

## Adherence to the management of type i diabetes among Palestinian patients in Nablus city: a cross-sectional study

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### ABSTRACT

The purpose of this study is to investigate the adherence to the management of Type I Diabetes and to investigate factors associated with non-adherence among Palestinian Type 1 Diabetes patients. One hundred and twenty-six patients diagnosed with Type 1 Diabetes were enrolled in an observational cross-sectional study. Diabetes self-care adherence was measured using the Self Care Inventory (SCI). The patients were recruited from a diabetes clinic in Nablus city in Palestine. One-way ANOVA test and simple linear regressions were used in the statistical analysis. Participants age ranged from 3-43 years; 56% of them were females. The mean age at diagnosis for them was 10 years (+/-6.25). The mean glycosylated hemoglobin (A1C) was 9 +/-2.32. 66% of patients reported significant non-adherence to glucose testing, 89% reported non-adherence to diet recommendations, 79% reported non-adherence to exercise, and 21% reported non-adherence to administering insulin on time. Age ( $r = 0.29$ ,  $P < 0.05$ ), A1C ( $r = 0.21$ ,  $P < 0.05$ ), sex ( $P < 0.05$ ), and patient educational level ( $P < 0.05$ ) were significantly related to adherence score. Adherence to treatment among patients with Type 1 Diabetes is poor and is associated with age, sex, A1C, and patient educational level. Designed education programs should be implemented among patients with Type 1 Diabetes, which address the importance of adherence to the management of the diseases. More strategies should focus on monitoring the diet and insulin administration.

**Keywords:** Type 1 Diabetes; Adherence; Self Care Inventory; Palestine.

### INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is a chronic illness previously called “insulin dependent diabetes” or “juvenile-onset diabetes,” occurs due to cellular-mediated autoimmune destruction of the pancreatic b-cells. T1DM can occur at any age. However, three-quarters of all cases of T1DM are diagnosed in individuals younger than 18 [1].

The management of type 1 diabetes includes a combination of insulin medications, dietary modifications and exercise that all should be balanced and frequently evaluated with feedback from blood glucose monitoring to achieve glycemic control [2].

Adherence has been defined as the extent to which a person’s behavior (taking medication, making lifestyle modifications) corresponds with the agreed recommendations from a health care provider [3]. It is the “active, voluntary and collaborative involvement

of the patients in a mutually acceptable course of behavior to produce a therapeutic result” [4].

Diabetes is considered to be psychologically and behaviorally demanding chronic disease, and adherence to diabetes regimens is often problematic for patients of all ages [5, 6]. Non-adherent patients are at risk for significant medical complications including diabetic ketoacidosis (DKA), neuropathy, nephropathy, retinopathy, and cardiovascular diseases. Although achieving good glycemic control helps prevent these complications, many patients fail to achieve good control, mostly due to poor adherence [7, 8].

Non-adherence results also in increased morbidity and mortality, excessive use of healthcare services, and negative impact on clinical decisions made by health care providers such as prescribing incorrect insulin doses [9, 10].

Adherence is a complex behavioral process determined by several interacting factors [3]. In general, the more complex the treatment regimen, the less likely the patient will be to follow it. Age, gender, stress, disease duration, social support, and quality of the relationship between patients and providers can affect adherence in different ways. Furthermore, economic, political, geographical, and cultural factors are also involved.

Few studies have investigated adherence among diabetic patients in Palestine but mainly amount focused on Type 2 diabetes or included all diabetic patients regardless of the type of diabetes. No previous study was performed among T1DM patients alone [11, 12].

Many studies have found that T1DM children are more likely to be adherent than adolescents. Although developing adequate treatment-related behaviors may be particularly important in adolescence, as it marks a critical time for the development of disease management behaviors that may persist through adulthood, adherence and glycemic control are found to be worsening across adolescence [13, 14].

This issue can be explained by a number of factors including heightened concerns about social context and peers, premature shift in responsibility for management from parents to teens, incomplete knowledge and understanding of treatment regimens and future health risks, fatigue from care of a chronic illness ('diabetes burnout'), and physiological changes that lead to greater insulin resistance during puberty [15]. In addition, adherence will likely grow more difficult as providers intensify regimens to improve glycemic control for better outcomes with the inadvertent result of increasing burden and reducing health-promoting behaviors [16, 17].

Accurate measurement of medication adherence is necessary for effective management of diabetes. However, there are no gold standard measurements that allow comparison to be made between studies and across populations [18].

