DOI: 10.4274/jcrpe.galenos.2023.2022-8-4

Research article

Chronic Disease Management of Children Followed with Type 1 Diabetes Mellitus

Running title: Type 1 Diabetes Chronic Disease Management

Senay Guven Baysal1, Nurdan Ciftci2, Ismail Dundar2, Mehmet Akif Buyukavcı3, Fatma Hilal Yagin4, Emine Camtosun2, Derya Gumuş Dogan3, Aysehan Akinci2
1Developmental and Behavioral Pediatrics Unit, Gazi Yaşargil Training and Research Hospital Diyarbakır, Turkey
2Pediatric Endocrinology Unit, Department of Pediatrics, Faculty of Medicine, Inonu University, Malatya, Turkey
3Developmental and Behavioral Pediatrics Unit, Department of Pediatrics, Faculty of Medicine, Inonu University, Malatya, Turkey
4Department of Biostatistics and Medical Informatics, Faculty of Medicine, Inonu University, Malatya, Turkey

What is already known on this topic?
The daily life of the child with type 1 diabetes mellitus (T1DM) and their family usually functions normally, to the extent that the family is able to manage the chronic illness and cope with the difficulties experienced. Improving the management of the disease may be possible by evaluating the possible future effects of the disease.

What this study adds?
High education level, increase in family income, use of an insulin pump and longer duration since diagnosis positively affected the management of T1DM and the daily life of the child with T1DM . However, the presence of chronic diseases other than T1DM negatively affects diabetes management.

ABSTRACT
Objective: With the diagnosis of chronic illness in children, a stressful period is likely to begin in children and their families. The aim of this study was to investigate the factors affecting chronic disease management by the parents of children with T1DM diagnosed with Type 1 Diabetes Mellitus (T1DM).
Methods: The sample consisted of 110 children, aged between 4-17 and their mothers. The patients had been diagnosed with T1DM for at least one year, and had attended pediatric endocrinology outpatients or were hospitalized in a single center. First, sociodemographic information about the child with T1DM were obtained. Then, the "Family Management Measure" (FaMM) was applied. The FaMM is constructed to measure family functioning and management in families who have a child with a chronic illness.
Results: Paternal years of education *(p*=0.036*)*, family income *(p*=0.008*)*, insulin pump use *(p*=0.011*)*, time elapsed after diagnosis *(p*=0.048*)* positively affected both the management of T1DM and the child's daily life but presence of chronic diseases in addition to T1DM *(p*=0.004*)* negatively affected diabetes management. Higher maternal education year *(p*=0.013*)* and family income level *(p*=0.001*)* increased parental mutuality scores. However, as the time after diagnosis increased, parental mutuality scores decreased.
Conclusion: It is important to evaluate the child with chronic disease with a biopsychosocial approach. This approach aims to evaluate the problems of the child and his/her family who experience the disease with a holistic approach.
Keywords: Type 1 diabetes mellitus, chronic disease, children, family management measure

Senay Guven Baysal, MD, Developmental and Behavioral Pediatrics Unit, Gazi Yaşargil Training and Research Hospital Diyarbakır, Turkey
0000-0002-5454-923X
+90 505 365 72 60
24.08.2022
20.01.2023

Published: 26.01.2023

INTRODUCTION

Mokkink et al have provided a consensus definition of childhood chronic disease, consisting of four criteria as follows: "a disease or condition is considered to be a chronic condition in childhood if: (1) it occurs in children aged 0 up to 18 years; (2) the diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods or instruments according to professional standards; (3) it is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment; and (4) it has been present for longer than three months or it will, very probably, last longer than three months, or it has occurred three times or more during the past year and will probably reoccur" (1). As stated in the Turkey Chronic Diseases and Risk Factors Survey, the prevalence of chronic diseases is increasing rapidly in our country, as well as globally (2). In recent years, the prevalence of chronic diseases in children has increased and now affects around 12%-16% of children (3). It is estimated that this frequency is between 10-15% in the population under the age of thirteen. If children with mental, emotional, learning and behavioral problems are included in this, the incidence of chronic disease can increase up to 30-40% (4). In the thesis study conducted by Mustafayev in 2019, investigating the risks impairing child development in our country, it was reported that having a chronic disease had the highest risk rate among the independent risk factors identified (5).
Type 1 diabetes mellitus (T1DM) is a chronic metabolic disease characterized by insulin deficiency and hyperglycemia, which occurs when beta cells of the pancreas are affected by autoimmune or non-autoimmune pathologies (6). The estimated prevalence of diabetes among children and adolescents has also been increasing in recent years globally (7). It is estimated that there are approximately 20,000 children under the age of 18 living with T1DM in Turkey and at least 15,000 of these are of school age and around 1500-1700 children are diagnosed with T1DM each year (8). The overall mean incidence of T1DM was 16.7/100 000 persons per year. The regional incidence rates of T1DM varied from 10.2 to 24.1/100 000 persons per year, between 2009 and 2019 (9).
The diagnosis of chronic illness in children is likely to be accompanied by increased stress, both for the affected child and their families. Thus, this affects the entire family system. The daily life of both the child and the family usually functions normally, to the extent that the

Uncorrected proof

family is able to manage the illness and cope with the difficulties (10). However, they often need the help of healthcare professionals in their efforts to manage the disease.

