ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

DEPARTMENT OF NURSING

HEALTH RELATED QUALITY OF LIFE AND ASSOCIATED FACTORS AMONG CHILDREN AND ADOLESCENT CANCER PATIENTS AT TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA, 2020: CHILD AND PARENT PERSPECTIVE

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A THESIS SUBMITTED TO ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING IN PARTIAL FULFILMENT OF THE REQUIRMENT OF DEGREE OF MASTERS OF SCIENCE IN PEDIATRICS AND CHILD HEALTH NURSING

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APPROVAL BY THE BOARD OF EXAMINATION

This thesis by Freweyni G/egziabher is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of masters in pediatrics and child health nursing.

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LIST OF ACRONYMS AND ABBREVIATIONS

AAU – Addis Ababa University

ANOVA – Analysis of variance

CDC - Center for Disease Control

CI- Confidence interval

ETB – Ethiopian birr

FMoH – Federal Ministry of Health

HRQoL – Health related quality of life

PedsQL – Pediatrics quality of life

QoL- Quality of life

SPSS – Statistical package for social science

TASH – Tikur Anbessa specialized hospital

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ABSTRACT

Cancer is one of the most devastating diseases in children. Diagnosis and treatment of cancer in children has effects that can limit their functional roles in daily life which will cause disruption in their quality of life. However, there is a limited study that assess the quality of life of children in Ethiopia. This study aimed to assess health related quality of life and determinant factors among children and adolescent cancer patients at Tikur Anbessa Specialized Hospital cancer center, Addis Ababa, Ethiopia. The study was conducted from May-June 26, 2020 using cross sectional study design. Sixty-nine children and adolescents with their parents/proxy had participated. Data was collected using PedsQL Inventory tool of the generic core scale, cancer module and multidimensional fatigue scale from both child and parents/proxy. Data was analyzed using SPSS 24 and ANOVA and t test were used to evaluate mean difference among variables. Multiple linear regression was used to identify predictors of HRQoL. Children and adolescents aged from 8-18 participated in this study and 40 were male while females were 29. This study found generic quality of life mean score of 69.0 and 66.8 also cancer quality of life mean score of 74.5 and 72.48 based on child self and parent/proxy reports respectively. Lower scores were observed in physical function, emotional function, nausea and communication. Clinical characteristics of patients had shown significant relation with generic and cancer scores. Fatigue, treatment duration, cancer type and treatment status predicted HRQoL of children and adolescent cancer patients. Symptom management and Psychological support in the initial phases of the treatment should get attention by clintians.

Key words: Childhood/adolescent cancer, Health related quality of life, parent/proxy

CHAPTER ONE

1. Introduction

1.1. Background

Cancer is rare in children. In developed countries, it represents less than 1% of all cancers. But in low- resource settings, where children may make up half of the population, the proportion of childhood cancer can be 5 times higher. Cancer is the leading disease-related cause of death for children and adolescents (1,2). It is also one of the most devastating diseases for the patient and their families. The disease itself and treatment duration have considerable limiting effects on Quality of Life (QoL)(3). Treatment can cause Fatigue, infection due to immunosuppression, nausea, vomiting, diarrhea, skin irritation, hair loss and also scare from a surgery. This lowers the child's self-esteem, distances the child from peer groups and therefore requires help, in many cases by a psychologist (4,5).

Quality of Life is individuals' 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 (6). While Health related quality of life (HRQoL) is about perceived physical, mental and social health function. It is an important component of health surveillance and generally considered valid indicator of health service needs and intervention outcomes (7). When it comes to children, Quality of Life is a concept with numerous dimensions. Children have their own parts/duties in family, school, and social life and being physically and emotionally healthy is vital in order to fulfill the needs of these responsibilities (3).

In Ethiopia Tikur Anbessa specialized hospital (TASH) in Addis Ababa is the first to give service for oncology patients. Pediatric hematology/oncology unit was established in April 2013. The hospital established its cancer and hematologic center in 2016 which gives service for patients from all over the country. Treatment like chemotherapy, surgery, and radiotherapy are provided at the institution. Unavailability of oncology service at regions increase the patient load as well as number of patients with advanced stage of cancer at the TASH cancer center (8,9)**.** Due to this there could be reduction in the quality of service provided for patients and also QoL of patients.

1.2. Statement of problem

Children and adolescents are different from adults since they are in the development/changing process and this can disrupt their life together with the cancer making fulfilling daily roles/needs harder for them. Considering the difference, Studies on HRQoL of pediatric patients should involve not only parents but also the children on their own matter since it highly affects their daily life (10–12).

When compared to other chronic illness pediatric cancer patient has diminished physical and psychosocial domains of life (3,13,14). Many studies had shown children with cancer had significantly lower QoL than other children. The reduction in QoL could be due to pain, depressive feelings related to their diagnosis, their appearance and treatment (15–18). Being unable to perform daily routine activities like they used to as a result of physical pain, tiredness and side effect of treatment has undeniable negative effect on patient emotional, social and school function. Children with low QoL can be emotionally depressed which in return affects their relationship with family as well as friends. unable to keep up with others in school due missing a lot of days or worse dropping out of school is another problem they could face.

In Childhood cancer not only the children QoL is impaired but also parents/families are highly affected. Having a child with cancer makes parents stressful, sleepless depressed and also disturb family functioning. Furthermore, it affects the family financially due to high coast of treatment and frequent hospitalization (19–22). This burden can impair the child's QoL even more.

In order to solve problems regarding QoL of children and adolescent cancer patients, different intervention like exercise, painting and group art therapy had been tried out in some countries and had shown great impact on improving fatigue level, sleep pattern, physical, emotional and social functioning (23,24).

In Ethiopia, Federal Ministry of Health (FMoH) has a National cancer control plan that aims to ensure a better quality of life for those living with the disease by improving palliative care service and community mobilization. The strategic plan covers the years 2015/16 to 2019/20 (9). Even though cancer is getting attentions now days, researches done on QoL of cancer patients focus more on adults and patient's family not the pediatric

population. Hence this study aims to assess the HRQoL of children and adolescent cancer patients and also it will identify the associated factor at TASH.

1.3. Significance of the study

In order to enhance the quality of care given for pediatric cancer patients studies should be conducted on children using tools that are appropriate for their age. As per the researcher level of knowledge and search on **Google scholar, PubMed and CINHAL** there was no published study in Ethiopia on this area specified to pediatrics.

Quality of life should be incorporated in the care of pediatric oncology treatment and care and understanding problems faced by children and adolescent cancer patients can help to so. Since nursing is a holistic approach knowing the QoL of patients helps to improve health care service by making a change in the approach of treatment and care for pediatric cancer patients and gives more guidance on palliative care service. The result of this research will also help health professionals to incorporate the child and family together in the health care service of cancer patients. Additionally, it will be used as a base line for next researchers and academic purpose.

CHAPTER TWO

2. Literature review

2.1. Introduction

Health related quality of life is multidimensional which encompasses physical, social, psychological/emotional functional domains of life. So measurement of HRQoL should incorporate these domains (25). The Pediatric Quality of Life Inventory (PedsQL) is one of the most commonly used tool by researchers to measure HRQoL of children and adolescents. It was developed by Varni James to measure QoL of children with chronic disease using disease specific tool and generic core score. The generic core score can also be used for healthy children. These instruments can be utilized as outcome measures in pediatric cancer clinical trials, research, and clinical practice for HRQoL outcome assessment (26).

