Quality of life of Children and Adoloscents with Type 1 Diabetes Mellitus: A Questionnaire Based Study

[1]B S Shakuntala, [2]Priyanka N, [3]Rajas Mahalle

[1]Professor and Head, [2]Postgraduate student, [3]Postgraduate student
[1]Pediatric and Preventive Dentistry,
[1]RajaRajeswari Dental College and Hospital, Bengaluru, India
[1]shakuntalabethur@gmail.com, [2]priya30gani@gmail.com, [3]rajasvi19@gmail.com

Abstract—**BACKGROUND AND PURPOSE**: Type 1 diabetes mellitus (T1DM) is a chronic disease requiring complex management including blood glucose monitoring, insulin administration along with diet restrictions which can have negative impact on quality of life (QOL) of both children and parents. The stringent routine can be quiet stressful for both child and parent affecting the physical, mental, psychosocial functions.
OBJECTIVES: To assess the quality, factors affecting the life of children with T1DM children and their parents.
MATERIALS AND METHODS: A cross sectional study was conducted on a total of 200 children of both sexes in the age range of 5-15 years were selected for the questionnaire survey, 100 children were diagnosed with T1DM and 100 were normal children. The QOL was assessed using Pediatric Quality of Life Inventory (PedsQL) and Quality of Life instrument in Indian Diabetics (QOLID) Questionnaire.

RESULTS: Based on the questionnaire analysis parents of T1DM children faced significantly more distress in terms of physical activity (100%) ,physical endurance(100%) ,symptom botherness(99%) ,financial worries(100%) emotional health (100%). The T1DM children also had significantly higher distress in terms of physical health (100%), emotional health (100%), social function (100%) and school (98%).
CONCLUSION: The overall outcome of this study showed that QOL of children with T1DM was more compromised than normal children and the QOL can be improved by involving the family in diabetes education and enable them to take responsibility
Index Terms— quality of life, T1DM, Peds QL, QOLID

I. INTRODUCTION

Type 1 diabetes mellitus (T1DM) is one of the most common autoimmune diseases, affecting 1 in every 400-600children and adolescents. Intensive treatment is necessary to prevent or delay acute and chronic complications [1,2]. T1DM treatment involves daily insulin injections, self-monitoring, food restrictions, physical exercise, and adjustments to insulin dosage.

Type 1 diabetes patients face short and long-term impacts of hyperglycemia and hypoglycemia, which can affect their daily activities [3]. Early childhood normative dependence on parental caregiving leads to parental accountability for completing daily diabetes management duties [4,5]. Consequently, it effects a child's quality of life (QOL) by affecting their physical, social, and psychological well-being and functioning [4,5,6]. Health related quality of life (HRQoL) is a varying concept including wellbeing in terms of patients physical, emotional, mental, and social behaviors and is defined as the way the effects of a disease and or its treatment perceived by patient [1]. One of the international tools for assessment of HRQoL of children is the Pediatric Quality of life Inventory (PedsQL). This instrument provides both child self-report and parent proxy-report [1] The objective of this study is to evaluate the QoL of children and adolescents with T1DM and non-diabetic children and adolescents using QOLID questionnaire.

II. SUBJECTS AND METHODS

Participants

A total of 200 children of both sexes and their parents in the age range of 5-15 years were selected for the questionnaire survey.100 children diagnosed with T1DM atleast 6 months before the study and who were on regular follow up at pediatric diabetic clinic at RajaRajeswari medical college and hospital were enrolled. Children and parents who were ready to participate in this

questionnaire study were included. Children with co-existing inborn malformations, chronic diseases other than T1DM, psychiatric diseases and those with associated acute disease during the study were excluded.

III. STUDY PROCEDURE-

QUESTIONNAIRE FOR EVALUATION

Parents and guardians of children and adolescents were asked to provide written informed consent. The core demographic profile was gathered together with additional data such as the family's socioeconomic status and HbA1C.

