

Quality of life and Associated Factors among Children aged 5 to 18 years with Diabetes Mellitus at St. Francis Hospital Nsambya and Mulago National Referral Hospital

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Abstract

Background: This study aimed to determine the quality of life and describe associated factors among children aged 5-18 years with diabetes Mellitus at St. Francis Hospital Nsambya and Mulago National Referral Hospital.

Methods: An explanatory sequential study design was used between November 2018 and March 2019. Univariate analysis together with bivariate logistic regression analysis was used to determine quality of life and identify association between the quality of life at a p -value < 0.05 respectively. Factors found to have a p -value < 0.25 were included in the Multivariate logistic regression. A backward method was then applied to determine the best model that predicts quality of life among children. Data was analysed using STATA version 14. Data on the perception of quality of life of children with diabetes mellitus from the perspective of the children, caregivers and health workers was used to obtain qualitative results.

Results: 115 children were recruited from the paediatric diabetic clinics. A low quality of life with a mean score of 77 ± 15.58 was reported with a mean age of 13 ± 3.9 . Factors associated with quality of life included: age groups of 8-12 and 13-18 years, primary education, secondary education, tertiary education, a single parent, living with relatives and primary care giver being a relative other than the biological parents.

Conclusion: A sub-optimal quality of life was observed among children with type 1 diabetes mellitus. The factors associated with good quality of life included; age between 5- 7 years, a child living with biological parents, a child being in primary school and higher parental level of education.

Recommendation: Community health education and sensitization should be more focused towards the adolescent patients, single mothers, guardians and benefactors of children with diabetes mellitus. There is greater need for healthcare support in schools to mitigate the stigma experienced by these children.

Keywords: Quality of life, Type I Diabetes mellitus, Children, Uganda

Introduction

Type 1 Diabetes Mellitus (T1DM) is one of the most common endocrine and metabolic diseases in childhood, with a rapidly increasing incidence especially in the younger children [1]. Globally, it was estimated that 1,106,500 children under 20 years were affected by T1DM [2, 3]. Among the African population, the estimated incidence is 5.8 while prevalence was 35.7 per 100,000 persons per year. In Uganda, the incidence and prevalence were estimated

to be 0.1 and 0.9 per 100,000 persons per year respectively [4]. Standard care to children with diabetes mellitus in Africa is yet to be achieved despite the significant improvements over the last 6 years that includes; training of 60 paediatric endocrinologists and healthcare providers, increased availability of insulin together with the introduction of patient education materials in native languages [5].

Psychosocial challenges have been reported among the children living with diabetes mellitus in Uganda but their quality of life in relation to the chronic illness has not been assessed [6]. The

World Health Organization defines quality of life (HRQOL) as the individual's quality of life associated with their physical, mental and social well-being [7-9]. HRQOL is a measure of activity (execution of a specific task), participation (real-life situations), physiological body functioning (for example, neuro-musculoskeletal function and pain) and/or contextual factors (that is to say, environmental and personal).

Chronic illnesses have varying effects on a person's functioning and how the community or other people view their quality of life. The measurement is therefore made through the assessment of the individual's perspective or using parent proxy reports (frequently used for children who are either too young or unwell) [10]. Dual reports can also be obtained to provide insight into the different perceptions of functioning. Generic assessment tool provides a comparison of the quality of life between individuals in the community ill or not ill while the disease specific assessment tools provide insight in specific treatment outcome/ effects. Condition-specific tools may also be more clinically meaningful as they explore the specific difficulties related to a given condition [10].

Many children and adolescents with Diabetes are unable to cope emotionally and are often embarrassed, discriminated against and have limitations in their social relationships. The parents on the other hand experience a financial burden, may have to reduce their working hours or even entirely give up work to care for their child [11]. In a study carried out in Spain among patients attending diabetes outpatient endocrinology clinic, QoL was observed to worsen with increasing HbA1c, female sex, severity of complications, and lower education [12]. Specific factors observed to lead the deterioration of quality of life in another study included public assistance, time since diagnosis, sedentary lifestyle, and being female [13].

Among patients with type 1 diabetes in Brazil, women demonstrated poorer QoL perceptions whereas younger patients demonstrated poor QoL perception, suggesting that glycaemic control can impact on QoL [14]. A study carried out in Dar es Salaam – Tanzania, revealed that being of younger age, having the mother as the primary caregiver, caregiver knowledge of diabetes, adherence to blood glucose monitoring regimen and diabetes duration of less than 1 year were associated with better glycaemic control [15]. A systematic review found that there was a significant relationship between some health-related quality of life scales and blood glucose profiles and higher quality of life may be associated with better control of blood glucose in diabetics [16]. In a German study however, it was found that a longer duration of the disease was associated with better Physical function [17]. The disease control was positively related to Physical and Psychological functioning over time while mental health problems were negatively associated with four HRQoL dimensions over time [17].

