

# **MATERNAL DISTRESS IN THE MANAGEMENT OF CHILDREN WITH TYPE 1 DIABETES MELLITUS**

**Rejitha R, Dr. Mini Joseph**

## **ABSTRACT**

Type 1 diabetes mellitus (T1DM), is an autoimmune disease that frequently occurs in children, adolescents, and young adults in which the body's immune system attacks the insulin-secreting beta cells of the pancreas which leads to hyperglycemia. Diabetes-related distress refers to an emotional response, worries, concerns, and fear associated with diabetes that requires chronic care and management. Parents of children with T1DM are more stressed than normal children due to the high levels of commitment required to effectively manage T1DM. Mothers of T1DM, primary caregivers are more responsible for doing the majority of routine disease-related tasks and are reportedly more stressed. 100 mother of children who have been diagnosed with T1DM was included in the study. The mean age of the children was 14.88 $\pm$ 2.47 and their BMI was 20 $\pm$ 2.89. Using Problems Associated with Diabetes – Parents Revised (PAID-PR) questionnaire measured the degree of maternal distress under 4 subdimensions - Diabetes-related emotional problems, treatment-related problems, food-related problems, and social support-related problems. 5 points Likert scale type was used for answering the questionnaire. A score of 2-2.9 indicates moderate distress and  $\geq 3$  indicates high distress. The PAID-PR questionnaire found that the mean Total Diabetes Distress score was 3.1 and their subdimension scores were 3.18, 2.98, 2.61, and 2.24. The most distressing feeling was concern about the child's future on possible chances of diabetic complications (61%) and uncontrolled diabetes (61%). Similarly, 72% and 80% were less distressed about factors like the child being deprived of food and feeling excluded from activities/events because of his/her diabetes respectively. We observed definitive high levels of maternal distress when considering the total diabetes distress score and diabetes-related emotional problems. No significant correlation was found between PAID-PR with HbA1c and the duration of the disease. We suggest that diabetes-related emotional problems are to be more addressed followed by treatment-related problems, food-related problems, and social support-related problems.

**Keywords:** Type 1 diabetes mellitus, Diabetes-related distress.

## **Introduction**

Type 1 Diabetes Mellitus (T1DM) is a chronic autoimmune disorder resulting in hyperglycemia due to insulin deficiency and the individual becomes dependent on exogenous insulin (Atkinson et al., 2014)

After diagnosing T1DM, the emotions and denial nature of the patient, parents, and immediate caregivers are major challenges. Commonly observed emotions are fear, anger, anxiety, weariness, guilt, frustration, vagueness, despair, and shame, leading to the tendency to hide the disease, and discontinue treatments. The negative feelings might arise due to the difficulties faced by the treatment process, lifestyle, dependence, and lack of social support. All these factors may lead to the mismanagement of T1DM (Celik et al., 2015).

Inadequate, improper, and lack of knowledge about the disease, the need for insulin, diet choices, the importance of monitoring, and maintaining blood glucose levels, and the need for preventing complications are also challenging factors affecting the management of T1DM (Khamis A, Hoashi S, Duffy G, et al. Diabetes Knowledge Deficits in Adolescents and Young Adults with Type 1 Diabetes Mellitus. *Endocrine Abstracts*. 2004;7:71 - Google Search, n.d.).

T1DM necessitates a lot of discipline in lifestyle changes, including physical activity and following diet plans, monitoring SMBG, insulin injections, and regular clinical visits. These were reported as consequential challenges of T1DM management (Kesavadev et al., 2014).

Diabetes-related distress refers to an emotional response, worries, concerns, and fear associated with diabetes that requires chronic care and management. Diabetes-related distress is a part of the diabetes spectrum and is not a surrogate for clinical depression (Fisher et al., 2014). Diabetes-related distress includes emotional reactions to the diagnosis of diabetes, the burden of diabetes management, fear of complications, inadequate social and family support, and access to health care services (Gonzalez et al., 2011).

Compliance with aggressive management of T1DM is stressful and causes distress to parents as well as youth (Lohiya et al., 2021). Parent distress is more prevalent among children with T1DM than among parents of healthy youth and it showed an association with parental well-being. Supportive parenting is related to better glycemic control, while reduced parental well-being, parental distress, and problem behaviors of young people with T1DM are related to poor glycemic outcomes (Eilander et al., 2017).

