ADDIS ABABA UNIVERSITY
COLLAGE OF HEALTH SCIENCE
SCHOOL OF NURSING AND MIDWIFERY
DEPARTMENT OF NURSING AND MIDWIFERY

ASSESSMENT OF QUALITY OF LIFE AND ASSOCIATED FACTORS IN CHILDREN AND ADOLESCENTS WITH DIABETES MELLITUS AT GOVERNMENTAL HOSPITAL, ADDIS ABABA ETHIOPIA, 2018.

INVESTIGATOR: DESALEGN GIRMA

A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, AND SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING AND MIDWIFERY FOR PARTIAL FULFILLMENT OF THE REQUIREMENTS OF MASTER'S DEGREE IN PEDIATRICS AND CHILD HEALTH NURSING.

JUNE, 2018

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Abbreviations

DKA-Diabetics Ketoacidosis

DRQoL Disease Related Quality of Life

GCS= Generic Core Scale

HRQoL-Health Related Quality of Life

IDF-International Diabetic Federation

PedsQL-Pediatrics Quality of Life Inventory

QoL -Quality of Life

T1DM-Type 1 Diabetes

TASH-Tikur Anbesa Specialized Hospital

USA-United State of America

WHO –World Health Organization

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Abstract

Background: Quality of life (QoL) is a multidimensional construct incorporating an individual's subjective perception of physical function, emotional function, and social well-being. Looking for QoL after a diagnosis of diabetes used to detect problems which may be faced by children and adolescents and to manage these problems.

Objective: This study aimed to assess quality of life and associated factors in children and adolescents with diabetes.

Method A prospective cross sectional study was done from March 1 to April 30/2018 at Tikur Anbesa, Yekakit 12 and zewuditu hospitals. Systematic sampling method was used to select 234 study participants. The interview data collection technique was used. A 23-item multidimensional PedsQL™ 4.0 Generic Core Scales instrument was used to measure general health related quality of life (HRQoL) and a 28-item multidimensional PedsQL™ 3.0 Diabetes Module instrument was used to assess diabetes related quality of life (DRQoL) of children and adolescents. Multivariable linear regression was done and a significant association was declared at $p<0.05$.

Result: The mean score for HRQoL of children and adolescents were 78.8±15.6 reported by children and adolescents and 61±7.9 reported by parents. The mean score for DRQoL children and adolescents were 78.3±14.6 reported by children and adolescents and was 60.5±7.9 reported by parent. About 35.5% mean score of school function and 35.8% mean score of emotional function of children and adolescents fell more than one standard deviation (>1 SD) below the mean of HRQoL of children and adolescents of self-reports. About 37.6% mean score of treatment barriers, 34.9% mean score of communication and 34.5% mean score of worry of children and adolescents fell more than one standard deviation (>1 SD) below the mean of DRQoL of children and adolescents of the self-reports.

Conclusion and Recommendation: This study found that there was lower score in school and emotional function of HRQoL and lower score in treatment barriers, worry and communication sub scale score of DRQoL. Glycemic level, health education of diabetes, frequency of hospital admission was clinically significant factors of HRQoL and DRQoL are scoring. This study recommended for the sustainable health education program on diabetes for children and adolescents with diabetes.

Keyword: Quality of Life, Children, Adolescents, Diabetic Mellitus, Associated Factors

CHAPTER ONE
1. INTRODUCTION

1.1. Background

Up on the definition of health by world health organization(WHO) in 1948 about health, many definition about quality of life (QoL) had emerged by linking health and quality of life, frequently emphasized the component of happiness and satisfaction of life in the absence of universally accepted definition. Quality of life broader include health related and non-health related of life(1).

Quality of Life (QoL) is perception of individual about their life related to their culture and value systems in which they live and in relation to their achievement, expectations, and there concern. It affects individuals physical health, psychological state, level of independence ,personal beliefs and social relationships (2, 3).

Quality of life is a key outcome when treating patients with chronic diseases. It is considered as an important indicator of the outcome of treatments that refers to child's well-being and functioning and it is used to describe the impact of the health condition on the child as well as the effects of treatment strategies in the case of pediatric diabetes (4).

Globally, diabetes ranked as the third highest risk factor for premature mortality, after hypertension and smoking (5).It is a life-end illness which has major effects on physical and mental health . Psychological health may be difficult to quantify and so measuring QoL is one of useful tool in the evaluation of a patient's well-being(6).

Uncontrolled diabetes can end up in severe complications such as diabetic ketoacidosis, hyperosmolar hyperglycemic state, and also chronic microvascular and macrovascular complications. These devastating complication have negatively affected the quality of life and survival of patients (5, 7, 8).

Diabetes mellitus in children and adolescents are challenging .It need them to adapt restrictive lifestyle and diet, and monitor their blood sugar level frequently. Exceeding to this challenges, living with diabetes lead to life threatening complications and deterioration health related quality of life. Children and adolescent face emotional and psychological difficulties and mal adaptive coping strategies (9) .

1.2. Statement of problem

Diabetes is now became one of the health related emergencies of the 21st century. It increases with 3% of Annual incidence rate and about 8600 children were expected to develop new cars per year globally in 2015. The prevalence increased towards younger people and it impose its burden on future generations. The burden of diabetes is not only in the increment numbers of people with diabetes, but also increasing in number of premature deaths due to diabetes (5).

Diabetes one of lifelong diseases, can end up in devastating health related complication and a number of disabilities such as heart attack, stroke, kidney failure, vision loss and nerve damage this are preventable consequences (8, 10).

Like other chronic illness, diabetes can deteriorate health related quality of life of children and adolescent. Children with diabetes need a lifesaving and lifelong treatment, daily monitoring of blood glucose level and careful eating habit. This hurt and, interferes with daily life of children and their parents (11, 12).

Psychological problem is one of the major impact of diabetes in children and adolescents. They have an increased risk of depression, and worries about their disease condition (6, 10, 13-16). A systemic review conducted on 16 different article described that the prevalence of depressive disorders ranged from 8.7% to 21.4% and the prevalence of anxiety ranged from 10.1% to 27.2 %. Children and adolescents with diabetes 1.7 times at higher risk for developing depression than non-diabetic control group (OR= 1.722, (95% CI= 1.347 to 2.202, $p< 0.001$) (17).

Diabetes in children and adolescent affect their coping strategies, they use maladaptive coping strategies like avoidance and they avoid to inject insulin themselves to escape from stress, which negatively affect their quality of life and negatively influence glycemic control (18).

Children with chronic illness experienced a greater frequency of peer rejection and asocial behavior compared with healthy peers. It has potential impact on their future development and mental health outcomes (19).

In another way, all quality of life related problems have negative impact on life saving treatment and outcome of diabetes. Previous research showed that most of the time ,children and adolescents who have poor glycemic control have a low score on quality of life (6, 20-

25). Generally, evaluation of quality of life and addressing its determining factor should be one part of diabetes management for better out come in addition to medical management (15, 23, and 26). Previous study showed that factors related to quality of life of children and adolescents were sociodemographic, family-related and poor glycemic control and duration diabetes (24, 26-31).

Until recently research on quality of life of children and adolescent with diabetes were understudied at local area and only few studies conducted on adults. Most of the studies conducted in other foreign countries. Since there is a great difference in the health care delivery system, religion, culture and family dynamics in different societies, there is a need to do quality of life studies in different communities and need to know determinant factor of quality of life .Therefore, the purpose of this study was to assess Quality of life of children and adolescent with diabetes and to determine its associated factors.

1.3. Significant of the study

In order to reduce the devastating complications of diabetes, QoL assessment should be incorporated with medical management for children and adolescents with diabetes. QoL assessments provide valuable information about the effect of diabetes on quality of life of children and adolescents and exceed to assess the effect of other commodities on children and adolescents with diabetes. This study will assess and detect problems which faced by children and adolescents with diabetes and will helps to manage their problems. This study will assess and detect problems which faced by children and adolescents with diabetes and will helps to manage their problems.

This study will alarm health professionals; 1) to consider the general health perception of patients in conjunction with medical management, 2) help them to develop specific management programs with respect to a patient's condition, 3) help them to think broadly to identify negative impact of other comorbidities on metabolic controlling, 4) help them to predict disease progress and 5) it helps in prioritization of health resources.

It alarm guide line developer to incorporate quality of life assessment in medical practice and it also helps them in formulating diabetes care programs.

It also aware parents to identify there gaps on their children diabetes care and to know the effect of parenting on children's quality of life and disease outcome, it increased the awareness of parents on their children home care, and extends to know there role on management of diabetes in their children. Finally this study will be basis for other researchers who want to study on related topics.

CHAPTER TWO

LITERATURE REVIEW

2.1. **Magnitude of diabetes in children**

Type 1 diabetes is one of the most common endocrine and metabolic conditions in children and adolescences. It is raising rapidly, according to the 1`international diabetics federation (IDF) report in 2015 the number of children with diabetes exceed half a million for the first time. About 54200 children were expected to having diabetics at worldwide (2015/IDF). Europe had the highest number of children with type 1 diabetes; approximately 140,000 children lived with diabetes and about 21,600 new cases were diagnosed per year. Out of estimated 54200 children living with diabetes, 46,400 children were estimated to living with diabetes in Africa alone with 7,600 children were newly diagnosed per year. Among newly diagnosed children with diabetes globally about 26% of them came from Europe and 22% from the Caribbean and North America(5).

About 23.1 million people or 7.2% of the U.S.A population had diagnosed diabetes in 2015.Out of 23.1 million population living with diabetes 132,000 of them were younger than age 18 years and 193,000 of them were younger than age 20 years (32).

In Europe region incidence of type 1 diabetes, varying from the highest in Finland (43.9/100,000/year) and some of the other Scandinavian countries to the lowest being reported in Macedonia (3.2/100,000/year(11, 33).

A study conducted in India in the Karnataka region on the diabetes registry from 1995 to 2008 the incidence of T1DM were 0.32/100,000 per year (34).

A study on incidence and prevalence of type 1 diabetes in Africa were few, due to this the contribution of African continent for the estimation of global T1DM incidence is low ,despite this the incidence of T1DM in children less than 14 years were 6.4/100,000 new case per year in the African region had been reported(35).

A systematic review conducted in eight African countries, namely Algeria, Ethiopia, Ghana, Libya, Nigerian Igbo and North-West Nigeria region, Sudan, Tanzania, and Tunisia about the incidence and prevalence of T1DM. Both prevalence and incidence of T1DM in Algeria and

Sudan were reported. In Algeria the prevalence and incidence of T1DM were 0.27/1 00011 and 8.1/100 00011 respectively, and in Sudan the incidence of T1DM in age between 0-14 years were 10.1/100 00018 and the prevalence were reported in different age group between 7-14 years were 0.95/1 00019. In Ethiopia, Libya and Tanzania only incidence was reported that 2.1/100 00012 at age between 0-78 years, 7.8/100 00014 at age between 0-14 years and 1.5/100 00020 in age between 0-19 years respectively. In Ghana and in two Nigerian region at Nigerian Igbo and North-West Nigeria were only prevalence were reports that 0.75/1 00013, 0.25-0.46/1 00016 at age between 5-17 years and 3.1/1 00017 presented at age 10 ±4. 5 years respectively, and in Tunisia only the prevalence of T1DM was reported in two age groups that 6.76/100 00021 at age between 0-14 years and 6.95/100 00021 in age between 0-19 years (36).

A retrospective study conducted in Nile Delta region in Egypt between a year January 1, 1994 and December 31, 2011 about the incidence and prevalence of T1DM in children aged between 0-18 shows that incidence and prevalence were increased over the past 18 years (1994-2011). The age-adjusted incidence of T1DM in 1996, 2006 and 2011 were 0.7, 2.0 and 3.1/105/year, respectively, and the age-adjusted prevalence of T1DM in the same years was 1.9, 15.5 and 26.8/105/year (37).

A population based studies conducted Abidjan district in Cote D'Ivoire about the prevalence of diabetes in children and adolescents. About 1572 children and adolescents aged 02–19 years were incorporated. About 0.4% of them were reported to be having diabetes (38).

Cross-sectional descriptive study conducted Tikur Anbessa Specialized Teaching Hospital from July 2013 to January 2014 at pediatrics OPD on children's aged 7–12 years presented with complaints other than symptoms of diabetes mellitus that prevalence of diabetes mellitus was 2.81/1000 cases(39).

2.2. **Quality of life in children and adolescents with diabetes**

In chronic disease like diabetics which is lifelong disease ,measurement of health related quality of life in clinical practice have para amount importance ,such as it indicate treatment out came, it can detect other comorbidity with diabetes, it provide important information regarding patients disease condition ,it help to early prediction of the progress of disease and also it enhance medical decision making (1, 15).

Despite availability of advanced treatments and new technologies, management of type 1 diabetes in childhood is challenging and overwhelming .Treatment of diabetes is not only fixed to adequate glycemic control but also it addresses prevention of its complications; disability limitation and rehabilitation. To prevent diabetes related morbidity and mortality, immense self-care behaviors, including food choices, physical activity, proper medications intake and daily blood glucose monitoring from the patients are highly needed (40).

An observational cross-sectional study conducted in Brazil on 110 diabetics patient shows that about 60% them have anxiety symptom, and 53.6% have depression symptoms(41).

A qualitative study conducted in Zambia on 22 adolescent with diabetes are interviewed about their disease condition .About 59% [13/22] adolescents report that they faced physical stressors and about 27% [6/22] of them experienced social stigmatization from peers and society especially among girls with diabetes who are seemingly not wanted for marriage(18).

Regarding the cognitive performance still controversy, children's with diabetes scores mildly lower cognitive scores across most cognitive domains ,with moderately lower performance compared with control subject(42).

A study conducted in Sweden to examine the impact of diabetes on academic performance of student ,about 16 compulsory school and 19 upper secondary school students are participated shows that diabetes had a negative effect on mean final grades compulsory school student ($\beta = -0.07$, $p<0.001$) and theoretical programmed in upper secondary school student($\beta=-0.07$,$p=0.001$)(43).

A similar comparative study conducted for 1 year from September 2011 to June 2012 to compare academic performance of children with type 1 diabetics and non-diabetics control group .Their score on selected courses were compared and the result shows that students who were diagnosed with diabetes received significantly lower mean examination scores compared with the matched nondiabetic controls (44).