Materials and Methods

A mixed methods explanatory sequential design was used. Children aged 5 to 18 years with DM receiving diabetic care and management from either Mulago National Referral Hospital (MNRH) and/or St. Francis Hospital Nsambya (SFHN) during the study period that met the inclusion criteria were recruited. St. Francis Hospital Nsambya and Mulago National Referral Hospital paediatric diabetic clinics are located within each facility by the immunisation clinic and on ward 15 respectively. At both clinics (SFHN and MNRH paediatric diabetic clinics), children with diabetes are provided with

insulin at no cost through the International Diabetes Federation (IDF), Changing Diabetes in Children (CDiC). In addition, they are provided with glucose monitors (if available and when not, the parents are encouraged to buy one), strips and diaries for self-monitoring and recording of blood glucose at home. Monitoring the child's glucose level was done at least 3 times a day at specified times and readings recorded in their diaries. HbA1c was also measured every 3–6 months for every patient. Patients and guardians were often sensitized about diabetes and on appropriate nutrition. Both paediatric diabetic clinics were supervised by a Paediatrician and the patient management involved diabetic nurses, doctors (paediatricians and paediatric residents), nutritionists and laboratory technicians. In addition to the above-mentioned staff, the MNRH paediatric diabetic clinic was boosted by a paediatric endocrinologist.

Inclusion criteria

Children aged 5 to 18 years with type 1 diabetes mellitus attending either Mulago National Referral hospital or St. Francis Hospital Nsambya Paediatric diabetic clinic for a minimum of three months. These children must have been accompanied by either a caretaker and/or parent. Children aged 8 to <18 years of age that assented to participate in the study as this is the required age of assent [18]. Parents of assented children consented to the study as they are required to consent after the child assents [18]. Children aged 18 years of age were consented into the study. A participant who's HbA1c had been carried out within 6 months at the time of enrolment into the study as HbA1c was being done biannually for each child. If a participant was found to have a serious issue that impacted on their quality of life, the child would have to be appropriately linked for medical care.

Exclusion criteria

Critically ill children as their quality of life will be compromised by the illness [19].

Sample size

For the Quantitative objective: Yamane simplified formula for calculating sample size from a finite population [20].

$n = \frac{N}{1 + Ne^2}$ where n was the sample size, N was the population size of 162 patients and e was anticipated level of precision of about 5%.

$n = \frac{162}{1 + 162(0.05^2)} = 115$ children expected sample size was 115 children with diabetes. A sample size of 115 children was calculated from 162 children who regularly attended the clinics.

For the Qualitative objective

Thirteen interviews were conducted. Six of which were in-depth interviews for children aged 8 to 18 years (three from each clinic, one was aged 16 years and the remaining five children were aged 18 years. Four of them were in secondary school, one had dropped out of school at the age of 10 years and one was working in a hardware store for about a year. Three were male and three were female).

Four of which were in-depth interviews with parents (three of the parents were from MNRH paediatric diabetic clinic while one was from SFHN paediatric diabetic clinic, three were female while one was male. Three of the parents were married while one was a single mother. Two of the parents were educated up to the tertiary level, one parent educated up to the primary level of education while one was uneducated) Lastly, three were key informant

interviews; two key informants were from St. Francis Hospital Nsambya while one was from Mulago National Referral Hospital paediatric diabetic clinics. Two of the informants were diabetic nurses while one was a paediatrician with St. Francis Hospital Nsambya. Consecutive enrolment and purposive sampling were employed during recruitment of the participants.

Data instruments

For the quantitative objective: The 23-item PedsQL questionnaire developed and validated by James W. Varni was used to collect data [21]. The PedsQL has been found to be reliable and accurate with an α value of 0.95 in the Ugandan children [22]. It has thus been validated in the Uganda paediatric population with 90% reliability [22]. The tool contained 23 items that were used to measure four QoL dimensions/domains in children with diabetes which included Physical, Emotional, Social and School functioning

For the qualitative objective: Pre-tested semi-structured Key Informants and/or In-Depth Interview guides were used to collect data. These were undertaken in either Luganda or English language. The interviews were conducted in a well-lit, private room that was located in the paediatric diabetic clinics. The semi-structured interview guides contained questions selected based on factors found to be associated with low HRQoL in the quantitative analysis.

