

## Association of Glycemic Control in Type 1 Diabetic Adolescents And Diabetes Related Distress among Their Parents

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**Abstract:** Introduction: Parents, who are primary caregivers in most cases, play a vital role in the treatment of type 1 diabetic adolescents. They have to participate in the aspects of management like blood glucose monitoring and insulin administration on a daily basis. Parents of adolescents with type 1 diabetes worry more about health of their children compared to parents of healthy adolescents. Greater child related distress is described in parents of type 1 diabetes influencing parent child relation. Clearly Parenting distress is a risk factor when it comes to child's diabetes outcome as supportive parenting and positive communication empower children in their diabetes self care.

**Aim:** To find the association between glycemic control among type 1 diabetic adolescents and Diabetes related distress among their parents in the patients and parents attending a N.G.O. camp.

**Materials and Methods:** Sample Size: 42 subjects and 42 caregivers

**Type of study:** Cross-sectional study.

**Study tools:** Diabetes distress scale for parents of teens with type 1 Diabetes, HbA1c value of type 1 diabetic adolescents collected from their medical records.

**Results:** Poorer glycemic control among adolescents is associated with higher diabetes related distress among their parents

**Key words:** Diabetes related distress, glycemic control, type 1 diabetes, Adolescents.

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### I. Introduction

Type 1 diabetes mellitus is a metabolic disease with common childhood and adolescent onset. Parents, who are primary caregivers in most cases, play a vital role in the management of type 1 diabetic adolescents. They have to participate in the aspects of management like blood glucose monitoring and insulin administration on a daily basis.

Parents of adolescents with type 1 diabetes worry more about health of their children compared to parents of healthy adolescents. Greater child related distress is described in parents of type 1 diabetes influencing parent child relation. Clearly parenting distress is a risk factor when it comes to child's diabetes outcome as supportive parenting and positive communication empower children in their diabetes self care.

Type 1 diabetes mellitus can be a stressful condition owing to its unexpected and dramatic onset in childhood or early adulthood, the life-threatening nature of severe abnormalities in plasma glucose levels, and the potential long-term complications that can cause disability, employment difficulties, and career problems.<sup>1</sup>

The families of young patients with diabetes experience high levels of stress like parental worries, conflicts over T1DM management, such as diet issues, poor adherence to treatment, and patient resistance to the painful process of injection and measurement<sup>2</sup> that influence not only the family itself but also the treatment process and thus the patients' glycemic control. Those patients with diabetes who experience high levels of family conflict, and hence family stress, show poor adherence to treatment and poorer glycemic control.<sup>3</sup>

The concentration of HbA1c, generally expressed as the proportion of hemoglobin that is HbA1c, is known to correlate with average blood glucose levels over the preceding 3 months. The recommended target HbA1c for all ages is below 7.5%

Previous studies showed that parental distress and negative parenting relate to worsened HbA1c of adolescents, a negative relation between parental wellbeing and HbA1c is hypothesized. This has, however, not yet been widely studied.

This study is aimed to understand the association between glycemic control of adolescents in the form of HbA1c value with type 1 diabetes mellitus and diabetes related distress among primary care givers of those adolescents, who are parents in majority of cases.

**Aim:** To find the association between the diabetes distress among parents of adolescents with type 1 diabetes mellitus and glycemic control of adolescents with type 1 diabetes mellitus.

## **II. Materials and Methods**

**Study Design:** Cross sectional observational study

**Sampling Method:** Convenience sampling

**Study Group:**

The study group consisted of 42 adolescent Subjects with type 1 diabetes mellitus and their primary care giver parents who are attending a N.G.O. camp for type 1 diabetes children and adolescents where free endocrinologist consultation, investigations and medicines were provided.

**Inclusion criteria:**

- Age: 10 years to 19 years
- Diagnosis of type 1 diabetes mellitus
- On regular medication since at least 6 months
- Primary care giving parents of the subjects who fulfilled the inclusion criteria
- Subjects and parents who gave informed consent

**Exclusion criteria:**

- Subjects with other co morbid chronic medical or neurological illness
- Subjects with any disability
- Parents of subjects with known history of psychiatric illness
- Parents meeting International Classification of Diseases-10 criteria for drug dependence.
- Subjects and caregivers who refused to participate.