Incorporating the management of a chronic disease into the mechanisms of family life and making it a natural part of daily life is possible when the child's disease care needs have been fully identified, strategies for the management of the disease have been developed, routines have been established and the possible future effects of the disease have been evaluated. To date, there is no published study in Turkey concerning the factors affecting chronic disease management of families of children with T1DM. The aim of this study, which was undertaken in İnönü University Faculty of Medicine, Departments of Developmental Pediatrics and Pediatric Endocrinology, was to investigate the factors affecting chronic disease management of the parents of children with T1DM.

Materials and Methods

The study center serves as a referral hospital in the East and Southeast regions of Turkey. Children who were admitted to the pediatric endocrinology outpatient clinic or who were hospitalized and diagnosed with T1DM at least 1 year previously and their families were eligible for the study. A one-year duration since diagnosis ensured that the child and family had time to understand the reality of the diagnosis and develop an approach to condition management. Exclusion criteria were maternal caregivers who could not read or speak Turkish. Ethics committee approval for the study was obtained from İnönü University Health Sciences Research and Publication Ethics Committee (Approval number: E-129717/ 06/01/2022).

At the beginning of the interview, the principal researcher explained the purpose, content, duration, and how the descriptive study would be conducted to the mothers of the children who met the sampling conditions. The consent form was read aloud or read to the families, and their informed written consent was obtained by asking whether they would like to participate. Subsequently, a face-to-face interview was conducted by the researcher with the mothers who consented to participate. It was emphasized throughout the process that participation was voluntary. First, sociodemographic information and information about the child with T1DM were obtained. Then, the "Family Management Measure" (FaMM) was completed with the mothers. The duration of the interview was between 22-47 minutes. The author conducted the data collection between January 2022 and April 2022. In addition, an invitation to participate in the study was sent to the social media group for T1DM patients followed in the pediatric endocrinology outpatient clinic. The invitation to participate included the contact details of the first and second authors. Parents were given the option to complete an online or print version of the questionnaire. If they completed the survey online, the consent form was issued as part of the online survey. Parents were encouraged to contact the correspondent author if they had any questions or concerns. All data were checked by the researcher and transferred to a database.

Data Collection Tool

Family Management Measure (FaMM)

The FaMM is constructed to measure family functioning and management in families who have a child with a chronic illness. The FaMM has good internal consistency, measured by Cronbach's alpha, ranging from 0.72 to 0.90 for mothers (10). The Turkish validity and reliability studies of the scale, which was originally in English, were carried out by Ergün et al (11). Data were collected from a total of 395 parents with a child diagnosed with chronic disease. The general content validity index was 95% and the results were found to be valid, reliable, appropriate and satisfactory for Turkish culture and psychometric characteristics. The Turkish version of the scale, which originally consisted of 53 items and six sub-dimensions, consists of 42 items and three sub-dimensions (see Table 1). Each item in the scale is scored using a five-point Likert scale. There are reverse scored items in each sub-dimension.

High scores in the sub-dimension of disease management and the child's daily life (19 questions) indicate a more normal life and that families find themselves more capable with disease management. High scores in the sub-dimension (16 questions) related to life difficulties and the occurrence of disease effects indicate that the situation is more serious and more difficulties are experienced. The last sub-dimension is related to parental mutuality (7 questions). High scores indicate that parents are working together for the child's disease management. The Cronbach's alpha of the first dimension was 0.68, while for the second dimension this was 0.76 and for the third dimension it was 0.80.

The sub-dimensions focus specifically on how chronic disease management is incorporated into daily life, how families define family life in the context of a child's chronic illness, and key aspects of management. The aim is to explain the perspectives of families about the management activities of their children's disease and how they make sense of them. The sub-dimensions also contribute to the development and testing of interventions to change problematic aspects of family management and strengthen aspects that support optimal child and family outcomes.

Statistical Analysis

Categorical (qualitative) variables were expressed as numbers (percentage). Quantitative variables are summarized as mean ± standard deviation (SD) and median and interquartile range (25th to the 75th quartile). Mann-Whitney U, independent groups t, one-way ANOVA and Kruskal Wallis tests were used where appropriate. Spearman rank correlation coefficient was calculated for the variables thought to be related to the scale scores. Statistical tests with a $p<0.05$ were considered significant. All statistical analyzes were performed using IBM SPSS for Windows, version 26.0 (IBM Inc., Armonk, NY, USA) (12).

