

Psychosocial Factors and the Role of Family in Children with Type 1 Diabetes Mellitus

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Keywords

Diabetes mellitus type 1 · Psychosocial aspects · Family conflict · Glycemic control

Abstract

Purpose: The psychosocial aspects of type 1 diabetes mellitus (T1DM) are still a neglected area, especially among children in India. This study was planned to evaluate and screen the children with T1DM for family support, symptoms of anxiety and depression, and to assess the role of these psychosocial aspects in glycemic control. **Methods:** This cross-sectional observational questionnaire-based study conducted over a year included 70 children aged 8–18 years diagnosed with T1DM for at least a year. The child and caregiver answered pre-validated standard questionnaires and the children underwent HbA1C testing once every 3 months. The methods used for inferential statistical analysis were reliability analysis, correlation analysis, χ^2 test, and factor analysis. **Results:** Poorer glycemic control was noted by children raised by single parents (mean HbA1C 14.4, $p < 0.001$). It was also noted that children whose mothers had formal education beyond 10th standard had better glycemic control. 14 children (20%) had anxiety/depression of medium to high severity. The relationship between family

conflict and glycemic control was not significant in either the parent or the child scoring. **Conclusion:** Children with T1DM experience considerable stress related to the diagnosis and management. Many families experience significant depression and anxiety which leads to increase in family conflicts which have a negative effect on parenting, the child's quality of life, and their glycemic control.

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Introduction

Type 1 diabetes mellitus (T1DM) is a metabolic disorder that necessitates ongoing insulin therapy [1]. Children, teenagers, and parents face challenges because diabetes is a chronic and progressive condition that requires special care to manage. The Diabetes Control and Complications Trial has demonstrated the long-term advantages of early intensive glycemic control (DCCT) [2, 3]. In India, the incidence of type 1 diabetes is found to be 10.5/100,000 annually, with the peak incidence occurring between the ages of 10 and 12. The incidence of 3.7/100,000 boys and 4.0/100,000 girls is reported from South India [4].

Even highly motivated patients who have T1DM find it challenging to meet the demands of self-management. As managing T1DM entails numerous finger pricks for blood glucose monitoring, multiple injections, carbohydrate counting, anxiety regarding hypoglycemia prevention, the requirement to calculate insulin dosage and make adjustments every day of their lives, patients must have a high level of commitment [5, 6].

The first peak of T1DM occurs between the ages of 4 and 6; the second peak occurs in the early stages of adolescence. Considering its dramatic onset in childhood or early adulthood, T1DM can be a stressful condition. Blood glucose levels that are seriously abnormal could be fatal, and long-term complications could have a negative impact on one's career and create employment issues [7]. Disorders of eating, mood, anxiety, and behavior were found to be twice as likely to be diagnosed in children with T1DM when compared to peers without diabetes, based on evidence from population-based cohort studies [8].

Due to the changes that are taking place in the biological make-up and in how he or she interacts with the socioeconomic environment, the adolescent stage is of particular concern to parents and caregivers. Inability to cope with these changes may cause emotional distress, which can lead to depression or anxiety. A chronic illness may have a significant impact on an adolescent's overall well-being and may make it more difficult for them to manage daily tasks. Therefore, a teen with a chronic illness must be able to adjust to changes in their biological and intellectual make-up while also being able to handle the stress associated with having a chronic illness and the treatment of it. Teens find it challenging to be compatible, which puts them at risk for many problems like depression, anxiety, and other psychological issues [9]. Recent therapeutic developments have made managing diabetes easier. However, despite progress in patient education, adherence to recommendations that call for lifestyle changes is still low [10].

It has been demonstrated that psychosocial factors impact the etiopathogenesis and treatment of T1DM. The bidirectionality in the relationship between T1DM and psychosocial well-being has been emphasized by studies [11]. Because they have an impact on the management, symptom severity, and treatment compliance of chronic conditions like T1DM, psychosocial factors associated with these conditions are crucial [12]. Psychiatric disorders in adolescence have been linked to diabetes as a risk factor, particularly for internalizing behavioral issues like depression [13].

The psychosocial effects of T1DM, particularly in children, are still largely ignored. Numerous social and economic issues prevent India from providing adequate

patient-centered care. Awareness regarding the psychological effects of a chronic illness like T1DM is lacking among doctors, patients, and caregivers. The purpose of the present study was to assess the family support, anxiety and depressive symptoms, and the role of these psychosocial factors in glycemic control in children with T1DM.

