ANKARA
MEDICAL
JOURNAL

Research Article
Ankara Med J, 2022;(4):520-532 // 10.5505/amj.2022.44522

THE IMPACTS OF DIABETES ON FAMILIES WITH A CHILD DIAGNOSED WITH TYPE 1 DIABETES MELLITUS AND INFLUENCING FACTORS

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Submitted: 26.01.2022 // Accepted: 19.09.2022

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Abstract

Objectives: This study aimed to determine the impacts of diabetes on families with a child diagnosed with Type 1 Diabetes Mellitus (DM) and influencing factors using the Diabetes Family Impact Scale (DFIS).

Materials and Methods: The population of our study, which is a descriptive cross-sectional type, consists of the parents of 289 school-aged children diagnosed with Type 1 DM and followed for at least one year in the Department of Pediatric Endocrinology of Sivas Cumhuriyet University Faculty of Medicine. The study questionnaire was completed in a face-to-face interview with the parents of 121 of the 289 children who volunteered to participate in the study. The first 21 questions of the research questionnaire were related to sociodemographic data, and the following 14 questions, which included some characteristics of the disease, were related to DFIS.

Results: The mean DFIS scale score of the participants was 14.60±10.82. In our study, the mean DFIS scale score and the mean scores of the School and Work subscales were significantly higher in families with a child who had a high mean HbA1c and had been hospitalized for diabetes in the last year. It was also found that the DFIS scale score was significantly higher in low-income families than in high-income families. While there was a negative correlation between the DFIS scale score and the child's age with Type 1 DM, and the mother's age, there was a positive correlation between the DFIS scale score and the HBA1c values.

Conclusion: The impact of Type 1 DM on families is widespread and multifactorial. In our study, as the diabetic control deteriorates and the age of the child decreases, the level of influence of the families in different aspects increases.

Keywords: Type 1 diabetes mellitus, diabetes family impact scale, family.

Introduction

Diabetes mellitus (DM) is a metabolic disorder characterized by chronic hyperglycemia caused by inadequate insulin function and/or secretion.[1] Type 1 DM is a common form of DM caused by damage to pancreatic β-cells in children and adolescents.[2,3] According to American Diabetes Association, about 1.25 million people in the United States are diagnosed with Type 1 DM, and about 40,000 children are diagnosed each year.[4] About 25,000 children diagnosed with Type 1 DM continue to be followed in Turkey, and about 2500 children are newly diagnosed each year.[5,6] Type 1 DM affects not only the children with the disease but also the family members (i.e., parents and siblings). They face financial, social, emotional, behavioral, cognitive, and psychological pressures, and these effects last for a long time.[7] Family members and caregivers play an essential role in diabetes management.[8] Therefore, parents should acquire new knowledge and skills to manage their children's diseases.[9]

On the other hand, Type 1 DM can hurt school attendance and academic success.[10] Although the impact of Type 1 DM on the family has been investigated in some studies, the number of studies assessing this issue with valid and reliable scales is limited.[7,10,11] In Turkey, there are also studies investigating the impact of Type 1 DM on children with the disease, their school life, family financial situation, and family relationships. [12-15] Our study is the first known study conducted in our country using the Diabetes Family Impact Scale (DFIS). The DFIS was developed in 2015, and its Turkish validity and reliability study was done in our country in 2020.[10,16] This study aims to determine the impacts of diabetes on families with a child diagnosed with Type 1 DM and the influencing factors using the DFIS.

Materials and Methods

Type of the study

This study is a descriptive cross-sectional study.

Design

The population of the study consists of the parents of 289 children of school-age (6-18 years) who have been followed up in the Department of Pediatric Endocrinology at Sivas Cumhuriyet University Faculty of Medicine (SCUFM) with a diagnosis of Type 1 DM for at least one year. Parents of 112 of the 289 children who visited the outpatient clinic of Pediatric Endocrinology between November 2020 and February 2021 and agreed to participate in the study were included. The research questionnaire was administered to the participants by one of the researchers in a face-to-face interview. Before the interview, participants were informed about the study, and their informed consent was obtained.