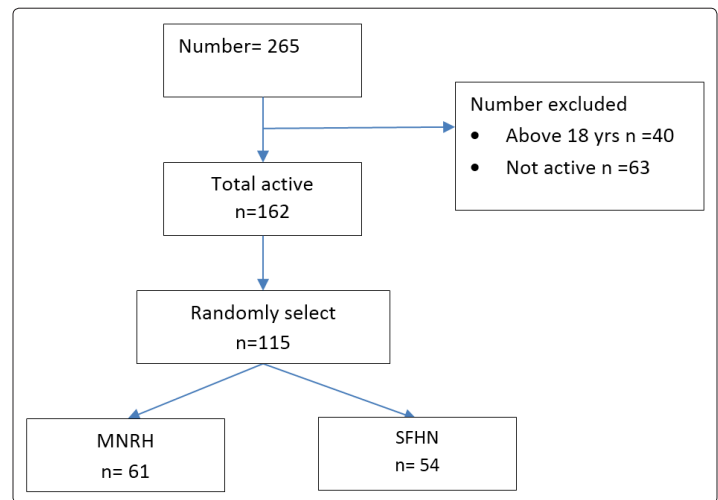
Statistical analysis

For the quantitative objective: Descriptive analysis and cross tabulation were used to assess the basic characteristics of the patients. Continuous variables were presented using mean and standard deviation or median and interquartile range while categorical variables were presented as proportion and/percentages. The primary outcome i.e. Quality of life was categorized as good (≥ 84) and poor (≤ 83) while the independent variables were measured as continuous variables but categorized as dichotomous variables. Bivariate logistic regression analysis was used to determine the association between independent factors and quality of life outcome variable at a p-value of ≤ 0.05 for statistical significance. Factors found to have a p-value of ≤ 0.25 were included in a multivariable logistic analysis to determine independent factors associated with quality of life. Stata 14 was used in the analysis of the study results.

For the qualitative objective: All IDIs and KIIs audio-recorded data was transcribed verbatim by the research assistant. The PI also independently transcribed and translated the transcripts to ensure validity. Both transcriptions were compared for discrepancies. The transcriptions were analysed and coded by using a qualitative phenomenological approach, taking into account both manifest and latent content to determine themes and sub-themes of perceptions of the children on their HRQoL together with that of the care-takers and health workers' perceptions of the children's HRQoL that emerged. Specific categories of the perceptions were analysed and the PI coded using the content thematic approach, another coder (the supervisor) also coded the transcriptions independently to enhance consistency. The researcher and co-coder jointly compared and finalized the themes and labelled them.

Study Results

Study profile



Study demographics

The mean age of study population was 13.96 ± 3.90 years. Of the recruited participants, 69% were aged between 13 and 18 years, 50% had attained secondary together with tertiary level of education. The study also revealed a relatively young parental population with approximately 44% falling between 36 to 45 years of age with a mean of 40.5 ± 8.32 years and with a predominance of female parental gender accounting for 70% of the parental population as shown in Table 1 below.

Table 1: socio-demographic of the study population

Characteristics	NUMBER (%)
Children's Gender	
Males	53
Females	62
Children's Age group	
5-7	11 (9.57)
8-12	25 (21.74)
13-18	79 (68.7)
Child's education level	
None	2 (1.74)
Kindergarten	7 (6.09)
Primary	49 (42.61)
Secondary	54 (46.96)
Tertiary	3 (2.61)
Parent's Age group	
21-35	33 (28.7)
36-45	50 (43.48)
46-55	24 (20.87)
56+	8 (6.96)
Parent's gender	
Male	34 (29.57)
Female	81 (70.43)
Parent's education level	

None	8 (6.96)
Primary	27 (23.48)
Secondary	42 (36.52)
Tertiary	38 (33.04)
Primary care giver	
Mother	64 (55.65)
Father	27 (23.48)
Sibling	11 (9.57)
Other Relative	13 (11.3)
Family Structure	
Both Parents	64 (55.65)
Single parent	33 (28.7)
Relatives	16 (13.91)
Orphan	2 (1.74)
Average Monthly Income	
0-300,000	51 (44.35)
300,001-500,000	31 (26.96)
> 500,000	33 (28.7)
Changes in monthly income	
Very unstable	17 (14.78)
Unstable	33 (28.7)
Stable	49 (42.61)
Missing	16 (13.91)

The average duration in diabetic care for children was 4.36 ± 3.55 years with the majority having been in care for 6 and above years as shown in figure 1 below

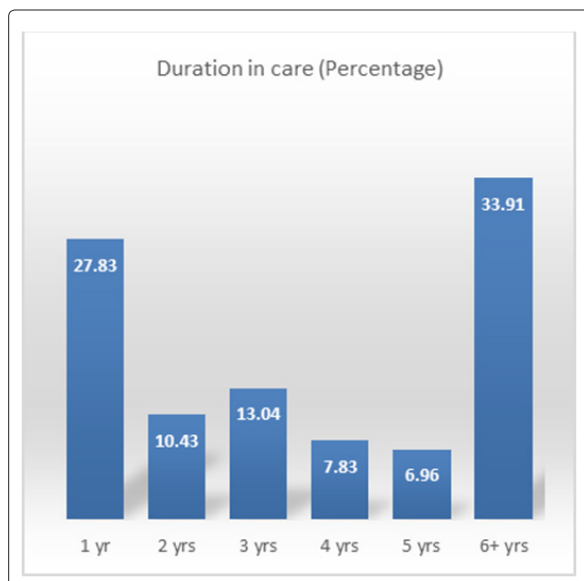


Figure 1: Duration in care of the study population

Approximately 9% of the study population had a good glycaemic control of $\leq 7.5\%$ as shown in Figure 2 below

