Parental monitoring status of the children with type 1 diabetes mellitus (DM) and their quality of life

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Abstract

Objective This study was carried out to determine the relationship between parental monitoring status of the children with type 1 DM and their quality of life.

Methods This descriptive-correlational type study was conducted in the pediatric endocrine outpatient clinic of a university hospital located in the northern region of Turkey and included 126 children with type 1 diabetes. The data of the study were collected with the "Parental monitoring of diabetes care scale (PMDC) in adolescents with type 1 diabetes" and "Pediatric quality of life inventory (PedsQL 3.0) diabetes module for children."

Results It was determined that 20.6% of the children were hospitalized for a reason related to diabetes and 7.1% received psychological support due to their disease. The mean score of the parents on the parental monitoring in diabetes care scale in adolescents with type 1 diabetes was found to be 65.40 ± 15.38, and the mean score on the pediatric quality of life inventory for children with type 1 diabetes was found to be 109.11 ± 16.99. No statistically significant correlation was determined between the parents' scores of the parental monitoring in diabetes care scale in adolescents with type 1 diabetes and the scores of the pediatric quality of life inventory for children with type 1 diabetes ($p > 0.05$).

Conclusion Although it was observed in the study that the levels of parental monitoring in type 1 diabetes care and pediatric quality of life were above the moderate level, parental monitoring was not found to affect children's quality of life.

Keywords Type 1 diabetes · Psychopathology · Parental monitoring · Quality of life

Introduction

Although the adolescence period is a period in which an individual's knowledge and self-care regarding type 1 diabetes can be at the highest level, it is also a period when the management and metabolic control of the disease are most difficult, and children and parents experience more problems. Studies have also shown that parents of children with type 1 diabetes experience problems with the management of the disease and have concerns about poor metabolic control during adolescence. In this context, parental monitoring and follow-up are especially important in chronic diseases such as type 1 diabetes [1]. Parental monitoring includes parental attitudes covering the communication between the adolescent and the parent and the importance given to the child's whereabouts, what he does, and the management of the disease. Another phase of parenting attitudes, that is the monitoring attitude, is the parent's knowledge of the activities that the adolescents do outside home. In type 1 diabetes, parental monitoring is expressed as a set of parental behaviors that include paying attention to monitoring the child's whereabouts, activities and compliances [2]. Studies have also stated that disease management and metabolic control will be better as parental monitoring increases [3–5]. It has been reported in a study by Ellis et al. that parental monitoring plays a protective role in adolescents with type 1 diabetes as well as in healthy adolescents [2]. Moreover, previous studies have shown that managing

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children's diabetic conditions requires changes in routines, diet, and lifestyle, and this new reality has direct implications for the entire family [1, 3, 6]. It is stated that parents of T1DM patients experience deep emotional distress; the daily routine may become a source of family discussions and conflicts; and especially adolescents may not always understand and meet parents' expectations regarding compliance with testing and care protocols [1, 5]. In addition, these families experience the difficulty of living with the constant threat of deterioration, repeated hospitalizations, and gradual loss of functionality, which creates additional stress and burden beyond the daily care of their children [3, 7]. Again, many studies have shown that treatment compliance and follow-up of the families of children with type 1 DM are effective in maintaining children's metabolic control [8–10].

Quality of life has become an important concept in the evaluation of children with chronic diseases. Chronic disease directly affects the individual's quality of life because it causes changes in lifestyle during the follow-up and treatment process of the disease [11]. Many studies have shown that the quality of life in children with diabetes is lower than in healthy children [12]. Quality of life reflects people's capacity and ability to manage diabetes treatment and achieve treatment goals. They appear to be effective in managing the disease, ensuring good metabolic control and preventing the development of secondary complications in children with diabetes who have a good quality of lifes [13]. When the quality of life is negatively affected in children with diabetes, they are at risk of psychological problems, decreased compliance with treatment, and also poor metabolic controls [11–14].

Studies have shown that parental support in the management of the disease in type 1 DM positively affects child's glycemic control, quality of life and general diabetes outcomess [10, 13, 15]. However, it has been observed that the effects of some characteristics of the parents (sociodemographic characteristics, communication characteristics, anxiety and anxiety states of the parents, and conflict situations) on the child's disease management (metabolic control, Hba1c levels, etc.) and quality of life were mostly investigated in the literature. No study has been found regarding the impact of the family's follow-up and monitoring of the disease on the child's quality of life. In this context, the study was carried out to determine the relationship between the disease monitoring status of the families of children with type 1 DM and the children's quality of life.

Material and methods

Study design

This was a descriptive and correlational-type study.

