

Emotional, behavioral and cognitive profile, and quality of life of Indian children and adolescents with type 1 diabetes

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ABSTRACT

Background and Aims: The psychological stress associated with type 1 diabetes (T1D) may be higher in children from developing world due to limited health resources. The aims of the study were to assess the quality of life (QoL), emotional well-being, behavioral, and cognitive profile of children/adolescents with T1D diagnosed at least 6 months prior. **Materials and Methods:** Forty-nine children with T1D, aged 6–18 years were assessed using DAWN Youth QoL questionnaire, WHO-5 Well-Being Index, Child Behavior Checklist (CBCL), and Malin's Intelligence Scale for Indian children (MISIC). The association of the scores was studied with age, gender, socioeconomic status (SES), frequency of hypoglycemia, HbA1c, and age of onset and duration of T1D. **Results:** The mean (standard deviation (SD)) for DAWN QoL, WHO-5, CBCL, and MISIC scores was 24.7 (16.7), 74.6 (19.4), 52.6 (8.8), and 96.0 (11.2), respectively. The significant associations noted were: Elevated HbA1c with poorer emotional well-being; higher negative impact on 'symptoms of disease' and 'future prospects' sub-areas of QoL; shorter duration of disease with more behavioral issues; lower maternal education with more 'withdrawn/depressed' behaviors and 'worry about future prospects'; and lower SES with lower MISIC scores. Earlier onset (age <5 years) was associated with fewer behavioral problems and less negative impact on QoL. **Conclusion:** Children with recent diagnosis, older age at onset, lower maternal educational level, elevated HbA1c, or belonging to lower SES were identified to have higher prevalence of various psychological and cognitive problems. In resource-limited settings, these children should be prioritized for behavioral and cognitive evaluation.

Key words: Behavior, children, cognition, quality of life, type 1 diabetes

INTRODUCTION

Type 1 diabetes (T1D) can cause significant stress in the affected children, due to its chronic nature and multipronged management; involving multiple daily injections, blood glucose monitoring, dietary restrictions, and risk of complications.^[1,2] In developing countries, financial constraints, suboptimal health infrastructure, lack of universal health insurance, scarce

school health facilities, poor health-seeking behavior in the community, and the social stigma attached to the disease are likely to further aggravate the psychosocial and cognitive profiles of children/adolescents with T1D, as compared to developed nations. There is, however, a paucity of reports on these aspects from developing countries. It is imperative to understand the extent of psychological comorbidity in children/adolescents with T1D, because this has a significant impact on the self-management of diabetes, and glycemic control in the patient.^[3]

The study was undertaken with the objective of assessing the quality of life (QoL), emotional well-being, and behavioral and cognitive profile of Indian children and adolescents with T1D; and to examine the influence of sociodemographic factors, glycemic control, age of onset, and duration of diabetes on these parameters.

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MATERIALS AND METHODS

The study was approved by the ethics committee of our institute. We enrolled 49 children/adolescents aged 6-18 years with T1D under follow-up at the Pediatric Endocrinology Clinic of our tertiary care institute, for at least 6 months, after obtaining voluntary informed consent from parents and assent from the subjects. Information regarding age of onset, duration of disease, socioeconomic status (based on modified Kuppaswamy scale^[4]), and mother's education were recorded. Degree of glycemic control was assessed by last HbA1c (considered normal if \leq American Diabetes Association (ADA) cut-offs, i.e., 8.5% for age < 6 years, 8% for age 6-12 years, and 7.5% for age > 12 years),^[5] and number of episodes of perceived or documented hypoglycemia (blood glucose < 60 mg/dl or symptomatic) in past 1 month. Presence of comorbidities was also noted.

The following instruments were used to assess QoL, emotional adjustment, behavioral problems, and cognition in the subjects.

