ASSESSMENT OF PARENTS' PERCEPTIONS REGARDING QUALITY OF PEDIATRICS DIABETIC CARE IN JIMMA UNIVERSITY MEDICAL CENTER

BY

SHEGITU MIRESSA (Pediatric Resident)

A RESEARCH THESIS TO BE SUBMITTED TO THE DEPARTMENT OF PEDIATRICS, FACULTY OF MEDICINE,JIMMA UNIVERSITY; IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR SPECIALITY IN PEDIATRICS (MEDICAL DOCTOR)

SEPTEMBER, 2017

JIMMA, ETHIOPIA

JIMMA UNIVERSITY

INSTITUTE OF HEALTH SCIENCE

FACULTY OF MEDICINE

DEPARTMENT OF PEDIATRICS

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Abstract

Background: *Standardized pediatrics diabetic care supported by family education is vital for the control of diabetes and prevention or delay of long-term complications among diabetic pediatrics. Though significant number of pediatrics is living with diabetes in Ethiopia, little is known about the perception of parents regarding quality of pediatrics diabetes care.*

Objective: *The objective of this study was to assess parents' perception regarding quality of pediatric diabetic care in Jimma University Medical Centre (JUMC).*

Methodology: *Institution based cross-sectional study design was conducted from May 1 to June 30, 2017 at JUMC. All parents coming to the hospital with their kids were included in the study. Data were collected by using face-to-phase interview and document review for relevant clinical profiles. The data were checked, entered, and analyzed by using Epidata manager and SPSS 20 statistical packages. Descriptive statistics were used for relevant variables. Whereas, logistic regression was done to identify factors associated with perceived quality of pediatrics diabetic care in study area. A significance level (α) of 0.05 was used in all cases. Finally, the results were summarized and presented by tables, charts, graphs and statements.*

Result: *Total of 110 parents were interviewed with a response rate of 80%. The mean age of the pediatric diabetics was 11.7 ± 2.9year. The mean score of overall quality of diabetic care reported by parents was 48.58 ± 11.31. The overall quality of pediatric diabetic care score achieved above the mean score is 54.5%. According to one item that measures the overall quality of diabetic care, 59.1% of parents reported that the overall quality of pediatrics diabetic care was of high quality. Of the total items of organizations and consultation, the high quality of diabetic care was reported by 59.1% and 62.7% regarding the ease of making new appointments and with the value of the services that their child's caregiver provided respectively. Among diabetes clinical care variables, the regression analysis indicated good counseling on health nutrition(AOR=18.48; P = 0.001), receiving medication review in the past 12 months (AOR=.030; p-value=.013) and ongoing structured on insulin therapy (AOR=16.31; P=0.038), management of psychological problems (OR= 15.06; p-value=.029) and access to a specialist diabetes team (AOR=36.11; P=0.001,) were independent significant predicators of high overall perception score for quality of diabetic care.*

Conclusion: *Significant proportion of parents perceived the overall quality of service provision as low quality. Good counseling on health nutrition, receiving medication review in the past 12 months, ongoing structured on insulin therapy, management of psychological problems and access to a specialist diabetes team were the most significant factors attributed to higher quality of overall pediatrics diabetic care.*

Recommendations: *For the improvement of the overall quality of pediatrics diabetic care the hospital should have an organized specialist diabetes team including trained physicians and nurses. Further qualitative research is needed for exploring the needs and parents' contribution in the improvement of quality of pediatrics diabetic care.*

Key words: *Diabetes, Children, parents' perception, Quality of care, JUMC*

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List of abbreviations and Acronyms

ADA	American diabetes association
CI	Confidence Interval
DCCT	Diabetes control and complication trials
DM	Diabetes mellitus
FBG	Fasting blood glucose
HbA1c	Hemoglobin A1c
IDF	International diabetes federation
IDDM	Insulin dependent diabetes mellitus
QOC	Quality of care
SD	Standard Deviation
SMBG	Self- monitoring of Blood Glucose
T1DM	Type 1 diabetes mellitus
WHO	World health organization

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CHAPTER ONE: INTRODUCTION

1.1 Background

Diabetes mellitus (DM) is "a group of metabolic disorders characterized by hyperglycemia with disturbance in carbohydrate, protein and fat metabolism resulting from defects in insulin secretion, insulin action or both (1)''.

There are four classifications of diabetes mellitus, namely: type 1, type 2, gestational diabetes mellitus, and other specific types of diabetes. Type 1 and type 2 diabetes mellitus are the major and more common types of diabetes mellitus. Three-quarters of all cases of type1 diabetes are diagnosed in individuals <18years of age. Type 1 DM is characterized by beta-cell destruction often leading to absolute insulin deficiency (2, 3) while type 2 diabetes mellitus (type 2 DM) is characterized by a relative insulin deficiency resulting from a reduced sensitivity of tissues to insulin and impairment of insulin secretion from pancreatic ß-cells (4).

Type 1 diabetes accounts for 5 to 10 percent of all diagnosed cases of diabetes and is the type found most frequently in children. It is the most common chronic disease of childhood, exceeded only by asthma (5).

When a child or adolescent is diagnosed with diabetes, all of a sudden everyday life involves multiple injections of insulin. Because of the need to monitor blood glucose several times a day, modification of meals and engagement in activities, diabetes management affects the life of the child or adolescent, family, teachers and friends (6).

1.2 Statement of the Problem

Diabetes is a significant and growing health problem worldwide with 80% of diabetic patients living in low and middle-income countries (1, 7).The International Diabetes Federation estimated that 79,100 children under 15 years are estimated to develop type 1 diabetes annually worldwide. Of the estimated, 26% live in the Europe, where the most reliable and up-to-date estimates of incidence are available, and 22% in the North America and Caribbean region (8).

Diabetes mellitus is also an important problem in Africa. The highest prevalence of diabetes in the Africa region is on the island of Réunion (15.4%), followed by Seychelles (12.1%), Gabon (10.7%) and Zimbabwe (9.7%). Some of Africa's most populous countries have the highest numbers of people with diabetes, including: Nigeria (3.9 million), South Africa (2.6 million), Ethiopia (1.9 million), and the United Republic of Tanzania (1.7 million). However, data to estimate the numbers of children with type 1 diabetes remain very scarce (8).

In spite of modern insulin treatment and individual education, diabetes prevalence is alarmingly increasing (9, 10) often accompanied by various chronic and acute complications that may affect the productivity and quality of life inevitably (10). Severe hypoglycemia and diabetic ketoacidosis remain serious diabetic complications in children and adolescents. An individual with type 1 diabetes is at increased risk of developing many serious long-term health complications, including blindness, nerve damage, cardiovascular and kidney disease. In the absence of any effective means of curing type 1 diabetes, the health service has to provide high-quality care. Quality of diabetes care is usually measured and reported as the level of glycated hemoglobin (HbA1c) (6,11).

The paradigm that underlies the measurement of quality of care is that of Avedis Donabedian (12, 13), who divided quality of care into three structural categories: 1) structure of care – the relatively stable characteristics of the provider, i.e. equipment, resources, and the physical and organizational settings (e.g. hospital facility, staffing ratios); 2) process of care – what is actually done in the process of giving and receiving care (e.g. patient seeking care, practitioner defining diagnosis, recommending treatment); and 3) outcome – the effect on the health status of the patient (e.g. medical complications, health-related quality of life), patient knowledge, and the level of patient satisfaction (14).

Quality of care, defined by the Institutes of Medicine as healthcare that is 'safe, effective, patient-centered, timely, efficient and equitable'(15). This means that patients and healthcare providers must be well involved in the process of defining, measuring and improving quality of care (16).

Process of care of patients with diabetes is complex which requires extensive self-care and comprehensive knowledge (17), frequent self-monitoring of blood glucose, exercise, dietary modifications and administration of medications and/ or insulin on schedule (18). Non-adherence to prescribed treatment schedule continues to be a major problem of the world, especially for medications in chronic diseases (19).

Parents of children with T1DM have to assume great responsibility for their child's management of the disease, and medical as well as psychosocial factors affecting their everyday life (20,21). Parents influence how seriously diabetes will affect their children because they manage diabetes in the younger years and prepare their older children to care for themselves independently and incorporate lifelong health habits (22).

This disease requires continuing medical care and education to prevent acute complications and to reduce the risk of long-term complications. Poor glycemic control is the most common cause of hospital admissions and complications in diabetes (23). These complications affect the patient's quality of life, increase mortality, morbidity and economic cost to society (19,24). The diabetes control and complication trial (DCCT) and other intervention studies demonstrated that achieving optimal glucose control through adherence to medications, exercise and diet prevents or minimize serious long-term complications (18,25). Better adherence will certainly translate in improved treatment efficacy, better intervention outcomes and reduction of cost of burden on health care (26).

However, to our knowledge studies related to parents' perception regarding quality of diabetic care among pediatric diabetic patients is not conducted in Ethiopia yet. Therefore, this study was designed to assess parents' perception regarding the quality of diabetic care among diabetic children on chronic follow up at JUMC.

1.3 Significance of the study

The finding of this study will provide basic information for health policy makers, diabetes educators and other health care practitioners involved in pediatrics diabetic care. It may help to device strategies for the improvement of quality of diabetic care in pediatrics. It could also be used to direct parents' contributions in improvement of quality of care for pediatrics with diabetics. The finding may also be used as a base line for other related studies. Moreover, it can also be used by organizations and different sectors working on the care and control of diabetes in pediatrics.

CHAPTER TWO: LITERATURE REVIEW

Type 1 diabetes mellitus (T1DM) presents a significant health burden for patients and families and is associated with substantial but modifiable morbidity and mortality risks. The quality of diabetes care can be assessed with reliable utilization measures (27,28).

The care provider must consider the unique aspects of care and management of children and adolescents with type 1 diabetes, such as changes in insulin sensitivity related to physical growth and sexual maturation, ability to provide self-care, supervision in the child care and school environment, and neurological vulnerability to hypoglycemia and hyperglycemia in young children, as well as possible adverse neurocognitive effects of diabetic ketoacidosis (29,30). Due to the paucity of clinical research in children, the recommendations for children and adolescents are less likely to be based on clinical trial evidence. A multidisciplinary team of specialists trained in pediatric diabetes management and sensitive to the challenges of children and adolescents with type1 diabetes and their families should provide care for this population (31).