2.2. Health related quality of life

A cross sectional study done in Jordan on 70 children aged 5-16 years, the PedsQL 4.0 Generic Core Scale self -report total mean score was 65.5 SD 17.6. Social functioning 78.14 SD 23.92 and School functioning 48.25 SD 23.18 were the highest and the lowest score reported respectively (27). Similarly, a study conducted in Brazil on 38 children and adolescents aged 8-18 using the Pediatric PedsQL^{TM} self-report showed lower mean total HRQoL on both generic and cancer score of children and adolescents. It found that generic core scale of 61.1 SD 17.0. and cancer scale 59.1 SD 16.7. The subscale worry was the lowest score to be reported from cancer specific module (28). In contrast, a study in Saudi Arabia including 51 children 8-15 years of age showed better QoL with total cancer mean score of 73.48 SD 15.78. Highest subscale mean score of 92.54 in cognitive problem and 82.67 in communication as reported. However, Lowest value was scored on Procedural anxiety 60.78 and worry 61.76 (29).

According to a study in Taiwan pediatric cancer patients had better QoL. The study involved 150 children and adolescents aged 7-18 and the total mean score for Generic core scale was 80.37 SD 14.94. They had reported relative better score in all sub domain of QoL (30). On the contrary a research conducted in Gaza Strip on 122 children aged 7 – 18 using PedsQL 4.0 generic score found that the total mean percentage of QoL to be 52.53%; physical functioning 57.94%, emotional functioning 47.13%, social functioning 60.98%, school functioning 48.85%. this shows children in Gaza Strip had better scoring in social functioning compared to the other subscales (31).

Parent perspective study on QoL of children living with cancer was done in Lebanon on children aged 7-18 years. According to this study a total cancer mean score of 72.73 SD 15.47 was reported with highest subscale mean score of 86.56 for communication and 80.47 for cognitive problems. Nausea and treatment anxiety had the lowest mean score 55.22 and 67.74 respectively (32). Inversely a study in Egypt found that mean score for worry (44.11), perceived physical appearance (50.6), and procedural anxiety (55.34) to be the lowest cancer subscale scores. The study was conducted on children aged 8-12 and it showed that total QoL to be relatively low with mean value of 62.29 (33).

On the other hand, studies were done based on both child /self and parent report. A study on agreement between child self and parent report of cancer patients involving 75 hospitalized children aged between 8 and 17 years in two Portuguese hospitals found that the total cancer QoL mean score of children report was higher than those of parents 66.0 SD 13.3 and 60.3 SD 15.0 respectively. Subscales of physical appearance (79.0 SD 21.2) and treatment anxiety (79.0 SD 27.2) from the child report and communication (78.6 SD 22.8) and perceived physical appearance (70.8 SD 24.8) from the parent report showed highest score of all. Lowest score was found on the subscale of worry with mean score of self/child report 39.2 SD 28.1 and proxy report mean score 37.4 SD 29.1 (34). On the other hand, a study in china mainland age 2-18 reported a generic QoL mean score of 68.56 and 65.5 based on child /adolescents and parents respectively. School function was the lowest score in both reports (35). Additionally, study in Pakistan had shown parents perceived their child generic QoL to be low (mean score of 42.07) and self-report mean score was 46.11 (36).

2.3. Factors associated with HRQoL

2.3.1. Sociodemographic factor of child and HRQoL

A study in Singapore on HRQoL of leukemia age 1-21 stated that age had a significant positive relationship with Physical Functioning, Physical Health, and the Total Scale Score on the PedsQL. Another study in Athens also showed that adolescents had better QoL score than children on all treatment phases (37)

A study on HRQoL and its association with self -esteem and fatigue among children with cancer in Jordan stated that gender had statistical significance with the total QoL score and also with the subscales. In the study boys had better quality of life and physical functioning than girls (27). Another study in Lebanon based on Parent report stated that when compared to male, female children had lower total cancer score and also subscales; pain and hurt, perceived physical appearance and communication (32). Similarly study in Egypt found that female patients had suffered more than males from treatment anxiety and worry (33).

2.3.2. Sociodemographic factor of parents/proxy and HRQoL

Factors like family size, family structure, parental education status and monthly household income had showed significant association in some studies of different countries. A study in Gaza Strip showed there is statistical significance association between QoL and family size. Children with less family member had better school functioning (31) Similarly Larger family size was associated with a negative effect on communication subscale according to a study done in Egypt. Patients with small family member (<5 members) had better communication score (33). Beside family size, family structure also had significant association with QoL. Those children with nuclear family had showed better QoL than other children with cancer in Taiwan (30).

A study in Greece stated that parental education level specifically fathers education level had a significant correlation with child QoL (38). On the other hand, according to the study in Gaza Family income had a significant association with QoL of children and adolescent. Children with better family income had lower QoL (31).

2.3.3. Clinical factors and HRQoL

In this study clinical factors includes age at diagnosis, time since diagnosis, cancer type, treatment duration and treatment type. A study in Egypt found that age at diagnosis had significant relation with QoL. According to the study children who were little or under 5 at the time of diagnosis had shown increase in pain and hurt (33). In the contrast, according to a study in Taiwan being diagnosed at younger age was significantly associated with better QoL. Moreover , Longer time since child diagnosis (the time from diagnosis until the time of data collection) also had shown great association with better QoL (30). Inversely, study in Lebanon found children living with cancer for more than 9 months had significantly lower total cancer score They were more worried and had cognitive, perceived physical appearance and communication problems compared to the group who are diagnosed with cancer for less than 9 months (32).

A study in Canada on children aged 2 -18, children with hematological malignancy had poor QoL than who had solid and CNS tumor (39). Inversely, a study in Lebanon stated that children with solid tumors had statistically significant lower scores on the nausea and cognitive problems subscales than those with blood cancer (32). According to a study in Singapore treatment duration had a significant positive relationship with school functioning (40). A study in North India found that children who had been treated with chemotherapy or chemotherapy and surgery had better QoL than those who received other combination therapy (12).

Frequent hospitalization/hospital visit was also one of clinical factors that showed significant positive relation with QoL of children and adolescent cancer patients and studies in Saudi Arabia(29) and Egypt(33) had confirmed this relation.

2.3.4. Fatigue and HRQoL

Fatigue had shown significant correlation with QoL of children and adolescents in many studies. The study in Jordan indicated that there were significant positive correlations between the PedsQL Multidimensional Fatigue Scale and all of its subscales and the PedsQL 4.0 Generic Core Scale. Children with high levels of fatigue experienced lower quality of life. And also age of the child had week negative association with multiple

fatigue scales and its subscales (27). Another study on adolescents in Virginia found there is a strong association between fatigue and psychosocial QoL (41).

Finding from a study in Brazil showed fatigue had strong correlation with total Generic QoL score and the cancer total score including their subscales. Except for worries and physical appearance which did not show any relation with fatigue (28). Similarly, according to a research in Taiwan, QoL pediatric cancer patients had significant positive association with multidimensional fatigue score and its subscales; general fatigue, sleep fatigue and cognitive fatigue. The study stated that children with less fatigue had better QoL (30).

