DIABETES MELLITUS CONTROL AND QUALITY OF LIFE IN ADOLESCENT IN RWANDA

GAKUBA ALEXIS

College of MEDECINE

School of MEDECINE

Master of PEDIATRICS

2016

DIABETES MELLITUS CONTROL AND QUALITY OF LIFE IN ADOLESCENT IN RWANDA

By

GAKUBA ALEXIS

213 00 3802

A dissertation submitted in partial fulfilment of the requirements for the degree of

MASTER OF PEDIATRICS

In the College of MEDECINE

Supervisor: DR RUTAGARAMA FLORENT

Co-Supervisor:

DR NATALIE McCall

DR DIANE STAFFORD

APRIL 2016

DECLARATION

I declare that this Dissertation contains my own work except where specifically acknowledged

GAKUBA ALEXIS

213003802

Signed……..

Date……..

Acknowledgement

It is my pleasure to extend my sincere thanks to my supervisors DrRutagarama Florent, DrNatalie McCall and Dr Diane Stafford for their invaluable input.

I thank DrKabayiza Jean Claude, Dr Tanya Rogo, and all the pediatricians in the department of pediatrics for their advice and guidance.

I also thank ethical and research committees of the School of Medicine-College of Medicine and Health Sciences- University of Rwanda for their review, comments and approval.

I would like to thank my fellow classmate postgraduates for their support and the student life that we shared.

I thank Rwandan Diabetic Association (RDA) staff for their help in data collection and I thank all the adolescents who participated in this research.

Dedication

This work is dedicated to my wife Niyibaho Jeanne and my child: Gakuba N. Lee, you make me happy, I love you so much. This also goes to my Brothers, Uncle, and Mother in low.

ABSTRACT

Background

The adolescent with diabetes mellitus (DM) can have some difficulties related the reality of his/her long term chronic illness. The main objective of diabetes management is glycemic control and some problems related to diabetes quality of life can affect metabolic control.

As there is little existing information about quality of life and diabetes mellitus control in our region, we used the diabetes related quality of life for youth short form (DQOLY-SF) questionnaire to assess quality of life (QOL) and determine factors that lead to improve QOL in Rwandan adolescents.

Methods

In thisqualitative study where 140 adolescents living with diabetes aged 10 to 18 years were recruited from RDA clinic, we determined whether there is correlation between DQOLY-SF score and diabetes control. The study period was September to December/ 2015. DQOLY-SF consists of 22 items on impact of diabetes, worries and health perception. DQOLY-SF score less than 21 relate good QOL while above relate poor quality of life. We usedPatient characteristics and medical conditions from patient logbook and we only considered HbA1c of the day of visit.

Results

In bivariate analysis the variable province was associated with DQOLY-SF, p value(0.001) and with Pearson correlation of HbA1c with DQOLY-SF score was found to be statistically significant with weak correlation $r(138) = 0.188$, $p < 0.05$, with Hb1Ac levels explaining 0.3% of variation in DQOLY-SF Score. In multivariate analysis four factors such as age (p value 0.048), Hypoglycemic episodes (p value 0.042), province south or north ($p < 0.005$), live with someone different to his/her parents (p value 0.008) added were predictor for DQOLY-SF score $F (20, 99) = 2.10$, $p =0.008$, $R2 = 0.29$, $p< 0.05$.

Conclusion

Good metabolic control (Low HbA1c) was associated with better diabetes related quality of life, less worries about diabetes and good health perception. Older age, hypoglycemic episodes, living with someone different to his/her parents, residence area(from south or north)were associated with poor Diabetes related quality of life in Rwandan adolescents.

List of abbreviation

Abbreviations

DQOLY-SF: Diabetes quality of life for youth short form

HbA1c: Glycated hemoglobin

DCCT: Diabetes Control and Complications Trial

DKA: Diabetic Keto-acidosis

DAWN: Diabetes attitudes wishes and needs

IDF: International Diabetes Federation

ISPAD: International Society for Pediatric and Adolescent Diabetes

UR: University of Rwanda

CMHS: College of Medicine and Health Sciences

Table of content

I.Introduction.....1
I.1. Background.....1
I.2 Rationale of the study.....1
I.3 Research questions.....1
I.4. Literature review.....2
II.Aims and Objectives.....3
III. Methods and materials.....4
III.1 Study description.....4
III.2 Study setting.....4
III.3 study population.....4
III.4 selection of Study population 4
III.5 study design and sample.....5
III.6 Ethical consideration and Procedure.....5
III.7 Study instrument.....5
III.7.A.DQOLY-SF.....5
III.7.B.Patients characteristics and medical conditions.....6
III.8 Data management and analysis.....7
IV: RESULTS.....7
IV.1 Characteristic of study participants 7
IV.2. DQOLY-SF score and health perception assessment.....8
IV.3.Analysis of association(tables).....10
IV.3.1.Analysis of the association of DQOLY-SF score with Patients characteristics.....10
IV.3.2. Analysis of association of HbA1c with DQOLY-SF scales score 10

IV.3.3.Analysis of association of HbA1c level with Health perception.....10

IV.3.4. Analysis of association of HbA1c with DQOLY-SF overall score(figure).....14

IV.3.5. Analysis of multivariate analysis(table 4) 15

V. Discussion 17

VI Conclusion 19

VII. Tables 20

VIII References..... 28

IX.Appendix…….30

I. INTRODUCTION

I.1. Background

Children moving to adolescence face many changes: physical, psychological or social but also have increased responsibility for self-care. The adolescent with diabetes mellitus (DM), like an adolescent with another chronic disease can have some difficulties related the reality of his/her long term chronic illness. This can manifest in various ways including, acting out, rebellion, risk-taking behavior and the feeling of burn-out [1], which can lead to poor compliance with treatment. The risk of depression and eating disorders is increased putting this young person at a risk of not being able to follow a lifestyle that requires careful regulation of insulin injection, blood glucose monitoring, exercise and diet. The co-morbidity of diabetes and depression in children and adolescents can be a significant problem. With 20% of youth with diabetes having depression compared to less than 7% of youth without diabetes [2].Assessment of adolescent with a chronic condition such as diabetes should include not only physical assessment of blood glucose control, but also assessment of their mental well-being. Diabetes, like other chronic diseases can impact quality of life (QOL) and affect adolescent's mental health, with a subsequent impact on compliance to treatment.