Quality of care is considered a multidimensional concept that has been given different meanings in the literature. Patients' views on what is important in connection with the care they receive may be seen as one aspect of quality of care, and patient satisfaction has increasingly come to be used as an indicator of this quality (32)

Limited research on children and adolescents with type 1 diabetes has focused on parents' perception regarding quality of diabetes care. In available studies, (11) found that on average, a high perceived quality of care was reported from both parents and adolescents (response rate 71% and 65% respectively); highest regarding possibility to talk to nurse/doctor in privacy, respect, general atmosphere, continuity in patient-physician relationship and patient participation. Lower perceived reality with higher subjective importance was seen for information about results from medical examinations and treatments and information about self-care, access to care and waiting time.

Research conducted by Carol J. Howe MSN (2012) reveal that Parents in that study offered insightful advice to providers in regards to the relationships and interactions they hope for with their child and themselves as they live with diabetes. The theme, laying the foundation, outlined

provider qualities and characteristics of interaction that were core to a successful working relationship (33).

Parents at diabetes center shared their wisdom and experience and in doing so revealed a wide array of factors that make a difference in whether they can successfully raise a child who both is emotionally resilient and has good diabetes control. Many of the factors that they say influence their success can be affected by clinicians who are sensitized to their needs, especially if clinicians are willing to incorporate a biopsychosocial model of care that addresses issues beyond diabetes care in the office setting (34).

Perceptions of QOC measures among patients and families from rural versus urban communities were assessed and the findings reveal that appointment adherence, patient–provider communication, diabetes-related hospitalizations and one of the measures of congruency with diabetes standards of care (foot care) were all found to be significantly poorer among the rural respondents. Appointment adherence has been linked to poor diabetes care outcomes in linear fashion such that as appointment adherence worsens, HbA1c increases along with a greater overall risk of hospitalization and developing DKA. Similarly, patient–provider communication has long been recognized as a factor in patient satisfaction and adherence to treatment recommendations (35).

Additionally, study done in Sweden (36), showed Specific areas that were identified as needing improvement included information about self-care, waiting time at outpatient clinics and for treatment, and access to care. Diabetes seemed to reduce HRQOL. Subjects with better metabolic control and with higher frequency of injections reported slightly higher HRQOL, as did those living with both parents compared to those with separated parents. only 35% of children and adolescents with diabetes in Sweden had an HbA1c level below the treatment target value. Mean HbA1c showed a correlation with mean insulin dose, diabetes duration, and age. A difference between centers was found, but this could not be explained by differences in insulin dose, diabetes duration, or age. Adolescent girls reported lower HRQOL, as did parents of girls aged <8 years. Girls also had poorer metabolic control, especially during adolescence. In teams with the lowest and the most decreased mean HbA1c, members gave a clear message to patients and parents and had a lower HbA1c target value. Members of these teams appeared more engaged,

with a more positive attitude and a greater sense of working as a team. Members of teams with the highest mean HbA1c gave a vaguer message, felt they needed clearer guidelines, and had a perception of poor collaboration within the team. High insulin dose, large centre population, and larger teams also seemed to characterize diabetes centers with low mean HbA1c.

Several studies (25,37), including the Diabetes Control and Complications Trial (DCCT), have shown that intensive therapy and improving metabolic control is important to prevent, delay, or slow the progression of diabetic retinopathy, nephropathy and neuropathy in patients with IDDM. HbA1c is the standard index of glycaemic control over the preceding period of 8-12 weeks.

However, little is known about the perception of parents regarding quality of diabetic care that these children receive and which factors are associated with better quality of care. This study will assess the status of perception of parents regarding quality of diabetic care and factors associated with poor quality of care among pediatric diabetic patients on chronic follow up at JUMC.

2.2. Conceptual framework

The conceptual framework was adapted from previous research and modified as to the present objective (38). As depicted in the diagram it was hypothesized that parents' perception regarding quality of diabetic care is affected by socio demographic factors, diabetes history and diabetes clinical care factors.

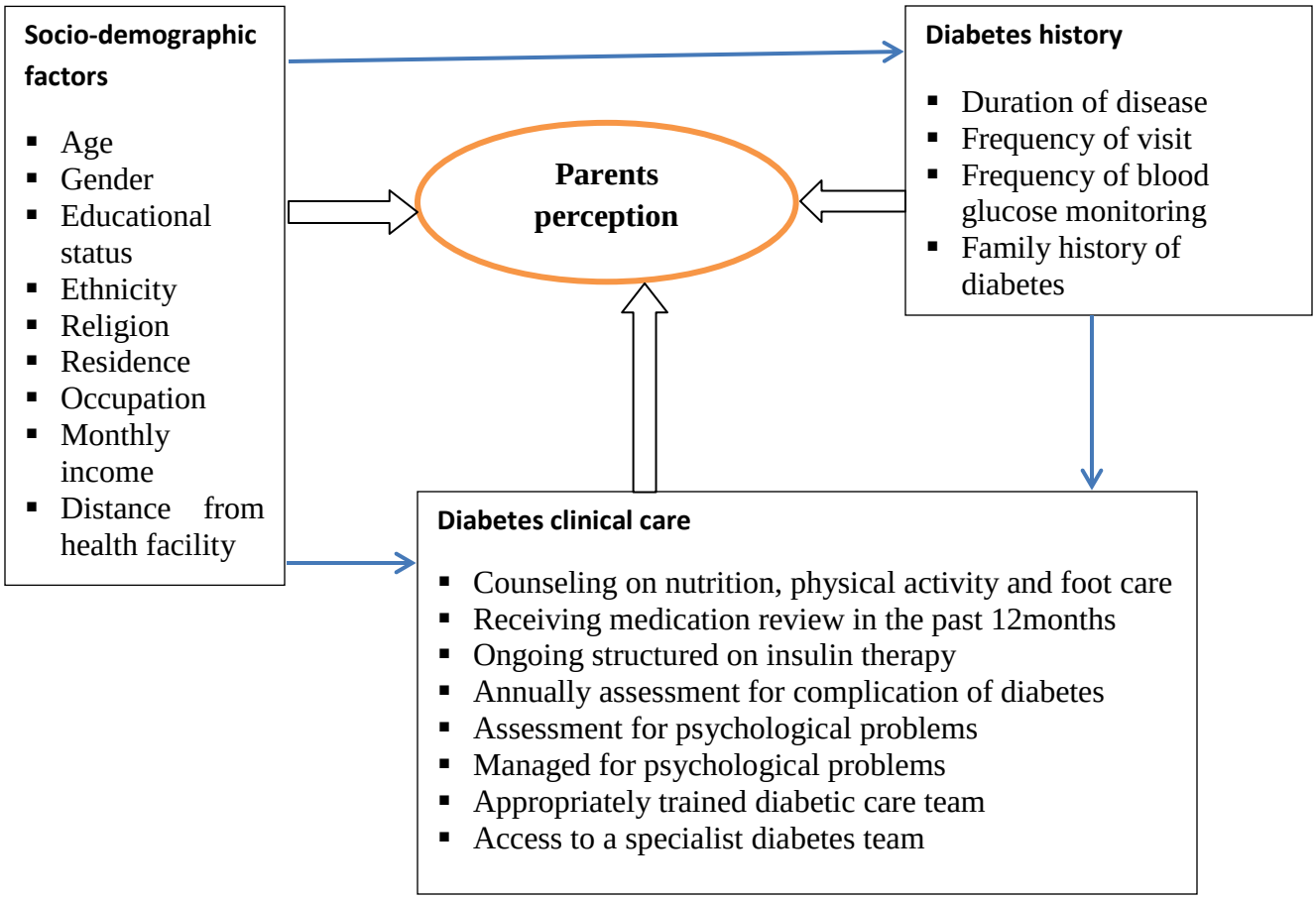

Figure 1: Conceptual frame work developed for study of parents' perception regarding quality of pediatric diabetic care JUMC, 2017.

CHAPTER THREE: OBJECTIVES

3.1. General objective

To assess parents' perception regarding quality of pediatric diabetic care in JUMC

3.2. Specific objectives

1. To assess the level of parents' perception regarding quality of pediatric diabetic care in JUMC
2. To determine factors associated with quality of pediatric diabetic care in JUMC

CHAPTER FOUR: METHODS AND SUBJECTS

4.1. Study Area and Period

The study was conducted from May 1 to June 30, 2017 at pediatric diabetic clinic in JUMC. JUMC is a teaching and referral hospital located in Jimma town, Southwest of Ethiopia. Diabetes clinic is one of the clinics of chronic follow-up clinics in the hospital providing care for 137 pediatrics with diabetes one day per week with the team of pediatricians, pediatric residents, and nurses. Frequency of follow-up visits is at least 6 times a year and depends on proximity to hospital and need for close follow-up. Patients with evidence of complications get more frequent check-ups. On each visit patients have fasting blood glucose test. Based on their complain, physical examination, FBG and other tests like urine test are also done usually. The hospital also supports the surrounding health centers providing care for pediatrics with diabetes.

4.2. Study design

A quantitative institution-based cross-sectional study design was conducted from May 1 to June 30, 2017.

4.3. Population

4.3.1. Source population

All parents of children having follow-up care in JUMC were the source population.

4.3.2. Study population

The study populations were all parents of children with diabetes included in the study.

4.4. Inclusion and exclusion criteria

4.4.1. Inclusion criteria

Children less than fifteen years of age coming with their family to the diabetic clinic during the study period

4.4.2. Exclusion criteria

Parents with newly diagnosed pediatrics at the time of data collection, non-resident patients like temporary visitors and parents with critically sick pediatrics were excluded from the study.

4.5. Sample size determination and sampling technique

Because only 137 pediatrics have follow up at the clinic, all of them were included in the study.

4.6. Study variables

4.6.1. Dependent variable

Parents' perception

4.6.2. Independent variables

Socio-demographic characteristics

- ✓ Age
- ✓ Sex
- ✓ Residency
- ✓ Parents' educational level
- ✓ Parents 'occupation
- ✓ Ethnicity
- ✓ Religion
- ✓ Distance from health facility
- ✓ Family income

Diabetes history

- ✓ Duration of diabetes
- ✓ Frequency of visit
- ✓ Frequency of blood glucose monitoring
- ✓ Family history of diabetes

Diabetes clinical care

- ✓ Counselling on nutrition
- ✓ Counselling on physical activity
- ✓ Counselling on foot care
- ✓ A review of treatment to minimize hypoglycemia
- ✓ Received medication review in the past 12months
- ✓ Ongoing structured on insulin therapy
- ✓ Annually assessed for complication of diabetes
- ✓ Assessed for psychological problems
- ✓ Managed for psychological problems

- ✓ Appropriately trained to care for people with diabetes
- ✓ Have access to a specialist diabetes team

4.7. Data collection tool and procedure

Data collection questionnaire has four parts: socio-demographic characteristics of study participants (children and parents), diabetes history and health service care, diabetes clinical care and parents' perception regarding quality of diabetes care. A structured questionnaire with five Likert-scale types of 14 items was adapted after review of relevant literatures. Each question was scored on five-point Likert-scale from 'poor' to 'excellent'. All 14 items taken together yield a maximum score of 70 and minimum score of 14. To perform logistic regression analysis the five Likert-scale responses were dichotomized as high quality and low quality. Guards or parents of the children were interviewed by trained data collectors. Charts of the study participants were simultaneously reviewed for characters related to co-morbidities and FBS.

