Parents' awareness of type 1 diabetes: knowledge status

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ABSTRACT

Purpose: Type 1 diabetes is a common disease in children and teenagers, but it can occur at any age. This study aimed to determine the awareness and knowledge of type 1 diabetes in parents' to diagnose early.

Materials and methods: This study is a descriptive type. Data were collected from 1 April to 1 July 2020 date in Turkey. The study sample consisted of 214 parents who accepted to participate in the study and completed the questionnaire were included in the sample.

Results: It was found that the knowledge level of the parents participating in the study about type 1

diabetes was close to medium level (6.10±1.89). The study's findings revealed that there are misperceptions about the incidence of type 1 diabetes in parents. Parents are often confused about the reasons for type 1 and type 2 diabetes.

Conclusions: In this study, although the knowledge level of the parents about type 1 diabetes is close to medium level, it is below the intermediate level. It is important and necessary for families to know about type 1 diabetes and its symptoms, observe their child or children and diagnose the disease early.

Keywords: Family, children, parent, type 1 diabetes, nursing

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INTRODUCTION

Diabetes is one of the emergency public health problems of the 21st century globally. International Diabetes Federation (IDF) reported that according to 2019 data there are 463 million people with diabetes in the World, and this number will reach 700 million in 2045. According to the recently published Diabetes Atlas of IDF [1]; it is estimated that the proportion of children and young people under the age of 20 with type 1 diabetes worldwide is 1.1 million. In Turkey, children and adolescents aged 0-19 with type 1 diabetes has been reported to be equal to 25953 [1,2].

Type 1 diabetes is a disease that occurs in childhood and teenagers, but it can occur at any age and cannot be prevented. Although type 1 diabetes is most common in childhood, there is an increase in the incidence of type 2 diabetes in older children due to overweight and obesity in childhood [1,3]. Today, there is no effective and safe approach to prevent type 1 diabetes in evidence-based medicine practices [1,2]. Developing approaches for the complications, management, and prevention of type 1 diabetes remains the biggest difficulties. These difficulties stem from the lack of awareness of type 1 diabetes in the population [4]. It was found that in many countries with a low socioeconomic level, type 1 diabetes is often confused with diseases such as malaria and pneumonia, so it cannot be diagnosed early. It was stated that misdiagnosis or late is the most common cause of death in children with type 1 diabetes globally, increasing the risk of serious complications and mortality [1]. Despite efforts to improve diabetes awareness in some developed countries, type 1 diabetes is still not diagnosed early. In many countries, it has been reported that children are diagnosed late with the presence of lifethreatening diabetic ketoacidosis (DKA) [1,5-7]. Despite the implementation of national-level strategies to increase diabetes awareness, a significant reduction in DKA rates at the time of diagnosis has not been achieved in Turkey [8]. It is predicted that with the early diagnosis of type 1 diabetes, the risk of developing DKA will decrease [6].

In the literature review, no research was found to determine the type 1 diabetes awareness of the parents of healthy children. Therefore, it should be aimed to increase the level of knowledge and awareness of families to diagnose type 1 diabetes early and decrease the incidence of DKA. Accordingly, there is a need for a measurement tool specific to type 1 diabetes to evaluate and measure type 1 diabetes knowledge and awareness levels. Using scales specific to type 1 diabetes in scientific research can be a basis for determining large-scale strategies that increase the awareness and knowledge level of families. These strategies can contribute to the management of type 1 diabetes. Therefore, it is

important to find an objective measurement tool that can be used to determine families' knowledge and awareness of type 1 diabetes. In the literature review, no validated tools were found to measure type 1 diabetes knowledge and awareness levels [6, 9, 10].

This research is the first and original study designed by researchers as a measurement tool specific to type 1 diabetes. This study, it was aimed to determine the awareness and knowledge of type 1 diabetes in families to diagnose type 1 diabetes early.