Understanding the impact of diabetes on QOL in adolescent canhelp determine which the most appropriate treatment regimen is. Better identifying adolescents with a low QOL will help to provide further counseling and improve their physical, psychological, and social life. There is little existing information in Africa about diabetes mellitus and quality of life in adolescents. Consequently, it is important to know how DM and its treatment influence the adolescent's QOL. The main aims of diabetes care are to achieve optimal glycemic control, maintaining lower HbA1c and normal psychosocial development. DQOLY-SF questionnaire had been validated and seems to be easier questionnaire and more specific for diabetic patients. This questionnaire is composed of fivequality domains of 22 items: impact of symptoms, impact of treatment, and impact on activities, parent issues, worries about diabetes and health perception. Each quality of domain is evaluated on items and each item has five possible scores 0 to 4; with 0 representing never and 4 all the time. Impact of symptoms (3items), Impact of treatment (3items), Impact on activities (5items), Parents' issues (3items), Worries about diabetes (7items). The maximum raw total score is 84 with 21 score as the

cutoff where the score ≤ 21 relates to less impact of diabetes and greater quality of life while above 21 indicate a more negative impact of diabetes and poorer QOL. By using the DQOLY-SF, we hope to carry out an initial assessment of the impact of diabetes care on children in Rwanda

I.2.Study rationale

There is little existing information about diabetes mellitus (DM) in our region and the quality of life of adolescents with diabetes in Africa. Using the validated DQOL-SF questionnaire, our goal is to provide an analysis of the relationship between diabetes care and quality of life in Rwandan children with diabetes.

I.3.Research question

Does diabetes mellitus control effect quality of life, adjusting for other factors that affect quality of life, in adolescents?

I.4. Literature reviews

Adolescents with diabetes have an increased risk (compared to other adolescents) of developing eating disorders, depression and substance abuse, leading to deterioration of diabetescontrol. There have been different scales used to measure QOL in adolescents with diabetes among them Diabetes Control and Complication Trial (DCCT), Diabetes Quality of Life (DQOL). The questionnaire had been used in adults and adolescents in combination with intensive management. In adults, their study found that intensive treatment improved glycemic control with increased risk of hypoglycemia, but did not changes quality of life. In adolescents, improved glycemic control as associated with increased risk of hypoglycemia, decreased school satisfaction and greater personal distress. Ingersoll and Marrero developed Diabetes Quality of Life for Youth (DQOLY) questionnaire of 52 items with four sections: impact of symptom, worries about diabetes, satisfaction with life, health perception. Subsequent studies with adolescents have not consistently supported idea of an association between QOL and metabolic control in adolescents with diabetes. At 52 items the DQOLY is a lengthy instrument, which limits its clinical utility. In 2006, Skinner et al published a study performed in 22 pediatrics centers in 18 countries to evaluate the construct validity of the

DQOLY 52 item questionnaire and a revised DQOLY-SF questionnaire with 22 items examining quality of life and health perception in a large representative sample of young people with type 1 diabetes mellitus. They conducted a multicultural cohort study of 2,077 patients with type 1diabetes aged between 10 and 18 years participated from 22 centers in 18 countries in Europe, Japan and North America with the aim to examine the construct validity of the DQOLY-SF version compared with the original and thereby enhancing its measurement properties and clinical utility. The original questionnaire did not show construct validity while the revised short form improved construct validity with adequate internal consistency, more precision, association with HbA1c, and acceptable use in a clinical setting. The results is that the shortened scale (designated the short-form DQOLY [DQOLY-SF]) will enhance the acceptability of assessing quality of life in adolescents with diabetes, making it more feasible to introduce as part of routine care [3].Hillary H. et al in a study published in 2001showed a relationship between QOL and diabetes control. This study involved 2,101 adolescents aged 10–18 years, from 21 centers in 17 countries in Europe, Japan, and North America and found that lower HbA1c was associated with lower impact (P=0.0001), fewer worries (P=0.05), greater satisfaction (P=0.0001), and better health perception (P= 0.0001) for adolescents and lower perceived family burden as assessed by parents and health professionals [4].Nemeh A. et al (2010) published a study on quality of life and associated factors among 145 Jordanian adolescents with type 1 diabetes mellitus from two centers of diabetes and hospitals between October 2007 and February 2008. In this study DQOLY-SF had been used for quality of life, demographic data, diabetes duration and HbA1c. Diabetes duration, HbA1c values, gender, and age were the only factors that were significantly associated with QOL and they concluded on better glycemic control may contribute to the improvement of QOL. [5]

II. Aims and objectives

The aim of this study is to use the DQOLY-SF questionnaire to assess the quality of life of children with diabetes in Rwanda with the goal of determining factors that lead to improved QOL.

Objectives

- To assess the level of control in adolescents with diabetes in Rwanda.
- To determine the relationship between quality of life as measured by DQOLY-SF and characteristics such as demographic and social factors and medical characteristic including HbA1cin adolescents with DM

III. METHODS

III.1. Study description

This was a cross-sectional study, with data obtained from adolescent with DM followed by the Rwandan Diabetic Association (RDA) clinic and using interviewer administered questionnaire.

III.2. Study setting

The RDA clinic is a private clinic based in Kigali city open to all Rwandan living with diabetes and providing routine medical evaluation and provision of consumables at no charge. The RDA staff also holds outreach clinics in each province in the country, where insulin, glucometers and test strips and test for HbA1c are provided at no charge. As part of routine diabetes care, patients undergo HbA1c testing every 3 months.

III.3. Study population

The study population includes adolescents with diabetes mellitus aged 10-18years seen in the RDA program from September 10th 2015 to December 31st 2015meeting inclusion criteria and consenting to participation.

III.4. Selection of study population

Inclusion criteria

Adolescents' 10-18years living with DM who are followed by RDA and who attend during the study period as out patient

Exclusion criteria

Any patient presenting acute illness (DKA, Hypo/hyperglycemia) and requiring inpatient care

III.5. Study Design and sample

This was a qualitative studywith a small quantitative component where 362 patients were seen during the study period from September to December 2015. Of these, 222 were excluded based on age (less than 10 and above 18), leaving one hundred forty adolescents who were recruited for the study. All patients consented for the study and were able to complete the questionnaire. They were seen in the RDA clinic in Kigali city or in the RDA outreach clinic in District Hospitals from the East; West, South and North provinces.140 adolescents were eligible and were included in study (79girls and 61 boys) with diabetes mellitus. We obtained voluntary parental consent and assent for all adolescents attending for medical checkup and consumable provision. Among them 34(24.29%) had dropped out from school.

III.6.Ethical consideration and Procedures

Ethical approval was obtained from College of Medicine and Health Sciences (CMHS) Institutional Review Board (IRB). The primary researcher and two trained nurses were responsible for screening for eligibility, explaining the purpose of study and obtaining informed consent. Once informed consent and assent were obtained, patients were included in the study. After explanation, the questionnaire was read in Kinyarwanda to the patient and the data collector completed the questionnaire. Only HbA1c results from the day of visit were included in data collection, hyperglycemia and hypoglycemia in the last month from medical records (logbook). Results of capillary blood sugar and HbA1c were given to the patients in their logbook.