The study was carried out with children and their parents who admitted to pediatric endocrine outpatient clinic of a university hospital located in a large city in the northern part of Turkey and who were diagnosed with type 1 DM between September 2022–June 2023. The universe of the study was composed of 152 children with type 1 DM between 7 and 12 years old who were monitored for at least six months in this hospital for check up purposes; and the sample of the study included 126 children and their parents who brought their children to regular check-ups during the indicated time period. Participation rate was 83%. The following are the inclusion criteria: being able to read and write Turkish, having a child over 7 years old who has been monitored at least for 6 months due to the diagnosis of type 1 diabetes, and having no physical or psychological disease.

Data collection instruments

"Child-parent information form," "Parental monitoring in diabetes care scale in adolescents with type 1 diabetes," and "Pediatric quality of life inventory (PedsQL 3.0) diabetes module for children" were used as data collection instruments.

Child-parent information form

This form was developed by the researcher in line with the literature. It consists of questions including the sociodemographic characteristics of the families (5 questions) and the disease process (5 questions) [4, 16].

Parental monitoring in diabetes care scale in adolescents with type 1 diabetes (type 1 PMDC)

The scale, which was developed (2008) and revised by Ellis et al. (2012), and whose Turkish validity and reliability studies were conducted by Türk et al., consists of 27 items [2, 4, 17]. The scale is a five-point Likert type scale. "At least once a week" is scored as "1," and "more than once a day" is scored as "5." The highest score from the scale is 135, and the lowest score is 27; parental monitoring increases as the score increases. In the study conducted by Türk et al., the Cronbach alpha value of the scale was calculated as 0.85 [4]. In this study, it was found to be 0.89.

Pediatric quality of life inventory (type 1 PedsQL 3.0) type 1 diabetes module for children

The Turkish validity study of the scale, which was developed by Varni et al. (2001, 2003), was conducted by Ayar and Ozturk (2016) [18–20]. PedsQL 3.0 Diabetes Scale (28 items), which evaluates the quality of life in children with

type 1 and type 2 DM consists of five subscales including diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence (7 items), worry (3 items), and communication (3 items). In this five-point Likert scale, $0 = 100$ points indicate that it never creates a problem, $1 = 75$ points indicate that it rarely creates a problem, $2 = 50$ points indicate that it sometimes creates a problem, $3 = 25$ points indicate that it often creates a problem, and $4 = 0$ points indicate that it always creates a problem. Each item in the scale receives a score between 0 and 100, and it is thought that the higher the total score that can be obtained from the scale, the better the health-related quality of life is perceived. In the original child form of the scale, internal consistency coefficient of the total scale was 0.71; and the reliability coefficients of the subscales were found to be 0.81 for the diabetes symptoms, 0.66 for the treatment barriers, 0.66 for the treatment adherence, 0.63 for the worry, and 0.77 for the communication [19]. In this study, the internal consistency coefficient of the child form of the pediatric quality of life inventory diabetes module was found to be 0.88. In the study, the internal consistency coefficients for the subscales were found to be 0.83 for the diabetes symptoms, 0.45 for the treatment barriers, 0.82 for the treatment adherence, 0.81 for the worry, and 0.76 for the communication.

Implementation of data collection instruments

After obtaining the necessary ethics committee and institutional permissions to conduct the study, the researchers informed the parents about the study, and the parents who volunteered to participate were asked to fill out the necessary forms. The cover page of the data collection instruments is a document containing brief information about the research and obtaining the participant's voluntary consent in writing.

Ethical aspect of the study

Approval was obtained from the ethics committee of the relevant university to conduct the study (Date: 03.13.2020/ Ref. No: 2020–209). The data collection process in the study was initiated after obtaining the necessary ethics committee and institutional approval. Permission was also obtained for the scales used in the study. Additionally, written and verbal consents were obtained from the child and his/her family before the data collection forms were distributed.

Statistical analysis

The data were analyzed with SPSS 26.00 package program. While investigating the conformity of the variables for normal distribution, the skewness and kurtosis values of the scale scores were checked whether they were between $+1$ and -1, and it was determined that the data were not normally distributed. Descriptive statistics were carried out for the sociodemographic data. Differences between scale scores based on sociodemographic characteristics were analyzed using non-parametric tests (Mann-Whitney U, Kruskal Wallis test), and Spearman's correlation analysis was used to examine the correlation between the scales. When interpreting the results, the significance level was accepted as $p < 0.05$.

Results

91.3% of the parents participating in the research were mothers, and their mean age is 38.80 ± 4.71 years. The parents of 54% of the children were high school graduates, and the income of the family was lower than expenses in 56.3%. The mean age of the children is 9.94 ± 1.56 years, and 53.2% are females (Table 1).