MATERIALS AND METHODS

Study design, setting, and sample

This study is a descriptive type and was conducted to determine the parents' awareness of type 1 diabetes between 01 April-01 July 2020 in Turkey. The universe of the research; parents with children between the ages of 0-18 in social media. Since the universe of the study was not fixed, 214 parents who accepted to participate in the study and completed the questionnaire without a purposeful sampling were included in the sample. The effect size was calculated (Cohen's d = (5.79 - 6.29)/1.844587 = 0.271063) [11]. A post hoc power analysis was performed and the method has been added to the section for 214 people. Linear multiple regression in the t tests was used for power analysis. The strength of the post hoc analysis result of this study was 1,0000.

The inclusion criteria were as follows: (i) Being between the ages of 18-65 (ii) willingness to participate in the research (iii) Having children (iv) using a smartphone.

Data collection

Nowadays, the widespread use of the internet has made it possible to reach individuals who have different experiences and live in other regions in the general population [12]. Internet usage in work and social life increased during the pandemic process [13]. For this reason, the internet was used instead of meeting face to face in data collection methods. The data collection tools were created using the Google Documents website, and the study was conducted via the internet. The link of the questionnaire forms was distributed via social media and the volunteers agreed to participate in the survey. In the collection of research data, "Parents "Type 1 Diabetes Information Form" and Information Form" developed by the researchers in line with the literature were used.

Instruments

Parents Information Form

It consists of two parts. In the first part, there are 9 questions, including some introductory information of the participants (such as age, gender, educational status, employment status, economic status, number of children, age of children). In the

second part, there are six questions about the type 1 diabetes of the participants (family history, polyuria, polydipsia, dry mouth, weight loss, and fatigue symptoms in the child, education about diabetes). *Type 1 Diabetes Information Form*

Prepared by the researchers in line with the literature, there were 13 questions about the parents' knowledge of diabetes. The information form includes questions about type 1 diabetes (including its etiology and risk factors). The questions in the form were answered as "yes, no, no idea" and 8 items (1, 2, 4, 5, 7, 8, 9, 11) were reverse, 5 items (3, 6, 10, 12, 13) it was calculated straight. The range of points that can be taken from the form is between 0-13. The content validity index (CVI) was calculated to measure the appropriateness and comprehensibility of each item of the questionnaire form to measure the situation desired to be measured. A total of five nurse faculty members who have worked in the field of diabetes for CGI were asked to evaluate each of the 13 items in the information form with a score between 1 and 4 (4: Very suitable, 3: Quite appropriate but requires minor changes, 2: Somewhat appropriate, revision of the statement. must, 1: Not available). According to the expert opinions obtained as a result of the evaluations, the CVI value of the form was calculated as 98.6% [14]. After obtaining expert opinion, the questionnaire was pre-applied to 5 people. These persons were not included in the study. Each item contained clear statements in the pre-application. Therefore, no changes were made in the questionnaire.

Statistical analysis

Descriptive statistics were analyzed using parametric and non-parametric tests. The number, percentage, mean \pm standard deviation, and chisquare for categorical variables were used in the evaluation of descriptive statistics for continuous variables, and the t-test / Mann Whitney U test and Kruskall Wallis test were used for comparing independent groups. Multiple linear regression analysis was performed using the backward method to determine the relationship between some independent variables and the type 1 diabetes knowledge score of the parents. All statistics were evaluated at a significance level of p <0.05.

Limitations of the study

Firstly, it was one of the limitations of this study that the participants were not questioned whether they have a first-degree relative with type 1 diabetes. Secondly, since there were no validated tools to measure type 1 diabetes knowledge and awareness levels, an "homegrown" questionnaire was used.

Ethical considerations

For the study, permission was obtained from the Non-Interventional Clinical Research

Ethics Committee of a state university in Turkey (decision no: 06.03.2020/9). The Helsinki Declaration was complied with to conduct the study. Informed consent was obtained from the parents who voluntarily accepted to participate in the study.