Data collection tool

The data form used in the study consisted of a total of 35 questions. The first 21 questions of the questionnaire were related to sociodemographic data and some characteristics of the disease, and the following 14 questions were related to Diabetes Family Impact Scale (DFIS).[10,16] HbA1c levels in children with Type 1 DM were classified as HbA1c <7.0%, 7-9%, and >9% according to the International Guidelines Society for Pediatric and Adolescent (ISPAD) Diabetes Clinical Practice Consensus Guidelines 2018.[17]

We asked parents how often their child had hypoglycemia (<50 mg/dl, 50-70 mg/dl, and frequency of loss of consciousness due to hypoglycemia).[17] In addition to these questions, height, weight, body mass index, blood pressure, and HbA1c levels (%) in the last year were retrospectively retrieved from the hospital information management system in the children of parents who gave informed consent (61.2%; n=74).

Diabetes Family Impact Scale was developed by Katz et al. in 2015. [10] The Turkish validity study of the scale was performed by Çetintaş.[16] The scale consists of 14 items and is a 4-point Likert-Type with scores ranging from 0 to 3 (0 = never, 1 = sometimes, 2 = often, 3 = always). The Cronbach's alpha value was 0.881 for the internal consistency analysis of the data belonging to the scale's Turkish validity and reliability study. The scale consists of 4 sub-dimensions (School, Work, Financial Status, and Well-Being). The reliability coefficients of the four sub-dimensions of the scale ranged from 0.703 to 0.857. In the School subscale, questions were asked about the impacts of diabetes on the child's school performance, while in the Work subscale, questions were asked about the impacts of diabetes on the work areas of the child's family members. While the subscale Financial Situation included questions about the effect of diabetes on the family's financial situation, the subscale Well-Being included questions about sleep duration and family relationships of the child's family members with Type 1 DM. The higher the total score of the scale or sub-dimensions/dimensions, the greater the negative impact of diabetes on the family.

The collected data were analyzed using the SPSS program (Statistical Package for Social Sciences) for Windows Version 25 package. Normality analysis of numerical data was performed using the Shapiro-Wilk test. Firstly, a descriptive statistical analysis of the data was carried out. Frequencies for categorical data and measures of central distribution (Mean ± Standard Deviation) for numerical data were calculated. Independent Samples T-test was used to analyze whether normally distributed numerical data means differ significantly between two independent groups. The one-way ANOVA test analyzed whether there was a significant difference between more than two independent groups, whereas a chi-square test compared categorical data. Pearson Correlation test was conducted to analyze the relationship between scale and sub-dimension scores and different numerical data. A p-value of less than 0.05 was considered statistical significance, with a 95% CI.

Results

Demographic data and characteristics of the family

Parents of 121 children were included in the study; the mean age of these children was 12.32 ± 3.24 years (minimum: 6.01- maximum: 17.71). The mean age of the mothers of the children was 38.57 ± 6.25, and the mean age of the fathers was 42.44 ± 5,68. The demographic data of the 121 children are shown in Table 1.

Table 1. Demographic data of the children

	n	%
Sex		
Girl	72	59.57
Boy	49	40.54
Family structure		
Nuclear family	85	70.24
Extended family	31	25.63
Parents separated	5	4.23
Mother's educational status		
Primary Education	54	44.65
High School	35	28.91
University and above	32	26.53
Father's educational status		
Primary Education	18	14.99
High School	70	57.90
University and above	33	27.21
Family income level		
Below minimum wage	54	44.63
2500-5000 TL	41	33.92
> 5000 TL	26	21.55
Mother's age (M/SD)	38.57	6.249
Father's age (M/SD)	42.44	5.667

Data on the health status of the children

22.33% (n=27) of the children had a chronic disease in addition to Type 1 DM. Considering the insulin use patterns, 88.41% (n=107) were using pens, and 11.69% (n=14) were using pumps. They measured blood glucose at a median of 7.00 (min:2 - max:15) times per day. Our study examined how often blood glucose levels of children with type 1 DM fell below 50, how often they ranged between 50 and 70, and whether they experienced hypoglycemia at a level that would cause loss of consciousness. 89.30% (n=108) of the families of children participating in the study reported that their children did not experience hypoglycemia at a level that would lead to loss of consciousness (Table 2). Table 2 shows the frequency of children experiencing hypoglycemia.