2.3. Does diabetes itself affect quality of life?

Regarding effect of diabetes on QoL, studies report mixed result. A comparative study conducted in Greek on 117 children and adolescents with diabetes and healthy group showed that children with T1DM reported Poorer physical HRQoL ($F= 11.08$, $p =0.001$), poorer

emotional HRQoL (F=5.00, p = 0.026), poorer school HRQoL (F= 7.88, p = 0.005), and poorer total generic HRQoL (F = 7.02, p = 0.009) compare to healthy control. And both have no difference in the level of social functioning HRQoL (F= 0.314, p = .57)(45).

Similar study conducted in Kuwait pedsQL generic scale version 4.0 and pedsQL diabetics module version 3.0 were used to assess quality of life of children and adolescents with diabetics. Children and adolescents with T1D scored lower total generic QoL (75.6 ± 8.9) than healthy control (83.5 ± 9.5, p = 0.001) (20). Another similar comparative study conducted in Egypt on about 412 children's with diabetes and healthy children. Both children complete PedsQL™ 4.0 Generic Core Scales to assess the difference between quality of life of children and adolescents with diabetes and healthy peers revealed that children and adolescents with diabetes had significantly low QoL (t =13.8 , p < .0001) compare to healthy peers(24).

In other way diabetes have no effect on QoL. A comparative cross sectional Study conducted Taranaki children and adolescents with diabetics and their sibling. About 56 diabetic's children /adolescents and 35 healthy sibling and their parents were participated. Both parents and their children had complete PedsQL™ 4.0 Generic Core Scales show that both diabetics children and adolescents and healthy sibling reported similar HRQOL scored (β= -4.37, 95%CI [-10.67, 1.92]; p=0.17) (6).Similarly a comparative Studies conducted in Greek origin on children and adolescents with diabetes and healthy peer. PedsQL generics scoring version 4 and PedsQL diabetes module version 3.0 were used. Result show that there is no differences were found among children and adolescents with diabetes and control group in both instruments. Surprisingly children with diabetes reported better QoL in subscale of social functioning(46).

A non-comparative cross-sectional studies conducted at Bursa, Turkey, 64 children and 85 adolescents and their parents were participated. Both children/adolescent and parents complete PedsQL generic version 4.0 to assess QoL of children and adolescents with diabetics, result show that children and adolescents had good QoL scoring. Two of QoL domain namely affective and school functions somewhat low, and they have higher scoring of in subscale social function. The parent PedsQL scores and children, adolescents were coincide each other(47).

A cross sectional study conducted at Saud Arabiya on 315 adolescents with diabetes and their care givers to assess disease specific QoL of adolescents. PedsQL Diabetes Module 3.0 were used. QoL of adolescents' diagnosed with T1D reported by the teens and their parents scoring. Adolescents reported a cumulative mean HRQoL score of 64.8, while parents reported significantly lower mean scores of 60.3 ($p = 0.003$).). Both adolescents and parents were worried about disease condition and have highest score on subscale of Treatment adherence(48).

2.4. Factors affecting quality of life of children with diabetes

2.4.1. Quality of life and age

Here finding are mixed. Several studies found that older age group have low QoL than young age group. A Cross sectional study conducted Saud Arabiya show that younger adolescents in younger aged 13–15 years had higher QoL scores compared to older adolescents aged 16–18 years ($\beta = -7.62$, $p = 0.0002$) (48) .Inversely Other study conducted at university hospital bursa, Turkey on children and adolescents with diabetes show that age have positive significant relationship ($r=0.304$,$P<0.01$) with total QoL scoring (47) and Whereas studies conducted at Egypt(24), Chicago(49), Greek origin(46)shows there is no age related difference in QoL.

A review conducted on 33 articles of this six studies compared generic QoL across different age groups. Three of them compared young adolescents (age range 11-14) with older adolescents (age range 15-19) indicate that older adolescents reported better QoL than younger ones ,Effect sizes (d+ 0.59 for total QoL) .The other two studies found no differences in generic QoL between the two age groups. Reversely three studies compared younger groups of children. Compared 8- 12 year olds with 13-16 year olds. Shows that older age have lower QoL than younger one, effect size for total QoL (d= -0.46) (50).

2.4.2. Quality of life and gender

Studies reported that gender have mixes effect on QoL on children and adolescents with diabetes. A cross sectional Studies conducted at Kuwait (20), Alexandria city, Egypt(21) and Saud Arabiya(48) male sex had better QoL score than female ($p =<0.05$,$p=0.001$ and

p=<0.001 respectively).Other studies conducted at Egypt (24) and Greek(46) showed that no statistical significant difference regarding gender.

A review conducted on 33 articles showed that girls with T1D reported lower generic and disease-specific QoL than boys with T1D. Three studies shows boys have better generic sore of QoL than girls. The rest two of studies, reported that boys and girls have no significant differences in generic QoL scoring. And other ten studies reports about disease specific differences of QoL girls and boys of this eight studies shows girls are worried about diabetes and had lower overall disease-specific QoL than boys. And only one study reported that absence of gender related differences in diabetes-related QoL(50).

2.4.3. Quality of life and Education level of parents

A study conducted in Egypt reported that Children's having educated mother had higher total QoL scores and higher education of mother had significantly associated with social function (F= 4.5, p=0.004) and school functioning (F=2.9, p=0.03) and total health related QoL (F=3.2,p=0.02)of children with diabetes. Similarly children whose fathers has university and higher education showed significantly higher scores for emotional (F=4.0 ,p=0.008), school (F= 2.9,p=0.04) and total QOL (F=4.8, p=0.003) than those whose fathers had lower educational levels (24). Inversely research conducted at Greek show that parents education level had no significant on QoL of children and adolescents with diabetes (46).

Attendance at diabetes education

A cross sectional l Study conducted in Zambia shows compliance have significant 0.01 Positive correlation (r = 0.468; p =0.002) with quality of life. Information that provide for adolescents the intervention period have paramount significant effect in the lives adolescents and also influenced positive behavior change to the treatment regimens(51).

2.4.5. Quality of life and glycemic control

Most of the studies reported that children and adolescents having well control glycemic had better QoL. A descriptive correlational study conducted on school-age children and adolescents from 10 to 18 years with diabetics at Chicago shows children /adolescents having poor metabolic control experienced greater ill effects related to diabetes (r = .23, p 0.05). As a result children and adolescents perceive as being physically ill, limitations on social and

school activities with peers, and experienced disruptions in sleep, dietary, and exercise(49). Similarly studies conducted Bursa, Turkey ($P < 0.05$) (47) , Kuwait ($r = -0.7$, $p = 0.001$) (20) and Greek (**(**$\beta = -0.27$, $p = 0.000$) (45) report that children with better glycemic control had better QoL. In other way a comparative cross sectional study done in Egypt show that glycemic control have no effect on QoL(24).

A review conducted on 76 articles about factor affecting QoL indicates glycemic control have mixed effect on QoL. About 10 articles reported that children/adolescents having better metabolic control confirmed having better QoL whereas other 5 studies describes glycemic control have no relation with QoL (30).

2.4.6. Quality of life and duration of diabetes

Duration of diabetes have mixed effect on QoL. A study conducted in Kuwait shows children and adolescents with diabetics for longer duration have significantly poor QoL ($p < 0.001$)(20).whereas studies conducted in Chicago(49) and Saud Arabiya ($p = 0.9705$)(48) revealed that disease duration have no association with quality of life and study conducted in Egypt duration of diabetes only affect emotional domain of QoL($p=0.03$) (24).SEARCH for diabetes youth study revealed that duration of diabetes was significantly associated QoL domain of school functioning subscale (P=.02); youths with longer diabetes duration had better school functioning(52).

2.4.7. Quality of life, treatment regimen and number of injection per day

A comparative cross sectional study conducted Kuwait there was a significant relationship between insulin regimen and QoL in all age groups. Patients using insulin pumps, even those less than 4 years old, had better QoL compared to children taking multiple daily insulin injection and children and adolescents having multiple daily injections was associated with worse QoL in the younger age group (2–4 years, $p < 0.05$)(20).

SEARCH for diabetes youth study shows children and adolescents taking insulin injecting at least 3 times a day had better emotional functioning (P=.04),school functioning (P=.03), and psychosocial functioning (P=.02) compared with taking oral medication (52).

2.4.8. Quality of life and number of admission

Admission to hospital deprives children and adolescents time spent with their family members, play groups and school. A study conducted at Alexandria city, Egypt adolescents who had more hospital admission in the last 6 months had statistically lower QoL scoring (P = 0.006) (21).Reversely study conducted by SEARCH for diabetes youth study showed children and adolescents with diabetes having hospital admission in the last 6 months had significantly better HRQoL (52) and similar research done in Taranaki children had more admission was predictor of better QoL scoring(6).

2.4.9. Economic status of family

A study conducted at Yale University USA show that socioeconomic significant associated factor that Children and adolescent's from high-income group reported significantly fewer symptoms of depression, lower levels of perceived stress, and better QOL than those in the moderate or low-income groups ($p < 0.05$)(27).

Similar study conducted in Egypt children from middle and high social class had significantly better scores of social (p=0.03), school (p=0.004 and total QOL (p=0.01) compared from the low socioeconomic class(24).

2.4.10. Family setting

A descriptive study conducted in Spain on 136 children with diabetes indicates that; single-parent families, ($\beta = -15.2$) were to be an influential factors of HRQOL(31).Similarly other study shows children and adolescents with single parents were risk for diabetes-related stress and worse glycemic control of children with diabetes (29)

Other distractive study conducted university hospital Bursa, Turkey revealed that a rise in the number of children in family had significant negative relationship with the quality of life of children and adolescents with diabetes (r= -0.256, P<0.05) (47).

2.4.11. Family history of diabetes

A study conducted in Egypt revealed that Children who had diabetic parent had significantly better score in their social QoL(t=2.6, p=.01) while on the contrary, they had significantly lower scores in their school related QoL(t=2.2,p=.03)(24).

2.5. Conceptual frame work

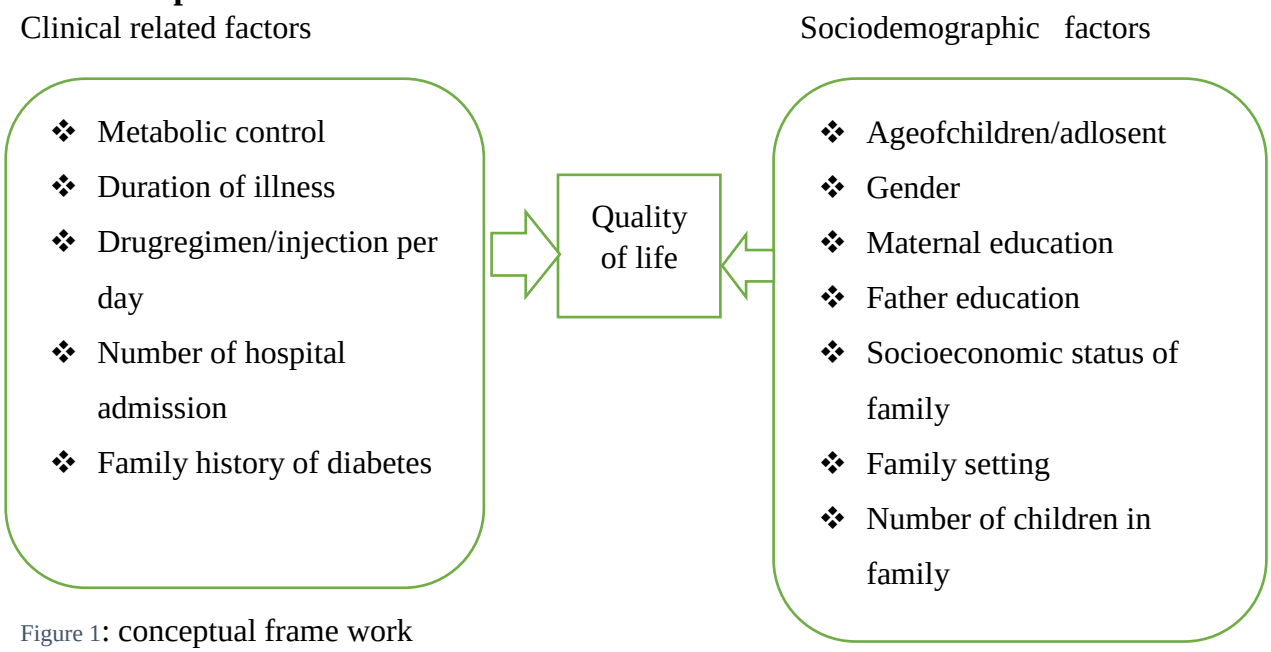

Figure 1: conceptual frame work

Source adapted from research conducted Egypt ,2017 **(24)**

The above conceptual framework adapted from research conducted from at Egypt ,2017**(24)**. In the above conceptual frame work there are factors that are not included in this study, like family function, self-esteem, self-efficacy, coping, depression because it is difficult to measure those factors in our situation. Other than the above factors including clinical characteristics such duration of disease, glycemic control, number of admission and drug regime, family history of diabetes and sociodemographic characteristic like age of children/adolescents, gender, parental education level, socioeconomic status, family setting, and number of children in family and family history of diabetes is determinate factor of QoL of children and adolescents are included in this study.

CHAPTER THREE
OBJECTIVE

3. 1 .General objective

- To assess quality of life and associated factors among children and adolescents with diabetics patients at governmental Hospitals, Addis Ababa, Ethiopia, 2018.

3.2. Specific objective

- To asses health related quality of life in children and adolescents with diabetes.
- To asses diseases related quality of life in children and adolescents with diabetes.
- To determine factors affecting QoL in children and adolescents with diabetes.

