



**ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE OF CHILDREN WITH  
CHRONIC KIDNEY DISEASE ON FOLLOW UP AT PEDIATRIC RENAL CLINIC,  
TIKUR ANBESA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA**

**BY: GETASEW CHEKOL (PEDIATRICS AND CHILD HEALTH RESIDENT)**

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BY: GETASEW CHEKOL (PEDIATRICS AND CHILD HEALTH RESIDENT)

PRINCIPAL ADVISOR: DR. BEZAYE ABEBE

(MD, ASSISTANT PROFESSOR OF PEDIATRICS AND CHILD HEALTH, PEDIATRIC NEPHROLOGIST)

CO-ADVISOR DR. PRIYA PAIS

( MD, ASSOCIATE PROFESSOR, PEDIATRIC NEPHROLOGIST, BANGLORE, INDIA )

Thesis Has No Conflict Of Interest With The Authors And Its Part Of Study Being Conducted On Quality Of Life Of Childrens With Ckd And Costing Of Care In Low And Middle Income Countries

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## Acronyms

CKD.....chronic kidney disease

AKI.....Acute kidney injury

eGFR.....Estimated glomerular filtration rate

ESRD..... End Stage Renal Disease

KRT.....Kidney replacement therapy

CKID..... Chronic Kidney Disease in Children

HRQoL.....Health related quality of life

PedsQL.....Pediatric quality of life inventory

QOL.....Quality of life

OOP.....out of pocket

CHE.....Catastrophic health expenditure

NAPRTCS..... The North American Pediatric Renal Collaborative Trials

CAKUT .....Congenital Anomalies of kidney and urinary tract

LLMICs .....Low and Low middle income countries

NKF- KDOQI.....National Kidney Foundation Kidney Disease Outcomes Quality Initiative

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## **Abstract**

### **Background**

Children with chronic kidney disease face lifelong increases in morbidity, mortality, and decreased quality of life. As most of other chronic illnesses, CKD has hard impact on ill children's and care givers life style, peer relationship, pain interference and social functioning moreover CKD has impact on intellectual functions and behavioral characteristics including anxiety and depression.

**Objective-** To assess health related quality of life of children with CKD as well as their caregivers' perception on their Childs performance and to determine the factors that adversely affect it.

**Methods and material:** A cross-sectional analytical study conducted using a pre coded, pretested structured questionnaire including PedsQoL™ 4.0 scale score generic core and family impact module. Data obtained for demographic and clinical parameters of children and for each domain of generic core and family impact module and data was analyzed using IBM SPSS® version 26.

**Results-** 105 children with CKD aged 2-18 years, 61(58.1%) males and 44(41.9%) females were included in this study. Among the child self reported domains of generic core scale, child's 'school performance' was most affected with mean of 74.91 (SD±22.29) followed with child 'physical performance' 77.6±26.41. In the family impact module domains with mean also, the most affected being 'school performance' with 75 (SD±19.89) followed with 'physical functioning' with 78.13 (SD±24.96).

**Recommendation:** 'School performance' and 'physical functioning' were the most affected domains in child generic scale and family impact modules. Optimal care requires attention not only to medical management, but also to an assessment of health related Quality of Life factors, that may help promote pediatric CKD patient's health like Implementation of a standardized tool and Multidisciplinary approach in addressing HRQoL in all CKD patients on follow up.

## **1: Introduction**

### **1.1 Background**

Chronic kidney disease (CKD) is a major health problem worldwide with increasing incidence and prevalence defined as the presence of kidney damage, either structural or functional, or by a decline in glomerular filtration rate (GFR) below 60 mL/min/1.73 m<sup>2</sup> of body surface area for more than 3 months with implications to health [1].

Therefore, the term CKD defines renal dysfunction as a continuum, rather than a discrete change in renal function, this definition has been formulated for the adult population, where CKD is a common and well-known health problem, but the KDIGO guidelines for definition and staging are not fully applicable to the pediatric population. Indeed, pediatric CKD, while sharing the basic pathophysiologic mechanisms with the same disease in the adult population, could be in some ways considered a stand-alone nosologic entity [1].

The prevalence of pediatric chronic kidney disease (CKD) ranges from 15 to 74.7 cases per 1 million children. Mortality among children who progress to end-stage kidney disease (ESKD) is 30 to 50 times higher compared to that in the general population. Most of the data on pediatric CKD comes from the developed world. The North American Pediatric Renal Collaborative Trials (NAPRTCS) data show a progression rate from CKD stages II to IV to ESKD of 17% at 1 year and 39% at 3 years, with the median time to ESRD being 4.5 years.

CKD is listed as one of the top common chronic renal condition in our setting, accounting to 4 % of renal related hospital admissions in Tikur Anbessa Specialized Teaching Hospital in Addis Ababa, Ethiopia [2,3].

Primary causes of CKD in children significantly differ from those that are responsible for the adult onset of the disease. In fact, the main etiologic factors of CKD in children are represented by CAKUT, steroid-resistant nephrotic syndrome (SRNS), chronic glomerulonephritis (e.g. lupus nephritis, Alport syndrome) that account for approximately 49.1%, 10.4%, 8.1 % of cases, respectively and for more than 70% of all pediatric CKD cases when considered together [4].

As in every chronic physical illness, In general, most chronic diseases including CKD have hard impact on ill children's life style, physiological and physical development. In the last years, even

if medical cures allowed these children to live longer and to have a better quality of life, today both their families and themselves have to face a lot of difficulties due to the kind of pathology. These children show behavior troubles, bad sociability, aggressiveness, poor school performance, anxiety and depression, subjects with chronic renal failure show also a retard in neurological and cognitive development. Besides, they are faced by possible collateral effects of the illness and of its treatments on development [5].

## **1.2 Statement of the problem**

Chronic kidney disease (CKD) is a significant health concern and an important contributor to morbidity and mortality from non-communicable diseases globally, The Global Burden of Disease (GBD) study ranked CKD the 19<sup>th</sup> leading cause of morbidity and death in 2013. CKD is characterized by young age of patients in LLMICs, huge morbidity and premature deaths. About 90% of patients with CKD die within 90 days of starting dialysis [5].

Early detection, timely interventions and higher rates of transplant are associated with better outcomes in children with CKD in high income countries (HIC) as compared to those in low and low middle income countries (LLMIC) Like ours, where there is a delay in diagnosis and initiation of treatment, poor access to care, greater morbidity and lower rates of dialysis [4,6,7]. Only 30 - 45% of LLMIC children in ESRD initiate maintenance dialysis and even fewer accomplish renal transplantation. Premature discontinuation of treatment, commonly seen in low resource settings, occurs during all stages of CKD, but is particularly frequent (40 – 50%) in children requiring KRT [8, 9]. As centers providing KRT to children are very few, discontinuation of treatment is presumed to lead to death. Thus in LLMICs mortality rates of pediatric CKD are assumed to be high.

Parents and primary care givers are also facing serious impact of disease a manifested with inferior quality of life in the aspects of emotional psychiatric and financial difficulties adding to the burden they already hold.

### **1.3 Rationale of study**

This study aims in the assessment of health-related quality of life in children and adolescents with CKD and ESRD on follow up at pediatric renal clinic, Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia. It is designed to help us understand the impact of the disease and interventions in the health-related quality of life of the children and adolescents as well as caregivers. The findings of this study can help the clinicians understand the magnitude of effect on quality of life and the clinical and demographic factors associated with inferior quality of life, moreover integrate the aspects of life impacted by the disease as a routine clinical evaluation and practice in the patient as well as care giver. One can generate an integrated management guideline specific to the study population including assessment, evaluation and intervention modalities with provision of comprehensive care addressing health-related quality of life. The study can serve as baseline data and can be used as a holistic valuable tool for the current approach towards pediatric family centered care management as it signifies the burden of the patients as well as care givers hopefully will help as reference for further study.

## **2: Literature review**

### **2.1 Assessment of health-related quality of life**

Pediatric health-related quality of life (HRQOL) has emerged as an important health outcome in clinical trials and healthcare research, for which HRQOL assessment instruments have played an important role. A practical, validated generic measure of HRQOL facilitates assessing risk, tracking health status, and measuring treatment outcomes in pediatric populations. The PedsQL (Pediatric Quality of Life Inventory) (Children's Hospital and Health Center, San Diego, California) is a modular instrument for measuring health-related quality of life (HRQOL) in children and adolescents ages 2 to 18. The PedsQL 4.0 Generic Core Scales are multidimensional child self-report and parent proxy-report scales developed as the generic core measure to be integrated with the PedsQL Disease-Specific Modules. The PedsQL 4.0 Generic Core Scales consist of 23 items applicable for healthy school and community populations, as well as pediatric populations with acute and chronic health conditions.(10)(11) .

A study by Varni J W. et al. to assess its validity and reliability in 2001, PedsQL 4.0 Generic Core Scales (Physical, Emotional, Social, School) was administered to 963 children and 1,629 parents (1,677 subjects accrued overall) recruited from pediatric health care settings. Item-level and scale-level measurement properties were computed. Internal consistency reliability for the Total Scale Score ( $\alpha = 0.88$  child,  $0.90$  parent report), Physical Health Summary Score ( $\alpha = 0.80$  child,  $0.88$  parent), and Psychosocial Health Summary Score ( $\alpha = 0.83$  child,  $0.86$  parent) were acceptable for group comparisons. Validity was demonstrated using the known-groups method, correlations with indicators of morbidity and illness burden, and factor analysis. The PedsQL distinguished between healthy children and pediatric patients with acute or chronic health conditions, was related to indicators of morbidity and illness burden, and displayed a factor-derived solution largely consistent with a prior conceptually-derived scales.

To assess validity and reliability of PedsQL™ Family Impact Module, Varni JW. et al. In 2001 performed the 36-item module which was administered to 23 families of medically fragile children with complex chronic health conditions who either resided in a long-term care convalescent hospital or resided at home with their families. Internal consistency reliability was

demonstrated for the PedsQL™ Family Impact Module Total Scale Score ( $\alpha = 0.97$ ), Parent HRQOL Summary Score ( $\alpha = 0.96$ ), Family Functioning Summary Score ( $\alpha = 0.90$ ), and Module Scales (average  $\alpha = 0.90$ , range = 0.82 - 0.97). The PedsQL™ Family Impact Module distinguished between families with children in a long-term care facility and families whose children resided at home.

Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns [12]. HRQoL is used as a metric to measure the effectiveness of treatment interventions and also in an effort to define and alter models of health care delivery [10]

Cross sectional studies have shown poor quality of life in children with CKD, especially in physical and emotional domains [12-14]. ESRD patients especially suffer from a multitude of physical and emotional symptoms, exhibit a particularly high prevalence of depression, and experience substantial deterioration in quality of life resulting in higher mortality and hospitalization rates. Furthermore, dialysis treatment schedules are burdensome and interfere with school attendance and participation in peer-related activities, thereby compromising opportunities for attaining academic and psychosocial potential [16-18]. Better HRQoL scores have been described in kidney transplant recipients as compared to those on peritoneal or haemodialysis [19-21].

## **2.2 What is known about pediatric CKD and ESRD in LLMIC?**

Inadequate access to pediatric CKD care: the shortage of nephrologists and lack of universal access to KRT has been well described in adults with CKD. The access to pediatric nephrology care is even worse, although accurate data from LLMICs are unavailable. Harambat et al estimated that less than 10% of children with ESRD in South Asian and Sub-Saharan LLMICs receive KRT (5).

Limited data indicate poor outcomes and survival: It is generally acknowledged that outcomes of pediatric CKD in LLMICs are poor, but prospective studies describing the extent of morbidity and mortality are lacking. In the absence of hard evidence, outcomes are often described in terms of premature 'discontinuation of treatment' or loss to follow up. Discontinuation of treatment, largely unknown in high-income countries, occurs frequently in low resource settings, and is

usually presumed to result in the child's death. The mortality rates of untreated pediatric ESRD children in Africa were 90% (5). Rates of discontinuation of treatment ranged from 10% in early CKD to 50% in ESRD in our centre (1). Premature discontinuation of ESRD care was associated with greater travel distances, delayed diagnosis of CKD and low family socioeconomic status (3,11). These data indicate that poor access to care and high costs might occur in other centers also.

**Public and Private Sector hospitals:** Although public hospitals provide free or almost free treatment, pediatric CKD care and KRT are often not available at these centers. The majority of KRT for children is currently provided at private hospitals with payment occurring OOP by families (12).

A comparison of patient outcomes and OOP expenses in public vs private hospitals is not available.

**Low rates of initiation and maintenance of KRT:** Although more centers in LLMICS now have provide acute dialysis, maintenance dialysis services for children are very limited (13). In India, it is estimated that only 30% of children with ESRD receive maintenance dialysis, due to non-availability of pediatric KRT or family refusal to consider dialysis (4). Whether refusal to initiate KRT is a result of inadequate finances or parental preference is unknown. Renal transplantation is not available in many LLMIC countries. Even in transplant centers, only 5 - 20% receive a kidney transplant (12,13).

**High Out of pocket expenditure (OOP) and frequent catastrophic health Expenditure (CHE):** Children have inequitable access to publicly funded KRT programs (14). Thus, payment for CKD care and KRT is largely by OOP expenditure. In a retrospective analysis of the financial burden associated with CKD at our center, hospital admissions for CKD care were associated with high costs, exceeding annual incomes in 33% of cases.

These CHE occurred more frequently in ESRD compared with earlier stages of CKD (9). In a qualitative study of parents of children with ESRD, stress due to financial hardship was a major theme (15).

