributed to actual differences in DMQ between the two groups, but it may relate to random error as the result of age effects from cognitive and behaviour development. In this case, the impact of these age effects is that the total score of DMQ may be subject to misinterpretation based on levels of developmental competence with relation to the suitability of domains and items, readability/language, response burden or options, and recall time.

In this study, we noticed an agreement between both child and parent reports which may suggest better awareness and involvement of parents in the management of their child's diabetes. Our findings showed a positive moderate correlation between reports of adherence to diabetes management among children/adolescents and their parents.

Factors associated with adherence to diabetes managements were family income and duration of diabetes. This is consistent with an earlier study in Jordan by Odeh et al. (2022) where monthly income associated with better glycemic control among Jordanian and migrant/refugee children with T1DM. This may relate to the financial cost associated with diabetes and which might not seem clear early at the time of diagnosis. The financial costs associated with children's steady needs for multiple insulin injections and blood glucose strips would negatively impact children's ability to adequately adhere to complex diabetes care regimens. In Jordan, the average cost of insulin injection and glucose strips is approximately 100–200 JD per month (approximately 70–140 USD) depending on the insulin dosage, types of insulin, and costs of follow-up visits. This average monthly cost is equal to or more than the minimum wage for some families. Our findings are inconsistent with reports from other developing countries, like Nigeria (Ogugua et al., 2021). In Ogugua, et al.'s study, socio-economic status and duration of diabetes did not associate with children/adolescent's adherence to diabetes management. The availability of free diabetes

**Table 4**
Multiple linear regression analysis results.

| Model | Unstandardized Coefficients B | Std. Error | Standardized Coefficients Beta | T value | P-value | 95%CI for B | |
|---|---|---|---|---|---|---|---|
| | | | | | | lower | upper |
| Income 301–400 JD | −14.659 | 2.889 | −0.454 | −5.074 | **<0.001**** | **−8.922** | **−20.395** |
| Income 401–500 JD | −7.384 | 3.398 | −0.197 | −2.173 | **0.032** | **−0.636** | **−14.131** |
| Income 501–600 | −2.371 | 4.456 | −0.048 | −0.532 | 0.596 | −11.219 | 6.477 |
| Time since diagnosis 1−6 months | 12.343 | 3.499 | 0.306 | 3.528 | **<0.001**** | **5.394** | **19.291** |
| Time since diagnosis 1−3 years | 6.758 | 2.800 | 0.217 | 2.413 | **0.018*** | **1.197** | **12.318** |
| Time since diagnosis 3−5 years | 0.954 | 3.092 | 0.027 | 0.309 | 0.758 | −5.186 | 7.094 |

* $p < 0.05$, ** $p < 0.001$, $^{adj}R^2 = 28\%$, Anova F = 7.660.

care services, public health policies, and good health insurance coverage are vital in promoting health equity across groups.

*Limitations*

One of the limitations is this study is the use of a self-reported outcome measure that, even if outwardly sound, could be subject to recall bias and could generate social desirability responses. Nevertheless, using the validated Arabic version of the DMQ and using a proxy-report should have minimized this bias. The cross-sectional design is a second limitation. Although the cross-sectional design is suitable for estimating the level of adherence to diabetes management among this population, it fails to estimate the causal relationship between factors considered and the risk of poor glycemic control.

One more limitation of the study was the fact that we did not inquire if the parents/ caregiver were diabetes patients themselves. For instance, parents or carers who have diabetes and who have other children with diabetes may have better knowledge and experiences that adherence to their child's medication regimens is of primary importance. This is in addition to the use of a convenience sample which may not be representative of all children with T1DM in Jordan. Though the response rate was high, our data collection was limited to one setting and a non-response analysis could not be performed due to lack of non-respondent data. Therefore, our results should be interpreted with caution as a bias due to selective non-response that cannot be ruled out. Lastly, while Jordan lacks effective and national programs for enhancing diabetes management, our study did not collect information about how families were educated about their child's diabetes management. Parents and children trained by a diabetes educator or attended a diabetes management program may have better adherence than children who were not trained or those who were educated by nonprofessional educators.

*Implications*

This study generates knowledge and understanding of the circumstances that regulates children's and adolescents' struggles with diabetes in Jordan. The Jordanian government as presented by its Ministry of Health (MOH) may consider placing subsidies on the insulin injections, strips and diabetes medications to make them affordable for families and patients. At the clinical settings, nurses and other healthcare professionals may suggest building a special fund for poor families to augment children who may not afford payments for their diabetes medication. In this regard, funds may be solicited from governments, charities, or international organisations, such as the World Diabetes Foundation (WDF) and US-AIDS. It may consider developing a diabetes nurse clinic which may go a long way to increase attendance of children/adolescents and their caregivers at the diabetes clinics across the country.

Research-wise, our findings suggest the need for using mixed methods in future studies to help enrich data and to help investigate other aspects that may have been overlooked in the current literature. Other research designs could be used to compare our findings with other studies and to utilize objective measures to evaluate the effectiveness of current health education programs or training, if any, and its impact on children's metabolic control.

## Conclusion

To the best of our knowledge, this is the first study in Jordan to measure the adherence to diabetes management among school-aged children and adolescents living with T1DM. The children/adolescents in this study achieved satisfactory results in terms of the level of adherence to diabetes management and achieved good agreement with their parent's-proxy reports of diabetes adherence. However, the result showed children had poor glycemic control which may suggest that children's and adolescent's level of adherence to diabetes management did not reflect on their HbA1c test. Factors associated with better adherence to diabetes management were family income and diabetes duration (time since diagnosis).

## Credit author statement

**Malak Sabbah:** Writing - Original Draft, and Project administration. **Dr. Diana Arabiat:** Conceptualization, Validation, Writing - Review & Editing and Supervision. **Anees Hjazeen:** Methodology and Formal analysis.

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## CRediT authorship contribution statement

**Malak Murad Sabbah:** Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Writing – original draft. **Anees Adel Hjazeen:** Formal analysis, Resources, Writing – original draft. **Diana H. Arabiat:** Conceptualization, Supervision, Visualization, Writing – review & editing.

## Declaration of Competing Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2023.11.021.

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