

# The Role of the Health Literacy Levels of Parents in the Management of Type 1 Diabetes in Children and Adolescents

## Çocuk ve Ergenlerde Tip 1 Diyabet Yönetiminde Ebeveynlerin Sağlık Okuryazarlık Düzeylerinin Rolü

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### Abstract

**Introduction:** Health literacy is defined as the extent to which individuals can find, understand, and utilize information and amenities to inform health-related decisions and actions for themselves and others. Diabetes regulation in children and adolescents is an issue that requires family participation and supervision. This study was conducted to investigate the relationship between the glycemic outcomes of children diagnosed with type 1 diabetes and the health literacy levels of their parents.

**Materials and Methods:** Parents of 103 children aged 2-18 years who were given the diagnosis of type 1 diabetes at least 6 months ago participated in this study. The relationships between the health literacy levels of the participants and their socio-demographic data and the glycemic control results of their children were investigated.

**Results:** In our study, Turkish Health Literacy Scale (TSOY-32) scores differed significantly based on the educational statuses of the parents ( $p=0.045$ ) and according to the number of hospitalizations due to ketoacidosis ( $p=0.039$ ). There was a negative and statistically significant relationship between HbA1c and TSOY-32 in the parents of children in the 2-10 age group ( $\rho=-0.275$ ;  $p=0.046$ ). On the other hand, no statistically significant relationship was identified between HbA1c and TSOY-32 in the group concerning children over 10 years of age ( $\rho=-0.098$ ;  $p=0.497$ ). There was no statistically significant difference between monthly income levels (income less than expenses, income equals expenses, income more than expenses) and HbA1c values and levels ( $p=0.149$ ).

**Conclusion:** The data collected in this study highlighted the role and importance of parental health literacy levels in the glycemic control-related outcomes of children with type 1 diabetes. The health literacy levels of parents should be evaluated and supported for effective diabetes management.

### Öz

**Giriş:** Sağlık okuryazarlığı, bireylerin kendileri ve başkaları için sağlıklı ilgili kararları ve eylemleri için bilgi ve hizmetleri bulma, anlama ve kullanma becerisine sahip olma derecesidir. Çocuk ve ergenlerde diyabetin regülasyonu aile katılımını ve denetimini gerektiren bir konudur. Bu çalışmada tip 1 diyabetli çocukların glisemik sonuçları ile ebeveynlerinin sağlık okuryazarlık düzeyleri arasındaki ilişki araştırılmıştır.

### Keywords

Health literacy, type 1 diabetes, glycemic control, glycosylated hemoglobin

### Anahtar kelimeler

Sağlık okuryazarlığı, tip 1 diyabet, glisemik kontrol, glikozile hemoglobin

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**Gereç ve Yöntem:** Bu çalışmaya en az 6 aydır tip 1 diyabet tanısı ile takipli, 2-18 yaş arası 103 çocuğun ebeveynleri katılmıştır. Katılımcıların sağlık okuryazarlık düzeyleri ile sosyo-demografik verileri ve çocuklarının glisemik kontrol sonuçları arasındaki ilişkiler incelenmiştir.

**Bulgular:** Çalışmamızda anne-baba eğitim durumuna göre ve ketoasidoz nedeniyle hastaneye yatış sayısına göre Türk Sağlık Okuryazarlığı Ölçeği (TSOY-32) puanları anlamlı farklılık gösteriyordu ( $p=0,045$ ,  $p=0,039$ ). Yaşları 2-10 yıl arasında değişen gruptaki çocukların ebeveynlerinde HbA1c ile TSOY-32 arasında negatif ve istatistiksel olarak anlamlı bir ilişki vardı ( $\rho=-0,275$ ;  $p=0,046$ ). Yaşı 10 yıl ve üzeri olan çocuklarda ise HbA1c ile TSOY-32 arasında istatistiksel olarak anlamlı bir ilişki saptanmadı ( $\rho=-0,098$ ;  $p=0,497$ ). Aylık gelir düzeyleri (gelir giderden az, gelir eşittir gider, gelir giderden fazla) ile HbA1c değerleri ve düzeyleri arasında istatistiksel olarak anlamlı fark yoktu ( $p=0,149$ ).

**Sonuç:** Çalışmamızın sonuçları tip 1 diyabetli çocukların glisemik sonuçlarında ebeveynlerin sağlık okuryazarlığının rolünü ve önemini vurgulamıştır. Etkili diyabet yönetimi için ebeveynlerin sağlık okuryazarlık düzeyleri değerlendirilmeli ve desteklenmelidir.