### **2.3 What are the knowledge gaps in Paediatric CKD in LLMICs?**

There are no national registries tracking children with CKD or ESRD and therefore datasets monitoring clinical outcomes, HRQoL and caregiver burden are unavailable. Quality of life and caregiver burden studies mostly described in HICs may not reflect an accurate picture of the perceptions in LLMICs [16-21, 27]. \

There is a dearth of data from LLMICs. Late diagnosis, more severe comorbidities and conservative treatment in ESRD children are some of the unique situations and challenges that interfere with the management of chronic kidney disease in LLMICs. Unlike developed countries where the government provides financial support for chronic conditions, in LLMICs it is largely an OOP expenditure [28]. We hypothesize that the HRQoL for children with CKD and caregiver burden in LLMIC is worse than in those in HIC. Prospective studies are needed to examine the impact of CKD on HRQoL over time, as well as the relationship between HRQoL and outcomes such as CKD progression and mortality. In order to describe the scope of the problem, we need better data from LLMICs than single centers reports (7, 29, and 30).

### **3: Objectives**

#### **3.1 General objective**

To assess the health-related quality of life of children and adolescents with CKD and ESRD on follow up at Tikur Anbessa Specialized Hospital, pediatric renal follow up clinic.

#### **3.2 Specific objectives**

- To assess care givers perception of health related quality of life of the children and adolescents with CKD on follow up at,TASH .
- To identify factors associated with poor quality of life in children with CKD.

## **4: Methods and materials**

### **4.1 Study area**

The study was conducted in Tikur Anbessa Specialized Hospital, pediatrics department in the pediatric renal follow-up clinic. Tikur Anbessa is Ethiopia's largest general public hospital. In 1998 Tikur Anbessa Hospital, which is also the largest referral hospital in the country was given to Addis Ababa University (AAU) by the Ministry of Health (MoH) for the faculty as a main teaching hospital. The faculty is the oldest and the largest among the health training institutions in the country, staffed with the most senior specialists. The hospital provides a tertiary level referral treatment and is open 24 hours for emergency services. The hospital is administered by Addis Ababa University and is the largest and oldest teaching hospital among all in Ethiopia providing teaching for about 300 medical students and 350 Residents every year. Black Lion hospital offers diagnosis and treatment for approximately 400,000 patients a year.

The pediatric department has one renal clinic seeing patients on Tuesday and Thursday where all renal patients are followed. Renal clinic and rounds are attended by pediatric nephrologist and pediatrics residents.

The clinics on average saw 80 – 120 patients on monthly basis which will give us reliable estimate of sample

### **4.2 Study design and period**

An analytical cross-sectional study was conducted from the study period from Jun 15, 2021 to September 30, 2021 G.C. Data was collected from log books for sampling frame and tracing patients and patient charts for clinical and investigational parameters. A self-administered questionnaire was used for children age more than 5yrs and parents. For children less than 5 years data was collected from their parent as proxies to complete the generic core and family modules of PedsQoL™. Due to current COVID-19 pandemic and decreased patient flow to the clinic some of the questionnaires were filled via phone call interview for children, parent and parent proxies.

### **4.3 Source population**

All children and adolescent patients who have follow up at TASH pediatric renal clinic

#### 4.4 Study population

All children and adolescents With CKD who are on follow up at Tikur Anbessa Specialized Hospital, pediatrics department, pediatric Renal follow up clinic who are willing to participate in the study

#### 4.5 Inclusion criteria and exclusion criteria

##### 4.51 inclusion criteria

All children and adolescents above 2 yrs of age with CKD and ESRD who are on follow up since at least three months prior to data collection time and on follow up during study period at Tikur Anbessa Specialized Hospital, pediatrics department, pediatric Renal follow up clinic Or at least one primary care giver available who gave consent .

##### 4.52 Exclusion Criteria

- ✓ Received a renal transplant or on dialysis
- ✓ Other comorbid chronic illness like cancer
- ✓ incomplete chart data

#### 4.6 : Sample Size Determination and Sampling Technique

The reported mean QOL score obtained using PedsQL scale on ESRD children is  $58.4 \pm 15.4$ . Hence to estimate the QOL score among the CKD children with standard deviation of 15.4, and precision of 3 for the mean QOL score with 95% Confidence interval the required minimum sample size is 101 CKD patients

<b>One sample mean estimation</b>	
<b>Standard Deviation (<math>\sigma^2</math>)</b>	15.4
<b>Confidence interval</b> $Z_{(1-\frac{\alpha}{2})}^2$	95%
<b>Precision (d)</b>	3 %
<b>Sample size (n)</b>	101

$$\text{Formula } n = \frac{Z_{(1-\alpha/2)}^2 * \sigma^2}{d^2}$$

$\sigma$  - Standard deviation

d – Precision

$Z_{(1-\alpha/2)}$  – standard value for the confidence interval

By adding 10 % non-responder rate N becomes 111

#### **4.7 : Sampling technique**

The study subjects Were selected using convenient sampling technique by taking their list from follow-up registration book. Childrens satisfying the inclusion criteria were enrolled in the study after obtaining the list of all childrens and adolescents with CKD and ESRD on follow up at Pediatric renal clinic at TASH.

#### **4.8: Data collection Tools**

Data collection was by using validated, structured and pre-tested questionnaire. It was prepared in English and was translated to Amharic version by professional translator which was reviewed again by investigator and advisor,. It was consisting of socio-demographic information, selected clinical variables and Pediatric Quality of Life Inventory™ (PedsQoL™) version 4.0 generic and family impact module which is free tool. after we obtained permission from the MAPI Research Trust ,France, after signing the User Agreement with knowledge of the author Dr. Varni, James Walter with official Email communication (see annex 2 for agreement) for assessment of impact on life quality . The validated and age appropriate version of PedsQoL 4.0, Pediatric Quality of Life Inventory™(PedsQoL™) version 4.0 generic questionnaire was parent administered for those children below 5 years and child administered for those children aged above 5 yrs. The family impact module was administered by parents. The parameters on the questionnaire were scored on a five-point Likert scale. The completed questionnaires were assessed for data entry. The scores were generated according to the developer’s scoring system and were then reversed and linearly transformed to a 0-100 scale where 0=100, 1=75, 2=50, 3=25, 4=0. Higher scores indicate better HRQoL and factors evaluated for their role in affecting Health related quality of life. Data collection was undertaken by the principal investigator, two assigned residents who received brief explanation about data collection before study period.

## **4.9 Dependent and independent variables**

### **4.91 Dependent variable**

Health related quality of life in children with CKD and ESRD and Their care takers.

### **4.92 Independent variable**

- Age
- Sex
- Family size
- Monthly income of caregiver
- Residency
- Stage of the CKD
- Duration of illness

## **4.10 Data processing and analysis**

After data collection, each data set was checked for completeness based on the code given during data collection. The data was entered in to SPSS version 26 statistical package. Coding of individual questionnaires was checked before data entry into the software. Further data cleaning was performed to check for outliers, missed values and any inconsistencies before the data were analyzed using the software. Descriptive analysis along with pearsons correlation coefficient were used to perform statistical analysis. The results were presented using tables and figures.

The magnitude of the association between the different variables in relation to the Health-related quality of life was measured using odds ratios (OR). A confidence limit of 95% and p value less than 0.05 was considered statistically significant.

### **a) Pediatric Inventory of Quality of Life Core Scale**

Health related quality of life of all eligible children was evaluated using Pediatric Inventory of Quality of Life Core Scales (PedsQL™, Version 4.0). It is a 23 item generic HRQoL instrument that assesses physical, emotional, social and school functioning in children and adolescents [13].

#### b) PedsQL™ End-Stage Renal Disease Module 3.0

This module was used for only those in end stage renal disease. It includes seven domains covered by 23 questions: general fatigue, kidney disease-related problems, treatment-related problems, family and peer interaction, worry, perceived physical appearance and communication [13].

Respondents was instructed to review a list of problem statements and rate the degree to which each has been experienced over the past month. The domain scores were derived by summing the problem frequency within each domain and then linearly transforming the resulting sum into a standardized score. The overall HRQOL score was calculated by summing the problem frequency endorsements from the entire survey and dividing by the number of items answered.

Those who were unable to understand the questions or fill the questionnaire were assisted by interpreters.

#### **4.11 Data Quality Assurance**

The questionnaire was pretested and the pretest results will not be included in the study

The main investigator supervised the data collection

Each day the collected data was checked for accuracy and completeness

#### **4.12 Ethical Consideration**

The proposal was submitted and clearance was obtained from the DRPC of Addis Ababa University, College of Medicine. Parents were given a written consent and children were requested for assent prior to their participation in the study. A written consent form has been developed that stipulates clearly that their participation were voluntary, they have the freedom to refuse to respond to any of the questions, and also, they have a full freedom to withdraw from the evaluation at any time. It was made clear from the beginning that no payment was made to individuals in return for participating in the study and confidentiality & storage of data was explained to the participants. It was made clear that the answers provided during the course of

the interview will be treated with utmost confidentiality and used for study purpose only. The written consent and assent were translated to Amharic language.

#### 4.14 Operational Definitions

<u>Term</u>	<u>Definition</u>
Chronic kidney disease (CKD)	Kidney damage for $\geq 3$ months, as defined by structural or functional abnormalities of the kidney, with or without decreased GFR or $GFR < 60 \text{ml/min/1.73m}^2$ for $\geq 3$ months with or without kidney damage [1]
Stage 5/End Stage Renal Disease (ESRD)	Kidney failure, $GFR < 15 \text{ml/min/1.73m}^2$
Estimated GFR (eGFR)	Glomerular filtration rate calculated using modified Schwartz formula [33]
Conservative treatment	Medication only
Primary caregiver	The parent who has the greatest responsibility for the daily care of rearing of the child
Health-related quality of life (HRQOL)	An individual's or perceived physical and mental health over time.
Child's Health-related quality of life (CHRQoL):	A child's perceived physical ability, social, emotional health and school performance over past one month
Family Health-related quality of life (FHRQoL):	parents/caregivers perceived child performance on physical ability, emotion, social functioning and school performance over past one month.
Better Health-related quality of life	those participants scoring average score of child or family HRQoL module above the median (88.7,88) from the whole study population
Poor Health-related quality of life	Those participants scoring average score of child or family HRQoL module below the median (88.7,88) calculated from the whole study population
	are individuals who are responsible for the rearing of the child
Pediatric age:	age less than 18 year
Adolescent:	WHO defines an adolescent as any person between ages 10 and 19

## **5 : RESULTS**

### **5.1 : Socio-Demographic and clinical Characteristics**

Of the total 111 calculated study participants 108 were approached and participated in the study, and 105 were children with chronic kidney disease (CKD) and 3 were children with ESRD and only descriptive analysis was done as their number are so scanty .

Of the study participants 61 (58.1%) were male children whereas, 44 (41.9%) were female. 35 (33.3%) of the participants were, in the age range of 2-4 years and 25 (23.8%) were in the age group of 13 – 18 years. Concerning residence of subjects, 67 (63.8%) of the participants were Addis Ababa dwellers while 16 (15.2%) of the participants came from half day travel from Addis Ababa, 16 (15.2%) came from one day travel from Addis Ababa and 6 (5.7%) were from more than one day travel from Addis Ababa. Of the total participants, 53 (50.5%) were living in a family having a family size of 2-4 and 52 (49.5%) were living in a family having a family size of 5-7. Of the children's family 53 (50.5%) were earning monthly income of  $\geq$  4000 ETB. See( table 1)

Of the total participants 44 (41.9%) were diagnosed as stage 1 and 2 CKD, 61 (58.1%) were diagnosed with stage 3 and stage 4 CKD, respectively. In 47 (44.8%) of the study participants the duration since the diagnosis of CKD was between 1-3 years see (Table3).

There were 3 children in the study that were diagnosed with ESRD, and 2 of the children were males while 1 was Female. The Age of the two of children with ESRD ranged from 8 to 12 years and one is 15 years. Two of the children with ESRD reside in Addis Ababa while one came from a one-day travel from Addis Ababa. Of the children with diagnosis of ESRD family 2 were earning monthly income of between 1000- 4000 ETB and 1 earning more than 4000 ETB. For all children with diagnosis of ESRD the duration of illness was more than 3 years (Table2)

Table

<b>age</b>	2 to 4 yrs.	35	33.3
	5 to 7 yrs.	14	13.3
	8 to 12 yrs.	31	29.5
	13 to 18 yrs.	25	23.8
<b>Sex</b>	Male	61	58.1
	Female	44	41.9
<b>Residence</b>	Addis Ababa	67	63.8
	1/2-day travel from Addis Ababa	16	15.2
	1 day travel from Addis	16	15.2
	> one day travel from Addis	6	5.7
<b>Family size</b>	2 to 4	53	50.5
	5 to 7	52	49.5
<b>Income</b>	< 1000 ETB	6	5.7
	1000 ETB - 4000 ETB	46	43.8
	4000ETB -12000 ETB	53	50.5

1.Socio-

Demographic characteristics among children with CKD on follow up at renal clinic, TASH, Addis Ababa, Ethiopia from jun15, 2021 – September 30, 2021 G.C

	8 to 12 yrs.	2
	13 to 18 yrs.	1
<b>Sex</b>	Male	2
	Female	1
<b>Residence</b>	Addis Ababa	2
	1/2-day travel from Addis Ababa	
	1 day travel from Addis	1
	> one day travel from Addis	
<b>Family size</b>	2 to 4	
	5 to 8	3
<b>Income</b>	< 1000 ETB	
	1000 ETB - 4000 ETB	2
	>4000ETB ETB	1
<b>Stage</b>	ESRD	3
<b>Duration</b>	< 1yr	
	1 - 3yr	
	>3yr	3

**Table 2: Sociodemographic and clinical characteristics data for ESRD**  
**5.2: Clinical Characteristics**

Among the children with CKD, 61 (58.1%) of children were having stage 3 and above CKD and in about 38 children (36.2%) Duration of the illness is greater than 3 years. (Table 3)

**Table 3** : clinical

<b>Stage</b>	stage 1 CKD	15	14.3	
	stage 2 CKD	29	27.6	
	stage 3 CKD	40	38.1	
	stage 4 CKD	21	20	
	<b>Duration</b>	< 1yr	20	19
		1 - 3yr	47	44.8
		>3yr	38	36.2

characteristics of study participants

**5.3 : Child and parent mean scores of quality-of-life domains**

The total QoL mean score for child report was 80.76±19.31 SD while the total QoL mean score for family report was 80.64±18.23 SD. The child report and parent report mean scores of all quality-of-life domains (physical, emotional, social, and school domains) are summarized in (Table 4). Only 7 children from age group 2- 4 attende preschool so school functionin and psychosocial domain analysis was not feasible.