Quality of life questionnaire (published by the DAWN youth project)

This is a 22-item validated questionnaire to assess possible problems in the following six domains: Impact of symptoms related to diabetes, impact of the treatment, impact on activities, parents' issues, worry about the future, and perception of one's own health^[6]. This was administered by the physician to subjects aged 10-18 years ($n = 34$). Each question has five possible responses, ranging from '0' (never) to '4' (all the time), and the responses are added up to get the total score for the subscale. Higher scores indicate greater adverse impact on QoL. For this study, we considered the adverse impact on QoL in a domain to be significant, if the score for that domain was in the upper half of the possible range.

WHO-5 well-being Index (1998 version)

This was administered by the psychologist to subjects aged 10-18 years ($n = 34$). It comprises of five positively worded items; related to positive mood, vitality, and general interests; which are rated on a 6-point Likert scale from '0' (not present) to '5' (constantly present). Higher scores indicate better well-being. A score < 52 indicates low mood while score < 28 suggests depression. It has been shown to be a reliable tool to assess emotional well-being over the preceding 2 weeks.^[7-9]

Child behavior check list (CBCL/6-18)

This was administered by the psychologist to parents of children aged 6-18 years ($n = 49$). This is a standardized

measure of parent-reported behavioral problems, comprising of 120 questions, with responses graded on a Likert scale, as 0-2.^[10] The responses are then summated as directed by the instrument to yield scores for nine behavior syndromes. The summation of the responses of some of the individual syndromes yields scores for internalizing behaviors (IS), externalizing behaviors (ES), and overall scores for total behavior problems (TS). Internalizing behaviors include behaviors such as anxious/depressed, withdrawn/depressed, and somatic; and externalizing behaviors include rule-breaking, aggression, and inattention. Lower scores indicate fewer behavioral problems. For this study, a score ≥ 60 was considered as indicative of possible behavior problems. The range for each of the scores TS, ES, and IS is 0-100.

Malin's Intelligence Scale for Indian Children (MISIC)

This intelligence quotient (IQ) scale is the Indian adaptation of Wechsler Intelligence Scale for Children and provides scores for verbal IQ (VIQ), performance IQ (PIQ), and full scale IQ (FSIQ).^[11] This was administered by the psychologist to children aged 6-16 years ($n = 41$).

Statistical analysis was carried out using STATA 9.0 (College Station, Texas, USA). Data is presented as number (percentage) or mean (standard deviation). Bivariate analysis was carried out using Student's *t*-test (for categorical variables) and Spearman's rank correlation (for continuous variables) to assess the strength of association with potential predictors. $P < 0.05$ was considered statistically significant.

RESULTS

The clinicodemographic features of the enrolled subjects are summarized in Table 1. The mean age of subjects was 11.7 ± 3.1 years. Forty-three percent of subjects belonged to lower socioeconomic class, and the glycemic control was inadequate in a majority. The overall results of the QoL, WHO-5, CBCL, and MISIC administered to the patients are summarized in Table 2. Nearly a third of the subjects had a significant adverse impact on QoL due to their diabetes. Amongst the subdomains, the maximally reported adverse impact was related to symptoms of diabetes and perception of health, while the minimally reported was the impact on activities. WHO-5 well-being index indicated presence of low mood in 21.3% of the subjects. Possible behavioral problems were detected in 25.6% of the subjects using the CBCL questionnaire. Abnormal internalizing behaviors were more commonly observed than externalizing behaviors.

The results of bivariate analysis for the association of various potential predictors with the overall results are

Table 1: Demographic and clinical characteristics of patients (n=49)

Variable	Summary statistic
Male/Female* (%)	27 (55)/22 (45)
Present age (years)	11.7±3.1, range 6.5-18
Age at onset (years) [§]	7.4±2.8
Onset of T1D <5 years* (%)	10 (20.4)
Time since diagnosis (months) [§]	51.3±44.7
Socioeconomic status* (%)	
Lower	21 (42.9)
Middle or high	28 (57.1)
Mother's education* (%)	
Up to high school	16 (32.6)
Beyond high school	33 (67.4)
Comorbidities* (%)	
Hypothyroidism	6 (12.2)
Celiac disease	2 (4.1)
Measures of disease control (%)	
HbA1c [§]	9.5±2.01
Patients with elevated HbA1c*	37 (77.1)
Episodes of hypoglycemia (>1/month)*	7.2 (11.1)

