Journal of Public Health
https://doi.org/10.1007/s10389-022-01698-z

ORIGINAL ARTICLE

Examining the caregiver burden of parents whose children have type 1 diabetes

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Received: 29 September 2021 / Accepted: 9 February 2022

Abstract

Aim The aim of this research is to examine the caregiver burden of parents whose children have Type 1 diabetes mellitus (T1DM).

Subject and methods This descriptive and cross-sectional study was conducted with 105 parents. Data were obtained through face-to-face interviews, using the Zarit Burden Interview and completion of a personal data form.

Results In the sample, 61.9% of the parents are between 36 and 60 years of age, The height/weight of 41.0% of the children are in the 25–50 percentile, 55.2% of the children can apply insulin themselves, 67.6% of the children report having been negatively affected by T1DM in terms of daily life activities, and 81.9% of the children had T1DM training with their parents from a designated nurse. It was also identified that there are statistically significant differences on the Burden Interview score depending on the age when the child is diagnosed with diabetes, the duration of diabetes, whether there is an additional illness or not, the person who applies insulin, an incident of having a problem while applying the insulin, and the health worker who provided the T1DM training ($p < 0.05$). In this study, the parents' Burden Interview mean score has been found 19.46 ± 6.31 indicating a moderate level of burden.

Conclusions Consequently, these parents have demonstrated a burden of risk that may benefit from additional support while caring for their children.

Keywords Diabetes · Caregiver burden of parents · Children

Introduction

T1DM is a costly chronic disease widely seen among children worldwide that requires lifelong treatment–monitoring–care (Barnard et al. 2010; Malerbi et al. 2012; Herbert et al. 2015a, b). At first glance, pathophysiology and control of the disease seem simple; however, when confronted with T1DM, its control is found to be complex and difficult (Di Meglio et al. 2018). Control of T1DM includes insulin shots 2–4 times a day or by using an insulin pump, monitoring blood glucose values, planning of a regular diet, and physical activity (Bowes et al. 2009; Malerbi et al. 2012; Herbert et al. 2015a, b). Knowledge of how to control T1DM is necessary in order for families to control their children's blood glucose value and to enable children to control their blood glucose value by themselves. Although T1DM can be controlled with the improved technology and knowledge in recent years, there is still a significant morbidity. Acute (life-threatening) and chronic complications occur in children with T1DM, and parents have to manage these complications (Bowes et al. 2009).

Highlights
- Parents claimed a moderate care burden.
- The younger the child, the higher the burden of care for the parents.
- There is a need for healthcare professionals to provide more education to the patient and their relatives about the disease.

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Published online: 21 February 2022

Control of T1DM in children is managed by parents (Barnard et al. 2010; Malerbi et al. 2012; Herbert et al. 2015a, b; Keklik et al. 2020). In fact, parents control T1DM completely until the child reaches the age of 8, then together with the child between the ages of 8–11, and continue to support during adolescence while still taking the major care burden (Barnard et al. 2010). To be both the caregiver and the parent of a child who is diagnosed with T1DM is difficult and complicated. Parents take charge of caregiver responsibilities that are perceived to be multidimensional (such as emotional, physical, and social) in addition to household chores and parenthood responsibilities. When caregiver's responsibilities accelerate, the relationship of caregiver and caretaker can turn into a one-way, dependent, intense and long-term obligation that causes difficulty to the caregiver's life (Erdem et al. 2013). Starting and maintaining new routines, learning new information, and developing functional coping strategies for the child are considered to be burdens for parents whose child is diagnosed with T1DM (Barnard et al. 2010). Due to the fact that children who are diagnosed with T1DM and their parents face various difficulties in terms of controlling the disease emotionally and socially, their caregiver burden accelerates. Foremost among these are controlling blood glucose value (hypoglycemia), providing growth and development based on the child's developmental stage, planning for "picky eating", preventing any possible complications, balancing between physical activity and nutrition, and decreasing the negative impact of the disease on the child's quality of life (Ginsburg et al. 2005;Herbert et al. 2015a, b; Harrington et al. 2017; Commissariat et al. 2020). Caregiving to a child who is diagnosed with T1DM affects the life of parents in every way, and results in an increased need for help and support. Depending on the acceleration of a caregiver's burden, anxiety, depression, stress, chronic sadness, fear, distress, shock, sorrow, grief, sadness, disappointment, guilt, accusation, insecurity, somatization, and post-traumatic stress disorder symptoms may occur (Ginsburg et al. 2005;Herbert et al. 2015a, b; Harrington et al. 2017; Commissariat et al. 2020).