Questionnaires in both native and English were used to measure QOL, with some modest adjustments made for the paediatric group. Each form's contents are nearly the same. The purpose of the parent proxy-report forms, which run concurrently with the child self-report forms, is to gauge how parents perceive their child's health-related quality of life. Questionnaires were divided into two groups. Group 1 consists of a questionnaire for parents, which includes the Quality of Life Instrument in Indian Diabetics (QOLID) questionnaire. QOLID consists of 19 items covering 5 domains, which cover role limitations due to physical health, physical endurance, symptom frequency, financial worries, and emotional health each consisting of 6, 4, 3, 3 and 2 items.

Group 2 consists of questionnaires which includes PedsQL GCS for children.

The PedsQL 4.0GCS consist of 20 items assessing the level of physical and psychosocial functioning of children. Physical functioning consists of 7 items. Psychosocial functioning is divided into three subscales: emotional, social and school functioning each consisting of 4, 4 and 5 items. All the parent and child's response was recorded in 0-4 point scale and the lower score represents better QOL.

0=never ,1=almost never ,2= sometimes ,3=often ,4=almost always.

IV. PROCEEDURE

The questionnaires were given at the outpatient clinics in the hospitals. Children and their parents responded to the questions of the instrument while waiting for their medical assessment. The questions took around ten minutes to fill, and the children and their parents answered them separately. Children over the age of ten completed the questionnaire on their own, while parents assisted children under the age of ten in filling it out.

V. RESULTS

A total of 200 patients including 57(57%)males and 43 (43%) females with the mean age 9.39±2.97 years (age range of 5-15 years) enrolled in the study. Large number of children from both diabetic and non-diabetic group were belonging to lower economical occupational status. In the present study the individual responses from patient and parent perception was recorded on 4 point scale.

The responses to various sections on PedsQL questionnaire by study children in diabetic group showed significantly high percentage, especially in missing school and falling sick (42% and 52%).(fig 1)

The responses to different domains on the QOLID questionnaire by parents in diabetic children showed high percentage (41%) of economic burden on parents. (fig 4)

The Mann-Whitney Test is used to compare the mean scores of parents and children with diabetes for each domain of the questionnaires. All domains showed statistically increased responses from children with diabetes. (Tables 1 and 2)

TABLE 1:Comparison of mean scores for each domain of QOLID questionnaire by parents between Diabetics and Non-diabetic group using Mann Whitney Test

Domains	Groups	N	Mean	SD	Mean Diff	p-value
About Health & Activities	Diabetic	100	6.69	2.90	6.69	<0.001*
	Non-diabetic	100	0.00	0.00		
Physical Endurance	Diabetic	100	4.39	2.35	4.39	<0.001*
	Non-diabetic	100	0.00	0.00		
Symptom Botherness	Diabetic	100	4.69	2.26	4.64	<0.001*
	Non-diabetic	100	0.05	0.22		
Financial Worries	Diabetic	100	9.10	2.19	9.10	<0.001*
	Non-diabetic	100	0.00	0.00		
Emotional Health	Diabetic	100	2.25	1.26	2.25	<0.001*
	Non-diabetic	100	0.00	0.00		

TABLE 2:Comparison of mean scores for each domain of Peds QL questionnaire by study children between Diabetics and Non-diabetic group using Mann Whitney Test

Domains	Groups	N	Mean	SD	Mean Diff	p-value
About my Health & Activities	Diabetic	100	4.99	2.60	4.99	<0.001*
	Non-diabetic	100	0.00	0.00		
Emotional Functioning	Diabetic	100	3.74	2.48	3.74	<0.001*
	Non-diabetic	100	0.00	0.00		
Social Functioning	Diabetic	100	1.71	2.16	1.71	<0.001*
	Non-diabetic	100	0.00	0.00		
About School	Diabetic	100	6.65	2.56	5.09	<0.001*
	Non-diabetic	100	1.56	1.81		

VI. DISCUSSION

Due to limited financial means and low socioeconomic status (SES), most of children experienced a detoriated quality of life (QOL), varying slightly in severity and degree.