**Operational Procedure:**

Subjects fulfilling the inclusion criteria and their primary care givers were taken up for the study. These cases were enrolled after taking informed consent from them to be included in the study.

The socio-demographic data and illness history of the subjects were obtained. The caregivers' socio-demographic data was also taken. Following this, their diabetes related distress was assessed using relevant rating scales. HbA1c values were taken from medical records of the subjects later. Blood was drawn at the camp for routine assessment of HbA1c.

**Ethical Issues:**

Informed consent was obtained from each subject and their caregiver prior to inclusion into the study. All were explained regarding the nature and the rationale of the study.

**Study Tools:**

Self-designed semi-structured data questionnaires were used which includes the following:

- (a) Socio-demographic data sheet.
- (b) Clinical profile sheet.

**Parent Diabetes distress Scale:** Developed by Hessler D, Fisher L, Polonsky W, Johnson N<sup>4</sup>. It consists of 20 items which are rated on a 4-point scale. A total scale score is derived by averaging the scores of individual items, with a higher score indicating higher levels of distress with scores greater than 2 are considered as moderate distress and scores greater than 3 are considered as severe distress and scores less than 2 are considered as minimal or no distress. The scale has 4 sub scales which are personal distress, teen management distress, parent –teen related distress and health care team distress. Grading of distress for sub scales is same as that of whole scale. The scale has established reliability (Cronbach's alpha of 0.88-0.93).

**Glycated haemoglobin (HbA1c) Values:** The HbA1c value which is indicative of average plasma levels of glucose in past 8 to 12 weeks<sup>5</sup> is taken from medical records of the subjects with prior consent. Blood samples were drawn on the day of examination.

**Statistical analysis:** Statistical analysis of the data was carried out using SPSS software version 23. Mean and standard deviation were presented for all the continuous variables. To examine the relationship between HbA1c values of subjects and diabetes distress among parents of subjects relevant statistics were applied.

**Results:** Statistical analysis of the data was carried out using SPSS software version 23. Mean and standard deviation were presented for all the continuous variables. To examine the relationship between HbA1c, diabetes distress among parents, relevant statistics were applied.

Total sample of the study is 42. Among the sample 19 were boys and 23 were girls. Mean age of the sample is 14.69 with a standard deviation of 2.12. Mean age of the boys was 14.263 with a standard deviation of 2.28. Mean age of the girls was 15.04 with a standard deviation of 1.96. Most of the primary caregivers are mothers (n= 29) followed by fathers (n=11) and grandmothers (n=2). In the sample only 4 of the caregivers were illiterate, 8 of the caregivers studied up to primary education, 15 studied up to secondary education, 7 studied up to intermediate and 8 of the sample were graduates. According to Modified Kuppaswamy scale,<sup>6</sup> in the sample, 6 subjects belonged to lower socioeconomic status, 8 belonged to the upper lower group, 17 belonged to the lower middle group, and 11 subjects belonged to the upper middle group.

In this study HbA1c value less than 8 is considered as good control of diabetes mellitus<sup>7</sup>. 18 subjects (42.8%) were grouped under good glycemic control and 24 subjects (57.2%) were grouped under poor glycemic control.

The mean total Diabetes related distress among caregivers of adolescents with poor glycemic control is 2.17 with a S.D. of 0.42 and among those in good glycemic control group is 1.49 with a S.D. of 0.26 and the difference is significant with a p value of < 0.05 (p=0.024).

The mean Diabetes related personal distress among caregivers of adolescents with poor glycemic control is 1.62 with a S.D. of 0.39 and among those in good glycemic control group is 1.37 with a S.D. of 0.31 and the difference is not statistically significant with a p value of > 0.05 (p=0.77).