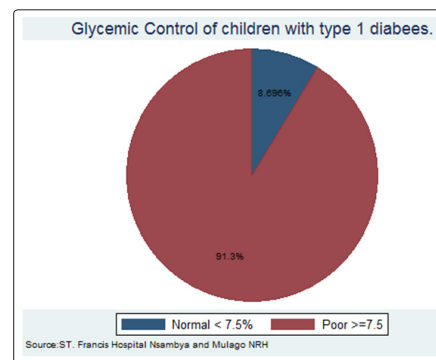


Figure 2: Glycemic Control of children with type 1 diabetes attending Nsambya and Mulago Diabetic clinics

Health related quality of life among the children aged 5-18 years with type I diabetes

On general assessment of quality of life, overall Health Related Quality of Life was reported to be 77.46 ± 15.6 as shown in Table 2, below

Table 2: Health Related Quality of Life of the study population

	mean(sd)
Physical Functioning	82.31 (17.40)
Psychosocial Health	74.86 (17.34)
Emotional Functioning	74.52 (20.88)
Social Functioning	88.0 (17.37)
School Functioning	62.08 (27.17)
Overall HRQoL	77.46 (15.58)

Table 3: Health Related Quality of Life of the study population

Status	Physical	Psychosocial	Emotional	Social	School
Worse	43 (37.39)	56 (48.7)	53 (46.09)	36 (31.3)	71 (61.74)
Better	72 (62.61)	59 (51.3)	62 (53.91)	79 (68.7)	44 (38.26)

Table 4: Health Related Quality of Life of the study population

Status	Physical	Psychosocial	Emotional	Social	School
Worse	43 (37.39)	56 (48.7)	53 (46.09)	36 (31.3)	71 (61.74)
Better	72 (62.61)	59 (51.3)	62 (53.91)	79 (68.7)	44 (38.26)

Table 5: Health Related Quality of Life by clinic site

Characteristics	Quality of Life			
	Worse	Better	Chi square	p-value
Recruitment Site			0.0018	0.966
Nsambya	25 (46.3)	29 (53.7)		
Mulago NRH	28 (45.9)	33 (54.1)		

Clinic site was not statistically significant as shown above in Table 5 above.

Table 6: Stratification of HRQoL by clinic site

Characteristics	SFHN				Mulago NRH			
	Worse	Better	Chi sq.	p-value	Worse	Better	Chi sq.	p-value
Age group			5.94	0.05			2.69	0.259
5-7	1 (12.5)	7 (87.5)			0 (0)	3 (100)		
8-12	7 (70)	3 (30)			7 (46.67)	8 (53.33)		
13-18	17 (47.22)	19 (52.78)			21 (48.84)	22 (51.16)		
Child's gender			0.004	0.95			2.90	0.088
Male	11 (45.83)	13 (54.17)			10 (34.48)	19 (65.52)		
Female	14 (46.67)	16 (53.33)			18 (56.25)	14 (43.75)		
Child's education			2.71	0.26			1.65	0.438
Kindergarten	12 (40)	18 (60)			17 (62.96)	27 (100)		
Primary	12 (60)	8 (40)			14 (48.28)	29 (100)		
Post Primary	1 (25)	3 (75)			2 (40)	5 (100)		
Insulin Adherence			0.89	0.34			1.21	0.27
Good	18 (42.86)	24 (57.14)			25 (49.02)	26 (50.98)		
Average	7 (58.33)	5 (41.67)			3 (30)	7 (70)		
Parent's gender			0.001	0.97			2.27	0.131
Male	7 (46.67)	8 (53.33)			6 (31.58)	13 (68.42)		
Female	18 (46.15)	21 (53.85)			22 (52.38)	20 (47.62)		
Parent's education			4.35	0.22			14.06	0.003
Tertiary	12 (52.17)	11 (47.83)			1 (6.67)	14 (93.33)		
Secondary	6 (31.58)	13 (68.42)			13 (56.52)	10 (43.48)		
Primary	5 (50)	5 (50)			9 (52.94)	8 (47.06)		
None	2 (100)	0 (0)			5 (83.33)	1 (16.67)		
Primary care giver			1.60	0.66			4.57	0.206
Other Relative	1 (20)	4 (80)			5 (62.5)	3 (37.5)		
Sibling	4 (50)	4 (50)			1 (33.33)	2 (66.67)		
Father	5 (45.45)	6 (54.55)			4 (25)	12 (75)		
Mother	15 (50)	15 (50)			18 (52.94)	16 (47.06)		
Family Structure			1.86	0.39			4.71	0.095
Both Parents	14 (41.18)	20 (58.82)			11 (36.67)	19 (63.33)		
Single parent	5 (45.45)	6 (54.55)			10 (45.45)	12 (54.55)		
Relatives	6 (66.67)	3 (33.33)			7 (77.78)	2 (22.22)		
Parental Involvement BGM			0.776	0.68			0.95	0.619
Minimal	7 (50)	7 (50)			13 (41.94)	18 (58.06)		
Moderate	8 (53.33)	7 (46.67)			5 (41.67)	7 (58.33)		
Optimal	10 (40)	15 (60)			10 (55.56)	8 (44.44)		
Insulin injection involvement			0.03	0.99			2.56	0.279
Minimal	10 (47.62)	11 (52.38)			14 (41.18)	20 (58.82)		
Moderate	6 (46.15)	7 (53.85)			3 (33.33)	6 (66.67)		
Optimal	9 (45)	11 (55)			11 (61.11)	7 (38.89)		
Meals taken			1.40	0.50			5.15	0.076
Two meals	4 (66.67)	2 (33.33)			2 (50)	2 (50)		
Three meals	7 (38.89)	11 (61.11)			22 (41.51)	31 (58.49)		