Table 2. Frequency of patients experiencing hypoglycemia

	Blood Glucose between 50 – 70 mg/dl **n(%)**	Blood Glucose below 50 mg/dl **n(%)**	Loss of consciousness due to hypoglycemia **n(%)**
Never	6 (5.01%)	43 (35.51%)	108 (89.30%)
1-2 times a month	22 (18.20%)	43 (35.53%)	10 (8.25%)
1-2 times a week	74 (61.23%)	33 (27.34%)	2 (1.73%)
1-2 times a day	19 (15.66%)	2 (1.72%)	1 (0.82%)

43.01% (n=52) of children were hospitalized for Type 1 DM within the last year. Of these, 75.90% (n=44) were hospitalized for blood glucose regulation, 20.71% (n=12) for diabetic ketoacidosis, and 3.42% (n=2) for hypoglycemia.

When asked about children's of children physician visits due to Type 1 DM, the proportion of those who came for check-ups at intervals of more often than six months was 87.6% (n=106), and the proportion of those who came for check-ups at intervals of longer than six months was 12.40% (n=15).

The proportion of parents of children who gave consent for their children's data to be studied from the system was 61.20% (n=74). Mean values for height, weight, body mass index, systolic/diastolic blood pressure, and HbA1C for the last year of children of consenting parents are given in Table 3.

Scale scores and comparisons

The mean DFIS scale score of participants was 14.60±10.82. The school subscale mean score of the participants was 3.22±3.12, the job subscale mean score was 2.42±3.01, the financial status subscale mean score was 4.73±3.12, the well-being subscale mean score was 4.12±3.61. In our study, the mean scores of the DFIS total scale (p=0.007) and subscales on work (p=0.040), school (p=0.014), and financial situation (p<0.001) were significantly higher in low-income families than in high-income families. Among children with Type 1 diabetes DM, the mean score of the DFIS scale was significantly higher (21.41±11.92) in the families of those who had other chronic diseases in addition to diabetes than in those without additional diseases (12.72±9.73) ($p<0.001$). Similarly, in all subgroups of the scale, mean scores were significantly higher in patients with additional diseases ($p<0.05$). Total DFIS ($p=0.043$), school ($p=0.002$), and work ($p=0.015$) subscale scores of families who received support from a caregiver in child care were significantly higher compared to those who received no support or support from their family. There was no significant difference between the education level of the mother and the total DFIS score ($p=0.262$). The school subscale scores of mothers with university or higher education were significantly lower than those of primary school graduates ($p=0.026$). Table 4 compares various sociodemographic data of families of diabetic children with their DFIS scale total scores.

Table 3. Percentile values and mean HbA1C values of the patients

	M ± SD	Min	Max
Height (SDS)	-0.41 ± 1.145	-2.41	2.51
Height (percentile)	39.07 ± 30.984	0.80	99.40
Weight (SDS)	-0.30 ± 1.275	-2.63	2.77
Weight (percentile)	42.30 ± 32.252	0.43	99.72
BMI (SDS)	-0.195 ± 1.245	-2.42	2.15
BMI (percentile)	46.19 ± 33.462	0.78	98.46
Systolic BP (mm/Hg)	105.35 ± 12.169	80	130
Diastolic BP (mm/Hg)	63.59 ± 9.716	50	90
HbA1C (%)*	8.71 ± 2.310	5.10	15.50
HbA1C (IFCC)*	71.43 ± 23.367	33.10	123.70

* The mean of the last 1-year values was taken. (SD: Standard deviation)

In our study, no significant association was found between the mean score of the DFIS scale in the families and insulin use patterns of the child with Type 1 DM ($p=0.900$) and frequency of self-monitoring blood glucose per day ($p=0.937$). Those with HbA1c >9% had a significantly higher DFIS mean score ($p=0.026$), Work subscale score ($p=0.024$), and Financial Status subscale score ($p=0.047$) than those with <7%. Those who lost consciousness due to hypoglycemia more than 1-2 times a month or more often had significantly higher DFIS score mean ($p=0.011$), school subscale, score ($p<0.001$), and work subscale score ($p=0.009$) compared to those never. The DFIS score means ($p=0.009$), the school subscale score ($p=0.012$) and the Financial Status subscale score ($p=0.004$) were significantly higher in those who had a history of hospitalization in the last year compared to those who did not. The comparison of DFIS scores with different variables related to the child's disease DM Type 1 is given in Table 5.