4.8. Definition of Terms and Operational Definition

Quality of care: the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.

Fasting blood sugar: blood glucose measured from venous blood without caloric intake for at least 8 hrs.

Perception: is intuitive understanding and insight or the way in which something is regarded, understood, or interpreted.

Perceived low quality: Out of five Likert-scale responses poor, fair and good (scored as 1,2 and 3 respectively) for each 14 items of perceived quality of diabetic care evaluation item.

Perceived high quality:Out of five Likert-scale responses very good and excellent (scored as 4 and 5 respectively) for each 14 items of perceived quality of diabetic care evaluation item.

4.9. Data collection quality control

The questionnaire was pretested by interviewing it to 7 parents of diabetic children at JUMC diabetic clinic two weeks prior to the actual data collection period to determine the approximate time needed to complete the entire questionnaire, the wording, and item clarity. Based on the pretest feedback appropriate modification was made to the questionnaire and the 7 questionnaire filled out for pre-test were excluded. Before data collection, data collectors were trained for one day. Moreover, filled out questionnaire were checked on daily bases for completeness and any ambiguity.

4.10. Data processing, analysis and presentation

Following collection, data were entered to epidata manager using double entry method and then transported to SPSS 20 statistical packages for analysis. As frequency distribution done for each variable to check for discrepancies between the two data set that might occur during data entry. Frequency distributions were used for socio-demographic characteristics and clinical related variables. For the association of dependent variable and independent variables logistic regression test was used with p-value <0.05 considered as significant association. Finally, the results were presented by tables, graphs, charts and statements.

4.11. Ethical consideration

Ethical approval letter was obtained from institutional review board (IRB) of Jimma University Institute of Health Science. In addition, permission was obtained from JUMC. Moreover, all respondents were informed about their free choice to participate and to withdraw whenever they wished during data collection period. The questionnaire was anonymous and written assent was obtained from all respondents before the interview. In order to ensure the patient's privacy and confidentiality, the data collection was conducted only in the presence of the interviewer and the interviewee.

4.12. Dissemination plan

The finding of the research will be submitted to Jimma University, school of postgraduate studies and to pediatric diabetic clinic of JUMC. The result will also be presented on scientific conferences and finally the report will be published on relevant local or international peer-reviewed journals.

CHAPTER FIVE: RESULT

5.1. Socio Demographics Characteristics

5.1.1. Socio Demographics Characteristics *of Children*

A total of 110 pediatrics diabetic patients were included in the study of which 57(51.8%) were females. Out of which more than half (52.7%) were above 12 years, and 38.2% between6 and 12 years. The mean age of diabetic children was 11.7±2.9years. Majority of the 56.4% (62) were grade 1-4 students, whilst, 25.5% (28), 6.4% (7), 1.8% (2) were grade 5-8, greater than grade 8 students and kindergarten, respectively, and 10% (11) had no formal education. Out of 11 children those who had no formal education only one child was less than school age. (Table1).

Table 1: Distribution of sociodemographic characteristics of pediatric diabetic patients on follow-up at JUMC southwest of Ethiopia, June2017 (n=110)

Characteristics / variables	Frequency	Percentage
Age		
▪ Less than 3 years	1	0.9
▪ 3-6 years	9	8.2
▪ 6-12 years	42	38.2
▪ Greater than 12 years	58	52.7
Sex		
▪ Male	53	48.2
▪ Female	57	51.8
Educational status		
▪ Can't read and write	11	10
▪ Kindergarten	2	1.8
▪ 1-4 grade	62	56.4
▪ 5-8 grade	28	25.5
▪ Greater than 8 grades	7	6.4

5.1.2. Socio Demographics Characteristics of Family

A total of 110 parents of children with diabetes were included in the study of which 75 (68.2%) of them were females. The mean ages of respondents were 41.97 ±10.8years old and 59.1% (65) of them were between 30-45 years. Regarding residence, 71 (64.5%) of the respondents were from rural and the rest 35.5% (39) were from urban.

Most of the participants were not educated, which accounted for 61% (67) and 67 (60.9%) of the study participants were farmer. Out of the total of 110 respondents 71 (64.5%), 31 (28.2%) and 8 (7.3%), had monthly income of <500, >1000, and 500-1000 ETB respectively. The finding concerning distance from health care facility distribution points that around half of them (49.1%) were from within 30km radius from the hospital, 33(30%) were within 30-60 km and 23 (20.9%) were from greater than 60km (Table 2).

Table 2: Distribution of socio-demographic characteristics of the family of pediatric diabetic patients on follow-up at JUMC southwest of Ethiopia, June 2017 (n=110)

Characteristics / variables	Frequency	Percentage
Age		
▪ Less than 30 years	14	12.7
▪ 30-45 years	65	59.1
▪ 45-55 years	18	16.4
▪ Greater than 55 years	13	11.8
Sex		
▪ Male	35	31.8
▪ Female	75	68.2
Residence		
▪ Rural	71	64.5
▪ Urban	39	35.5

Ethnicity		
▪ Oromo	75	68.2
▪ Amhara	20	18.2
▪ Gurage	6	5.5
▪ Tigre	3	2.7
▪ Yem	3	2.7
▪ Others	3	2.7
Religion		
▪ Muslim	64	58.2
▪ Orthodox	32	29.1
▪ Protestant	10	9.1
▪ Catholic	3	2.7
▪ Others	1	0.9
Occupation		
▪ Farmer	67	60.9
▪ Daily laborer	20	18.2
▪ Merchant	13	11.8
▪ Civil servant	7	6.4
▪ Others	3	2.7
Monthly income		
▪ Less than 500	71	64.5
▪ 500-1000	8	7.3
▪ Greater than 1000	31	28.2
Educational status		
▪ Literate		
▪ Illiterate	43	39.0
	67	61.0
Distance from health facility		
▪ Less than 30 km		
▪ 30-60 km	54	49.1
▪ Greater than 60 km	33	30.0
	23	20.9

5.2. Diabetes History and health service care

Eighty-six (78.2%) of the participants lived with diabetes for less than 5 years, followed by 20.9% (23) who lived with the condition for 5 to 10 years. The mean duration of diabetes was 44.52 ± 29.76 months with minimum of 2 months and maximum of 132 months. The majority of participants 87 (79.1%) were visiting health facility every 2 months (6 times per year), 10 (9.1%) every 3 months (4 times per year) and 5 (4.5%) every one month (12 times per year).

The mean waiting time to be served when they come for follow up was 8.55 ± 6.64 minutes with 90.0% (99) served within less than 10 minutes followed by 9.1% (10) served between 10-30 minutes. Of the total parents, 97.3% of them ever attended diabetic education. 54(49.1%) attended 3-6 education sessions per year, 45(40.9%) attended less than 3 education sessions per year and only 8 (7.3%) attended6-12 education sessions per year.

All of participants reported that insulin and insulin syringe was provided free and 90%of them had had glucometer for self-monitoring of blood glucose. Majority of the respondents 91(82.7%) monitored their child's blood glucose less than 4 times per month. Family history of diabetes was reported by16 (14.5%) of diabetic children and only 7(6.4%) of diabetic children suffer from other comorbidities (Table 3).

Table 3: Diabetes history and health service care among pediatric diabetic patients on follow-up at JUMC Southwest of Ethiopia, June 2017

Characteristics / variables	Frequency	Percentage
Duration since the child diagnosed for diabetes		
Less than 60 months	86	78.2
60-120 months	23	20.9
Greater than 120 months	1	0.9
Frequency of visit to diabetic follow-up clinic per year		
Less than 3 times per year	8	7.3
4 times per year	10	9.1
6 times per year	87	79.1
12 times per year	5	4.5
Approximate time spent on follow up visit		
Less than 10 minutes	99	90.0
10-30 minutes	10	9.1
Greater than 30 minutes	1	0.9
Ever attended diabetes education provided at JUMC		
Yes	107	97.3
No	3	2.7
Number of diabetic education sessions attended per year		
Less than 3 education sessions	45	40.9
3-6 education sessions	54	49.1
6-12 education sessions	8	7.3
Child's access to self-monitoring of blood glucose		
Yes	99	90.0
No	11	10.0
Frequency of glucose self-monitoring per month	91	82.7
Less than 4 times	8	7.3
Greater than 4 times		

Family history of diabetes		
Yes	16	14.5
No	94	85.5
Comorbidities		
Yes	7	6.4
No	103	93.6

5.3. Glycemic control and admission related diabetes complications

The mean recent fasting blood sugar of the pediatrics was 193.65 ± 102.45 mg/dl. Majority of the diabetic children (70%) had recent FBS greater 126 mg/dl, 29(26.4%) had between 70-126 mg/dl and 4 (3.6%) had less than 70 mg/dl. All of the participants were on NPH and regular insulin (Fig 1).