Parents of children with T1DM are highly stressed than normal children due to the high levels of commitment required for the effective management of T1DM (Yi-Frazier et al., 2018). In addition to the associated extra responsibilities, worries about a child's health also increase the stressors of parents (Niedel et al., 2013). Mothers were more stressed than children and adolescents with T1DM (Lohiya et al., 2021). Mothers of T1DM are more responsible for doing the majority of routine disease-related tasks and are reportedly more stressed and suffer from posttraumatic stress symptoms compared with their fathers (Rechenberg et al., 2017). It was reported that when compared to mothers, fathers experience relatively low levels of parenting stress but have important implications for child and family adjustment (Mitchell et al., 2009). Reports suggested that separated and unemployed parents of T1DM have high levels of stress (Aldubayee et al., 2020).

Parents of children and adolescents having T1DM are often worried about the incidence of hypoglycemic episodes and their associated complications (Driscoll et al., 2016). Episodes of severe hypoglycemia lower the parent's confidence in managing diabetes and increase disease-specific stress and anxiety (Streisand & Monaghan, 2014). Hypoglycemia can be precipitated by physical exertion, and such fears can force the parents to limit or pull back children from physical activities (Kesavadev et al., 2014). Fear of hypoglycemia, its management, and sequela was reported as one of the reasons for high levels of anxiety (Aldubayee et al., 2020). Unnecessary parental fear of hypoglycemia and anxiety might lead to superfluous and anticipated correction of hypoglycemia and in turn negatively affect glycemic outcomes (Barnard et al., 2010).

Although parents have concerns about the disease, prognosis, and life, the lion's share of parents' minds is loaded with concerns relating to a child's future such as marriage, parenthood, and career (Celik et al., 2015). Generally, most parents are unwilling to disclose the state of the disease, even to close relatives or friends due to marital concerns, especially for female patients (Kesavadev et al., 2014).

The factors like insulin treatment, comorbid illness, complications, and poor health status demand intensive treatment and significantly increase the burden of treatment contributing to parental distress (Fisher et al., 2014).

## Methods

### The objective of the study

The objective of the study was to evaluate the level of distress associated with mothers of children who have been diagnosed with Type 1 Diabetes mellitus.

### Inclusion / Exclusion criteria

Mothers of those children who have been diagnosed with T1DM for  $\geq 1$  year and are on multiple daily doses of insulin injections attending endocrine/pediatric centers in Thiruvananthapuram district, Kerala were included in the study. The age of children ranged between 8-18 years. Mothers of children who have Type 2 diabetes mellitus, other forms of diabetes, and mothers of mentally challenged children with any form of diabetes were excluded.

### Data collection

The Problem Areas in Diabetes- Parents Revised (PAID-PR) questionnaire, which contained 18 questions was administered to mothers to assess the maternal distress resulting from daily diabetes-related tasks in response to diabetes care in their children. The questionnaire was translated to Malayalam with the help of a translator and back-translated to check its reliability. Likert scale points ranging from 0 to 4 were used for each question whereas 0 denoted "not a problem", 1 denoted "minor problem", 2 denoted "moderate problem", 3 denotes "somewhat serious problem" and 4 indicated "serious problem" were used in the questionnaire. A total score of 0-72 was derived from the PAID -PR questionnaire. The response on the Likert scale for the questionnaire was estimated using four subdimensions: diabetes-related emotional problems, treatment-related problems, food-related problems, and social support-related problems. The baseline characteristics like age, gender, BMI, HbA1c, duration of disease, and age of mothers were also collected.

The study procedures and tools used for data collection were reviewed and approved by the Institution's University Level Ethical Committee (University of Kerala).

### Statistical Analysis

The collected data was entered in the SPSS version 29. All discrete variables were expressed as numbers and percentages and continuous variables were expressed as mean ( $\pm$ SD). Pearson Correlation analysis was performed to calculate the relation of PAID-PR with the duration of disease and HbA1c. P value  $<.05$  was considered significant.