No.	Mean±SD	No.	Mean±SD	<0.001
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<b>physical QoL mean score</b>	70	77.6±26.41	105	78.13±24.96
<b>emotion QoL mean score</b>	70	83.84±17.13	105	79.5±14.7
<b>social QoL mean score</b>	70	86.83±25.26	105	90.28±21.26
<b>school QoL mean score</b>	70	74.91±22.29	77	75±19.89
<b>Psychosocial QoL mean score</b>	70	81.93±18.9	77	81.37±17.4
<b>Physical health summary QoL mean score</b>	70	77.38±27	105	78.3±24.98
<b>total QoL mean score</b>	70	80.76±19.31	85	80.64±18.23

Table 4 : Child and parent mean scores of quality-of-life domains for child and parent proxy report

<b>General fatigue</b>	49.17±11.27	52.08±3.61
<b>About kidney disease</b>	55.42±5.05	60.42±13.01
<b>Treatment</b>	60.42±13.01	60.42±13.01
<b>Family and peer</b>	61.11±24.06	52.78±20.97

<b>Worry</b>	16.67±14.43	16.67±14.43
<b>Physical</b>	55.55±20.97	55.55±20.97
<b>Communication</b>	76.67±12.58	76.67±12.58
<b>Total</b>	53.57±2.24	53.51±3.71

**Table 5 :** Child and parent mean scores of quality-of-life domains for ESRD

#### 5.4 Correlation among Child HRQoL Tool Parameters

There were a strong and positive correlation between all domains (physical, emotion, social, psychosocial and physical health summary domains) of child health related quality of life as well as the generated average score used for final analysis indicating that the average score is representative for all the domains and all the domains are having significant positive correlation with each other (Table 4)

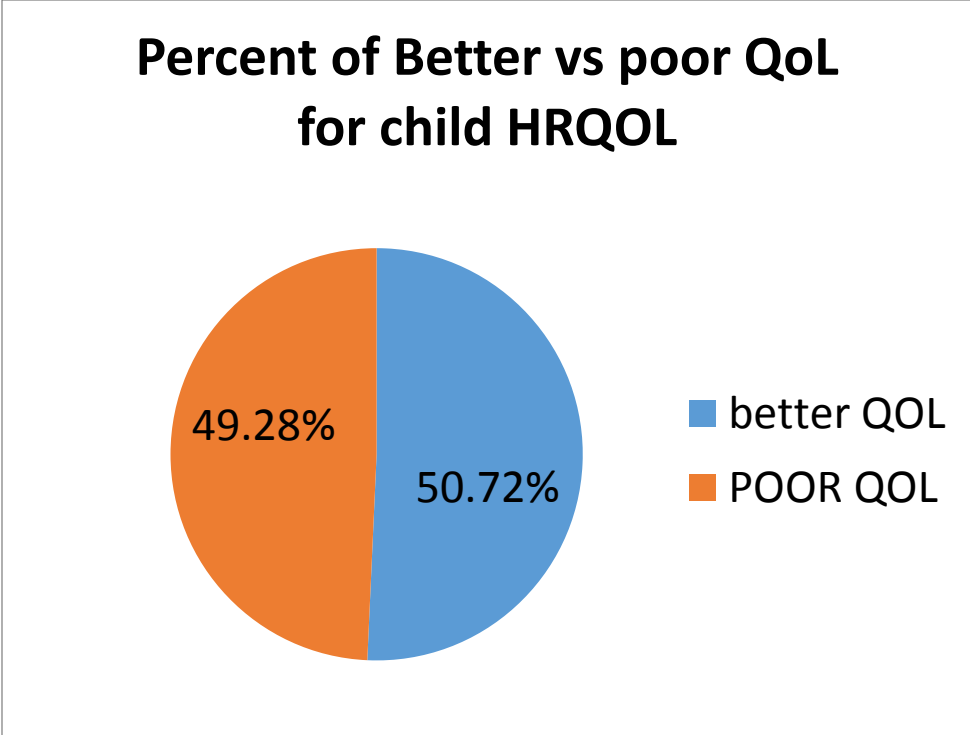
<b>physical QoL mean score</b>	87.5 (71.8 – 96.6)	0.844	<0.001
<b>emotion QoL mean score</b>	90 (72.5 - 100)	0.808	<0.001
<b>social QoL mean</b>	100 (81.7 - 100)	0.918	<0.001
<b>school QoL mean score</b>	80 (80 – 87.5)	0.798	<0.001
<b>Psychosocial QoL mean score</b>	89.3 (78.85 – 93.33)	0.968	<0.001
<b>Physical health summary QoL mean score</b>	87.5 (71.8 – 96.6)	0.834	<0.001

**Table 6:** Correlation of Child HRQoL domains among children with child module average

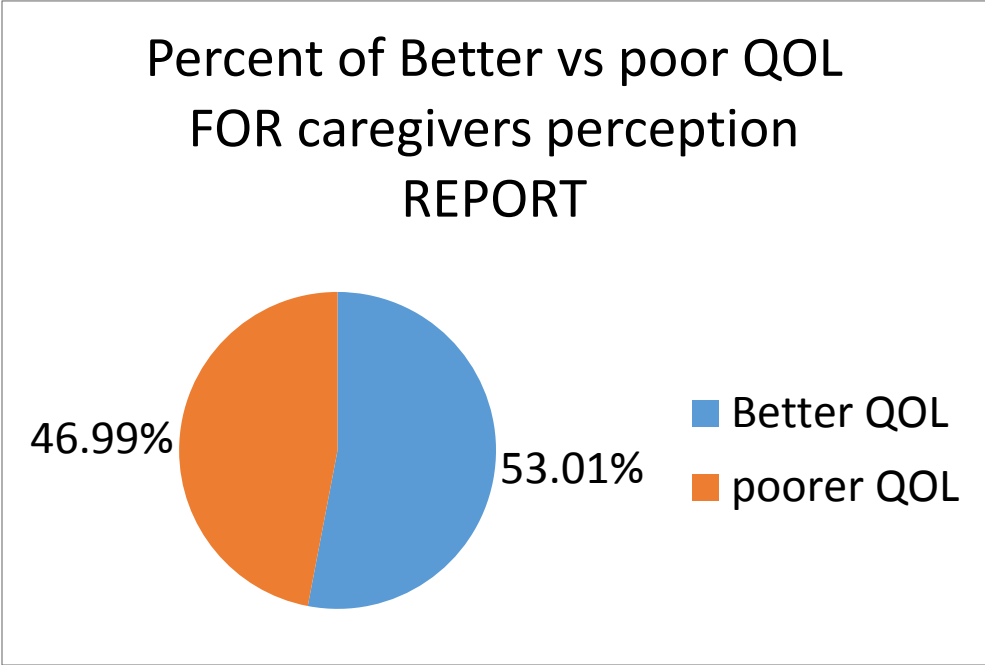
Also, there was a strong and positive correlation in between all domains of family health related quality of life as well as the generated average score used for final analysis indicating that the average score is representative for all the domains and all the domains are having significant positive correlation with each other. Table 6

<b>physical QoL mean score</b>	87.5 (68.7 – 96.6)	0.857	<0.001
<b>emotion QoL mean score</b>	80 (75 - 90)	0.805	<0.001
<b>social QoL mean</b>	100 (83.3 - 100)	0.911	<0.001
<b>school QoL mean score</b>	80 (73.9 – 83.33)	0.832	<0.001
<b>Psychosocial QoL mean score</b>	86.6 (78.58 – 90)	0.965	<0.001
<b>Physical health summary QoL mean score</b>	87.5 (68.7 – 96.6)	0.882	<0.001

**Table 7:** Correlation of Family HRQoL tool parameters among children with family module average



**Fig1 : Percent of Better vs poor QOL for child HRQOL**



**Fig 2 : Percent of Better vs poor HRQOL for caregivers perception**

### 5.5 Factors associated with poor Child health related quality of life (Child HRQoL) among children with CKD on follow up at renal clinic, TASH, Addis Ababa, Ethiopia

Bivariable logistic regression analysis was done for seven variables supposed to have an association with quality of life of children. Thereby, four variables, having a p-value of less than 0.25 were taken to the multivariable logistic regression as candidates (Table 5).

Finally, two variables having a p-value of less than 0.05 were found to have a statistically significant association with poor health related quality of life of child. The current study revealed, children who were in the age group between 8 to 12 years were at 87.8% decreased odds of developing poor child health related quality of life than those between age group 13 to 18 years. Additionally, children with duration of illness between 1 to 3 years were 19.991x more likely of developing poor child health related quality of life than those with duration of illness more than 3 years

\*Median of total /Average score of Child QOL = 88.7( < median of total score poor QOL, above the median is better QOL )

	poorer	better		
	No. (%)	No. (%)		
<b>Age</b>				
<b>5 to 7 yrs.</b>	4 (11.8)	10 (28.6)	1.786 (0.43-7.35)	0.422
<b>8 to 12 yrs.</b>	20 (58.8)	11 (31.4)	0.393 (0.131-1.18)	0.095
<b>13 to 18 yrs.</b>	10 (29.4)	14 (40)	1	
<b>Sex</b>				
<b>Female</b>	19 (55.9)	16 (45.7)	0.665 (0.257-1.717)	0.399
<b>Male</b>	15 (44.1)	19 (54.3)	1	
<b>Residence</b>				
<b>Addis Ababa</b>	21 (61.8)	23 (65.7)	1	

<b>1/2-day travel from Addis Ababa</b>	5 (14.7)	8 (22.9)	1.461 (0.413-5.172)	0.557
<b>1 day travel from Addis</b>	7 (20.6)	3 (8.6)	0.391 (0.089-1.712)	0.213
<b>&gt; one day travel from Addis</b>	1 (2.9)	1 (2.9)	0.913 (0.054-15.54)	0.95
<b>Family size</b>				
<b>2 to 4</b>	17 (50)	14 (40)	0.667 (0.257-1.73)	0.405
<b>5 to 7</b>	17 (50)	21 (60)	1	
<b>Income</b>				
<b>&lt; 1000 ETB</b>	3 (8.8)	0		1
<b>1000 ETB - 4000 ETB</b>	17 (50)	15 (42.9)	0.618 (0.233-1.636)	0.332
<b>&gt;4000ETB</b>	14 (41.1)	20 (57.1)	1	
<b>Stage</b>				
<b>stage 1 CKD</b>	0	9 (25.7)	-	
<b>stage 2 CKD</b>	3 (8.8)	10 (28.6)	12.5 (2.29-68.245)	0.004
<b>stage 3 CKD</b>	16 (47.1)	12 (34.3)	2.813 (0.742-10.67)	0.128
<b>stage 4 CKD</b>	15 (44.1)	4 (11.4)	1	
<b>Duration</b>				
<b>&lt; 1yr</b>	0	4 (11.4)		1
<b>1 - 3yr</b>	5 (14.7)	23 (65.7)	16.675 (4.8-57.86)	<0.001
<b>&gt;3</b>	29 (85.3)	8 (22.9)	1	

**Table 8:** Bivariable analyses of factors associated with poor Child health related quality of life (Child HRQoL) among children with CKD on follow up at renal clinic, TASH, Addis Ababa, Ethiopia

<b>Age</b>		
<b>5-7yr</b>	0.592 (0.025-13.963)	0.745
<b>8-13</b>	0.122 (0.018-0.844)	0.033
<b>13-18yr</b>	1	
<b>Residence</b>		
<b>Addis Ababa</b>	1	
<b>1/2-day travel from Addis Ababa</b>	1.137 (0.173-7.65)	0.894
<b>1 day travel from Addis</b>	0.192 (0.004-9.71)	0.41
<b>&gt; one day travel from Addis</b>	0.48 (0.02-11.296)	0.649
<b>Stage</b>		
<b>stage 1 CKD</b>		1
<b>stage 2 CKD</b>	3.053 (0.336-27.71)	0.321
<b>stage 3 CKD</b>	2.092 (0.339-12.91)	0.427
<b>stage 4 CKD</b>	1	
<b>Duration</b>		
<b>&lt;1yr</b>		1
<b>2-3yr</b>	19.991 (3.01-132.75)	0.002
<b>&gt;3yr</b>	1	

**Table 9 :** Multivariable analyses of factors associated with poor Child health related quality of life (Child HRQoL) among children with CKD on follow up at renal clinic, TASH, Addis Ababa, Ethiopia

### 5.6 Factors associated with poor Family health related quality of life (Family HRQoL)

Bivariable logistic regression analysis was done for seven variables supposed to have an association with health-related quality of life of family. Then six variables, having a p-value of less than 0.25 were taken to the multivariable logistic regression as candidates (Table 8).