Most studies regarding non-adherence to treatment were done in developed countries, where the health care delivery system is dif-

ferent from developing countries. In developing countries, only few studies were conducted [19], this study was therefore carried out among a sample of T1DM patients to determine the adherence to prescribed treatment regimen and factors associated with non-adherence. It exclusively includes T1DM patients which usually manifests at a younger age. It aims to determine the socio-demographic characteristics for non-adherent patients so that these patients can be recognized by health care providers and have better care to improve their quality of life.

## METHODS

### *Study design*

Cross sectional study conducted among T1DM patients attending diabetes clinics of the Ministry of health in Nablus city. A convenient sample was taken over a period of four months from October 2016 to January 2017.

### *Participants*

The study was conducted on Monday each week as it is the day specified for T1DM patients at Al-Makhfia healthcare center. All participants met the following inclusion criteria: 1) T1DM patients or parents accompanying their children attending ministry of health diabetes clinics in Nablus city, 2) currently insulin dependent, and 3) at least 1-year duration of the disease to decrease the potential impact of residual insulin production by the pancreas "honey-moon" period that will affect blood glucose level. Exclusion criteria were: 1) patients who refused to participate, 2) patients diagnosed with mental retardation, and 3) candidates who were included in the pilot study.

One hundred and forty-six patients were addressed (72.2% of all T1DM patients who were registered in diabetes clinics). Of them, 126 met the inclusion criteria and agreed to participate. The remaining 20 patients were excluded (2 patients refused to participate, and 18 patients didn't meet the inclusion criteria)

## Tools

### The Self-Care Inventory (SCI)

A 14-item scale that measures adherence to treatment among T1DM patients. Items are rated on a 5-point Likert-type scale (1: never do it, 3: follow recommendations about 50% of the time, 5: always do this as recommended without fail). The SCI measures different aspects of diabetes self-management, including glucose testing and recording, administration of insulin, maintenance of a regular meal plan, and exercise [20]. The questionnaire was translated into Arabic, which is the native language in Palestine. The SCI has been reported to have adequate internal consistency (Cronbach's alpha = 0.80) [21], the measure was also found to be internally consistent with our sample, Cronbach = 0.737.

### Glycosylated hemoglobin (A1C)

A1C was used as an index of the patient's mean blood glucose level for the past 3 months. It reflects average plasma glucose over the previous eight to 12 weeks. It can be performed at any time of the day and does not require any special preparation such as fasting. These properties have made it the preferred test for assessing glycemic control in diabetic patients [22, 23]. The Endocrine Clinic at the Alfred I. DuPont Hospital classifies patients into four groups based on level of control; Level 1, "well-controlled," includes individuals with A1C < 7.3%, indicating average blood glucose levels between 100 and 180. Level 2, "good to fair control," includes individuals with A1C of 7.4-9.3%, indicating average blood glucose levels of 180-250. Level 3, "fair to poor control," is used to describe individuals with A1C of 9.4-11.3%, indicating average blood glucose levels of 250-300. Level 4, "poor control," describes patients with A1C values > 11.4%, indicating average blood glucose levels greater than 300 [24].

### Procedure

Patients or parents of the children attending the diabetes clinic for routine medical assessment were interviewed and questionnaires were filled. The study was approved by the Institutional Review Board, and the patients or the parents were told that their

participation in the study was voluntary. For more precise results, a pilot study was conducted as this was the first time the questionnaire used in Palestine.

### Statistical analysis

Survey scores were converted to a 0 to 100-point scale for ease of interpretation by subtracting the minimum possible item score from the individual's averaged raw score, multiplied by 100. This value was then divided by the difference of the minimum possible item score subtracted from the maximum possible item score ( $[\text{mean raw score} - \text{minimum}] / (\text{maximum} - \text{minimum})$ ) [25]. All questions were calculated in this equation except for questions 3 and 12.

Analyses were performed using SPSS software version 21 (SPSS Inc., Chicago, Illinois, USA). A  $p$ -value of < 0.05 was considered statistically significant. Descriptive statistics were used to summarize socio-demographic and clinical characteristics of the patients. Categorical values were expressed as frequency and percentage, whereas numerical values were expressed as mean  $\pm$  SD. Normality test for SCI score was performed by using Shapiro and Kolmogorov-Smirnov tests, and it was normally distributed. Univariate analysis between the dependent variable (adherence) and the categorical independent variables (patients' socio-demographic and clinical characteristics) were examined using one-way ANOVA, while simple linear regression was used to examine the relationship between the dependent variable (adherence) and the continuous independent variables (age, A1C, and duration of the disease).