Methodology

The hospital-based observational study was carried out from November 2020 to November 2021. The study participants were T1DM children who visited the pediatric OPD at a tertiary care facility in Bangalore, Karnataka. 70 child-parent pairs were enrolled in the study by convenience non-probability sampling. A questionnaire was administered after receiving approval from the Institutional Ethical Committee.

Children between the ages of 8 and 18 who had been diagnosed with T1DM in accordance with the ISPAD 2018 recommendations and had been following-up regularly were included. Exclusion criteria:

- 1: Presence of a chronic illness other than T1DM
- 2: Major psychiatric or neurocognitive disorder in the child or in the parents

Parent-child duo who gave written informed consent was enrolled in the study, and assent was obtained in children above 12 years. Demographic data and details regarding blood glucose monitoring, insulin regimen, and dose of insulin were noted. Once enrolled, the child and caregiver were administered with pre-validated standard questionnaires (as mentioned below) by the principal investigator. The questionnaires were translated to Kannada and Tamil which were the local languages spoken and validated again. The questionnaires were scored and interpreted accordingly. All the included children underwent HbA1c testing once every 3 months as a part of routine follow-up, for which 2 mL blood was drawn into an EDTA tube and sent to the laboratory for evaluation. Questionnaires used:

Revised Child Anxiety and Depression Scale [14] (short version): to identify youth needing anxiety and depression treatment. The total score of the RCADS-25 will be calculated by assigning 0–3 to the response categories of “never,” “sometimes,” “often,” “always,” respectively.

The responses to the Revised Child Anxiety and Depression Scale were analyzed by tallying the sum of all 25 items. The Total Anxiety subscale is the sum of items 2, 3, 6, 7, 9, 11, 12, 14, 17, 18, 20, 22, 23, and 25. The Total Depression subscale is the sum of items 1, 4, 8, 10, 13, 15, 16, 19, 21, and 24. The total scores were converted to T-scores and account for the gender and grade of each child. In all instances, a higher score reflects a greater degree of symptom severity. Converted scores on the total scale and both subscales are divided into scoring ranges, where: (a) scores below 65 represent low severity (no referral treatment indicated), (b) scores between 65 and 70 represent medium severity and are on the borderline clinical threshold, and (c) scores above 70 represent high severity and are above the clinical threshold.

Table 1. Clinical and demographic data of the studied patients ($n = 70$)

Variable	
Age, years (mean, SD)	12.87±2.2
Gender, female, n (%)	41 (58.5)
Duration of diabetes, years	5.163±0.48
HbA1c, %	10.71±2.42
Insulin	
Intermediate plus short acting, n (%)	58 (82.8)
Short plus long acting, n (%)	12 (17.1)
SMBG/fortnight	15±2.3
Hospitalization, n (%)	4 (5.7)
Clinic visits in the last year	5.2±1.4

Updated and Revised Diabetes Family Conflict Scale [15]: to identify the degree of conflict between participant and the family regarding diabetic management of the participant. Both participant and caregiver were administered with the questionnaire separately. The level of family conflict related to diabetes-specific tasks was rated on a 3-point Likert scale (1 = never argue, 2 = sometimes argue, and 3 = always argue), yielding a scale range of 19 to 57 (19 = no conflict to 57 = high level of conflict).

Statistical Analysis

Based on the number of children with T1DM who visited our endocrinology OPD annually over the previous 5 years based on the previous records, the sample size for our study was determined in relation to the number of T1DM patients living in our region. Formula used (Slovin's formula):

$$\frac{N}{1 + Ne^2},$$

N = population count – 225 (the population is restricted to the venue of the study), e = degree of precision – 10%. Hence, $n = 70$. All the tests were carried out at 5% level of significance.

Frequency was used to describe categorical information like gender, caregiver education level, and insulin regimen (percentage). Age, time since diagnosis, BMI, HbA1c, and other continuous data were expressed as mean or median with standard deviation depending on the data's normality.

The results of the diabetes family conflict questionnaire and the revised child anxiety and depression scale, which underwent descriptive analysis, were presented as proportions. The socio-demographic variables' relationships with the chosen study variables were examined. Reliability analysis, correlation analysis, 2-sample t -test, the χ^2 test, and factor analysis were the techniques used for inferential statistics.