It is important that health-care workers get involved when parents' resources come to an end, and some problems occur depending on the accelerating caregiver's burden (Er 2006; Commissariat et al. 2020). It is important that health workers provide appropriate and timely emotional support to parents and help them by taking the ongoing caregiver's burden into consideration (Bowes et al. 2009). It is more likely that parents who have been trained well by the health workers can apply all the treatment methods that were suggested and carry out all the applications that required to be done at home. Therefore, this education would allow the child who is provided constant and correct treatment and care to live a smooth life, thus decreasing the caregiver's burden (Er 2006).

Studies that indicate caregiver's age, gender, affinity to the child, whether he/she is willingly to give the care, education level, financial status, whether he/she has any health problem, his/her coping mechanisms, beliefs, social support, his/her access to health services and whether the cultural aspects of the society in which he/she lives affect the caregiver's burden are usually conducted with caregivers who provide care to adult patients. Studies that are related to children who are diagnosed with chronic diseases and caregiver's burden are limited and have mostly focused on the difficulties that parents had faced (Erdem et al. 2013). This study is aimed at examining the caregiver's burden in parents whose children have been monitored with T1DM diagnosis in a child endocrinology and metabolism polyclinic in a university research hospital.

Method

Type, location, and time of research

This cross-sectional and descriptive study was conducted between February 4 and June 30, 2019, at the polyclinic of child endocrinology and metabolism in a university research hospital located in Gaziantep.

Target population of the study and sample group

The target population of the study is composed of the parents of 132 children who were diagnosed with T1DM at the polyclinic of child endocrinology and metabolism in the university hospital in between the dates mentioned; the sample group is composed of 105 parents who participated in the research voluntarily and represented 79.54% of the target population of the study.

Data collection tools

Research data was collected through a personal data form and a Zarit Burden Interview.

Personal data form The personal data form was developed by the researchers in line with the knowledge of the literature (Ginsburg et al. 2005; Bowes et al. 2009; Barnard et al. 2010; Erdem et al. 2013;Herbert et al. 2015a, b; Harrington et al. 2017), and it consists of 27 questions in total. This form includes questions that are thought to affect sociodemographic aspects of children, mother, and father, and the caregiver burdens of parents whose children diagnosed with T1DM.

Zarit Burden Interview: The Zarit Burden Interview was developed by Zarit, Reever, and Bach-Peterson in 1980

(Zarit et al. 1980). It has been used for evaluating the difficulty of caregiving for people who provide care to the individuals who need care. The scale is composed of 22 questions that determine the impact of caregiving on the caregiver. The scale uses a 4-point Likert scale that ranges from 0 to 4: never (0), rarely (1), sometimes (2), often (3), and always (4). The total score for the items may range between 0 and 88, and a high score indicates the difficulty being experienced is high. Validity and reliability of the scale in Turkish was conducted by İnci and Erdem in 2008. In the studies conducted, it has been found that the internal consistency of the scale is between 0.87 and 0.94 and the test–retest reliability factor is 0.71 (İnci and Erdem 2008). The Burden Interview's Cronbach-alpha internal consistency factor is calculated to be 0.80 for this study.

Data collection

Data was collected during the daytime on weekdays when the polyclinic was operating on the dates mentioned. Written and verbal informed consents were taken by the researchers after providing parents of the children with the necessary explanations about the research. Data collection forms were collected by the researchers through face-to-face interviews.