More than 3 meals	14 (46.67)	16 (53.33)			4 (100)	0 (0)		
Average Monthly Income			0.813	0.66			9.39	0.009
0-300,000	9 (47.37)	10 (52.63)			20 (62.5)	12 (37.5)		
300,001-500,000	6 (37.5)	10 (62.5)			6 (40.0)	9 (60.0)		
> 500,000	10 (52.63)	9 (47.37)			2 (14.29)	12 (85.71)		

Factor associated with HRQoL of the study population

At bivariate analysis, a parent having not attained any level of education, child living with a relative and parental average monthly income of >UGX 500,000 were factors found to be statistically significant with a p value of < 0.05 and thus reflected a poorer quality of life as shown in Table 7 below. A child's age being >7 years, child and parental education level together with a child living with a relative were found to be associated with HRQoL. Children aged 13-18 and 8- 12 years were 98% and 95% times less likely to attain a better Health Related Quality of life. Children whose parents had attained a secondary and primary level of education were 1.33 and 1.95 times more likely to attain a better HRQoL respectively when compared to children whose parents had attained tertiary/university level of education as shown in Table 7 below

Table 7: Factors associated with Poor Health Related Quality of Life for children with diabetes at Mulago NRH and Nsambya hospitals

CHARACTERISTICS	Number (%)	Bivariate		Multi variable	
		Crude OR(95% CI)	p-value	Adjusted OR (95% CI)	p-value
Age group	11 (9.57)	1			
5-7	25 (21.74)	0.08 (0.009 - 0.711)		1	
8-12	79 (68.7)	0.11 (0.013 - 0.883)	0.024	0.05 (0.003-0.961)	0.047
13-18			0.038	0.02 (0.001-0.385)	0.009
Child's education	54 (46.96)	1			
Post Primary	49 (42.61)	0.51 (0.236 - 1.112)		1	
Primary	7 (6.09)	0.78 (0.190 - 3.246)	0.091	0.21 (0.051-0.821)	0.025
Kindergarten			0.739	0.06 (0.004-0.990)	0.049
Comorbidities	105 (91.3)	1			
No	8 (6.96)	0.27 (0.052 - 1.401)		1	
Yes			0.119	0.17 (0.021-1.344)	0.093
Parent's education	38 (33.04)	1			
Tertiary	42 (36.52)	0.63 (0.255-1.555)		1	
Secondary	27 (23.48)	0.48 (0.176-1.325)	0.316	1.33 (0.389-4.542)	0.650
Primary	8 (6.96)	0.07 (0.008-0.67)	0.158	1.95 (0.447-8.503)	0.374
None			0.021	0.06 (0.005-0.853)	0.037
Primary care giver	13 (11.3)	1			
Other Relative	11 (9.57)	1.03 (0.205-5.154)		1	
Sibling	27 (23.48)	1.71 (0.443-6.629)	0.973	0.39 (0.038-4.05)	0.432
Father	64 (55.65)	0.81 (0.244-2.661)	0.435	0.36 (0.044-2.983)	0.345
Mother			0.722	0.09 (0.011-0.805)	0.031
Family Structure	64 (55.65)	1			
Both Parents	33 (28.7)	0.77 (0.329 - 1.799)		1	
Single parent	18 (15.65)	0.24 (0.078 - 0.776)	0.545	0.9 (0.302-2.674)	0.848
Relatives			0.017	0.05 (0.008-0.347)	0.002
Average Monthly Income	51 (44.35)	1			
0-300,000	31 (26.96)	2.09 (0.84 - 5.189)		1	
300,001-500,000	33 (28.7)	2.31 (0.938 - 5.674)	0.113	1.51 (0.411-5.578)	0.532
> 500,000			0.069	0.96 (0.246-3.711)	0.948

Children from Mulago NRH paediatric diabetic clinic whose parents had attained no education had a 98% less likely to attain a better quality of life compared to those whose parents had attained a tertiary level of education. It was also noted that the children attained a better quality of life as the parents' income increased however, the children whose parents earned > UGX 500,000 were 12 times more likely to attain a better quality of life when compared to those whose parents earned between UGX 0 to UGX 300,000. This could on the other hand be a chance finding as the confidence interval was very wide as noted in Table 8 below.