While there was a negative correlation between the DFIS scale score and the child's age with Type 1 DM, the mother's age and the father's age, there was a positive correlation with the mean HBA1c values (%) (Table 6). In addition, there were significant negative correlations between the age of the child and all subscales ($p<0.05$).

Table 4. Comparison of Diabetes Family Impact Scale (DFIS) with family sociodemographic characteristics

	DFIS scores	**p**
Sex		
Girl	14.21±11.521	0.629
Boy	15.22±9.913	
Mother's education level		
Primary education	16.01±11.013	0.262
High School	14.82±11.414	
University and above	12.01±9.856	
Father's education level		
Primary education	13.61±10.443	0.337
High School	15.82±11.787	
University and above	12.68±8.865	
Family structure		
Nuclear family	13.43±10.221	0.159
Extended family	16.95±11.263	
Parents separated	20.29±16.584	
Family income level		
Below minimum wage	17.10±10.923	**0.007**[a]
2500-5000 TL	14.92±11.458	
Above 5000 TL	9.04±7.814	
Childcare support		
No one	14.21±10.858	**0.043**[b]
Family elder	12.92±8.813	
Caregiver	22.73±13.454	
Child chronic disease		
Present	21.43±11.954	**<0.001**
Absent	12.79±9.736	

DFIS: Diabetes Family Impact Scale, TL: Turkish liras
Bonferroni post hoc analyses; a: 2500–5000 TL, b: family elder-caregiver

Table 5. Comparison of Diabetes Family Impact Scale (DFIS) and its subscales with different variables related to child's disease with DM type 1

	DFIS scores	p
Insulin use patterns		
Pump	15.02±7.434	0.900
Pen	14.61±11.289	
Frequency of self-monitoring blood glucose per day		
≤ 6 times	14.77±11.454	0.937
> 6 times	14.56±10.512	
HbA1c (%)		
<%7	9.30±11.103	**0.026**[a]
%7-9	13.72±10.058	
> %9	19.12±12.046	
Frequency of hypoglycemia (50-70 mg/dl)		
1-2 times a month or less	14.62±12.912	0.548
1-2 times a week	15.27±10.268	
1-2 times a day	12.24±10.098	
Frequency of hypoglycemia (<50 mg/dl)		
Never	12.47±11.178	0.249
1-2 times a month	15.58±10.387	
1-2 times a week or more often	16.29±11.135	
Loss of consciousness due to hypoglycemia		
Never	13.72±10.614	**0.011**
1-2 times a month or more often	21.89±10.969	
Hospitalization in the last year		
Yes	17.54±10.813	**0.009**
No	12.43±10.458	
The frequency of physician visits due to DM		
at intervals 6 months or more often	14.74±11.78	0.764
at intervals longer than 6 months	14.01±8.554	

DFIS: Diabetes Family Impact Scale
Bonferroni post hoc analyses; a: HBA1c (%) between >9 % and <7 %

Table 6. Correlation of Diabetes Family Impact Scale and its sub-scales with different variables

	DFIS	
	r	p
Child's age (year)	-0.270	**0.003****
Mother's age (year)	-0.204	**0.025***
Father's age (year)	-0.254	**0.005****
Duration of DM (month)	-0.194	0.091
Frequency of self-monitoring blood glucose per day	0.147	0.107
HbA1c (%)	0.298	**0.009****

DFIS: Diabetes Family Impact Scale; DM: Diabetes mellitus type 1; HbA1c: Hemoglobin A1c
** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the 0.05 level (2-tailed)

Discussion

Although there are several studies on the impact of a child with Type 1 DM on the family, our study is the first known study conducted in our country using the DFIS scale.[10,18,19]

Parents of children with Type 1 diabetes are exposed to severe stress and burden. In the study by Herbert et al., families of school-aged children with Type 1 DM reported that they felt most stressed when their children were exposed to intensive medical treatment for various diseases.[20] In our study, parents of children with additional chronic diseases besides diabetes had higher DFIS scores. This situation is consistent with the literature. In the study conducted by Harrington et al., the parents of a child with Type 1 DM stated that the most common problem they perceived as a burden of diabetes was the child's hypoglycemic episodes.[21] Haugstvedt et al.'s study revealed that parents of children with hypoglycemic episodes, especially with nocturnal hypoglycemia and loss of consciousness, experience higher diabetic burden and emotional stress.[22] In a qualitative study by Commissariat et al., some families with a child with Type 1 DM mentioned that they were concerned about the occurrence of hypoglycemic episodes in their children and delays in treatment.[23] However, no significant association was found in our study between the frequency of hypoglycemia and DFIS score; in contrast, a significant increase in the scale score for severe hypoglycemic episodes with loss of consciousness due to DM was found, similar to the literature.