**Results and discussion**

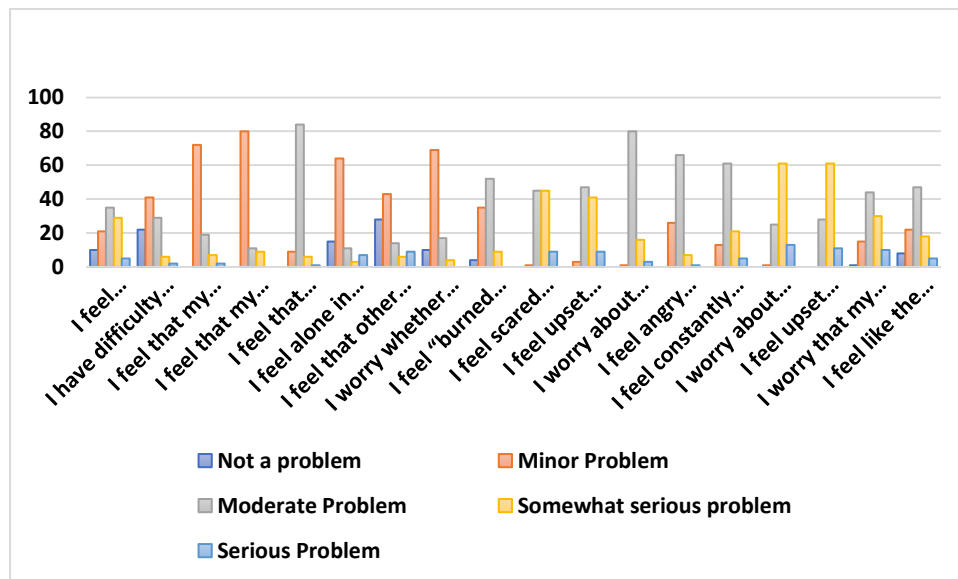
A total of 100 participants completed the questionnaire, about 50% were mothers of male children. Table 1 included the baseline characteristics like age, gender, BMI, duration of disease, and HbA1c of the children. The mother’s age was 39.84±3.61.

**Table 1. Baseline characteristics of children with Type 1 Diabetes Mellitus**

Baseline characteristics		N=100
Age		14.9 +/- 2.5
Gender	Females	50 (50%)
	Males	50 (50%)
BMI		20 +/- 2.89
Duration of disease		7.3 +/-2.7
HbA1c		8.4 +/- 1.2

Abbreviations: BMI- Body Mass Index; HbA1c- Glycated hemoglobin; N- Number of patients.

**Figure1: Frequency of scores obtained for various PAID-PR questions**



Using Problems Associated with Diabetes- Parents Revised (PAID-PR) questionnaire it was found that around 84 per cent of mothers expressed a moderate level of distress about the required mental and physical energy to manage the disease condition. Similarly, 80 per cent of mothers considered hypoglycemia as a moderately distressing item(Driscoll et al., 2016). Whilst 72 per cent and 80 per cent of mothers were perceived as less distressed about items feeling that their child is deprived of food and meals, and their child is excluded from activities or events due to diabetes respectively(Lohiya et al., 2021).

61 per cent of mothers considered the probable chance of serious complications and uncontrolled diabetes as a somewhat serious problem and the same number of mothers are worried about the eating options of their child. Higher levels of dedication demanded for the successful management of T1DM might be the reason for the increased distress observed among mothers (Marshall et al., 2009; Stallwood, 2005).

The less distressing items observed with mothers are – feeling that their child is deprived of food (72%), feeling that diabetes limits her child from activities / events (80%), feeling that she is alone in the child's diabetes management (64%) and worrying that child whether or not remember to eat snack (69%).

The maximum frequency of serious problems was observed in the subdimension “Diabetes-related emotional problem”. Somewhat serious problems reported by mothers are concerns about the future and the possibility of serious complications (61%) and uncontrolled diabetes management (61%). Increased parenteral distress reduces the efficacy of routine decision-making of T1DM (Eckshtain et al., 2010).

**Table2. Mean score of Total Diabetes distress and their subdimensions.**

Assessment of diabetes Distress	Mean Score
Total Diabetes distress	3.1± .58
<b>Sub dimensions</b>	
Diabetes-related emotional problem	3.18± .51
Treatment-related problems	2.98± .01
Food-related problems	2.61± .01
Social support-related problem	2.24± .59

The total diabetes distress score was 3.1± .58. The maximum score (3.18± .51) of serious problems was observed in the subdimension “Diabetes-related emotional problem”. The subdimension- social support was found less distressing (2.24± .59) when compared to other subdimensions, which might be due to the increasing involvement of the diabetes management support group (Lohiya et al., 2021). It was found that PAIR-PR had no significant correlation ( $P > 0.05$ ) with children's glycated hemoglobin (HbA1c) levels and duration of disease. Patient-friendly clinics, awareness programs, motivations by young adults with T1DM, interaction with the diabetes management team, access to medical care facilities and state government-supported projects are provided for the betterment of T1DM.