III.7. Instrument

A. Quality of life

A short form of the Diabetes Quality of Life for Youth (DQOLY-SF) questionnaire (see appendix) designed for measuring **quality of life in adolescents** between 10 and 18 years of age was used for this study. The original questionnaire was in English and it was translated into Kinyarwanda by a Psychologist andreviewed by the principal investigator for language clarity. This questionnaire is composed of five quality domains and health perception assessed in 22 items. Each item has five possible scores with a value from 0 to 4, with score 0 representing never, score1: veryseldom, score 2: sometimes, score 3: often and 4 all the time. The maximum raw total score is 84 with 21 as the cutoff of score where ≤ 21 relate less impact of diabetes and good overall perceived quality of life while score above 21 indicate a more negative impact of diabetes and pooroverall perceived QOL. This tool uses the summation of raw score. Impact of symptom (3items), raw score 0-12 with≤3 less impact, Impact of treatment(3items) raw score 0-12 with ≤3 less impact of treatment of diabetes on quality of life, Impact on activities (5items): raw score 0-20 with ≤5 less impact of diabetes on activities. Parents issues (3items): raw score 0-12 with ≤3 low perceived parental concern about impact of DM. Worries about diabetes (7items): raw score 0-28 with ≤7 low level of worries. Item 22nd for health perception, which asks the young: "how do you feel your life is in general in comparison to your peers?" scored 1 to 4 respectivelyexcellent, good, fair and poor heath perception.

B. Patient characteristics and medical conditions

They were collected from the records on the same day. As RDA staff visit different health facilities every three month, blood sugar, HbA1c are routinely assessed in all patients seen and data collected are from the same visit. Demographic and social data gathered included sex, age, living circumstances (live with at least one parent, live with someone else, orphan), duration of diabetes, hypoglycemia (below 70mg\dl) in the last month, hyperglycemia (above 200 mg\dl) in the last month, number of insulin injection per day (1, 2, 3 or more), type of insulin [Rapid-acting(Humalog-novalog), short-acting (regular), intermediate (NPH), pre-mixed (regular and NPH), long acting(Lantus)] and DKA in the year prior to the study.

III.8. Data analysis

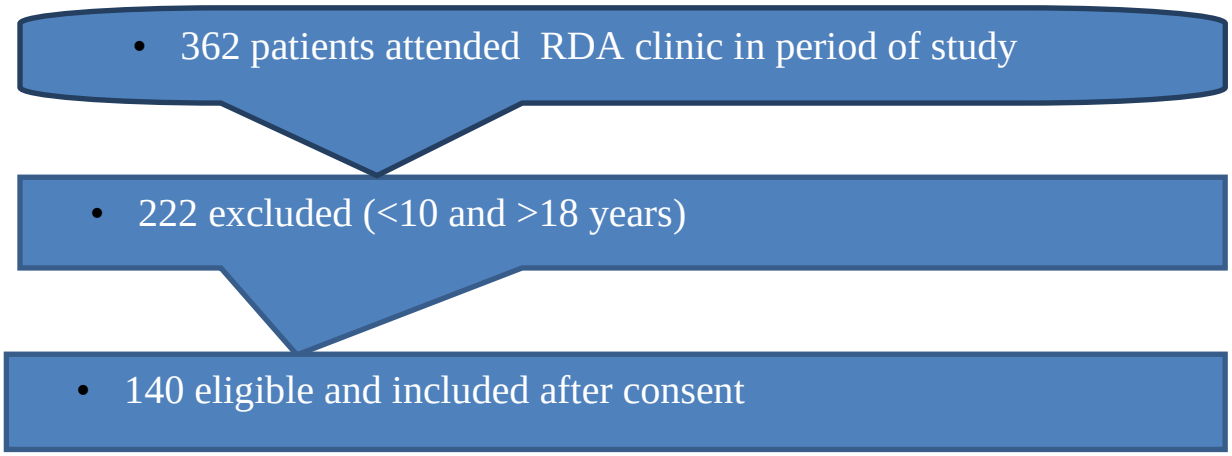
Epidata was used for data entry and STATA/MP 13.0 for statistical analysis.

A bivariate linear regression analysis was conducted to determine if **DQOLY-SF** score was different for patients with different characteristics and a multivariate linear regression analysis was run to predict **DQOLY-SF** Score from multiple patients' characteristics**.** The dependent variables were adolescents' overall **DQOLY-SF score**, impact of symptoms, impact of treatment, impact on activities, parent issues, worries about diabetes scores and health perception. The adolescents' gender, age, living with at least one parent, living with someone else, orphan, Duration of diabetes, Insulin type, insulin dose per day, episodes of hypoglycemia, episodes of hyperglycemia, and HbA1c level were the independent variables. A P value of less than .05 was considered statistically significant. A Pearson's product-moment correlation was run to assess the relationship between Hb1Ac levels and DQOLY-SF Score. Means, frequencies, and percentages were reported as appropriate for descriptive purposes.

IV. RESULTS

IV.1.Introduction

We received 362 patients during the study period from September to December 2015. Of these, 222 were excluded based on age (less than 10 and above 18), leaving one hundred forty adolescents who were recruited for the study



IV.2. Characteristics of study participants

Table 1: Represents the characteristic of study participants of 140 patients studied, 56.4% of participants were female and most (94.3%) lived with a parent,75.7% had been living with diabetes longer than one year, 22.3% reported having had at least one episode of diabetic ketoacidosis (DKA) in 2014 (the calendar year before the study period). Based on review of logbook blood glucose records, the rate of having at least one episode of hyperglycemia (above 200mg/dl) was 45.7%, within the month of data collection and hypoglycemia below 70mg/dl was 23.7%. 41 patients (29.2%) had HbA1c range of 5-7% and 24 patients (17.1%) had HbA1c above 14%. The mean HbA1c of our population sample was 9.7% (SD 2.8) which is above the recommended value of 7.5% for those with diabetes (normal non diabetic range is usually 4-6%).In terms of insulin regimens, 126 patients (88.7%) were using both short acting and intermediate insulin and 78 patients (56.1 %) are taking three and more injections per day.