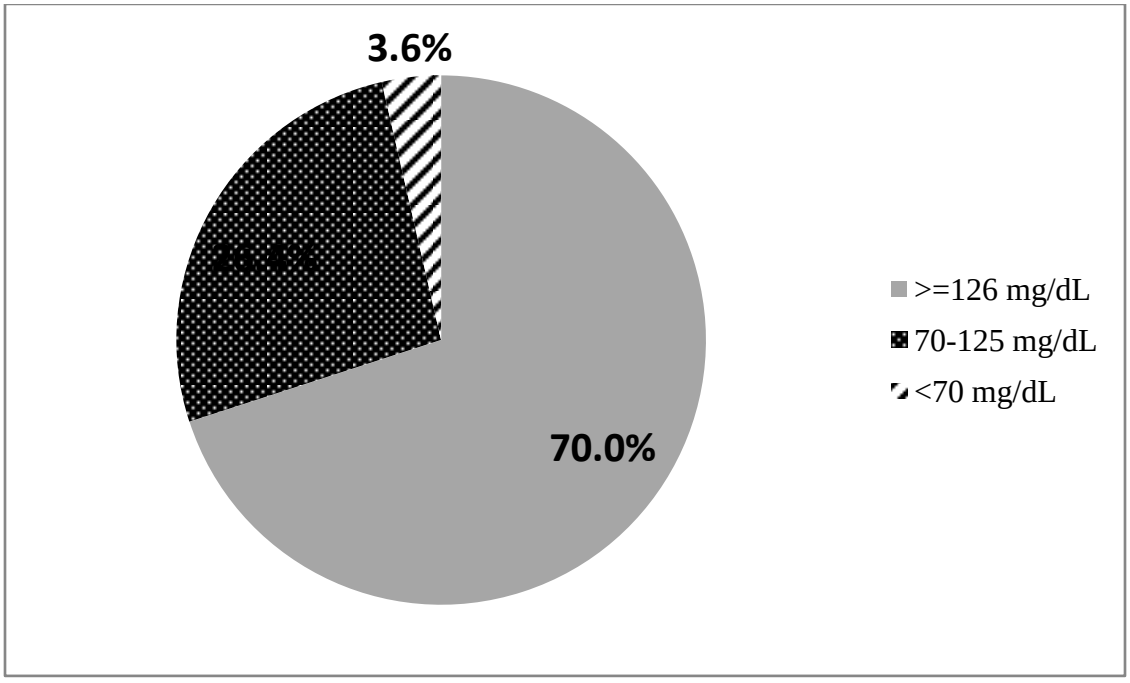

Fig 2: Recent fasting blood sugar level of diabetic pediatrics attending JUMC diabetic clinic, June 2017.

Since diagnosis of diabetes was made, out of 110 diabetic children, 72(65.5%) patients had been admitted to the hospital once, 26 (23.6%) twice and only 1(0.9%) patient admitted 5 times. Over the past one year 32 (29.1%) of patients reported hospital admission once and 1(0.9%) patient twice due to diabetes related conditions or DKA incidence.

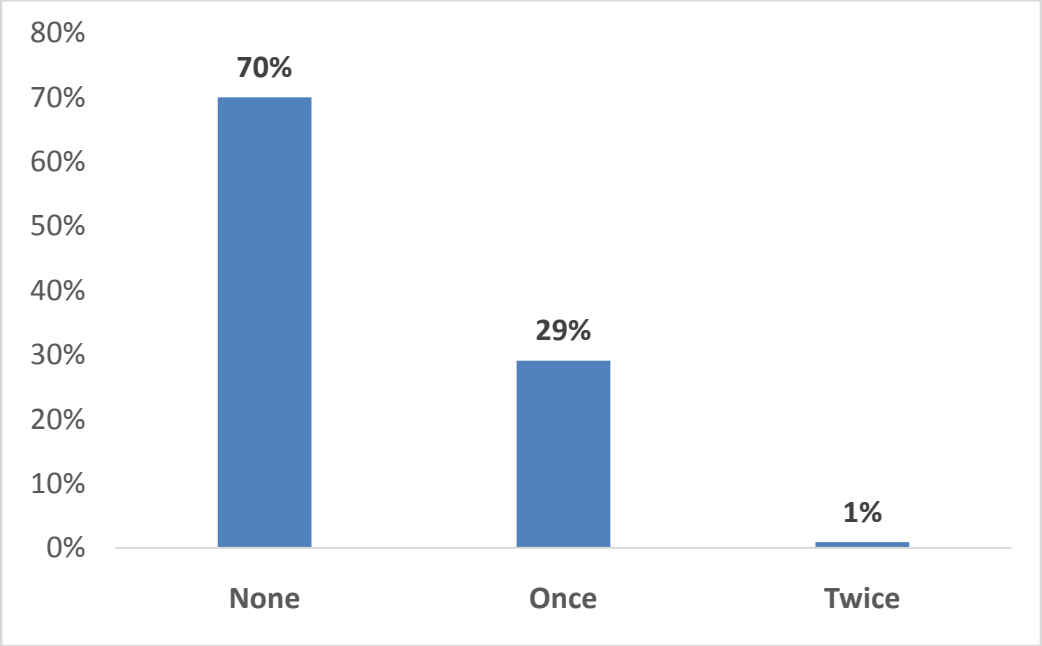

Fig 3: Diabetes-related hospitalization/DKA incidence over the past one-year JUMC pediatric diabetic clinic, June 2017.

5.4. Parents perception regarding quality of diabetic care

From the 14 items of maximum score of 70 and minimum of 14 score, the mean score of overall quality of diabetic care was 48.58 ± 11.31 with a maximum score of 67 and minimum of 20.In this study, the overall quality of pediatric diabetic care score achieved above the mean score is 54.5% (60).

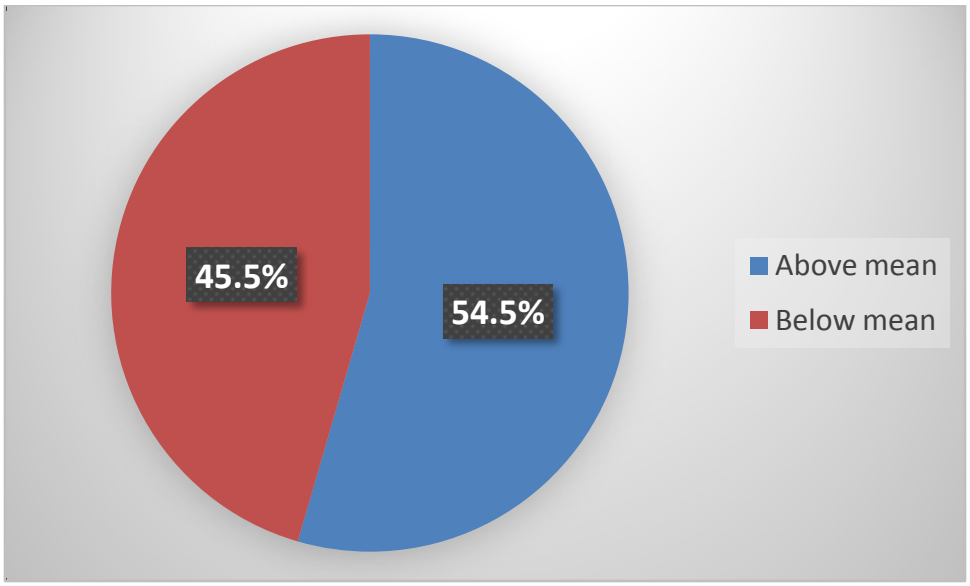

Fig 4: The overall quality of pediatrics diabetic care score perceived by parents at JUMC diabetic clinic, June 2017.

According to one item that measures the overall quality of diabetic care 59.1% of parents reported that the overall quality of pediatrics diabetic care was of high quality. Under organizational related quality of diabetic care, out the total 110 parents 41.8% (46), 44.5% (49), 45.5% (50), and 59.1% (65) reported that the waiting time before consulting, the waiting time until the next appointment, the duration of consultation, and the ease of making new appointment was of high quality respectively. Under consultation item related quality of diabetic care, out of the total 110 parents 50.9% (56),50.9% (56), 50.9% (56), 53.6% (59),54.5% (60),55.5% (61), 58.2% (64), 60.9%(67), 62.7%(69)reported that the clarity of information, usefulness of information, the emotional support given, the opportunity to ask question during consultation, the medico-technical competence, the amount of information, the extent to which caregivers informed about past treatment, the opportunity to share decisions, the value of the services that your child's caregiver provided was of high quality. (Table4).

Table 4: Frequency distribution of parents' evaluation of quality of diabetic care among pediatric diabetic patients on follow-up at JUMC, south west of Ethiopia, June 2017

Quality measurement items	Level of quality		
	High quality No (%)	**Low quality No (%)**	**Total %**
Organization item The waiting time before consulting	46 (41.8)	64 (58.2)	110 (100.0)
The duration of the consultation	50 (45.5)	60 (54.5)	110 (100.0)
The waiting time until the next appointment	49 (44.5)	61 (55.5)	110 (100.0)
The ease of making new appointments	65 (59.1)	45 (40.9)	110 (100.0)
Consultation item			
The clarity of information	56(50.9)	54(49.1)	110 (100.0)
The amount of information	61 (55.5)	49 (44.5)	110 (100.0)
Usefulness of information	56 (50.9)	54 (49.1)	110 (100.0)
The opportunity to ask question during consultation	59(53.6)	51 (46.4)	110 (100.0)
The emotional support given	56 (50.9)	54 (49.1)	110 (100.0)
The medico-technical competence	60 (54.5)	50 (45.5)	110 (100.0)
The extent to which caregivers informed about past treatment	64 (58.2)	46 (41.8)	110 (100.0)
How you value the services that your child's caregiver provides	69 (62.7)	41 (37.3)	110 (100.0)
The opportunity to share decisions	67(60.9)	43 (39.1)	110 (100.0)
Overall Overall quality of diabetic care	65 (59.1)	45 (40.9)	110 (100.0)

5.5. Factors associated with quality of diabetic care

Bivariate analysis indicated that there was no statistically significant association between all of the socio-demographic factors and overall quality of diabetic care. Similarly, on bivariate analysis there was no significant association between diabetes history and health service care and the overall parents' perceived quality of pediatrics diabetic care.

Bivariate logistic regression revealed that all counseling on health nutrition, physical activity and foot care, receiving a review of treatment to minimize hypoglycemia, medication review in the past 12months and ongoing structured on insulin therapy, annual assessment for complication of diabetes and psychological problems and its management, appropriately trained staff to care for people with diabetes and access to a specialist diabetes team were significantly associated with quality of diabetic care. After interning these variables in to multivariate logistic regression counseling on health nutrition, receiving medication review in the past 12 months, ongoing structured on insulin therapy, managed for psychological problems and access to a specialist diabetes team independently are associated with quality of diabetic care.

The odds of reporting high overall quality of diabetic care was 18.48 times more likely (AOR=18.48, P = 0.001, 95% CI: 3.26, 104.72) among parents of diabetic children who reported high quality of nutritional counseling than those who reported low quality of nutritional counseling. Similarly, the odds of reporting high overall quality of diabetic care was16.31 times higher (AOR 16.31, p=0.38, CI: 1.17, 228.43) among parents of diabetic pediatrics who received ongoing structured insulin therapy than their counterparts.