CHAPTER FOUR
METHODOLOGY

4.1. Study area and period

This study was conducted in Addis Ababa from March 1 to April 30/2018. Based on the population projection of the Central Statistical Agency of Ethiopia (CSA) in 2013, Addis Ababa has a total population of 3,433,999 of whom 1,624,999 are men and 1,809,000 women; all of the population is urban inhabitants (53). According to Addis Ababa Regional Health Bureau (AARHB) 2006 report, under its administration there are six hospitals, one Public health laboratory and two health Science colleges. There are also 52 hospitals in the metropolis, of which 6 are owned by AARHB, 5 by the federal government, 3 by NGO's, 3 by Defense force and police and 35 by the private owners. Three governmental hospitals namely Tikur Anbesa specialized hospital (TASH), Yekakit 12, and zewuditu had a pediatric endocrinology clinic which was incorporated under this study. A total of 470 children and adolescents with diabetes were in follow from September 30 to November 30 in three of the hospitals, from a total of 470 children with diabetes about 212 of them were from Tikur Anbesa, 183 of them were from Yekakit 12 and the rest 75 of them were from Zewuditu hospital (54)

4.2. Study design:

- An institution based, prospective, cross sectional study was used.

4.3 Population

4.3.1 Source population

- All children and adolescent with diabetes attending a diabetes / endocrinology clinic in selected governmental hospitals in Addis Ababa.

4.3.2. Study population: all those children and adolescents who fulfill the eligibility criteria

4.3.2 .**Sampled population**: All systematically selected children and their parents, and adolescents with diabetes attending a diabetes / endocrinology clinics who full fill inclusion criteria in the sleeted governmental hospitals.

4.4 Eligibility Criteria

Inclusion criteria

- Diabetic patients from school age up to eighteen years had been on follow up for at least 3 or more month duration.

Exclusion Criteria

- Diabetic patients whose age was less than 6 years old and more than 18 years old.

  Children and adolescents who had chronic illness other than diabetes

4.5. Sample size determination

Sample size was calculated using single population proportion formula. By considering the following assumption, about 50% of the population proportion had good quality of life, 95% confidence interval, 5 % margin of error the sample size calculated as follows.

$$n = \frac{(Z_{\alpha/2})^2 \times p(1-p)}{d^2}$$

Where

n - Initial Sample size

z- Standard normal value at 95% CI which is 1.96

P- 50% Estimated the population proportion have good health related quality of life

d- Possible margin of error tolerated which is 5%.

$$n = \frac{(1.96)^2 \times 0.5(1-0.5)}{(0.05)2di} = 384$$

Since the source population is <10,000, which is 470 population correction formula is used determine to adjusted minimum sample size as follows

$$nf = \frac{n}{1+n/N}$$

Where

n= initial maximum sample size (384)

N=total number of children and adolescents with diabetes

n_f= minimum final sample size

Thus $nf = \frac{n}{1+n/N} = \frac{384}{1+384/470} = 384/1.8 = 213$

By adding 10% of non-respondents rate final sample size was 234

4.6. Sampling technique and procedure:

The study subjects were selected from Addis Ababa selected governmental hospitals. These hospitals include TASH, Yekakit 12 and Zewuditu hospitals, which have diabetic clinics for children and adolescents were selected purposefully. A total of 470 children was identified who had been on diabetic, follow up from September1 to November 30, 2017 on those hospitals. For the total number of children who had been in follow up about 212 of them were from Tikur Anbesa, 183 of them from Yekakit and the rest 75 of them were from Zewuditu hospitals. The sample size was proportionally allocated for each hospital (see fig2). Children and adolescents with respective to their parents were selected from each hospital using a systematic sampling method of calculating the sampling interval, k = 2, for each hospital. The first eligible study subject was selected randomly. Then every two interval of children and adolescents with diabetes respective to their parents who were visiting the Endocrinology clinic during the data collection period were selected.

Proportional for each selected hospitals

$$\text{TASH} = \frac{\text{children had been on diabetic follow up at TASH} * \text{Total sample size}}{\text{Children had been on diabetics follow up at selected hospitals}}$$

$$= \frac{212 * 234}{470} \quad 106 \text{ patients}$$

$$\text{Yekakit 12 hospital} = \frac{\text{children had been on diabetic follow up at yekakit 12} * \text{Total sample size}}{\text{Children had been on diabetics follow up at selected hospitals}}$$

$$= \frac{183 * 234}{470} = 91 \text{ patients}$$

$$\text{Zewuditu hospital} = \frac{\text{children had been on diabetic follow up at zewuditu} * \text{Total sample size}}{\text{Children had been on diabetics follow up at selected hospitals}}$$

$$= \frac{75 * 234}{470} = 37 \text{ patients}$$

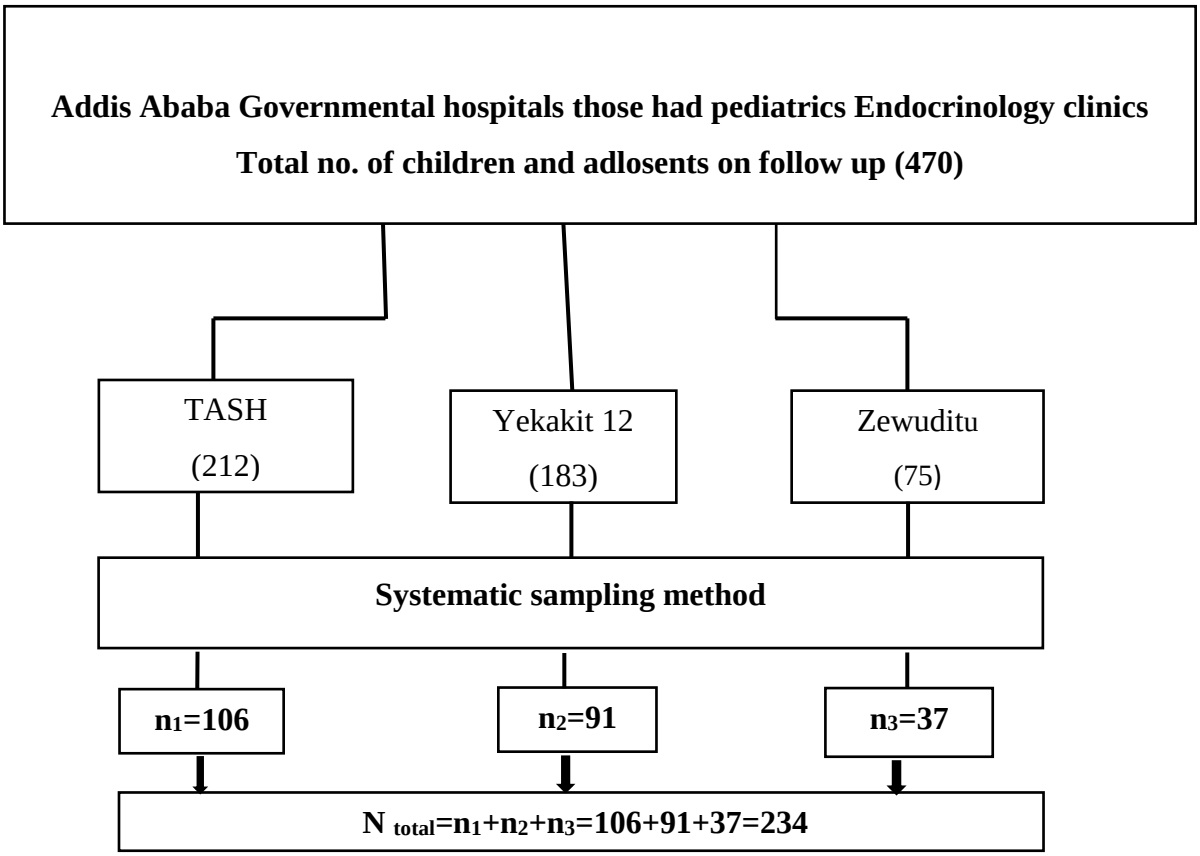

Figure 2: Showing schematic presentation of sample size allocation.

4.7. Operational definition

Poor HRQoL and DRQoL: Those respondents who score one standard deviation (1SD) below the sample mean in relative to population sample.

Good HRQoL and DRQoL: Those respondents who score one standard deviation (1SD) above the sample mean in relative to population sample.

Glycemic control: for the purpose of this study fasting glucose level (FBS) will be used

- Well controlled FBS level : 90-130mg/dl

Poor glycemic control: FBS level <90 or >130mg/d.

Children: from 6-11 years old

Adolescents: from 12 to 18 years old

4.8. Variables

4.8.1. Dependent variable

Quality of life in children and adolescents with diabetes

4.8.2. Independent variables

Sociodemographic variable

- Age of children/adolescent
- Gender
- Maternal education
- Father education
- Socioeconomic status of family
- Family setting ,Number of children in family

Clinical related variable

- Metabolic control
- Duration of illness
- Drug regimen/injection per day
- Number of hospital admission
- Family history of diabetes

4.9. Data collection tool and procedure

Data collection was started by obtaining permission from TASH, Yekakit 12 and Zewuditu hospitals. Children and adolescents with their respective parents those who met the inclusion criteria were interviewed. The purpose of the study were explained and confidentiality was assured. The data collectors and supervisors were 6 diploma and 2 BSC trained health professionals respectively Data was collected through face to face interview from March 1 up to April 30/2018.The instrument includes:

Part-1: socio demographic condition and medical related question which was developed from different literature.

Part –II: It used to measure general health related quality of life (HRQoL) rather disease related quality of life. It has a 23-item, multidimensional quality-of-life instrument. Items in each four sub Scales were, Physical functioning (8 items), Emotional Functioning, Social Functioning, and School Functioning (5items for each).It was reported with both children and adolescents and parents. Children and adolescents and their parent were asked how much of a problem in each item had been during the last one month and they rate problem in five Likert scale from 0-4. (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem).Then each items were reversely scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0), so that

higher scores indicate better HRQOL. Scale scores were computed as the sum of the Items divided by the number of items answered. If >50% of the items in the scale are missing, the scale score is not computed.

Part III: It has 28-item multidimensional module that encompasses five scales: Diabetes symptoms, Treatment barriers, Treatment adherence, Worries, Communication will be conducted to assess diabetes related quality of life (DRQoL).The format, instructions, Likert-type response scale, and scoring method are identical to PedsQL™ 4.0 Generic Core, with higher scores indicating fewer symptoms or problems. The scoring method is the same as the one of PedsQL™ 4.0 Generic Core.

Both the PedsQL™ 4.0 Generic Core and PedsQL™ 3.0 Diabetes module were adopted from. https://ePROVIDE.mapi-trust .org. pediatrics'(55).The instruments were adopted in English and translated to Amharic. It was translated back to English by independent translator to maintain consistency of the tool. The internal consistency reliability coefficient of Cronbach α for both child and parent report for both instrument is approached to 0.70 studies in Greek(46) .

4.10. Pretest

Pretest was conducted 20 patients at Saint Paulo's hospital and there was a clarity problem during English to Amharic translation, and it was reword /or rephrased again.

4.11. Data quality control.

Data quality was ensured during collection, coding, entry and analysis. To increase the quality of data internal consistency reliability test was done. The Cronbach's Alpha for PedsQL™ 4.0 Generic Core scale was (α=.86) and for PedsQL™ 3.0 Diabetes module (α=. 73), it indicates reliable Systematic sampling method was used to select study participants. And during data collection three teams, namely data collectors, supervisors and investigators were assigned and properly designed, structuredand pretested Amharic translated questioner were used and it was translated back to English by an independent translator to maintain consistency of the tool. Training was given to the data collectors and supervisors to prevent any confusion and had a common understanding about the tool. Supervision of data collectors was done by supervisors and includes observation of how the data collectors were collecting data. The filled questioner was checked by data collectors, supervisors and Principal

investigators for completeness and clarity on a daily basis. Problem was encountered and it was solved immediately.

4.12. Data Processing and Analysis

All the returned questioners were checked for completeness and clarity, cleaned manually, coded and were entered in to Epi data version 4.20 and exported to SPSS version 21 statistical package for further analysis and cleaned, edited and analyzed by the principal investigator. Frequencies, Percentage, mean and standard deviation were used to summarize descriptive statistics and table was used for data presentation. Paired t-test was done to compare children and adolescents self-report and parent proxy reports. One sample independent t-test and ANOVA were done to compare mean score of children for both HRQoL and DRQoL according to sociodemographic and clinical characteristics of children and adolescents. Finally factor which had statically difference in mean score of HRQoL and DRQoL of children and adolescents in bivariate analysis were adjusted in multivariable linear regression analysis to explore the real difference in mean score and to identify significant predictor factor of both HRQoL and DRQoL of children and adolescents. Statistical significance was declared at $p< 0.05$.

4.13. Ethical consideration

Ethical clearance was obtained from institutional review board (IRB) of Addis Ababa University, collage of health science, department of nursing and midwifery, and department of pediatrics and child health research publication committee (DRRPC). After ethical clearance received, permission to conduct the research was obtained from TASH, Yekakit 12, and Zewuditu hospitals. Information sheet was prepared and read to all eligible participants of the study. All participants were informed the purpose of the study and their participation was on voluntary basis. Verbal informed consent and assent for adolescent (12-18 years) was received from all participants. Name of the participants were omitted from the questionnaire; instead medical record number was used to ensure confidentiality.

4.14. Dissemination of the result

The result of this study will be presented to Addis Ababa University College of health science, department of nursing and midwifery as partial fulfillment of the requirement of master degree in child health nursing. Furthermore the result will be shared with endocrinology unit of TASH, Yekakit 12 and zewuditu hospitals and also the manuscript of the research will be prepared and submitted to appropriate journals for possible publication.

CHAPTER FIVE: RESULT

5.1 Sociodemographic Characteristics.

The Sociodemographic characteristics of participants were presented in (Table 1). A total of 229 participants were include in the study give a response rate of 97 %, from this about 127 (55.5%) of them were males and about 102 (44.5%) of them were females, about 27% of them were live with single parent and other and one fourth 58 (25.3%) of them were member family having more than four children .The mean age of children and adolescents were 12±3. Regarding educational status of parents, about 66 (28.8%) of children mother and about 41 (17.7%) children father were illiterate and can read and write ,the rest 163 (71.2%)of children mother had primary, secondary and above while 188(82.3%) of children father had primary ,secondary and above.