Table1: Characteristics of study participants

A. Demographic characteristics

	N	%
Gender		
Female	79	56.4
Male	61	43.6
Age groups in year		
10 to 12	15	10.7
13 to 15	46	32.9
16 to 18	79	56.4
Province		
East	28	20.0
Kigali	36	25.7
North	31	22.1
South	41	29.3
West	4	2.9
Caretaker status		
Live with a parent	132	94.3
Orphan live alone	5	3.6
Live with someone else	3	2.1

B. Diabetes control characteristics

Duration of diabetes		
Equal or less than 1year	34	24.3
Above 1year	106	75.7
Diabetes Ketoacidosis in the last year		
Yes	27	22.3
No	94	77.7
Hyperglycemia in the last month		
Yes	64	45.7
No	76	54.3
Hypoglycemia in the last month		
Yes	33	23.7
No	106	76.3
Hb1Ac level		
5 to 7.5	41	29.2
7.6 to 9.5	32	22.9
9.6 to 11.5	32	22.9
11.6 to 13.0	7	5.0
13.1 to 14.0	4	2.9
Above 14.0	24	17.1
Type of insulin		
Rapid + Short acting	6	4.2
Rapid + Intermediate	2	1.5
Rapid + Premixed	1	0.7
Rapid + Long acting	4	2.8
Short acting + Intermediate	126	88.7
Short acting + Premixed	1	0.7
Short acting + Long acting	1	0.7
Intermediate + Long acting	1	0.7
Premixed + Long acting	0	0
Number of injection per day		
One injection	2	1.4
Two injections	59	42.5
three and more injections	78	56.1

IV.2. DQOLY-SF score and health perception

The total score of DQOLY-SF was 58; the mean was 20.08 with standard deviation 10.8. The score for impact of symptom equal or less than 3: 83patients 59.3% of our sample, above 3: 57patients 40.7% and the mean of score 3.8 with standard deviation 5.2. For the impact of treatment score equal or less than 3: 88 patients 62.9%, score above 3:52 patients 37.1% mean 2.9 with standard deviation 2.6. For the impact on activities score equal or less than 5: 125 patients 89.3% and above 3: 15patients 10.7% the mean 1.66 with standard deviation 3.18. For parents` issues score equal or less than 3: 10patients 7.1% above 3: 130patients 92.3% mean 8.94 with standard deviation 3.32. For worries about diabetes score equal or less than 7: 112patients 80.0%, above score 7:28 patients 20% and the mean 3.87 with standard deviation 5.22.Health perception score: excellent 10patients 7.1%, Good 45patients 32.1%, Fair 71patients 50.7%, and Poor 14patients 10.1%.

Table 2: DQOLY-SF score and health perception

	N	%
Impact of symptoms		
Low impact (score <=3)	83	59.3
High impact (score >3)	57	40.7
Impact of treatment		
Low impact (score <=3)	88	62.9
High impact (score >3)	52	37.1
Impact on activities		
Low impact (score <=5)	125	89.3
High impact(score >5)	15	10.7
Perceived Parental concern about impact of DM		
Low concern (score <=3)	10	7.1
High concern(score >3)	130	92.3

Level of Worry about diabetes		
Low level (score <=7)	112	80.0
High level (score >7)	28	20.0
Overall perceived QOL raw score		
Good QOL (score <=21)	92	65.7
Poor QOL (score >21)	48	34.3
Health Perception		
Excellent	10	7.1
Good	45	32.1
Fair	71	50.7
Poor	14	10.1

QOL:65.7% of the sample had DQOLY-SF score equal or less than 21related to good quality of life and 34.3% had score above 21 related to poor QOL.

Health perception: 7.1% of our sample perceived health as excellent, 10.1% poorhealth perception compered to their peers without diabetes.

IV.3. ANALYSIS OF ASSOCIATION

IV.3.1.Association of DQOLY-SF score with patients' characteristics

A simple linear regression analysis (Table 3) was conducted to determine if DQOLY-SF score was different for patients with different gender, duration of diabetes, type of insulin, caretaker status, number of insulin injections per day, episode of DKA in the last year, hypoglycemia or hyperglycemia history in the last month, age and random blood glucose level on day of visit.

Table.3. A bivariate linear regression analysis

	Bivariate analysis DQOLY-SF score		Sig
	Mean	SE	
Gender			
Male	20.4	10.2	0.949
Female	20.5	11.8	
Age groups			
10 to 12 years	18.4	8.8	0.562
13 to 15 years	19.7	9.7	
16 to 18 years	21.3	11.9	
Province			**0.001**
East	18.8	10.0	
Kigali	15.0	8.7	
North	24.6	12.7	
South	23.2	10.5	
West	21.0	4.1	
Caretaker status			0.318
live with a parent	20.1	10.5	
Orphan live alone	25.3	15.3	
Live with someone else	27.3	21.5	

Duration of diabetes			0.470
equal or less than 1year	21.6	10.7	
above 1year	20.1	11.0	
Diabetes ketone-acidosis in the last year			0.639
Yes	19.5	10.4	
No	20.6	11.5	
Hyperglycemia in the last month			0.979
Yes	20.5	10.4	
No	20.4	11.4	
Hypoglycemia in the last month			0.599
Yes	22.1	12.7	
No	19.9	10.4	
Hb1Ac level			0.978
<7.5	20.4	11.2	
>=7.5	20.4	10.8	
Type of insulin			0.821
Short acting +Intermediate	20.5	11.0	
Other	19.8	10.1	
Random Blood Sugar			0.129
Low(<72mg/dl)	24.3	13.7	
Normal(72-100mg/dl)	21.9	9.5	
High(>100mg/dl)	19.3	10.4	
Number of injection per day			0.705
One injection	24.5	12.0	
Two injections	21.0	11.3	
three and more injections	19.8	10.8	

Legend:

Sig: significant level =“P value”

Only province was associated with DQOLY-SF score P (0.001) by bivariate analysis of the association of DQOLY-SF score with patients’ characteristics

IV.3.2. Analysis of the association of Hb1Ac with different DQOLY-SF subscales

Test for association of HbA1c level with adolescents' Worries about diabetes

```
. spearman q6 q15e

 Number of obs =     140
Spearman's rho =       0.2235

Test of Ho: q6 and q15e are independent
    Prob > |t| =       0.0079
```

A Spearman's correlation was run to assess the relationship between HbA1c levels and Worries about diabetes. There was a weak positive correlation which was statistically significant, rs =0.223, p=0.007.

IV.3.3. Analysis of association of HbA1c with Health perception scores

```
. spearman q6 q18

 Number of obs =      140
Spearman's rho =        0.1665

Test of Ho: q6 and q18 are independent
    Prob > |t| =        0.0492
```

There was a slight positive correlation between HbA1c and Health perception which was statistically significant,rs=0.166,p=0.049

IV.3.4. Association of HbA1c with DQOLY-SF scores.