Table 8: Factors associated with Health Related Quality of Life among Mulago NRH children

Characteristics	Mulago NRH		Bivariate		Multivariate	
	Worse	Better	cOR(95% CI)	p-value	aOR(95% CI)	p-value
Child's gender						
Male	10 (34.48)	19 (65.52)	1	1	1	1
Female	18 (56.25)	14 (43.75)	0.41 (0.15-1.15)	0.091	0.33 (0.07-1.54)	0.16
Parent's gender						
Male	6 (31.58)	13 (68.42)	1	1	1	1
Female	22 (52.38)	20 (47.62)	0.42 (0.13-1.31)	0.136	5.7 (0.07-490.88)	0.44
Parent's education						
Tertiary	1 (6.67)	14 (93.33)	1	1	1	1
Secondary	13 (56.52)	10 (43.48)	0.05 (0.01-0.49)	0.009	0.08 (0.01-1.15)	0.06
Primary	9 (52.94)	8 (47.06)	0.06 (0.01-0.60)	0.016	0.16 (0.01-2.25)	0.17
None	5 (83.33)	1 (16.67)	0.01 (0.00-0.27)	0.005	0.02 (0.00-0.60)	0.02
Family Structure						
Both Parents	11 (36.67)	19 (63.33)	1	1	1	1
Single parent	10 (45.45)	12 (54.55)	0.69 (0.23-2.13)	0.524	0.88 (0.18-4.28)	0.87
Relatives	7 (77.78)	2 (22.22)	0.17 (0.03-0.94)	0.042	0.15 (0.01-2.56)	0.19
Average Monthly Income						
0-300,000	20 (62.5)	12 (37.5)	1	1	1	1
300,001-500,000	6 (40.0)	9 (60.0)	2.50 (0.71-8.78)	0.153	2.2 (0.32-15.08)	0.42
> 500,000	2 (14.29)	12 (85.71)	10.0 (1.90-52.55)	0.007	12.63 (0.76-210.24)	0.08

Qualitative Findings

Characteristics of study population

The in-depth interviews were conducted among a total of six children and four parents together with key informant interviews that included a total of three health workers as shown in the table below

Table 9: Characteristics of qualitative study population

Characteristics	Number
Age range	
Children	
8-12	2
13- 18	4
Parents	
21-35	2
36-45	1
46+	1
Sex	
Children	
Female	3
Male	3

Parents	
Female	3
Male	1
Education level	
Children	
Primary	2
Secondary	4
Tertiary	
Parents	
None	1
Primary	1
Secondary	1
Tertiary	1
Clinic location	
Mulago National Referral Hospital	7
St. Francis Hospital Nsambya	6
Key informants	
Speciality	

Nurses	2
Doctors	1
Place of work	
Mulago National Referral Hospital	1
St. Francis Hospital Nsambya	2

Summary of qualitative results

Interviews with the children with diabetes mellitus revealed that they experience a lot of stigma especially while at school yet have little or no psychosocial support. The parents were burdened with ensuring the children had a balanced diet but with very minimal finances. Below are the themes that emerged from the interviews.

Poor social support

This was in relation to the children receiving minimal support from their families noted especially with the older children

Stigmatization

It was noted that the children with Diabetes mellitus were bullied, isolated, labelled and that the children feared to disclose at school to both the administration and the students that they had Diabetes.

Healthcare worker (HCW) factors

The healthcare workers often diagnosed these children after suffering a few complications and most of them (children) reported to have been managed in a number of health centres before diagnosis. It was also noted that confrontational counselling was often used by the HCWs, which causes these children to have a wall between them and their healthcare providers ultimately leading to poor glucose control.

Myths

Societal myths about Diabetes Mellitus drove the parents of these children to believe in herbal medication as a treatment choice. Poverty among the parents of these children led to poor clinic attendance and inappropriate meals due to lack of funds.

Diet

On the other hand, diet as a whole was a terribly huge challenge for these children, as they had to do away with sweet or sugary foods, which are favourites for any normal child resulting in poor adherence to the dietary recommendations

Ignorance of childhood Diabetes Mellitus

It was also noted that there was a lot of ignorance on childhood DM at the societal level, which led to parents not accepting the fact that their children had DM and thus the children lived in denial together with their parents often resulting into the developmental of the complications of DM.

Autonomy

The adolescent children with DM had a lot of autonomy and often times faulted on their medication and clinic attendance thus compromising their quality of life.

Challenges experienced by the children with diabetes together with their parents

The children mainly experienced dietary challenges, which were reported in relation to restricted diet that entails avoiding sweet

and sugary foods while the parents were challenged with lacking funds for transport to the clinic and maintaining a proper diet for the children as shown in the table below

Table 10: Challenges experienced by the children and parents

Lack of family support: Fathers abandon children and their parents	Family Support
Lack of family support: no support from extended family	
High transport costs	Transport
Lack of transport	
Lack of transport fees	
Lack of transport fees	
Lack of transportation fees	
Fear of infertility and/or impotence	Cultural Norms
Myths and misconceptions about DM: children with DM can't manage school	
Community myths: children with DM are bewitched	
Use of herbal medication	
Avoiding sweets or sugar	Dietary challenges
Missing meals	
no meals/poorly balanced meals	Poverty
No education; no funds	
Work to survive	
Mis-diagnosis	Health worker factors
No home follow ups	
late diagnosis	

Perceptions of the children with diabetes on their quality of life.