Finally, two variables having a p-value of less than 0.05 were found to have a statistically significant association with poor health related quality of life of family. Families having a child within age group 8 to 12 years had 88.7% decreased odds of developing poor HRQoL than those families having a child age group 13 to 18 years. Additionally, families having a child with duration of illness 1 to 3 years were 10. Times more likely to develop poor HRQoL than those having a child with duration of illness more than 3 years (Table 8).

\*Median of total /Average score of Child QOL = 87( < median of total score poor QOL, above the median is better QOL )

	poorer	better		
	No. (%)	No. (%)		
<b>Age</b>				
<b>2 to 4 yrs.</b>	7 (17.9)	8 (18.2)	0.571 (0.152-2.145)	0.407
<b>5 to 7 yrs.</b>	5 (12.8)	9 (20.5)	0.9 (0.226-3.592)	0.881
<b>8 to 12 yrs.</b>	19 (48.7)	11 (25)	0.289 (0.094-0.894)	0.031
<b>13 to 18 yrs.</b>	8 (20.5)	16 (36.4)	1	
<b>Sex</b>				
<b>Female</b>	21 (53.8)	16 (36.4)	0.49 (0.203-1.18)	0.112

<b>Male</b>	18 (46.2)	28 (63.6)	1	
<b>Residence</b>				
<b>Addis Ababa</b>	22 (56.4)	28 (63.6)	1	
<b>1/2-day travel from Addis Ababa</b>	4 (10.3)	11 (25)	2.161 (0.605-7.72)	0.236
<b>1 day travel from Addis</b>	9 (23.1)	4 (9.1)	0.349 (0.095-1.286)	0.114
<b>&gt; one day travel from Addis</b>	4 (10.3)	1(2.3)	0.196 (0.02-1.885)	0.158
<b>Family size</b>				
<b>2 to 4</b>	23 (59)	19 (43.2)	0.529 (0.221-1.266)	0.153
<b>5 to 7</b>	16 (41)	25 (56.8)	1	
<b>Income</b>				
<b>&lt; 1000 ETB</b>	3 (7.7)	2 (4.5)	0.545 (0.082-3.627)	0.531
<b>1000 ETB - 4000 ETB</b>	18 (46.2)	20 (45.5)	0.909 (0.373-2.216)	0.834
<b>&gt;4000ETB</b>	18 (46.2)	22 (50)	1	
<b>Stage</b>				
<b>stage 1 CKD</b>	0	10(22.7)	-	1
<b>stage 2 CKD</b>	8 (20.5)	14 (31.8)	4.9 (1.282-18.725)	0.02
<b>stage 3 CKD</b>	17 (43.6)	15 (34.1)	2.471 (0.719-8.493)	0.151
<b>stage 4 CKD</b>	14 (35.9)	5 (11.4)	1	
<b>Duration</b>				
<b>&lt; 1yr</b>	5 (12.8)	7 (15.9)	3.780 (0.972-14.695)	0.055
<b>1 - 3yr</b>	7 (17.9)	27 (61.4)	10.414 (3.455-31.393)	<0.001
<b>&gt;3yr</b>	27 (69.2)	10 (22.7)	1	

**Table 10:** Bivariable/logistic analyses of factors associated with poor family health related quality of life for CKD pts (family HRQoL)

<b>Age</b>		
<b>2 to 4 yrs.</b>	0.288 (0.015, 5.477)	0.407
<b>5 to 7 yrs.</b>	0.142 (0.01, 1.958)	0.145
<b>8 to 12 yrs.</b>	0.113 (0.018, 0.704)	0.019
<b>13 to 18 yrs.</b>	1	
<b>Sex</b>		
<b>Female</b>	0.33 (0.078-1.396)	0.132
<b>Male</b>	1	
<b>Residence</b>		
<b>Addis Ababa</b>	1	
<b>1/2-day travel from Addis Ababa</b>	1.281 (0.164-10.04)	0.813
<b>1 day travel from Addis</b>	0.173 (0.012-2.405)	0.191
<b>&gt; one day travel from Addis</b>	0.272 (0.016-4.734)	0.371
<b>Family size</b>		
<b>2 to 4</b>	0.33 (0.078-1.396)	0.132
<b>5 to 7</b>	1	
<b>Stage</b>		
<b>stage 1 CKD</b>	-	
<b>stage 2 CKD</b>	3.056 (0.342-27.331)	0.318
<b>stage 3 CKD</b>	1.362 (0.232-8.009)	0.732
<b>stage 4 CKD</b>	1	
<b>Duration</b>		
<b>&lt; 1yr</b>	2.031 (0.059-70.305)	0.695

<b>1 - 3yr</b>	19.552	(3.421- 0.001 111.743)
<b>&gt;3yr</b>	1	

**Table 11:** Multivariable analyses of factors associated with poor Family health related quality of life (Family HRQoL)

## 5. DISCUSSION

The relatively younger mean age of participants in this study lies in the range of 5 -7 yrs.

- ✓ In study done in USA done by Gearson et al (13) mean age of the participants 11 years, attributed to younger age of patients in low income countries due to poor access for timely detection and intervention from correctable factors

The total HRQoL mean score for child report and for family report was  $80.76 \pm 19.3$  &  $80.64 \pm 18.23$  respectively .

- ✓ in a similar study done in Poland by Pstrusińska et al (32), HRQoL mean score for child & family report revealed 71.74 (57.61-81.52), 65.76 (51.09–78.26) respectively

This could be due to in that study

- ✓ Participants were advanced stage of illness and patients on hemodialysis and peritoneal dialysis were also involved
- ✓ multicentered study , larger sample size with better representation of HRQoL

The literature data regarding the agreement of the child self-report and family perception reports are conflicting. In some studies, children evaluated themselves more negatively than their parents did and vice versa in other studies indicating the importance of Asking both.

There was a strong and positive correlation in between all domains of child health related quality of life as well as the generated average score used for final analysis. This indicates that the average score is representative for all the domains and all the domains are having significant positive correlation with each other showing the pervasive nature of the disease in affecting the child's social wellbeing, physical performance, emotion and school performance. Further the most affected component of the child module was school characterized by missed school days due to hospital visit or sickness, reduced attention at school and inability in keeping up with peers .a study by Gearson et al (13) on health related quality of life of children with mild or moderate CKD also showed similar result , Poorer educational set up in developing countries to

address children with difficulties can also be incriminated for the significant impairment in school performance.

It is quite evident in this study that ESRD affects negatively all life dimensions including physical, social, emotional, and school functioning as well. The total mean for quality of life for both self and parent report for ESRD in the current study is  $53.57 \pm 2.24$  which is comparable with the study done by Elshafai on the Assessment of Quality of Life among Children with End-Stage Renal Disease: A Cross-Sectional Study in Egypt (17) which showed total mean of  $58.4 \pm 15.3$ . Lower scores for ESRD patients could be explained by clinical facts that ESRD patients suffer from many short term and long-term complications that alter their life such as frequent hospitalization, painful medical procedures, school absence, and restriction of activities which have behavioral and negative emotional outcomes .

According to this study, adolescent childrens were at increased odds of encountering poor child HRQoL attributed to diseases multiple influence on social , emotion and peer interaction. On the contrary to our expectations children who had CKD for a longer period of time (ie, greater percentage of life with CKD) were observed to have better quality of life functioning than youth who had CKD for a shorter period of time. These findings are interesting and may suggest that with the passage of time, children and their families accommodate to having kidney disease such that their perception of the negative impact of CKD on physical, emotional, and social functioning decreases over time. This phenomenon has been observed in other chronic illness groups and has been labeled as response shift.

Similarly impact of CKD on life quality of parents and care givers is overlooked with scant literatures aimed at assessing the degree of impact as well as factors associated with poor HRQOL. parent proxy ratings on physical activity, social and school functioning domains were higher (i.e., better) child self ratings, confirming the importance of obtaining both sources of information.

the relatively lesser emotion domain of family proxy report also showed the emotional turmoil this parents were having as the result of uncertainty about their ability to cope, to deliver complex medical interventions, and about their child's outcome. They felt burdened with technical procedures and continuous clinic visits, and experienced relationship stresses .study done by Tong et el (24) in Australia also signify this.

## **6. LIMITATION OF THE STUDY**

For better understanding of the burden of CKD on HRQoL stratification and comparison of children with CKD with their healthy counterparts can give a better perspective but this design was more time and resource consuming since it requires wider community assessment, the occurrence of the global COVID-19 pandemic has reduced the patients seen at the clinic requiring phone call interviews for addressing the total sample size this could affect the quality of data obtained.

## **7. Conclusion**

This study revealed that CKD can disturb the HRQoL of children and parents in multiple domains of life. factors responsible for relatively poorer HRQoL have been identified even if some of this factor are not modifiable these higher risk groups can be identified and receive a better attention and support. Information obtained from HRQoL scores should also be addressed and followed.

## **8. Recommendation**

- Preparation of scheduled educational sessions on the clinical features, treatment and complications of CKD and proper counseling on each visit.
- Implementation of a tool in addressing HRQoL in all CKD patients on follow up.
- Multidisciplinary approach for children and parents with lower scores should be looked in to with Educators, counselors and psychotherapists and formation of small support groups.
- More open-ended interviews with parents and children should be made in addressing concerns about disease and complications.
- Follow up visits should look over the progress of their scores and difficulties faced on addressing problems.
- Further studies on national or multicentric level should be conducted to develop a special program for quality of life improvement.

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## **Annex 1: Consent and Informed Assent**

### **Annex 1.1 Written Consent**

Addis Ababa University, Faculty of medicine, department of pediatrics and child health

Assessment of Health-related Quality of life in children with CKD on follow up renal clinic at Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia

Code \_\_\_\_\_

Hello, my name is Dr Getasew Chekol and I am conducting a research on Assessment of Health-related Quality of life in children with CKD on follow up at renal clinic, Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia. You are kindly requested to be involved in the study which will improve the quality of care that we are providing. The questionnaire will only take a few minutes of your time. I want to inform you that the information you give will be kept confidential and also you have the right to withdraw from participation at any time during the interview. The study has approval and ethical clearance from the department as well as from hospital's ethical committee. If you are willing to participate in the study, please confirm it with your signature on the space provided below.

I place my signature as a sign of agreement to participate\_\_\_\_\_.

Thank you for your cooperation!! Data Collector\_\_\_\_\_

Signature\_\_\_\_\_ Date\_\_\_\_\_

**አባሪ፡ የጽሁፍ ስምምነት ቅጽ**

የአዲስ አበባ ዩኒቨርሲቲ ሜዲካል ፋካልቲ የህጻናት ህክምና ክፍል

የጥናቱ ርዕስ፡ በጥቁር አንበሳ ሆስፒታል ህክምና ኮሌጅ የህጻናት ህክምና ክፍል የኩላሊት ህክምናና ክትትል ክሊኒክ ክትትል ላይ ያሉ የኩላሊት ድክመት ህመም ያለባቸው ህፃናት የኑሮ ጥራት ደረጃ ጥናት

የኮድ ቁጥር፡\_\_\_\_\_

ጤና ይስጥልኝ ስሜ ዶ/ር ጌታሰው ቸኮል ይባላል። በጥቁር አንበሳ ሆስፒታል የህጻናት ህክምና ክፍል የኩላሊት ህክምናና ክትትል ክሊኒክ ክትትል ላይ ያሉ ያለባቸው ህፃናት የኑሮ ጥራት ደረጃ ጥናት እየሰራው እገኛለሁ። ጥናቱ የኩላሊት ድክመት ህመም ያለባቸው ህፃናት የኑሮ ጥራት ደረጃ እና አሉታዊ ተፅዕኖ ያላቸውን ችግሮች በመለየት መፍትሄ ለመጠቀም አስተዋጾ ያደርጋል። እርስዎ በዚህ ጥናት ተሳታፊ እንዲሆኑ ተጋብዘዋል። ፈቃደኛ ከሆኑ ከ5 እስከ 10 ደቂቃ የሚፈጁ ጥያቄዎች አሉኝ። የሚሰጡኝ መረጃ ሚስጥራዊነቱ ሙሉ በሙሉ ይጠበቃል። ለዚህ ጥናት ስም አያስፈልግም። ምናልባት በጥናቱ መሳተፍ ካልፈለጉ አሻፈረኝ ማለት ይችላሉ። እንዲሁም በመጠይቁ መሀል ማቋረጥ ወይም መመለስ የማይፈልጉትን ጥያቄ ማለፍ ይችላሉ። ሊጠይቁት የሚፈልጉት ጥያቄ ካለ ለመመለስ ዝግጁ ነኝ። ስለ ትብብርዎ በቅድሚያ በጣም አመሰግናለሁ።

በዚህ ጥናት ለመሳተፍ ዝግጁ ነዎት አዎ \_\_\_ አይደለሁም \_\_\_

ከዚህ በላይ የተዘረዘረውን በግልጽ ማስረዳትንና የጽሁፍ ስምምነቱን ቅጽ መሙላትን በፊርማዬ አረጋግጣለሁ\_\_\_\_\_

የጥናቱ አድራጊ ፊርማ \_\_\_\_\_ ቀን\_\_\_\_\_

ከዚህ በላይ በተሰጠው መረጃ መሰረት በዚህ ጥናት ለመሳተፍ መስማማቴን በፊርማዬ አረጋግጣለሁ

የጥናቱ ተሳታፊ ፊርማ \_\_\_\_\_ ቀን\_\_\_\_\_

## **Informed Assent Form Template for Children/Minors**

Informed Assent Form for Children with CKD and ESRD on follow up at Tikur Anbesa Specialized hospital renal follow up clinic

**Principle Investigator** Dr. Getasew chekol

Addis Ababa University, College of medicine and health science of medicine

Assessment of Health-related Quality of life in children with CKD and ESRD having follow up at renal clinic in Tikur Anbesa Hospital, Addis Ababa, Ethiopia

### **Part 1: Information Sheet**

My name is Dr. Getasew Chekol, I am a final year pediatrics and child health resident working on my research on Assessment of Health-related Quality of life in children with CKD and ESRD on follow up renal clinic at Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia. I am going to give you information and invite you to be part of a research study. You can choose whether or not you want to participate. We have discussed this research with your parent(s)/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent(s)/guardian also have to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed. You may discuss anything in this form with your parents or friends or anyone else you feel comfortable talking to. You can decide whether to participate or not after you have talked it over. You do not have to decide immediately. There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at any time and I will take time to explain. You don't have to be in this research if you don't want to be. It's up to you. If you decide not to be in the research, its okay and nothing changes. This is still your clinic; everything stays the same as before. Even if you say "yes" now, you can change your mind later and it's still okay.