Ethical considerations

Ethics committee approval from Hasan Kalyoncu University Faculty of Health Sciences (Ethics Committee Resolution No: 2019/05), research approval from university hospital (Research Approval No: 91786782/663.09/E5997), and verbal and written informed consents of all the parents who participated in the study were obtained. It was conducted in line with the Helsinki Declaration in all phases of the research.

Data analysis

Statistical software SPSS 24.0 (Statistical Package of Social Sciences for Windows) was used to analyze data. Categorical variables used in the analysis were given in numbers (percentage), while continuous variables were given as ± average standard deviation. Whether dispersion of continuous variables adjusted to the normal dispersion or not was controlled by using Kolmogorov–Smirnov and Shapiro–Wilk tests. For the data that show normal dispersion, *t*-test and unilateral variant analysis (ANOVA) were used in independent groups. For the data that did not show normal dispersion, Mann–Whitney U and Kruskal–Wallis tests were conducted. Cronbach's alpha was calculated for internal consistency. As the indicator for statistical significance, $p < 0.05$ value was set.

Limitations to the research

There are a few limitations to the research. The study was conducted in one center and some parents whose children are sick were not willing to allocate time for the research.

Results

It was observed that 61.9% of the parents were aged between 36 and 60, 81.9% of them were mothers, 61.9% of parents' educational status was primary school and below, 69.5% of mothers were not employed, 79.0% of fathers were employed, and 66.7% of the parents had three or more children (Table 1). It was determined that 65.7% of the children who were diagnosed with T1DM were female, 61.0% of them were aged between 6 and 12 years when first diagnosed with T1DM, the body weight of 41.0% and standing height of 41.9% were between 25 and 50 percentile values, 58.1% were diagnosed with T1DM 2–5 years ago, 84.8% did not have any coexisting disease (comorbidities), 59.0% monitored their blood glucose value a minimum of 6–10 times a day, 93.3% adjusted to insulin treatment, 55.2% applied insulin themselves, 83.8 had no difficulties while applying insulin, 67.6% had been affected negatively in their daily activities due to T1DM, 87.6% had refreshments 3 times per day, 62.9% were engaged in sport, 60.0% were perceived as vulnerable by their parents, and 85.7% had a monitoring frequency of once in 3 months. In this study, it was observed that 81.9% of the parents received T1DM training from a nurse together with their children, and 91.4% found that this training was sufficient (Table 1).

It was determined that the parents' average Burden Interview score in this study was 19.46 ± 6.31. When the relationship between parents' average Burden Interview score and relational features of children and their parents was examined, it was found that the Burden Interview average score of employed fathers (18.75 ± 9.14) was statistically significantly lower compared to unemployed fathers ($p = 0.02$). It was identified that the Burden Interview average score of the parents whose children were diagnosed with T1DM at the age range 3–5 was 72.22 ± 8.22 and statistically significantly higher compared to the average score of the parents whose children were diagnosed with T1DM in the age ranges 6–12 and 13–18 ($p = 0.006$). It is found that the Burden Interview average score of the parents whose children's diagnosis duration was between 1 month and 1 year was 24.67 ± 10.01, which was statistically significantly determined higher than the average score of the parents whose children's diagnosis duration was between 2 and 5 and 6–10 years ($p = 0.0001$). It was observed that the Burden Interview average score of the parents whose child had coexisting disease (comorbidities) (19.69 ± 8.86) was higher than the Burden Interview

Table 1 Dispersion of sociodemographic features concerning the child and parents ($n = 105$)