*Number (percentage), [§]mean±standard deviation, T1D: Type 1 diabetes

Table 2: Results of tests for quality of life, emotional well-being, behavior, and cognition

Test	Score (%)
DAWN QoL score* (n=34)	29.3±15.8
Significant adverse impact on QoL*	10 (29.4)
Significant adverse impact in DAWN QoL sub-domains*	
Impact of symptoms related to diabetes	11 (32.3)
Impact of treatment	9 (26.5)
Impact on activities	4 (11.8)
Parent issues	8 (23.5)
Worries about diabetes	8 (23.5)
Health perception	12 (35.3)
WHO-5 score (n=34)*	74.6±19.4
Low mood (score <52)*	10 (21.3)
Likely depression (score <28)*	1 (2.0)
CBCL (n=49)	
Total score*	52.6±8.8
Clinical-range TS*	11 (25.6)
Clinical-range internalizing score*	16 (37.2)
Clinical-range externalizing score*	10 (23.3)
MISIC (n=41)	
Score*	96±11.2
Low score (<85)*	5 (10.2)

*Number (percentage), [§]mean±standard deviation, QoL: Quality of life, CBCL: Child behavior checklist, TS: Total behavior problems

presented in Table 3. Early onset of T1D (<5 years of age) was associated with significantly lower adverse impact on QoL, and lower score on CBCL, suggestive of fewer behavioral problems. Elevated HbA1c level was associated with lower (worse) emotional well-being score. Duration of disease was inversely associated with CBCL score, suggesting that behavioral problems decrease as the duration of diabetes increases. MISIC score was lower by 10.77 units in children from lower SES compared to children with higher SES. No significant association of gender, current age, presence of comorbid condition, and frequency of hypoglycemia was observed with the scores

for any of the tests employed in the study, and hence their data is not presented in Table 3.

The association of the potential predictors with the subdomains of these tests is presented below.

QoL

Onset of T1D before 5 years of age was associated with significantly lesser 'worries' ($P = 0.047$), lesser negative impact on 'activities' ($P = 0.023$), and better health perception ($P = 0.019$). 'Worries' were fewer ($P = 0.033$) among children whose mothers were educated beyond high school. There was a trend towards significance for the association between elevated HbA1c and 'symptoms of diabetes' ($P = 0.092$), and 'worries' ($P = 0.077$).

A significant inverse correlation was noted between the WHO and QoL score ($r = 0.518$, $P = 0.016$), indicating that emotionally well-adjusted children perceived a lower adverse impact of the disease on QoL.

CBCL

The duration of diabetes was inversely associated with ES ($P = 0.016$), indicating that recently diagnosed children are more likely to have externalizing behaviors, and these become less common with increasing duration. Children from lower SES, and those whose mothers' educational level was below high school, had more withdrawn/depressed behaviors ($P = 0.051$ and 0.075 , respectively).

MISIC

Lower SES was associated with lower scores in information, arithmetic, analogies/similarities, general information, awareness, attention, concentration, and immediate memory and recall.

DISCUSSION

Being a life-long condition with significant burden of treatment, in terms of regular injections, monitoring blood sugar, restrictions on diet and lifestyle, planned and emergency hospital visits, and financial impact on the family; compounded by the effect of fluctuating blood glucose on mood and cognition, T1D has a significant influence on the quality of life, emotional well-being, cognitive profile, and behavior of the affected children.^[1,2] Shorter duration since diagnosis, poor glycemic control, low SES, and female gender have been noted to be associated with greater negative impact on these parameters, in studies reported from developed countries.^[1,2] Our results are amongst the very few reported from developing countries.^[11,12]

The mean DAWN QoL score in our subjects was 29.3 (with maximum (worst) possible score of 84). This is comparable

Table 3: Association of potential predictors with outcomes (QoL, WHO-5, CBCL and MISIC) on bivariate regression analysis

