



## Barriers to Adherence to Treatment Regimen among Adolescents with Type-1 Diabetes Mellitus

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### ABSTRACT

**Background:** Type-1 diabetes mellitus (T1DM) is one of the most widespread chronic endocrine diseases among children and adolescents globally. Many barriers contribute to the challenge of adherence to treatment regimens among adolescents with T1DM. **Purpose:** This study explores the barriers that influence adherence to treatment regimens among adolescents with T1DM. **Methods:** Cross-sectional, descriptive, and exploratory designs were utilized. Convenience sampling was used to recruit 76 adolescents with T1DM from three hospitals in Jordan who were asked to complete the T1DM Parents' and Adolescents' Knowledge Questionnaire- related barriers section (T1DM-PAKQ). **Results:** Multiple regression revealed that six out of 12 factors significantly explained about 32% of the model. Barriers that significantly affect adherence to the treatment regimens among adolescents with T1DM include: psychological support ( $\beta = 0.998, t = 21.218, p < 0.001$ ), the cost of reaching the hospital ( $\beta = 0.961, t = 13.810, p < 0.001$ ), time available to communicate with the physician ( $\beta = 0.981, t = 16.524, p < 0.001$ ), overcrowding of the outpatient clinic ( $\beta = 0.921, t = 11.269, p < 0.001$ ), the hospital is far from home ( $\beta = 0.885, t = 10.221, p < 0.001$ ), sick leave from my school or workplace ( $\beta = 0.880, t = 9.939, p < 0.001$ ). **Conclusion:** For individuals with T1DM, adherence to a treatment regimen is crucial for managing the condition effectively and maintaining overall health. The findings from the present study suggest that adolescents' adherence to treatment regimens is influenced by barriers that could be managed. **Implications for Nursing:** Nurses in different positions should support adolescents with T1DM and assist them in adherence to treatment regimens.

**Keywords:** Adolescents, Type-1 diabetes mellitus, Barriers, Treatment regimen, Adherence.

### What does this paper add?

1. The current study explores the barriers that affect adherence to treatment regimens among adolescents with T1DM.
2. The current study's results should be considered in hospital policies to improve adherence among adolescents with T1DM.
3. The results of this study will help healthcare providers understand the barriers that affect the care

of adolescents with T1DM.

### Introduction

Type-1 diabetes mellitus (T1DM) is one of the most prevalent chronic endocrine diseases among children and adolescents in the world. In 2022, the International Diabetes Federation (IDF) documented over 1.52 million cases of T1DM among adolescents and children under 20 years of age (International Diabetes

Federation, 2022). The International Diabetes Federation (IDF) disclosed that in 2021, there were 192,500 cases of T1DM among children and adolescents under 19 years of age in the Middle East and North Africa. In Jordan, the IDF reported that 1,246 adolescents within the same age group were diagnosed with T1DM (International Diabetes Federation, 2021).

T1DM is a chronic disease that needs to be largely self-managed. Hence, the outcome of diabetes management is highly dependent on patient adherence to personal self-care behaviors (Robert et al., 2018). Adolescence represents a prominent phase in human development, marked by transitioning from childhood to adulthood. This period is characterized by notable changes in various aspects of life, including cognitive and emotional dimensions (World Health Organization, 2023). Adolescents with T1DM suffer additional stress, as potential complications may arise in the future (Hagger et al., 2016), such as diabetic ketoacidosis (DKA) and hypoglycemia (Center for Disease Control and Prevention, 2019; Lucier & Weinstock, 2023). In addition, treatment of T1DM requires insulin therapy at least twice daily with self-monitoring of glucose in the blood (Shojaeian, 2020).

Many non-adherent adolescents reported friends and family negatively affecting adherence, whereas adherents reported that good health care and social support systems promoted adherence (Al-Burno et al., 2022). Family support is considered a significant predictor of self-management among adolescents with T1DM (Lee et al., 2019). Almeida et al. (2020) reported that high quality of life and adherence to treatment plans among adolescents with T1DM are influenced by many factors, such as family conflict and the relationship between parents and adolescents with T1DM. In addition, psychological factors such as depression are associated with poor glycemic control (Alvarado et al., 2019; Hong et al., 2021; Lee et al., 2019). The absence of health insurance is another factor associated with poor glycated hemoglobin (HbA1c) levels and distress among adolescents with T1DM (Hong et al., 2021).