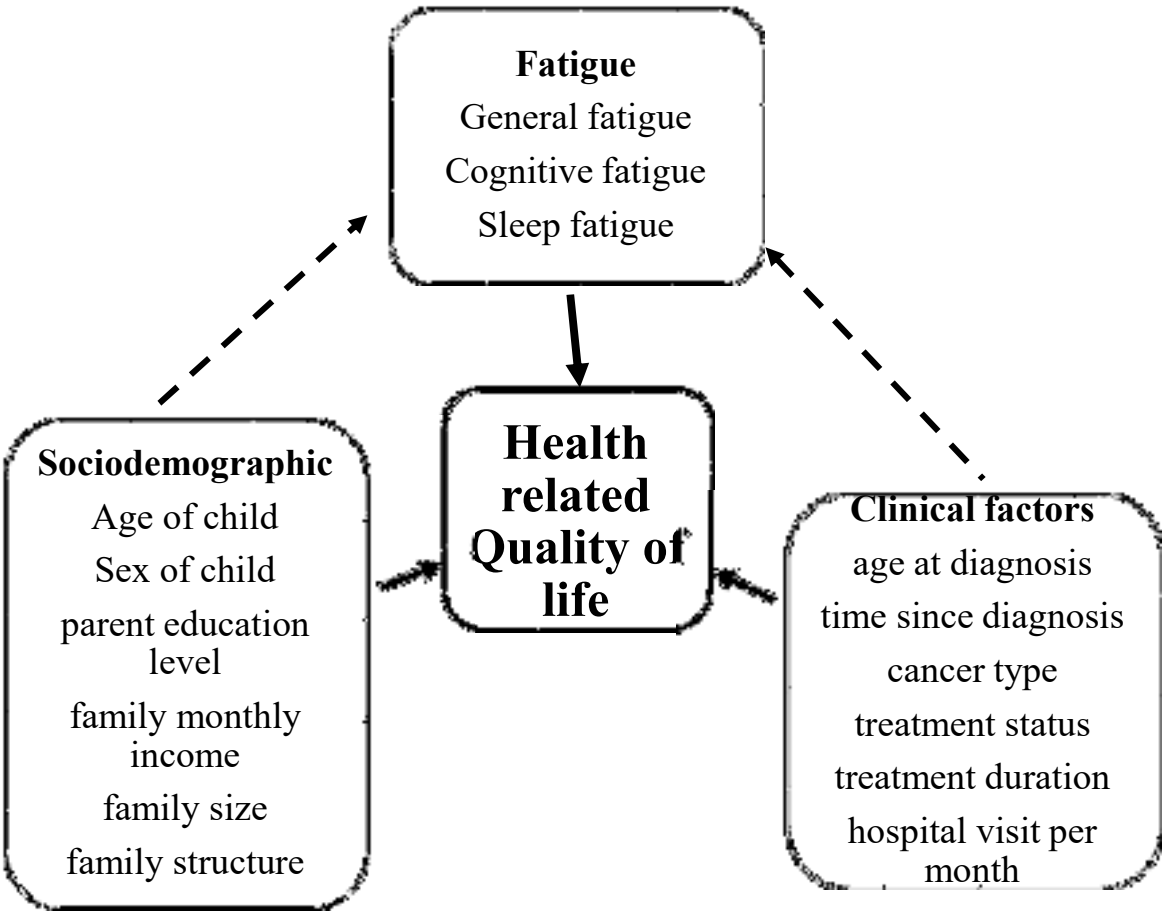

Figure 1: Conceptual frame work for health related quality of life of children and adolescent cancer patients (12,17,30–33,37,38,40)

CHAPTER THREE

3. OBJECTIVES

3.1.General objective

- To assess health related quality of life and determinant factors among children and adolescent cancer patients at TASH, Addis Ababa, Ethiopia, May- June 26, 2020

3.2. Specific objectives

- To assess health related quality of life of children and adolescent cancer patients at TASH, Addis Ababa, Ethiopia, 2020
- To identify factors associated with health related quality of life of children and adolescent cancer patients at TASH, Addis Ababa, Ethiopia, 2020
- To assess the difference between child self and parent/proxy report of Health related quality of life of children and adolescent cancer patients at TASH, Addis Ababa, Ethiopia, 2020

CHAPTER FOUR

4. METHODS AND MATERIALS

4.1. Study area and period

The study was conducted from May – June 26, 2020 at cancer and hematological center of TASH, Addis Ababa, Ethiopia. TASH is one of the biggest hospitals found in Addis Ababa, the capital city of Ethiopia located in Lideta sub-city. Health service for cancer patients is given at TASH hematology/oncology unit and the cancer center which was established in 2016 and it is located separately outside the TASH compound, Lideta sub-city, Woreda 8. There were totally 42 patient beds; 26 in hematology unit and 16 in the cancer center. The hematology unit is for patients with leukemia who are on induction phase of chemotherapy. The cancer center gives inpatient and outpatient service for cancer patients and other blood disorders. It had around 268 pediatric patients on follow up for treatment one month before data collection and from these 105(this number has repetition) where children and adolescents aged 8 -18. Patient might stay for hours or days for treatment.

4.2.Study design

Cross sectional study design was employed.

4.3.Population description

Source population: - All children and adolescent cancer patients who have follow up for treatment at TASH cancer center and their parent/proxy

Study population: - All children and adolescent cancer patients on treatment and their parent/proxy who are available at the time of data collection.

4.4.Eligibility criteria

4.4.1. Inclusion criteria

- ✓ Children and adolescent cancer patients aged from 8-18 with any type of cancer.
- ✓ Children and adolescent cancer patients on treatment for more than 1month

- ✓ Parent/proxy who have a day to day/close relationship with the patient for more than a month

4.4.2. Exclusion criteria

- ✓ Children and adolescents with mental instability and developmental problems like mental retardation, down syndrome and others because their mental development might not be appropriate for their age which will affect their response in the study
- ✓ Children and adolescents with additional chronic illness.

4.5. Sample size determination and Sampling procedure

Sample size will be determined by using the following formula:

$$n = \frac{Z_{\alpha/2})^2 * S^2}{d^2}$$

Where

n - Initial Sample size

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

S- estimated standard deviation 0.5

d- margin of error 5%.

$$\mathbf{n = \frac{(1.96)^2 * (0.5)^2}{(0.05)^2} = 384}$$

Since the source population is <10,000, correction formula will be used to determine the minimum sample size as follows

Where

n- initial sample size

N- source population size which was **105** (children and adolescents age 8-18 on treatment at TASH cancer center)

n_f - final sample size

$$\mathbf{n_f = \frac{n}{1 + n/N} = \frac{384}{1+384/105} = 82}$$

By using 10% non-response rate the final sample size will be **90.**

But due to small source population size all children and adolescent cancer patients on treatment at TASH cancer center who were available within the study period were included in the study.

4.6. Operational definition

Health related quality of life: is the perceived physical, emotional, school and social health function and also symptom related problems.

- ✓ Scoring is scaled 0-100
- ✓ Higher scores indicating better HRQoL

Parent/proxy: family member/ an individual who is responsible for taking care of the patient.

Child – age 8-12 (42)

Adolescent - age 13-18 (42)

4.7. Study variables

4.7.1. Dependent variable

- Health related quality of life

4.7.2. Independent variables

- **Sociodemographic factors**: age of child, sex of child, educational status of child, educational status of parent/proxy, residence, family monthly income, family structure, family size
- **Clinical factors**: age at diagnosis, time since diagnosis, type of cancer, treatment status, treatment duration, hospital visit per month
- **Fatigue**: general fatigue, sleep fatigue, cognitive fatigue

4.8. Data collection tool and procedure

Data was collected using structured standard PedsQL Inventory questioner. The data was collected through interview with children and adolescents and their parent/proxy when they came for treatment follow-up at the cancer center. Patient card was reviewed in order to confirm their cancer diagnosis type, treatment status and treatment duration. Data was

collected by two BSC nurses that do not work at the cancer center and a person with MSc degree in pediatrics and child health nursing supervised the process.