The likelihood of reporting high overall quality of diabetic care was 15 times (AOR 15.06, p=0.29, CI: 1.33, 171.08) among parents of diabetic pediatrics who reported their children managed for psychological problem than those did not managed for. Similarly, the likelihood of reporting high overall quality of diabetic care was 36.11 times higher (AOR=36.11, P=0.001, 95% CI: 4.21, 309.66) among parents of diabetic children who reported high quality of having access to a specialist diabetes team than their counterparts. On the other hand, the odds of reporting high overall quality of diabetic care was 97% less likely among those who received medication review than who did not received (AOR 0.03, p=0.013, CI: 0.002, 0.479) (Table 5).

Table 5: Multivariate logistic regression of clinical care for diabetic pediatrics with perceived overall quality of diabetic care among pediatric diabetic patients at JUMC, south west of Ethiopia, June 2017.

Predicting variable	**Low quality No (%)**	**High quality No (%)**	**COR**	**AOR**	**P value**	**CI 95%**	
						Lower	**Upper**
Counseling on health nutrition**	43 (39.1)	67(60.9)	19.23	18.48	**.001**	3.26	104.72
Counseling on physical activity	53(48.2)	57(51.8)	0.71	1.59	.805	.040	62.53
Counseling on foot care	54(49.1)	56(50.9)	0.08	3.02	.520	.104	87.27
Received a review of treatment to minimize hypoglycemia	53(48.2)	57(51.8)	14.16	5.55	.111	.676	45.53
Received medication review in the past 12months*	46(41.8)	64(58.2)	6.13	.030	**.013**	.002	.479
Received ongoing structured on insulin therapy*	49(44.5)	61(55.5)	10.30	16.31	**.038**	1.17	228.43
Assessed annually for complication of diabetes	48(43.6)	62(56.4)	6.25	.083	.108	.004	1.73
Assessed for psychological problems	46(41.8)	64(58.2)	11.00	.305	.329	.028	3.31
Managed for psychological problems*	47 (42.7)	63(57.3)	12.36	15.06	**.029**	1.33	171.08
Appropriately trained to care for people with diabetes	47(42.7)	63(57.3)	10.20	.132	.122	.01	1.72

Have access to a specialist diabetes team**	41(37.3)	69(62.7)	19.59	36.11	**.001**	4.21	309.66

* *Significant association at p<0.05*

** *Significant association at p<0.01*

Adjusting for sociodemographic characteristics of diabetic pediatrics and their parents, the likely hood of reporting high quality of duration of consultation with the caregivers (shorter duration) was 3 times more likely among parents with female diabetic pediatrics than parents with male diabetic pediatrics (AOR 3.4, p=0.01, CI: 1.33, 8.60). Similarly, the odds of reporting high quality of duration of consultation with the caregivers was 3.6 times more likely among parents who reported monthly family income of ETB 500 to 1000 as compared to those with monthly family income of ETB <500.

On the other hand, the likely hood of reporting high quality duration of consultation with caregivers was 93.8% less likely by parents older than 55 years as compared to those younger than 30 years (AOR 0.062, p=0.009, CI: 0.008, 0.495). Similarly, those from beyond 60km radius were 79% less likely to report high quality duration of consultation than those from within less than 30km radius (Table 6).

Table 6: Multivariate logistic regression of socio-demographic factors and duration of consultation with the caregivers among pediatric diabetic patients at JUMC, south west of Ethiopia, June 2017

Predicting variable	**COR (95% CI)**	**P value**	**AOR (95% CI)**
Sex			
Male^	-	-	-
Female*	.483(.225,1.04)	**.010**	**3.387**(1.33, 8.60)
Age of the family			
<30 years^	-	.035	-

30-45years	.643(.200, 2.062)	.509	.629(.159, 2.49)
45-55 years	.938(.229, 3.835)	.987	.986(.193, 5.03)
>55 years**	.136(.022,0.86)	**.009**	**.062**(.008, .495)
Monthly income			
<500 ETB^	-	.031	-
500-1000 ETB*	.551(.122, 2.48)	**.014**	**3.556**(1.289, 9.81)
>1000 ETB	.438(.181,1.06)	.945	1.066(.176, .176)
Distance from healthy facility			
<30 km^	-	.050	-
30-60 km	3.88(1.26,11.95)	.759	.859(.325, 2.272)
>60 km*	3.83 (1.15,12.74)	**.016**	**.207**(.058, .744)

* *Significant association at p<0.05*

** *Significant association at p<0.01*

^*shows indicator variable*

Multivariate logistic regression of sociodemographic and time until next appointment showed that the odds of reporting high quality time (favorable) until the next appointment was 6 times more likely among parents of female diabetic pediatrics than parents with male diabetic pediatrics (AOR 5.89, p=0.000, CI: 2.17, 15.97). As the age of diabetic pediatrics family age increases the likelihood of reporting favorable time until the next appointment decreases. The odds of reporting high quality time (favorable) until the next appointment was 6 times more likely among parents who reported monthly family income of ETB 500 to 1000 as compared to those with monthly family income of ETB <500 (Table 7).

Table 7: Multivariate logistic regression of socio-demographic factors associated with time until the next appointment among pediatric diabetic patients at JUMC, south west of Ethiopia, June 2017

Predicting variable	COR (95% CI)	P value	AOR (95% CI)
Sex			
Male^	-	-	-
Female* **	3.053 (1.40, 6.67)	**.000**	**5.89** (2.17, 15.97)
Age of the family			
<30 years^	-	.011	-
30-45years **	7.33(1.16,46,23)	**.004**	**26.100** (2.92, 233.35)
45-55 years **	4.71 (.968,22.97)	**.001**	**18.76** (3.13,112.42)
>55 years **	5.50 (.939,32.21)	**.005**	**16.54** (2.33,117.29)
Monthly income			
<500 ETB^	-	.004	-
500-1000 ETB **	3.31(1.32,8.39)	**.002**	**5.62** (1.91,16.55)
>1000 ETB	1.723(0.334,8.91)	.992	1.01 (.169,6.03)

* *Significant association at p<0.05*
** *Significant association at p<0.01*
*** *Significant association at p<0.001*
^*shows indicator variable*

Multivariate logistic regression of socio-demographic variables and opportunity to share decision showed that the odds of reporting high quality of opportunity to share decision was 4 times more likely among parents of female diabetic pediatrics than parents with male diabetic pediatrics (AOR 4.03, p=0.006, CI: 1.49, 10.87). Similarly, the odds of reporting high quality of opportunity to share decision was 4 times more likely among parents of diabetic children >12 years of age as compared to those parents of diabetic children <3 years of age (AOR = 4.03, p=0.003, CI: 1.49,10.87).The odds of reporting high quality of opportunity to share decision was

91.8% less likely by parents older than 55 years as compared to those younger than 30 years (AOR = 0.082, p=0.02, CI: 0.1, 0.68) (Table 8).

Table 8: Multivariate logistic regression of socio-demographic factors associated with opportunity to share decision among pediatric diabetic patients at JUMC, south west of Ethiopia, June 2017

Predicting variable	**COR (95% CI)**	**P value**	**AOR (95% CI)**
Sex			
Male^	-	-	-
Female**	.563 (.26, 1.23)	**.006**	**4.03** (1.49, 10.87)
Age of the family			
<30 years^	-	.020	-
30-45years	.782 (.22,2.78)	.935	.933 (.174,5.01)
45-55 years	.629 (.141,2.81)	.738	.729(.115,4.64)
>55 years**	.120 (.02,.68)	**.020**	**.082** (0.1,.68)
Age of the child			
<3 years^	-	.026	583055039.6
3-6 years	.000	1.000	1.25(.197,7.96)
6-12 years	.000	.811	4.76(1.71,13.23)
>12 years**	.000	**.003**	**4.03**(1.49,10.87)

[*] *Significant association at p<0.05*

** *Significant association at p<0.01*

*** *Significant association at p<0.001*

^*shows indicator variable*

CHAPTER SIX: DISCUSSION

Quality of diabetic care can properly be assessed if the perception of care receiver is taken into account. In Africa, there is a notable lack of studies related the patients' perception regarding the quality of pediatric diabetic care provided by caregivers. This institutional based cross-sectional study was done to assess the level of parents' perception regarding quality of pediatric diabetic care in JUMC. This study found that the mean score of overall quality of diabetic care was 48.58 ± 11.31 and more than half of parents (54.5%) scored above the mean score. This finding is less than the study conducted at Saudi Arabian where 65.6% of the participants reported a moderate "overall quality of diabetes care"(39). This difference may be related to the fact that because of economic variation the standard of pediatrics diabetic care in Saudi Arabia which is supposed to be better than that of JUMC.

The present study found that, of the total items of organizational and consultation domain, the high quality of diabetic care reported were 59.1%, which was reported regarding the ease of making new appointments and 62.7% with the value of the services that their child's caregiver provided, respectively. Study done in Saudi Arabia showed high quality of care were reported (62.2%) and (68.0%), regarding ease of getting appointments and medicotechnical competence of the physicians respectively. Whereas, the study done in Sweden found that on average, a high perceived quality of care was reported from both parents and adolescents (response rate 71% and 65% respectively); highest regarding possibility to talk to nurse/doctor in privacy, respect, general atmosphere, continuity in patient-physician relationship and patient participation(11).

Ninety percent (90%) of the parents reported that waiting time before consulting caregivers was less than 10 minutes. This may be related to relatively less load, as the number of diabetic pediatrics on routine follow-up was less for the tertiary hospitals like JUMC. However, more than half (58.2%) of the parents reported that waiting time before consulting the caregiver is lengthy. This discrepancy may be related to mix up of time required to get the whole service including until the end of collection of medications.

The mean recent fasting blood sugar was 193.65 ± 102.45 mg/dl. This finding is comparable with study in Addis Ababa where mean fasting blood glucose was 190±89.6 mg/dl (40). But our finding is much higher than the American Diabetic Association recommendation (41).Based on the recent FBS more than 2/3rd of the pediatrics had uncontrolled diabetes which was greater

than or equal to 126mg/dl. This may be related to the fact that around 2/3rd of the pediatrics were from rural and around 79% of them had follow up at the diabetic clinic every 2 months which is less frequent to monitor and take recommended medical actions like medication adjustments.

In our study regression analysis was revealed that there was no association between parents' perception of overall quality of diabetic care and sociodemographic variables and diabetes history and health service care. However, study done in Saudi Arabian showed that the regression analysis indicated low educational level (OR=2.57 p-value=0.001) and the duration of disease (OR= 2.27; p-value=0.004) were significant predictors of the patients' low overall evaluation score for quality of care (39). This difference could be related to small number of study population.