Results

The sample consisted of 110 children, aged between 4-17 years, and their mothers. Of the children, 63 (57.3%) were girls and 47 (42.7%) were boys. The mean age of the mothers of the children was 38.5±6.0 years, and the mean age of the fathers was 42.9±6.5 years. Other sociodemographic data is given in Table 2.

The median (IQR) time after diagnosis of T1DM was 29.92 (16.3-54.7) months. Ninety-eight (89.1%) of the children were going to school and 87 (79.1%) of the families reported that they regularly visited the outpatient clinic. Most (n=93, 84.5%) of the families had received diabetes training. Eighteen of the children (16.4%) were using an insulin pump. Chronic disease other than T1DM had been diagnosed in 14 of the children (12.7%). Pubertal staging at the last hospital visit showed that 47 (42.7%) were in the prepubertal stage and 63 (57.3) were in the pubertal stage. Hemoglobin A1c (HbA1c) levels in the previous one year were analyzed from file records and assessed according to The International Society for Pediatric and Adolescent Diabetes (ISPAD) 2018 criteria which are: target HbA1c <7, therefore below 7% is considered good control, between 7% and 9% is considered moderate control and above 9% is considered bad control. Based on these criteria 27 (24.5%) patients were in the bad control group, 59 (53.6%) were in the moderate control group and 24 (21.8%) were in the good control group.

When the families were asked what challenges they faced with T1DM, they reported regulating the diet of their children (n=76, 69%), monitoring blood sugar (n=60, 54%), regulating meals (n=55, 50%), adjusting insulin doses (n=45, 41%), exercising (n=45, 41%) and difficulties in obtaining drugs and materials (n=31, 28%).

FaMM scale scores are given in Table 3-4-5. There was a significant difference in condition management and child's daily life scores when comparing the groups stratified by presence or absence of other chronic disease (p=0.004), the years of education of the father (p=0.036), the income level of the family (p=0.008), insulin pump use (p=0.011), and time since diagnosis (p=0.048) (Table 3). There was no statistically

Uncorrected proof

significant difference between the groups of the variables in terms of Family life difficulty and view of condition impact score (Table 4). Significant variables affecting parental mutuality scores were limited to years of education of the mother (p=0.013) and the income level of the family (p=0.001) (Table 5).

On correlation analysis, two significant relationships were identified. The first was a negative correlation between duration since diagnosis (months) and parental mutuality score (Spearman rank (r)=-0.204, p=0.033). Thus, as duration from diagnosis increases there appears to be a decrease in parental co-operation. Secondly, a positive correlation was found between HbA1c level and time after diagnosis (months) (r=0.275, p=0.004).

Discussion

When diagnosed with a chronic illness, sick children and their families face a variety of challenges (13). The daily life of both the child and the family functions normally, as long as the family is able to manage the illness and cope with the difficulties experienced. It has been shown that variables, including family demographics, are closely related to the child's and family's adaptation to the disease and management outcomes (14).

In addition to the medical problems related to treatment and care in the period starting with the diagnosis of a chronic disease, limited economic resources are one of the problems encountered (15). In the review of Didsbury et al., which included 6957 children and young patients with T1DM, it was reported that there was a significant relationship between at least one socio-economic determinant and quality of life (16). These authors showed that low parental education and low income were associated with low quality of life in children with chronic diseases (16). In the present study, low disease management scores were associated with lower family income levels and when father had fewer years of education. If the income level is low, it will be difficult for the parents to adjust the family budget for their child's illness and to cope with the difficult treatment process (17). Having a high level of education will not only make it easier for fathers to manage the process, but it will also make it easier to adapt to the life-style changes. Interestingly, no relationship was found between maternal education level and disease management score, although there was an association with parental mutuality scores.

Chronic illness of a family member can also affect the relationship between all family members. When parents support each other, parents' trust in each other increases, but conflict between spouses causes stress and decreases parental motivation (18). In our study, there was a significant difference between the groups divided by maternal years of education and the income level of the family in the parental mutuality score. Parental mutuality appeared to increase as both the education level of the mother increased and the income level of the family increased.

It has been shown that conflicts between spouses, divorce, financial problems, lack of social support, and problems that may occur in family functionality may make it difficult for the child to adapt to the disease (19). Case et al conducted a prospective, longitudinal study of 127 children, aged 5–9 years and their parents, within 12 months of diagnosis of T1DM at two pediatric diabetes clinics in the USA and followed participants for 27 months. They found that as the time after diagnosis increased, parental mutuality decreased and parental conflict increased (20). The results of our study are consistent with these findings, because as the time after diagnosis increased, the parental mutuality score between parents decreased. We believe that this is the result of the financial problems that the family may face as the duration of chronic illness increases, the increasing anxiety caused by having a child who requires constant monitoring, and the decrease in the motivation to cope with the stress of the disease over time.