During the interviews children aged 13 to 18 years reported their lives to be normal. They compared themselves to the other children without diabetes and felt that there was no difference. As noted in the statement below;

‘Most people don’t believe I am diabetic they think I am lying because of my normal life.’... (IDI 1, 18years/Male, has had DM for 15 years, MNRH)

The children seemed to be making a deliberate attempt to appear and act normal as the following quotes illustrate.

‘It is a normal life I don’t withdraw myself or give chance to someone to trash me....’ (IDI 6, 18 years/Male, has had DM for 3 years SFHN)

Health workers and caretakers’ perceptions on the quality of life of the children with diabetes

Although the caretakers of all age groups reported that the children’s quality of life was normal, it was mainly based on what they perceived as physical well-being this is as seen in the quotations of some of the care takers of the children below;

‘They are not bothered at all they don’t know what is going on in their lives. They are living a very normal life like others (IDI 8, 42 years/female, and married, mother to female twins aged 8 years attending at SFHN)

'They commonly tell us that kids with diabetes tend not to understand well academically or generally but my kids are not like that. They really understand things better; I do not see any weaknesses in school. They don't withdraw from others...' (IDI 10, 49 years/Male, married, father to two sons 15 and 8yrs in MNRH)

The caregivers emphasized that their children exhibited normal behaviour and reported that the children sometimes withdrew in fear of experiencing stigma as seen in the statement below;

'She is the same as other children she does not withdraw herself, is not sad and at home she really interacts well with her friends... it is at school where she does not mix with other children' (IDI 7, 32 years /Female, single mother, child is MNRH)

The health workers on the other hand perceived the quality of life of the children with diabetes to be poorer than that of a healthy child but postulated that the quality of life of the children below 12 years was better than that of children aged more than 12 years with diabetes. They believed that this was mainly attributed to the child's maturity, social support and glycaemic control this is reflected in the extract shown below:

'The older ones from 12 years are more affected because they can understand the whole issue they are going through but for young ones I don't really see any issues.' (KII 1- Nurse, SFHN)

Discussion

In this study, the average overall total HRQoL of children between 5-18 years was found to be 77.5 ± 15.6 ; this was thus sub-optimal HRQoL as it is comparable to the mean standard HRQoL of 80.4 ± 12.9 . A child attending either clinic (SFHN or Mulago NRH paediatric diabetic clinic) did not influence or affect the child's quality of life. The children perceived their lives as normal. They compared themselves to other children without diabetes and felt that there was no difference, however in reality their statements revealed that they were struggling psychologically. Although the caretakers of all age groups reported that the children's quality of life was normal, it was mainly based on what they perceived as physical well-being. The health workers on the other hand perceived the quality of life of the children with diabetes to be poorer than that of a healthy child and postulated that the quality of life of the children below 12 years was better than that of children aged more than 12 years living with diabetes mellitus. They believed that this was mainly attributed to the child's maturity, social support and glycaemic control. The results however showed that the children 13 years and more have a poorer HRQoL compared to the younger ones. These results are comparable to results reported in another chronic disease study for children who have been in cancer care for a period of 3-6 months (73.7 ± 17.3) in Uganda [23]. However, the study's self-reported HRQoL results were lower than those reported in the comparative paediatric chronic disease study (80.4 ± 12.9) in Boston Massachusetts, USA and in another With an overall average of (83.0 ± 11.1), but better than the HRQoL results reported in another study carried out in Kuwait (75.6 ± 11.1) [24, 25]. In this study, 46% of the children reported poor quality of life compared to 83% who reported poor quality of life in a study carried out among children with cerebral palsy at Mulago Hospital in Uganda.

Dimensions of HRQOL

Lowest scores on the QoL assessment tool included school and emotional functioning of the children. Emotionally, the children

seemed to be making a deliberate attempt to appear and act normal. They (children) had concerns with regard to others knowing that they were sick or had diabetes as this often resulted into being labelled, isolated and bullied while at school. This therefore showed that the children were faced with a huge challenge of stigmatization both at the individual and societal level.

School functioning scored low as the children's school attendance was low mainly as a result of sick days and the need to attend the diabetic clinics during school time. The children's diet while at school was also a concern from both the children and parents as they required better diets and food than that offered at school. The results for physical health score (82.31 ± 17.40) and Psychosocial Health score (74.86 ± 17.34) obtained in this study were lower than the Physical Health score (85.89 ± 13.33) and Psychosocial Health score (77.34 ± 14.62) reported in the comparative paediatric chronic disease study. Another study carried out in Boston, Massachusetts USA which reported better health related quality of life in dimensions of physical health score of (86.5 ± 13.3) and Psychosocial score (81.1 ± 11.9) among their children [24-26].