## Introduction

Type 1 diabetes (T1D) is one of the most commonly encountered metabolic diseases in childhood. Data reported in large epidemiological studies have indicated that the incidence of T1D has been rising at a rate of 2-5% worldwide (1). Cases with T1D need lifelong medical care, and if optimal blood glucose regulation is not achieved (HbA1c  $<7.5\%$ ), serious complications such as retinopathy, nephropathy, or neuropathy may develop (2). Diabetes regulation in children and adolescents is an issue that requires family participation and supervision, and diabetes management can be much more difficult and complicated in this age group. Parents are responsible for dealing with the reality of severe responses to insulin, medical complications that are and will be encountered, recurrent hospital admissions, and the child's adherence to daily therapy (3). The explanation of health literacy (HL) was revised in August 2020, and the new definition focuses on the ability of individuals to use health-related information rather than just comprehend such information. Personal health literacy is the extent to which people can find, understand, and utilize information and amenities to inform health-related decisions and behaviors for themselves and others (4). Studies in adult populations have reported an elevated possibility of hospitalization and higher healthcare expenditures independently related to HL and that HL levels are associated with lower HbA1c values regardless of educational background in adults (5,6). According to the data of the World Diabetes Federation, it is estimated that the number of newly diagnosed cases in children aged 0-14 in Türkiye increased by 83%, and the number of children with T1D rose by 148% from 2000 to 2021 (7). According to the data published by the Turkish Ministry of Health, 7

out of 10 people in Türkiye have low levels of HL, and this is associated with an increase in chronic diseases (8). Health literacy and childhood diabetes emerge as important issues that need to be emphasized in Türkiye. In our study, we aimed to investigate the role of the health literacy levels of parents in the management of T1D in children and adolescents.

## Materials and Methods

Parents who had their children regularly followed up for diabetes in a pediatric endocrinology clinic participated in this study. One hundred and three volunteers were included in the study using an online questionnaire. The inclusion criteria for the study were determined as being over the age of 18, being the mother or father of a child aged 2-18 diagnosed with T1D at least 6 months ago, having the ability to speak, read, and write in Turkish for the informed consent form and related assessment scales, voluntarily agreeing to take part in the study, and providing written informed consent. The questionnaire applied to the participants consisted of two parts. In the first part, the age, gender, income status, marital status, education level, the age and sex of the child with diabetes, the HbA1c value of the child checked in the last 3 months, and the number of hospitalizations experienced by the child due to ketoacidosis were questioned. The children of the parents who were included in the study divided into three groups based on their HbA1c levels as good ( $<7.5\%$ ), moderate (7.5-9%), and poor ( $>9\%$ ) glycemic control based on the recommendations of the American Diabetes Association/International Diabetes Federation/International Society for Pediatric and Adolescent Diabetes (2). In the second part, the Turkish Health Literacy Scale (TSOY-32) was used as a health literacy measurement tool (9). Each item in

the 32-item questionnaire is evaluated with a 5-point Likert-type scale. The response options of each item are scored as 1: Very easy, 2: Easy, 3: Difficult, 4: Very difficult, or 5: I have no idea. The parents were asked to mark the most suitable option for themselves. The study was started after obtaining the approval of the Beykent University Ethics Committee for Social Sciences and Humanities (decision no: 237, date: 01.07.2022). The study was conducted between July and September 2022.

### Statistical Analysis

The data that were collected in this study were analyzed using the IBM SPSS Statistics (IBM Corp., Armonk, New York, USA) program. Descriptive statistics are presented in frequency (n), percentage (%), mean  $\pm$  standard deviation (mean  $\pm$  SD), median (M), minimum (min), maximum (max), and interquartile range (IQR) values. The normal distribution of the numeric data was tested with the Shapiro-Wilk test. The Kruskal-Wallis H test was utilized for the comparison of the numeric variables based on groups with more than two categories. If the Kruskal-Wallis H test result was found to be significant, multiple comparisons were made with the Dunn-Bonferroni test. The relationships between the numeric variables were analyzed with the Spearman correlation coefficient. Fisher's exact test was used to test the relationships between the categorical variables. A p value of  $<0.05$  was accepted to show statistical significance.

### Results

The general characteristics of the parents in the sample and their children are summarized in Table 1.

The health literacy levels of the participants were measured according to their Turkish Health Literacy Scale scores, and the outcomes of these measurements are summarized in Table 2.