## Conclusion

Maternal distress associated with mothers of children with T1DM is high as they are primary caregivers among the majority of children. A better understanding of T1DM and its management reduces maternal distress and vice versa evaluation of maternal distress and timely intervention, are found effective.

## Limitations of the study

The study failed to explore whether there exists any distress difference experienced at the time of diagnosis and after adapting the routines in T1DM.

## Conflicts of interest

None declared

## References

- Aldubayee, M., Mohamud, S., Almadani, K. A., Alabbad, A. A., Alotaibi, A. G., Alkhodair, A. A., & Babiker, A. (2020). Parental levels of stress managing a child diagnosed with type 1 diabetes in Riyadh: A cross sectional study. *BMC Psychiatry*, 20(1), 5. <https://doi.org/10.1186/s12888-019-2414-y>
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *Lancet (London, England)*, 383(9911), 69–82. [https://doi.org/10.1016/S0140-6736\(13\)60591-7](https://doi.org/10.1016/S0140-6736(13)60591-7)
- Barnard, K., Thomas, S., Royle, P., Noyes, K., & Waugh, N. (2010). Fear of hypoglycemia parents of young children with type 1 diabetes: A systematic review. *BMC Pediatrics*, 10, 50. <https://doi.org/10.1186/1471-2431-10-50>
- Celik, S., Kelleci, M., & Satman, I. (2015). The Factors Associated With Disease Mismanagement in Young Patients with Type 1 Diabetes: A Qualitative Study. *International Journal of Community Based Nursing and Midwifery*, 3(2), 84–95.
- Driscoll, K. A., Raymond, J., Naranjo, D., & Patton, S. R. (2016). Fear of Hypoglycemia in Children and Adolescents and Their Parents with Type 1 Diabetes. *Current Diabetes Reports*, 16(8), 77. <https://doi.org/10.1007/s11892-016-0762-2>
- Eckshtain, D., Ellis, D. A., Kolmodin, K., & Naar-King, S. (2010). The Effects of Parental Depression and Parenting Practices on Depressive Symptoms and Metabolic Control in Urban Youth with Insulin Dependent Diabetes. *Journal of Pediatric Psychology*, 35(4), 426–435. <https://doi.org/10.1093/jpepsy/jsp068>
- Eilander, M. M. A., Snoek, F. J., Rotteveel, J., Aanstoot, H.-J., Bakker-van Waarde, W. M., Houdijk, E. C. A. M., Nuboer, R., Winterdijk, P., & de Wit, M. (2017). Parental Diabetes Behaviors and Distress Are Related to Glycemic Control in Youth with Type 1 Diabetes: Longitudinal Data from the DINO Study. *Journal of Diabetes Research*, 2017, e1462064. <https://doi.org/10.1155/2017/1462064>
- Fisher, L., Gonzalez, J. S., & Polonsky, W. H. (2014). The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision. *Diabetic Medicine: A Journal of the British Diabetic Association*, 31(7), 764–772. <https://doi.org/10.1111/dme.12428>
- Gonzalez, J. S., Fisher, L., & Polonsky, W. H. (2011). Depression in Diabetes: Have We Been Missing Something Important? *Diabetes Care*, 34(1), 236–239. <https://doi.org/10.2337/dc10-1970>
- Kesavadev, J., Sadikot, S. M., Saboo, B., Shrestha, D., Jawad, F., Azad, K., Wijesuriya, M. A., Latt, T. S., & Kalra, S. (2014). Challenges in Type 1 diabetes management in South East Asia: Descriptive situational assessment. *Indian Journal of Endocrinology and Metabolism*, 18(5), 600–607. <https://doi.org/10.4103/2230-8210.139210>
- Khamis A, Hoashi S, Duffy G, et al. Diabetes knowledge deficits in adolescents and young adults with type 1 diabetes mellitus. *Endocrine Abstracts*. 2004;7:71—Google Search. (n.d.). Retrieved February 2, 2022, from <https://www.google.com/search?q=Khamis+A%2C+Hoashi+S%2C+Duffy+G%2C+et+al.+Diabetes+knowledge+deficits+in+adolescents+and+young+adults+with+type+1+diabetes+mellitus.+Endocrine+Abstracts.+2004%3B7%3A71&oq=Khamis+A%2C+Hoashi+S%2C+Duffy+G%2C+et+al.+Diabetes+knowledge+deficits+in+adolescents>