When a school-age child is diagnosed with T1DM, one of the first problems parents face is the difficulties in adapting school life to their child's illness (21). In the qualitative study of Beacham and Deatrick, using FaMM with thirty-two school-going children aged 8-13 with chronic illness, the children mentioned the effort they needed to deal with their illness, the difficulties in managing the illness during school days, and the illness disrupting school. Patients stated that disease management was much easier at weekends or on non-school days (22). However, in the present study, no significant association was observed between school attendance and disease management. In our country, the School Diabetes Program was started in 2010 as a part of the national diabetes program, and the program is continuing successfully (23, 24). It is likely that disease management did not fail in school in our patient group was the positive effect of this program, but the low number of individuals in the preschool group (n=12, 10.9%) may have affected the statistical comparison.

Parents are faced with multiple stressors during and after the diagnosis process. Life changes can affect family routines, relationships, and parenting styles, due to the long-term burden of the disease, dietary restrictions, medications, and frequent visits to outpatient clinics (25). In the present study, more than half of the families stated that they had difficulties in regulating their children's diet, blood sugar monitoring and regulating meals during T1DM follow-up. Given the complexity of prioritizing diabetes treatment goals in themselves, prioritizing goals in multiple chronic conditions can be a challenge for families. When co-management of concurrent chronic diseases is required, the remaining time and energy to care for diabetes can be significantly reduced. Even if the combined management of concurrent chronic diseases is not attempted, the control of diabetes-specific risk factors may be poorer and this may negatively affect patients and cause them to miss opportunities to improve their quality of life. In a qualitative study by Beacham et al., an example was given of a child athlete with both diabetes and asthma who had to stop frequently before, during, and after training or matches to control blood sugar levels or to take inhalation treatments, and that it was difficult to manage these two diseases (22). However, in the study of Hadhrami et al., in which 210 Omani adults diagnosed with T1DM and the factors affecting the self-management of diabetes were evaluated, it was reported that those with additional chronic diseases had better disease self-management than those without diabetes. They interpreted the reason for this as individuals with T1DM affected by other chronic diseases fear that their condition will progress or worsen and thus gave higher priority to necessary lifestyle changes (26). This contrasts with the findings in the present study, and others (22, 27) The presence of a chronic disease in addition to diabetes adversely affected disease management of the families. Considering the difficulty of prioritizing the treatment goals of diabetes, it seems reasonable to accept that having more than one chronic disease may pose an increased challenge for families, which may further complicate diabetes management.

The insulin treatment option to be used also has an effect on disease management. Insulin pump therapy can provide a more comfortable life style for the patient by eliminating continuous insulin injections during the day. In a cohort study by Karges et al., among patients younger than 20 years of age with T1DM and a duration of diabetes greater than one year, insulin pump therapy was associated with better glycemic control and lower risks of severe hypoglycemia and diabetic ketoacidosis in the last year of therapy compared to insulin injection therapy (28). When the data obtained from The International Pediatric Registry SWEET for 25,654 participants with T1DM between the ages of 1-18 were examined, lower HbA1c level, fewer diabetic ketoacidosis episodes and a lower rate of severe hypoglycemia were detected in the participants using pumps (29). Kardaş and Gürol found that children using insulin pumps achieved better metabolic control and their quality of life increased as HbA1c levels decreased (30). These findings provide evidence for improved clinical outcomes associated with insulin pump therapy compared to injection therapy in children, adolescents, and young adults with T1DM. These benefits to young patients are likely to facilitate disease management by the parents (28). The findings from the present study, that the use of an insulin pump positively affected disease management, are consistent with these earlier studies.

Uncorrected Proof

The first period after diagnosis is a period that requires rapid knowledge and skill acquisition for disease management by parents and children, including blood glucose monitoring, insulin administration and carbohydrate counting. This may complicate the establishment of effective parent-child cooperation and disease management for diabetes care. The study of Case et al. showed that children with a diagnosis of T1DM had significantly higher Diabetes Self-Management Questionnaire-Summary scores at 27 months, mostly reported by their mothers (20). In our study, a significant increase was found in the disease management scores of the parents at three years after diagnosis compared to earlierThis finding suggests that families experience difficulties in accepting and understanding T1DM in the first years after diagnosis.