In a qualitative study, Momani et al. (2022) recognized barriers to adherence to treatment plans in Jordan, including the stigma related to T1DM and the insufficiency of educational programs. Due to the multi-faceted nature of treatment regimen adherence, mainly when dealing with adolescents, adherence becomes a complex and multi-factorial aspect. Accordingly, this

study was designed to explore barriers influencing adherence to treatment regimens among adolescents with T1DM in Jordan.

## **Methods**

### **Design**

Cross-sectional, descriptive, and exploratory designs were used to explore barriers influencing adherence to treatment regimens among adolescents with T1DM in Jordan.

### **Sample and Setting**

The participants were recruited from one governmental hospital and two university-affiliated hospitals, because these hospitals have diabetic clinics and electronic record systems, which helped follow up the patients. Convenience purposive sampling was used to select adolescents with T1DM. The inclusion criteria were adolescents with T1DM diagnosed with the disease for six years or less, aged between 13 and 18 years; otherwise, they were excluded. Calculations for sample size determination were utilized using G\*-power software, based on several parameters: a medium effect size (0.15), a significance level of 0.05, and a statistical power level of 0.8. Employing multiple regression analysis with 12 predictors, a minimum of 127 participants were deemed necessary.

### **Ethical Considerations**

Ethical approval was granted by the Institutional Review Board (IRB) at Jordan University of Science and Technology (#.2021/511). The aim, risk, significance, and benefits were explained to both participants and their parents. The parents signed the assent form with their adolescents, who agreed to participate. All participants were assured of anonymity and confidentiality of the information. Participants were assured that participation was voluntary and that if they withdrew, this would not affect their treatment. The researchers' contact numbers were provided to the participants.

### **Instrument**

The questionnaire included two sections. The first section comprises socio-demographic data such as (age and gender); and the last value of HbA1c (self-reported by adolescents with T1DM). The second section was part of the T1DM Parents' and Adolescents' Knowledge

Questionnaire (T1DM-PAKQ) related to the barriers to adherence to T1DM treatment regimen developed by Atiyeh (2020). The T1DM-PAKQ was used initially in Arabic. The scale content validity index revealed a value of 0.9 (Polit & Beck, 2014). The Kuder-Richardson (KR20) test was used to assess the reliability of the alpha coefficient, which was 0.792 (Kuder & Richardson, 1937). The current study used diabetes-related barriers that affect adolescents with T1DM's adherence to the treatment regimen (Atiyeh, 2020).

**Data Collection Procedure**

The data was collected over four months. Formal approval was obtained from the University's Institutional Review Boards (IRB) and the Ministry of Health to distribute the questionnaire. The researchers contacted diabetic health educators to get the contact information of the adolescents with T1DM. The researchers then contacted the participants and their parents by phone for a brief conversation to explain the purpose of the study. It was made clear that the participation is voluntary. Those who agreed to participate and met the inclusion criteria were sent a consent form *via* WhatsApp or e-mail based on their convenience and asked to sign the form and return it to the researchers. Later, the participants who agreed to participate were asked (adolescents) to complete an online questionnaire *via* WhatsApp or e-mail.

**Data Analysis**

Data was analyzed using the Statistical Package for Social Sciences (SPSS), version 23, for Windows. Descriptive statistics and regression analysis were used to analyze the data.

**Results**

**Participants**

A total of 256 adolescents with T1DM were approached by phone, whereby 250 participants agreed to participate. However, 162 were excluded, because the age was less than 13. Only 88 met the inclusion criteria. Of the 88 participants, only 76 completed the questionnaire, and the response rate was 86.4%.

**Demographic Data**

Seventy-six adolescents with T1DM completed the questionnaire; 55.3% were males, the mean age was 14.7 (SD=1.639), the mean duration since the first diagnosis with T1DM was 3.468 (2.04), and 60.55% of their parents had a high school education (Table 1).

**Adherence Variable**

Adherence to a treatment regimen is conceptually defined as the ability of a person to commit to his/her healthcare provider's recommendations, such as taking medication, following a healthy diet regimen, and making lifestyle changes (Chakrabarti, 2014). The current study measured HbA1c values to assess adolescent adherence. The most commonly declared value of HbA1c was between 8% and 10% (Table 1).