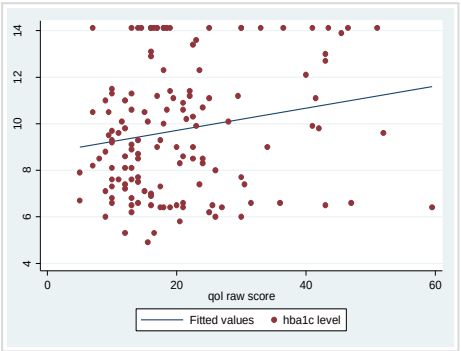


Figure 1: A Pearson's product-moment correlation was run to assess the relationship between HbA1c levels and DQOLY-SF Score. There was a mildly positive correlation between Hb1Ac levels and DQOLY-SF Score, r (138) = 0.188, p < 0.05, with Hb1Ac levels explaining 0.3% of the variation in QOL Score.

IV.3.5. A MULTIVARIATE LINEAR REGRESSION ANALYSIS

A multiple regression was run to predict QOL Score from different patient's characteristics, HbA1c level and other factors that affect glycemic control.

Table 4: A multiple regression was run to predict DQOLY-SF Score from different patient's characteristics.

	Multivariate Linear Regression		
	Coeff	SE	P value
Hb1Ac	0.4	0.4	0.377
Gender			
Male	Ref		
Female	0.2	1.9	0.920
Age	0.9	0.4	0.048
Province			
Kigali	Ref		
East	4.0	2.8	0.159
North	10.8	2.8	<0.005
South	10.1	2.6	<0.005
West	5.6	5.9	0.340
Caretaker status			
Live with a parent	Ref		
Orphan live alone	3.4	5.0	0.495
Live with someone else	17.3	6.4	0.008
Duration of diabetes			
Equal or less than 1year	Ref		
Above 1year	-3.4	3.1	0.278

Diabetes ketone-acids in the last year			
Yes	Ref		
No	3.8	2.7	0.166
Hyperglycemia in the last month			
Yes	Ref		
No	-2.3	2.3	0.314
Hypoglycemia in the last month			
Yes	Ref		
No	-4.6	2.2	0.042
Type of insulin			
Short acting +Intermediate	1.5	3.6	0.680
Other combination	Ref		
RandomBlood Sugar			
Low(<72mg/dl)	Ref		
Normal(72-100mg/dl)	-0.1	4.0	0.988
High(>100mg/dl)	-0.6	3.4	0.856
Number of injection per day			
One injection	Ref		
Two injections	-12.2	8.4	0.160
Three and more injections	-11.4	8.3	0.180

Only Province, Caretaker status, Age and Hypoglycemia in the last month significantly predicted QOL Score, F (20, 99) = 2.10, p =0.008, R2 = 0.29. All four variables added were associated with quality of life.

V. DISCUSSION

Diabetes mellitus is a chronic disease that affects people at a variety of ages, but often in childhood and adolescence particularly for diabetes type I.In this study we describedthe patient's characteristics, HbA1clevel, some factors that affect glycemic control, we assessed QOL, and we determined their association. Almost a quarter of the adolescents in our study have dropped out of school but the study did not evaluate the reasons for no school attendance and it had been found that the families providing warm and nurturing environment were associated with fewer school absence and fewer interruptions in social relationships [6].There was a slight positive correlation between Hb1Ac levels and DQOLY-SF Score implying that lower HbA1c level is associated with a low DQOLY-SF score and better QOL. Similar results had been found by many authors [6, 7] but other didn't found any association of HbA1c and quality of life.HbAlc levels were not associated with quality of life or any other psychosocial factors except in teenagers who perceived their families as providingmore guidance and control [8]. Our sample population had poor diabetes control: 23% had DKA within the last year, 45.7% had hyperglycemia episodes, and 23.7% had hypoglycemia episodes within the last month,HbA1cabove 11.5% in 25%, and HbA1c equal or above 14 % in 17.1% of our study population. Poormetabolic control in the region had been found in Kenya where the median HbA1c was11.1% in 28% and above 14 % in 32% of their studypopulation[9].In our study we didn't evaluate the risk factor for poor metabolic control but thestudy done in Japan 2013 about Individual and familial factors associated with metabolic control in children with type 1 diabetes they reported a number of risk factors such as older age, longer diabetes duration, higher hospitalization rate for acute complication were negatively associated with poor metabolic control while good school performance, regular hospital visit, young maternal age, high paternal education level and fewer numbers of siblings were found to be negatively associated with poor metabolic control in children[11].For the quality of life analysis, 34.4% of our participants had a high perceived overallQOL score relatingto poor quality of life when using DQOLY-SF tool. The mean perceived overall quality of life score 20.08 of our sample related togood quality of life is different from the study done in Jordanian adolescents in 2010 where the overall DQOLY-SF score mean was 56.4(18.0) [7]. Among 5 scales, the analysis of our study showed that patients with a high HbA1c were more worried about their diabetes; therefore more you have

a good metabolic control less perceived worries. This implies that patients may understand the significance of HbA1c for their overall health. It had been found that those who had higher worry score also were more likely to be depressed, coping with diabetes harder and more upsetting [8].Authors have showed that a good glycemic control was associated with less impact of diabetes and less worries [5, 7].In our study we did not found any association of HbA1c with impact of symptoms, impact of treatment, and impact on activities or parent's issues. There was a positive correlation between HbA1c and health perception in our study and similar results have been showed in different articles [4, 7].Greater HbA1c level may decrease the perception of health and poor control was associated with poor health perception. In analysis of other patient characteristics, only the province in which patients live was associated with DQOL score (p value 0.001) and this may be related to the diversity of a given region like diet, altitudes (north has higher altitude than south) and it may be related to difference in socioeconomic status. These differences between regions may also be due to the small sample size of each region.

In multivariate linear regression, four factors were predictor of DQOL (p value): age (p=0.048), living in south or north province (p<0.005, living with someone other than a parent (p=0.008) and having hypoglycemia within the last month (p=0.042). These results are consistent with findings from the study done in Jordanians, where the authors found that hypoglycemia, diabetes duration, HbA1c values, gender, and age were associated with DQOLY [5]. Surprisingly, factor like living with someone else in addition to other factors (hypoglycemia, residence of south or north, older adolescent) was associated with a poorer QOL than living alone (orphan). This is difficult to explain, but it may be due to the fact that adolescents who live alone may have been forced to become more independent and also lack the conflict with caregivers that frequently arise in adolescence around autonomy and thus issues around control of diabetes management. The research done from the Yale Children's Clinical Research Center on personal and family factor associated with quality of life in adolescents with diabetes, they found that the teenagers who perceived their quality of life as good also had good metabolic control and perceived that the family should maintain some guidance and control in management of diabetes [8] but it is difficult to find the degree of parental involvement to avoid over or under involvement of parents in management.In our study, age, duration of diabetes and gender separately were not associated with QOL as it has been found in other studies [7, 10, 11].One of the limitations of this study in assessment of Quality of Life in adolescents with chronic condition like diabetes may be in the questionnaire itself. This was translated into Kinyarwanda and some difference in the

language or in habits related to culture, etc. may be present as confounders as they may be different from the culture of the population where the study validation was performed. The study only included the adolescents that are followed by RDAwhich can be selection bias.