In regards to individual performance domains, the Ugandan children with type I diabetes were performing better in social (88.0 ± 17.37) and emotional functioning (74.52 ± 20.88) compared to both children in Kuwait and the USA in which they reported their social (Kuwait: 82.3 ± 9.4 , USA: 85.63 ± 16.24) and emotional functioning (Kuwait: 72.7 ± 10.4 , USA: 72.37 ± 19.57) [24, 26]. In terms of school functioning, the children in this study performed poorly when compared to the other two countries i.e. Uganda: (62.08 ± 27.17), Kuwait: (73.5 ± 10.9) and USA: (74.20 ± 18.08) [27, 28]. Similar lower scores for school QoL have been reported in Ugandan children with cancer, in which all the three different types of cancers studied showed poorer scores (Burkitt's Lymphoma 59.5 ± 21.2 , Leukaemia 45.8 ± 33.7 and Nephroblastoma 61.8 ± 33.7) compared to that reported by children with diabetes. This was attributed to frequent absence of children from school, subtle neurophysiological changes associated with poor glycaemic control (resulting from frequent reported hypoglycaemias while in school) and stigma associated to African cultural beliefs in which children with Chronic illness are believed to be unfit for school as they will yield nothing at the end. More flexible school schedules accommodating diabetes management have been shown to have helped children and adolescents adapt to their condition and socialize with minimal intervention in Kuwait [24].

Factors associated with health related quality of life

In this study, children's age group, education level, primary care giver and family structure were observed to be factors associated with Health Related Quality of Life. It was also observed that the children's glycaemic control did not affect their quality of Life. Tertiary parental education together with average monthly income of > UGX 500,000 were factors found to be associated with better quality of life for the children attending the Mulago National Referral Hospital paediatric diabetic clinic. On the other hand, no factors were found to positively or negatively affect the quality of life for children attending the St. Francis Hospital Nsambya paediatric diabetic clinic. The children whose parents had attained a secondary and primary level of education were less likely to attain a better HRQoL when compared to children whose parents had attained tertiary/university level of education and this is potentially as a

result of parental insight into the illness with regard to being able to read up on the illness and understanding counselling together with following instructions about their medications, exercises and diabetic care as a whole.

Study results also indicated that children with type I diabetes whose mothers were the primary care givers were less likely to attain better health related quality of life probably because the mothers were pre-occupied with other responsibilities other than the child's health. It was observed that as the children grew their quality of life got worse, a finding contrary to results reported by Abdul-Rasoul and others in which scores improved as the children grew older [24, 26, 29]. This can be explained by the minimal parental involvement and psychosocial support with regards to their diabetic care and management that the Ugandan older children (>13 years of age) had. A child with type I diabetes who stayed in a family structure controlled by relatives was less likely to have a better HRQoL. This finding is contrary to that observed by Abdul-Rasoul et al in which he noted that cultural and social factors associated with support from extended family could help these children to cope socially within and, subsequently, outside their families [24].

The health workers seemed to assume that there was a linear relationship between the child's quality of life and the glycaemic control. The findings in this study seem to suggest that the relationship is not that linear. Children's quality of Life was not that bad yet their glycaemic control was poor which was contrary to findings elsewhere. These findings differ from those observed in other reports [7, 21, 24]. The study findings, however, are similar to those reported by Anna Marie in which she reported that duration of diabetes and glycaemic control were not related to HRQOL dimensions as observed in our study [30, 31].

Conclusion

The quality of life of children with diabetes in Uganda was found to be suboptimal at a mean score of 77.46 ± 15.6 , which may be because the children were struggling with diabetes because of minimal psychosocial support and counselling. The psychosocial health summary score together with school functioning scored lowest for both summary and scale scores respectively among these children. The factors associated with good quality of life included; age between 5-7, a child living with biological parents, child being in primary school and high parental education level.

Strengths of the study

- This study utilized both qualitative and quantitative approaches of which each complimented the other.
- It is the first study to assess and determine the quality of life and its associated factors in children with diabetes and this gives us an insight about outcome.

Limitations of the study

We did not have normal population norms for physical, emotional, social and school functioning, so we cannot conclude what the individual scores in these dimensions mean in-terms of functionality. Secondly, the study population may not be representative of the general population of type 1 diabetes. There was no literature in middle or low-income countries on quality of life and associated factors among children and adolescents with diabetes mellitus thus a comparison of the study results with those in low-income countries

could not be done. The study was also faced with recall bias with regard to insulin adherence and parental involvement in blood glucose monitoring together with missing information from the glucometers for some participants.

Recommendations

In improving the quality of life of children living with diabetes mellitus, community health education and sensitization should be more focused towards the adolescent patients, single mothers, guardians and benefactors of children with diabetes mellitus. There is greater need for healthcare support in schools to mitigate the stigma experienced by the children with diabetes.

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