+and+young+adults+with+type+1+diabetes+mellitus.+Endocrine+Abstracts.+2004%3B7%3A71&aqs=chrome..69i57.2056j0j7&sourceid=chrome&ie=UTF-8

Lohiya, N. N., Kajale, N. A., Lohiya, N. N., Khadilkar, V. V., Gondhalekar, K., & Khadilkar, A. (2021). Diabetes distress in Indian children with type 1 diabetes mellitus and their mothers. *Journal of Pediatric Endocrinology and Metabolism*, 34(2), 209–216. <https://doi.org/10.1515/jpem-2020-0339>

Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with type 1 diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing*, 18(12), 1703–1710. <https://doi.org/10.1111/j.1365-2702.2008.02737.x>

Mitchell, S. J., Hilliard, M. E., Mednick, L., Henderson, C., Cogen, F. R., & Streisand, R. (2009). Stress among Fathers of Young Children with Type 1 Diabetes. *Families, Systems & Health : The Journal of Collaborative Family Healthcare*, 27(4), 314–324. <https://doi.org/10.1037/a0018191>

Niedel, S., Traynor, M., McKee, M., & Grey, M. (2013). Parallel vigilance: Parents’ dual focus following diagnosis of Type 1 diabetes mellitus in their young child. *Health (London, England: 1997)*, 17(3), 246–265. <https://doi.org/10.1177/1363459312451180>

Rechenberg, K., Grey, M., & Sadler, L. (2017). Stress and Posttraumatic Stress in Mothers of Children With Type 1 Diabetes. *Journal of Family Nursing*, 23(2), 201–225. <https://doi.org/10.1177/1074840716687543>

Stallwood, L. (2005). Influence of Caregiver Stress and Coping on Glycemic Control of Young Children With Diabetes. *Journal of Pediatric Health Care*, 19(5), 293–300. <https://doi.org/10.1016/j.pedhc.2005.04.003>

Streisand, R., & Monaghan, M. (2014). Young Children with Type 1 Diabetes: Challenges, Research, and Future Directions. *Current Diabetes Reports*, 14(9), 520. <https://doi.org/10.1007/s11892-014-0520-2>

Yi-Frazier, J. P., Cochrane, K., Whitlock, K., Rosenberg, A. R., Pascual, M., Beauregard, N., Mitrovich, C., Panlasigui, N., & Pihoker, C. (2018). Trajectories of Acute Diabetes-Specific Stress in Adolescents With Type 1 Diabetes and Their Caregivers Within the First Year of Diagnosis. *Journal of Pediatric Psychology*, 43(6), 645–653. <https://doi.org/10.1093/jpepsy/jsy003>

**Supplementary Material**

**Questionnaire to ascertain maternal distress**

**Directions:** Listed below are Problems Associated with Diabetes –Parents Revised (PAID-PR). Kindly note that, asking you to indicate the degree to which each item distressed you in your life. Depending on the intensity of distress you faced mark the column, e.g.: If you note that a particular item is not a challenge or a problem to you, you can mark the first column.

PARENTS	Not	a	Minor	Moderate	Somewhat	Serious
---------	-----	---	-------	----------	----------	---------

		problem	Problem	Problem	serious problem	Problem
1	I feel discouraged with my child's diabetes treatment plan.					
2	I have difficulty dealing with school staff (e.g., nurses, teachers, and principals).					
3	I feel that my child is deprived regarding food and meals.					
4	I feel that my child is excluded from activities/events because of his/her diabetes.					
5	I feel that diabetes takes up too much mental and physical energy.					
6	I feel alone in managing my child's diabetes.					
7	I feel that other family members are not supportive in managing my child's diabetes.					
8	I worry whether or not my child will remember to eat his/her snack.					
9	I feel "burned out" by the constant effort to manage diabetes.					
10	I feel scared when thinking about my child having/living with diabetes.					
11	I feel upset when my child's blood sugars are out of range.					
12	I worry about my child having low blood sugar.					
13	I feel angry when I think about my child having/living with diabetes					
14	I feel constantly concerned about what my child eats					
15	I worry about the future and the possibility of serious complications for my child					
16	I feel upset when my child's diabetes management is "off track".					
17	I worry that my child will not be taken care of when away from home.					
18	I feel like the "diabetes police".					