Table1: Socio-demographic characteristics of children and adolescent with diabetes, Addis Ababa, 2018

Variable		Frequency (N=229)	Percent
Age	6-12	99	43.2
	12-18	130	56.8
Sex	Male	127	55.5
	Female	102	44.5
Family dynamic			
	Both parents	167	72.9
	Single parent/other	62	27.1
No. children in family:	< 4	171	74.5
	≥4	58	25.3
Mother education level			
	Illiterate/read and write	66	28.8
	Grade 1-8	53	23.1
	Grade 9-12	49	21.4
	Above 12	61	26.6
Father education level			
	Illiterate read and write	41	17.7
	Grade 1-8	45	19.7
	Grade 9-12	45	19.7
	Above 12	98	42.8
Occupation of mother			
	Unemployed	47	20.5
	Government/privet employed	57	24.9
	Self employed	90	39.3
	House wife	35	15.3
Occupation of father			
	Unemployed	6	2.6
	Governmental/private employed	81	35.4
	Self employed	142	62
Monthly income :	Low	122	53.3
	Medium/high	107	46.7

5.1 Clinical characteristics.

The clinical characteristic of respondent were presented, in (Table 2).The mean onset of diabetes for participants were 7±3 (mean ±SD) years and the mean duration of diabetes for participants were 6±6.5 (mean ±SD) years. About 212 (92.6%) of children and adolescents were insulin only user. They had 185±81 mean level of fasting blood sugar (FBS) level. About 55(24%) children and adolescents had history of admission in the last six month and 30 (13.1%) of children and adolescents had family history of diabetes.

Table 2: Clinical characteristics of children and adolescent with diabetes, Addis Ababa, 2018

Variable	Frequency (N=229)	Percent
Age of onset/year./		
1-8	156	68.1
≥8	73	31.9
Duration of with diagnosis /year/		
<5	134	58.5
≥5	95	45.5
Attending education during follow up		
Yes	135	59.0
No	94	41.0
Injection per day		
1	29	12.7
≥2	200	87.3
Glycemic level		
control	120	52.4
uncontrolled	109	47.6
admission in last 6 month		
yes	55	24
no	174	76
frequency of admission		
1	35/55	63.6
≥2	20/55	36.3
Family history of diabetes		
Yes	30	13.1
No	199	86.9

5.3. Compression of patients self-reports and parent proxy reports of QoL

The paired sample t-test compares children and adolescents self-reports and parent proxy reports of PedsQL™ 4.0 Generic Core Scales and PedsQL™ 3.0 Diabetes Module scores of children and adolescents. There was statically significant difference in self-reports and parent proxy reports of PedsQL™ 4.0 Generic Core Scales scoring and PedsQL™ 3.0 Diabetes Module scoring of children and adolescents QoL (p=<0.001).

Total mean scores of self-reports for PedsQL™ 4.0 GCS of children and adolescents were 78.8±15.6 compared to their parents 61±7.9 (t =24.671, p=< 0.001).Both children and adolescents self-reports and parent proxy reports for school and emotional functioning were coincide each other, there were relatively low scores when compare to other sub scale scores. About 35.5% and 35.8% of children and adolescents were scored below one standard deviation from the total self-reports of HRQoL of children and adolescents in school function and emotional function respectively. With Similar pattern about 41.9% and 43.7% children and adolescents were scored below one standard deviation from the total parent proxy reports of HRQoL of children and adolescents in school function and emotional function respectively. Relatively they had better scores in social function and physical function that about 22.7% and 27.9 % of children and adolescents were scored below one standard deviation from the total self-reports of HRQoL of children and adolescents in social function and physical function respectively.

Total mean scores of self-reports for total PedsQL™ 3.0 Diabetes Module scoring was 78.3±14.6, compared to parent proxy report was 60.5±7 (t=24.66, p=< 0.001.The score of children and adolescent in sub scale of treatment barriers, in worry and communication of DRQoL of children and adolescents were relatively lower. Relatively they had better score in treatment adherence and about diabetes sin and symptom. That's about 37.6%, 34.9%, 34.5%, 26.6% and 22.7% of children and adolescents were scored below one standard deviation from the total self-reports of DRQoL of children and adolescents in treatment barriers, in communication, in worry about what happen in future, in diabetes sin and symptoms and in treatment adherence respectively.

Table3: Compression of children and adolescents self-report and parent proxy reports of HRQoL and DRQoL of children and adolescents (mean ± Standard deviation), Addis Ababa, 2018

	Children and adolescents reports	Parent reports	t- test	P value
PedsQL GCS				
Physical function sub scale	81.9±19.6	63.6±10	19.14	< 0.001
Emotional functioning	75.6±19.5	58.3±11.7	18.1	< 0.001
Social functioning	85.8±18.8	64±11.6	25.5	< 0.001
School functioning	71.9±15.8	58.4± 8.9	18.5	< 0.001
Psychosocial function sub scale	77.8±15	60±8.3	25.3	< 0.001
Total QoL	78.8±15.6	61±7.9	24.7	< 0.001
PedsQL DM				
Diabetes symptoms	77.5±16	57.8±9.8	23.5	< 0.001
Treatment barriers	74±17.8	57.8±9.8	17.4	< 0.001
Treatment adherence	82±17.5	61.9±11	24.9	< 0.001
Worry	79 ±21	61.9±12.7	18.2	< 0.001
Communication	78.37±20.9	62.9±11	15.9	< 0.001
Total	78.3±14.6	60.5±7	24.7	< 0.001

GCS = Generic Core Scale; DM = Diabetes Module. Higher score indicate better quality of life

5.6. Multivariable linear regressions analysis of factor associated with HRQoL

In bivariate analysis, age group (t=04.233, p=0.00),sex of participants (t=2.061,p=0.041), number of children in the family (t=5.2,p=0.000),maternal educational level (t=3.108,p=0.002), father educational level (t=4.582,p=0.000),health education of diabetes(t = 4.262,p=0.000), blood glycemic level of children (t=9.525,p=0.000), monthly incomes of parents (t= -8.035, p=0.000), children hospital admission in the last six month (t=3.033,p=0.003) and frequency of admission (t=3.971,p=0.002) of children and adolescents were significantly associated to HRQoL of children and adolescents, thus, included in the multivariate analysis.

In multivariable linear regression analysis, female sex, number of children in the family, monthly income of parents, health education of diabetes, glycemic level and frequency of hospital admission of children and adolescents were an independent influencing factors for HRQoL scoring of children and adolescents which explain approximately to half of the variability of total HRQoL scores of children and adolescents (R2=0.493, F= 37.910, p<0.001).

Glycemic level, number of children in the family, health education of diabetes and monthly income of parents were an independent influencing factors of total HRQoL score and sub scale score of HRQoL of children and adolescents. Children and adolescents who had well controlled glycemic level had better score in all sub scale of physical functioning (β =17.57, p<0.001) emotional function (β =8.4, p<0.001), social function (β =13.48, p<0.001) school function (β =8.6 p<0.001) and total HRQoL (β=11.8 p<0.001) than children and adolescents who had no well controlled glycemic level.

Similarly monthly income of parents and health education of diabetes had significant positive association to HRQoL scoring of children. Children and adolescents who were a member of families having medium/high monthly income had better HRQoL score in all sub scale score of physical functioning (β =10.482, p<0.001), emotional function (β =12.2, p<0.001), social functioning (β =10.21, p<0.001), school function (β =3.99, p<0.05) and total HRQoL (β =9.432, p<0.001) than children and adolescents who were member of low monthly income families.

Regarding participation of children and adolescents in health education of diabetes, children and adolescents whom were participated in health education had better HRQoL score in all sub scale of physical functioning (β = 6.382 p<0.01), emotional functioning (β =5.966, p<0.01), social functioning (β = 6.28, p<0.01), school function (β =4.936, p<0.01) and total HRQoL scoring (β =5.92, p<0.001) than who were not participated in health education of diabetes..

On the other hand, number of children in the family and HRQoL score was negatively associated. Children and adolescents who were member of the family had more than four children had significantly lower HRQoL score in all sub scales of physical functioning (β= -2.371, p<0.05), emotional functioning (β= -3.916, p<0.05), social functioning (β = -3.916, p< 0.001), school functioning (β =-3.673, p<0.01) and total HRQoL score (β -2.92, p<0.01) than children and adolescents who were a member of family having less than four children.

Gender and frequency of hospital admission of children and adolescents were only an independent influencing factor of social functioning, school function and total HRQoL score. The female had significantly lower HRQoL scores in sub scale of social functioning (β = -3.944, p < 0.05), school function (β =-4758, p<0.01) and in a total HRQoL score (β= -3.643 p<0.05) than male participant. Similarly, children and adolescents who were admitted for two or more times in hospital in the last six months had poor HRQoL scores in sub scale of social function (β =-3.346, p <0.05), school function (β =-3.673, p<0.05) and total HRQoL sore (β =-2.614, p<0.05) than children and adolescents admitted once time only.

Table 3. Multivariable linear regression analysis of predictor of HRQoL and its β coefficients (95% confidence interval) of children and adolescent with diabetes, governmental hospitals, Addis Ababa, 2018.

	Items of generic quality of life report					
	Physical sub scale	Emotional function	Social function	School function	Psychosocial sub scale	Total
Sex (male=Ref)	- -	- -	-3.944 (-7.42, -.46)*	-4.758 (-8.3 , -1.18) *	-3.855 (-6.826 ,-.885) *	-3.643 (-6.587 -.699)*
No of children family (< 4 children=Ref)	-2.371 (-4.687 ,-.055) *	-2.773 (-5.352, -.19)*	-3.916 (-5.9 , -1.8) *	-3.673 (-5.784 -1.56)*	-3.177 (-4.9 , -1.4)*	-2.927 (-4.6 ,-1.3) *
Monthly income(low =Ref)	10.482 (6.46, 14.5)*	12.2 (7.7,16.7) *	10.21 (6.6 , 13.8) *	3.99 (.341,7.652) *	9.130 (6.1 , 12.2) *	9.432 (6.4, 12.4) *
Attend education during follow up (No=Ref)	6.382 (2.4, 10.4)*	5.966 (1.520,10.4)*	6.28 (2.76 , 9.8) *	4.936 (1.3 , 8.5) *	5.811 (2.809,8.8) *	5.92 (2.9, 8.9) *
Glycemic level (uncontrolled=Ref)	17.57 (13.5, 21.7) *	8.4 (3.8,12.9) *	13.48 (9.8 , 17.1) *	8.6 (4.8 , 12.3) *	10.06 (6.9 , 13.18) *	11.8 (8.7,14.9) *
Frequency of admission(<2=Ref)	- -	- -	-3.346 (-5.9 ,-.75) *	-3.673 (--5.4, -.092) *	-2.975 (-5.19 , -.76) *	-2.614 (-.42,-.28) *
R adjusted square	0.42	0.25	0.488	0.277	0.462	0.49

*= significant at p<0.05, Ref: indicates a category used as a standard reference.

5.7. Multivariable linear regression analysis of factor associated with DRQoL.

In bivariate analysis, age group (t=2.535,p=0.012),number of children in the family (3.966, p=0.000),monthly incomes of parents (t=-6.727,p=0.000),health education of diabetes (t=3.813,p=0.000),glycemic level (t=9.668.p=0.000), children hospital admission in the last six months (-4.186,p=0.000), father educational level (t=3.850,p=0.000) and maternal educational level (t=2.727,p=0.007) were significantly associated with DRQoL of children and adolescents. Thus , included in the multivariate analysis.

In multivariable regression analysis, number of children in the family, monthly incomes of the parents, participation of children in health education, glycemic control and frequency of hospital admission were independent influencing factors of DRQoL of children and adolescents. Those five determinant factors of DRQoL which explained near to half of the variability of DRQoL scoring of children and adolescents ($R2=0.453$, $F=38.823$, $p<0.001$).

Well controlled glycemic level, monthly income of parents and health education of diabetes like HRQoL, they had a statistical significant positive association with DRQoL.

Children and adolescents who had well controlled glycemic level was scored better DRQoL score in all sub scale score of diabetes symptom (β =10.085, $p<0.001$), treatment barrier (β=11.784, $p<0.001$), treatment adherence (β =10.975, $p<0.001$), worry about what happen in the future (β =15.047, $p<0.001$), communication to health profession (β =18.00, $p<0.001$) and total DRQoL sore (β =12.054, $p<0.001$) when compare to children and adolescents who had uncontrolled glycemic level. Similarly, children and adolescents whom were member of family had medium/high monthly incomes had better DRQoL score in all sub scale of diabetes symptom (β 9.262, $p<0.001$), treatment barrier (β=5.524, $p<0.05$, treatment adherence (β =8.291, $p<0.001$), worry about what happen in the future (β =6.766, $p<0.01$), communication sub scale (β =7.886, $p<0.01$) and total DRQoL sore (β =7.023, $p<0.001$) than children and adolescents from low monthly incomes family member.

Health education of diabetes for children and adolescents had statically significant positive association to total DRQoL score (β =4.836, $p<0.001$) but when it analyses separately it had no association in sub scale score of worry and communication. In other hand it had a significant positive relation in sub scale score of diabetes symptom (β =4.087$p<0.05$),

treatment barrier (β =5.105, p<0.05) and treatment adherence (β=7.450, p<0.001) of children and adolescents.

Frequency of children hospital admission had statically significant negative association to DRQoL. Children and adolescents who had two or more admission had lower scores in sub scale of diabetes symptom (β=-4.937,p<0.001), treatment barrier(β=3.314,p<0.05),treatment adherence (β=4.598,p<0.001),worry about what happen in future(β= -7.409,p<0.001) and total DRQoL score(β = -4.012,p<0.001) when compare to children and adolescents had only one admission in the last six month. But it had no effect on communication of children.

Age and gender were only independent influencing factors of treatment adherence and worry sub scale of DRQoL of children and adolescents respectively. The older children had better score in sub scale of treatment adherence (β =2.771, p<0.01) than younger children. Regarding the gender, females were worried (β =-5.761, p<0.05) when compared to males.

Table 4. Multivariable linear regression analysis of predictor of DRQoL and its β coefficients (95% confidence interval) of children and adolescent with [diabetes], governmental hospitals, Addis Ababa, 2018.