The mean Diabetes related teen management distress among caregivers of adolescents with poor glycemic control is 2.39 with a S.D. of 0.62 and among those in good glycemic control group is 1.73 with a S.D. of 0.19 and the difference is significant with a p value of < 0.05 (p=0.037).

The mean Diabetes related parent teen relation distress among caregivers of adolescents with poor glycemic control is 2.68 with a S.D. of 0.33 and among those in good glycemic control group is 1.61 with a S.D. of 0.41 and the difference is significant with a p value of < 0.05 (p=0.019).

The mean Diabetes related health care team distress among caregivers of adolescents with poor glycemic control is 1.36 with a S.D. of 0.24 and among those in good glycemic control group is 0.94 with a S.D. of 0.90 and the difference is not statistically significant with a p value of > 0.05 (p=0.61).

**Table 1: Demographic characteristics of the sample**

		Males	Females	Total
Subjects	Good glycemic control	9 (46.7%)	9 (43.3%)	18 (42.85%)
	Poor glycemic control	10(53.3%)	14(56.7%)	24 (57.15%)
	Mean Age	14.263 years (S.D: 2.28)	15.04 years (S.D: 1.965)	14.69 years (S.D.:2.12)
Care givers	Mothers	29 (69%)		
	Fathers	11 (26.24%)		
	Grandmothers	2 (4.76%)		

**Table 2: Mean diabetes distress values**

Diabetes distress type	Caregivers of good glycemic control subjects( n=18)	Caregivers of poor glycemic control subjects (n=24)
Personal	1.37 (S.D: 0.31)	1.62 (S.D: 0.39)
Teen Management	1.73 (S.D: 0.19)	2.39 (S.D: 0.62)
Parent –teen relation	1.61 (S.D: 0.41)	2.68 (S.D: 0.33)
Health care team	0.94 (S.D. : 0.90)	1.36 (S.D. : 0.24)
Total distress	1.495(S.D: 0.26)	2.17(S.D:0.42)

### Discussion

The mean diabetes distress scores were higher in parents of poor glycemic control group compared to those of good glycemic control group. The difference is statistically significant in total diabetes related distress. This is in similar lines with studies done by Eilander M et al<sup>8</sup>, Anderson BJ et al<sup>9</sup>, and Duke DC et al<sup>10</sup>. When compared sub groups of diabetes distress teen management distress and parent teen relation distress are higher in caregivers of poor glycemic control group and had statistically significant difference when compared

with those of good glycemic control group. Whereas sub groups personal diabetes distress and health care team related distress had no statistically significant distresses among the two groups even though caretakers of poor glycemic control group has slightly higher values. Study subjects attending regularly to a free N.G.O. camp which provides free consultation, investigations, insulin every 3 months might be the reason for low health care distress.

The results of the study were same even when calculated gender wise indicating diabetes distress among caregivers is independent of gender of the adolescent. This finding is in similar lines with the study done by Jacobson AM et al <sup>10</sup>.

Teen management and parent teen relation are the two key areas of distress according to this study which are contributing mainly to the Diabetes distress of the caregivers and psychosocial interventions to address these might improve the overall status of both caregiver and adolescent. Studies with larger samples and control groups might give results which can be more generalized.

### III. Conclusions

Diabetes related distress is higher in parents of adolescents with type 1 diabetes mellitus. This distress is higher among parents of adolescents with poor glycemic control compared to those with good glycemic control. This trend is seen irrespective of gender. Teen management distress and parent-teen relation distress are significantly higher in parents of adolescents with poor glycemic control. Even though personal distress and health care management distress are also higher among parents of adolescents with poor glycemic control, differences are not statistically significant when compared with parents of adolescents with good glycemic control. Focusing on the distress of caregivers of adolescents of type 1 diabetes mellitus is necessary and integrating it into the management of type 1 diabetes mellitus is needed.

### Limitations

Our study was a cross sectional study. As type 1 Diabetes mellitus is a chronic illness, a prospective study would have been more useful. A larger sample would have more practical implications. As the study was carried out in a N.G.O. camp, it cannot be generalized to community.

Conflict of Interest: Authors declare no conflict of interest

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