**Table 1. Adolescents' with type-1 diabetes socio and clinical characteristics**

<b>Age (M/SD):</b> 14.77 (1.639)	
<b>Duration (years ) since diagnosis (M/SD):</b> 3.468 (2.04)	
<b>Category</b>	<b>N (%)</b>
<b>Gender</b>	
Male	34 (44.75)
Female	42 (55.25)
<b>Place of residence</b>	
Inside city	57 (75)
Outside city	19 (25)
<b>Mother's/caregiver's education level</b>	
High school or less	46 (60.55)
Higher education	30 (39.45)
<b>Employment status of caregiver</b>	
Yes	23 (30.25)
No	54 (69.75)

HbA1c values	
5-6	10 (13.15)
6-7	13 (17.1)
7-8	6 (7.9)
8-9	14 (18.45)
9-10	11(14.45)
10-11	10 (13.15)
11-12	4 (5.25)
12-13	5 (6.6)
13-14	3 (4.05)
More than 14	0 (0)
Total	76 (100)

N= 76.

### Barriers Affecting Adherence to Treatment Regimen among Adolescents with T1DM Using Regression Coefficients

There were 12 predictors entered into the model. The model was significant and explained 32% (Adj. R-square= 0.322, F=3.973, P <0.001). Many predictors considered as barriers affect the adherence to treatment regimens among adolescents with T1DM. The highest

barrier was "no psychological support provided" ( $\beta = 0.998$ ,  $t = 21.218$ ,  $p < 0.001$ ), then "there is not enough time to communicate with the physician" ( $\beta = 0.981$ ,  $t = 16.524$ ,  $p < 0.001$ ) and" the cost of reaching the hospital" ( $\beta = 0.961$ ,  $t = 13.810$ ,  $p < 0.001$ ). The lowest barrier was " I have to take sick leave from my school or workplace ( $\beta = 0.880$ ,  $t = 9.939$ ,  $p < 0.001$ )," (Table 2).

**Table 2. Barriers affecting adherence to treatment regimen among adolescents with T1DM**

Barriers	B	95% CI	$\beta$	t	P
There is not enough time to communicate with the physician	0.234	(0.877-1.117)	0.981	16.524	0.000
The hospital is far from the home	0.236	(0.712-1.057)	0.885	10.221	0.000
The cost of reaching the hospital	0.210	(0.882-1.099)	0.961	13.810	0.000
Overcrowding of the outpatient clinic	0.244	(0.758-1.084)	0.921	11.269	0.000
I have to take sick leave from my school or workplace	0.262	(0.703-1.056)	0.880	9.939	0.000
No psychological support provided	0.191	(0.880-1.090)	0.998	21.218	0.000
Insulin types are not always covered by health insurance	-0.019	(-0.017-0.055)	-0.121	-1.051	0.297
Insulin strips are not covered by health insurance	-0.12	(-0.058-0.034)	-0.060	-0.515	0.608
HbA1c test covered by insurance is not always available	-0.014	(-0.016-0.030)	-0.074	-0.640	0.524
The physician did not listen to me effectively during the clinic visit	-0.012	(-0.035-0.021)	-0.059	-0.035	0.611
Busy parents/primary caregivers at follow-up times	-0.017	(-0.045-0.010)	-0.146	-1.267	0.209
Healthcare providers are not always available to answer questions when needed	-0.010	(-0.037-0.025)	-0.044	-3.037	0.706

Model summary:  $R^2 = 0.431$ , Adj.  $R^2 = 0.322$ , F=3.973,  $P < 0.001$ , N=76.

Note: B: unstandardized beta; CI=confidence interval for B;  $\beta$ =standardized beta.

### Discussion

To the authors' knowledge, this study is the first in Jordan among adolescents with T1DM. The current study revealed that many barriers affect adherence among adolescents with T1DM and are associated with high levels of HbA1c. Barriers include taking sick leave from school or the workplace for physician appointments, busy parents, limited time to communicate with physicians, and crowded outpatient

clinics. Adolescents with T1DM should thoroughly understand their condition, including the importance of monitoring blood sugar levels, administering insulin, and following a healthy lifestyle. Education can empower individuals to take control of their health. Rawdon et al. found that good communication between adolescents with T1DM, their parents, and healthcare providers during physician follow-up appointments positively affects adherence to treatment plans and

diabetic self-management among adolescents with T1DM (Rawdon et al., 2020). Previous research results revealed that participants wanted information and diabetes self-management education (DSME) to be tailored to their circumstances (Al-Burno et al., 2022). Supportive communication from healthcare providers and parents has positively impacted adherence among adolescents with T1DM (Goethals et al., 2020).