	Items of diabetes related quality of life					
Variables	Diabetes symptom	Treatment barriers	Treatment adherence	Worry	Communication	Total
Age (11-12)	-	-	2.771 (.788, 4.75)*	-	-	-
Sex (meal=Ref)	-	-	-	-5.761	-	-
	-	-	-	(-10.55,-.96)*	-	-
No of children family(<4 Ref)	-	-	-2.324 (-4.59, -.05) *	-	-	-1.768 (-3.46,-.071) *
	-	-				
Monthly income (low =Ref)	9.262 (5.6,12.8))*	5.524 (1.26, 9.7)*	8.291 (4.36, 12.2) *	6.766 (1.8, 11.6)*	7.886 (2.8 , 12.8)**	7.023 (4.1,9.96)*
Attend education during follow up(No=Ref)	4.087 (.50, 7.6) *	5.105 (.89, 9.3)*	7.450 (3.6 , 11.3) *	-	-	4.836 (1.9, 7.74)*
Glycemic level (uncontrolled= Ref)	10.085 (6.4, 13.7)*	11.784 (7.47,16.1) *	10.975 (6.9 , 14.9) *	15.047 (10.1, 20) *	18.000 (13.1, 22.9)***	12.054 (9.04,15.1)*
Frequency of admission(< 2 times=Ref)	-4.937 (-7.5, -2.3) *	-3.314 (-6.3, -.27)*	-4.598 (-7.4, -1.79) *	-7.409 (-10.9 , -3.8) *	-	-4.012 (-6.1,-1.89)*
Adjusted R square	0.33	0.22	0.33	0.29	0.21	0.45

*= significant at p<0.05, Ref: indicates a category used as a standard reference.

CHAPTER SIX

DISCUSSION

This study revealed that, children and adolescents scores in emotional and school function sub scale of HRQoL were low, reported in a similar pattern in both self-reports and parent proxy reports of HRQoL of children and adolescents and they had better score in social function sub scale scores which was in line with studies done in Turkey (47). Impaired emotional function might be due to their worry about long term complications of diabetes. On the other hand reduction in school function might be due to children and adolescents were missed class for hospital follow up or might be due to being unwell. The better scores in a social function sub scale might be the fact that in Ethiopian culture, every individual is wholehearted about patients and support their patients rather than isolating. So health professional, school community and parent must work integrally to improve emotional and school function of children and adolescents.

In this study self- reports of children and adolescents and parent proxy reports of HRQOL and DRQoL of children and adolescents were statically different ($P<0.001$), parent proxy reports of children and adolescents QoL were lower than self-reports of children and adolescents which was similar to previous studies finding Kuwait and Greek (20, 45). This might be explained by the burden of diabetes on parents, responsibilities and involvement of parents to their children forced them to perceive more likely than their children that diabetes influence their children's quality of life. This indicates that health professionals should not depend only on the information of care giver should be flexible to incorporate children's information in clinical practice.

In this study, age was not associated with HRQoL of children and adolescents which was consistent with studies done in Egypt (24) and Greek origin (50) and it was inconsistent with studies conducted in Kuwait (20) and Turkey (47) revealed that age was positively associated with HRQoL of children and adolescents and studies conducted in Saudi Arabiya (48) showed older age was associated with poorer HRQoL scoring. This might be explained related to parent supports of both young age and older age children. The fact that family supports and needs of children for support were different related to stage of development of children. Parent support should be provided at each stage of development of children and

should adjust faced a situation at each stage of development to improve QoL of children and adolescents(56).

In another way age was an independent influencing factor to treatment adherence sub scale score of DRQoL. Young age children should be getting special care from parents in self-managements of diabetes, they were scored lower in treatment adherence of DRQoL when compared to older children which was congruent with studies conducted in Kuwait (20), this might be explained as older aged children felt the devastating consequence of diabetes better than younger age children, so that they adhere better than young age children and older children cooperated better than young children in self-management of diabetes.

This study showed that gender was statistically significant predictors of children and adolescents total HRQoL. Females reported lower HRQoL scores compared to males. But when it analyzed in separate gender had no effect on subscale score of physical and emotional function of HRQoL. Which was in agreement with studies done in Saudi Arabiya and Kuwait(20, 48) and nd it was in contrary to studies conducted in Egypt and Greek that gender had no effect on HRQoL (24, 46). On the other hand gender was an independent influencing factor in the worry sub scale of DRQoL of children and adolescents.The females were worried than the male, which was consistent with studies done in Kuwait(20) with exception female had poor score in all sub scales and total DRQoL score in Kuwait. The possible justification might be due to females supposed to work in home, like caring young children and home activities this will limits time of peer play or it might be due to more social pressure and self-consciousness, related to marriage and future birthing as girls approach to puberty and adolescent.

In similar to study conducted in Zambia (51) this study showed that health education about diabetes had significant positive associations with QoL of children and adolescents with diabetes. Children and adolescents who were participating in health education were score better QoL than children and adolescent who was not participating in health education of diabetes. So health professional should provide health education on diabetes self-management and diabetes cares of children and adolescents to improve their QoL.

In this study, children and adolescents who had well controlled blood glucose level had statically significantly better scores in both HRQoL and DRQoL, this finding was in

agreement with previous studies (20, 23, 45, 47) and It was in contrary to previous studies (24, 30, 57) thus revealed that glycemic control had no effect on QoL. The result of the current study could be explained by the fact that children and adolescents who had well controlled blood glucose level was associated with a decrease in change in cognitive function , associated with less structural changes in the brain(58) and they had better academic performance (59) and they able to minimize the episode of common acute complication of DM of children and adolescents ,like hypoglycemia ,hyperglycemia and DKA. This implies that children and adolescents should monitor and manage their blood glucose level in a controlled range. A health professional should strength their education in diabetes self-management and parents must work integrally to improve their children QoL.

he other observed finding of this study was the monthly income of the parents had statically significant positive association with both HRQoL and DRQoL score of children and adolescents. Children and adolescents who were member of the family having medium or high monthly incomes were scored better QoL. Which was in line with studies conducted in Egypt (24) , this explained as having a good monthly income, enables family to pay the requested fee for medical laboratories, medication and enable them to purchase needed materials in diabetes self-managements, like glucometer to detect early warning sign of complication and to prevent any emerging complication of a disease. So that governmental or non-governmental organization must compensate children and adolescent who are family members having low monthly incomes.

This study showed that children and adolescents who had two or more hospital admission in the last six months had lower scores in both HRQoL and DRQoL than children and adolescents who were admitted less than two times in the last six months in the last six months. Children and adolescent should be monitoring their blood glucose level and health profession and parents must work, integrity to support admitted children and adolescents. This finding was contrary to study done Taranaki children indicated that more hospital admission was a predictor of better QoL scoring(6). The result of the current study might be due to children who had frequent hospital admission, they spent more time in hospital, so that they lost from class and have limited time for peer play or the admission might be due to by an upset problem of the disease itself. Children and adolescents must be monitored, controlled their blood glucose level, and prevent complication of diabetes.

The other observed finding of this study regarding family was the rise in the number of children in the family had statically significant negative association to QoL this was in line with finding conducted in Turkey(47), this might be due to siblings may not aware well about the impact of disease on their sister or brother or the rising in the number of children in family member may contribute to reducing of support from parents So sibling must have been incorporated in diabetics' education and children and adolescents should support from all family members.

CHAPTER SEVEN
STRENGTH AND LIMITATION

Strength

The strength of this study was, the data of the participants were obtained from three different hospitals of Addis Ababa which maximize representation of data. And the study use of both PedsQL™ 4.0 Generic Core Scales and the PedsQL™ 3.0 Diabetes Module tools and it looks both diseases related quality of life and generic health related quality of life of children and adolescents.

Limitation

The main limitation of this study was include: 1) this study had no control group to compare with the study group, 2) There are other determining factors of QoL which are not explored in this study such as family conflict, family relation.

CHAPTER EIGHT
CONCLUSION AND RECOMMENDATION

8.1. CONCLUSION

In conclusion, this study found that there was reduction of school function and emotional function and better score of social function and physical function of HRQoL of children and adolescents.

Similarly, there were lower score in treatment barriers, worry about what happen in future, and communication and better score in treatment adherence and disease symptom of DRQoL of children and adolescents.

This study also concludes that, well controlled blood glucose level, medium/high monthly incomes and health education of diabetes were an important predictor of better HRQoL and DRQoL sore among children and adolescents.

Having more hospital admission in the last six months and having raised a number of children in the family were an important predictor of impaired generic HRQoL and DRQoL score of children and adolescents.

Female gender was an influencing predictor of poor HRQoL scores.

8.2. RECOMMENDATIONS

Based on the result, this study will recommended to:

Health professional: Health education program about diabetes were encouraged and it should be sustainable and long lasting to improve quality of life of children and adolescents.

School community: Children and adolescents with diabetes must be supported from school, like preparing a tutorial for their missed class, making conducive environment for injection and checking of blood glucose monitoring.

Children's Parents: Children from large sibling should be incorporated in diabetes education, so that all take responsibility for diabetes care of their brother or sister.

Organization: Government and non-Government (NGO) organization must look for children and adolescents with diabetes, those are member of family have low monthly income and must prioritize them for compensation.

Researchers: There might be another factor which determines QoL beyond what we examined, this study recommend researcher to explore other factor.

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10. Annex

Annex I: Information sheet

Hello. My name is _____ and I am data collector of the study conducted by Desalegn Girma master's student at Addis Ababa university school of aliened health science , conducting this research for partial fulfillment of master's degree in child health nursing. We would very much appreciate your participation in this survey. The information you provide will help us to know quality of life and to improve quality of life of children /adolescents with diabetes. The interview takes between 10-20 minutes to complete. I shall also interview your child

Name of advisor; Mrs.Rajalaksh Mimurugan (Asst. professor, PhD Fellow) and Kalkidan Wondossen (MSC)

Name of the organization: Addis Ababa University, College of Health Sciences, Department Of Nursing and Midwifery.

Name of the Sponsor: Addis Ababa University

Title of the Research Project: assessment quality of life in children and adolescents with diabetes, governmental hospitals Addis Ababa, Ethiopia, 2018

Introduction: Information sheet , consent and assent form will be prepared for parents and children/adolescents respectively who attending service in endocrinology clinic who will be volunteer to participate in research project.

Purpose: The purpose of this study is to find out Quality Of Life of diabetic children. The information that you provide are very essential, not only for the successful accomplishment of the study but also for producing relevant information which will help in improving the provision of the service to diabetic children and adolescents.. I will provide research results to concerned body for intervention.

Procedure: **:** In order to achieve the above objective, information which is necessary for the study will be taken from children/adolescents with diabetes and their parents .Your responses will not be linked to you or the child and are completely anonymous and confidential. There are no right or wrong answers.

Risk/ Discomfort: By participating in this research project, you may feel that it has some discomfort especially on spending your time. We hope you will participate in the study for the

sake of the Benefit of the research result. I am Sure there is no risk in participating in this research project.

Benefits: there may not be direct benefit to you but your Participation is likely to help us in assessment of quality of lfe and asssosted factor in children and aldolesnt with diabetes so that it help to improve quality of life and healthcare service delivery in diabetic patients. You will not be provided any incentive or payment to take part in this project.

Alternative Procedures You may choose your child not to participate in this study and it will not affect the health care that will be provided to you

Confidentiality: The information collected from this research project will be kept confidential and All records and other information obtained will be kept strictly confidential and your child's protected health information will not be used without permission. All data collection tools will be identified by number or otherwise coded to protect any information that could be used to identify your child.

Number of Participants: 234 diabetic children school age up – 18 years. For all participants parent proxy report shall be obtained.

Voluntary Participation: It is up to you to decide whether your child takes part in this study. Refusal for participation for research has no penalty or loss of benefits to which your child is otherwise entitled. This will not affect your relationship with the investigators. If you are voluntery to give information for the study, you can show your willingness by saying "yes".

1. If yes, proceed to the next page 2. If no, thank you, and skip to the next participant

Name of data collector _____Signature of interviewer: -------Date: ----------/--------/---

If you have questions, complaints or concerns about this study, you can contact the principal investigator Desalegn Girma.Cell Phone; +251933704490, Email address: desegir@gmal.com.

Annex II: Consent and assent form

1. Consent form

I understand all conditions stated above. I have understood that Participation in this study is entirely voluntarily. I will tell that the answers to the questions will not be given to anyone else. If respondent does not agree to be interviewed, let those thanks and go to the next respondent. If respondent say "YES" continue.

1. Name of interviewer_____ Signature_____ date_____/_____/____

(Signature of interviewer certifying that respondent has given informed consent verbally)

2. Assent form (12-18 years)

Your parent has agreed that you take part in our study where we are looking at the quality of life of diabetic children. Your participation in the study is fully voluntarily. Any information you provide not be given to anyone else. If respondent does not agree to be interviewed, let those thanks and go to the next respondent. If respondent say "YES" continue

1. Name of interviewer_____ Signature_____ date_____/_____/____

(Signature of interviewer certifying that respondent has given informed consent verbally)

Annex III: English version of questionnaire

Tool I. Socio-Demographic and clinical related questioners

Direction: The following socio-demographic and medial related questioners are developed from different Literature. For each question parents will be participated if question is difficult for children to answer it.

	A .Socio-demographic Questioners	
No	Question	Coding Categories
101	What is the age of the child (Enter in the space)	_____ year
102	The child sex?	1. Male 2. Female
103	Family Setting: Who do you live with?	1. Lives with both parents 2. Lives with mother 3. Live with father 4. Others, specify_____
104	Number of children in family (enter space)	_____ number
105	What is the child mother educational level?	1. Unable to read & write 2. Read and Write 3. Grade 1-8 4. Grade 9-12 5. Above 12
106	What is the child father educational level?	1. Unable to read & write 2. Read and Write 3. Grade 1-8 4. Grade 9-12 5. Above 12
107	Occupation of the child mother/guardian	1. Unemployed 2. Government/private employee 3. Self employed 4. Other specify(_____)
108	Occupation of the child father/guardian	1. Unemployed 2. Government/private employee 3. Self employed 4. Other specify_____
109	What is the average family income per months?	_____ birr

	B .Clinical Related Questioners	
110	At what age was the patient diagnosed?	_____year or/month
111	How long has he/she been on medication/follow up	_____year or month
112	Have you ever attended diabetes education provided at this Hospital?	1. Yes 2. No
113	Which drug regimen you are following currently for your Diabetes?	1. Oral anti diabetic medications only 2. Insulin only 3. Insulin and oral anti diabetic medications
114	Who injects you?	1.self 2.parent 3.care giver
115	How many time do you inject per day?(Enter space)	_____ times/day
116	Previous FBS at least three times (Reviewed from card)	1 _____ mg/dl 2 _____mg/dl 3 _____mg/dl
117	Is HBA1C done, records at least three time (Reviewed from card)	1. _____% date taken_____ 2. _____%date taken _____ 3. _____%date taken _____
118	Have you been admitted in the previous 6 months?	1. yes 2. no
119	If your answer yes for above question, for how many time (enter space).	_____time/Number
120	Is there family history of have diabetes?	1. Yes 2. No

Tool II: PedQoL pediatric quality of life inventory generic version 4.0 (child / teen report)

Direction. On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month ,**0** if it is never a problem, **1** if it is almost never a problem ,**2** if it is sometimes a problem,**3** if it is often a problem,**4** if it is almost always a problem.