In our study, TSOY-32 scores differed significantly based on the educational statuses of the parents ( $p=0.045$ ). The TSOY-32 scores of the participants who were university graduates were significantly higher than the scores of those who were middle school graduates. Additionally, the TSOY-32 scores of the participants differed significantly according to the number of hospitalizations of their children due to ketoacidosis ( $p=0.039$ ). The TSOY-32 scores

Table 1. Participant characteristics	
Variables	Statistics
Age, (years)	
$\bar{x} \pm SD$	39.7 $\pm$ 7.1
M (min-max)	40.0 (25.0-60.0)
Gender, n (%)	
Male	19 (18.4)
Female	84 (81.6)
Marital status, n (%)	
Single	5 (4.9)
Married	98 (95.1)
Education, n (%)	
Primary school	35 (34.0)
Middle school	23 (22.3)
High school	21 (20.4)
University	24 (23.3)
Monthly income, n (%)	
Income less than expenses	46 (44.7)
Income equals expenses	49 (47.6)
Income more than expenses	8 (7.8)
Children's age, (years)	
$\bar{x} \pm SD$	10.4 $\pm$ 3.8
M (min-max)	10.0 (2.0-17.0)
Children's sex, n (%)	
Girl	53 (51.5)
Boy	50 (48.5)
Diabetes duration, (months)	
M (min-max)	24 (6-132)
Number of hospitalizations, n (%)	
None	76 (73.8)
One	13 (12.6)
Two	11 (10.7)
Three or more	3 (2.9)
HbA1c (%)	
$\bar{x} \pm SD$	8.24 $\pm$ 1.79
M (min-max)	7.80 (6.2-15.0)
Diabetes regulation, n (%)	
Good	42 (40.8)
Moderate	36 (35.0)
Poor metabolic control	25 (24.2)
$\bar{x}$ : Mean, SD: Standard deviation, M: Median, Min: Minimum, Max: Maximum	

of the parents whose children had three or more hospitalizations due to ketoacidosis were significantly lower compared to the scores of those whose children had no hospitalizations or had been hospitalized twice. The relationships between the TSOY-32 scores of the parents and their educational status, monthly income, gender, and the frequency of hospitalization of their children due to diabetic ketoacidosis are summarized in Table 3.

In our study, when the cases were grouped according to their TSOY-32 scores, the groups did not show any statistically significant difference from each other regarding HbA1c, diabetes regulation, educational status, monthly income, and number of hospitalizations (Table 4).

There was a negative and statistically significant relationship between HbA1c and TSOY-32 in the parents of children in the 2-10 age group ( $\rho=-0.275$ ;

Health literacy level	n	%
Inadequate	12	11.7
Problematic - limited	34	33.0
Sufficient	34	33.0
Excellent	23	22.3
Total	103	100.0

	TSOY-32	Test statistics	
	M (IQR)	Test value <sup>‡</sup>	p-value
<b>Education status</b>			
Primary school	33.8 (11.5) <sup>ab</sup>	<b>8.073</b>	<b>0.045</b>
Middle school	32.3 (13.4) <sup>a</sup>		
High school	33.9 (16.4) <sup>ab</sup>		
University	36.9 (15.2) <sup>b</sup>		
<b>Monthly income, n (%)</b>			
Income less than expenses	31.7 (12.5)	4.404	0.111
Income equals expenses	33.9 (13.0)		
Income more than expenses	38.5 (13.6)		
<b>Number of hospitalizations, n (%)</b>			
None	34.4 (12.8) <sup>a</sup>	<b>8.369</b>	<b>0.039</b>
One	29.6 (14.3) <sup>ab</sup>		
Two	36.7 (8.1) <sup>a</sup>		
Three or more	26.5 (4.5) <sup>b</sup>		
<b>Diabetes regulation n (%)</b>			
Good	34.4 (14.3)	2.813	0.215
Moderate	33.3 (6.6)		
Poor metabolic control	34.9 (12.7)		
<b>Gender n</b>			
Men (n=19)	32.8 (7.8)	0.617	0.537
Women (n=84)	33.8 (13.5)		

M: Median, IQR: Interquartile range, <sup>‡</sup>: Kruskal-Wallis Analysis superscripts a and b show the TSOY-32 score differences between categories. No statistically significant difference is found in the TSOY-32 scores between the categories with the same superscripts. Categories containing the superscript "ab" are no different from other groups.