The questionnaire had generic core scale, cancer module, multidimensional fatigue scale and sociodemographic information sections. All questions in the PedsQL Inventory are negatively directed.

PedsQL 4.0 Generic Core Scales

The 23-item multidimensional PedsQL 4.0 Generic Core Scales encompass 4 scales: 1) physical functioning (8 items), 2) emotional functioning (5 items), 3) social functioning (5 items), and 4) school functioning (5 items). It has parallel child self-report and parent proxy-report formats. The parent proxy-report forms are designed to assess the parent's perceptions of their child's HRQoL. A 5-point Likert response scale is utilized across child self-report for ages 8–18 years and parent proxy-report (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem).

Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 =50, 3 =25, 4 = 0), so that higher PedsQL 4.0 scores indicate better HRQoL. Scale scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If greater than 50% of the items in the scale are missing, the scale score is not computed (26). Total Score is the Sum of all the items over the number of items answered on all the Scales (42).

PedsQL 3.0 Cancer Module

The 27-item multidimensional PedsQL 3.0 Cancer Module Acute Version encompasses 8 scales: 1) pain and hurt (2 items), 2) nausea (5 items), 3) procedural anxiety (3 items), 4) treatment anxiety (3 items), 5) worry (3 items), 6) cognitive problems (5 items), 7) perceived physical appearance (3 items), and 8) communication (3 items). The format, instructions, Likert response scale, and total scoring method are identical to the PedsQL 4.0 Generic Core Scales Acute Version (26).

PedsQL Multidimensional Fatigue Scale

This encompasses 18 items with 3 subscales: 1) general fatigue (6 items), 2) sleep/rest fatigue (6 items), and 3) cognitive fatigue (6 items). The format, instructions, Likert response scale, and total scoring method are identical to the PedsQL 4.0 Generic Core Scales Acute Version (26). And higher score means less fatigue level.

Sociodemographic information related questions were adopted from different literatures (17,30,32,37).

4.9.Data quality control

The data collection instrument was translated to Amharic language and then back to English by language experts to ensure consistency. Training was given for data collectors and supervisor for 1day duration. Pretest was conducted on 6 cancer patient in the TASH cancer center prior to data collection (these patients were not included in the data collection) and all the necessary modification was made. Data was checked for completeness before entry and missed data (50%) were not computed. Additionally, internal consistency was checked for all HRQoL measurements: generic QoL Cronbach alpha 0.88 and 0.90 and cancer specific QoL Cronbach alpha 0.84 and 0.85 for child and parent report respectively.

4.10. Data entry and analysis

The collected data was coded and entered in to Epi data version 4.6.0.2 and exported to SPSS version 24. Mean, standard deviation and percentage were used to describe the statistics of total score and subscales of QoL. ANOVA (for three and more categorical variables) and independent t-test (for dichotomous variables) were used to evaluate the difference between mean scores of variables. Pearson's correlation was used to detect correlation between continuous variables then Multiple linear regression was used to identify predictors of QoL. Independent t-test was done to identify mean difference between child self-report and parent/proxy report. P value <0.05 was considered statistical significant.

4.11. Ethical consideration

To conduct this research, ethical clearance was obtained from AAU, College of Health sciences, school of nursing and midwifery ethical review committee and department of pediatrics and child health research committee (DRPC) of TASH. Next, Official letter was submitted to the TASH cancer center coordinator.

Verbal informed consent (proxy/parent) and assent (children) was obtained from each study subject prior to data collection process. Each respondent was informed about the objective of the study that it will contribute necessary information to improve quality of care at the cancer center, for policy makers and other concerned bodies. Any study subjects who were not willing to participate in the study were not forced to participate. They were also informed that all data obtained from them would be kept confidential by using codes (like 1001, 1002…) instead of any personal identifiers and it was meant only for the purpose of the study.

During data collection process the data collectors had informed each study participant about the purpose and anticipated benefits of the research project. The study participants were also informed they have full right to refuse, withdraw or completely reject part or all of their part in the study. Not Participating in this study did not affect the care patients received.

4.12. Dissemination plan

The study result will be presented to Addis Ababa University, College of health science, Department of Nursing. Soft and hard copy will be given to department of nursing, library, oncology department of TASH. In addition, the researcher will make an effort to publish the research findings and present at conferences.

CHAPTER FIVE

5. RESULT

5.1. Socio-demographic characters of patient and parent/proxy

This study included 69 children and adolescents between the age 8-18 years (mean 10.7 years) and 58% of them were male patients. Fathers (55%) were the most frequent respondent for the parent/proxy report. Because of their illness 88.4% of the patients were not enrolled in school. More than half of the respondents lived in rural area (37,53%). Parent/proxy (mothers 42.4%, fathers 53.1%) in this study were farmers. (Table 1 below shows sociodemographic character of patient and their parent/proxy).

Table 1. Sociodemographic information of children and adolescent cancer patients at TASH cancer center, 2020

Variables	**Frequency**	**Percent%**
Age (in years)	Mean=10.7±2 Range 8-18	
Gender		
Male	40	58.0
Female	29	42.0
Kinship with the child		
Mother	23	33.3
Father	38	55.1
Relative	8	11.6
Educational status of child		
Did not start school	4	5.8
Dropout	57	82.6
Grade 1-4	6	8.7
Grade 5-8	2	2.9
Mother/proxy education(N=65)		
Unable to read and write	21	32.3
Primary education	23	35.4
Secondary education	15	23.1
Higher education	6	9.2

Father/proxy education(N=64)		
Unable to read and write	16	25.0
Primary education	19	29.7
Secondary education	21	32.8
Higher education	8	12.5
Marital status		
Single	3	4.3
Married	60	87.0
Divorced	1	1.4
Widowed	5	7.2
Mother/proxy occupation		
Unemployed/Housewife	23	34.8
Government employee	4	6.1
Merchant	11	16.7
Farmer	28	42.4
Father/proxy occupation		
Unemployed	2	3.1
Government employee	9	14.1
Merchant	10	15.6
Farmer	34	53.1
Private organization	4	6.3
Daily labor	2	3.1
Others	3	4.7
Address		
Urban	32	46.4
Rural	37	53.6
Religion		
Orthodox	27	39.1
Muslim	24	34.8
protestant	18	26.1
Monthly income(ETB)	Mean 2542 ETB Range 400-8000	
Family size		
≤5	28	40.6
>5	41	59.4
Family structure		
Nuclear family	50	72.5
Extended family	15	21.7
Single parent	4	5.8

5.2. Clinical character of patient

Of all the patients 44 of them were diagnosed with hematological cancer and the rest 25 had solid cancer with mean age at diagnosis 9.6 years (range 5-14 years). Patients who were on Chemotherapy accounted for 72.5% and the rest 27.5% had been treated with combination therapies. The mean treatment duration was 12.5 years. (Table 2 shows the clinical characters of children and adolescent cancer patients).