		Never	Almost Never	Some times	Often	Almost always
	ABOUT MY HEALTH AND ACTIVITIES (problems with…)					
1	It is hard for me to walk more than one block	0	1	2	3	4
2	It is hard for me to run	0	1	2	3	4
3	It is hard for me to do sports activity or exercise	0	1	2	3	4
4	It is hard for me to lift something heavy	0	1	2	3	4
5	It is hard for me to take a bath or shower by myself	0	1	2	3	4
6	It is hard for me to do chores around the house	0	1	2	3	4
7	I hurt or ache	0	1	2	3	4
8	I have low energy	0	1	2	3	4
	ABOUTMY FEELINGS (problems with…)					
1	I feel afraid or scared	0	1	2	3	4
2	I feel sad or blue	0	1	2	3	4
3	I feel angry	0	1	2	3	4
4	I have trouble sleeping	0	1	2	3	4
5	I worry about what will happen to me	0	1	2	3	4
	How I Get Along with Others *(PROBLEMS WITH…)*					
1	I have trouble getting along with other kids	0	1	2	3	4
2	Other kids do not want to be my friend	0	1	2	3	4
3	Other kids tease me	0	1	2	3	4
4	I cannot do things that other kids my age can do	0	1	2	3	4
5	It is hard to keep up when I play with other kids	0	1	2	3	4
	ABOUT SCHOOL (problems with...)					
1	I t is hard to pay attention in class	0	1	2	3	4
2	I forget things	0	1	2	3	4
3	I have trouble keeping up with schoolwork	0	1	2	3	4
4	I miss school because of being unwell	0	1	2	3	4
5	I miss school to go to the hospital	0	1	2	3	4

Tool II :.PedQoL pediatric quality of life inventory version 4.0 /parent report

Direction. On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each of them has been for your child during the past One month, **0** if it is never a problem, **1** if it is almost never a problem, 2 if it is sometimes a problem, **3** if it is often a problem, **4** if it is almost always a problem.

		Never	Almost Never	Some-times	Often	Almost always
Physical functioning (problems with…)						
1	walk more than one block	0	1	2	3	4
2	Running	0	1	2	3	4
3	Participating in sports activity or exercise	0	1	2	3	4
4	lift something heavy	0	1	2	3	4
5	take a bath or shower by him/her self	0	1	2	3	4
6	doing chores around the house	0	1	2	3	4
7	Having hurts or aches	0	1	2	3	4
8	low energy level	0	1	2	3	4
Emotional functioning						
1	Feeling afraid or scared	0	1	2	3	4
2	Feeling sad or blue	0	1	2	3	4
3	Feeling angry	0	1	2	3	4
4	trouble sleeping	0	1	2	3	4
5	worrying about what will happen to him or her	0	1	2	3	4
Social functioning						
1	Getting along with other kids	0	1	2	3	4
2	Other kids not wanting to be his or her friend	0	1	2	3	4
3	Getting teased by other	0	1	2	3	4
4	Not able to do thing that other kids do on his or her age	0	1	2	3	4
5	keep up when playing with other kids	0	1	2	3	4
School functioning						
1	pay attention in class	0	1	2	3	4
2	forgetting things	0	1	2	3	4
3	keeping up with schoolwork	0	1	2	3	4
4	Miss school because of being unwell	0	1	2	3	4
5	Missing school to go to the doctor/hospital	0	1	2	3	4

Tool III : PedQoL diabetic module version 3.0 (CHILD / TEEN REPORT)

Children with diabetes sometimes have special problems. On the following page is a list of things that might be a problem for you Please tell us how much of a problem each one has been for you during the past ONE month. **0** if it is never a problem, **1** if it is almost never a problem, 2 if it is sometimes a problem, **3** if it is often a problem, **4** if it is almost always a problem.

		Never	Almost never	Some times	Often	Almost always
	ABOUT MY DIABETES (problems with)					
1	I feel hungry	0	1	2	3	4
2	I feel thirsty	0	1	2	3	4
3	I have to go to the bathroom too often	0	1	2	3	4
4	I have stomachaches	0	1	2	3	4
5	I have headaches	0	1	2	3	4
6	I go "low"	0	1	2	3	4
7	I feel tired or fatigued	0	1	2	3	4
8	I get shaky	0	1	2	3	4
9	I get sweaty	0	1	2	3	4
0	I have trouble sleeping	0	1	2	3	4
11	I get irritable	0	1	2	3	4
	Treatment I (problem with)					
1	It hurts to prick my finger/give insulin shots	0	1	2	3	4
2	I am embarrassed about having diabetes	0	1	2	3	4
3	My parents and I argue about my diabetes care	0	1	2	3	4
4	It is hard for me to stick to my diabetes care plan	0	1	2	3	4
	TREATMENT - II (problems with)					
1	.It is hard for me to take glucose tests	0	1	2	3	4
2	It is hard for me to take insulin shots	0	1	2	3	4
3	It is hard for me to exercise	0	1	2	3	4
4	It is hard for me to keep track of carbohydrates	0	1	2	3	4
5	It is hard for me to wear my diabetic ID	0	1	2	3	4
6	It is hard for me to carry a fast acting carbohydrate	0	1	2	3	4
7	It is hard for me to eat snacks	0	1	2	3	4
	WORRY (problems with)					
1	I worry about 'going low'	0	1	2	3	4
2	I worry whether or not medical treatment are working	0	1	2	3	4
3	I worry about long term complications diabetes	0	1	2	3	4
	Communication(problem with)					
1	It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2	It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3	It is hard for me to explain my illness to other people	0	1	2	3	4

Tool III : PedQoL diabetic module version 3.0 (parent report)

Direction: Children with diabetes sometimes have special problems. On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each of them has been for your child during the past one month. **0** if it is never a problem, **1** if it is almost never a problem, **2** if it is sometimes a problem, **3** if it is often a problem, **4** if it is almost always a problem.

		Never	Almost never	Some times	often	Almost always
	ABOUT DIABETES (problems with)					
1	Feeling hungry	0	1	2	3	4
2	Feeling thirsty	0	1	2	3	4
3	Having to go to the bathroom too often	0	1	2	3	4
4	Having stomachaches	0	1	2	3	4
5	Having headaches	0	1	2	3	4
6	Going "low"	0	1	2	3	4
7	Feeling tired or fatigued	0	1	2	3	4
8	I get shaky	0	1	2	3	4
9	Getting sweaty	0	1	2	3	4
10	Having trouble sleeping	0	1	2	3	4
11	Getting irritable	0	1	2	3	4
	Treatment I (problem with)					
1	Needle sticks causing him/her pain	0	1	2	3	4
2	Getting embarrassed about having diabetes	0	1	2	3	4
3	Arguing with my spouse about diabetes care	0	1	2	3	4
4	Sticking to my diabetes care plan	0	1	2	3	4
	TREATMENT - II (problems with)					
1	It is hard for him /her to take glucose tests	0	1	2	3	4
2	It is hard for him/her to take insulin shots	0	1	2	3	4
3	It is hard for him /her to exercise	0	1	2	3	4
4	It is hard for him /her to keep track of carbohydrates	0	1	2	3	4
5	It is hard for me to wear my diabetic ID	0	1	2	3	4
6	It is hard for me to carry a fast acting carbohydrate	0	1	2	3	4
7	It is hard for him/her to eat snacks	0	1	2	3	4
	WORRY (problems with)					
1	Worrying about 'going low'	0	1	2	3	4
2	Worrying whether or not medical treatment are working	0	1	2	3	4
3	Worrying about long term complications diabetes	0	1	2	3	4
1	.It is hard for him /her to tell the doctors and nurses how he/she feeling	0	1	2	3	4
2	It is hard for him /her to ask the doctors and nurses questions	0	1	2	3	4
3	It is hard for her/him to explain my illness to other people	0	1	2	3	4

Annex 1V :<u>**ለጥናቱ ተሳታፊዎች የሚሰጥ መረጃ**</u>

ጤና ይስጥሌኝ፡ ስሜ ---------- ይባላል። እኔ በአዲስ አበባ ዩኒቨርስቲ ፣በጤና ሳይንስ ኮሌጅ ፤ በ ነርሲንግና በሚድዋይፈሪ ት/ክፍል ተማሪ በሆኑነት ደሳለኝ ግርማ አማካኝነት በሚከናወነው ጥናትና ምርምር ላይ መረጃ ሰብሳቢ ሁኜ እይሰራሁ እገኘዓለሁ፡፡ የእርሶዎንም ሆነ የእርሶዎ ልጅን ተሳትፎ በጣም እናበረታታለን ፡፡ እርሶዎም ሆኑ የእርሶዎ ልጅ የሚሰጡት መረጃ የስኳር ታማሚ ህፃናትንና የታዳጊ ወጣቶቶችን የህይወት ደረጃ ለማወቅና የህይወት ደረጃቸውን ለማሻሻል ይረዳል፡፡ ቃለ መጠይቁ ከ 10-20 ደቂቃ ሊፈጅ ይችላል፡፡ እርሶዎ ልጅዎ መረጃ እንዲሰጥ/እንድጥሰጥ ከፈቀዱለት/ላት ልጅወትንም ልንጠይቅ እንችላለን፡፡ ለጥናቱ መረጃ ለመስጠጥ ፈቃደኛ ከሆኑ ፈቃደናነቶዎን አዎ በማለት ሊገልጹልን ይችላሉ፡፡

የአማካሪዎች ስም፡ ራጃ ሙርጋን (**Asst. professor, PhD fellow**) እና ቃልኪዳን ወንዶሰን (**BSc, MSc**)
የተቋሙ ስም፡ አዲስ አበባ ዩኒቨርሲቲ፣ ጤና ሳይንስ ኮሌጅ፣ የነርሲግ እና ሚድዋይፈሪ ት/ክፍል
የድጋፍ ሰጪ ተቋም ስም፡ አዲስ አበባ ዩኒቨርሲቲ

የጥናቱ ርእስ፡ የስኳር ታማሚ ህጻናትን እና የታዳጊ ወጣቶችን የህይወት ደረጃ ምንነት የዳሰሳ ጥናት በአዲስ አበባ የመንግት ሆስታሎዎች ውስጥ 2010፡፡

መግቢያ፡ በስኳር ህመም ወደ መንግስት ሆስፒታሎች ለአገልግሎት/ለክትትል ለሚመጡ እና በጥናቱ ላይ ለመሳተፍ ፍቃደኛ ለሆኑ ወላጆች እና ለታዳጊ ወጣቶች የመረጃ እና የፈቃደኝነት ማረጋገጫ ቅጽ ተዘጋጅቷል፡፡

ዓላማ፡ ይህ ጥናት የስኳር ታማሚ ህጻናትን እና የታዳጊ ወጣቶችን የህይወት ደረጃ ምንነትን ለማወቅ ይረዳል፡፡ በተጨማሪም እርሶዎም ሆኑ ልጅዎ የሚሰጡን መረጃ ለጥናቱ መሳካት ብቻ ሳይሆን አገልግሎቱን ለማሻሻል፣ ለስኳር ታማሚ ህጻናት እና ለታዳጊ ወጣቶች ትክክለኛውን መረጃ ለመስጠጥም ከፍተኛ አስተዋጾ ይኖረዋል፡፡ በመጨረሻም የጥናቱ ውጤት ለሚመለከታቸው አካላት ይሰጣል፡፡

አካሔድ፡ ከላይ የጠተቀሰውን ዓላማ ለማሳካት አስፈላጊው መረጃ ከስኳር ታማሚ ህጻናት እና ታዳጊ ወጣቶች እንዲሁም ከወላጆቻቸው ይወሰዳል፡፡ የሚሰጡትን መረጃ በጠቅላላ በሚስጥር ኮድ ተደርጎ ለማንም ሳይሰጥ ታሽጎ ይቀመጣል፡፡

ጉዳት/ስጋት፡ በጥናቱ ላይ በመሳተፍ ግዚዎትን እንደምንሻሞዎት ሊሰሞት ይችላል፣ ሆኖም ግን የጥናቱ ውጤት ለሚያመጣው ለውጥ ብለው እንደሚሳተፉ እናምናለን፡፡ እንዲሁም በጥናቱ በመሳተፎ ምንም አይነት ጉዳት አያደርስቦትም፡፡

ጥቅም፡ ቀጥተኛ የሆነ ጥቅም በዚሁ ጥናት ላይ በመሳተፎ ላያገኙ ይችላሉ፡፡ ነገር ግን እርሶዎም ሆኑ ልጅዎ የሚሰጡን መረጃ የስኳር ታማሚ ህጻናትን እና የታዳጊ ወጣቶችን የህይወት ደረጃ ምንነትን ለማወቅም ሆነ አገልግሎቱን ለማሻሻል ይረዳል፡፡ በጥናቱ ላይ በመሳተፎ የተለየ ጥቅም ወይም ክፍያ አያገኙም፡፡

የተለየ አካሔድ፡ ልጅዎ በጥናቱ ላይ እንዳይሳተፍ የማድረግ ሙሉ መብት አሎት እንዲሁም በጥናቱ እንዳይሳተፍ በማድረጓዎ ለልጅዎ በሚሰጠው ማነኛውም አገልግሎት ላይ ተጽኖ አያመጣም፡፡

የተሳታፊዎች ቁጥር፡ 234 የስኳር ታማሚ ህጻናት እና ታዳጊ ወጣቶች ያካትታል፡፡በተጨማሪም ለሁሉም ተሳታፊዎች ከወላጆቻቸው ተጨማሪ መረጃም ይወሰዳል፡፡