Features		*N*	%
Parents' age	17–35 age range	40	38.1
	36–60 age range	65	61.9
Which parent of the child is the caregiver	Mother	86	81.9
	Father	19	18.1
Parents' educational status	Primary and below	65	61.9
	High school and above	40	38.1
Employment status of the mother	Employed	32	30.5
	Unemployed	73	69.5
Employment status of the father	Employed	83	79.0
	Unemployed	22	21.0
Number of children	1–2 child(ren)	35	33.3
	3 children and above	70	66.7
Gender of the child	Female	69	65.7
	Male	36	34.3
Body weight percentile	3–10 percentile	24	22.9
	25–50 percentile	43	41.0
	75–97 percentile	38	36.2
Standing height percentile	3–15 percentile	27	25.7
	25–50 percentile	44	41.9
	75–97 percentile	34	32.4
How old he/she was when diagnosed with diabetes	3–5	9	8.6
	6–12	64	61.0
	13–18	32	30.5
Duration of diabetes diagnosis	1 month to1 year	28	26.7
	2–5 years	61	58.1
	6–10 years	16	15.2
Coexisting disease (comorbid)	Yes	16	15.2
	No	89	84.8
Control of blood glucose	2–5 times per day	43	41.0
	6–10 times per day	59	59.0
Adjustment to insulin treatment	Good	98	93.3
	Bad	7	6.7
Who applies insulin	Child	58	55.2
	Mother/father	47	44.8
Having difficulty while applying insulin	Yes	17	16.2
	No	88	83.8
Impact of the disease on the child's daily life	Negatively affecting	34	32.4
	Not affecting	71	67.6
Number of refreshments/meals	1–2 times per day	13	12.4
	3 times per day	92	87.6
Does the child engage in sport	He/she does	39	37.1
	He/dhe does not	66	62.9
Vulnerability perception of the parent	Vulnerable	63	60.0
	Not vulnerable	42	40.0
Monitoring frequency	Once in 3 months	90	85.7
	Once in 6 months	15	14.3
From whom T1DM training was received	Nurse	86	81.9
	Doctor	19	18.1
Sufficiency level of the training	Sufficient	96	91.4
	Not sufficient	9	8.6

average score of the parents whose child didnot have any coexisting disease (comorbidities) and the difference was statistically significant ($p=0.03$). It was determined that the Burden Interview average score of the parents who apply insulin to their children was 22.14 ± 9.95 and statistically significantly higher than the average score of the parents whose children applied insulin themselves ($p=0.01$). The Burden Interview average score of the parents who faced difficulty in applying insulin (24.58 ± 9.85) was statistically significantly higher than the average score of parents who stated no difficulty in applying insulin ($p=0.01$). The Burden Interview average score of the parents who stated that T1DM had negatively affected their child's daily life activities was 24.26 ± 7.68 and was determined to be statistically and significantly higher than the Burden Interview average score of the parents who stated that T1DM had no impact on their child's daily life activities ($p=0.0001$). It was observed that the Burden Interview average score of the parents who perceived their child as vulnerable was 21.74 ± 7.13, statistically significantly higher than the Burden Interview average score of the parents who did not perceive their child as vulnerable ($p=0.003$). It was determined that the Burden Interview average score of the parents who said that T1DM training was provided by a doctor (24.63 ± 4.65) was statistically significantly higher than the Burden Interview average score of the parents who said that T1DM training was provided by a nurse ($p=0.001$) (Table 2).

Discussion

Preventing children diagnosed with T1DM from developing acute or chronic complications depending on the disease, constantly monitoring their blood glucose level, regulating a diet, and helping the child to continue his/her life by adjusting to these differences are the parents' responsibility. In this study, we have presented the data from the research conducted in the polyclinic of child endocrinology and metabolism in a university research hospital that examined the caregiver's burden of parents whose children had been diagnosed with T1DM and were being monitored.

The caregiver burden of those parents whose children are T1DM patients may be increased depending on the difficulties of controlling the disease. Moreover, parents may often be worried about their children's future, long-term medical complications, economic problems, and control of the disease when their child is at school or is being cared by someone else. In this study, the caregiver burden of both the mothers and fathers was found to be moderately high, and it is considered that counseling and/or psychological and economic support should be provided for the parents to cope with the increasing caregiver's burden. Studies support this situation. In many studies, it has been reported that the care burden of parents with children with diabetes is increased (Malerbi et al. 2012; Moreira et al. 2013; Erdem et al. 2013; Commissariat et al. 2020; Keklik et al. 2020). In this study, the caregiving burden of parents whose children were diagnosed with T1DM was determined to be moderate.