HbA1c measurements are made to evaluate glycemic control in the follow-up of diabetes patients. Nirantharakumar et al. investigated HbA1c levels and the time elapsed since diagnosis in a study of 4525 patients diagnosed with T1DM from The Health Improvement Network database, between 1995 and 2015. HbA1c levels increased after diagnosis and started to stabilize after an average of five years after diagnosis (31). In our study, a positive correlation was found between HbA1c level and the duration (months-years) since diagnosis. This may be due to less stringent disease management over time, or it may be due to the result of falsely low assessment of HbA1c levels due to increased hypoglycemia rates in the early stages of the disease. Studies evaluating the time spent at target blood glucose with devices that measure blood glucose continuously will give more accurate results in this regard. Further studies are needed in this area.

Limitations

Firstly, all participants were treated in the same large children's hospital which may have led to homogeneity of participating families experience of disease follow-up and treatment, which in turn may have affected the FaMM scores. Secondly, we specifically requested the participation of mothers in our study, as we hypothesized that mothers would play an important role in the management of T1DM in their children. However, the views of other family members, in particular the patients themselves, but also their fathers, siblings and other relatives involved in disease management may have provided additional insights into disease management in this cohort. Future research to address the limitations of the current study is needed.

Conclusion

It is important to evaluate the child with chronic disease using a biopsychosocial approach. Such an approach aims to evaluate the problems of the child and his/her family who experience this disease through a holistic approach because the chronic disease experienced by the child is a difficult process that affects not only the child but also their families for many years. The aim should be to strengthen the patients, ensure the functionality of their families, and provide additional psychological, practical and emotional support to ameliorate the physical challenges of chronic illness. The use of FaMM provided a better understanding of the family unit by identifying the strengths that families and children develop, as well as their weaknesses, that will help improve the results of interventions.

Ethics

Ethics committe approval: The study was approved by InonuUniversity Ethics Committee (approval number:- E-27942812-100-129717)
Peer-review: Externally peer-reviewed.

Authorship Contributions

Medical Practices: Senay Guven Baysal, Nurdan Ciftci, Mehmet Akif Buyukavci, Ismail Dundar, Emine Camtosun, Derya Dogan, Aysehan Akinci
Concept: Senay Guven Baysal, Nurdan Ciftci, Mehmet Akif Buyukavci, Ismail Dundar, Derya Dogan, Aysehan Akinci
Design: Senay Guven Baysal, Nurdan Ciftci, Mehmet Akif Buyukavci, Ismail Dundar
Literature Search: Senay Guven Baysal, Nurdan Ciftci
Data Collection or Processing: Senay Guven Baysal, Nurdan Ciftci
Analysis or Interpretation: Fatma Hilal Yagın, Senay Guven Baysal, Nurdan Ciftci
Writing: Senay Guven Baysal, Nurdan Ciftci, Mehmet Akif Buyukavci, Ismail Dundar

References

1. Mokkink LB, van der Lee JH, Grootenhuis MA, Offringa M, Heymans HS. Defining chronic diseases and health conditions in childhood (0-18 years of age): national consensus in the Netherlands. European journal of pediatrics. 2008;167(12):1441-7.
2. Türkiye Cumhuriyeti Sağlık Bakanlığı Türkiye Halk Sağlığı Kurumu. Türkiye Kronik Hastalıklar ve Risk Faktörleri Sıklığı Çalışması 2013. Yayın no: 909.
3. Raphael JL, Rueda A, Lion KC, Giordano TP. The role of lay health workers in pediatric chronic disease: a systematic review. Academic pediatrics. 2013;13(5):408-20.
4. Çavuşoğlu H. Çocuk sağlığı hemşireliği Cilt 1. Ankara; Sistem Ofset Basımevi 2011; 71-90.
5. Mustafayev R. Gelişimi İzleme ve Destekleme Rehberi Uluslararası Standardizasyon Çalışması'nın Türkiye örnekleminde gelişimsel risklerin belirlenmesi. T.C. Ankara Üniversitesi Tıpta UzmanlıkTezi, Ankara, 2019.
6. Ogurtsova K, da Rocha Fernandes J, Huang Y, Linnenkamp U, Guariguata L, Cho NH, et al. IDF Diabetes Atlas: Global estimates for the prevalence of diabetes for 2015 and 2040. 2017;128:40-50.
7. Lawrence JM, Divers J, Isom S, Saydah S, Imperatore G, Pihoker C, et al. Trends in prevalence of type 1 and type 2 diabetes in children and adolescents in the US, 2001-2017. 2021;326(8):717-27.
8. Yeşilkaya E, Cinaz P, Andıran N, Bideci A, Hatun Ş, Sarı E, et al. First report on the nationwide incidence and prevalence of Type 1 diabetes among children in Turkey. Diabetic medicine : a journal of the British Diabetic Association. 2017;34(3):405-10.
9. Esen I, Okdemir D. Trend of type 1 diabetes incidence in children between 2009 and 2019 in Elazig, Turkey. Pediatr Diabetes. 2020;21(3):460-5.
10. Knafl KA, Deatrick JA, Havill NL. Continued development of the family management style framework. Journal of family nursing. 2012;18(1):11-34.
11. Ergun A, Sisman FN, Erol S, Gur K, Kolac N, Kadioglu HJJopn. The family management of childhood chronic conditions: measurement in a Turkish sample. 2019;47:e16-e23.
12. IBM SPSS Statistics for Macintosh, Version 26.0.
13. Knafl K, Deatrick JA, Gallo A, Dixon J, Grey M, Knafl G, et al. Assessment of the psychometric properties of the family management measure. 2011;36(5):494-505
14. August GJ, Realmuto GM, Joyce T, Hektner JM. Persistence and desistance of oppositional defiant disorder in a community sample of children with ADHD. J Am Acad Child Adolesc Psychiatry .1999;38(10):1262-70.
15. Erdem E, Korkmaz Z, Tosun Ö, Avcı Ö, Uslu N, Bayat M. The burden of care in the mothers of the children with chronic disease. JHS. 2013;22(2):150-7.