Table 4. Results of comparison of HbA1c by health literacy (TSOY-32) classes, educational status, monthly income status, and frequency of hospitalization

	TSOY-32				Test statistic	
	Insufficient n=12	Problematic limited n=33	Sufficient n=35	Excellent n=23	Test value	p-value
HbA1c (%)						
M (IQR)	8.75 (1.28)	7.70 (2.35)	7.70 (2.30)	7.30 (1.80)	5.704 <sup>‡</sup>	0.127
Diabetes regulation n (%)						
Good	2 (4.8)	15 (35.7)	13 (31.0)	12 (28.6)	5.082	0.539
Moderate	6 (16.7)	11 (30.6)	12 (33.3)	7 (19.4)		
Poor metabolic control	4 (16.0)	7 (28.0)	10 (40.0)	4 (16.0)		
Education status						
Primary school	4 (11.4)	11 (31.4)	13 (37.1)	7 (20.0)	9.649 <sup>‡</sup>	0.375
Middle school	5 (21.7)	8 (34.8)	8 (34.8)	2 (8.7)		
High school	3 (14.3)	6 (28.6)	6 (28.6)	6 (28.6)		
University	0 (0.0)	8 (33.3)	8 (33.3)	8 (33.3)		
Monthly income, n (%)						
Income less than expenses	6 (13.0)	19 (41.3)	13 (28.3)	8 (17.4)	4.933 <sup>‡</sup>	0.515
Income equals expenses	6 (12.2)	12 (24.5)	18 (36.7)	13 (26.5)		
Income more than expenses	0 (0.0)	2 (25.0)	4 (50.0)	2 (25.0)		
Number of hospitalizations, n (%)						
None	6 (7.9)	25 (32.9)	25 (32.9)	20 (26.3)	12.660 <sup>‡</sup>	0.099
One	4 (30.8)	4 (30.8)	3 (23.1)	2 (15.4)		
Two	1 (9.1)	2 (18.2)	7 (63.6)	1 (9.1)		
Three or more	1 (33.3)	2 (66.7)	0 (0.0)	0 (0.0)		

M: Median, IQR: Interquartile range, ‡: Kruskal-Wallis analysis, †: Fisher's exact test

$p=0.046$ ). On the other hand, no statistically significant relationship was identified between HbA1c and TSOY-32 in the group concerning children over 10 years of age ( $\rho=-0.098$ ;  $p=0.497$ ). There was no statistically significant difference between monthly income levels (income less than expenses, income equals expenses, income more than expenses) and HbA1c values and levels ( $p=0.149$ ).

### Discussion

In our study, we evaluated the health literacy levels of parents with children and adolescents diagnosed with T1D and the relationships of these competencies with social determinants of health and glycemic control outcomes. We found that as the education levels of the parents increased, their health literacy scores increased, while health literacy levels did not affect the

HbA1c levels of their children significantly. Moreover, health literacy skills were negatively associated with diabetes-related hospitalizations. According to the data published by the Turkish Ministry of Health, the health literacy levels of 7 out of 10 people in Türkiye are low (8). In this context, when the results of this study and the health literacy data published by the Turkish Ministry of Health are compared [if the sum of the deficient and the problematic-limited is considered low,  $n=12+34=46$  (44.7%)], the low health literacy levels in this study were similar to those of the Turkish Ministry of Health ( $z=1.661$ ;  $p=0.185$ ). Based on the data provided by the Turkish Ministry of Health, the health literacy levels of men are higher than those of women (8). In our study, no statistically significant difference was identified between the TSOY-32 scores of the male and female participants ( $p=0.537$ ).