Studies have also reported that the low economic status of a family and the absence of a job for one of the parents have a negative effect on the burden of care. It has been determined that the care burden of parents with low economic status is high (Piazza-Waggoner et al. 2008; Lindley and Mark 2010; Kobos and Imiela 2015). In this study, it was shown that there is a statistically significant difference in the Burden Interview average score based on the employment status of the father; the score where the father is unemployed is significantly higher. This result is in line with the findings of these other studies and affirms that having lower financial and social resources increases the caregiver burden of parents whose children have been diagnosed with T1DM.

Younger children are utterly dependent on the parents for the control of diabetes. On the other hand, the role of the parents for controlling T1DM is quite complicated, because preparing and applying low-dose insulin, monitoring early warning signals of hypoglycemia in the case of a child's inability to define and/or convey the symptoms depending upon child's limited communication channels and cognitive skills, a child's choosy eating, unpredictable physical activity, and lack of skill and experience of the parent may cause them to face distinctive difficulties. In our study, it was found that there was a statistically significant difference between the Burden Interview average score and the age when the child was diagnosed with T1DM. The Burden Interview average score of the parents whose children were diagnosed T1DM at ages between 3 and 5 was found to be higher than to the average score of the parents whose children were diagnosed at ages 6–12 and 13–18. This evidence may suggest that the younger the child is diagnosed, the higher the caregiver burden of the family becomes. This has also been observed in other studies. Many researchers have reported that parents with young children have a higher burden of care and worry about their children (Müller-Godeffroy et al. 2009; Moreira et al. 2013; Kobos and Imiela 2015; Harrington et al. 2017).

Control of T1DM requires lifelong treatment and regular monitoring. In this study, it was found that there is a statistically significant difference between the Burden Interview average score and the diagnosis duration of the child. It was shown that the Burden Interview average score of parents whose children were diagnosed with T1DM in the last 1 year was higher. In other studies, it has been stated that parents have difficulties when their child is diagnosed with T1DM, and the younger the child diagnosed with T1DM, the higher the caregiver burden of the parent (Smaldone and Ritholz 2011; Malerbi et al. 2012; Whittemore et al. 2012; Keklik et al. 2020).

Table 2 Comparison of the Burden Interview score and sociodemographic features concerning the child and the parent ($n = 105$)