In line with prior findings, our study revealed that children with type 1 diabetes had a lower general quality of life than typical children.

This may be due to the disease's demands on parents and kids to maintain correct glycaemic control.

Students' QOL scores were high when they missed school due to physical constraints or illness.

Subtle neurophysiological alterations linked to inadequate glycaemic management are to blame for this. Because patient age is a major determinant of quality of life, a broad range of participants (5–15 years old) were chosen for the current study to evaluate the quality of life of children with type 1 diabetes, as the most of the prior research was conducted in the adolescent age group.

As the kids in the diabetes module grew older, they were able to handle the condition more autonomously and subjectively. The American Diabetes Association addresses the necessity of reducing parental supervision as a kid enters adolescence and permitting a gradual transition to independence.

Due to differences in the health care delivery system, family dynamics, attitudes, and knowledge of diabetes, children in India require different monitoring, as strict eating habits and frequent pricks can negatively impact their quality of life. Diabetic centers take care of such children but do not look on psychological aspects. The majority of parents lack the literacy necessary to comprehend how to regulate blood sugar and insulin at home. It is further exacerbated by budgetary limitations. There are hardly few limited studies in India regarding QOL in children with T1DM and this study provides more light into the diabetic care in Indian children.

VII. CONCLUSION

Financial worries had a detrimental effect on the parents' quality of life, and most of the children's QOL suffered in every way. Regular child care must include the evaluation of children's quality of life (QOL), since this may reveal the strength of the family unit in supporting children as they deal with the challenges and disappointments brought on by a diabetes diagnosis.

VIII. ETHICAL COMMITTEE CLEARANCE

Ethical clearance is obtained from RajaRajeswari dental college and hospital.

IX. CONFLICT OF INTEREST

No conflicts of interest found.

X. REFERENCES

[1]. Nikitina IL, Kelmanson IA. Health-related quality of life in 4-to-6-year-old children with type 1 diabetes mellitus estimated by children and their mothers. Eur J Pediatr 2022;181(2):549-60.

[2]. Jafari P, Forouzandeh E, Bagheri Z, Karamizadeh Z, Shalileh K. Health related quality of life of Iranian children with type 1 diabetes: reliability and validity of the Persian version of the PedsQL™ Generic Core Scales and Diabetes Module. HQLO 2011;9:1-6.

[3]. Kumar R, Patodia J, Malhi P, Dayal[4] D. Quality of Life for Indian Diabetic Children. J Postgrad Med Edu Res 2019;53(2):61-8.

[4]. Varni JW, Delamater AM, Hood KK et al. Pediatric Quality of Life Inventory (Peds QL) 3.2 Diabetes Module for youth with Type 2 diabetes: reliability and validity. Diabet Med 2019;36(4):465-72.

[5]. Abdul-Rasoul M, AlOtaibi F, AlMahdi M, AlKandari H. Reliability and validity of the Arabic version of the PedsQLTM 4.0 generic ore scales and PedsQLTM 3.0 diabetes module. J Diabetes Mellit. 2012;2(03):301-7.

[6]. Abdul-Rasoul M, AlOtaibi F, Abdulla A, Rahme Z, AlShawaf F. Quality of life of children and adolescents with type 1 diabetes in Kuwait. Med princ pract 2013;22(4):379-84.

[7]. Özyazıcıoğlu N, Avdal EÜ, Sağlam H. A determination of the quality of life of children and adolescents with type 1 diabetes and their parents. Int J Nurs Sci 2017;4(2):94-8.

[8]. De Wit M, Delemarre-van de Waal HA, Bokma JA et al. Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being: a randomized controlled trial. Diabetes Care 2008;31(8):1521-6.