Fostering a supportive environment for adolescents with T1DM, whether through family, friends, healthcare providers, or support groups, can provide encouragement and motivation for adherence. Dybdal et al. found that adolescents who are diagnosed with T1DM have a high risk of complaining from psychological problems, such as anxiety and mood disorder (Dybdal et al., 2018). In the current study, the lack of psychological support is considered a barrier to adherence to the treatment regimen. Rechenberg et al. emphasized that anxiety is associated with poor HbA1c among youth with T1DM (Rechenberg et al., 2017), and depression is also associated with poor HbA1c (Alvarado et al., 2019). In the same realm, another study found that family support significantly predicts self-management among adolescents with T1DM (Lee et al., 2019). Busy parents are one of the barriers that affect adherence to treatment regimens among adolescents with T1DM. Previous studies revealed that inadequate attention from parents to adolescents with T1DM was associated with poor adherence among adolescents with T1DM (Goethals et al., 2018; Turner et al., 2018).

Addressing barriers to healthcare access can improve treatment adherence. The distance between the hospital and home was one of the factors that affected adherence to treatment regimens among adolescents with T1DM. In Britain, it was found that pediatrics with T1DM who traveled for a short time were associated with low levels of HbA1c (Fox et al., 2018). Also, the cost of transportation, insulin treatment, and insulin strips are essential barriers that affect treatment plans among adolescents with T1DM. In the United States, it was found that the cost of treatment among adolescents and children with T1DM increased annually for different types of care, such as insulin treatment, diabetes supply, and diabetes technology (Crossen et al., 2020).

### **Implications for Nursing**

Exploring the barriers to treatment regimens among adolescents with T1DM has crucial implications for

nursing practice. Nurses are essential in patient education, organizing crowded outpatient clinics, and improving communication between healthcare providers and adolescents with T1DM. Nurse educators could communicate with adolescents with T1DM outside clinics through applications or mobile phones for any inquiry, and that could improve psychological support among adolescents with T1DM. Also, nurses' communication with schools to highlight the importance of adhering to appointments will enhance adherence to treatment regimens among adolescents with T1DM. In addition, nursing administration can add new strategies to improve care delivery and education for parents and adolescents with T1DM in the form of lectures.

### **Limitations**

The study results should take into consideration the limitations of the study. The limitations include the small sample size, which was difficult to overcome due to recruitment difficulties, and thus, the findings can be taken as a pilot for future study. Future studies should have larger samples, looking for other factors influencing treatment adherence to regimens. The second limitation lies in the self-reporting method, potentially leading to bias (Demetriou et al., 2015). The third limitation is the cross-sectional design (Wang & Cheng, 2020). Future studies should have a longitudinal design to monitor treatment adherence.

### **Conclusions and Recommendations**

In conclusion, this study's results revealed different barriers affecting adherence to treatment regimens among adolescents with T1DM. Maintaining a proactive approach to managing T1DM among adolescents can enhance their adherence to treatment regimens and improve their quality of life. Approaches as education and awareness: public campaigns to raise awareness about T1DM, its management, and the importance of adherence to treatment, help reduce stigma, and increase understanding.

Training programs for healthcare providers to enhance their knowledge and skills in managing T1DM and improve communication are needed. One of the approaches used is telemedicine and remote monitoring. Patient self-care management could be improved by providing proper, cost-effective, timely, and accessible information, which can be achieved using telemedicine as a mobile health education application (Akhu-Zaheya

et al., 2023). Investing in telemedicine and remote monitoring technologies to facilitate virtual consultations, remote monitoring of blood sugar levels, and medication management are essential to improve adherence. These technologies can improve access to care and support adherence, especially in remote or underserved areas with difficulty in accessing crowded clinics. A supportive environment promotes adherence to treatment for individuals with T1DM, ultimately improving health outcomes and quality of life for adolescents with T1DM.

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## Conflict of Interests

The researchers have no conflict of interests to declare.

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