**I have checked with the child and they understand that participation is voluntary**

---

(Signature)

You will read questionnaire and fill the answers based on your experience on the spaces provided.

**I have checked with the child and they understand the procedures \_\_\_\_\_**

(Signature)

The Questionnaire will only take few minutes of your time any there will be no harm in doing so

**I have checked with the child and they understand the risks and discomforts**

\_\_\_\_\_

(Signature)

After filling this questionnaire, you will help us understand the quality of life in children with CKD and ESRD so we can help you better.

**I have checked with the child and they understand the benefits \_\_\_\_\_**

(Signature)

The answers you provide will be kept a secret and no names will be mentioned on the paper. After completing the research, we will describe what we find about you

#### Certificate of Assent

I understand the research is about assessment of health-related quality of life in children with CKD and ESRD agree to fill out the questionnaire.

I have read this information ( or had the information read to me) I have had my questions answered and know that I can ask questions later if I have them.

I agree to take part in the research.

Print name of child \_\_\_\_\_

Signature of child: \_\_\_\_\_

Date: \_\_\_\_\_ A literate witness must sign .

I have witnessed the accurate reading of the assent form to the child, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness (literate and not parent) \_\_\_\_\_ AND Thumb print of participant

Signature of witness \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

I have accurately read or witnessed the accurate reading of the assent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given assent freely.

Print name of researcher \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_

**Statement by the researcher/person taking consent**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands that he/she will fill out a questionnaire. I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this assent form has been provided to the participant.

Print Name of Researcher/person taking the assent \_\_\_\_\_

Signature of Researcher /person taking the assent \_\_\_\_\_

Date \_\_\_\_\_

Copy provided to the participant \_\_\_\_\_ (initialed by ) researcher/assistant)

Parent/Guardian has signed an informed consent \_\_\_ Yes \_\_\_No \_\_\_ (initialed by researcher/assistant)

**አባሪ 2: ለልጆች / ለአካለመጠን ያልደረሱ ህጻናት የእውቅና እና ስምምነት ማረጋገጫ ቅጽ**

**ጥናት አድራጊ: ዶክተር ጌታሰው ቸኮል**

የአዲስ አበባ ዩኒቨርሲቲ፣ የህክምና ኮሌጅ እና የህክምና ሳይንስ ኮሌጅ

የጥናቱ ርዕስ: በጥቁር አንበሳ ሆስፒታል ህክምና ኮሌጅ የህጻናት ህክምና ክፍል የኩላሊት ህክምናና ክትትል ክሊኒክ ክትትል ላይ ያሉ የኩላሊት ድካም ህመም ያለባቸው ህጻናት እና አስታማሚዎች የኑሮ ጥራት ደረጃ ጥናት

**የመረጃ ወረቀት**

ስሜ ዶክተር ጌታሰው ቸኮል ይባላል። በጥቁር አንበሳ ሆስፒታል ህክምና ኮሌጅ የህጻናት ህክምና ክፍል፣ የኩላሊት ህክምና ክትትል ክሊኒክ፣ ክትትል ላይ ያሉ የኩላሊት ድክመት ህመም ያለባቸው ህጻናት እና አስታማሚዎች የኑሮ ጥራት ደረጃ ጥናት በመስራት ላይ የምገኝ የመጨረሻ ዓመት የሕፃናት ህክምና ተማሪ ነኝ። ስለ ጥናቱ እኔ መረጃ እሰጥዎታለሁ እናም የምርምር ጥናት አካል እንድትሆኑ እጋብዛችኋለሁ። ለመሳተፍ ይፈልጉ ወይም አይፈልጉ መምረጥ ይችላሉ። ይህንን ጥናት ከወላጅዎ ጋር ተስማምተናል እናም እርስዎም ስምምነታችንን እንደምንጠይቅዎት ያውቃሉ። በጥናቱ ውስጥ ለመሳተፍ የሚፈልጉ ከሆነ ወላጅዎ መስማማት አለባቸው። ነገር ግን በምርመራው ውስጥ መሳተፍ የማይፈልጉ ከሆኑ፣ ወላጆችዎ የተስማሙ ቢሆኑም እንኳን ማድረግ የለብዎትም። በዚህ ቅጽ ማንኛውንም ነገር ከወላጆችዎ ወይም ከጓደኞችዎ ወይም ለማነጋገር ከሚመችዎት ማንኛውም ሰው ጋር መወያየት ይችላሉ። ከተወያዩ በኋላ ለመሳተፍ ወይም ላለመሳተፍ መወሰን ይችላሉ። ወዲያውኑ መወሰን የለብዎትም። ምናልባት እርስዎ ያልተረዱዎቸው አንዳንድ ቃላት የበለጠ እንዲገለጹ የሚፈልጉትን ነገሮች ለማብራራት ዝግጁ ነኝ። እባክዎን በማንኛውም ጊዜ እንዳቆም ይጠይቁኝ እና ለማብራራት ጊዜ እወስዳለሁ። ካልፈለጉ በዚህ ጥናት ውስጥ መሆን የለብዎትም። በጥናቱ ውስጥ ላለመሆን ከወሰኑ ምንም ነገር አይለወጥም። ይህ አሁንም የእርስዎ ክሊኒክ ነው፣ ሁሉም ነገር ልክ እንደበፊቱ ይቀጥላል። ምንም እንኳን አሁን “አዎ” ቢሉም፣ በኋላ ላይ ሃሳብዎን መለወጥ ይችላሉ።

ስምምነቱ በፈቃደኝነት የሚደረግ ነው \_\_\_\_\_ (ፊርማ)

መጠይቅ ያነቡ እና በተሰጡት ክፍት ቦታዎች ባገኙት ተሞክሮ ላይ በመመስረት መልሱን ይሞላሉ።

**የአሰራር ሂደቱን ተረድተዋል \_\_\_\_\_ (ፊርማ)**

መጠይቁ ጥቂት ደቂቃዎችን ብቻ ይወስዳል ምንም ችግር የሚፈጥረው አይኖርም

**አደጋዎችን እና ጉዳዮችን ተረድተዋል \_\_\_\_\_ (ፊርማ)**

ይህንን መጠይቅ ከሞሉ በኋላ እኛ በተሻለ መልኩ በኩላሊት ህመም በተያዙ ሕጻናት ውስጥ ያለውን የህይወት ጥራት እንድንገነዘብ ይረዳናል።

**ጥቅሞቼን ተረድተዋል \_\_\_\_\_ (ፊርማ)**

የተሰጠው መልስ በሚስጥር ይያዛሉ እናም በወረቀቱ ላይ ምንም ስሞች አይጠቀሱም። ምርምሩን ካጠናቅቁ በኋላ ስለ እርስዎ ምን እንደተረዳን እንገልጻለን።

Annex 2 : General Terms , Agreement and condition for use of Pediatric Quality of Life Inventory™ (PedsQL™) version 4.0

Mapi Research Trust, a not-for-profit organization subject to the terms of the French law of 1st July 1901, registered in Lyon under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France (hereafter referred to as “MRT”), and the User, as defined herein (each referred to singularly as a “Party” and/or collectively as the “Parties”), do hereby agree to the following User Agreement General and Special Terms (hereafter, the “AGREEMENT”).

WHEREAS MRT facilitates access to information on Clinical Outcome Assessment (COAs) and epidemiology and encourages exchanges between various users around the world by providing, in particular, the availability, translation(s) (where appropriate) and distribution of COAs.

WHEREAS the User wishes to be able to have access to one or several COAs and to use each such COA in accordance with the terms and conditions set forth in the AGREEMENT.

Now, therefore, MRT and the User agree to enter into this AGREEMENT subject to the following terms and conditions.

Affiliate

Means, with respect to either Party, any company, corporation, firm, partnership, or other entity that controls, is controlled by, or is under common control with such Party, where control means the power, direct or indirect, to direct or cause the direction of the management and policies of such entity, whether by contract, through the by-laws of the aforementioned entities or otherwise.

Author

Means the person(s) or legal entity that developed the COA and the Documentation that may accompany it.

Beneficiaries	Means third-party individuals or legal entities, clinical research site/staff and vendors engaged by the User in connection with the conduct of the Stated Purpose who may administer the COA and use the Data as part of their activity.
COA	Means the licensed Clinical Outcome Assessment which is licensed by MRT for the countries and Licensed Languages listed in the Special Terms.
Collaboration Agreement	Refers to the separate agreement between the Author or the Copyright Holder and MRT by which the Author or the Copyright Holder grants the right to MRT to sublicense and reproduce the COA.
Confidential Information	Means all information disclosed to a Party (or its Affiliates) by the other Party or its Affiliates, agents or employees in any manner, whether orally, visually or in tangible form (including, without limitation, documents, devices and computer readable media) and all copies thereof, whether created by such Party, for the purpose of the AGREEMENT
Copyright Holder	Means the person or legal entity who owns the copyright on the COA and/or on any Documentation
Data	Means any data, result or report obtained or prepared from a lawful use and administration of the COA.
Documentation	Means all documentation provided by MRT to the User, including, if available, scoring instructions or administration guidelines,

	manuals, translation certificates, or any other documents accompanying the COA or related to or referencing the COA
Effective Date	Means the date of acceptance by the User of this Agreement.
e-Version of the COA or eCOA	Means the electronic version of the COA including – but not limited to – electronic versions for hand held devices, tablets, web-based and Interactive Voice Response (IVR) versions.
IT Company	Means the company that performs the electronic migration of the COA and delivers e-Version(s) of the COA to the Users.
License	Means the license granted by MRT to the User as defined in this AGREEMENT, as further described in Section 3.01
Licensed Languages	Means the language versions of the COA licensed to the User in the Special Terms
Mode	Means the format of the COA as approved by MRT and as described in the relevant User License Agreement Special Terms. Modes include, but are not limited to, paper format and electronic format
AGREEMENT	Means this User License Agreement General Terms, its Appendixes and User License Agreement Special Terms which binds the User to MRT.
Screenshot	Means the screen captures of the e-Version of the COA as implemented in the electronic mode by the IT Company.
Stated Purpose	Means the context of use of the COA by the User, as detailed in the Special Terms. It refers to all types of studies, clinical trials, research projects or any other project, as defined in the Special Terms, for which MRT

grants the User the right to use the COA.

User	Means the user of the COA as defined herein and that is a Party to this AGREEMENT.
Special Terms	Means the User License Agreement special terms applicable to the COA licensed by the User.

## ARTICLE II. AUTHOR'S AND COPYRIGHT HOLDER'S RIGHTS

**2.01** Each COA is proprietary content, information and material that is protected by applicable intellectual property and other laws, including but not limited to copyright. The User shall not use the COA except for the Stated Purpose as permitted pursuant to this AGREEMENT and the Special Terms.

**2.02** The Author and/or the Copyright Holder owns all of the economic rights in the COA and any derivative work from the COA including but not limited to existing and future translations, and in particular the rights to reproduce, perform, amend, adapt and translate the COA. 32

**2.03** The Author also owns all of the moral rights on the COA, and therefore has, in particular, the right to authorship of the COA, the right to preserve the integrity of the COA, to perform or prevent it from alteration, distortion or destruction and the right of withdrawal.

**2.04** Through the Collaboration Agreement, the Author and/or the Copyright Holder have granted MRT the right to sublicense, and have authorized MRT to grant, on a non-exclusive basis, a portion of these rights to the Users interested for specific purposes, and in particular to the User for the Stated Purpose.

## ARTICLE III. GRANT OF LICENSE

3.01 Subject to the terms and conditions of this AGREEMENT MRT hereby grants to the User and the User accepts, the following non-exclusive, non-transferable, non-assignable, non-sublicensable worldwide license, during the term specified in the Special Terms:

(i) To use the COA for the Stated Purpose in the authorized Modes and Licensed Languages, including the right to communicate it to the Beneficiaries only; and

(ii) To reproduce the COA for the Stated Purpose, including the right to physically establish the COA or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not

protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries and/or the Sponsor only; and

(iii) To translate the COA or have it translated when the COA has not been translated into the Licensed Language(s),

hereafter, the “**License**”.