ምስጢራዊነት፡ በዚሁ ጥናት ላይ የሚገኘው መረጃ በሙሉ ምስጢራዊነቱ ተጠብቆ ይቀመጣል፡፡ የእርሶዎም ሆነ ልጆዎ የሚሰጡን መረጃ በፍይል ከእርሶዎ ሆነ ከልጆዎ ስም ውጪ በኮድ ተደርጎ ይቀመጣል፡፡ በተጨማሪም ከጠናቱ ውጪ ለማንም ሰው አይሰጥም፡፡

በጥናቱ ያለመሳተፍ መብት፡ እርሶዎም ሆነ ልጆዎ በጥናቱ ያለመሳተፍ ሙለ መብት አለዎት፡፡ በጥናቱ ውስጥ ላሉ ጥያቄዎችም መልስ ያለመስጠት መብት አለዎት፡፡ በማንኛውም ግዜ ከጥናቱ ያለመሳተፍ መብት አለዎት፡፡ለጥናቱ መረጃ ለመስጠጥ ፈቃደኛ ከሆኑ ፈቃደናነቶዎን አዎ በማለት ሊገልጹልን ይችላሉ፡፡

1. አዎ ፤ ቃለመጠይቁ ይቀጥሉ፡
2. አይደለሁም፤ ቃለ መጠይቁን ያቋርጡ፡፡

የቃለ መጠይቁ ጠያቂው ስም ---------- ፊርማ ---------- ቀን----------

ተጨማሪ ጥያቄ ካለዎት በሚከተለው አድራሻ ያገኙናል፡፡

ደሳለኝ ግርማ፡ ስልክ፡ +251933704490 ኢሜል፡ desegir@gmail.com

Annex V <u>የፈቃድ እና የስምምነት መግለጫ ቅጽ</u>

1.የወላጅ ፈቃድ

ከላይ የተጠቀሱትን በሙሉ ተረድቻለሁ፡፡ በዚህ ጥናት ላይ የምሳተፈው በሙሉ ፈቃደኝነት ነው፡፡ እንደተነገረኝ ከሆነ የምሰጠው መልስ ለሌላ ለማንም ሰው አይሰጥም፤ እንዲሁም ስለኔ ማንነት ለማንም አይገለፅም፡፡ ስለሆነም በጥናቱ ላይ ለመሳተፍ ፍቃደኛ ነኝ፡፡ ተሳታፊዋ ፍቃደኛ ካልሆኑ አመስግነው ወደሚቀጥለው ተሳታፊ ይለፍ፡፡ ተሳታፊው ፍቃደኛ ከሆኑ ግን ይቀጥሉ፡፡

የጠያቂው ስም ---------- ፊርማ ---------- ቀን / /

(የቃለ መጠይቁ ጠያቂ ፊርማ፤ተሳተፊዉ፤ሙለ በሙለ፤ፍቃደኛ፤መሆኑን፤ያረጋግጣል)

2.የልጆቹ የስምምነት ቅጽ (12-18 ዓመት)

በስኳር የተጠቁ ህፃናትን የኑሮ ደረጃ የምንመለከትበት ጥናት ላይ እንዲሳተፉ ወላጆዎ ፈቅድውለታል፡፡ በዚህ ጥናት ላይ የምትሳተፈው/ፊው በሙሉ ፈቃደኝነት ነው፡፡ ማንኛውም መልስ ለሌላ ለማንም ሰው አይሰጥም፡፡ ተሳታፊዋ ፍቃደኛ ካልሆኑ አመስግነው ወደሚቀጥለው ተሳታፊ ይለፍ፡፡ተሳታፊው ፍቃደኛ ከሆኑ ግን ይቀጥሉ፡፡

የጠያቂው ስም ---------- ፊርማ ---------- ቀን / /

(የቃለ መጠይቁ ጠያቂ ፊርማ፤ተሳተፊዉ፤ሙለ በሙለ፤ፍቃደኛ፤መሆኑን፤ያረጋግጣል)

Annex VI: የአማረኛ መጠይቅ ቅጽ

ክፍል ፡ ማህበረሰባዊ እና ግላዊ ጥያቄዎች

መመሪያ: የሚከተሉት ማሕበራዊ እና የሕክምና ጥያቄዎች ለህጻናት የሚከብዱ ከሆነ ጥያቄው ላይ የሕጻናት ወላጆችም ሊጠየቁ ይችላሉ፡፡

ተ/ቁ	1. ማህበረሰባዊ እና ግላዊ ጥያቄዎች	
101	የህጻኑ/ኗ እድሜ ስንት ነው?	_____ዓመት
102	የህጻኑ/ኗ ፆታ	1. ወንድ 2. ሴት
103	ከማንጋርነውየምትኖረው/ሪው	1. ከአባቴናከእናቴጋር 2. ከአባቴጋርብቻ 3. ከእናቴጋርብቻ 4. ሌላግለጽ/ጭ_____
104	በቤተሰባችሁ ውስጥ ምን ያሕል ልጆዎች አሉ?	_____በቁጥር
105	የእናትህ/ሽ የትምህርት ደረጃ	1. ማንበብ እና መፃሐፍ የማትችል 2. ማንበብ እና መፃሐፍ የምትችል 3. ከ 1-8ኛ ክፍል የተማረች 4. ከ 9-12ኛ ክፍል የተማረች 5. 12ኛ እና ከዚያ በላይ የተማረች
106	የአባህ/ሽ ትምህርት ደረጃ	1. ማንበብ እና መፃሐፍ የማይችል 2. ማንበብ እና መፃሐፍ የሚችል 3. ከ 1-8ኛ ክፍል የተማረ 4. ከ 9-12ኛ ክፍል የተማረ 5. 12ኛ እና ከዚያ በላይ የተማረ
107	የእናትህ/ሽ የመተዳደሪያ ስራ ምንድ ነው	1. ስራ ዓጥ 2. የመንግስት/የግል ድርጅት ሰራተኛ 3. የግል ስራ 4. ሌላ ካለ ይጥቀሱ_____
108	የህጻኑ/ኗ አባት/አሳዳጊ የመተዳደሪያ ስራ ምንድ ነው	1. ስራ አጥ 2. የመንግስት/የግል ድርጅት ሰራተኛ. 3. የግል ስራ 4. ሌላ ካለ ይጥቀሱ_____

	2. የህክምና ሁኔታን በተመለከተ የሚጠየቁ ጥያቄዎች	
110	ለመጀመሪያ ጊዜ የስኳር ሕመምተኛ ነህ/ሽ ተብለህ/ሽ የተነገረህ/ሽ በስንት ዓመትህ/ሽ ነበር?	_____ዓመት
111	ለምን ያህል ግዜ የስኳር ህመም መድሃኒት ስትወስድ/ጂ ቆየህ/ሽ?	_____ዓመት
112	በዚህ ሆስፒታል የሚሰጠውን የስኳር ህመም ትምህርት ተከታትለው ያውቃሉ?	1. አዎ 2. አይለደም
113	ለስኳር ህመሞ የትኛው የመድሃኒት አይነት በአሁኑ ወቅት ይከታተላሉ?	1. በአፍ የሚወሰድ የፀረ ስኳር ህመም መድሃኒቶችን ብቻ 2. ኢንሱሊን ብቻ 3. ኢንሱሊን እና በአፍ የሚወሰድ የፀረ ስኳር ህመም መድሃኒቶች
114	ማነው የሚከትብህ/ሽ?	1. እራሴ 2. ወላጆቼ 3. እንቅብካቤ ሰጭዬ
115	በቀን ምን ያህል የኢንሱሊን ክትባት ትከተባለህ/ሽ	በቁጥር----------
116	የኤፍቢ ኤስን (FBS) ውጤትን ከካርድ ላይ በማየት፡ ካለ ቢያንስ ሶስት ጊዜ መዝግብ/ቢዬ	1. _____mg/dl, 2. _____mg/dl, 3. _____mg/dl
117	የሆሞግሎቢን ኤ ነሲ (HBA1C) ውጤትን ከካርድ ላይ በማየት፡ ካለ ቢያንስ ሶስት ጊዜ መዝግብ/ቢዬ	1. _____% 2. _____% 3. _____%
118	ባለፈው ስድስት ወር ውስጥ ለክሕምና በሆስፒታል ተኝተው ያቃሉ	1. አዎ 2. አይለደም
119	ለጥያቄ ቁ 120፡ መልሶዎ አዎ ከሆን ለምን ያህል ጊዜ ተኝቶ/ሽ ነበር	_____ጊዜ
120	በቤተሰባችሁ ውስጥ የስኳር ህመም የነበረበት/ባት አባል አለ/ች	1. አዎ 2. የለም

<u>ክፍሌ 2</u>: <u>የህፃናት ህክምና የህይወት ደረጃ የቆጠራ አጠቃላይ ቅጽ 4.0 (ህፃን/ታዳጊ ወጣት ሪፖርት)</u>

መመሪያ: በሚከተለው ቅጽ ውስጥ ችግር ተብለው የሚገመቱ ችግሮች ተዘርዝለዋል፡ ባለፈው አንድ ወር ውስጥ ችግሮቹ ምን ያህል እንደተከሰቱ በሚከተለው *መመሪያ* መሰረት ችግር ፈጽሞ ከሌለ **0**፤ ችግር በዝቅተኛ ደረጃ የሚገኝ ከሆነ **1**፤ አልፎ አልፎ ችግር ካለ **2**፤ ሁልጊዜ ችግር ካለ **3**፣ ሁልጊዜ በሚባል ደረጃ ችግር ካለ **4** በማለት ክበቡ

		ችግሩ ፈጽሞ የለም	ችግሩ በዝቅተኛ ደረጃ አለ	ችግሩ አልፎ አልፎ አለ	ችግሩ ሁላ ጊዜ አለ	ችግሩ ሁላ ጊዜ በሚባል ደረጃ አለ
ስለአካላዊ እንቅስቃሴን (ስለ አሉብኝ ችግሮች)						
1	ከ 1 ደረጃ በላይ በእግሬ መራመድ ይከብደኛል፤	0	1	2	3	4
2	መሮጥ ይከበደኛል፤	0	1	2	3	4
3	የአካል ማነልመሻ እንቅስቃሴ ወይም የሰውነት እንቅስቃሴማድረግ ይከብደኛል፤	0	1	2	3	4
4	ከባድ ነገር ማንሳት ለእኔ ከባድ ነው፤	0	1	2	3	4
5	እራሴን ችዬ ሻወር መውሰድ ወይም ሰውነቴን መታጠብ ይከብደኛል፤	0	1	2	3	4
6	ቤት ውስጥ ስራዎችን ማከናወን ይከብደኛል፤	0	1	2	3	4
7	የአካል እንቅስቃሴ ማከናወን / ማድረግ እጠላለሁ፤	0	1	2	3	4
8	አቅም በጣም ያንሰኛል፤	0	1	2	3	4
ስለ ስሜቶቼ (ስለ አሉብኝ ችግሮች)						
1	እፈራለሁ፤	0	1	2	3	4
2	አዝናለሁ	0	1	2	3	4
3	እቆጣለሁ	0	1	2	3	4
4	የመተኛት ችግር አለብኝ፤	0	1	2	3	4
5	ምን ያጋጥመኝ ይሆናል ብዬ እሰጋለሁ፤	0	1	2	3	4
ስለ ማህበራዊ መስተጋብር (ስለ አሉብኝ ችግሮች)						
1	ከሌሌች ህፃናት ጋራ አብሮ የመሆን ችግር አለብኝ፤	0	1	2	3	4
2	ሌሎች ህፃናት የእኔ ጓደኛ መሆን አይፈልጉም፤	0	1	2	3	4
3	ሌሎች ህፃናት ያፌዙብኛል፤	0	1	2	3	4
4	በእኔ እድሜ ክልል ውስጥ የሚገኙ ሌሎች ህፃናት የሚሰሯቸውን ስራዎች መስራት አልችልም፤	0	1	2	3	4
5	ከሌሎች ህፃናት ጋር ስጫወት እንደ እነሱ መቀጠል ይከብደኛል፤	0	1	2	3	4
ስለ ትምህርት ቤት (ስለ ሚገጥሙኝ ችግሮች)						
1	በክፍል ውስጥ ትኩረት ሰጥቶ መከታተል ይከብደኛል፤	0	1	2	3	4
2	ነገሮችን እረሳለሁ፤	0	1	2	3	4
3	የትምህርት ቤት ስራን የማስቀጠል ችግር አለብኝ፤	0	1	2	3	4
4	ጤናዬ በመጓደሉ የተነሳ ከትምህርት ቤት እቀራለሁ፤	0	1	2	3	4
5	ወደ ሆስፒታል በመሄድ በሚል ከትምህርት ቤት እቀራለሁ፤	0	1	2	3	4

<u>ክፍሌ 2</u>፡ የህፃናት ህክምና የህይወት ደረጃ የቆጠራ አጠቃላይ ቅጽ 4.0 (በወላጆች ሪፖርት የሚደረግ)

መመሪያ: በሚከተለው ቅጽ ውስጥ ችግር ተብለው የምገመቱ ችግሮች ተዘርዝለዋል፡፡ በባለፈው አንድ ወር ዉስጥ በልጅወት ላይ ምን ያህል ችግሮች እንደተስተዋሉ ይናገሩ፡፡ ችግር ፈጽሞ ከሌለ **0**፣ ችግር በዝቅተኛ ደረጃ የሚገኝ ከሆነ **1**፣ አልፎ አልፎ ችግር ካለ **2**፣ ሁልጊዜ ችግር ካለ **3**፣ ሁልጊዜ በሚባል ደረጃ ችግር ካለ **4**