Results

Data were collected from 70 T1DM parent-child pairs. Table 1 details the clinical and demographic information of the subjects under investigation.

Education beyond tenth grade was common to both the mothers and fathers, according to the comparison (37%). 27 (38%) of the mothers were working mothers, while 43 (61.4%) were stay-at-home moms. In total, 59 patients (84.28%) were teenagers, and 11 patients (15.7%) were children.

Diabetes Management of the Children

Our patients were given insulin supplies for 2 months only; hence, the majority of our patients ($n = 63$, 90%) required five or more hospital visits in a year. When compared to children in the age group of 8–10 years (9.1 ± 0.86), mean HbA1c was higher in the age group of 10–18 years (11.01 ± 2.49). The majority of the children ($n = 58$, 82.8%) were on a combination of short-acting insulin (human regular insulin) and isophane insulin, 10 (14.28%) were on basal bolus regimen with Actrapid and glargine, and only 2 of them (2.8%) were on Actrapid and insulin degludec.

According to the department protocol, the majority of the children ($n = 68$, 97.1%) monitored their blood sugar levels at least 6 to 7 times per day for minimum 3 days a week. Three of them (4.2%) needed to be hospitalized due to intercurrent illness and diabetic ketoacidosis, and only one (1.4%) of them needed to be admitted due to persistent hypoglycemia.

Psychosocial Factors' Effects on T1DM Management

It was also noted that children with mothers who had formal education beyond the 10th grade had better glycemic control. The children raised by a single parent ($n = 4$, 5.7%) had poorer HbA1c (mean = 14.4; p 0.001) when compared to those children raised by both the parents.

As shown in Table 2, high severity cases of depression and anxiety were found in 2 (2.86%) patients each, while medium severity cases of depression and anxiety were found in 3 (4.29%) patients and 2 (2.86%) children, respectively. These children were identified, and referred to the psychologist for additional counseling and therapy.

According to the results of the Updated and Revised Diabetes Family Conflict Scale, which was given to both parents and children, 23 (32.8%) of the children had higher conflict (score >38). 22 (31.4%) of the parents reported having a lot of conflict.

According to Table 3, consolidated scoring was performed with the criteria that when a specific question received the same score from the parent and the child, the score was kept as it is, and if they disagreed, the score was assigned as 0. The frequency table was then drawn accordingly.

The results of the factor analysis are listed in Table 4 as direct management tasks and indirect management tasks,

Table 2. RCADS – total depression, anxiety, and anxiety and depression

Groups (T-score)	Total depression	Total anxiety	Total anxiety and depression
Low severity (<65)	66 (94.29)	65 (92.86)	65 (92.86)
Medium severity (65–70)	2 (2.86)	3 (4.29)	1 (1.43)
High severity (>70)	2 (2.86)	2 (2.86)	4 (5.71)
Total	70 (100)	70 (100)	70 (100)

Table 3. Updated and Revised Diabetes Family Conflict Scale

RDFCS (Consolidated)	Difference of opinion	Almost never	Sometimes	Almost always
1	27 (38.57)	13 (18.57)	26 (37.14)	4 (5.71)
2	26 (37.14)	19 (27.14)	21 (30.00)	4 (5.71)
3	34 (48.57)	15 (21.43)	8 (11.43)	13 (18.57)
4	35 (50.00)	13 (18.57)	8 (11.43)	14 (20.00)
5	28 (40.00)	19 (27.14)	20 (28.57)	3 (4.29)
6	40 (57.14)	13 (18.57)	8 (11.43)	9 (12.86)
7	26 (37.14)	18 (25.71)	16 (22.86)	10 (14.29)
8	23 (32.86)	17 (24.29)	23 (32.86)	7 (10.00)
9	30 (42.86)	16 (22.86)	18 (25.71)	6 (8.57)
10	28 (40.00)	22 (31.43)	15 (21.43)	5 (7.14)
11	29 (41.43)	20 (28.27)	14 (20.00)	7 (10.00)
12	28 (40.00)	21 (30.00)	16 (22.86)	5 (7.14)
13	26 (37.14)	21 (30.00)	18 (25.71)	5 (7.14)
14	32 (45.71)	12 (17.14)	20 (28.57)	6 (8.57)
15	23 (32.86)	20 (28.57)	25 (35.71)	2 (2.86)
16	26 (37.14)	20 (28.57)	20 (28.57)	4 (5.71)
17	26 (37.14)	24 (34.29)	14 (20.00)	6 (8.57)
18	25 (35.71)	13 (18.57)	30 (42.86)	2 (2.86)
19	23 (32.86)	20 (28.57)	16 (22.86)	11 (15.71)

which are the two components that were produced. Cronbach alpha was enlisted to assess each component's consistency. The Updated and Revised Diabetes Family Conflict Scale, as entered by children, also underwent factor analysis.