Around half of the parents reported that the clarity of information, the usefulness of information, and the emotional support given at the clinic was of low quality. This may be due to the reason that there was no well-organized and trained diabetic education and care giver team in the clinic. The independent significant predictors of the quality of pediatrics diabetic care are the counseling on health nutrition, receiving medication review in the past 12 months and ongoing structured on insulin therapy, management for psychological problems and access to a specialist diabetes team.

The high overall quality of diabetic care was perceived more likely by parents of diabetic children who reported high quality of nutritional counseling than those who reported low quality of nutritional counseling. Even though no supporting literature found, may be counseling provides a supportive and collaborative environment where one can discuss problems and concerns, clarify situation, gain new perspectives and work towards change which drives to quality diabetic care services. Odds of reporting high overall quality of diabetic care was by far higher among parents of diabetic children who reported high quality of having access to a specialist diabetes team than their counterparts. This may be, parents of diabetic children perceive specialist diabetes team provide specialist care, treatment, support and education to patients with diabetes and their carers.

Respondents having high quality of received ongoing structured on insulin therapy perceive high overall quality of diabetic care when compared with individuals' having low quality of received ongoing structured on insulin therapy.

The high quality of duration of consultation with the caregivers (shorter duration) and time (favorable) until the next appointment perceived more likely by parents with female pediatric diabetic patients and those reported monthly family income of 500-1000 birr; and less likely reported by parents aged >55 years and those coming from beyond 60 km. The high quality of opportunity to share decision was reported by respondents with female pediatric diabetic patients and diabetic children >12yrs of age.

This study also detected the association of age of family with clarity of information, age of the family and sex with amount of information. In Italy a cross sectional study of more than three thousand diabetic patients about their relationship with their physicians detected those subjects with low level of school education were more dissatisfied about the information received and their involvement in diabetes management (42).

Due to lack of studies related to parents' perception regarding quality of pediatric diabetic care, which is difficult to compare our finding with other. Since this is cross sectional causal relationship between the independent and dependent variables cannot be established. Because of financial and time shortage, only JUMC was included in the study with less sample size.

CHAPTER SEVEN: CONCLUSION AND RECOMMENDATION

7.1. Conclusion

Generally, more than 2/3rd of the participants had lived with diabetes for less than five years and visit to the hospital was less frequent, where majority of them were visiting the hospital every two months. The mean recent FBS was beyond the target for control of hyperglycemia and more than 2/3rdof the pediatrics had uncontrolled diabetes.

Over half of the parents reported that for almost all of items under the organizational domain the quality of pediatrics diabetic care in the hospital was of low quality. Moreover, over 1/3rd to half the parents had perceived low quality of consultation domain items.

Significant proportion of the parents reported that the overall quality of the service provided in the clinic of low quality. Good counseling on health nutrition, receiving medication review in the past 12 months and ongoing structured on insulin therapy, management for psychological problems and access to a specialist diabetes team were the most significant factors contributed in the evaluation results**.**

7.2. Recommendation

- The hospital should have organized a specialist diabetes team including trained physicians and nurses.
- Health care should be aware of that majority of patients do not achieve adequate level of glycemic control and should work to improve the frequency of visit to every month, which is easy to adjust the dose of the insulin therapy.
- Health care should promote patients counseling on health nutrition and providing management of psychological problems associated with diabetes.
- Health care should promote providing clear, important, useful information considering age, culture, language and literacy of the parents.
- Health care should promote providing them medication review and ongoing structured on insulin therapy.
- Further qualitative research is needed for exploring the needs and parents contribution in the improvement of pediatrics diabetic care.

ANNEX:

Questionnaire

JIMMA UNIVERSITY

COLLEGE OF PUBLIC HEALTH AND MEDICAL SCIENCES

DEPARTMENT OFPEDIATRICS

QUESTIONNAIRE**ON ASSESSMENT OF QUALITY OF DIABETIC CARE AMONG PEDIATRIC DIABETIC PATIENT**

I. Information sheet

Good morning/afternoon [According to its convenience]. I am _____ who is the data collector for a research to be conducted by Dr. Shegitu Miresa. Today, I am here to collect information on "***Assessment of parents' perception regarding quality of diabetic care among pediatric diabetic patients in JUMC***," so I want to ask you some questions.

There is no immediate and direct benefit in terms of money that you will earn from this information; rather I hope, you might get moral satisfaction due to the information you give now, where it is a resource in contributing for the community welfare in general specially for those diagnosed with diabetes and taking insulin for prolonged duration. We believe that the study findings will help in order to improve quality of diabetic care and concerns from health care providers.

If you take part in the study it will not take us more than 30 minutes, your name will not be included in the information, I promise to keep the confidentiality of your reply. There is no risk that comes due to your involvement in the study. Your participation is completely voluntary and you have full right to withdraw at any time in the course of data collection even after you get involved without being subject to any intimidation and incrimination to you. Your choice either to involve or not will not compromise any services that you ought to get from this clinic/hospital. However, I hope that you will participate in this study considering that single genuine information you provide will contribute a lot to the fulfillment of the objective of the study.

As a result, I request you sincerely to participate in the interview by providing authentic answers.

Do you have any questions that you need to be clarified more?

Assent form

I have been briefly informed about the study and I clearly understood the objective. Since it does not affect my child and my own personal life, I agreed to take part in the study. Consequently, I here approve my consent to take part in the study as an interviewee with my signature.

a. Agreed to participate ☐ Sign and proceed to interview

b. Not agreed to participate ☐ Thank the respondent and End the interview

Signature: _____

Date: _____

Questionnaire

Date: _____

Health Institution: _____

Interviewer: _____

Part I: Socio - demographic Characteristics of Study Participants (family and the child)

I.I. Child

1.1.1. Age of child in year: _____

1.1.2. Sex: 1) Male 2) Female

1.1.3. Educational status: Highest grade completed: _____ grade.

I.II. Family

1.2.1. Age (How old are you?) ---------

1.2.2. Sex 1. Female 2. Male

1.2.3. Residence 1. Urban 2. Rural

1.2.4. Ethnicity

1. Amhara 2. Oromo 3. Guragie 4. Tigre 5. Yem 6. Others [Specify]

1.2.5.Religion

1. Orthodox 2. Muslim 3. Protestant 4. Catholic 5. Others [specify]

1.2.6. Family Occupation: -

1) Farmer 2) Merchant 3) Daily laborer 4) Civil servant 5) Fisher 6) Others

1.2.7. Estimated family monthly income in Birr: _____

1.2.8. Educational status of the family 1. Literate 2. Illiterate

1.2.9. How far is your home from this health care facility? _____ Km

Part II: Diabetes History and health service care

2.1. How many years back were you/your child diagnosed by health professional to have diabetes?

2.2. How many times do your child visit diabetic follow up clinic per year? _____ times.

2.3. Approximately how long does it take for your child to be served when you come for follow-up? _____ minutes.

2.4. Have you ever attended diabetes education provided at this hospital?☐Yes ☐No

2.5. If "Yes" to QNo2.4, how many times per year? ____ times

2.6. Where do you bring your insulin and insulin syringe?☐ Purchase ☐ Free distribution

2.7. If you purchase, how can you assess the cost of your anti-diabetic medications?

☐Cheap ☐Costly

2.8. Do you/your child have access to self-monitoring of blood glucose ☐ Yes ☐ No

2.9. If "yes" to QNo 2.9 how many times you monitor your blood glucose per month? ____ times

2.10. Family history of diabetes ☐Yes ☐ No

2.11. Do your child/you suffer from other diseases other than diabetes ☐ Yes ☐ No

Part III. Parents' perception regarding quality of diabetes care

Instructions: The following 15 questions cover different aspects of diabetes care. As parents of your child please judge, the diabetes care your children have received during follow-up. Please try not to skip any questions. If two or more different caregivers have treated you during this follow up, please try to give mean score for this caregiver.

No	Items	Responses				
		Poor	**Fair**	**Good**	**Very Good**	**Excellent**
3.1	The waiting time before consulting the caregivers					
3.2	The duration of the consultation with the caregivers					
3.3	The time you have to wait until your next appointment with the caregivers					
3.4	The clarity of information you receive from the caregivers					
3.5	The amount of information you receive from the caregivers					
3.6	The usefulness of the information you receive from the caregivers					
3.7	The opportunity to ask questions to the caregivers during the consultation					
3.8	The emotional support given by the caregivers					

3.9	The medico-technical competence of the caregivers (e.g. knowledge about diabetes, ability to maintain/achieve favorable effects on your child diabetes)
3.10	The extent to which the caregivers are informed about the (past) treatment of your child diabetes
3.11	The opportunity to share decisions with the caregivers about the treatment of your child diabetes
3.12	The ease of making new appointments with the caregivers
3.13	How you value the services that your child's caregiver provides to your child and you
3.14	The extent to which you satisfied with yourchild's diabetic care
3.15	The overall quality of your child diabetes care by the caregivers is
3.16	Individualized counseling received on healthy nutrition
3.17	Individualized counseling received on physical activity
3.18	Individualized counseling received on foot care

3.19	Received a review of treatment to minimize hypoglycemia in the previous 12 months
3.20	Received a medication review in the past 12 months
3.21	Received ongoing structured support to initiate and manage insulin therapy
3.22	Assessed annually for the risk and presence of complications of diabetes, and these are managed appropriately
3.23	Assessed for psychological problems
3.24	Managed for psychological problems
3.25	Appropriately trained to care for people with diabetes
3.26	Have access to a specialist diabetes team

Part IV: checklist to review patient's medical record

No.	**Question**
4.1	Recent FBS: _____
4.2	Average of Fasting blood sugar level: _____
4.3	Which drug regimen patient is following currently? _____ _____ _____
4.4	How many times he / she have been admitted? _____ times
4.5	Diabetes-related hospitalization or DKA incidence over the past one year? _____ times

This is all what I want to ask you. Thank you for spending your time and valuable information you gave us. Do you have any question that I can address for you?

_____
_____
_____

GAAFFILEE QORANNOO ILAALCHA MAATIIN QULQULLINA YAALA/EEGGANNOO DHUKKUBA SUKKAARAA DAA'IMMAN DHUKKUBA SUKKAARAA QABANIIF GODHAMAN IRRATTI QABAN

I. Fuula odeeffannoo

Akkam bultan/barfattan(akka yeroosaatti)? Ani _____kanan jedhamu ragaa funaantuu qorannoo Dr.Shaggituu Mirreessatiin hojjetamuuti. Guyyaa har'aa kanan asitti argameef qorannoo" Ilaalcha maatiin qulqullina yaala/eeggannoo dhukkuba sukkaaraa daa'imman dhukkuba sukkaaraa qabaniif godhaman irratti qaban, Giddugala fayyaa yuuniversiitii jimmaatti" godhamuuf waan ta'eef gaaffilee muraasa sin gaafachuun barbaada.