RESULTS

In the study, 62.1% of the 214 parents were mothers, their average age ranged between 20-45 years, and 69.9% were in the age range of 36-45. It was determined that 63.1% of the parents participating in the study are university graduates, 92.1% are working, 29.9% are healthcare workers, and 56.5% of them express their income as medium level. 51.4% of the participants have two children and 34% of the children are between the ages of 4-9. Nearly half of the parents (48.1%) stated that they had received prior education about diabetes as sources of information; 45.6% of health workers, 54.4% of other sources (teachers/schools, books, websites, etc.) reported (Table 1). 40.7% of the parents who participated in our study stated that there are individuals with diabetes in their family and the symptoms of type 1 diabetes in their children. They stated that they encountered symptoms of polydipsia (26.2%), polyuria (9.8%), fatigue (7.5%), and dry mouth (3.7%) (Table 2).

In line with the answers given by the parents to the type 1 diabetes information form, the knowledge point average was calculated as $6.10 \pm$ 1.89 (min.0, max.11). The knowledge score average of the mothers (6.29 ± 0.17) was higher than the knowledge score average of the fathers (5.79 ± 0.19) , and a statistically significant difference was found between them (p = 0.048). When comparing the age groups of the parents, the knowledge score average of young parents (21-30 years old) was lower than the parents of other age groups, but no statistically significant difference was found between them (p = 0.051). When the knowledge score averages of the participants were compared, it was found that the knowledge score average of the parents with postgraduate education was significantly higher than the other education levels (p <0.001). When the occupational status and the average knowledge score were compared, the average knowledge score of the health care worker parents was higher than other occupational groups, and a statistically significant difference was found between them (p <0.001). No significant difference was found statistically between the number of children of the parents and their knowledge score average (p = 0.857). When the knowledge score average was evaluated according to the status of having received education about type 1 diabetes before, the knowledge score average of those who received education was found to be significantly higher than those who did not receive an education (p < 0.001) (Table 1) (Table 3).

Regression analysis was performed and the factors that significantly affect the type 1 diabetes knowledge score of the parents are as the following; parents' educational status, profession, and receiving

a training about type 1 diabetes. These variables explained 25% of the parents' knowledge level of type 1 diabetes (Table 4).

Table 1. Comparison of participants' sociodemographic characteristics and type 1 diabetes information scores (n=214)

Variables	n	%	X±SD	p*
Parents				
Mother	133	62.1	6.29±0.17	p=0.048**
Father	81	37.9	5.79±0.19	
Age				
20-30	27	12.6	4.62 ± 0.64	p=0.051***
31-35	38	17.8	6.15±0.33	
36-45	149	69.6	6.19 ± 0.14	
Education				
First-secondary education	10	4.7	4.70 ± 0.68	p<0.001***
High school	25	11.6	5.32 ± 0.43	
Bachelor	135	63.1	6.02 ± 0.15	
Graduate	44	20.6	7.13 ± 0.24	
Profession				
Unemployed	17	7.9	4.64 ± 0.41	p<0.001***
Health employee	64	29.9	7.12 ± 0.18	
Other professional groups	133	62.2	5.79±0.16	
Number of children				
1	80	37.4	6.07 ± 0.20	p=0.857***
2	110	51.4	6.19 ± 0.18	
3 and above	24	11.2	5.79 ± 0.39	
Receiving a training about diabetes				
Yes	103	48.1	6.94 ± 0.15	p<0.001**
No	111	51.9	5.32 ± 0.17	
Total	214	100.0		
Source of a training about diabetes	_	_		
Health employee	47	45.6	6.77±0.31	p<0.001**
Others (teacher/school, books, web site etc).	56	54.4	6.18±0.51	
Total	103****	100.0		
Type 1 diabetes information form mean score	214	100.0	6.10±1.89	6.00 (0-11)
				Med (Min-Max)

X: Average, SD: Standard Deviation, Med: Median, Min: Minimum, Max: Maximum *p<0.05, ** Mann Whitney U test, *** Kruskal Wallis test, **** Those who have prior training about diabetes