VI. CONCLUSION

In general, adolescents with diabetesmellitus followed-up in RDA clinic had poor metabolic control, good overall QOL scores, and compared with others of same age, they would say that their healthwas fair but they were more worried about diabetes. High HbA1c, age, Hypoglycemia, living with someone else, residence from south or north were associated with poor QOL.

We recommend to stakeholders in non-communicable diseases (NCD) to emphasize on adherence to medical treatment, appropriate parental involvement, and pay more attention to the adolescent living with someone different to his/her parent along with education about diabetes. For better metabolic control, QOL assessment should be routine as medical checkup. We also recommend, to conduct a wide studyon adherence to treatment, risk factors forpoor metaboliccontrol in Rwandanadolescents.

VII.TABLES

Table.1. Characteristics of study participants

	N	%
Gender		
Female	79	56.4
Male	61	43.6
Age groups		
10 to 12	15	10.7
13 to 15	46	32.9
16 to 18	79	56.4
Province		
East	28	20.0
Kigali	36	25.7
North	31	22.1
South	41	29.3
West	4	2.9
Caretaker status		
live with a parent	132	94.3
Orphan live alone	5	3.6
Live with someone else	3	2.1
Duration of diabetes		
equal or less than 1year	34	24.3
above 1year	106	75.7
Diabetes ketoacidosis in the last year		
Yes	27	22.3
No	94	77.7
Hyperglycemia in the last month		
Yes	64	45.7

No	76	54.3
Hypoglycemia in the last month		
Yes	33	23.7
No	106	76.3
Hb1Ac level		
5 to 7.5	41	29.2
7.6 to 9.5	32	22.9
9.6 to 11.5	32	22.9
11.6 to 13.0	7	5.0
13.1 to 14.0	4	2.9
Above 14.0	24	17.1
Type of insulin		
Rapid + Short acting	6	4.2
Rapid + Intermediate	2	1.5
Rapid + Premixed	1	0.7
Rapid + Long acting	4	2.8
Short acting + Intermediate	126	88.7
Short acting + Premixed	1	0.7
Short acting + Long acting	1	0.7
Intermediate + Long acting	1	0.7
Premixed + Long acting		
Number of injection per day		
One injection	2	1.4
Two injections	59	42.5
three and more injections	78	56.1

Table .2.DQOLY-SF score and health perception

	N	%
Impact of symptoms		
<=3	83	59.3
>3	57	40.7
Impact of treatment		
<=3	88	62.9
>3	52	37.1
Impact of activities		
<=5	125	89.3
>5	15	10.7
Parents' issues		
<=3	10	7.1
>3	130	92.3
Worries about diabetes		
<=7	112	80.0
>7	28	20.0
DQOLY total raw score		
<=21	92	65.7
>21	48	34.3
Health Perception		
Excellent	10	7.1
Good	45	32.1
Fair	71	50.7
Poor	14	10.1

DQOLY-SF: Diabetes related quality of life for youth short form.

Table.3. Analysis of the association of QOL score with patients' characteristics

A bivariate linear regression analysis

	Bivariate analysis		
	QOL score Mean	SE	Sig
Gender			
Male	20.4	10.2	0.949
Female	20.5	11.8	
Age groups			
10 to 12 yrs	18.4	8.8	0.562
13 to 15 yrs	19.7	9.7	
16 to 18 yrs	21.3	11.9	
Province			0.001
East	18.8	10.0	
Kigali	15.0	8.7	
North	24.6	12.7	
South	23.2	10.5	
West	21.0	4.1	
Caretaker status			0.318
live with a parent	20.1	10.5	
Orphan live alone	25.3	15.3	
Live with someone else	27.3	21.5	
Duration of diabetes			0.470
equal or less than 1year	21.6	10.7	
above 1year	20.1	11.0	
Diabetes ketoacidosis in the last year			0.639
Yes	19.5	10.4	
No	20.6	11.5	
Hyperglycemia in the last month			0.979
Yes	20.5	10.4	

No	20.4	11.4	
Hypoglycemia in the last month			0.599
Yes	22.1	12.7	
No	19.9	10.4	
Hb1Ac level			0.978
<7.5	20.4	11.2	
>=7.5	20.4	10.8	
Type of insulin			0.821
Short acting +Intermediate	20.5	11.0	
Other	19.8	10.1	
Random Blood Sugar			0.129
Low(<72mg/dl)	24.3	13.7	
Normal(72-100mg/dl)	21.9	9.5	
High(>100mg/dl)	19.3	10.4	
Number of injection per day			0.705
One injection	24.5	12.0	
Two injections	21.0	11.3	
three and more injections	19.8	10.8	

Legend: A simple linear regression analysis conducted to determine if QOL score was different for patients with different gender, duration of diabetes, type of insulin, caretaker status, number of insulin injections per day, DKA, Hypoglycemia or Hyperglycemia history in the last year, age and blood sugar levels.

Table.4. A multivariate linear regression analysis.

	Multivariate Linear Regression		
	Coeff	SE	P value
Hb1Ac	0.4	0.4	0.377
Gender			
Male	Ref		
Female	0.2	1.9	0.920
Age	0.9	0.4	0.048
Province			
Kigali	Ref		
East	4.0	2.8	0.159
North	10.8	2.8	0.000
South	10.1	2.6	0.000
West	5.6	5.9	0.340
Caretaker status			
live with a parent	Ref		
Orphan live alone	3.4	5.0	0.495
Live with someone else	17.3	6.4	0.008
Duration of diabetes			
equal or less than 1year	Ref		
above 1year	-3.4	3.1	0.278
Diabetes ketoacidosis in the last year			
Yes	Ref		
No	3.8	2.7	0.166
Hyperglycemia in the last month			
Yes	Ref		
No	-2.3	2.3	0.314
Hypoglycemia in the last month			
Yes	Ref		
No	-4.6	2.2	0.042

Type of insulin			
Short acting +Intermediate	1.5	3.6	0.680
Other combination	Ref		
Random Blood Sugar			
Low(<72mg/dl)	Ref		
Normal(72-100mg/dl)	-0.1	4.0	0.988
High(>100mg/dl)	-0.6	3.4	0.856
Number of injection per day			
One injection	Ref		
Two injections	-12.2	8.4	0.160
three and more injections	-11.4	8.3	0.180

Legend: A multiple regression was run to predict DQOLY-SF Score from different patient's characteristics. Only Province, Caretaker status, Age and Hypoglycemia in the last month statistically significantly predicted DQOLY-SF Score, $F(20, 99) = 2.10$, $p = 0.008$, $R2 = 0.29$. All four variables added statistically significantly to the prediction, $p < 0.05$.