[9]. Babiker A, Al Aqeel B, Marie S et aI. Quality of life and glycemic control in Saudi children with type 1 diabetes at different developmental age groups. Clin.Med.Insights: Endocrinol.Diabetes. 2021;14:1179551421990678.

[10]. Kalyva E, Malakonaki E, Eiser C, Mamoulakis D. Health-related quality of life (HRQoL) of children with type 1 diabetes mellitus (T1DM): self and parental perceptions. Pediatri.Diabetes. 2011;12(1):34-40.

[11]. Maahs DM, West NA, Lawrence JM, Mayer-Davis EJ. Epidemiology of type 1 diabetes. Endocrinol Metab Clin North Am. 2010;39:481–497.

[12]. Hilliard ME, Minard CG, Marrero DG et al. Assessing health-related quality of life in children and adolescents with diabetes: development and psychometrics of the Type 1 Diabetes and Life (T1DAL) Measures. J Pediatr Psychol. 2020;45:328–339.

[13]. Cameron FJ. The impact of diabetes on health-related quality of life in children and adolescents. Pediatr Diabetes. 2003;4:132–136.

[14]. Nagpal J, Kumar A, Kakar S, et al. The development of 'Quality of Life Instrument for Indian Diabetes patients (QOLID): a validation and reliability study in middle and higher income groups. J Assoc Physicians India 2010;58:295-304

[15]. Ausili E, Tabacco F, Focarelli B, et al. Multidimensional study on quality of life in children with type 1 diabetes. Eur Rev Med Pharmacol Sci 2007;11(4):249-255.

[16]. Grey M, Boland EA, Yu C, et al. Personal and family factors associated with quality of life in adolescents with diabetes. Diabetes Care 1998; 21(6):909-914.

[17]. Ingerski LM, Laffel L, Drotar D, et al. Correlates of glycemic control and quality of life outcomes in adolescents with type 1 diabetes. Pediatr Diabetes 2010;11(8):563-571.

[18]. Hao Y, Tian Q, Lu Y, Chai Y, Rao S. Psychometric properties of the Chinese version of the Pediatric Quality of Life Inventory™ 4.0 generic core scales. *Qual Life Res* 2010 Oct;19:1229-33.

[19]. Gkoltsiou K, Dimitrakaki C, Tzavara C, Papaevangelou V, Varni JW, Tountas Y. Measuring health-related quality of life in Greek children: psychometric properties of the Greek version of the Pediatric Quality of Life Inventory TM 4.0 Generic Core Scales. *Qual Life Res*2008 Mar;17:299-305.