Features		Burden Interview average ± SD	Significance
Parent's age	17–35 age range	18.20 ± 8.60	U = 2.52
	36–60 age range	20.24 ± 8.79	$p = 0.11$*
Which parent of the child is caregiver	Mother	18.96 ± 9.04	$t = 0.26$
	Father	21.73 ± 6.96	$p = 0.14$**
Parents' education status	Primary and below	18.89 ± 9.38	U = 1101.00
	High school and above	20.40 ± 7.59	$p = 0.18$*
Mother's employment status	Employed	20.75 ± 7.19	U = 919.50
	Unemployed	18.90 ± 9.32	$p = 0.08$*
Father's employment status	Employed	18.75 ± 9.14	U = 622.50
	Unemployed	22.13 ± 6.51	***p = 0.02****
Number of children	1–2 child(ren)	20.34 ± 8.28	U = 1099.00
	3 children or more	19.02 ± 8.98	$p = 0.39$*
Gender of the child with diabetes	Female	19.46 ± 8.19	U = 1183.00
	Male	19.47 ± 9.83	$p = 0.69$*
Body weight percentile	3–10 percentile	22.95 ± 8.16	$X^2 = 9.71$
	25–50 percentile	17.62 ± 9.92	$p = 0.08$****
	75–97 percentile	19.34 ± 7.04	
Standing height percentile	3–15 percentile	19.37 ± 7.67	$X^2 = 4.08$
	25–50 percentile	18.18 ± 9.39	$p = 0.13$****
	75–97 percentile	21.20 ± 8.59	
How old he/she was when diagnosed with diabetes	3–5 old	72.22 ± 8.22	$F = 5.34$
	6–12 old	19.65 ± 9.16	***p = 0.006*****
	13–18 old	19.46 ± 8.73	
Duration of the diabetes	1 month −1 year	24.67 ± 10.01	$F = 8.27$
	2–5 years	18.06 ± 7.83	***p = 0.0001*****
	6–10 years	15.68 ± 5.41	
Coexisting disease (comorbid)	No	19.69 ± 8.86	$t = 1.17$
	Yes	15.00 ± 3.53	$p = 0.03$**
Control of blood glucose	2–5 times per day	19.37 ± 10.00	U = 1247.00
	6–10 times per day	19.53 ± 7.82	p = 0.69*
Adjustment to insulin treatment	Compatible	19.17 ± 8.79	U = 217.00
	Incompatible	23.57 ± 7.27	$p = 0.57$*
Who applies insulin	Child	17.29 ± 6.97	U = 962.00
	Mother/Father	22.14 ± 9.95	***p = 0.01****
Having dificulty in applying insülin	Yes	24.58 ± 9.85	U = 460.50
	No	18.47 ± 8.20	***p = 0.01****
Impact of the disease on the child's daily life	Negatively affecting	24.26 ± 7.68	U = 556.50
	Not affecting	17.16 ± 8.31	***p = 0.0001****
Number of refreshments/meals	1–2 time(s) per day	22.84 ± 14.28	U = 534.50
	3 times per day	18.98 ± 7.64	$p = 0.53$*
Is the child engaged in sport?	Engaged	17.64 ± 6.38	$t = 1.17$
	Not engaged	20.54 ± 9.75	$p = 0.06$**
Parent's vulnerability perception	Vulnerable	21.74 ± 7.13	$t = 3.15$
	Not vulnerable	16.54 ± 9.47	***p = 0.003****
Monitoring frequency	Once in 3 months	19.42 ± 8.97	U = 640.50
	Once in 6 months	19.73 ± 7.65	$p = 0.75$*
From whom training was received	Nurse	18.32 ± 9.03	U = 349.50
	Doctor	24.63 ± 4.65	***p = 0.001****

Table 2 (continued)

Features		Burden Interview average ± SD	Significance
Sufficiency level of the training	Sufficient	19.01 ± 7.82	U = 360.00
	Not sufficient	24.33 ± 15.37	$p = 0.40$*
Total	**Min:17.77**	**19.46 ± 6.31**	**Max: 21.15**

* Mann–Whitney U, ** *t* test in independent groups,*** one-way ANOVA, **** Kruskal–Wallis

It is a known fact that diagnosing a co-existing disease with T1DM will be an additional burden and challenge. In this study, a statistically significant increase was found in the mean score of Burden Interview with a comorbidity (comorbidity). Other studies have shown that the burden of caregivers increases when there is another disease (comorbid) in a child with T1DM (Haugstvedt et al. 2011; Malerbi et al. 2012; Erdem et al. 2013; Commissariat et al. 2020; Keklik et al. 2020).

T1DM must be treated with insulin injection or intense insulin diets through subcutaneous insulin infusion. Children who are diagnosed with a T1DM require more than one daily insulin injection or constant subcutaneous insulin infusion to keep the blood glucose at the desired level by using fast, short-, medium- or long-term effective insulin combinations. Controlling this situation can be difficult for parents. In our study, there was found to be a statistically significant increase in the Burden Interview average score with regard to the person who applies insulin.

In our study, it was determined that the burden of parents who administered insulin to their children was higher. Other studies have shown that most of parents are overwhelmed by insulin therapy, show signs of depression, and are afraid of their children going into hypoglycemia(Patton et al. 2011; Malerbi et al. 2012). In this study, there was a statistically significant increase in the Burden Interview average score when the child had difficulty while insulin was administered. It was identified that children were noncompliant because they are scared, and the Burden Interview average scores of the parents of these children was higher. Parents stated that the problems mostly occur due to "fear". The child who resists due to fear pressures the parent and increases the caregiver burden of the parent.

