# **Original Research Article**

Quality of Life of Diabetic Children in Public Diabetes Specialized

Clinics, Khartoum State, Sudan

### ABSTRACT

**Background**: Quality of life assessment can be a good baseline measures to determine the efficacy of health policies that <u>are</u> designed to reduce or eradicate the detrimental disease effect. **Aim:** This study aimed to study theat assessing the different dimensions of quality of life in children with diabetes including physical, social, emotional and school function. **Materials and Methods:** <u>The</u> <u>S</u>study was conducted in Khartoum state - Sudan with <u>using</u> a cross sectional design<sub>25</sub> Data wasere obtained in 2018 at three outpatient diabetes clinics, using systematic random sampling, with sample size <u>ofwas</u> 138 diabetic children aged <u>between</u> (2-18) years, via structured interviews<sub>25</sub> Descriptive statistics and inferential statistics were used to analyze the data. **Results:** Those with diabetes reported personal and adverse social effects, <u>most of them have</u> poor control; HA1C more than 6.5% in 90% of participants. Mean generic quality of life was (80.03 ± 27) and (80.84 ± 28) for parents and children report respectively. **Conclusion:** Diabetes has burden and social effect on diabetic children, Diabetes adversely affects the quality of life of diabetic children. *quality of life which is* influenced by history of hospitalization. Further studies on Diabetes quality of life are recommended.

Key words: diabetes, burden, quality of life, generic, diabetic children, Khartoum, Sudan.

# 1. INTRODUCTION:

Diabetes mellitus is one of the metabolic disorders. Cases of diabetes in children and adolescents caused by type 2 diabetes has risen recently, However type 1 diabetes remains the most common form of diabetes mellitus in children<sup>(1)</sup>. Health-related quality of life (HRQOL) refers to the measure of a patient's functioning, well-being, and general health perception in each of three domains: physical, psychological, and social. Along with survival and other types of clinical outcomes, therefore patient QOL is one of the most important indicators of the effectiveness of the medical care they receive <sup>(2)</sup>. Center for Disease Control and prevention (CDC) addresses the need for measuring Health Related Quality Of Life (HRQOL) to supplement public health traditional measures of morbidity and mortality<sup>(3)</sup>.

Burden of disease is a concept that covers various aspects of the disease impact on the health outcomes in a country, specific regions, communities, and even individuals.<sup>(4)</sup> However burden of Disease can range from the incidence or prevalence of disease to its effect on longevity, morbidity along with the decrease in health status and quality of life (QoL), along with financial aspects including direct and indirect expenditures that result from premature death, disability or injury due to corresponding disease and/ or its comorbidities <sup>(4, 5)</sup>.

Diabetes mellitus is one of the metabolic disorders. Cases of diabetes in children and adolescents caused by type 2 diabetes has risen recently, However type 1 diabetes remains the most common form of diabetes mellitus in children<sup>(1)</sup>. Diabetes mellitus is amongst the most common chronic illnesses in the Sudan. His prevalence is increasing. Sudanese pPeople with diabetes awere also significantly more likely to suffer from serious complications and comorbidities, such as Diabetic Ketoacidosis (DKA), cardiovascular disorders and foot ulcers. Those with diabetes reported a higher proportion of personal adverse social effects on patients and their families, such as being prevented from doing paid work or participating in education and exert a negative impact on the school performance of children<sup>(6)</sup>.

Different tools have been developed and validated to assess quality of life, including generic and disease specific questionnaires. Also the issue of quality of life had been widely investigated on international level<sup>(2, 7)</sup>. The Pediatric Quality of Life Inventory (PedsQL) instrument was designed to measure health-related quality of life (HRQOL) in child<u>ren</u> and adolescents aged 2–18 years <sup>(8)</sup>.

Quality of life assessment can be a good baseline measures to determine the efficacy of health policies, programs, or any types of interventions that are designed to reduce or eradicate the detrimental disease effects.