		ችግሩ ፈጽሞ የለም	ችግሩ በጣም ዝቅተኛ ደረጃ ነው	ችግሩ አልፎ አልፎ ነው	ችግሩ ሁሌ ነው	ችግሩ ሁሌም በጣም ከፍተኛ ደረጃ ነው
ስለአካላዊ እንቅስቃሴ (ልጅዎ ያለበት/ባት ችግር)						
1	ልጅዎ ከ 1 ደረጃ በላይ በእግሩ/ሮዋ መራመድ ይከብደዋል/ዳታል	0	1	2	3	4
2	ልጅዎ መሮጥ ይከብደዋል/ዳታል	0	1	2	3	4
3	ልጅዎ የአካል ማነልመሻ እንቅስቃሴ ወይም የሰውነት እንቅስቃሴ ይከብደዋል/ዳታል	0	1	2	3	4
4	ልጅዎ ከባድ ነገር ማንሳት ለእሱ/ሳ ይከብደዋል/ዳታል	0	1	2	3	4
5	ልጅዎ እራሱ/ሷን ችሎ/ላ ሻወር መውሰድ ወይም ሰውነቱን/ታን መታጠብ ይከብደዋል/ዳታል	0	1	2	3	4
6	ልጅዎ ቤት ውስጥ ስራዎችን ማከናወን ይከብደዋል/ዳታል	0	1	2	3	4
7	ልጅዎ የአካል እንቅስቃሴ ማከናወን / ማድረግ ይጠላል/ትጠላለች፤	0	1	2	3	4
8	ልጅዎ አቅም በጣም ያንሰዋል/ሳታል ፤	0	1	2	3	4
ስለልጅዎ ስሜት ያሉ ችግሮች						
1	ልጅዎ ይፈራል/ትፈለች ፤	0	1	2	3	4
2	ልጅዎ ያዝናል/ታዝናለች	0	1	2	3	4
3	ልጅዎ ይቆጣል/ትቆጣለች	0	1	2	3	4
4	ልጅዎ የመተኛት ችግር አለበት/ባት፤	0	1	2	3	4
5	ልጅዎ ምን ያጋጥመኝ ይሆናል ብሎ/ላ ይሰጋል/ትሰጋለች፤	0	1	2	3	4
ስለ ማህበራዊ መስተጋብር ልጅዎ ያለበት ችግሮች						
1	ልጅዎ ከሌሌች ህፃናት ጋራ አብሮ/ራ የመሆን ችግር አለበት/ባት ብለው ያስባሉ፤	0	1	2	3	4
2	ሌሎች ህፃናት የልጅዎ ጓደኛ መሆን አይፈልጉም ብለው ያስባሉ፤	0	1	2	3	4
3	ልጅዎ ሌሎች ህፃናት ያፌዙበታል/ባታል ብለው ያስባሉ፤	0	1	2	3	4
4	ልጅዎ እድሜ ክልል ውስጥ የሚገኙ ሌሎች ህፃናት የሚሰሯቸውን ስራዎች መስራት አይችልም/አትችልም ብለው ያስባሉ፤	0	1	2	3	4
5	ልጅዎ ከሌሎች ህፃናት ጋር ሲጫወት/ስትጫዎት እንደ እነሱ መቀጠል ይከብደዋል/ዳታል ብለው ያስባሉ፤	0	1	2	3	4
ስለ ትምህርት ቤት ልጅዎ ያለበት/ባት ችግሮች)						
1	ልጅዎ ክፍል ውስጥ ትኩረት ሰጥቶ መከታተል ይሳነዋል/ናታል ብለው ያስባሉ፤	0	1	2	3	4
2	ልጅዎ ነገሮችን ትረሳለች/ይረሳል፤	0	1	2	3	4
3	ልጅዎ የትምህርት ቤት ስራን የማስቀጠል ችግር አለበት/ባታ፤	0	1	2	3	4
4	ልጅዎ ጤናው/ዋ በመጓደሉ የተነሳ ከትምህርት ቤት ይቀራል/ትቀራለች፤	0	1	2	3	4
5	ልጅዎ ወደ ሆስፒታል በመሄድ በሚል ከትምህርት ቤት ይቀራል/ለች፤	0	1	2	3	4

ክፍሌ 3፡ የስኳር ህመም ላይ የሚገኙ ሰዎች ህይወት ደረጃ በህፃናት ህክምና እይታ ሞጁል ቅጽ 3.0 (ህፃን/ታዳጊ ወጣት ሪፖርት የሚደረግ)

መመሪያ: ታዳጊ ህጽናቶችና ታዳጊ ወጣቶች አንዳንድ ገዜ ከስኳር ህመም ጋር ተያይዞ የተለየ የሚያጋጥሙ ችግሮች ሊኖሩ ይችላሉ፡፡ ከነዚህ ዉስጥ በሚከተለው ቅጽ ውስጥ ተዘርዝረዋል፡፡ ባንተ/ች ላይ ያሉ ችግሮች ባለፈው አንድ ወር ውስጥ ምን ያህሎቹ እንደተከሰቱ በሚከተለው መመሪያ መሰረት ይናገሩ፡፡ ችግር ፈጽሞ ከሌለ 0፣ ችግር በዝቅተኛ ደረጃ የሚገኝ ከሆነ 1፣ አልፎ አልፎ ችግር ካለ 2፣ ሁልጊዜ ችግር ካለ 3፣ ሁልጊዜ በሚባል ደረጃ ችግር ካለ 4

		ችግሩ ፈጽሞ የለም	ችግሩ በዝቅተኛ ደረጃ አለ	ችግሩ አልፎ አልፎ አለ	ችግሩ ሁላ ጊዜ አለ	ችግሩ ሁላ ጊዜ በሚባል ደረጃ አለ
	ስለ እኔ ስኳር ህመም (ስላሉብኝ ችግር)					
1	ይርበኛል፤	0	1	2	3	4
2	ይጠማኛል፤	0	1	2	3	4
3	አብዝቼ ወደ መፀዳጃ ቤት እሄዳለሁ፤	0	1	2	3	4
4	የሆድ ህመሞች አሉብኝ፤	0	1	2	3	4
5	የራስ ምታት አለብኝ፤	0	1	2	3	4
6	እራሴን መቆጣጠር ይሳነኛል፤	0	1	2	3	4
7	ይደክመኛል፤	0	1	2	3	4
8	ያንቀጠቅጠኛል፤	0	1	2	3	4
9	ያልበኛል፤	0	1	2	3	4
10	የመተኛት ችግር አለብኝ፤	0	1	2	3	4
11	እነጫነጫለሁ፤	0	1	2	3	4
	ህክምና 1- (ያሉብኝ ችግሮች)					
1	የኢንሱሊን መርፌ መውሰድ እጠላለሁ፤	0	1	2	3	4
2	የስኳር ህመምተኛ በመሆኔ ያበሳጨኛል፤	0	1	2	3	4
3	ወላጆቼ እና እኔ ስለ ስኳር ህመም እንክብካቤ እንጨቃጨቃለን፤	0	1	2	3	4
4	የስኳር ህመም እንክብካቤ እቅዴን ማስቀጠል ይከብደኛል፤	0	1	2	3	4
	ህክምና 11- (ያሉብኝ ችግሮች)					
1	የጉልኮስ ምርመራ ማድረግ ይከብደኛል፤	0	1	2	3	4
2	ኢንሱሊንበ አግባቡ መውሰድ ይከብደኛል፤	0	1	2	3	4
3	የአካል እንቅስቃሴን ማድረግ ይከብደኛል፤	0	1	2	3	4
4	ሐይል ሰጪ ምግቦችን በአግባቡ መውሰድ ይከብደኛል፤	0	1	2	3	4
5	የስኳር ህመምተኛ መታወቂያዬን ማድረግ ይከብደኛል፤	0	1	2	3	4
6	ፈጣን ሐይል ሰጪ መያዝ ይከብደኛል፤	0	1	2	3	4
7	መክሰሴን መውሰድ/መብላት ይከብደኛል፤	0	1	2	3	4
	ጭንቀት (ያለብኝ ችግር)					
1	እራሴን መቆጣጠር ይሳነኛል ብዬ እጨነቃለሁ	0	1	2	3	4
2	የህክምና ምርመራዎች መፍትሄ አየስገኙ/አይስጡም እንደው ብዬ እሰጋለሁ፤	0	1	2	3	4
3	ስለ ስኳር ህመም የረጅም ዘመን ችግር እጨነቃለሁ፤	0	1	2	3	4
	ግንኙነት (ያለብኝ ችግር)					
1	ለዶክተሮች እና ለነርሶች ምን እንደሚሰማኝ ለመናገር እቸገራለሁ፤	0	1	2	3	4
2	ዶክተሮች እና ነርሶችን ጥያቄ ለመጠየቅ እቸገራለሁ፤	0	1	2	3	4
3	ህመሜን ለሌሎች ሰዎች ለማብራራት እቸገራለሁ ፤	0	1	2	3	4

ክፍሌ 3፡ የስኳር ህመም ላይ የሚገኙ ሰዎች ህይወት ደረጃ በህፃናት ህክምና እይታ ሞጁል ቅጽ 3.0(በወላጅ የሚሞላ)

መመሪያ: ታዳጊ ህፃናቶችና ታዳጊ ወጣቶች አንዳንድ ገዜ ከስኳር ህመም ጋር ተያይዞ የተለየ የሚያጋጥሙ ችግሮች ሊኖሩ ይችላሉ::ከነዚህ ዉስጥ በሚከተለው ቅጽ ውስጥ ተዘርዝረዋል:: በባለፈው አንድ ወር ዉስጥ በልጅዎት ላይ ምን ያህሎቹ ችግሮች እንደተስተዋሉ ይናገሩ::ችግር ፈጽሞ ከሌለ **0**፣ ችግር በዝቅተኛ ደረጃ የሚገኝ ከሆነ **1**፣ አልፎ አልፎ ችግር ካለ **2**፣ ሁልጊዜ ችግር ካለ **3**፣ ሁልጊዜ በሚባል ደረጃ ችግር ካለ **4** ብለው ይሙሉ::

		ችግሩ ፈጽሞ የለም	ችግሩ በዝቅተኛ ደረጃ አለ	ችግሩ አልፎ አልፎ አለ	ችግሩ ገዜ አለ	ችግሩ ሁልጊዜ ማለት በሚባል ደረጃ አለ
ስለ ስኳር ህመም (ልጅዎ ስላለበት/ባት ችግር)						
1	ልጅዎ ይርበዋል/ታል፤	0	1	2	3	4
2	ልጅዎ ይጠማዋል/ታል፤	0	1	2	3	4
3	ልጅዎ አብዝቶ/ታ ወደ መፀዳጃ ቤት ይሄዳል /ትሄዳለች፤	0	1	2	3	4
4	የሆድ ህመም አለበት/አሉባት፤	0	1	2	3	4
5	ልጅዎ የራስ ምታት አለበት/ባት፤	0	1	2	3	4
6	ልጅዎ እራሱን/ሷን መቆጣጠር ይሳነዋል/ናታል፤	0	1	2	3	4
7	ልጅዎ ይደክመዋል/ታል፤	0	1	2	3	4
8	ልጅዎ ያንቀጠቅጠዋል/ታል፤	0	1	2	3	4
9	ልጅዎ ያልበዋል/ታል፤	0	1	2	3	4
10	ልጅዎ የመተኛት ችግር አለበት/ባት፤	0	1	2	3	4
11	ልጅዎ ይነጫነጫል/ትነጫነጫለች፤	0	1	2	3	4
ህክምና 1-(ልጅዎ ያለበት/ባት / ችግሮች)						
1	ልጅዎ ኢንሱሊን ሲሰጠው/ጣት ህመም ይሰማዋል/ታል፤	0	1	2	3	4
2	ልጅዎ የስኳር ህመምተኛ በመሆኑ/ና ያበሳጫዋል/ታል/፤	0	1	2	3	4
3	ስለ ልጅዎ ስኳር ህመም እንክብካቤ ከባለቤቴጋር ትጨቃጨቃላችሁ፤	0	1	2	3	4
4	ልጅዎ የስኳር ህመም እንክብካቤ እቅዱን/ዳን ማስቀጠል ይከብደዋል/ይከብዳታል፤	0	1	2	3	4
ህክምና 11- (ልጅወት ያሉበት/ባት ችግሮች)						
1	ልጅዎ የጉልኮስ ምርመራ ማድረግ ይከብደዋል /ይከብዳታል፤፤	0	1	2	3	4
2	ልጅዎ ኢንሱሊን መውሰድ ይከብደዋል/ይከብዳታል፤	0	1	2	3	4
3	ልጅዎ የአካል እንቅስቃሴን ማድረግ ይከብደዋል/ ይከብዳታል፤	0	1	2	3	4
4	ልጅዎ ሀይል ሰጪ ምግቦችን በተገቢው ሰዓት መወሰድ ይከብደዋል/ይከብዳታል፤	0	1	2	3	4
5	ልጅዎ የስኳር ህመምተኛመታ ወቂያዬን ማድረግይ ይከብደዋል/ይከብዳታል፤	0	1	2	3	4
6	ልጅዎ ፈጣን ሀይል ሰጪ ምግቦችን መያዝ ይከብደዋል/ይከብዳታል፤	0	1	2	3	4
7	ልጅዎ በተገቢው ሰዓት መክሰስ መብላት ይከብደዋል/ ይከብዳታል፤	0	1	2	3	4
	ጭንቀት (ልጅወት ያሉበት/ባት ችግሮች)					
1	ልጅዎ እራሴን መቆጣጠር ይሳነኛል ብሎ/ላ ይጨነቃል/ትጨነቃለች	0	1	2	3	4
2	ልጅዎ የህክምና ምርመራዎች መፍትሄ አየስገኙ/አይስጡም እንደው ብሎ/ላ ይሰጋል/ትሰጋለች፤	0	1	2	3	4
3	ልጅዎ ስለ ስኳር ህመም የረጅም ዘመን ችግር ይጨነቃል/ትጨነቃለች፤	0	1	2	3	4
	ስለ ግንኙነት ልጅዎ ያለበት/ባት ችግር					
1	ልጅዎ ለዶክተሮች እና ለነርሶች ምን እንደሚሰማዉ/ት ለመናገር ይቸገራል /ትቸገራለች ብለው ያስባሉ፤	0	1	2	3	4
2	ልጅዎ ዶክተሮች እና ነርሶችን ጥያቄ ለመጠየቅ ይቸገራል /ትቸገራለች ብለው ያስባሉ	0	1	2	3	4
3	ልጅዎ ህመሙን/ማን ለሌሎች ሰዎች ለማብራራት ይቸገራል /ትቸገራለች ብለው ያስባሉ፤	0	1	2	3	4