## RESULTS

Participants' age ranged from 3-43 years, nearly 56% of them were females, and the mean age at diagnosis was 10 years ( $\pm 6.25$ ). A1C mean was  $9 \pm 2.32$ . About three quarters of the patients and about 50% of parents accompanying their children did not reach tertiary education. The socio-demographic and clinical characteristics are presented in table 1.

**Table (1):** Sample characteristics.

Characteristic		N (%)
Age/years (mean $\pm$ SD)	18.4 $\pm$ 8.9	
Sex	Male	55 (43.7)
	Female	71 (56.3)
Patient educational level	Kindergarten	9 (7.1)
	Primary	51 (40.5)
	Secondary	31 (24.6)
	College	35 (27.8)
Parents' educational level	Illiterate	1 (1.6)
	Primary	19 (29.7)
	Secondary	30 (46.9)
	College	14 (21.9)
Marital status	Single	105(83.3)
	Married	21 (16.7)
Place of residence	City	49 (38.9)
	Town	74 (58.7)
	Camp	3 (2.4)
Center	Governmental	103(81.7)
	Governmental & private	21(16.7)
	Governmental & UNRWA	2(1.6)
Disease duration in years (mean $\pm$ SD)	8.4 $\pm$ 6.41	
HbA1c % (mean $\pm$ SD)	9.07 $\pm$ 2.63	

Abbreviations: SD, Standard Deviation; UNRWA, United Nations Relief and Works Agency; HbA1c, Glycated haemoglobin.

One-way ANOVA and linear regression analysis were conducted to test group difference between the dependent variable (SCI score) and the independent variables. Significant group differences were found on age ( $r$

$= 0.29$ ,  $p < 0.05$ ), A1C ( $r = 0.21$ ,  $p < 0.05$ ), sex ( $p < 0.05$ ), and patient educational level ( $p < 0.05$ ). Effects of socio-demographic and clinical characteristics on adherence are summarized in Table 2.

**Table (2):** Effects of socio-demographic and clinical characteristics on adherence.

Characteristic		SCI score (mean $\pm$ SD)	<i>p</i> -value
Age	Children	61.33 $\pm$ 11.25	0.01
	Adolescents	52.06 $\pm$ 16.83	
	Adults	46.64 $\pm$ 13.81	
Sex	Male	48.28 $\pm$ 17.06	0.04
	Female	54.04 $\pm$ 13.94	
Patient educational level	Kindergarten	57.42 $\pm$ 10.48	0.02
	Primary	55.71 $\pm$ 15.8	
	Secondary	49.13 $\pm$ 13.77	
	College	46.05 $\pm$ 16.13	
Parents' educational level	Illiterate	33.25	0.25
	Primary	56.11 $\pm$ 14.24	
	Secondary	53.62 $\pm$ 15.22	
	College	59.96 $\pm$ 12.89	
Marital status	Single	52.12 $\pm$ 16.09	0.35
	Married	48.59 $\pm$ 12.62	

Characteristic		SCI score (mean ± SD)	p-value
Place of residence	City	53.98±15.98	0.20
	Town	49.57±15.17	
	Camp	59.75±15.72	
Center	Governmental	50.38±15.16	0.17
	Governmental & Private	56.02±17.35	
	Governmental & UNRWA	63.63±4.42	
Disease duration (in years)	0-10	52.78±15.54	0.22
	11-20	47.52±15.75	
	21-30	53.38±14.53	
HbA1c	≤7.3	56.44±17.62	0.02
	7.4-9.3	52.48±12.01	
	9.4-11.3	48.61±15.83	
	≥11.4	47.21±18.94	

Table 3 represents the mean and SD for each question of SCI that were used to calculate the total score.

**Table (3):** Adherence to treatment according to Self-Care Inventory SCI.

Blood glucose regulation		Mean ±SD	Median
Blood glucose regulation	Glucose testing	3.00 ± 1.44	2
	Glucose recording	2.12 ± 1.53	1
	Adjust insulin based on blood	3.37 ± 1.56	4
Insulin and food regulation	Administer insulin at right time	4.17 ± 1.03	4
	Eat proper food/stick to diet	1.77 ± 1.09	1
	Eat meals on time	3.11 ± 1.39	3
	Eat regular snacks	3.09 ± 1.44	3
	Exercise		
Exercise	Exercise regularly	2.61 ± 1.23	3
	Exercise strenuously	1.29 ± 0.56	1
Emergency precaution			
	Carry sugar	3.28 ± 1.69	4
Other	Come in for appointments	4.00 ± 1.28	5

SCI: (1: never do it, 3: follow recommendations about 50% of the time, 5: always do this as recommended without fail).