## ARTICLE IV. OBLIGATIONS OF THE USER

### 4.01 General obligations

For each COA licensed pursuant to this AGREEMENT, and unless otherwise stated in the Special Terms, the User shall:

- • Insert the Copyright Holder’s copyright notice on the COA (paper or e-Version);
- • Not amend, modify, condense, adapt, reorganize the COA in any Mode whatsoever, even minor, without MRT’s specific written consent;
- • Refrain from using or reproducing the COA in any way and on any format whatsoever, with the exception of doing so for the purpose of fulfilling a requirement for the Stated Purpose;
  - If the COA is to be used in a publication, website or context other than research or clinical study:
    - o Cite the reference publications of the COA
    - o Indicate the details of MRT for any information on the COA, as follows: “[NAME OF COA] contact information and permission to use: Mapi Research Trust, Lyon, France, <https://eprovide.mapi-trust.org>”
    - o Not include any full copy of the COA, but a sample protected version with the indication “sample copy, do not use without permission”
    - o Provide MRT, as soon as possible, with a copy of any publication regarding the COA, for information purposes.

### 4.02 Translation of the COA

The User undertakes not to translate the COA nor have it translated by any means whatsoever other than those means stipulated in the AGREEMENT or the Special Terms. 33

The Special Terms User shall sign a Translation Agreement with MRT, which shall describe the requirements for translation of the COA, unless otherwise stated in the Special Terms.

#### **4.03** Obligations for the use of an e-Version of the COA

In the case of use of an eCOA for academic or non-commercial Stated Purposes, the User undertakes to submit the Screenshots of all the electronic pages where the e-Version of the COA appears to MRT to ensure compliance with section 4.1. Electronic migration guidelines will be provided to the User and/or the IT Company.

When the migration of the COA in e-Version is performed by an IT Company, the User shall ensure that the IT Company has signed the necessary license agreement with MRT before developing the e-Version of the COA.

### ARTICLE V. OWNERSHIP OF DATA

**5.01** Except as otherwise specified in the Special Terms, the Parties hereby agree that the Data will be the sole property of the User.

### ARTICLE VI. BENEFICIARIES

**6.01** The User shall authorize, under its sole responsibility, the Beneficiaries to use the COA and the Data as necessary in strict adherence to their function in the context of performing the Stated Purpose. Such use gives no rights to the Beneficiaries to use the COA beyond the use contemplated by this AGREEMENT.

**6.02** The User guarantees that the Beneficiaries will comply with the terms and conditions of this AGREEMENT and in particular the undertakings regarding confidentiality, and accepts liability for any breach of this AGREEMENT by the Beneficiaries.

### ARTICLE VII. TERM AND TERMINATION

#### **7.01** Term

This AGREEMENT shall be effective as of its acceptance by the User and shall continue for the period stipulated in the Special Terms unless terminated earlier by the Parties as permitted in this Article 7.

The confidentiality and non-disclosure obligations stipulated in Article 9 of this AGREEMENT shall survive expiration or termination of this AGREEMENT for any reason whatsoever and shall continue to apply without limitation.

#### 7.02 Termination

(a) Termination due to financial disruption of the Parties

If for any reason whatsoever, one or both Parties ceases to conduct all business activities, the AGREEMENT shall terminate immediately and without penalty and any compensation being owed by either of the two Parties to the other.

(b) Termination for breach

In the case of breach by a Party of one or more of its obligations pursuant to this AGREEMENT, the other Party may terminate this AGREEMENT with immediate effect if the breaching Party has not rectified the breach detailed in a registered letter with confirmation of receipt within a period of thirty (30) days from the date indicated on the registered letter.

(c) Termination of the Collaboration Agreement 34

In addition, in the event of termination of the Collaboration Agreement between the Copyright Holder of a COA and MRT, or in case MRT loses the right to distribute the COA, this AGREEMENT may consequently also be terminated immediately.

(d) Consequences of the termination

In the event of termination of the AGREEMENT for whatever grounds, the User shall remove, return or destroy, as instructed by MRT, all copies of the COA and Documentation and other materials, documents, data and information in its possession, whether held electronically or by other means, in relation to the AGREEMENT, within a period of thirty (30) days after such termination. However, the User may keep a single copy of such materials for the purposes of archiving information necessary for legal, tax or regulatory inspection and may use the Data as it deems fit, in accordance with the AGREEMENT and the Special Terms.

## ARTICLE VIII. PERSONAL DATA

The Parties shall comply with all relevant data protection obligations.

## ARTICLE IX. CONFIDENTIALITY

### **9.01** Disclosure of Confidential Information

In relation to this AGREEMENT, a Party or its Affiliates may disclose Confidential Information (as defined in the definition section) (“Discloser”) to the other Party, its agents, officers and/or Affiliates (“Recipient”). All such Confidential Information shall remain the property of the Discloser disclosing it and nothing in this AGREEMENT shall be construed as granting to the Recipient any license and/or other rights with respect to the Confidential Information of the Discloser or any part thereof, except as provided for in this AGREEMENT. The Recipient agrees that any such Confidential Information disclosed to it will only be used in connection with the legitimate purposes of this AGREEMENT. The Recipient shall be entitled to disclose

Confidential Information only to those agents, officers, Affiliates, contractors and third parties (excluding any competitors of the Discloser) who have a need to know it and are obligated to keep same in confidence, and safeguard it with all reasonable care.

#### **9.02 Non-Disclosure-Period**

In respect of Confidential Information disclosed in relation to this AGREEMENT, the obligations and rights of confidentiality as set out herein apply during the period of the Special Terms and for a period of five (5) years thereafter, in respect of Confidential Information otherwise disclosed under this AGREEMENT the obligations and rights of confidentiality as set out herein apply during the period of the AGREEMENT and for a period of five (5) years thereafter.

#### **9.03 Binding Other Parties**

The Recipient is responsible for ensuring its servants or agents, or any other persons or parties who receive Confidential Information through it, are bound to terms substantially similar to those set out in this Agreement.

#### **9.04 Exclusions**

The confidentiality obligations of the Recipient in Sections 9.1 to 9.3 do not extend to Confidential Information or any other information which:

- is or becomes generally available to the public otherwise than by reason of a breach by the Recipient of Sections 9.1 to 9.3 above; or
- is known to the Recipient and is at its free disposal prior to its receipt from the Discloser as established by written evidence; or 35
- is subsequently disclosed to the Recipient by a third party who the Recipient had no reason to believe was under a duty of confidence to the Discloser.

#### **9.05 Disclosure by Law**

Confidential Information may also be disclosed by the Recipient to the extent required by law (including statutory, regulatory, or similar legislative requirements), court orders and similar, provided that the Recipient making the disclosure of the Discloser's Confidential Information gives the maximum practical advance notice of same to the Discloser.

9.06 The Parties agree that MRT is entitled to give a copy of the AGREEMENT and the Special Terms to the Author and/or to the Copyright Holder upon simple request from either, and may do so without infringing this confidentiality obligation.

## ARTICLE X. INTELLECTUAL PROPERTY

**10.01** The User shall not do or authorize any third party to do any act which would invalidate or be inconsistent with any intellectual property rights regarding the COA(s).

**10.02** The User shall promptly give notice in writing to MRT in the event that it becomes aware of any claim brought by a third party that the COA infringes the intellectual property rights of such third party.

**10.03** MRT acknowledges that, to the best of its knowledge, neither the COA nor the Documentation infringe any third party rights and that it has the rights required to enter into this AGREEMENT.

**10.04** Except as to willful misconduct, negligence or breach of this AGREEMENT by the User, MRT undertakes in particular to indemnify the User, its officers, directors, employees and agents from any loss, damage, cost or expense, settlement, fines, disbursements (including reasonable legal fees) ("Loss) arising from any third party claim against the User for any damage caused by a breach or misappropriation by MRT of the copyright existing in the COA.

**10.05** The User shall indemnify MRT and its Affiliates and their officers, directors, employees and agents from any Loss arising from any third party claim relating to or which arises from: (i) the User's negligence or intentional misconduct; or (ii) the use / non-use or administration of the COA by or on behalf of the User, unless such Loss is caused by a breach or misappropriation by MRT of the copyright existing in the COA.

## ARTICLE XI. LIMITATION OF LIABILITY

**11.01** The User understands and agrees that the COA is provided "as is" with, as the case may be, its instruction manual, and that MRT and the Author and/or Copyright Holder accept no responsibility for any expenses, losses or actions incurred or undertaken by the User as a result of its use of the COA for the Stated Purpose.

**11.02** MRT may not be held liable for the termination of this AGREEMENT due to the termination of the Collaboration Agreement on the COA where MRT is not at fault for the termination of the Collaboration Agreement.

**11.03** Neither Party (including its affiliates) shall be liable to the other Party (including its Affiliates) for any indirect, consequential, special or incidental loss or damage or any loss of profits (whether direct or indirect), arising from or as a result of any claim or liability in contract, tort (including without limitation negligence and breach of statutory or other duty), for delay or failure to perform, or otherwise howsoever arising in relation or pursuant to this AGREEMENT. The foregoing limitation applies even if the loss, cost or damage was foreseeable or in the contemplation of either Party.

**11.04** Notwithstanding anything to the contrary suggested or contained in this AGREEMENT (but without prejudice to section 11.03) and to the fullest extent permissible under applicable law but in any case excluding personal injury claims; the maximum aggregate liability of MRT to the User (including its Affiliates) in contract, tort (including negligence, breach of statutory or other duty), misrepresentation, representation, restitution, delay, 36

failure to perform, claims under the indemnification obligations in this AGREEMENT or otherwise howsoever arising in relation to this AGREEMENT shall not exceed €10,000.00.

## ARTICLE XII. FORCE MAJEURE EVENT

**12.01** If the performance of the AGREEMENT is stopped or delayed further to a force majeure event such as third party strikes, third party lockouts, third party labor troubles, restrictive regulatory authority actions, orders or decrees, riots, insurrection, war, acts of God, severe inclement weather or other similar reason or cause which is unforeseeable or beyond the reasonable control of such Party, the Party affected by the force majeure event must (i) inform the other Party of the same immediately and (ii) take all appropriate measures in order to reduce or remove the impact of the force majeure event, and endeavor to recover the performance of the obligations which have been deferred or prevented by such event.

**12.02** Neither Party will be held liable for the delays or hindrances in performing its obligations due to a force majeure event, when the delay or hindrance is the result of such force majeure event.

**12.03** If a force majeure event affects one of the Parties and continues for more than thirty (30) days, either Party may by notice in writing to the other Party terminate the AGREEMENT.

## ARTICLE XIII. MISCELLANEOUS

**13.01** If any provision of this AGREEMENT is held to be unenforceable and/or legally invalid, the validity and enforceability of the enforceable portion of any such provision and/or the remaining provisions shall not be affected thereby. The Parties shall replace such unenforceable and/or legally invalid provision by an enforceable and legally valid provision that comes closest to the original commercial intent of such unenforceable and/or legally invalid provision (or part thereof).

**13.02** No modification of this Agreement shall be deemed effective unless in writing and signed by each of the Parties hereto and no waiver of any right or delay in enforcing such right set forth herein shall be deemed effective unless in writing and signed by the Party against whom enforcement of the waiver is sought.

**13.03** The User may not transfer or assign the AGREEMENT and the resulting rights and obligations, outside of the context of the Stated Purpose without MRT's prior written consent.

#### ARTICLE XIV. JURISDICTION AND APPLICABLE LAW

This Agreement is subject to Swiss law. The Parties will endeavor to settle their differences on an out-of-court basis prior to referring their case to the courts. In the case of disputes regarding the validity, interpretation or performance of the Agreement, exclusive jurisdiction is granted to the court with jurisdiction located in Basel, Switzerland, notwithstanding several defendants or the introduction of third parties, even for summary proceedings or proceedings on petition.

### **Annex 3: Questioner**

Assessment of Health-related Quality of life in children with CKD and ESRD on follow up at renal clinic, Tikur Anbesa Specialized Hospital, Addis Ababa, Ethiopia

#### Socio demographic Characteristics

1. Age: \_\_\_\_\_ Years

2. Sex

A. Male B. Female

3. Place of current residence

A. Addis Ababa

B. Half day travel out of Addis Ababa

C. One day travel out of Addis Ababa

D. More than one day travel out of Addis Ababa

4. Family size \_\_\_\_\_

5. Family income

A. less than 1000 birr per month B. 1000-4000 birr per month

C. 4000-12375 birr per month D. More than 12375 birr per month

#### **CLINICAL CHARACTERSTICS**

1) Stage of the CKD

A) Stage 1 B) Stage 2 C) Stage 3 D) Stage 4 E) ESRD

2) Duration of the CKD follow up

A) Less than 1 years

C) More than 3 yrs

B) Between 1 and 3 yrs

ሐ ከ አራት አመት በላይ

አባሪ 3 - የሥነ ሕዝብ መረጃ መጠይቅ

ይህ የኩላሊት ድካም ሕመም ላለባቸው ሕፃናት ከጤና ጋር የተዛመደ የኑሮ ጥራት ግምገማ የሥነ ሕዝብ መረጃ መጠይቅ ነው።

የሥነ ሕዝብ መረጃ

1) ዕድሜ \_\_\_\_\_

2) የታ ሀ) ወንድ ለ) ሴት

3) የመኖሪያ አድራሻ \_\_\_\_\_

ሀ) አዲስ አበባ

ለ) ከአዲስ አበባ ግማሽ ቀን የመኪና ጉዞ

ሐ) ከአዲስ አበባ የአንድ ቀን የመኪና ጉዞ

መ) ከአዲስ አበባ የአንድ ቀን በላይ የመኪና ጉዞ

4) የቤተሰብ ቁጥር ብዛት \_\_\_\_\_

5) የቤተሰብ ገቢ በወር

ሀ) ከአንድ ሺህ ብር በታች

ለ) ከአንድ

ሺህ ብር እስከ አራት ሺህ ብር

ሐ) ከአራት ሺህ ብር እስከ አስራ ሁለት ሺህ ብር

መ) ከአስራ ሁለት

ሺህ ብር በላይ

የበሽታው ዓይነት

1) የኩላሊት ህመሙ ደረጃ

ሀ) ደረጃ 1 ለ) ደረጃ 2 ሐ) ደረጃ 3 መ) ደረጃ 4 ሠ) ደረጃ 5

7) ለኩላሊት ህመም ክትትል ከጀመሩ ምን ያህል ጊዜያዊ ታል

ሀ) ከ ሁለት አመት በታች

ለ) ከሁለት አመት እስከ አራት አመት

**TEEN REPORTING FORM (age 13-18)**

**Directions** - On the following pages 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** by circling:

- 0** if it is **never** a problem                      **3** if it is **often** a problem
- 1** if it is **almost never** a problem            **4** if it is **almost always** a problem
- 2** if it is **sometimes** a problem

There are no rights or wrong answers. If you do not understand a question, please ask for help  
 In the past **ONE month**, how much of a **problem** has this been for you...