This study aimed to assess the different factors associated with the quality of life of children and adolescents who have diabetes mellitus.

### 2. MATERIALS AND METHODS:

This was a cross sectional, health facility based study conducted during January- December, 2018. The study area was Khartoum State. In 3 public specialized diabetes clinics, the study population was children diabetic males and females, bellow 18 years of age. Severely ill patients and those accompanied by someone other than parents were excluded from the study.

Sample size calculations was demonstrated for burden of illness by characterizing precision around estimates of mean, using the following formula <sup>(9)</sup>:

$$n = \left(\frac{1.96 * r}{y}\right)2$$

Where : n = size of sampling. r= ratio of expected standard deviation to mean. y= desired confidence interval width

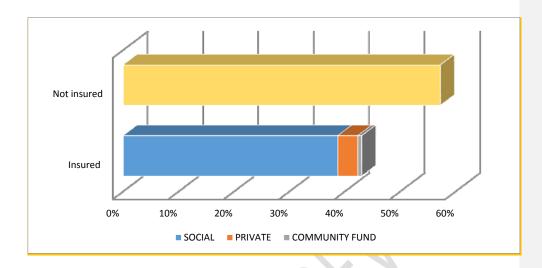
At 95% confidence interval, in order to relate cost of illness and quality of life, mean and standard deviation of diabetes cost expected to be 378 and 162 respectively as the estimate done in Sudan <sup>(10)</sup> At desired precision(y %) equal (5%) and ratio of standard deviation to mean (r) is about (0.3) sample size estimated to be 138.

Probability sampling using systematic random sampling <u>was applied</u> for selection of participants<sub>72</sub> <u>sS</u>ample was distributed proportional to average patient frequency in each facility.\_The sample<u>was</u> selected systematically as patients came in for consultation.

• Data<u>was</u> collected through administrating a standardized adapted generic core scale questionnaire constructed by Mapi Research Trust (MRT), pediatric quality of life inventory<sup>TM</sup>, Face to face interviews were conducted with both children (5-18 years and 2-4 year todllers) and their parents, age (5-18) and for parents of toddlers (2-4)years. The questionnaire consisted of four dimensions; physical functioning (8) items, emotional functioning (5) items, social functioning (5) items, school functioning (3) items<sup>(8)</sup>. A questionnaire was validated for Internal consistency and reliability (Alpha = 0.88 child, 0.89 parent-report) <sup>(11)</sup>.Data was analyzed using statistical package for social science software version 22. Descriptive statistics was used to assess the quality of life measured by Likert scale. Independent samples t test, analysis of variance and Pearson correlation were used to test the relationship between quality of life and other independent variables: demography ( age, gender, parents' education, age, residency and occupation), type of diabetes, type of treatment, duration of illness, control of diabetes\_and<sub>x</sub> insurance status

### 3. RESULTS:

Interviews were conducted with 138 diabetic child<u>ren with their and parents;</u> +The mean age of children was (11.1±3.64) years, and most frequent age group was (8-12) years, <math>-Trepresented by (43.5%). Most of participants; more than +T wo thirds of the participants were in primary school with- Ffemales making up to were (63%). And almost three quarters of the participants (73%) lived in urban areas. About 92.3% of children were found to have uncontrolled diabetes (HA1C  $\geq$  6.5). Regarding Insurance status; more than half of participants were not covered by any insurance scheme. Figure No (1):



# Figure No(1): Participants' insurance status in study of quality of life of diabetic children at public clinics in Khartoum, Sudan 2018 (n=138)

Type I diabetes was the most frequent type therefore insulin <u>was</u> found to be the main treatment (94%) followed by combined (oral +insulin) (5%) and oral hypoglycemic drugs (1%). <u>T</u>two thirds of participants were on- regular monthly follow up, whereas about one third every two months<u>,</u> <u>O</u>on the other hand about (13%)\_were not committed to follow up. Also two thirds of participants had history of hospitalization during the last year<u>,</u> among them nearly 90% <u>wereare</u> admitted (1-3) times and only 2 participants admitted about 15 times. Almost half of participants had diabetes for mean duration of (3.4±2.8).