Moreover, as shown in table 4, approximately 66% of patients reported significant non-adherence to glucose testing, 89% reported non-adherence to diet recommenda-

tions, 79% reported non-adherence to exercise, and 21% reported non-adherence to administering insulin at time.

**Table (4):** Frequency and percentage of adherence to treatment according to Self-Care Inventory SCI.

	Never do it N <sup>a</sup> (%)	Mostly not N (%)	Fifty-fifty N (%)	Usually N (%)	Always N (%)
Glucose testing	14 (11.1)	51 (40.5)	18 (14.3)	6 (4.8)	37 (29.4)
Administer insulin at right time	3 (2.4)	8 (6.3)	16 (12.7)	37 (29.4)	62 (49.2)

	Never do it N <sup>a</sup> (%)	Mostly not N (%)	Fifty-fifty N (%)	Usually N (%)	Always N (%)
Eating proper food/stick to diet	74 (58.7)	23 (18.3)	15 (11.9)	12 (9.5)	2 (1.6)
Exercise	29 (23)	29 (23)	42 (33.3)	14 (11.1)	12 (9.5)

a: frequency

## DISCUSSION

To our knowledge, this is the first study to investigate adherence among T1DM patients in Palestine. Non adherence to treatment is very prevalent in patients with diabetes, and varies according to the type of non-adherence that is measured. Accordingly, prevalence rates should be assessed by type of behavior. This study was carried out to explore the adherence to treatment among T1DM patients in Nablus city and factors associated with non-adherence.

Non-adherence was higher to diet and exercise than to medication. This result agrees with that of Broadbent et al and Ruggiero et al. who reported that both T1DM and Type 2 diabetes have rates of adherence to diet and exercise that are lower to that of medications [26]. High rates of adherence were found for coming in for clinic appointments and carrying quick-acting sugars to treat reactions. Hendrychova et al by using the SCI-R questionnaire have reported that patients were having high adherence rates in these areas, too [27].

Patients with higher adherence rates had significantly lower A1C values. Sex was found to be significantly associated with adherence. Females had higher rates of adherence than males. Furthermore, age was found to be a significant determinant of adherence, the younger the patients, the better the adherence to self-management. This agrees with that of La Greca et al who reported that children are more likely to be adherent than older patients [20]. This study showed that patients with higher educational level had poorer adherence to self-management than less educated patients. Although not significant, but children accompanied by their parents who had tertiary education were associated with higher adherence than children accompanied by parents with lower levels of education.

In this study, disease duration also was not significantly associated with adherence. This is in contrast to other studies, which found that disease duration had a negative relationship with adherence, the longer the duration is, the worse the adherence is [28, 29].

Ketone testing question was excluded when the total SCI score was calculated because patients were not recommended to do it when they were hyperglycemic. Although it was done routinely every 6 months for all patients, they did not know about it.

## LIMITATIONS

The present study findings must be interpreted cautiously when generalized to all T1DM patients in Palestine because it was limited to one city. In addition, results to be interpreted cautiously the correlations because of its cross sectional design.

## CONCLUSION AND IMPLICATIONS

It is important to assess the prevalence rates of non-adherence to treatment in T1DM patients by the type of behavior. This study showed that the prevalence rates were generally high. Adherence was worse for diet and exercise than that to medications. Also, non-adherence was significantly associated with sex of the patient, A1C level, and patient educational level.

Several interventions to improve patients' adherence to self-management actions should be implemented. On the individual level, patient education and increasing awareness about the positive effects of adherence on the quality of health is important. On the health provider level, physicians and nurses should be trained to provide patient-centered care; this may encourage patients to adhere more to self-management behaviors. On the system level, more financial support should be provided to the health sector to allow patients to receive better healthcare, A1C should be done more frequently for patients with poor glycemic control, and a

dietitian should be employed in the governmental diabetes clinics to provide patients with the suitable diet recommendations and help them achieve better adherence. These interventions will result in short term improvement in adherence rates on one hand, and delay and reduce long term complications in these patients on the other hand.

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#### DISCLOSURE AND ETHICAL APPROVAL

The authors report no conflict of interests in this work. The study was approved by An-Najah National University IRB

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