Parameter/Outcome	QoL score	WHO-5	CBCL (TS)	MISIC
Age at onset of T1D				
<5 years	13.8 (11.5)	83.6 (13.6)	46.2 (10.2)	97.8 (14.2)
≥5 years	28.1 (16.8)	72.4 (20.1)	54.3 (7.7)	95.6 (10.6)
<i>P</i> value	0.031*	0.124	0.013*	0.620
Socioeconomic status				
Low	22.5 (17.8)	74.3 (19.3)	52.7 (8.9)	90.0 (6.8)
Middle/high	27 (15.8)	74.8 (19.9)	50.6 (8.4)	100.7 (11.8)
<i>P</i> value	0.438	0.941	0.943	0.001*
Mother's education				
Below high school	28.8 (19.3)	72.6 (18.6)	53.2 (7.3)	93.3 (14.9)
High school and above	22.8 (15.4)	75.4 (20.0)	52.4 (9.4)	97.0 (9.7)
<i>P</i> value	0.332	0.650	0.798	0.359
HbA1c				
Elevated (above cut-off)	27.2 (17.4)	71.1 (19.4)	52.7 (9.2)	95.0 (11.9)
Not elevated	14.4 (3.4)	90 (7.4)	51 (6.8)	98.8 (9.1)
<i>P</i> value	0.115	0.004*	0.612	0.391
Duration of disease [®]				
Correlation coefficient	-0.155	-0.010	-0.500	-0.220
<i>P</i> value	0.503	0.966	0.022*	0.337

*level of significance $P < 0.05$. [®]as continuous variable, QoL: DAWN youth quality of life questionnaire score, WHO-5: Score on the WHO-5 well-being index, CBCL: Clinical behavioral checklist score, MISIC: Malin's intelligence scale for Indian children, T1D: Type 1 diabetes

to the QoL score of 97.5 (with maximum possible score of 255, using the diabetes quality of life for youth (DQOLY) questionnaire) reported by Matziou *et al.*, in their study in Greek adolescents aged 11-18 years.^[13] Amongst the possible predictors studied, early onset of diabetes (before age 5 years) was associated with significantly lesser negative impact on the overall QoL score as well as in most of the subdomains. In comparison to children who were diagnosed after 5 years of age, those with early onset were more optimistic about their life with diabetes, were less worried about the limitations imposed by diabetes on their current activities and future achievements, and had a more positive perception of their health. This may be related to the fact that being introduced to a way of life incorporating diabetes management at a tender age, they make fewer comparisons to their more carefree life before the diagnosis of diabetes, and hence adapt better.

In contrast to previous reports (Matziou *et al.*, 2011, Ingerski *et al.*, 2010), we did not find an association of poorer glycemic control with either the overall QoL score, or the 'perception of one's own health status' subdomain.^[13,14] This is indicative of a less robust understanding of the disease among our subjects, and suggests greater need for education and counseling of patients to help them prioritize their concerns.

The WHO-5 instrument is highly specific for depression, and a lower score indicates a greater prevalence of/predilection for depression.^[7-9] The overall mean (standard deviation (SD)) WHO-5 score in our study population was 74.6 (19.4), which is higher (indicating better emotional adjustment) than that reported by de Wit *et al.*, among Dutch diabetic children,

which was 63.38 (18.9).^[8] The score was significantly lower among those with elevated HbA1c compared to those with normal HbA1c (71.1 (19.4) vs 90 (7.4), $P = 0.004$). Similar to other studies, we found that lower WHO-5 scores correlated well with greater adverse impact on QoL.^[8,15,16] Using this simple instrument, we detected 'low mood' in 21.3% of the subjects. This assumes special significance in children as depression is easily missed among them. In fact, depressed children may be perceived as 'well-behaved' and 'well-adjusted'. Children with suboptimal disease control should undergo regular psychological review, and counseling.