Psychological and social development of a child/adolescent may also be negatively affected by T1DM, as observed in all chronic diseases. Enabling the child to develop the ability to control a lifestyle with T1DM not only decreases this negative impact but also controls the disease. With such an aim, not excluding the child from social activities, encouraging children to participate in activities outside the family, allowing the child to join common activities with his/her peers, and having a network of friends apart from the family can be suggested. In this study, it was determined that the Burden Interview average score of parents whose children's daily life activities were affected negatively by T1DM was higher. Parents bear most of the burden of treatment and care of a child who is diagnosed with T1DM, and this burden restricts the parents.

Vulnerable child syndrome is the state of constant anxiety by a parent perceiving his/her child as vulnerable although health problems during infancy and childhood have been dealt with or have been put under control. These parents have incorrect beliefs and perceptions about their children being vulnerable and exhibit protective and controlling behaviors towards their children. In our study, the Burden Interview average score of the parents who perceived their children as vulnerable was higher. In the study conducted by Findikkiran and Cigdem, it was stated that 75.5% of parents whose children were diagnosed with T1DM perceived their children as vulnerable (Fındıkkıran and Cigdem 2020). Parents who perceive their children as more special and vulnerable may have tried to control this situation with more anxiety than parents who do not perceive their children as vulnerable. Thus, it could be suggested that parents cannot function adequately, or that they could not be improved/supported by the team who monitors the child.

Care must be provided by a trained interdisciplinary expert team that is sensitive about the difficulties of parents, adolescents, and child with regard to controlling T1DM. Self-control and self-care have great importance in controlling the disease. Providing a diabetes self-control training/support that is culturally sensitive, is regulated in line with national standards, and is individualized according to developmental status is vital. In this study, it was determined that there was a statistically significant decrease in the Burden Interview average score of the parent when T1DM self-control training had been received. It was found that the caregiver burden of parents who received the training from a doctor is higher, and the caregiver burden of parents who received the training from a nurse is lower. According to this result, it can be said that diabetes nurses are more successful at this due to their communication skills and up-to-date knowledge regarding this issue and they provide more supportive information that will decrease the caregiver burden of the parents. In many studies, it has been reported that nurses are more beneficial than other health workers in

this regard (Bowes et al. 2009; Smaldone and Ritholz 2011; Commissariat et al. 2020).

Conclusion and recommendations

One significant conclusion of this study determined that parents with children with T1DM have a moderate caregiver burden, and parents whose children are diagnosed with T1DM at an earlier age have a higher caregiver burden. Additionally, it is concluded that the caregiver burden is affected by such factors as the Burden Interview, the age at which a child is diagnosed with diabetes, duration of diabetes, presence of coexisting disease (comorbidity), person who applies insulin, status of having difficulties while applying insulin, the fact that child is being perceived as vulnerable by the parents, and from which type of health worker T1DM training was received. In line with these conclusions, more research should be conducted that examines the impact of such features as family structure, intrafamilial relationships, environment, and social support that are thought to be affecting the caregiver burden of parents and child T1DM patients directly or indirectly.

Acknowledgements We would like to thank Rukiye Başţuhan, Fatma Mercandağı, Menekşe Işik, and Fatma Toprak, graduates of the 2020 Department of Nursing, who helped the students who answered the research questionnaires completely and with the data collection and data entry into the computer. The editing and/or editing of this article was done by native English speaker Brenda Lessen Knoll. Special thanks to Brenda Lessen Knoll for correcting the article: grammar, spelling, punctuation, sentence structure, phrasing, and style.

Financial support No financial support has been received for this article.

Author contributions Study conception and design: ZC, SG, MYC.
Data collection: ZC, SG, MYC.
Data analysis and interpretation: ZC, SG, MYC.
Drafting of the article: ZC, SG, MYC.
Critical revision of the article: ZC, SG, MYC.

Source of funding There are no funders for this study.

Declarations

Conflict of interest The authors declare no competing interests.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the studies.

Patient consent Patient consent was obtained from the participants in this study.

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