Faayidaan hatattamaa ykn kallattii bifa qarshiitiin odeeffannoo kanarraa argattan jiraachuu baatullee, odeeffannoo kennitanitti akka gammaddan abdiin qaba. Sababnisaas odeeffannoon kun walumaa galatti madda fayyummaa hawaasaaf hirmaannaa kan qabu waan ta'eef; keessumaa dhukkubsatoota dhukkuba sukkaaraa ta'uun baramee fi dawaa dhukkuba sukkaaraa(insuliinii) yeroo dheeraa fudhataniif. Bu'aan qorannoo kanaas qulqullina eeggannoo dhukkuba sukkaaraaf godhamuu fi xiyeeffannoo ogeessotni fayyaa dhukkuba sukkaaraa irratti qabaniif akka fayyadu ni amanna.

Yoo qorannoo kana keessatti qooda fudhattan daqiiqaa 30 caalaa nutti hin fudhatu, qabiyyeen odeeffannoo kanaas maqaa keessan hin dabalatu, deebii laattaniifis icciitii dhuunfaa keessanii eeguuf waadaan gala. Qorannoo kana keessatti hirmaachuu keessaniif miidhaan isinirra ga'us hin jiru. Hirmaannaan keessan guutummaatti fedhiirratti kan hundaa'ee fi hubannoo gahaa otoo hin qabaatiin yoo jalqabdan ta'ellee yeroo barbaaddanitti addaan kutuuf mirga guutuu qabdu. Qorannoo kana keessatti hirmaachuuf hirmaachuu dhiisuun tajaajila hoospitaala kanarraa argattan irratti gonkumaa dhiibbaa hin qabaatu. Haa ta'u malee odeeffannoon haqaa dhuunfaadhaan nuuf kennitan fiixaan ba'umsa kaayyoo qorannoo kanaa keessatti gahee guddaa waan qabaatuuf akka keessatti hirmaattan abdii guddaan qaba.

Kanaafuu odeeffannoo gahaa kennuudhaan hirmaattota qorannoo kanaa akka taatan kabajaan isin gaafanna.

Gaaffii akka ibsi dabalataa itti isiniif kennamu barbaaddan qabduu?

Unka waliigaltee

Waa'een qorannoo kanaa gabaabinaan natti himamee jira, anis gadifageenyaan kaayyoosaa hubadheera.

Jireenya dhuunfaakoorratti gonkumaa dhiibbaa geessisu waan hin qabneefis, qorannoo kana keessatti qooda qabaachuuf itti walii galeera. Gamanumaan, armaan gaditti gaafatamaa qorannoo kanaa yoon ta'u heyyamakoo mallattookootiinan mirkaneessa.

a. Keessatti hirmaachuuf waliigaleera ☐ mallatteessii gaaffiif deebii itti fufi.
b. Keessatti hirmaachuuf walii hin galu ☐ hirmaannaa keessaniif galatoomaa, gaafffiif deebii keenya xumuri.

Mallattoo: _____

Guyyaa: _____

Gaaffilee

Guyyaa: _____

Dhaabbata fayyaa: _____

Gaafataa: _____

Kutaa 1^{ffaa}: Haala hawaasummaa fi dinagdee qoratamtootaa (maatii fi ijoollee)

A. Daa'ima

1.1.1. Umurii:waggaatiin _____

1.1.2. Saala: 1) dhiira 2) dubara

1.1.3. sadarkaa barnootaa: kutaa_____

B. Maatii

1.2.1. Umurii (umuriinkee meeqa?)_____

1.2.2. Saala 1. Dhalaa 2. Dhiira

1.2.3. Bakka jireenyaa 1. Magaala 2. Baadiyaa

1.2.4. Sabummaa 1. Amaara 2. Oromoo 3. Guraagee 4. Tigiree 5. Kan biro (adda baasi)

1.2.5. Amantii 1. Ortodooksii 2. Musliima 3. Protestaantii 4. Kaatolikii 5. Kan biroo(adda baasi)

1.2.6. Hojii maatii 1. Qotee bulaa 2. Daldalaa 3. Dafqaan bulaa 4. Hojjetaa mootummaa 5. Qurxummii qabaa 6. Kan biro(adda baasi)

1.2.7. Tilmaama galii ji'aa maatii qarshiidhaan:_____

1.2.8. Sadarkaa barnoota maatii:

Haadha 1. Baratteetti 2. Hin baranne

Abbaa 1. Barateera 2. Hin baranne

1.2.9. Mannikee dhaabbata fayyaarraa hangam fagaata? _____km.

Kutaa 2^{ffaa}: Waa'ee dhukkuba sukkaaraa fi eeggannoo tajaajila fayyaan godhaman

2.1. Waggaa meeqaan dura dhukkuba sukkaaraa qabaachuunkee/daa'imnikee qabaachuusaa, kan hojjetoota fayyaatiin beekame?

2.2. Waggaatti yeroo meeqaaf hordoffii dhukkuba sukkaaraaf mana yaalaatti deddeebita? Yeroo_____

2.3. Tilmaamaan yeroo hordoffiif deddeebitu tajaajila argachuuf yeroo hangamii sitti fudhata? Daqiiqaa_____

2.4. Barumsa dhukkuba sukkaaraaf kennamu hospitaala kanatti hordoftee beektaa? Hordofee beeka ☐ Hordofee hin beeku ☐

2.5. Yoo hordoftee beekta ta'e(gaaffii 2.4^{ffaa}) waggaatti yeroo meeqa? Yeroo_____

2.6. Insuliinii fi lilmoo insuliinii ittiin waraannattan eessaa argatta? 1. Nan bita 2. Bilisa kennama

2.7. Yoo ni bitta ta'e gatii dawaa dhukkuba sukkaaraa kana akkamiin ilaalta?

Rakasa ☐ Qaalii ☐

2.8. Ati/daa'imnikee carraa ittiin hanga giluukoosii dhiiga keessaa ofiin ofto'atan ni qabaattuu? Eeyyee, ni qabna ☐ Lakki, hin qabnu ☐

2.9. Yoo ni qabda taate(gaaffii 2.8^{ffaa}) ji'atti yeroo meeqaaf hanga giluukoosii dhiigakee keessaa to'atta? _____

2.10. Sanyiinkee keessaa dhukkuba sukkaaraa kan qaban jiruu? Jiru ☐ Hin jiran ☐

2.11. Dhukkuba sukkaaraan alatti dhukkuni biraa ittiin dararamtu jiraa? Jira ☐ Hin jiru ☐

Kutaa 3^{ffaa}: Ilaalcha maatiin qulqullina eeggannoo dhukkuba sukkaaraaf godhamu irratti qaban

Qajeelcha: Gaaffileen 15 armaan gadii kallattii baay'ee eeggannoo dhukkuba sukkaaraaf godhamu ilaallata. Akka maatii daa'ima keessaniitti maaloo eeggannoo dhukkuba sukkaaraa daa'imni keessan yeroo hordoffiif deddeebi'u godhamuuf tilmaamaa. Maaloo gaaffii tokkollee akka irran tarreef yaali. Yoo yeroo hordoffiikee yaala kennitoota lamaa fi isaa oliin tajaajilamtee jiraatte, qabxii giddu galeessa ta'e yaala kennitoota kanaaf kenni.

Lakk.	**Wantoota**	**Deebii**				
		gadi bu'aa	**giddu galeessa**	**gaarii**	**Baay'ee gaarii**	**Baay'ee baay'ee gaarii**
3.1	Yeroo yaala kennitootaan mariisisuun dura fudhatu					
3.2	Yeroo yaala kennitoota waliin yaalamuuf fudhatu					
3.3	Yeroo ati hordoffiikee isa itti aanuuf eeguu qabdu					
3.4	Ifa ta'uu odeeffannoo yaala kennitootarraa					

siif kennamee

3.5 Hanga odeeffannoo yaala kennitootarraa argattee

3.6 Faayidaa qabeessummaa odeeffannoo yaala kennitootarraa argattee

3.7 yeroo yaala kennitootaan gorfaman carraa gaaffii gaafachuu

3.8 Deeggarsa kaka'umsa keessaa yaala kennitootni siif qaban

3.9 Ga'umsa teeknika fayyaa ogeessota fayyaa/yaala kennitootaa

3.10 Waa'ee yaala duraan daa'imnikee dhukkuba sukkaaraaf argate/ttee yaala kennitootatti hangam himamee jira

3.11 Carraa yaala daa'imakeerratti yaala kennitootaan godhamu duukaa murteessuu

3.12 Akka salphaatti isinttti tolee beellama itti aanu yaala kennitoota duukaa murteessuu

3.13 Tajaajila yaala kennitootni daa'ima keessanii fi siniif godhaniif gatii akkamii laattu

3.14 Yaala ogeessonni fayyaa daa'ima keessaniif godhan,hangam isin quubsee/gammachiisee jira

3.15 Waliigalatti qulqullummaan yaala ogeessa fayyaan daa'imakee dhukkuba sukkaaraa qabuuf kennamuu

3.16 Gorsa dhuunfaan gosa nyaata fayyaa sanaan walqabate irratti kenname

3.17 Gorsa dhuunfaa sosocho'insa qaamaa gochuu irratti kenname

3.18 Gorsa dhuunfaan eeggannoo miillaa/lukaa irratti kenname

3.19 Barumsa yaala gluukoosii dhiiga keessaa gadi bu'e hir'isuuf ji'oota 12 darban keessatti kenname

3.20 Barumsa daawwaa irratti ji'oota 12 darban keessatti kenname

3.21 Itti fufiinsaan gargaarsa yaala insuliinii calqabsiisuuf akkasuma eeggannoo isaatiif godhame

3.22 Qoratamuu miidhaa waggaatti dhukkuba sukkaaraan dhufanii fi jiraachuu isaanii, akkasumas haala gaariin yaalamuu isaanii

3.23 Dhiibbaa dhukkubni sukkaaraa sammuurratti qabuuf qoratamaniiruu

3.24 dhukkuba sammuu kanaatiifis yaalaargataniiruu

3.25 Dhukkubsatoota dhukkuba sukkaaraa

yaaluuf haalaan leenji’aniiruu

3.26 Carraa ispeeshaalistii dhukkuba sukkaaraatin yaalamuu ni argattuu

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Kutaa 4ffaa: Tuqaalee ragaa dhukkubsatootaa ittii sakattaanu

Lakk.	**Gaaffii**
4.1	Hanga giluukoosii dhiiga keessaa soorata lagannaan boodaa kan ammaa: _____
4.2	Giddugaleessa hanga giluukoosii dhiiga keessaa soorata lagannaan boodaa: _____
4.3	Gartuu dawaa kam fayyadamaa jirti/jira? _____ _____ _____
4.4	Yeroo meeqaaf ciistee/ciisee yaalamte/yaalame? yeroo _____
4.5	Waggaa tokko darbe keessatti yeroo meeqaaf sababa dhukkuba sukkaaraatiif ciiste/ciise(rakkoolee dhukkuba sukkaaraa duukaa dhufan)? yeroo_____

Gaaffiin ani isin gaafachuu barbaade hundi kan armaan oliiti. Yeroo keessan aarsaa gootanii fi odeeffannoo gati-qabeessa naaf kennitaniif baay'een isin galateeffadha. Gaaffii dabalataa akkan isiniif kaasu barbaaddan qabduu?