Fig 1:Quality of life instrument in indian diabetics

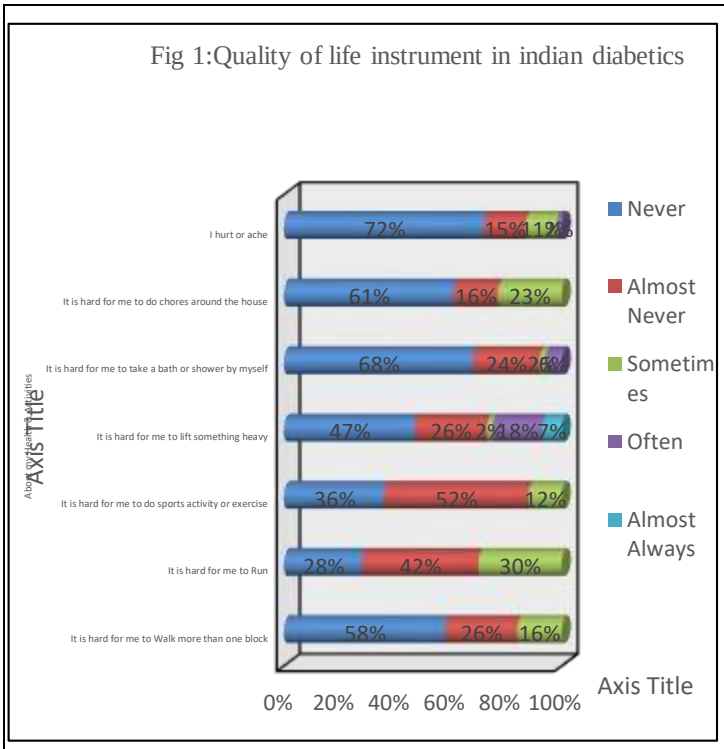

fig 2 Quality of life instrument in indian diabetics by children

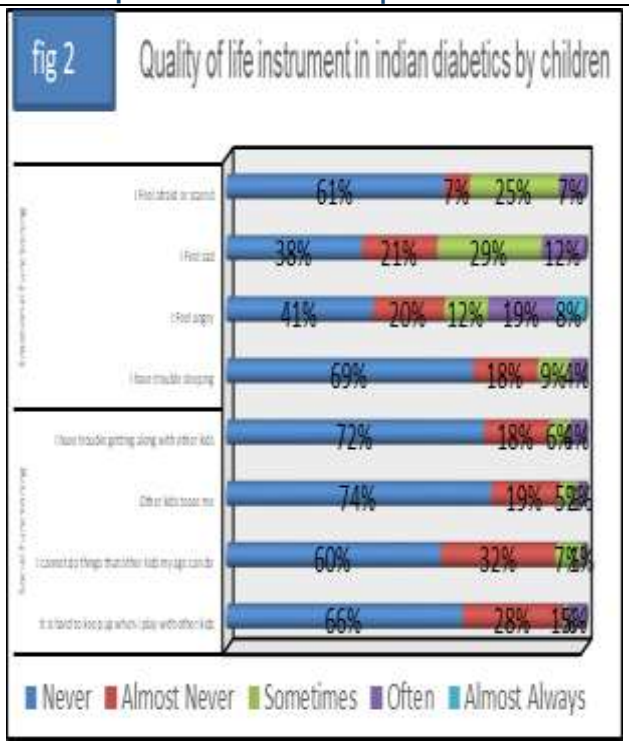