With the CBCL questionnaire, the percentage of borderline clinical and clinical scores, and the mean total scores found in our patients are comparable to those previously reported.^[17] Notably, internalizing behaviors were more common than externalizing behaviors. This is of special concern because the parents may not perceive such behaviors as abnormal and seek consultation. We observed a better level of adjustment and fewer behavioral problems in our patients with onset of T1D before the age of 5 years. Also, the behavioral problems were inversely associated with the duration of disease, suggesting that there is greater adjustment to the diagnosis with time. We did not find an association of CBCL scores with the degree of glycemic control as measured by the HbA1c. Comparing with previous studies among diabetic children/adolescents, while studies by Nardi *et al.*, and Akbaş *et al.*, also did not observe association between CBCL scores and HbA1c, Ohmann *et al.*, reported significantly higher prevalence of somatic complaints and internalizing behaviors in children with suboptimal glycemic control.^[18] Similarly, whereas

some of the previous studies also suggest fewer behavioral problems with increasing duration of disease as in our study. Delamater *et al.*, Kakleas *et al.*, Nardi *et al.*, reported higher prevalence of problems in the anxious/depressed, attention and hyperactivity and oppositional defiant scales as duration of disease increased.

We found an association of maternal educational level below high school with greater prevalence of clinical range internalizing behaviors. Among the domains of QoL also, lower maternal education was associated with more 'worries about the future'. The mother is the central caregiver in most families. Her lower education level may affect her understanding of the disease and its management, and the ability to cope with psychological stress associated with diagnosis. This may translate into inadequate emotional support/care for the child, leading to more behavioral problems/stress in the child. A similar association of lower maternal education with greater stress and more frequent behavior problems in the child was observed in an Indian study among caregivers of children with cerebral palsy.^[19] This finding also emphasizes the effect of the family on QoL, and emotional adjustment of the diabetic child, and potential of the family unit as a target for psychological therapy and intervention.

While we were limited by the lack of controls in our study, a full-scale IQ of 105.1 (7.75) among controls in an Indian study on children of alcoholic fathers has been reported.^[20] Thus, the mean IQ in our diabetic subjects is possibly lower than the normal population average. Findings from studies from the West have variably suggested that children with early diabetes onset (Ferguson *et al.*, 2005, Hannonen *et al.*, 2010, Naguib *et al.*, 2009)^[21-23], poor glycemic control (Ohmann *et al.*, 2010, Hannonen *et al.*, 2010, Naguib *et al.*, 2009),^[18,22,23] and episodes of severe hypoglycemia (Hannonen *et al.*, 2010)^[22] may be at greater risk for lower neurocognitive performance. However, in our patients, the above factors or the scores on the QoL and WHO-5 questionnaires did not have any significant association with cognitive performance. Lower SES emerged as a consistently strong association with lower full scale IQ score, as well as individual scores in specific components. McCarthy *et al.* (USA) have also reported that SES has a greater effect on academic performance in diabetic children than medical variables.^[24] The implication of this finding is that diabetic children from lower SES are at higher risk of cognitive impairment, and should be prioritized for IQ assessment.

We found a significant correlation between scores on the QoL and the WHO questionnaires, and significantly poorer QoL in patients with pathological WHO scores. The WHO

questionnaire is shorter and quicker to administer, and may be used as the initial screen in set-ups with a crunch of time-people resources, before moving on to administering the QoL on a regular basis.

It is important to recognize psychological problems in children with T1D, as these may lead to poor motivation and inability to coordinate the multipronged therapeutic plan. The consequent poor metabolic control may further impair the psychological status, thus propitiating a vicious cycle, with progressive worsening of clinical and psychological situation, and even lesser impetus to control disease. Psychological and behavioral interventions have been shown to have a beneficial effect on children and adolescents with diabetes evidenced in terms of better compliance to therapy, glycemic control as well as better relationships with family and peers and better coping capability.^[1,25,26] However, such interventions require time-people resources that are often missing in the setting of a developing nation. We hope that in resource-limited scenarios, where T1D is typically managed by a single physician, without the support of psychologists/social workers or diabetes counselors, our results will help in prioritizing children for behavioral monitoring and psychological evaluation.

Based on our findings, children with recent diagnosis, older age at onset, lower maternal educational level, elevated HbA1c, or belonging to lower SES are recommended for more frequent/detailed behavioral and cognitive evaluation.

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