Relationship between Children's Glycemic Control and Psychosocial Factors

Age, T-score for total anxiety and depression showed positive correlation and was significant, whereas RDFCS scores for child and parent had positive correlation which was not significant (Table 5). It was noted that the children with depressive and anxiety symptoms had a poorer glycemic control, mean HbA1c of 14.8 ($p = 0.005$). Although we anticipated that families with more diabetes-related family conflict would have worse glycemic control, neither the parent nor the child scoring's p value indicated that this was the case.

Discussion

The patient must adhere to a consistent treatment schedule in order to manage their diabetes. Therefore, it is important to keep an eye on psychosocial factors that have an impact on self-care, such as diabetes distress (burdens that are associated with diabetes, its treatment, and worries about negative outcomes), socioeconomic background, other psychological states and health literacy. All children with diabetes need to be evaluated at the first visit and then on a periodic basis during follow-up even in the absence of a patient-specific indication in order to detect setbacks early and prevent health deterioration [16, 17]. In addition, both the children and the parents agreed that it increased their conflict (according to the Diabetes Family Conflict Scale). Our study revealed that parents of children with T1DM believe that

Table 4. Updated and Revised Diabetes and Family Conflict Scale (Parents) – factor analysis

Question	Direct management tasks	Indirect management tasks
Direct management tasks, $N = 11$, $\alpha = 0.821$		
1 – Remembering to give shots	0.131	-0.020
2 – Taking more or less insulin depending on results	0.071	-0.036
3 – Remembering to check blood sugars	0.186	-0.067
4 – Remembering clinic appointments	0.181	-0.048
5 – Giving shots or boluses	0.134	-0.001
6 – Meals and snacks	0.205	-0.131
7 – Results of blood sugar monitoring	0.148	0.004
9 – What to eat when away from home	0.104	
15 – Supplies	0.081	0.070
17 – Rotating injection sites or infusion sets	0.144	-0.038
19 – Logging blood sugar results	0.130	0.029
Indirect management tasks, $N = 8$, $\alpha = 0.795$		
8 – The early signs of low blood sugar	0.049	0.086
10 – Making appointments with doctors	0.036	0.125
11 – Telling teachers about diabetes	-0.047	0.232
12 – Telling friends about diabetes	-0.146	0.266
13 – Carrying sugar/carbs for reactions	-0.012	0.194
14 – School absences	0.065	0.077
16 – Telling relatives about diabetes	-0.110	0.260
18 – Changes in health (weight or infections)	0.022	0.138
Total $\alpha = 0.856$		

Table 5. Association of the variables with HbA1c

Variables	Pearson correlation	Conclusion	p value
Age (in years)	0.304	Low degree of positive correlation	0.011 (significant)
Total depression (T-score)	0.556	High degree of positive correlation	<0.001 (significant)
Total anxiety (T-score)	0.544	High degree of positive correlation	<0.001 (significant)
RDFCS (child) total score	0.125	Low degree of positive correlation	0.304 (not significant)
RDFCS (parent) total score	0.002	Low degree of positive correlation	0.988 (not significant)

diabetes introduces several changes to the family dynamics. However, we did not find an optimum relationship between higher familial conflict negatively affecting the glycemic control, and this was probably because majority of our patients were from rural areas and belonged to joint families which ensured ongoing involvement of a caregiver in spite of parent-child conflict. The actual number of children with diabetes who had anxiety or depression was on the lower side; this could be attributed to the strengths within the Indian family groups such as being a part of a joint family with whom the caregiver and child could share their thoughts and distress with. This could also be due to the society which plays a supportive and understanding role. Studies have shown that psychological distress in parents of children with T1DM was related to lower child self-reports of quality of life, higher child self-reports of stress, depressive symptoms, and problematic child behavior. Detrimental effects of parental psychological distress on the management of diabetes has been emphasized upon [18]. Young people and their families are put under additional stress due to the requirement for strict blood glucose control, particularly if they are unable to achieve and maintain a good glycemic control [19].