Table 2. Clinical characteristics of children and adolescent cancer patients at TASH cancer center, 2020

Variables	**Frequency**	**Percent%**
Age at diagnosis (in years)	Mean=9.6±2.23 Range 5-14years	
Time since diagnosis (in month)	Mean=13.12±9.9 Range 1-48months	
Cancer type		
Hematological cancer	**44**	**63.8**
Leukemia	35	79.5
lymphoma (HL and NHL)	9	20.5
Solid cancer	**25**	**36.2**
Rhabdomyosarcoma	9	36
Ewing sarcoma	4	16
Osteosarcoma	3	12
Neuroblastoma	2	8
Germ cell tumor	2	8
Medulloblastoma	2	8
Nasopharyngeal carcinoma	2	8
Retinoblastoma	1	4
Treatment status/type		
chemotherapy	50	72.5
chemotherapy and radiation	6	8.7
chemotherapy and surgery	12	17.4
chemotherapy, radiation and surgery	1	1.4
Treatment duration (in month)	Mean=12.4±10.1 Range 1-48 months	
Hospital visit per month		
≤3/month	46	66.7
>3/month	23	33.3

5.3. QoL report of children/adolescents and parent/proxy

The total generic mean score of child report was 69.0±17.76 (range 23.6-100) while parents have report mean score of 66.86±19.6 (range 16.6 - 96.74). According to the self -report of children and adolescent physical function (62.36) was perceived to be lower than other domains. Similarly, parents also reported low score on physical function (60.23). There was no significant mean difference between child and parent report (t=0.672, p=0.502). The comparison between child self and parent generic QoL report is shown in table 3 below.

Table 3. Comparison of child self and parent/proxy report of generic QoL of children and adolescent cancer patients at TASH, 2020

PedsQL Generic domains	**Child/adolescent report Mean ± SD**	**Parent/proxy report Mean ± SD**	
Physical function	62.36 ± 25.36	60.23 ± 27.28	
Emotional function	72.02 ± 20.72	67.46 ± 21.17	
Social function	76.76 ± 15.92	76.66 ± 17.85	
School function (N=7)	86.43 ± 6.9	90.0 ± 5.00	
Total QoL	**69.0 ± 17.76**	**66.86 ± 19.61**	
	t test for equality of mean		
	t	Mean difference	Sig.
Total generic QoL	0.672	2.14171	0.502

Every domain of QoL are taken as continuous variable.

The other assessed outcome was cancer specific QoL and the reported mean scores by children and parents were 74.51 ± 14.27 (range 39.5-100) and 72.48 ± 15.03 (range 37.5-97.9) respectively. There was no significant mean difference between the two reports (t=0.817, p=0.415). According to the child self-report, children and adolescents perceived that nausea (66.88) and communication (54.2) to be more problematic. Parents also perceived that nausea (63.41) and communication (50.73) score to be lower than other subscales of their child QoL. The comparison between child self and parent cancer specific QoL report is shown in table 4 below.

Children and adolescent in this study reported multidimensional fatigue score of 77.9 ranging from 23.6 -100. Low score was observed in the general fatigue subscale with mean score of 69.86. The other subscale scores were 77.9 and 86.1 for sleep/rest fatigue and cognitive fatigue respectively.

Table 4. Comparison of child self and parent/proxy report cancer specific QoL of children and adolescent cancer patients at TASH, 2020

PedsQL cancer specific domains	**Child/adolescent report Mean ± SD**	**Parent/proxy report Mean ± SD**	
Pain and hurt	73.73±26.44	76.45±28.07	
Nausea	66.88±21.30	63.41±21.80	
Procedural anxiety	80.67±32.51	74.15±32.28	
Treatment anxiety	82.85±23.73	77.53±25.69	
Worry	80.92±16.85	76.33±20.19	
Cognitive problem	87.31±13.95	89.97±11.98	
Perceived physical appearance	78.07±26.13	80.97±26.77	
Communication	54.22±30.27	50.73±30.37	
Total QoL	**74.51±14.27**	**72.48±15.03**	
	t test for equality of means		
	t	Mean difference	Sig.
Total cancer specific QoL	0.817	2.03905	0.415

Every domain of QoL are taken as continuous variable

5.4. Relationship between child self- report of QoL and patient characters

ANOVA and independent t-test was done to select categorical variables with significant mean difference. Pearson Correlation was used for testing association between continuous independent variables and HRQoL score. Based on this tests family size (t=2.174, P-0.033), hospital visit per month (t=6.180, P-0.000), cancer type (t=4.129, P-0.000), treatment type (f=2.921, p-0.041), age at diagnosis (r=-0.379, p=0.001), treatment duration (r=0.572, p-0.000), and multidimensional fatigue (r=0.859, p-0.000) made significant difference on generic QoL score of child self-report. Except for age at diagnosis and family size, those variables associated with generic score had also significant relation with cancer specific score of child report: cancer type (t=2.049, p-

0.044), hospital visit per month (t=4.652, p-0.000), treatment type (f=2.874, p-0.043), treatment duration (r=0.566, p-0.000), and multidimensional fatigue (r=0.767, p-0.000).

There was also highly significant correlation between generic score and cancer score including its subscales. Additional to this multidimensional fatigue and its subscales (general fatigue, sleep and rest fatigue and cognitive fatigue) had significant correlation with both generic (r=0.859, p=0.000) and cancer total scores (r=0.767, p=0.000). There was no significant difference or association among total QoL (both generic and cancer scores) and other sociodemographic variables.

5.5 Multiple linear regression for QoL of child and adolescent report

Variables that showed difference/relation in the ANOVA, independent t test and Pearson's correlation were analyzed using multiple linear regression to find predictors of QoL. Based on this, treatment type, treatment duration and fatigue predicted generic QoL of child and adolescent report. And 80% of the variance in QoL was explained by this variables (R^2= 0.806, F=27.19, P=0.000). Similarly, treatment duration, fatigue and also cancer type predicted cancer related QoL. This factors explained more than half of the variance (R^2=0.68, F=19.219, P=0.000). In this study fatigue made unique contribution for both QoL scores.

Treatment duration showed significant positive association with generic QoL. As treatment duration increases One unit, generic and cancer related QoL also increases by 0.337 and 0.44 unit respectively. Children and adolescents who were on the treatment for longer time had better QoL. Similarly, multidimensional fatigue was also predictor of QoL with the highest contribution. As fatigue increases by one unit, generic and cancer related QoL increases by 0.740 and 0.591 respectively. Children and adolescent cancer patients with low fatigue score (high fatigue level) had an impaired QoL.

In the current study, as mentioned above treatment type was one of the predictors of generic QoL. chemotherapy and radiation therapy had significant association with generic QoL. When level of chemotherapy and radiation therapy increases by one-unit generic QoL decreases by 8.739 units. Patients on this therapy had shown lower generic scores (52.77±12.5).

On the other hand, cancer type had shown significant association with cancer related QoL of children and adolescent cancer patients (β=7.051, P=0.027). Solid cancer patients had shown lower cancer related QoL (69.95±14.1) when compared to those patients with hematological cancer (77.1±13.84). Table 5 and 6 below shows multiple regression analysis for child self-reported generic and cancer related QoL separately.