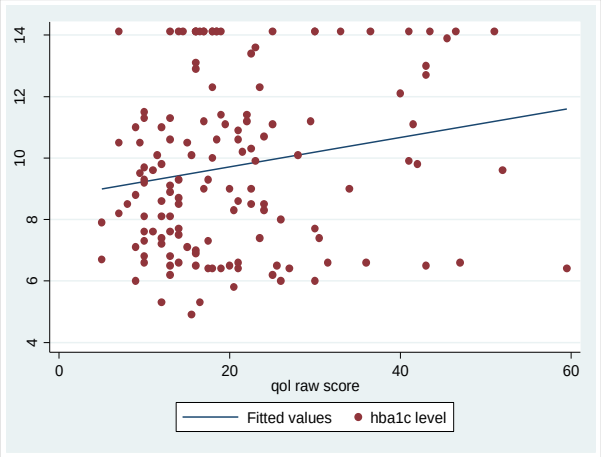
Figure

Analysis of the association of HbA1c with DQOLY-SF scores.

A Pearson's product-moment correlation was run to assess the relationship between HbA1c levels and QOL Score.

```
. pwcorr q6 q16, sig obs

             |       q6      q16
-------------+------------------
          q6 |   1.0000
             |
             |      140
             |
         q16 |   0.1882   1.0000
             |   0.0260
             |      140      140
```



There was a weak positive correlation between Hb1Ac levels and DQOLY-SF Score, r(138) = 0.188, $p < 0.05$, with Hb1Ac levels explaining 0.3% of the variation in QOL Score.

VIII. REFERENCES

1 Pocketbook for Management of Diabetes in Childhood and Adolescence in Under-Resourced Countries, diabetes and adolescence.p48.

2 Margaret Grey et al, Depression in Type 1 diabetes in children Natural history and correlates, Journal of Psychosomatic Research (conclusion).

3 Skinner T. et al, a short form of the Diabetes Quality of Life for Youth questionnaire: exploratory and confirmatory analysis in a sample of 2,077 young people with type 1 diabetes mellitus. Diabetologia (2006) 49: 621–628.

4 Hilary H.etal, Good Metabolic Control Is Associated with Better Quality of Life in 2,101 Adolescents with Type 1 Diabetes; Diabetes care, volume 24,number 11.

5 Nemeh A. et al, Quality of life and associated factors among Jordanian adolescents with type 1 diabetes mellitus; Journal of Diabetes and Its Complications.

6 Faulkner et al, Family Influence on Self-Care, Quality of Life, and Metabolic Control in School-Age Children and Adolescents with Type 1 Diabetes. Journal of Pediatric Nursing, (February), 2007.

7 Samardzic et al. Health-related quality of life of children with type 1 diabetes, J Pediatr Endocrinol Metab, 2016(Montenegro).

8 Grey et al, Personal and family factors associated with quality of life in adolescents with diabete.US National library of medicine.

9 Thomas et al, Glycemic Control in Kenyan Children and Adolescents with Type 1 Diabetes Mellitus, International Journal of Endocrinology 2015.

10 Lori et al, General Quality of Life in Youth with Type 1 Diabetes Relationship to patient management and diabetes-specific family conflict. Diabetes care in American diabetes association 2003.

11 Demirel et al, Individual and familial factors associated with metabolic control in children with type 1 diabetes, Pediatrics International 2013 Japan Pediatric Society.

12 Zashikhin A. et al, Health-related quality of life in adolescents with chronic physical illness in northern Russia. Pub med.

13 Zashikhina et al, Health and Quality of Life Outcomes 2014.pubmed

14 Vasileia G et al, Disturbed eating attitudes, coping styles, and subjective quality of life in adolescents with Type 1 diabetes, Journal of Psychosomatic Research.

15 Nyanzi R. et al, Diabetes and Quality of Life: A Ugandan Perspective, Hindawi Publishing Corporation .Journal of Diabetes Research 2014.

16 Fatemehsadat A. et al, Glycemic Control, Self-Efficacy and Fear of Hypoglycemia among Iranian Children with Type 1 Diabetes, Canadian Journal of Diabetes 2015.

17 Michael E et al, Health Care Transition in Adolescents and Young Adults with Diabetes, J Adolescent Health 1995.

18 Gitte R et al, Improving glycemic control and life skills in adolescents with type 1diabetes: A randomized, controlled intervention study using the Guided Self-Determination-Young method in triads of adolescents, parents and health care providers integrated into routine pediatric outpatient clinics, BMC Pediatrics 2011.

19 Guttmann et al, Metabolic control and quality-of-life self-assessment in adolescents with IDDM.US National library of medicine.

20 Katherine et al, Improving adherence in social situations for adolescents with type 1 diabetes mellitus (T1DM). Primary care diabetes 2 0 1 0.

21 Vasileia et al, Disturbed eating attitudes, coping styles, and subjective quality of life in adolescents with Type 1 diabetes. Journal of Psychosomatic Research (2005).

22 Hvidore study group, childhood diabetes quality of life: question about living with diabetes.

23 Steven et al, Integration of Clinical Psychology in the Comprehensive Diabetes Care Team. CLINICAL DIABETES, 2004.

24 Marisa et al, Psychological screening in adolescents with type 1 diabetes predicts outcomes one year later. Diabetes research and clinical practice 2011.

25 Shelagh et al, Self-management problem solving for adolescents with type 1diabetes: Intervention processes associated with an Internet program. Patient Education and Counseling 2011.

26 krishnavathana et al, the role of socioeconomic status, depression, quality of life, and glycemic control in type 1 diabetes mellitus. The Journal of Pediatrics .October 2006

27 K. Kakleas et al, Psychosocial problems in adolescents with type 1 diabetes mellitus, Review in science direct

28 K Kakleas et al,psychosocial problems in adolescents with type 1 diabetes mellitus, diabetes and metabolism.

29 GrennIsrael, Determining sample size: University of Florida.

30 Annika v. et al, Goal Disturbance and Coping in Children with Type I Diabetes Mellitus: Relationships with Health-Related Quality of Life and A1C; Canadian Journal of Diabetes 2013

IX.APPENDIX

Questionnaire form: number:

A. IBIBAZO BYEREKEYE UBUZIMA BW'URUBYIRUKO RUBANA NA DIABETE

Ibibazobikurikirabirarebananukoubonaubuzimabwawen'uburwayibwaDiabete.

Hitamoigisubizokikunogeye.Usubizeibibazobyose.