Table 2. Questions about type 1 diabetes symptoms' awareness of parents (n=214)

Symptoms		n	%
Do you have "dry mouth" in your child/children?	Yes	8	3.7
	No	206	96.3
Are there any signs of "drinking too much water" in your	Yes	56	26.2
child/children?	No	158	73.8
Is there a symptom of "frequent urination" in your child/children?	Yes	21	9.8
	No	193	90.2
Are there any signs of "excessive fatigue" in your child/children?	Yes	16	7.5
	No	198	92.5
Total		214	100.0

Table 3. Knowledge status about type 1 diabetes of parents (n=214)

Items		n	%
1. Type 1 diabetes is an infectious disease	Yes	9	4.2
	No	205	95.8
2. It is possible to prevent type 1 diabetes	Yes	184	86.0
	No	30	14.0
3. Type 1 diabetes is a serious disease	Yes	195	91.1
	No	19	8.9
4. Type 1 diabetes is a milder disease than tip 2 diabetes	Yes	88	41.1
	No	126	58.9
5. Type 1 diabetes can be controlled by diet	Yes	130	60.7
	No	84	39.3
6. Type 1 diabetes occurs in childhood and youth	Yes	35	16.3
	No	179	83.7
7. Type 1 diabetes is a genetically inherited disease	Yes	188	87.9
	No	26	12.1
8. Consuming too much sugary food leads to type 1 diabetes	Yes	148	69.2
	No	66	30.8
9. Insufficient physical activity is one of the causes of type 1 diabetes	Yes	180	84.1
	No	34	15.9
10. Type 1 diabetes symptoms come on suddenly	Yes	94	43.9
	No	120	56.1
11. Foods that diabetics should eat should be different from those	Yes	175	81.8
that healthy people eat	No	39	18.2
12. Type 1 diabetes affects an individual's entire life	Yes	168	78.5
	No	46	21.5
13. Parents should carefully watch their children for signs of diabetes	Yes	205	95.8
	No	9	4.2
Total		214	100.0

Table 4. The effect of some parents-related variables on type 1 diabetes information score (n=214)

Dependent variable: Type 1 diabetes information level					
Independent variables: Education, Profession, A training status	В	SE	В	<i>p</i> *	
Constant	7.719	0.982			
Education (1First-secondary education, 2High school, 3Bachelor, 4Graduate)	0.328	0.168	0.135	0.052	
Profession (1Unemployed, 2Health employee, 3Other professional groups)	-0.634	0.240	-0.193	0.009	
Receiving a training about diabetes (1Yes, 2No)	-1.179	0.249	-0.312	0.000	
R	0.501				
R^2	0.251				
F	23.396				
<i>p</i> *	0.000				

*p<0.05

DISCUSSION

The initiation and development process of type 1 diabetes is different from type 2 diabetes. Type 2 diabetes usually progresses slowly, whereas type 1 diabetes presents with a sudden and noisy picture with DKA or acute hyperglycemia. During

the development of type 1 diabetes in children and adolescents, symptoms and signs are observed due to hyperglycemia (polyuria, polydipsia, feeling of hunger, dry mouth, weight loss, and fatigue) [2]. In our study, possible diabetes findings that parents should notice in their children were questioned, and it was reported by their parents that approximately

one in four children drank more water than usual. Having these behaviors in the children of the participants does not mean that there is a risk of developing type 1 diabetes. Although the frequency of symptoms and signs of type 1 diabetes is different, it can develop in less than a month. It has been reported that the lack of awareness of type 1 diabetes in the family caused delays in diagnosis and an increase in the frequency of DKA development. Therefore, the family needs to know and recognize the classic signs of type 1 diabetes in advance [4, 6, 9, 10, 15]. In this context, it was predicted that the awareness levels of the parents included in our study would increase by providing symptom awareness regarding type 1 diabetes. In many countries, campaigns are being organized to raise awareness of type 1 diabetes through parents, healthcare professionals, and teachers [16]. It was reported that different practices such as flyers, brochures, posters, web pages, school, family, and primary health care workers' training were used in the campaigns. Studies on the general population have shown that it is effective in early diagnosis with campaigns aimed at making them aware of type 1 diabetes symptoms