Table 5. Multiple linear regression analysis of predictors of child self-report generic QoL for children and adolescent cancer patients at TASH, 2020

Variables	Predictors of Generic quality of life			
	B	**β**	**CI**	**P**
Family size	-2.185	-0.061	-6570, 2.199	0.323
Age at diagnosis	-0.673	-0.085	-1.757, 0.412	0.219
Cancer type	-2.975	-0.081	-9.309, 3.359	0.351
Treatment status Chemotherapy Chemotherapy and radiation Chemotherapy, radiation and surgery	 -2.852 **-8.739** 1.815	 -0.072 **-0.14** 0.012	 -9.620, 3.916 **-17.354, -0.124** -17.016, 20.647	 0.403 **0.047*** 0.848
Treatment duration	**0.337**	**0.192**	**0.079, 0.596**	**0.011***
Hospital visit per month	0.553	0.015	-5.506, 6.612	0.856
Total fatigue	**0.740**	**0.699**	**0.564, 0.916**	**0.000****

R square=0.806, CI-confidence interval
*statically significant at p<0.05
**statically significant at p<0.001
ANOVA-treatment type,
T-test- family size, cancer type, hospital visit per month
Pearson correlation- age at diagnosis, treatment duration, total multidimensional fatigue

Table 6. Multiple linear regression analysis of predictors of child self-report cancer specific QoL for children and adolescent cancer patients at TASH, 2020

Variables	Predictors cancer specific quality of life			
	B	**β**	**CI**	**P**
Cancer type	**7.051**	**0.239**	**0.818, 13.284**	**0.027***
Treatment type				
Chemotherapy	6.710	0.212	-0.35, 13.455	0.051
Chemotherapy and radiation	-1.745	-0.035	-10.316, 6.827	0.685
Chemotherapy, radiation and surgery	12.496	0.105	-5.568, 30.560	0.172
Treatment duration	**0.44**	**0.317**	**0.198, 0.698**	**0.001****
Hospital visit per month	2.674	0.089	-3.346, 8.694	0.378
Total fatigue	**0.591**	**0.694**	**0.418, 0.764**	**0.000****

R square= 0.688
*statically significant at $p<0.05$
**statically significant at $p<0.001$

CHAPTER SIX

DISCUSSION

The purpose of this study was to assess HRQoL children and adolescent cancer patients and factors associated based on child and parent perspective. Finding of the study showed patients and their parents reported generic QoL of 69.0 and 66.86 respectively and cancer specific QoL of 74.51 and 72.48. Factors associated with HRQoL were treatment duration, treatment status, cancer type and multidimensional fatigue.

In this study finding of child reported total generic QoL was better than studies done in Brazil (61.1) and Gaza strip (52.3) (28,31). This difference could be related to small sample size (in Brazil), increase in number of patient with larger family size (in Gaza). Having larger family size had shown significant relation with Generic QoL in different studies. Additionally, in the Brazilian study patients had shown lower scores in most of cancer related QoL and this might affect the general QoL. Yet the current score was lower when compared to the study in Taiwan which was 80.37(30). Inconsistency can be due involvement of patients who are off treatment in the Taiwan study and also bigger sample size taken from two hospitals.

When we see parent perspective generic QoL, the current study found mean score of 66.86 and it was consistent with the china mainland study which found 65.5 (35). Agreement can be explained by pain and hurt which was approximately similar in both studies. Pain can highly affect physical function of the children and this makes them feel down emotionally and socially. On the other hand, it disagreed with the study in Pakistan which found generic QoL of 42.07 (36). This difference could be due to small sample size and most of the parent/proxy respondents were mothers (96%) in the Pakistani study. Since mothers tend to spend more time with children at home there could be a difference in the perception of child's problems.

Another explanation for the lower generic QoL of children and adolescent cancer patient based on child self and parent report could be related to patient's school status. When compared to the studies mentioned in the former paragraphs, most of the patients in current study had dropped out of school. Since there is no special education system like home schooling in our county the children did not have a chance in continuing their education. This can affect their psychology/emotion and social relation. Parents should cheer their children to read and draw to enhance QoL.

Cancer specific QoL was also assessed in different countries. In this study children and adolescents had reported mean score of 74.51. The finding was congruent with result of Saudi Arabia mean score of 73.48(29). This might be related to age group and treatment type in which chemotherapy had high percentage in both. In contrast children in countries like Portuguese, brazil and Pakistan had reported lower Cancer QoL mean score of 66.0, 59.1 and 46.1 respectively(28,34,36). This can be explained by smaller sample size in the studies mentioned above and the mean for time since diagnosis was 4 months while it was 13 months in the current study. Low fatigue score (meaning high fatigue level) can also be another explanation for the difference with the Brazilian finding since studies had shown fatigue is highly correlated with QoL.

Parent perception of cancer related QoL was congruent with the Lebanon study 72.75(32) and better when compared to the study done in Egypt 62.29 and Portuguese 60.3 (33,34). Consistency with Lebanon study can be justified by the agreement in types of cancer in which most of the patients had hematological cancer and took chemotherapy. Solid cancer patients also had statistically significant lower score in both studies. And incongruence might be related to response being dominated by mothers in the Portuguese study and adolescents were not part of the Egypt study (only 8-12).

Despite better score in cancer specific QoL in both child self and parent reports, the current study observed low communication score compared to the other studies. This might be related to the cultural difference in child raising method and also children having only little clue about their illness. Parents and health professional have to help children to open up about their feelings, get them psychological support and involve them in decision of health care.

In this study even though there was no significant difference among child self and parent/proxy reports, parents reported lower generic and cancer specific QoL compared to their children. This can be related to the fact that parents are worried and frustrated about their children's condition and they might deflect their own feeling towards them. Evidences had shown that having a child with cancer can make parents distressed and disturb family relationship/functioning (19,20) and this might affect QoL of children. Because of this parents should get health care attention and they should be provided psychological and social support.

In the current study HRQoL was predicted by treatment duration, treatment status, cancer type and multidimensional fatigue. Treatment duration had a positive association with generic and cancer specific QoL. In which those who had a history of longer time since the start of treatment had better QoL. This can be explained at the initial phases of the treatment there is frequent hospitalization and administration of highly concentrated chemotherapy which also means more treatment side effects like nausea and fatigue. This can affect QoL as it appeared nausea and fatigue had significant correlation with QoL in the current as well as other studies (28,30).

Multidimensional fatigue was one of the predictors with the highest contribution in both QoL scores. This agrees with the finding of Taiwan (30). Since fatigue is a common side effect of cancer treatments and there could be similarity in the treatment protocols in different countries, it had shown significance relation with QoL in other studies (27,28,41). Nausea can also increase the feeling of tiredness due to low energy related to nutrition.

In this study being on combination of chemotherapy and radiation treatment had shown a statistical significant association with generic QoL. Radiation has its own early and late impacts on the patient (43,44). Being combined with chemotherapy can make the side effects worse in a range that could affect the physical function of the child which can lead to impaired psychosocial domains of life.

On the other hand, cancer type was significant predictor of cancer specific QoL. Children and adolescents with solid cancer had sown lower cancer related QoL than children with hematological cancer. This can be explained by the symptoms and treatment strategies for solid cancer. Patients with solid cancer had more pain, nausea, anxiety, cognitive problems, impaired perception of their physical appearance and fatigue in the current as well as other studies (28,32). Solid cancers are managed not only with chemotherapy but also with surgeries and/or radiation therapy(44). When these therapies are combined the side effect also increases and can make QoL more impaired. Additionally, surgeries are invasive procedures for children introducing fear/ anxiety and also leaves a scar which sometimes might impair body image.

Strength

The strength of this study was it included both children and parents for comparing.it also used both generic QoL and cancer specific/symptom related QoL which helped to assess general health aspects and also disease related problems more deeply and separately. Multidimensional fatigue was assessed as a factor.

Limitation

Since this study used cross sectional design, there were no control groups to compare with and also no chance of assessing changes that come with time. Other factors which might had effect on QoL were not included: distress, and family health related factors.