Itariki ……. ……

Uruharerw'ibimenyetsobyaDiabete Ni kangahe:	Scores				
	Never Ntanarimwe	Very seldom (Ni)Gake cyane	sometimes (Ni)Rimwenarimwe	Often (Ni)Kenshi	All the time (Ni)Burigihe
1. Wumvautamezenezamumubiri?	0	1	2	3	4
2. Usinziranabi?	0	1	2	3	4
3. UsibaishurikuberaDiabete?	0	1	2	3	4
Uruharerw'imiti: Ni kangahe(kukihegipimo): 4 Wumvaububabarebutewen'ubuvuzibwawe(kwifataisukari,kwiteraimiti)?	0	1	2	3	4
5 UbonaDiabeteihungabanyaubuzima mumuryangowawe?	0	1	2	3	4
6 Wumvaubangamiwen'imirireyawe?	0	1	2	3	4
Ingarukamukazi: Ni kangaheDiabete: 7 Ibangamiraumubanowawen'abandi?	0	1	2	3	4
8 Ikubuzagutwaraigarecyangwa Gukoreshaimachine (urugero: mudasobwa)?	0	1	2	3	4
9 Ibangamiraimyidagaduroyawe?	0	1	2	3	4
10 Ibangamiragahundazawe?	0	1	2	3	4
11 Ibangamiraimikorereyaweyokuishuli?	0	1	2	3	4
Ibyerekeyeababyeyi:					

Ni kangahewumvaababyeyibawe:						
12	Bakabyakukwitaho?	0	1	2	3	4
13	Bagiraimpungengezikabijekuberakouba nanadiabete?	0	1	2	3	4
14	Bakorankahodiabeteariiyabo Atari iyawe?	0	1	2	3	4
ImpungengezerekeyeDiabete: ***Ni kangaheuhangayikiraniba:***						
15	Uzashyingirwa?	0	1	2	3	4
16	Uzabyara?	0	1	2	3	4
17	Uzabonaakaziwifuza cg ukunda?	0	1	2	3	4
18	Uzataubwengecyangwaukagwahasi?	0	1	2	3	4
19	Uzabashakurangizaamashuriyawe?	0	1	2	3	4
20	UdateyenkabandikuberaDiabete?	0	1	2	3	4
21	Izakugirahoingarukazikomeye?	0	1	2	3	4
Ukoubonaubuzima (Health perception)				Good	Fair	Poor
22	Wigereranyijen'abandibomukigerocyawewavugakoubuzimabwaweari?	--------	Excellent 1 Bwizacyane	2 *Bwiza*	3 Buringaniye	4 Bubi

B.Diabetes control assessment

Patients' demographic characteristics

1. Sex: □f

   □ M

2. Age:……..yrs

3. Caretaker status:

   □ Live with at least one parent

   □ Someone else

   □ Orphan

Medical conditions

4. Predictor of diabetes control HbA1c level: ……..

   □ ≤7.5%

   □ 7.6-8.5

   □ 8.6-10

   □ 10.1-12

5. Duration of diabetes:

   □ ≤1yr

   □ >1yr

6. Type of insulin…

   □ Rapid(ex: lispro)

   □ Short acting(ex: actrapid)

   □ Intermediate(ex: NPH)

   □ Pre-mixed

   □ Long acting(ex: lentus)

7. Number of insulin injection per day:

   □ 1

   □ 2

   □ 3

   □ >3

8. DKA in the last year:

   □ Yes

   □ No

9. If hypoglycemia ≤70mg/dl in the last month

   □ Yes

   □ No

10. If hyperglycemia ≥200mg/dl in the last month

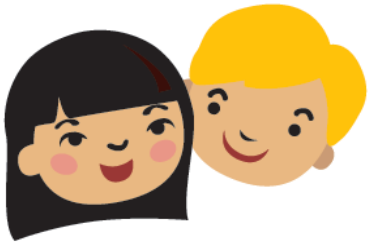
   □ Yes

   □ No

11 Randomglycemia:……..

quality of life for youth

Questions about living with diabetes



The following questions are about how you see your life with diabetes. Circle the number that gives the best answer for you. Please provide an answer for each question. Please bring the completed form with you to the next consultation where it will form the basis for a dialogue about how you are coping with your diabetes.

Patient name: Completion date: Interview date:

	Newer	Very seldom	Some times	Often	All the time	Total score 0-12
Impact of symptoms relating to diabetes						
How often do you…						
1. Feel physically ill?	0	1	2	3	4	
2. Have a bad night's sleep?	0	1	2	3	4	
3. Miss school because of your diabetes?	0	1	2	3	4	
Impact of treatment						0-12
How often…						
4. Do you feel pain associated with the treatment?	0	1	2	3	4	
5. Does diabetes interfere with your family life?	0	1	2	3	4	
6. Do you feel restricted by your diet?	0	1	2	3	4	
Impact on activities						0-20
How often does diabetes...						
7. Limit your social relationships and friendships?	0	1	2	3	4	
8. Prevent you from bicycling or using a machine (e.g. a computer)?	0	1	2	3	4	
9. Interfere with you exercising?	0	1	2	3	4	
10. Interrupt your leisure time activities?	0	1	2	3	4	
11. Prevent you from doing activities at school?	0	1	2	3	4	
Parent issues						0-12
How often do you feel that your parents…						
12. Are too protective of you?	0	1	2	3	4	
13. Worry too much about your diabetes?	0	1	2	3	4	
14. Act like diabetes is their disease, not yours?	0	1	2	3	4	
Worries about diabetes						0-28
How often do you worry about whether…						
15. You will get married?	0	1	2	3	4	
16. You will have children?	0	1	2	3	4	
17. You will not get a job you like?	0	1	2	3	4	
18. You will faint or pass out?	0	1	2	3	4	
19. You will be able to complete your education?	0	1	2	3	4	
20. Your body looks different because of diabetes?	0	1	2	3	4	
21. You will get complications?	0	1	2	3	4	
Health perception						0-4
22. Compared with others your age, would you say your health is?	Excellent 1	Good 2	Fair 3	Poor 4		

DQOLY-SF © 2006: H. Hoey, H. M. McGee, T. C. Skinner and S. E. Skovlund

DAWN Diabetes Attitudes Wishes & Needs YOUTH

Thank you for your help!

novo nordisk®

UNIVERSITY OF RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 10/09/2015
Ref: CMHS/IRB/**276**/2015

Dr GAKUBA Alexis
School of Medicine and Pharmacy, CMH, UR

Dear Dr GAKUBA Alexis

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled **"Diabetes control and Quality of Life in adolescent with Diabetes Mellitus."**

Having reviewed your application and been satisfied with your revised version incorporating the comments from IRB, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

Professor Kato J. NJUNWA
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:
- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate studies, UR