The World Health Organization defines non-medical factors such as education and income that affect health outcomes as social determinants of health (10). In the literature, there are many large-scale studies evaluating education levels, income levels, and health literacy adequacy (10-14). Some studies have reported that as monthly income increases, health literacy scores also increase (10,14). We did not find any statistically significant correlation between monthly income and health literacy levels ( $p=0.515$ ). Similar to our study, in a survey study conducted with 1127 university students to examine the relationship between health literacy levels and healthy lifestyle behaviors in Türkiye, no significant relationship between financial status and health literacy was reported (10). Regarding the relationship between education levels, which are another social skill, and health literacy, the TSOY-32 scores in our study differed significantly based on the education levels of the parents ( $p=0.045$ ). Studies in the literature have shown that there is a positive correlation between education levels and health literacy scores, similar to our study (14,15). This result indicates that education levels and health literacy are directly proportional. This is an indication that all segments of society should be supported to access, understand, and use health-related information. In a study performed with children, Pulgarón et al. (16) highlighted the significance of the role of parental health literacy, especially numeracy, in the planning of interventions to enhance the glycemic control capabilities of young diabetic children. Diabetes-related arithmetic is an analytical skill required for diabetic individuals to perform self-management tasks such as glucose monitoring, carbohydrate calculation, and insulin regulation (17). In a study conducted to measure diabetes-related arithmetic in 61 adolescents aged 12-17 with T1D mellitus, it was determined that young people's own arithmetic skills were related to their diabetes outcomes (18). The HbA1c test, which shows the course of diabetes, is the main test to help manage diabetes (15). The HbA1c test provides information about blood sugar and is a tool to support behavioral change for diabetes management (19). In this context, children's HbA1c levels and parents' TSOY-32 scores were examined in our study, and we found no statistically significant difference ( $p=0.215$ ), but there was a negative and statistically significant correlation between HbA1c and TSOY-32 in the

parents of children in the 2-10 age group. There was also no statistically significant correlation between HbA1c and the health literacy levels of the parents with children older than 10 years old. Although no significant correlation between TSOY-32 scores and HbA1c scores could be found, this may be due to the fact that our study included an online questionnaire. We think that answering the questions in the presence of a supervisor experienced in the field of diabetes may have affected the results. It could also increase the role of parents in diabetes management in the younger age group. A negative and statistically significant correlation was determined between HbA1c and TSOY-32 in the parents of children in the 2-10 age group.

In a study conducted with parents of children in a similar age group, parental health literacy, diabetes self-efficacy perceived by parents, diabetes numeracy, and glycemic control status in 70 children aged 3-9 years with T1D were investigated, and low levels of parental health literacy were found related to poor glycemic outcomes in children (16). Similar to our study, Janisse et al. (20) stated that parental health literacy levels had no significant effect on HbA1c in older age groups. It was also reported in a study carried out to define the health literacy levels of parents of adolescents aged 10-17 with insulin-dependent diabetes and investigate the relationship between parental health literacy and adherence to treatment, no significant correlation was determined between the health literacy of parents and their children's diabetes management and HbA1c values.

In another study evaluating the relationship between levels of participation in blood glucose monitoring and insulin administration and the metabolic control of 89 children aged between 10 and 15 years who were using insulin, it was found that HbA1c values improved as parental participation increased. In this context, parents who have low levels of knowledge about diabetes management and the prevention of ketoacidosis should be supported in terms of diabetes and ketoacidosis management (21). It has been reported in various studies that increasing the contribution of parents to diabetes management and improving health literacy competencies in the adolescent age group will improve blood glucose monitoring, treatment adherence, and metabolic control (14,22). It was also reported that the continuous education of parents and

children and family harmony are important for the successful management of diabetes in adolescents and children (23).

Low health literacy levels in parents are associated with negative behaviors such as an unhealthy diet and poor exercise levels in children (24). Additionally, low health literacy levels in parents are also associated with medication dosing errors (25). Parents who have poor levels of health literacy have difficulty in terms of helping their children adjust to their diabetes management regimen (20). In our study, we could not find any statistically significant relationship between the duration of diabetes in children and parental health literacy levels. Studies evaluating the relationship between diabetes duration and health literacy levels are limited in the literature. In their study conducted with parents of children with diabetes aged 3–9 years, Pulgarón et al. (16) did not report a statistically significant relationship between parental arithmetic skills and their children's diabetes duration. These results were also consistent with our study, and they indicated that parents need support for the development of their health literacy.

#### *Study Limitations*

One of the limitations of our study was that it was based on the data obtained through the online questionnaire. We believe that studies to be observed by an experienced supervisor will be useful. Long-term studies with larger samples are necessary to examine the relationship between health literacy and diabetes-related long-term complications.

#### **Conclusion**

In our study, there was a correlation between the health literacy levels of the parents and their educational statuses. Additionally, the frequency of hospitalization due to diabetic ketoacidosis was lower in the children of the parents with sufficient health literacy levels. Efforts for increasing the health literacy levels of parents should be supported as they will reduce hospitalization due to diabetes and related health expenditures.

#### *Ethics*

*Ethics Committee Approval:* The study was started after obtaining the approval of the Beykent University

Ethics Committee for Social Sciences and Humanities (decision no: 237, date: 01.07.2022).

*Conflict of Interest:* No conflict of interest was declared by the authors.

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