It has been reported that childhood obesity and high body mass index may be modifiable risk factors in regions with a high incidence of type 1 diabetes. It is predicted that these risk factors contribute to the increase in the incidence of type 1 diabetes [1, 17]. More than half of the parents participating in our study reported that type 1 diabetes is caused by lifestyle and diet. In a qualitative study conducted for the early diagnosis of type 1 diabetes, the majority of the participants stated that they thought that type 1 diabetes was caused by lifestyle or eating behaviors. According to the results of the study, it was determined that there are misperceptions about the incidence of type 1 diabetes in parents, as in our study.

It was found that the parents who accepted to participate in our study had a knowledge level close to the average (6.10±1.89) about type 1 diabetes. Parents' educational status, profession, and receiving a training about type 1 diabetes variables affected the parents' knowledge level of type 1 diabetes. Also, the knowledge level of type 1 diabetes was found to be high in the parents who had postgraduate education, had type 1 diabetes education before, and were healthcare workers (p <0.05). It was evaluated that parents confused about often the reasons for type 1 diabetes and type 2 diabetes. The reason for this was predicted to be that the education level of parents and their education about type 1 diabetes affected their knowledge and awareness levels. Studies have reported that the level of knowledge and awareness of the society is low [4, 6, 10]. In a study, it was determined that the participants experienced confusion between type 1

and type 2 diabetes, and it is similar to our study findings [9].

When the literature is examined, it has been shown that although it differs from society to society, although it is not global, the awareness of the disease is not sufficient in developing and developed societies [4,10]. Today, in some societies, some individuals are not aware of the possibility of diabetes in children aged 2 to 5 and who believe that diabetes affects only the middle age group. Therefore, for the early diagnosis of type 1 diabetes, diabetes awareness should be developed in the community [4]. In this direction, strategies and programs should be planned to raise awareness for society.

CONCLUSIONS

In this study, the knowledge level of the parents about type 1 diabetes is low, even if it is close to the middle level. Parents' education level, prior education, and profession were found to be factors affecting their knowledge and awareness of type 1 diabetes. Educating families about type 1 diabetes and monitoring their children in terms of symptoms is important and necessary for early diagnosis.

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Conflicts of interest

There is no conflict of interest to declare by the author.

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REFERENCES

- 1. IDF. International Diabetes Federation. IDF Diabetes Atlas. 9th ed. Brussels: 2019. Available at: https://www.diabetesatlas.org.
- TEMA. Turkish Endocrinology and Metabolism Association. Guidelines for diagnosis, treatment and follow-up of diabetes mellitus and its complications-2019. 12th Ed. Ankara, Turkey: ISBN, 978-605-4011-38-4.
- 3. Patterson CC, Karuranga S, Salpea P, Saeedi P, Dahlquist G, Soltesz G, Ogle GD. Worldwide