Regarding parents' socio-demographic characteristic; illiteracy among mothers is higher than fathers, most of mothers are house wives and few of them are officers or free workers, Mothers' mean age was  $(37.3\pm7.8)$  whereas fathers' mean age was  $(45.4\pm9.3)$ .

Parent-proxy report and children report for generic quality of life were nearly similar and there were no significant differences in means (p-value =0.73). Parents and children means and SD in physical dimension is around ( $82\pm26$ ), ( $81\pm29$ ) respectively. Emotional functioning showed lowest means among both parents and children ( $68\pm33$ ) and ( $75\pm32$ ) respectively. (table1).

Comment [ST1]: is this in years or months?

Dimension	Parents		Children	
	Mean	SD	Mean	SD
Physical Functioning	82.52	26.78	81	29
Emotional Functioning	68.51	33.98	75.04	32.3
Social Functioning	92.75	18.49	91.85	21.78
School Functioning	76.32	29.15	75.35	28.58
Overall	80.03	27.10	80.84	28.03

 Table No (1): Mean generic quality of life according to parents' and children reports in study of quality of life of diabetic children at public diabetes clinics in Khartoum, Sudan 2018 (n=138)

Quality of life was not affected by regular follow  $up_(p \text{ value} = .124)$  using parents report, whereas it's significantly lower among hospitalized than non-hospitalized in previous year (p value = .014). Insurance status of diabetic children found to have nothing to do with quality of life (p value = .94 and .22) from parents and children report respectively. On the other hand Quality of life was not significantly different with: age (p value = .37), gender (p value = .45), type of treatment\_(p value = .32), duration of illness\_(p value = .37), control of diabetes\_(p value = .06).

# 4. DISCUSSION:

Quality of life of children was assessed by both parents report and children reports for different age groups using generic tool. There was no significant difference in quality of life between two reports, whereas parents evaluation of quality of life was not significantly different than children's evaluation (p. value = .73), this finding was not aligned with study conducted in Saudi Arabia where it is significantly different<sup>(12)</sup>. Although it's significantly different in emotional dimension (p. value = .03), and that could be due to differences of perception and worrying between adult and children.

In comparison with study conducted in Iran, this study showed better overall mean score and variation on subscale dimensions. Difference of those finding could be due to differences between study populations and differences in tools used. In contrast to Iran study, in this study;\_duration of illness, treatment type, gender, and parents' level of education HA1C have nothing to do with quality of life since the p values was greater (.05)<sup>(13).</sup>

Despite that quality of life is associated with glycemic control in most of studiesstudies, this study finding does not counterbalance the instances of significant relationships. Since quality of life according to nationwide cohort study of patients with  $\geq 10$  years duration in Germany was inversely associated with HbA1c after 3 years in the course of type I diabetes <sup>(14)</sup>. This difference may be due to overall poor control among population of this study. On the other hand Andrea Luka, in Hungary found that blood glucose control, gender, age, insulin dosage and the duration of diabetes as independent variables were not significant in the regression model, which is consistent with this study finding<sup>(15)</sup>. Quality of life is significantly different among hospitalized and non-hospitalized, history of hospitalization among participants reversely affect the Quality of life.

### 5. CONNCLUSION AND RECOMMENDATIONS:

Quality of life of diabetic children <u>was</u> estimated to be (80.03 and 80.84) by parents and children respectively among -diabetic children in Khartoum, Sudan. Psychological pain, stress and anxiety were <u>shown to</u> adversely affect the quality of life of diabetic<sup>2</sup>s children. Strengthening non-communicable disease program to promote diabetes care and reduce complications, along with Promotion for research in areas of burden and quality of life by academic institutions and ministry of health is recommended.