<b>Physical ability</b>	Never	Almost never	Sometimes	Often	Almost always
It is difficult for me to walk more than 100 metres					
It is difficult for me to run					
It is difficult for me to do sports activity or exercise					

It is difficult for me to lift something heavy					
It is difficult for me to take a bath or shower by myself					
It is difficult for me to do chores around the house					
I feel pain					
I have low energy					

<b>Feelings</b>	Never	Almost never	Sometimes	Often	Almost always
I feel afraid or scared					
I feel sad					
I feel angry					
I have trouble sleeping					
I worry about what will happen to me					
<b>How to get along with others</b>	Never	Almost never	Sometimes	Often	Almost always
I have trouble getting along with other teens					
Other teens do not want to be my friend					
Other teens tease me					
I cannot do things that other teens of my age can do					
It is difficult to keep up with the teens of my age					

SCHOOL	Never	Almost never	Sometimes	Often	Almost always
It is difficult to pay attention in class					
I forget things					
I have trouble keeping up with my schoolwork					
I miss school because of not feeling well					
I miss school to go to the doctor or hospital					

**ለአካል መጠን ያልደረሱ ልጆች ተፅእኖ ግምገማ ዕድሜ (13-18)**

መመሪያዎች- በሚከተለው ገፅ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎን ባለፈው ወር ውስጥ ምን ያህል ተፅእኖ እንደነበረብዎት ይንገሩን።

- 0) በጭራሽ
- 1) በጣም ትንሽ ጊዜ
- 2) አንዳንድ ጊዜ
- 3) ብዙውን ጊዜ
- 4) ሁልጊዜ

ትክክል ወይም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ኋላ አይበሉ።

አካላዊ እንቅስቃሴ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከአንድ መቶ ሜትር በላይ					

ለመንዝ አቅም ያንሰዎታል					
2) ለመሮጥ አቅም ያንሰዎታል					
3) የአካል ብቃት እንቅስቃሴ ለመስራት አቅም ያንሰዎታል					
4) ከባድ የሆነ ነገር ማንሳት ይከብደኛል					
5) ብቻዬን ገላዬን መታጠብ ይከብደኛል					
6) የቤት ውስጥ የዕለት ተዕለት ሥራ ለመስራት አቅም ያንሰዎታል					
7) ስመም ይሰማዎታል					
8) የድካም ስሜት ይሰማዎታል					

ስሜት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ፍርሃት ይሰማዎታል					
2) ሐዘን ይሰማዎታል					
3) ይናደዳሉ					
4) የመተኛት ችግር አለብዎት					
5) በእኔ ላይ ስለሚሆነው ነገር እጨነቃለሁ					
ማህበራዊ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለብኝ					
2) ሌሎች ልጆች ጓደኛዬ መሆን አይፈልገኝም					
3) ሌሎች ልጆች ያሾፉብኛል					
4) እኩዮቼ ልጆች ማድረግ የሚችላቸውን ማድረግ አልችልም					
5) ከእኩዮቼ ልጆች ጋር እኩል መጫወት ይከብደኛል					

ትምህርት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1. በክፍል ውስጥ ትኩረት መስጠት ይከብደኛል					
2. ነገሮችን እረሳለሁ					
3. የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር አለብኝ					
4. በሕመም ምክንያት ከትምህርት እቀራለሁ					
5. ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት እቀራለሁ					

**PARENT REPORT for TEENS (ages 13-18)**

On the following page is a list of things that might be a problem for your teen, Please tell us how much of a problem each one has been for your teen during the past ONE month by circling:

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

There are no right or wrong answers.

If you do not understand a question, please ask for help.

<b>Physical functioning</b>	Never	Almost never	Sometimes	Often	Almost always
Walking more than 100 metres					
Running					
Participating in sports activity or exercise					
Lifting something heavy					
Taking a bath or shower by him or herself					
Doing chores around the house					
Having hurts or aches					
Low energy level					
<b>EMOTION</b>	Never	Almost never	Sometimes	Often	Almost always
Feeling afraid or scared					
Feeling sad					
Feeling angry					
Trouble sleeping					
Worrying about what					

will happen to him or her					
<b>SOCIAL FUNCTIONING</b>	Never	Almost never	Sometimes	Often	Almost always
Getting along with other teens					
Other teens not wanting to be his or her friend					
Getting teased by other teens					
Not able to do things that other teens of his or her age can do					
Keeping up with other teens					

<b>SCHOOL FUNCTIONING</b>	Never	Almost never	Sometimes	Often	Almost always
Paying attention in class					
Forgetting things					
Keeping up with school work					

Missing school because of not feeling well					
Missing school to go to the doctor or hospital					

የቤተሰብ ተፅእኖ ግምገማ (ዕድሜ 13-18)

መመሪያዎች- በሚከተለው ገፅ ላይ ለእርስዎ ልጅ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎትን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበረብዎት ይንገሩን።

- 0) በጭራሽ
- 1) በጣም ትንሽ ጊዜ
- 2) አንዳንድ ጊዜ
- 3) ብዙውን ጊዜ
- 4) ሁልጊዜ

ትክክል ወይንም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ጎሳ አይበሉ።

አካል ብቃት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
9) ከአንድ መቶ ሜትር በላይ ለመንዝ ይከብደዋል					
10) ለመሮጥ ይከብደዋል					
11) በስፖርት እንቅስቃሴዎች ውስጥ ለመሳተፍ ይከብደዋል					
12) ከባድ ነገር ማንሳት ይከብደዋል					
13) ገላውን ለመታጠብ ይቸገራል					
14) የቤት ውስጥ ሥራዎችን ለመሥራት ይከብደዋል					
15) ሕመም ይሰማዋል					

16) የድካም ስሜት ይሰማዋል					
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ስሜት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
6) ፍርሃት ይሰማዋል					
7) ሐዘን ይሰማዋል					
8) ይናደዳል					
9) የመተኛት ችግር አለበት					
10) በእርሱ/ሷ ላይ ስለሚሆነው ነገር እጨነቃለሁ					
ማህበራዊ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
6) ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለበት					
7) ሌሎች ልጆች የእሱ/የእሷ ጓደኛ መሆን አይፈልጉም					
8) ሌሎች ልጆች ያሾፉበታል					
9) እኩዮቹ ልጆች ማድረግ የሚችሏቸውን ማድረግ አይችልም					
10) ከእኩዮቹ ልጆች ጋር እኩል መጫወት ይከብደዋል					

ትምህርት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
6. በክፍል ውስጥ ትኩረት መስጠት ይከብደዋል					
7. ነገሮችን ይረሳል					
8. የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር አለበት					
9. በሕመም ምክንያት ከትምህርት ይቀራል					

10.ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት ይቀራል					
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PedsQL™

Version 4.0

**CHILD REPORT (ages 8-12)**

**Directions** - On the following pages 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** by circling:

**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

There are no rights or wrong answers. If you do not understand a question, please ask for help

<b>Physical activities</b>	Never	Almost never	Sometimes	Often	Almost always
It is difficult for me to walk more than 100 metres					
It is difficult for me to run					

It is difficult for me to do sports activity or exercise					
It is difficult for me to lift something heavy					
It is difficult for me to take a bath or shower by myself					
It is difficult for me to do chores around the house					
I feel pain					
I have low energy					

<b>Feelings</b>	Never	Almost never	Sometimes	Often	Almost always
I feel afraid or scared					
I feel sad					
I feel angry					
I have trouble					

sleeping					
I worry about what will happen to me					

<b>HOW I GET ALONG WITH OTHERS</b>	Never	Almost never	Sometimes	Often	Almost always
I have trouble getting along with other kids					
Other kids tease me					
I cannot do things that other kids of my age can do					
It is difficult to keep up when I play with other kids					
<b>SCHOOL</b>	Never	Almost never	Sometimes	Often	Almost always
It is difficult to pay attention in class					

I forget things					
I have trouble keeping up with my schoolwork					
I miss school because of not feeling well					
I miss school to go to the doctor or hospital					

**በኩላሊት ድካም ሕመም ለተጠቁ ሕፃናት የተዘጋጀ መጠይቅ (ዕድሜ 8-12)**

መመሪያዎች- በሚከተለው ገፅ በኩላሊት ድካም ለተጠቁ ሕፃናት ላይ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎትን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበረብዎት ይንገሩን።

- 0) በጭራሽ
- 1) በጣም ትንሽ ጊዜ
- 2) አንዳንድ ጊዜ
- 3) ብዙውን ጊዜ
- 4) ሁልጊዜ

ትክክል ወይንም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ኋላ አይበሉ።

አካል ብቃት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1)ከአንድ መቶ ሜትር በላይ ለመንዝ ይከብደኛል					

2)ለመሮጥ ይከብደኛል					
3)በስፖርት እንቅስቃሴዎች ወስጥ ለመሳተፍ ይከብደኛል					
4)ከባድ ነገር ማንሳት ይከብደኛል					
5)ብቻዬን ገላዬን መታጠብ ይከብደኛል					
6)የቤት ውስጥ ሥራዎችን ለመሥራት ይከብደኛል					
7)ሕመም ይሰማኛል					
8)አቅም ያንሰኛል					

ስሜት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1)ፍርሃት ይሰማኛል					
2)ሐዘን ይሰማኛል					
3)እናደዳለሁ					
4)የመተኛት ችግር አለብኝ					
5)በእኔ ላይ ስለሚሆነው ነገር እጨነቃለሁ					

ማህበራዊ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለብኝ					
2) ሌሎች ልጆች ጓደኛ መሆን አይፈልገም					
3) ሌሎች ልጆች ያሾፋቸዋል					
4) እኩዮቹ ልጆች ማድረግ የሚችሏቸውን ማድረግ አልችልም					
5) ከእኩዮቹ ልጆች ጋር እኩል መጫወት ይከብደኛል					

ትምህርት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) በክፍል ውስጥ ትኩረት መስጠት ይከብደኛል					
2) ነገሮችን እረሳለሁ					
3) የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር አለብኝ					
4) በሕመም ምክንያት ከትምህርት እቀራለሁ					
5) ወደ ሐኪም ወይም የጤና ተቋም ለመሄድ ከትምህርት ቤት እቀራለሁ					

**PedsQL™ Pediatric Quality of Life Inventory**

**PARENT REPORT for CHILDREN (ages 8-12)**

Physical functioning	Never	Almost never	Sometimes	Often	Almost always
Walking more than 100 metres					
Running					
Participating in sports activity or exercise					
Lifting something heavy					
Taking a bath or shower by him or herself					
Doing chores around the house					

Having hurts or aches					
Low energy level					
<b>Emotional functioning</b>	Never	Almost never	Sometimes	Often	Almost always
Feeling afraid or scared					
Feeling sad					
Feeling angry					
Trouble sleeping					
Worrying about what will happen to him or her					
<b>Social functioning</b>	Never	Almost never	Sometimes	Often	Almost always
Getting along with other children					
Other kids not wanting to be his or her friend					
Getting teased by other children					
Not able to do things that other children of his or her age can do					
Keeping up when playing with other children					
<b>SCHOOL</b>					

Paying attention in class					
Forgetting things					
Keeping up with school work					
Missing school because of not feeling well					
Missing school to go to the doctor or hospital					

**የቤተሰብ ተፅዕኖ ግምገማ (ዕድሜ 8-12)**

**በኩላሊት ድካም ለተጠቁ ሕፃናት**

መመሪያዎች- በሚከተለው ገፅ በኩላሊት ድካም ለተጠቁ ሕፃናት ላይ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። አባታችን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበረብዎት ይንገሩን።

- 0) በጭራሽ
- 1) በጣም ትንሽ ጊዜ
- 2) አንዳንድ ጊዜ
- 3) ብዙውን ጊዜ
- 4) ሁልጊዜ

ትክክል ወይም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ኋላ አይበሉ።

አካል ብቃት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከአንድ መቶ ሜትር በላይ ለመጓዝ ይከብደዋል					
2) ለመሮጥ ይከብደዋል					
3) በስፖርት እንቅስቃሴዎች ውስጥ ለመሳተፍ ይከብደዋል					