- estimates of incidence, prevalence and mortality of type 1 diabetes in children and adolescents: Results from the International Diabetes Federation Diabetes Atlas, 9th edition. Diabetes Res Clin Pract 2019 Nov;157:107842.
- 4. Kumar KM, Saboo B, Rao PV, Sarda A, Viswanathan V, Kalra S, Sethi B, Shah N, Srikanta SS, Jain SM, Raghupathy P, Shukla R, Jhingan A, Chowdhury S, Jabbar PK, Kanungo A, Joshi R, Kumar S, Tandon N, Khadilkar V, Chadha M. Type 1 diabetes: Awareness, management and challenges: Current scenario in India. Indian J Endocrinol Metab 2015 Apr; 19(Suppl 1):S6-8.
- Dabelea D, Rewers A, Stafford JM, Standiford DA, Lawrence JM, Saydah S, Imperatore G, D'Agostino RB Jr, Mayer-Davis EJ, Pihoker C; SEARCH for Diabetes in Youth Study Group. Trends in the prevalence of ketoacidosis at diabetes diagnosis: the SEARCH for diabetes in youth study. Pediatrics. 2014 Apr;133(4):e938-45.
- Deylami R, Townson J, Mann M, Gregory JW. Systematic review of publicity interventions to increase awareness amongst healthcare professionals and the public to promote earlier diagnosis of type 1 diabetes in children and young people. Pediatr Diabetes 2018 May;19 (3):566-73.
- Szypowska A, Ramotowska A, Grzechnik-Gryziak M, Szypowski W, Pasierb A, Piechowiak K. High Frequency of Diabetic Ketoacidosis in Children with Newly Diagnosed Type 1 Diabetes. J Diabetes Res 2016; 2016:9582793.
- 8. Acar S, Gören Y, Paketçi A, Anık A, Çatlı G, Tuhan H, Demir K, Bober E, Abacı A. Changes in the frequency of diabetic ketoacidosis in type I diabetes mellitus cases at diagnosis: A fifteenyear single-center experience. The Journal of Pediatric Research. 2017 Mar;4(3):143-8.
- 9. Townson J, Gallagher D, Cowley L, Channon S, Robling M, Williams D, Hughes C, Murphy S, Lowes L, Gregory JW. "Keeping it on your radar"-assessing the barriers and facilitators to a timely diagnosis of type 1 diabetes in childhood: A qualitative study from the early detection of type 1 diabetes in youth study. Endocrinol Diabetes Metab 2018 Jan;1(1): e00008.
- Silistre ES, Hatipoğlu HU. Assessment of knowledge of teachers employed at schools in Istanbul regarding the subject of type-1 diabetes: The effects of the four-year diabetes training program. A cross-sectional. *IAAOJ* | Health Sciences. 2019 Jan;5(2):128-36.
- 11. Socscistatistics.com. Effect Size Calculator for T-Test. [cited 2021 March 10]. Available from: https://www.socscistatistics.com/effectsize/defa ult3.aspx

- 12. Coulson N. Online Research Methods for Psychologists. Red Globe Press. 2015
- 13. Király O, Potenza MN, Stein DJ, King DL, Hodgins DC, Saunders JB, Griffiths MD, Gjoneska B, Billieux J, Brand M, Abbott MW, Chamberlain SR, Corazza O, Burkauskas J, Sales CMD, Montag C, Lochner C, Grünblatt E, Wegmann E, Martinotti G, Lee HK, Rumpf HJ, Castro-Calvo J, Rahimi-Movaghar A, Higuchi S, Menchon JM, Zohar J, Pellegrini L, Walitza S, Fineberg NA, Demetrovics Z. Preventing problematic internet use during the COVID-19 pandemic: Consensus guidance. Compr Psychiatry 2020 Jul;100:152180.
- 14. Aksayan S, Gözüm S. A guide for transcultural adaption of the scale. Nurs Res J 2002;4(1): 9-14.
- 15. Uçar A, Saka H. N. Type 1 Diabetes Report. J Clin Med Ped 2016 Dec;8(6):22-32.
- 16. Choleau C, Maitre J, Elie C, Barat P, Bertrand AM, de Kerdanet M, Le Tallec C, Nicolino M, Tubiana-Rufi N, Levy-Marchal C, Cahané M, Robert JJ; le Groupe d'étude de l'aide aux jeunes diabétiques (AJD Study Group). Effet à un an de la campagne nationale de prévention de l'acidocétose au moment du diagnostic de diabète de type 1 chez l'enfant et l'adolescent [Ketoacidosis at time of diagnosis of type 1 diabetes in children and adolescents: effect of a national prevention campaign]. Arch Pediatr 2015 Apr;22(4):343-51. (French)
- 17. Verbeeten KC, Elks CE, Daneman D, Ong KK. Association between childhood obesity and subsequent Type 1 diabetes: a systematic review and meta-analysis. Diabet Med 2011 Jan; 28(1):10-8.