It was determined that 49.2% of the children diagnosed with type 1 diabetes came for check-ups every 2–3 months and 94.4% were able to measure their own blood glucose. According to the statements of the parents, the rate of admitting to emergency service due to imbalance in the blood glucose of children in the last year was 11.9%, the rate of hospitalization for a diabetes-related reason was 20.6%, and the rate of receiving psychological support due to the disease was 7.1% (Table 2).

The mean score of parents on the parental monitoring in diabetes care scale in adolescents with type 1 diabetes was found to be 65.40 ± 15.38; and the mean score on the pediatric quality of life inventory for children with type 1 diabetes was found to be 109.11 ± 16.99. The mean scores of the subscales were found as 66.66 ± 15.00 for diabetes symptoms, 49.80 ± 20.01 for treatment barriers, 73.72 ± 22.45

Table 1 Sociodemographic characteristics of the parents and children

Parent's age ($X \pm$ SD) (min–max)		38.80 ± 4.71 (27–52)	
Child's age ($X \pm$ SD) (min–max)		9.94 ± 1.56 (7–14)	
		n	%
Parent's	Mother	115	91.3
	Father	11	8.7
Education status of the parents	Elementary and secondary school	46	36.5
	High school	68	54.0
	University and higher	12	9.5
Income status	Income lower than expenses	71	56.3
	Income equal to expenses	31	24.6
	Income higher than expenses	24	19.0
Child gender	Female	67	53.2
	Male	59	46.8

Table 2 Disease process-specific data of the children diagnosed with type 1 diabetes

Disease-specific data		n	%
The frequency of coming for check up due to the diagnosis of type 1 diabetes	0–1 month	2	1.6
	2–3 months	62	49.2
	3–6 months	51	40.5
	7 months and more	2	1.6
	When the doctor calls	9	7.1
Status of child to measure his/her own blood glucose	Able to	119	94.4
	Not able to	7	5.6
Status of admitting to emergency service due to the imbalance in blood glucose in the last year	Yes	15	11.9
	No	111	79.4
Status of hospitalization due to a diabetes-related reason in the last year	Yes	26	20.6
	No	100	79.4
Status of receiving psychological support due to the diagnosis of type 1 diabetes	Yes	9	7.1
	No	117	92.9

Table 3 The scores of parental monitoring in diabetes care scale in adolescents with type 1 diabetes and the pediatric quality of life inventory diabetes module for children with type 1 diabetes

	$X \pm SD$ (min–max)
Parental monitoring in diabetes care scale in adolescents with type 1 diabetes (type 1 PMDC)	109.11 ± 16.99 (72–135)
Pediatric quality of life inventory diabetes module for children with type 1 diabetes (type 1 PedsQL 3.0)	65.40 ± 15.38 (12–90)
Diabetes symptoms	66.66 ± 15.00 (20–90)
Treatment barriers	49.80 ± 20.01 (0–93)
Treatment adherence	73.72 ± 22.45 (0–100)
Worry	62.16 ± 30.10 (0–100)
Communication	2.14 ± 1.19 (1–5)

X mean, *Sd* standard deviation, *Min* minimum, *Max* maximum

Table 4 The correlation between type 1 PMDC and type 1 PedsQL

		Type 1 PMDC
Type 1 PedsQL	r	−0.045
	p	0.621

for treatment adherence, 62.16 ± 30.10 for worry, and 2.14 ± 1.19 for communication (Table 3).

No statistically significant differences were found between type 1 PMDC and type 1 PedsQL scores based on the sociodemographic characteristics of the parent and the child and some disease-specific data. No statistically significant relationship was determined between the parents' scores on the parental monitoring in diabetes care scale in adolescents with type 1 diabetes and the scores on the pediatric quality of life scale diabetes module for children with type 1 diabetes ($p > 0.05$) (Table 4).

Discussion

Parental monitoring in diabetes management plays a vital role in preventing direct and indirect diabetes-related complications and improving long-term health outcomes; and

it is considered a strong indicator of adaptation to the disease [17, 21]. In this current study, the mean score of the parental monitoring in diabetes care scale in adolescents with type 1 diabetes was found to be above the moderate level (109.11 ± 16.99). Similarly, in a study conducted with parents of the adolescents with type 1 diabetes, the mean score of the parent diabetes monitoring scale was found to be above the moderate level (97.2 ± 15.2). In a study conducted in Poland, it was observed that some socioeconomic factors such as the income level of the families and living in the city center affected the follow-up and monitoring of the children by the families [22]. Another study showed that families experienced more concerns; and therefore, complied with treatments more as the age of the child decreased [23].