4) ከባድ ነገር ማንሳት ይከብደዋል					
5) ገላውን ለመታጠብ ይቸገራል					
6) የቤት ውስጥ ሥራዎችን ለመሥራት ይከብደዋል					
7) ሕመም ይሰማዋል					
8) አቅም ያንሰዋል					
<b>ስሜት</b>	<b>በጭራሽ</b>	<b>በጣም ትንሽ ጊዜ</b>	<b>አንዳንድ ጊዜ</b>	<b>ብዙውን ጊዜ</b>	<b>ሁልጊዜ</b>
1) ፍርሃት ይሰማዋል					
2) ሐዘን ይሰማዋል					
3) ይናደዳል					
4) የመተኛት ችግር አለበት					
5) በእርሱ/ሷ ላይ ስለሚሆነው ነገር እጨነቃለሁ					
<b>ማህበራዊ</b>	<b>በጭራሽ</b>	<b>በጣም ትንሽ ጊዜ</b>	<b>አንዳንድ ጊዜ</b>	<b>ብዙውን ጊዜ</b>	<b>ሁልጊዜ</b>
1) ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለበት					
2) ሌሎች ልጆች የእሱ/የእሷ ጓደኛ መሆን አይፈልጉም					
3) ሌሎች ልጆች ያሾፉበታል					
4) እኩዮቹ ልጆች ማድረግ የሚችሏቸውን ማድረግ አይችልም					
5) ከእኩዮቹ ልጆች ጋር እኩል መጫወት ይከብደዋል					
<b>ትምህርት</b>	<b>በጭራሽ</b>	<b>በጣም ትንሽ ጊዜ</b>	<b>አንዳንድ ጊዜ</b>	<b>ብዙውን ጊዜ</b>	<b>ሁልጊዜ</b>
1) በክፍል ውስጥ ትኩረት መስጠት ይከብደዋል					
2) ነገሮችን ይረሳል					
3) የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር					

አለበት					
4) በሕመም ምክንያት ከትምህርት ይቀራል					
5) ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት ይቀራል					

**PedsQL™ Pediatric Quality of Life Inventory**

**YOUNG CHILD REPORT (ages 5-7)**

Instructions for the interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

I will read each question. Point to the pictures to show me how much of a problem it is for you.

Not at all                      Sometimes                      A lot

Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

<b>PHYSICAL FUNCTIONING</b>	Not at all	sometimes	A lot
Is it difficult for you to walk			
Is it difficult for you to run			
Is it difficult for you to play sports or exercise			
Is it difficult for you to pick up big things			
Is it difficult for you to take a bath or shower			

Is it difficult for you to help in the house (like pick up your toys)			
Do you have hurts or aches			
Do you ever feel too tired to play			
<b>EMOTIONAL FUNCTIONING</b>	Not at all	Sometimes	A lot
Do you feel scared			
Do you feel sad			
Do you feel angry			
Do you have trouble sleeping			
Do you worry about what will happen to you			
<b>SOCIAL FUNCTIONING</b>	Not at all	Sometimes	A lot
Is it difficult for you to get along with other kids			
Do other kids say they do not want to play with you			
Do other kids tease you			
Can other kids do things that you cannot do			
Is it difficult for you to keep up when you play with other kids			

በኩላሊት ድካም ሕመም ለተጠቁ ሕፃናት የተዘጋጀ መጠይቅ (ዕድሜ ከ5-7)

መመሪያዎች- በሚከተለው ገጽ በኩላሊት ድካም ሕመም ለተጠቁ ሕፃናት ላይ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎትን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እርስዎ ላይ አጋጥሞታል።

- 1) ምንም ዓይነት ችግር አላጋጠመኝም
- 2) አንዳንድ እንደዚህ ዓይነት ችግር ያጋጥመኛል
- 3) ብዙ ጊዜ ያጋጥመኛል

ትክክል ወይንም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ጎሳ አይበሉ።

አካል ብቃት	አላጋጠመኝም	አንዳንድ ጊዜ ያጋጥመኛል	ብዙ ጊዜ ያጋጥመኛል
17) መንዝ ይከብደኛል			
18) ለመሮጥ ይከብደኛል			
19) መጫወት ይከብደኛል			
20) ዕቃ ማንሳት ይከብደኛል			
21) ገላጭን መታጠብ ይከብደኛል			
22) በቤት ውስጥ ቀላል ሥራዎችን ማገዝ ይከብደኛል			
23) ሕመም ይሰማኛል			
24) አቅም ያንሰኛል			
ስሜት	አላጋጠመኝም	አንዳንድ ጊዜ ያጋጥመኛል	ብዙ ጊዜ ያጋጥመኛል
11) እፈራለሁ			
12) ሐዘን ይሰማኛል			
13) እናደዳለሁ			
14) ለመተኛት እቸገራለሁ			
15) በእኔ ላይ ስለሚሆነው ነገር እጨነቃለሁ			
ማህበራዊ	አላጋጠመኝም	አንዳንድ ጊዜ ያጋጥመኛል	ብዙ ጊዜ ያጋጥመኛል
11) ከሌሎች ልጆች ጋር ለመቀራረብ			

ችግር አለብኝ			
12) ሌሎች ልጆች ጓደኛዬ መሆን አይፈልጉም			
13) ሌሎች ልጆች ያሾፋብኛል			
14) እኩዮቼ ልጆች ማድረግ የሚችሏቸውን ማድረግ አልችልም			
15) ከሌሎች ልጆች ጋር እኩል መጫወት ይከብደኛል			
<b>ትምህርት</b>	<b>አላጋጠመኝም</b>	<b>አንዳንድ ጊዜ ያጋጥመኛል</b>	<b>ብዙ ጊዜ ያጋጥመኛል</b>
11. በክፍል ውስጥ ትኩረት መስጠት ይከብደኛል			
12. ነገሮችን እረሳለሁ			
13. የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር አለብኝ			
14. በሕመም ምክንያት ከትምህርት እቀራለሁ			
15. ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት እቀራለሁ			

pedsQL™

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

<b>PHYSICAL ACTIVITIES</b>	Never	Almost never	Sometimes	Often	Almost always
Walking more than 100 metres					
Running					
Participating in sports activity or exercise					
Lifting something heavy					
Taking a bath or shower by him or herself					
Doing small work, like picking up his or her toys					
Feeling pain					
Low energy level					
<b>Emotional health</b>	Never	Almost never	Sometime s	Ofte n	Almost always
Feeling afraid or scared					
Feeling sad					
Feeling angry					

Trouble sleeping						
Worrying about what will happen to him or her						
<b>SOCIAL ACTIVITIES</b>		Never	Almost never	Sometimes	Often	Almost always
Getting along with other children						
Other kids not wanting to be his or her friend						
Getting teased by other children						
Not able to do things that other children of his or her age can do						
Keeping up when playing with other children						
<b>SCHOOL ACTIVITIES</b>	Never	Almost never	Sometimes	Often	Almost always	
Paying attention in class						
Forgetting things						
Keeping up with school activities						
Missing school because of not feeling well						

Missing school to go to the doctor or hospital					
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**የቤተሰብ ተፅእኖ ግምገማ (ዕድሜ 5-7)**

መመሪያዎች- በሚከተለው ገፅ ላይ ለእርስዎ ልጅ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎትን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበረብዎት ይንገሩን።

- 0) በጭራሽ
- 1) በጣም ትንሽ ጊዜ
- 2) አንዳንድ ጊዜ
- 3) ብዙውን ጊዜ
- 4) ሁልጊዜ

ትክክል ወይንም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ኋላ አይበሉ።

አካል ብቃት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከአንድ መቶ ሜትር በላይ ለመጓዝ ይከብደዋል					
2) ለመሮጥ ይከብደዋል					
3) በስፖርት እንቅስቃሴዎች ውስጥ ለመሳተፍ ይከብደዋል					
4) ከባድ ነገር ማንሳት ይከብደዋል					
5) ገላውን ለመታጠብ ይቸገራል					
6) የቤት ውስጥ ሥራዎችን ለመሥራት ይከብደዋል					
7) ሕመም ይሰማዋል					
8) አቅም ያንሰዋል					

ስሜት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ፍርሃት ይሰማዋል					
2) ሐዘን ይሰማዋል					
3) ይናደዳል					
4) የመተኛት ችግር አለበት					
5) በእርሱ/ሷ ላይ ስለሚሆነው ነገር እጨነቃለሁ					
ማህበራዊ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለበት					
2) ሌሎች ልጆች የእሱ/የእሷ ጓደኛ መሆን አይፈልጉም					
3) ሌሎች ልጆች ያሾፉበታል					
4) እኩዮቹ ልጆች ማድረግ የሚችሏቸውን ማድረግ አይችልም					
5) ከእኩዮቹ ልጆች ጋር እኩል መጫወት ይከብደዋል					
ትምህርት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) በክፍል ውስጥ ትኩረት መስጠት ይከብደዋል					
2) ነገሮችን ይረሳል					
3) የትምህርት ቤት ሥራን እኩል ለማስቀጠል ችግር አለበት					
4) በሕመም ምክንያት ከትምህርት ይቀራል					
5) ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት ይቀራል					

# Pediatric Quality of Life Inventory (PedsQL™)

## PARENT REPORT for TODDLERS (ages 2-4)

### DIRECTIONS

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 one has been for your child during the past ONE month by circling:

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

There are no rights or wrong answers.

If you do not understand a question, please ask for help.

Physical activities	Never	Almost never	Sometimes	Often	Almost always
Walking					
Running					
Participating in active play or exercise					
Lifting something heavy					
Bathing					

Helping to pick up his or her toys					
Feeling pain					
Low energy level					

Emotion	Never	Almost never	sometimes	often	Almost always
Feeling afraid					
Feeling sad					
Feeling angry					
Trouble sleeping					
Worrying					

SOCIAL ACTIVITIES	Never	Almost never	Sometimes	Often	Almost always
Getting along with other children					
Other kids not wanting to be his or her friend					
Getting teased by other children					
Not able to do things that other children of his or her age can do					
Keeping up when playing with					

other children					
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**\*Please complete this section if your child attends school or daycare**

SCHOOL ACTIVITIES	Never	Almost never	Sometimes	Often	Almost always
Doing the same school activities as other children					
Missing school/daycare because of not feeling well					
Missing school/daycare to go to the doctor or hospital					

**የቤተሰብ ተፅእኖ ግምገማ (ዕድሜ 2-4)**

መመሪያዎች- በሚከተለው ገፅ ላይ እንደ እርስዎ ልጅ የኩላሊት ድካም ሕመም ላለባቸው ሕፃናት ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል። እባክዎትን ከታች የተዘረዘሩትን ጥያቄዎች ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበረብዎት ይንገሩን።

- 1) በጭራሽ
- 2) በጣም ትንሽ ጊዜ
- 3) አንዳንድ ጊዜ
- 4) ብዙውን ጊዜ
- 5) ሁልጊዜ

ትክክል ወይንም ስህተት መልስ የሚባል የለም። ግልጽ ያልሆነሎት ነገር ካለ እባክዎትን ለመጠየቅ ወደ ጎሳ አይበሉ።

አካል ብቃት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) መንዝ ይከብደዋል					
2) መሮጥ ይከብደዋል					
3) መጫወት ይከብደዋል					
4) ከባድ ዕቃዎችን ማንሳት ይከብደዋል					
5) ለመታጠብ ይከብደዋል					
6) መጫወቻዎችን ከመሬት ማንሳት ይከብደዋል					
7) ሕመም ይሰማዋል					
8) አቅም ያንሰዋል					
ስሜት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) ፍርሃት ይሰማዋል					
2) ሐዘን ይሰማዋል					
3) ይናደዳል					
4) ለመተኛት ይቸገራል					
5) ይጨነቃል					
ማህበራዊ	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1. ከሌሎች ልጆች ጋር መጫወት ይከብደዋል					
2. ከሌሎች ልጆች ጋር ለመቀራረብ ችግር አለበት					
3. ሌሎች ልጆች ከእሱ/ከእሷ መጫወት አይፈልጉም					
4. ሌሎች ልጆች ያሾፉበታል					
5. ሌሎች ልጆች የሚያደርጉትን ማድረግ አይችልም					
6. ከሌሎች ልጆች ጋር እኩል መጫወት ይከብደዋል					

እባክዎትን ልጁ የቀን መዋያ ወይንም ትምህርት ቤት ከገባ የሚከተሉትን ጥያቄዎች በመመለስ ይተባበሩን

ትምህርት	በጭራሽ	በጣም ትንሽ ጊዜ	አንዳንድ ጊዜ	ብዙውን ጊዜ	ሁልጊዜ
1) እንደ ሌሎች ልጆች ትምህርቱን በአግባቡ ይከታተላል					
2) በሕመም ምክንያት ከትምህርት ይቀራል					
3) ወደ ሐኪም ወይንም የጤና ተቋም ለመሄድ ከትምህርት ቤት ይቀራል					

**Addis Ababa University, School of Graduate Studies**

This is to certify that the thesis prepared by Dr. Getasew chekol, entitled “Assessments of Health-Related Quality of Life in Children with Chronic kidney disease on Follow-Up at the Renal Clinic of TASH, Addis Ababa, Ethiopia” submitted in partial fulfillment of the requirements for the certificate in pediatrics and child health complies with the regulations of the University and meets the accepted standards with respect to originality and quality Signed by the Examining Committee:



Advisor: Dr Bezaye Abebe Signature

Date 17/12/2021