_____

_____

_____

የመረጃና የፈቃደኝነት ማረጋገጫ

ሀ. የጥናቱ መረጃ

እንደምንአደረሱ፣እንደምንዋሉ፣እንደምንአመሹ [እንደአስፈላጊነቱ]፡፡

ስሜ----------ባላለሁ፡፡ እኔ የመጣሁት በጂማዩኒቨርሲቲ መዲካልሠንተር የህፃናት ሂኪሚና ረዚደንት በሆነቹ በዶ/ር ሽጊቱ ምሬሣ እየተሰራ ባለዉ ጥናታዊ ፅሁፍ ዙሪያ በመረጃ ሰብሳቢነት ሲሆን በዛሬው እለት አዚህ የተገኘሁት ለሱካር በሽታ ህፃናቶች ስለሚደረገው እንክብካቤ ላይ የቤቴሰብ ግንዛቤ በጂማ ዩኒቨርሲቲ መዲካል ሠንተር በሚመለከት በሚደረገው አነስተኛ ጥናት ዙሪያ መረጃ ለመሰብሰብነዉ፡፡ ስለሆነም አንዳንድ ጥያቄዎችን ላቀርብልዎ እፈልጋለሁ፡፡ በዚህ ጥናት በመሳተፍዎ የሚያገኙት ቀጥተኛ የሆነ ጥቅም የለሌ ሲሆን ነገርግን ከዚህ ጥናት የሚገኘዉ ዉጤት በቀጥታ ማህበረሰቡን የሚጠቅም ሲሆን ለእርስዎ ደግሞ እርካታን እንደሚሰጥዎት ተስፋ አደርጋለሁ፡፡

ስምዎት ከመረጃው ጋር አይካተትም፤ የሰጡኝን መረጃ ሁሉ በሚስጥር እንደምጠብቅልዎ ቃልእገባለሁ፡፡ ይህንንም ለማድረግ ከእኔጋር ወደ ግማሽ ሰዓት እንቆያለን፡፡ ይህ ጊዜዎትን የሚይዝ ቢሆንም መላውን የስካር ህሙማንን ሊጠቅም የሚችል የእገልግሎት ጥራት ማሻሻያ ለማድረግ የሚያግዝ በመሆኑ እንዲተባበሩኝ እጠይቅዎታለሁ፡፡

የተወሰኑ ደቂቃዎች ባነጋግርዎ ፈቃደኛ ነዎት?

ፈቃደኛ ነኝ □ ፈቃደኛ አይደለሁም □ አመሰግናለሁ!

ለ. የፈቃደኝነት ማረጋገጫ

የምርምር ጥናቱ ከፍል የሆኑ መረጃዎችና ሂደቶች ተብራርተውልኛል፡፡ እኔም በተብራራልኝ መንገድ ተረድቻለሁ፡፡ ምርምሩ ምንም አደጋ የማያስከትል በመሆኑ ለሚያደርጉት የተሳትፎ ክፍያ አይኖረውም፡፡ ስለዚህ በዚህ የምርምር ጥናቱ ላይ ለመሳተፍ ፈቃደኛ መሆኔን በፊርማዬ አረጋግጣለሁ፡፡

ፊርማ ----------

ቀን ----------

ቀን ----------

የጤና ድርጅቱ ስም----------

የጠያቂ ስም ----------

ክፍል አንድ፤ አጠቃላይ መረጃ (የተሳታፊው የማህበራዊና ኢኮኖሚያዊ መረጃ)

1. እድሜክ(ሺ) ስንት ነው?.....

2. ጾታ 1. ወንድ 2. ሴት

3. የመኖሪያ ቦታ 1. ከተማ 2. ገጠር

4. ብሔር 1. አማራ 2. ኦሮሞ 3. ጉራጌ

4. ትግሬ 5. ሌላ [ይገለጽ_____

5. ሐይማኖት 1. ኦርቶዶክስ ክርስቲያን 2. ሙስሊም

3. ፕሮቴስታንት ክርስቲያን 4. ካቶሊክ ክርስቲያን

5. ሌላ [ይገለጽ] _____

6. የቤተሰብ የሥራ ሁኔታ 1. ገበሬ 2. ነጋዴ 3. የቀንሥራ 4. ደመወዝተኛ [የመንግስት ተቀጣሪ]

5. አሳወጥማጅ 6. ሌላ[ይገለጽ] ----------

7. የወላጅ ወርሃዊ ገቢ በብር ----------

8. የወላጅ የትምህርት ደረጃ እናት 1. የተማሬች 2. ያልተማሬች

አባት 1. የተማሬ 2. ያልተማሬ

ክፍልሁለት፤የስኳርበሽታውታሪክናየጤናተቋምእንክብካቤ

9. የስኳርህመምእንዳሌብ/ክ/ሽ/ዎትለጤናባሌሙያከተነገርዎትስንትዓመትሆነዋል? ……. ዓመት

10. በዓመትስንትግዜየስኳርህሙማንክትትልወደሚደረገውጤናተቋምይሄዳሉ/ሄደሃል/

ሄደሻልወይምበዓመትስንትግዜወደዚህክሊኒክክትትሌያደርጋሉ/ አድርገሃል/አድርገሻል? …… ጊዜ

11. ለክትትልስመጡ/ ስትመጣ/ ስትመጪ/ ሒክሚናለማገኘትምንያህልግዜይቆያሉ/ትቆያለክ/ሽ?..... ዴቅቃ.

12. ቤታቹከጤናተቋምምንያህልይርቃል?..... .በኪሎሜትር.

13. ለስኳርህሙማንየሚሰጠውንየጤናትምህርትተከታትለዉያውቃሉ/ ታዉቃለህ/ሽ?

1.አዎ 2. አይደለም

14. ለጥያቄቁጥር 13 መሌስዎ/ክ/ሽአዎከሆነባለፈውዓመትስንትጊዜት/ቱንተከታተለዋል? ……. ጊዜ

15. እንሱሊንእናመርፌንከየትነውየሚታገኙት? 1. በግዥ 2. በነፃከሚታደል

16. በግዥከሆነየእንሱሊንዋጋንእንዴትይገመግሙታል/ ትገመግማለክ/ሽ? 1. ዉድነው 2. ርካሽነው

17. ልጆትየደሙን/የዴሞዎንስካርመጠንመለክያዘዴአለው/አላት? 1. አዎ 2. አይደለም

18. ለጥያቄቁጥር 17 መልስዎአዎከሆነበወርስንትጊዜይለካሉ?.....ጊዜ.

19. ቤቱሰብውስጥስካርህመምተኛአለ? 1. አለ 2. የለም

20. ከስካርበሽታዉጪሌላታመዉ/ሽታዉቃለክ/ሽ? 1. አዎ 2. አይደለም

21. ለጥያቄቁጥር 20 መሌስዎአዎከሆነምን ? ----------

ክፍልሶስት፡ለስካርበሽታስለምደረገውእንክብካቤላይየቤቴሰብግንዛቤ

መምሪያ፡የሚከተሉት 15 ጥያቀዎችለስካርበሽታየሚደረገውንእንክብካቤዎችየያዙትናቸው.

እባክዎትለክትትልስመጡየሚደረገውንእንክብካቤይገምግሙት.

በሁለትናከዚያበላይየጤናባለሙያዎችኪታከሙሁሉንምያማከለመልስይስጡ.

ቁጥር	የሚገመገሙትነገሮች	መልስ				
		ዝቅተኛ	መካከለኛ	ጥሩ	ከፊተኛ	በጣምከፊተኛ
1	ባለሙያንሳያማኪሩየጠበቁትጊዜ					
2	በአጠቃላይየማማከሪያጊዜ					
3	ለቀጣይቀጠሮየሚቆዩትጊዜ					
4	ከባለሙያውየሚታገኙትምክርግልጽነት					
5	የሚታገኙትምክርብዛት					
6	የሚታገኙትምክርጠቃምነት					
7	የማማከርያጊዜጥያቄየመጠየቅእድል					
8	የጤናባለሙያዎችህሊናድጋፍ					
9	የጤናባለሙያዎችየጤናቴክኒክብቃት					
10	ልጅህለስካርበሽታስያገኘየነበረውህክምናየጤናባለሙያዎችየተረዱትጥልቀት					
11	ልጆትየሚያገኘውህክምናዉሳኔውስጥየመሳተፍእድል					
12	የቀጣይቀጠሮጊዜአመችነቱ					
13	ለእርሶናለልጆትየሚደረገውንእንክብካቤእንደትያያሉ					
14	በመጀመርያበጤናባለሙያዎችምንያህልተደሰቱ					
15	በአጠቃላይየሚሰጥእንክብካቤጥራት					

ክፍልአራት: የህመምተኛንመዝገብለመፈተሽየሚረዱንነጥቦች

ቁጥር	ጥያቄ
1	በፆምየደምስካርመጠንየሁኔታ:
2	መካከለኛየፆምየደምስካርመጠን:
3	የትኛዉየመድሐንትዓይነትእየተጠቀመ/እየተጠቀመችነው? --- --- ---
4	ለስንትጊዜተኝቶታክመዋል/ተኝታታክማለች?
5	ከበሽታዉጋርተያያዥበለዉበሽታስንትጊዜበዓመትተኝተሀል

ሌጠይቃቹየፈለኩትጥያቄዎችእሄንኑይመስላሉ. ግዜአቹንመስአዋትስላደረጋቹልኝናስለሠጣቹኝመልስአመሰግናለው!!

የማኔሳላቹንጥያቄአለቹ?

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