Fig 3

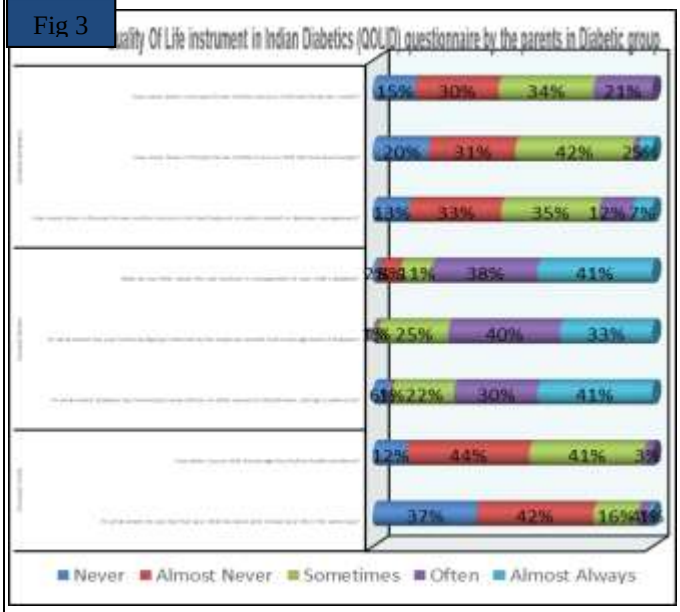

Fig 4

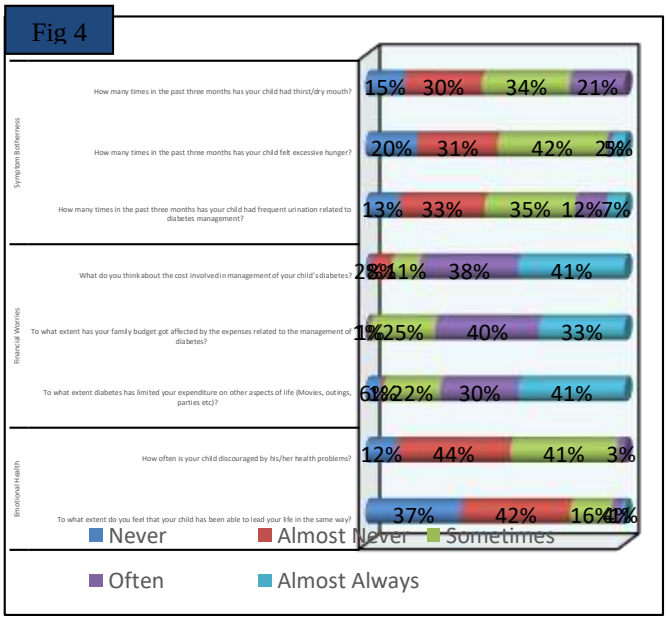

Fig 5

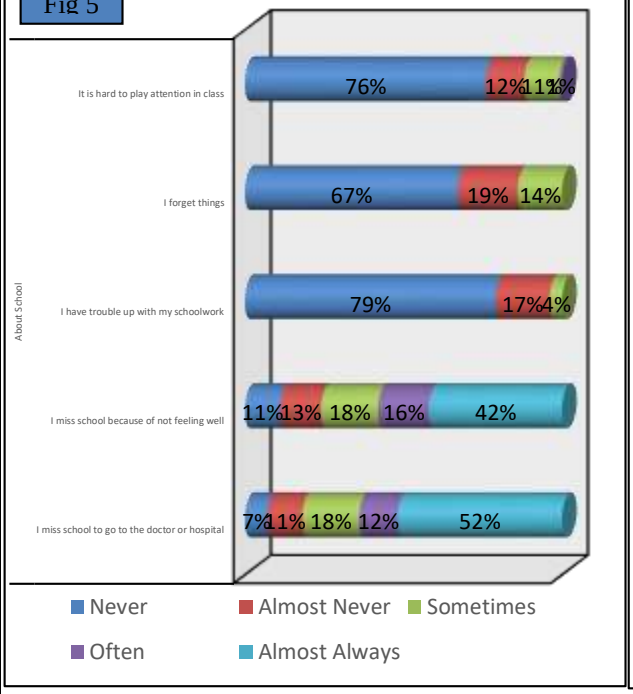

Fig 6

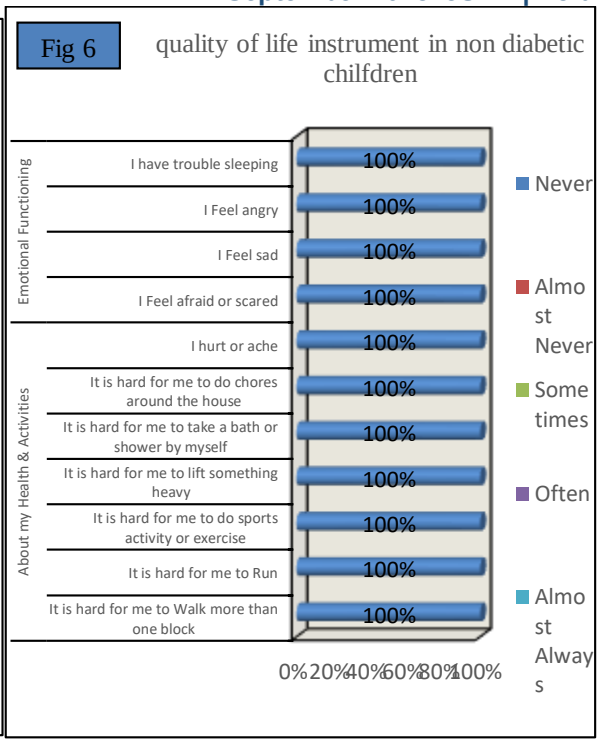

Fig 7