Uncorrected proof

16. Didsbury MS, Kim S, Medway MM, Tong A, McTaggart SJ, Walker AM, et al. Socio-economic status and quality of life in children with chronic disease: A systematic review. J Paediatr Child Health. 2016;52(12):1062-9.
17. Hood A, Grange DK, Christ SE, Steiner R, White DA. Variability in phenylalanine control predicts IQ and executive abilities in children with phenylketonuria. Mol Genet Metab. 2014;111(4):445-51.
18. Han JW, Lee HJBp. Actor and partner effects of parenting stress and co-parenting on marital conflict among parents of children with atopic dermatitis. 2020;20(1):1-10.
19. Soliday E, Kool E, Lande MB. Psychosocial adjustment in children with kidney disease. J Pediatr Psychol. 2000;25(2):93-103.
20. Case H, Williams DD, Majidi S, Ferro D, Clements MA, Patton SR.. Longitudinal associations between family conflict, parent engagement, and metabolic control in children with recent-onset type 1 diabetes. BMJ Open Diabetes Res Care 2021;9(1):e002461..
21. Glaab LA, Brown R, Daneman D. School attendance in children with Type 1 diabetes. Diabetic medicine : a journal of the British Diabetic Association. 2005;22(4):421-6.
22. Beacham BL, Deatrick JA. Children with chronic conditions: perspectives on condition management. Journal of pediatric nursing. 2015;30(1):25-35.
23. Hatun Ş. National childhood diabetes program activities in Turkey. Journal of clinical research in pediatric endocrinology. 2015;7(1):1-6.
24. Hatun Ş, Mutlu GY, Gökçe T, Avcı Ö, Yardım N, Aycan Z, et al. Care and Support of Children with Type 1 Diabetes at School: The Turkish Experience. 2021;13(4):370.
25. Hatzmann J, Valstar MJ, Bosch AM, Wijburg FA, Heymans HS, Grootenhuis MAJAP. Predicting health-related quality of life of parents of children with inherited metabolic diseases. 2009;98(7):1205-10.
26. Al-Hadhrami R, Al-Rawajfah O, Muliira J. Diabetes Self-Management and the Associated Factors Among Adult Omanis with Type 1 Diabetes. Sultan Qaboos Unıv Med J. 2020;20(4):e339
27. Piette JD, Kerr EAJDc. The impact of comorbid chronic conditions on diabetes care. 2006;29(3):725-31.
28. Karges B, Schwandt A, Heidtmann B, Kordonouri O, Binder E, Schierloh U, et al. Association of Insulin Pump Therapy vs Insulin Injection Therapy With Severe Hypoglycemia, Ketoacidosis, and Glycemic Control Among Children, Adolescents, and Young Adults With Type 1 Diabetes. Jama. 2017;318(14):1358-66.
29. Cardona-Hernandez R, Schwandt A, Alkandari H, Bratke H, Chobot A, Coles N, et al. Glycemic Outcome Associated With Insulin Pump and Glucose Sensor Use in Children and Adolescents With Type 1 Diabetes. Data From the International Pediatric Registry SWEET. Diabetes care. 2021;44(5):1176-84.
30. Kardaş G.N, Gürol A. İnsülin Kalemi ve Pompası Kullanan Tip 1 Diyabet Hastası Çocuklarda Metabolik Kontrol ve Yaşam Kalitesi Düzeyleri. Kocaeli Üniversitesi Sağlık Bilimleri Dergisi. 2022; 8(1):65-71.
31. Nirantharakumar K, Mohammed N, Toulis KA, Thomas GN, Narendran P. Clinically meaningful and lasting HbA(1c) improvement rarely occurs after 5 years of type 1 diabetes: an argument for early, targeted and aggressive intervention following diagnosis. Diabetologia. 2018;61(5):1064-70

Table 1 Psychometric properties of Turkish version of the FaMM (42 items).