#### **Ethical clearance:**

Ethical clearance was obtained from ethical committee in the Ministry of Health in Khartoum State. Participants had voluntary informed consent (from parents and children). Participants not harmed by any mean, confidentiality and questionnaire coding were conducted benefits and risks of the study were explained to participants. Approval from Mapi Research Trust was obtained to use their tools.

## **REFERENCES:**

 Cooke DW, Plotnick L. Type 1 diabetes mellitus in pediatrics. *Pediatr Rev.* 2008;29(11):374-84.
 Valderrábano F, Jofre R, López-Gómez JM. Quality of life in end-stage renal disease patients. *American Journal of Kidney Diseases.* 2001;38(3):443-64.

3. Moriarty DG, Zack MM, Kobau R. The Centers for Disease Control and Prevention's Healthy Days Measures–Population tracking of perceived physical and mental health over time. *Health and quality of life outcomes*. 2003;1(1):37.

4. Lee I-M, Shiroma EJ, Lobelo F, Puska P, Blair SN, Katzmarzyk PT, et al. Effect of physical inactivity on major non-communicable diseases worldwide: an analysis of burden of disease and life expectancy. *The lancet*. 2012;380(9838):219-29.

5. Jo C. Cost-of-illness studies: concepts, scopes, and methods. *Clinical and molecular hepatology*. 2014;20(4):327.

6. Elrayah H, Ostenson CG, Eltom M, Johansson P, Sparring V, Wahlstrom R. Economic and social impact of diabetes mellitus in a low-income country: A case-control study in Sudan. *Journal of diabetes*. 2017 Feb 22. PubMed PMID: 28224724.

7. Mucsi I, Molnar MZ, Ambrus C, Szeifert L, Kovacs AZ, Zoller R, et al. Restless legs syndrome, insomnia and quality of life in patients on maintenance dialysis. *Nephrology Dialysis Transplantation*. 2005;20(3):571-7.

8. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL<sup>™</sup> in type 1 and type 2 diabetes. *Diabetes care*. 2003;26(3):631-7.

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

9. Johnston K, Szabo S, Donato B, Bolzani A. Methods of sample size calculation in retrospective burden of illness studies. *Value in Health*. 2016;19(3):A101.

10. Elrayah-Eliadarous H. Economic burden of diabetes on patients and their families in Sudan: Institutionen för folkhälsovetenskap/Department of Public Health Sciences; 2007.

11. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL<sup>™</sup> in type 1 and type 2 diabetes: reliability and validity of the Pediatric Quality of Life Inventory<sup>™</sup> generic core scales and type 1 diabetes module. *Diabetes care*. 2003;26(3):631-7.

12. AlBuhairan F, Nasim M, Al Otaibi A, Shaheen NA, Al Jaser S, Al Alwan I. Health related quality of life and family impact of type 1 diabetes among adolescents in Saudi Arabia. *Diabetes research and clinical practice*. 2016 Apr;114:173-9. PubMed PMID: 26830857.

13. Rahmani F, Valizadeh S, Bagheriyeh F, Ghogazadeh M. Self-care Agency and Quality of Life among Iranian Adolescents with Diabetes Mellitus Type 1. *Nursing Practice Today*. 2018;5(1):260-7.

14. Stahl-Pehe A, Landwehr S, Lange KS, Bachle C, Castillo K, Yossa R, et al. Impact of quality of life (QoL) on glycemic control (HbA1c) among adolescents and emerging adults with long-duration type 1 diabetes: A prospective cohort-study. *Pediatric diabetes.* 2017 Dec;18(8):808-16. PubMed PMID: 28133885.

15. Lukacs A, Varga B, Kiss-Toth E, Soos A, Barkai L. Factors influencing the diabetes-specific healthrelated quality of life in children and adolescents with type 1 diabetes mellitus. *Journal of child health care : for professionals working with children in the hospital and community.* 2014 Sep;18(3):253-60. PubMed PMID: 23749254. Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

**Comment [ST2]:** Journal name should be in full for consistency