Chronic diseases are conditions that negatively affect the quality of life, are physically exhausting, cause negative emotional and spiritual effects on the child and their families, and require serious psychosocial support. In the current study, the mean score of the pediatric quality of ife inventory diabetes module for children with type 1 diabetes was found to be above the moderate level (65.40 ± 15.38). In literature reviews, it has been reported that quality of life scores varies between 59.2 and 73.8, and the development levels of countries are also effectives [13, 24, 25]. Studies have determined that the life quality of children diagnosed with different chronic diseases is lower than healthy children [26–30]. In addition, studies have also shown that children with diabetes have a lower quality of life compared to healthy children s

[12, 13, 16, 31, 32]. Duras et al. (2018) stated that the life quality of children diagnosed with type 1 diabetes mellitus is significantly lower than that of healthy childrens [27]. In the study by Bozbulut et al. (2022), quality of life was found to be 69.6 ± 14.9 compared to an adolescent [16].

This study showed that child and parent characteristics did not affect the life quality of the children with diabetes. Studies have shown that the quality of life of children with type 1 DM is affected by sociodemographic characteristics (age, gender) and some clinical indicators (HBA1c, frequency of hypo- and hyperglycemia attacks, etc.) [11, 13, 24, 25, 31, 33–35]. In an international cohort study, it was determined that three diabetes self-management behaviors (increasing the frequency of daily blood glucose monitoring, using carbohydrate counting, and exercising for at least 30 min per week) were significantly associated with better quality of life [36]. It has been observed that the low education level of the parents of children with type 1 diabetes and the presence of diabetes-specific family conflict negatively affect their quality of life [36]. In a study conducted in Brazil with a group of adolescents with type 1 DM between the ages of 10 and 19 years, it was determined that their quality of life was high; but the time since diagnosis, female gender, low family income, and parental education level affected their quality of life [37]. In a study conducted in Spain, it was determined that the quality of life was also negative in older children (> 11 years old) and patients with poor metabolic control [11]. Sundberg et al. (2014) found in their study that the life quality of underage children with type 1 DM was significantly lower than that of healthy children [33]. Moreover, in the study by Anderson et al. (2017), it was observed that the lowest quality of life was in the 19–25-year-old age group and female gender among the 8–12-, 13–18-, and 19–25-year-old age groups diagnosed with type 1 DM [36]. Additionally, studies have shown that the quality of life levels reported by the parents of children with diabetes is lower than the quality of life reported by their children [24, 32–34].

The study showed that parental monitoring in diabetes care did not affect the quality of life in children with type 1 diabetes. In another study, it was determined that the quality of life increased as parental monitoring increased [16]. In the study by Gorzny including adolescent patients with type 1 DM, it was found that adolescents, whose mothers followed their disease process more, had a higher quality of life than those who reported that their mothers monitored less; and it was also detected that adolescents had less depressive symptoms when their mothers participated in the diabetes management process more [15]. In a study conducted with adolescents with type 1 DM between the ages of 12 and 18 years, it was determined that adolescents who perceived that their parents had authoritarian parenting styles adapted better to the prescribed treatment plans and had a better perceived quality of life [38]. Besides, another study conducted with children with diabetes and their families showed that

increased family conflict and less parental supervision negatively affected the child's diabetes self-care and glycemic control [21].

Study limitations

The limitations of the study are that it was conducted in a single center, and thus, the results cannot be generalized for Turkey. Again, since the research data were collected during the COVID-19 period, this resulted in the participation of fewer children with diabetes and their families coming to the outpatient clinic for check up. Comprehensive multicentric studies are needed in this field.

Conclusions

Although it was observed in the study that the levels of parental monitoring and quality of life for the children with type 1 diabetes were above the moderate level, parental monitoring was not found to affect children's quality of life.

Due to the effects of parental attitudes of children with diabetes on adaptation to the disease and quality of life, psychopathology, parental attitudes, perceptions of quality of life, and their relationship with each other should be taken into consideration in the monitoring of the disease in children with chronic diseases as well as DM. In order for school-age children with diabetes not to feel excluded, the school health nurse should provide informative trainings including the family and teachers (Duras et al., 2018). In addition, it is important for diabetes nurses, who contribute to the disease process together with children, to plan and implement initiatives to encourage parental monitoring in diabetes management. It is thought that these initiatives will contribute to preventing or reducing health behaviors and family conflicts that will negatively affect the adolescent's quality of life in the future.

Declarations

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