Factors and items
Condition management and child's daily life
1. Our child's everyday life is similar to that of other children his/her age.
2. In the future we expect our child to take care of the condition.
3. Taking care of our child's condition is often overwhelming.
4. We have some definite ideas about how to help our child live with the condition.
5. Our child is different from other children his/her age because of the condition.
6. It is difficult to know when our child's condition must come first in the family.
7. We are looking forward to a happy future with our child.
8. When something unexpected happens with our child's condition, we usually know how to handle it.
9. Our child's friendships are different because of the condition.
10. We feel we are doing a good job taking care of our child's condition.
11. People with our child's condition have a normal length of life.
12. We often feel unsure about what to do to take care of our child's condition.
13. We have not been able to develop a routine for taking care of our child's condition.
14. Even though our child has the condition, we have a normal family life.
15. We have goals in mind to help us manage our child's condition.
16. It is difficult to fit care of our child's condition into our usual family routine.
17. Dealing with our child's condition makes family life more difficult.
18. We know when our child needs to be a child.
19. I am unhappy about the way my partner and I share the management of our child's condition.
Family life difficulty and view of condition impact
20. Our child's condition is like a roller coaster with lots of ups and downs.
21. Our child's condition is the most important thing in our family
22. It is very hard for us to take care of our child's condition
23. Because of the condition, we worry about our child's future.
24. We have enough money to manage our child's condition.
25. A condition like the one our child has makes family life very difficult.
26. Our child's condition rarely interferes with other family activities.
27. Our child's condition will be harder to take care of in the future.
28. We think about our child's condition all the time.
29. It seems as if our child's condition controls our family life.
30. It is hard to get anyone else to help us with our child's condition.
31. It takes a lot of organization to manage our child's condition.

Uncorrected proof

32. We are sometimes undecided about how to balance the condition and family life.
33. It is hard to know what to expect of our child's condition in the future.
34. Our child would do better in school if he/she didn't have the condition.
35. A condition like the one our child has makes it hard to live a normal life.

Parental mutuality

36. We are confident that we can take care of our child's condition
37. We are a closer family because of how we deal with our child's condition.
38. I am pleased with how my partner and I work together to manage our child's condition.
39. My partner and I argue about how to manage our child's condition.
40. My partner and I consult with each other before we make a decision about our child's care.
41. My partner and I have similar ideas about how we should be raising our child.
42. My partner and I support each other in taking care of our child's condition.

uncorrected proof

Table 2. Descriptive statistics on children and family

Age of child, (mean±SD)	10.83±3.81	
Order of child Median (25-75% percentiles)	2 (1-2)	
Number of children Median (25-75% percentiles)	3 (2-3)	
Mother education years, (mean±SD)	10.09±4.66	
Father education years, (mean±SD)	11.30±4.31	
Mother working status n (%)	Working	19 (17.27)
	Not working	91 (82.73)
Father working status n (%)	Working	88 (80)
	Not working	22 (20)
Family income level, n (%)	Less than minimum wage	25 (22.73)
	Minimum wage*	47 (42.73)
	More than minimum wage	38 (34.55)
Family structure, n (%)	Nuclear family	87 (79.09)
	Extended family	16 (14.55)
	Broken family	7 (6.36)
Place of residence, n (%)	City	67 (60.91)
	Suburbs	32 (29.09)
	Village	11 (10)
Type of accommodation, n (%)	Apartment	82 (74.55)
	Other	28 (25.45)
Contact with endocrinologist, n (%)	Yes	61 (55.45)
	No	49 (44.55)
Health insurance status, n (%)	Yes	87 (79.09)
	No	23 (20.91)
Access to diabetes nurse, n (%)	Yes	94 (85.45)
	No	16 (14.55)

* Minimum wage: The lowest wage level that can legally be paid to workers. In January 2022 this was 4,253 TL per month.

uncorrected proof

Table 3. Comparison of Turkish FaMM subscale scores for condition management and child's daily life.