CHAPTER SEVEN

CONCLUSION AND RECOMMENDATION

Conclusion

In summary, this study aimed to assess the HRQoL of children and adolescent cancer patients. findings indicated that both children and parents have perceived lower generic QoL but relatively better cancer related QoL. It is observed lower scores in Physical, emotional, nausea and communication domains. Parents perceived that their children had lower QoL. Treatment side effect and symptoms of the disease appeared to impair the general QoL of cancer patients.

Treatment duration, combination of chemotherapy and radiation treatment strategy, having solid cancer and fatigue had predicted the overall QoL of children and adolescent cancer patients. Clinicians should keep this in mind upon deciding health care options including nursing care.

In addition, health professionals should also give attention to patients with frequent hospital visit, older age at diagnosis and larger family size due to their significant relation with QoL. And it is better to consider this factors when health care is delivered.

Recommendation

Health professionals should use different technique in order to enhance communication with the patients. Managing disease and treatment related symptoms in patients with shorter treatment duration (in the initial phases of treatment) should get more concern. Additionally, giving consecutive psychological support/advices for the patients and parents/proxy at the initial phases of the treatment could help to enhance QoL of patients. clinicians should also consider patient's cancer type when choosing strategies for psychological and social support.

Parents has to encourage reading, solving math's problems and other methods that can distract children form worrying and feeling pain and increase cognitive ability. Also parents need to be thoughtful of what they say or do (emotionally) in front of their children.

Health policy makers should include HRQoL assessment in the patient follow-up care.

Organizations should collaborate with the cancer center in the process of solving problems encountered by patients and their parents.

Researchers should include more patient and family health related factors and do longitudinal study to see any change through time or have control groups to compare cancer patients with chronic patients or healthy once. Additionally, focusing on interventions (exercise, art therapy) is recommended.

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ANNEX I

Information sheet

Hello may name is _____ I am here on behalf of Freweyni G/egziabher who is studying at Addis Abeba university, college of health science, department of nursing now conducting a research on health related quality of life and determinant factors among children and adolescent cancer patients at TASH from May-June 26, 2020. Findings from this study helps to improve health care service given for pediatric cancer patients. And also it helps to evaluate the implementation of health strategy on improving quality of life cancer patients.

I would like to take your time to respond to the questions and it will take approximately half an hour. Your answer will not be revealed to the hospital or any other people, and the information you give will be treated anonymously and confidential. This research imposes no risk and therefore no compensation will be provided for your participation in this study. Your participation is totally voluntary and you can withdraw anytime or refuse to continue, and this will not affect the way you are treated in the institution/hospital.

For more information and question contact us:

Freweyni G/egziabher

Phone number- +251924143175

email address freweyni163@gmail.com

Consent form

The researcher had explained all information and procedures that are part of this research study and I have understood the same. The study aims to assess health related quality of life and determinant factors among children and adolescent cancer patients at TASH. I understand that this study will help to improve health care service given for pediatric cancer patients. This research imposes no risk and therefore no compensation would be provided to me or my child. I hereby agree to participate in this research study and give my voluntary consent. I also give rights to the researcher for collecting the data that are required for the study.

If respondent agree to participate continue.

Name of interviewer_____ signature _____ date_____

Assent form (12 -18 years)

Your parent has agreed that you take part in our study where we are assessing health related quality of life and determinant factors among children and adolescent cancer patients at TASH. this study will help to improve health care service given for you and other pediatric cancer patients. Your participation in the study is fully voluntarily. Any information you provided will not be given to anyone else.

If respondent agree to participate continue

Name of interviewer_____ signature _____ date_____

English version of questioner

Table for Sociodemographic data of children/adolescent cancer patients and parents		
No	**Questions**	**Answers**
101	Age of the child	_____ years
102	Sex	1. Male 2. Female
103	Relationship with the child	1. Mother 2. Father 3. Relative 4. Other
104	Child educational status	1. Did not start school 2. Dropout 3. Kindergarten 4. Grade 1-4 5. Grade 5-8 6. Grade 9-12
105	Mothers education level	1. Unable to read and write 2. Grade 1 – 8 3. Grade 9 - 12 4. Diploma, Degree and above
106	Fathers education level	1. Unable to read and write 2. Grade 1 – 8 3. Grade 9 - 12 4. Diploma, Degree and above
107	Mother occupational status	1. Unemployed 2. Government 3. Merchant 4. Farmer 5. Private organization 6. Daily labor 7. other
108	Father occupational status	1. Unemployed 2. Government 3. Merchant 4. Farmer 5. Private organization 6. Daily labor 7. other
109	Residence	1. urban 2. rural
110	Religion	1. Orthodox 5. other 2. Muslim 3. Catholic 4. protestant

111	Family monthly income	_____ birr
112	Family size	_____
113	Family structure	1. Nuclear 2. Extended 3. Single parent
Table for Clinical information of children and adolescent cancer patients		
114	Age at diagnosis in years	_____
115	Time since diagnosis in moths	_____
116	Type of cancer diagnosis	1. Hematological malignancy 2. Solid tumor 3. Other
117	Treatment type	1. Chemotherapy 2. Chemotherapy + radiation 3. Chemotherapy + surgery 4. Chemotherapy + radiation +surgery
118	Treatment duration in months	_____
119	Hospital visit per month	_____

The following tools were adopted from PedsQL Inventory ™. Permission to use and also translate the tool was obtained from Mapi Research Trust the legal distributer of the PedsQL Inventory.

PedsQL™ generic version 4.0 Child-and adolescent report

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

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

PedsQL™ generic version 4.0 parent/proxy report

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 during the past **one** month ,**0** if it is never a problem, **1** if it is almost never a problem, **2** if it is sometimes a problem, **3** if it is often a problem, **4** if it is almost always a problem.

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

PedsQL™ cancer module version 3.0 child-and adolescent report

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

	PAIN AND HURT *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	I ache or hurt in my joints and/or muscles	0	1	2	3	4
2	I hurt a lot	0	1	2	3	4

	NAUSEA *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	I become sick to my stomach when I have medical treatments	0	1	2	3	4
2	Food does not taste very good to me	0	1	2	3	4
3	I become sick to my stomach when I think about medical treatments	0	1	2	3	4
4	I feel too sick to my stomach to eat	0	1	2	3	4
5	Some foods and smells make me sick to my stomach	0	1	2	3	4

	PROCEDURAL ANXIETY *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Needle sticks (i.e. injections, blood tests, IV's) hurt	0	1	2	3	4
2	I get scared when I have to have blood tests	0	1	2	3	4
3	I get scared about having needle sticks (i.e. injections, blood tests, IV's)	0	1	2	3	4

	TREATMENT ANXIETY *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	I get scared when I am waiting to see the doctor	0	1	2	3	4
2	I get scared when I have to go to the doctor	0	1	2	3	4
3	I get scared when I have to go to the hospital	0	1	2	3	4

	WORRY *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	I worry about side effects from medical treatments	0	1	2	3	4
2	I worry about whether or not my medical treatments are working	0	1	2	3	4
3	I worry that my cancer will come back or relapse	0	1	2	3	4

	COGNITIVE PROBLEMS *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
2	I have trouble solving math problems	0	1	2	3	4
3	I have trouble writing school papers or reports	0	1	2	3	4
4	It is hard for me to pay attention to things	0	1	2	3	4
5	It is hard for me to remember what I read	0	1	2	3	4