As in the study by Anderson et al. [20], adolescents in our study had significantly higher HbA1c levels (poorer glycemic control), which is likely related to the fact that parents of this group were less involved in the administration of insulin shots and monitoring blood glucose levels. Teenagers may be more at risk of not receiving good parental involvement that has been associated with good management adherence and glycemic control. It has been determined that there is a “vulnerable period” for the emergence of family and psychological issues that lasts for about 2 years after the diagnosis of T1DM. In those families where there was high conflict, it may be best to intervene early to promote positive family interactions which aid in the better management of T1DM [21].

Numerous studies have discovered that adolescents glycemic control tends to deteriorate as they have poorer control when the parents abdicate their duty to manage diabetes in their adolescents early. This occurs when kids manage diabetes on their own when they are not mature enough to handle it. Therefore, parental involvement must continue throughout adolescence [20]. But when doing so, it is crucial to remember that it is not always advantageous because excessive involvement can harm the adolescent’s capacity for adaptation [22].

The prevalence of psychosocial problems was found to be 20% in a study by Agrawal et al. [23], which was comparable to our study in which we discovered anxiety and depression in 20% of the children of medium to high severity. T1DM children were found to have lower overall self-esteem scores and higher defensiveness scores on the lie scale [24]. In their study, Mc Grady and Hood discovered that adolescents with T1DM had a prevalence rate for depressive symptoms that was twice as high as that of adolescents who were otherwise healthy [25]. In numerous studies, the percentage of parents reporting psychological distress ranged from 10% to 74%, with an average of 33.5% reporting it at diagnosis and 19% reporting it one to 4 years later [18]. 116 children with T1DM and 73,508 healthy children were compared in a large population-based study conducted in Brazil on adolescents. The findings revealed that mental health symptoms were more prevalent in children with T1DM [26].

A positive sense of self-efficacy, a sense of usefulness, the ability to take care of oneself, adequate coping mechanisms, the ability to make decisions and solve problems under the stress of managing a chronic illness, and the capacity for self-reflection are the main protective factors that may help a child with diabetes cope with the disease [27, 28]. Overall self-esteem and social support have been linked positively to adjustment and negatively to stress; as a result, both factors work to lower stress and thus increase the likelihood that T1DM will be managed well during childhood [29].

We think that uniformity was attained in the administration of questions because only one researcher administered it. One of our study’s limitations was the small sample size.

Large-scale studies must be conducted in order to develop standardized tools that can help us in the periodic evaluation of psychological status of the child and the family regarding diabetes management. Children with T1DM may have better glycemic control and overall well-being if timely interventions are made after categorically identifying conflict and psychological stressors. The second major limitation is that while correlating the HbA1c and family psychosocial support and conflict, we have not been able to account for the impact of missed insulin therapy due to factors such as the family running out of insulin supplies, glucometer strips, or their inability to procure them due to financial constraints.

Conclusion

The demands of treatment and management, as well as the trauma of diagnosis, cause children with T1DM and their parents a lot of stress. The majority of the families experience significant levels of psychological distress, including signs of depression, anxiety, and post-traumatic stress, despite the fact that many of them find routines and other sources of support to help them manage this stress. These symptoms are detrimental to parenting, the child's quality of life, and their ability to control their blood sugar. Families in conflict may be easier to spot if parents have a better understanding of what it is like to raise a child with T1DM.

Statement of Ethics

This study has been approved by the Institutional Ethical Committee of Indira Gandhi Institute of Child Health. All procedures performed in the study were in accordance with the ethical standards of the Institutional Research Committee and with the 1964 Helsinki Declaration and its later amendments. Informed written consent was obtained from all the individual participants included in the study. Approval number: IGICH/ACA/PG-MD (PED)/EC-01/2020-21/742. Approval date: 21st January 2020.

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Conflict of Interest Statement

None of the authors have a conflict of interest regarding this manuscript.

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Author Contributions

Conceptualization, formal analysis, and methodology: Dhanya Soodhana Mohan and Vani HN; data curation: Dhanya Soodhana Mohan and Rajendra Kiragsur Made-gowda; writing – original draft: Dhanya Soodhana; and writing – review and editing: Vani HN and Raghupathy Palany.

Data Availability Statement

The data that support the findings of this study are not publicly available due to their containing information that could compromise the privacy of research participants but are available from the corresponding author (D.S.M.) upon reasonable request.

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