In the qualitative study of Abolhassan and his friends, the situation that families are most worried about for their children with diabetes; stated that there was a possibility of falling into a coma due to changes in blood sugar.[24] In the qualitative study of Wennick et al., they stated that the most affected issue for family members with children with diabetes is the changes (sudden rises and falls) in their children's blood sugar levels. In the same study, it was determined that the level of anxiety in families increased with the type and frequency of insulin use.[7] In our study, however, there was no significant difference between the type of insulin use and DFIS.

In the study conducted by Emre et al., it was determined that the school performance of children with poor diabetic control was more affected.[13] In a different study, they stated that the parents of adolescent children with diabetes thought the most about their children's academic success at school and future anxiety.[25] In our study, students with high HbA1c scores were found to be higher than those with low school subscale scores, although there was no significant difference. This situation is compatible with the literature.

Our study observed that families with a child who had a high HbA1c mean and had been hospitalized for diabetes in the last year had a significantly higher mean DFIS score and higher scores in the School and Work subscales. In a study conducted with diabetic children under the age of seven, the child's uncontrolled diabetes with Type 1 DM and risk of diabetes complications were among the issues of greatest concern to families.[21] In another study, families of children hospitalized for diabetes were found to have high levels of anxiety and worry, especially about school.[20]

In Harrington et al.'s study, the only study in the literature that used the DFIS scale, families with a child diagnosed with Type 1 DM reported experiencing limitations in their workspace due to childcare.[21] Katz et al. pointed out that children with Type 1 DM affect their families, primarily in the areas of work, finances, and school absenteeism.[24] In our study, the Work subscale score of the DFIS increased significantly, especially among families with children with a high HbA1c mean. This finding suggests that families with diabetic children may experience different work-related problems.

Several studies have determined that the effect of diabetes on the family increases with the decreased age of the child diagnosed with Type 1 DM.[8,20] Our study also had a negative correlation between the child's age and the DFIS total score and all subscale scores except the school score, which is consistent with the literature.

In the study by Haugstvedt et al., it was concluded that parents whose child has Type 1 DM and who self-monitor their child's blood glucose levels more frequently have a higher perceived burden and psychological distress related to diabetes. The same dissertation study also found that better glycemic control was achieved as the mother's educational level increased, but the child's perception of social constraints increased.[22]

In the study conducted by Kobos et al. in Poland, it was shown that mothers with a low level of education felt more burdened by their diabetic children. In the same study, parents whose fathers do not work and whose income level is low were more affected.[8] Similarly, in our study, the DFIS score was higher in parents whose mothers had low education levels and whose income was below the minimum wage.

In our study, there was no significant difference between the frequency of going to the hospital controlled due to diabetes and DFIS. In the study conducted by Wennick et al., they found that families who regularly go to check-ups every three months due to their diabetes were affected positively by this situation because they contacted the diabetes team at the hospital more frequently.[7]

The impact of Type 1 DM on families is widespread and multifactorial. The main finding of our study is that children with poorly controlled diabetes and Type 1 DM affect their families in different ways the younger they are. Recognizing and addressing the impact of children with Type 1 DM on their families not only affects the quality of life of family members but can also provide them with the support and resources they need to better care for their children. Parents can also help adapt their children to diabetes. Social support and ongoing education are also paramount in adapting to a chronic illness. Therefore, it is crucial to set up psychosocial support groups where families of children with Type 1 DM can be educated together and talk about their problems. In this way, diabetics and families can expect better blood glucose control in the future.

Limitations

Although our study is the first study conducted in our country using DFIS, the results cannot be generalized to the whole country as it was conducted in a single center. There is a need for multicenter studies on this topic.

Ethical Considerations: The Ethics Committee of Cumhuriyet University for noninvasive clinical research approved the study (2020/10-09). Permission to use the scale in our study was obtained from Çetintaş via email.

Conflict of Interest: The authors declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

Funding: The authors received no financial support for the research, authorship, and/or publication of this article.

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