		Condition management & child's daily life		
		Mean ± SD	Median (25th - 75th quantile)	*p*-value
Gender	Girl		65 (57-70)	0.53*
	Boy		67 (55-72)	
School status	Pre-school	62.1±8.2		0.37**
	School group	65.2±11.5		
Presence of other chronic disease	Yes	56.8±11.6		**0.004****
	No	66.0±10.7		
Mother education years	Eight years and below	63.6±11.4		0.25**
	More than 8 years	66.0±10.9		
Father education years	Eight years and below	61.8±10.5		0.036**
	More than 8 years	66.5±11.3		
Family income level	Lower than minimum wage		59.5(52-67.5)	**0.008*****
	Minimum wage		65(54-71)	
	More than minimum wage		67(63-75)	
Use of insulin pump	Yes	71±9.5		**0.011****
	No	63.6±11.1		
Regular outpatient visits	Yes	64.6±10.9		0.63**
	No	65.9±12.4		
Received diabetes education	Yes	65.3±11.6		0.28**
	No	62.2±8.4		
Disease control ****	HbA1c >9.0% (poor control)		62(56-74)	0.90***
	HbA1c 7.0 to ≤ 9.0% (moderate control)		67(55-73)	
	HbA1c <7.0% (Good control)		66.50(61.5-69)	
Pubertal stage	Prepubertal period	63.7±9.8		0.34**
	Pubertal period	65.7±12.1		
Post diagnosis period	Less than three years	62.4±9.5		**0.048****
	Over three years	67.4±13.3		

**Mann-Whitney u test*
*** Independent sample t test*
**** Kruskal Wallis test*
***** According to ISPAD 2018* (ISPAD: The **International Society for Pediatric and Adolescent Diabetes**)

Uncorrected proof

Table 4. Comparison of Turkish FaMM subscale scores for family life difficulty and view of condition impact.

		Family life difficulty and view of condition impact		
		Mean ± SD	Median	*p*-value
Gender	Girl	56.7±13.2		0.38**
	Boy	54.5±12.7		
School status	Pre-school	59.7±12.8		0.26**
	School group	55.3±13.0		
Presence of other chronic disease	Yes	59.5±13.0		0.25**
	No	55.2±13.0		
Mother education year	Eight years and below		57(45-67)	0.943*
	More than eight years		55(48-65)	
Father education year	Eight years and below	57.5±12.3		0.287*
	More than eight years	54.8±13.3		
Family income level	Lower than minimum wage		58(46-69)	0.59***
	Minimum wage		58(47-66)	
	More than minimum wage		53.5(45-65)	
Use of insulin pump	Yes		56(41-61)	0.29*
	No		57(47.5-67.5)	
Regular outpatient visits	Yes	55.66±13.28		0.81*
	No	56.30±12.24		
Received diabetes education	Yes		57(45-66)	0.392*
	No		54(52-68)	
Disease control *****	HbA1c >9.0% (poor control)	56.67±14.90		0.27****
	HbA1c 7.0 to ≤ 9.0% (moderate control)	53.98±12.81		
	HbA1c <7.0% (Good control)	58.96±10.60		
Pubertal stage	Prepubertal period	57.1±12.3		0.36**
	Pubertal period	54.8±13.5		
Post diagnosis period	Less than three years		57(48-68)	0.22*
	Over three years		57(45-63)	

**Mann-Whitney u test*
*** Independent sample t test*
**** Kruskal Wallis test*
***** One-way Anova test*
****** According to ISPAD 2018* (ISPAD: The **International Society for Pediatric and Adolescent Diabetes**)

Uncorrected proof

Table 5. Comparison of Turkish FaMM subscale scores for parental mutuality.

		Parental Mutuality	
		Median (25th - 75th quantile)	*p*-value
Gender	Girl	27(23-31)	0.65*
	Boy	28(23-31)	
School status	Pre-school	29.5(20.5-31)	0.85*
	School group	27(23-31)	
Presence of other chronic disease	Yes	24.5(20-31)	0.28*
	No	28(23-31)	
Mother education year	Eight years and below	26(20.5-30)	**0.013***
	More than eight years	29(26-32)	
Father education year	Eight years and below	26(23-31)	0.294*
	More than eight years	28(23-31)	
Family income level	Lower than minimum wage	24(19.5-27.5)	**0.001*****
	Minimum wage	28(23-31)	
	More than minimum wage	30.5(27-33)	
Use of insulin pump	Yes	27.5(26-29)	0.87*
	No	28(22-31)	
Regular outpatient visits	Yes	28(23-31)	0.51*
	No	27(22-31)	
Received diabetes education	Yes	28(23-31)	0.38*
	No	27(22-30)	
Disease control ****	HbA1c >9.0% (poor control)	28(24-31)	0.85***
	HbA1c 7.0 to ≤ 9.0% (moderate control)	27(21-31)	
	HbA1c <7.0% (Good control)	27.50 (24.5-30.5)	
Pubertal stage	Prepubertal period	28(23-31)	0.84*
	Pubertal period	28(23-31)	
Post diagnosis period	Less than three years	28(24-31)	0.25*
	Over three years	27(21.5-31)	

**Mann-Whitney u test*
*** Independent sample t test*
**** Kruskal Wallis test*
***** According to ISPAD 2018* (ISPAD: The **International Society for Pediatric and Adolescent Diabetes**)

uncorrected proof