	PERCEIVED PHYSICAL APPEARANCE *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	I feel I am not good looking	0	1	2	3	4
2	I don't like other people to see my scars	0	1	2	3	4
3	I am embarrassed when others see my body	0	1	2	3	4

	COMMUNICATION *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2	It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3	It is hard for me to explain my illness to other people	0	1	2	3	4

PedsQL™ cancer module version 3.0 parent/proxy report

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

PAIN AND HURT *(problems with…)*		**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Aches in joints and/or muscles	0	1	2	3	4
2	Having a lot of pain	0	1	2	3	4

NAUSEA *(problems with…)*		**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Becoming nauseated during medical treatments	0	1	2	3	4
2	Food not tasting very good to him/her	0	1	2	3	4
3	Becoming nauseated while thinking about medical treatments	0	1	2	3	4
4	Feeling too nauseous to eat	0	1	2	3	4
5	Some foods and smells making him/her nauseous	0	1	2	3	4

PROCEDURAL ANXIETY *(problems with…)*		**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Needle sticks (i.e. injections, blood tests, IV's) causing him/her pain	0	1	2	3	4
2	Getting anxious about having blood drawn	0	1	2	3	4
3	Getting anxious about having needle sticks (i.e. injections, blood tests, IV's)	0	1	2	3	4

TREATMENT ANXIETY *(problems with…)*		**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Getting anxious when waiting to see the doctor	0	1	2	3	4
2	Getting anxious about going to the doctor	0	1	2	3	4
3	Getting anxious about going to the hospital	0	1	2	3	4

	WORRY *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost**
1	Worrying about side effects from medical treatments	0	1	2	3	4
2	Worrying about whether or not his/her medical treatments are working	0	1	2	3	4
3	Worrying that the cancer will reoccur or relapse	0	1	2	3	4

	COGNITIVE PROBLEMS *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Difficulty figuring out what to do when something bothers him/her	0	1	2	3	4
2	Trouble solving math problems	0	1	2	3	4
3	Trouble writing school papers or reports	0	1	2	3	4
4	Difficulty paying attention to things	0	1	2	3	4
5	Difficulty remembering what he/she reads	0	1	2	3	4

	PERCEIVED PHYSICAL APPEARANC *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Feeling that he/she is not good looking	0	1	2	3	4
2	Not liking other people to see his/her scars	0	1	2	3	4
3	Being embarrassed about others seeing his/her Body	0	1	2	3	4

	COMMUNICATION *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1	Difficulty telling the doctors and nurses how he/she feels	0	1	2	3	4
2	Difficulty asking the doctors or nurses questions	0	1	2	3	4
3	Difficulty explaining his/her illness to other people	0	1	2	3	4

PedsQL ™ Multidimensional Fatigue Scale Version 3.0 child and adolescent report

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past **one** month 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

GENERAL FATIGUE ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel tired	0	1	2	3	4
2. I feel physically weak (not strong)	0	1	2	3	4
3. I feel too tired to do things that I like to do	0	1	2	3	4
4. I feel too tired to spend time with my friends	0	1	2	3	4
5. I have trouble finishing things	0	1	2	3	4
6. I have trouble starting things	0	1	2	3	4
SLEEP/REST FATIGUE ***(problems with…)***					
1. I sleep a lot	0	1	2	3	4
2. It is hard for me to sleep through the night	0	1	2	3	4
3. I feel tired when I wake up in the morning	0	1	2	3	4
4. I rest a lot	0	1	2	3	4
5. I take a lot of naps	0	1	2	3	4
6. I spend a lot of time in bed	0	1	2	3	4
COGNITIVE FATIGUE ***(problems with…)***					
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4
6. I have trouble remembering more than one thing at a time	0	1	2	3	4

Amharic version of questioner

የመረጃ ወረቀት

ጤና ይስጥልኝ ስሜ _____ ይባላል። እዚህ የመጣሁት በአዲስ አበባ ዩኒቨርሲቲ የጤና ሳይንስ ኮሌጅ ፣ የነርሲንግ ት/ት ክፍል ውስጥ ማስተርስ ት/ት እየተከታተሉ የሚገኙትን ወ/ሪት ፍሬወይኒ ገ/እግዚአብሄርን በመወከል ነው ። በአሁን ሰአት በሕፃናት እና በጉርምስና ዕድሜ ላይ የሚገኙ የካንሰር ታማሚዎች የህይወት ጥራት እና ጤና ነክ ጉዳዮች ላይ ምርምር እያደረጉ ይገኛል። የዚህ ጥናት ግኝት ለህፃናት ካንሰር ህመምተኞች የሚሰጠውን የጤና አገልግሎት ለማሻሻል ይረዳል ።

ለጥያቄዎቹ መልስ ለመስጠት ጊዜዎን መውሰድ እፈልጋለሁ እና ግማሽ ሰዓት ያህል ይወስዳል ። መልስዎ ለሆስፒታሉ ወይም ለሌላ ማንኛውም ሰው አይገለጽም ፣ እናም የሚሰጡት መረጃ በምስጢር ይያዛል ። ይህ ጥናት ምንም ጉዳት አያስከትልም። ስለሆነም በዚህ ጥናት ውስጥ እርስዎ ለሚያደርጉት ተሳትፎ ምንም ካሳ አይሰጥዎትም ። ተሳትፎዎ ሙሉ በሙሉ በፈቃደኝነት ነው እናም በማንኛውም ጊዜ መውጣት ወይም ማቁዋረጥ ይችላሉ ፣ እናም ይህ በተቋሙ / ሆስፒታል በሚታከሙበት መንገድ ላይ ተጽዕኖ የለውም ፡

ማንኛውንም መረጃ ለማግኘት ወይም ጥያቄ ካሎት፡

ፍሬወይኒ ገ/እግዚአብሄር

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የፈቃድ ቅጽ

የዚህ የምርምር ጥናት አካል የሆኑ ሁሉም መረጃዎች እና ሂደቶች ተብራርተውልኛል እና እኔም በሚገባ ተረድቻለሁ። ጥናቱ ህጻናት እና ጉርምስና እድሜ ላይ ያሉ የካንሰር ታማሚዎች የህይወት ጥራት ላይ ያተኮረ ነው። ጥናቱ ለታማሚዎቹ የሚሰጠውን የህክምና አገልግሎት እና እንክብካቤን ለማሳደግ/ለማሻሻል እንደሚረዳ ተገንዝቤአለሁ። በመሆኑም ምንም አይነት ጉዳት ወይም ችግር እንደማያስከትል እና ምንም ካሳ እንደማይሰጥ አውቄአለሁ። በዚህ የምርምር ጥናት ውስጥ ለመሳተፍ እና አስፈላጊውን መረጃ ለመስጠት እስማማለሁ ።

መጠይቁን ያደረገው ሰው ስም _____ ፊርማ _____

ቀን _____

የልጆች የፈቃድ ቅጽ (12-18 ዓመት)

የሕፃናት ካንሰር ህሙማን ኑሮ ጥራትን የሚመለከት ጥናት ላይ ለመሳተፍ ወላጅዎ ተስማምቷል ። ጥናቱ ለህፃናት ካንሰር ታማሚዎች የሚሰጠውን የህክምና አገልግሎት እና እንክብካቤን ለማሳደግ/ለማሻሻል ይረዳል። በጥናቱ ውስጥ ያለዎት ተሳትፎ ሙሉ በሙሉ በፈቃደኝነት ነው ። የሚሰጡት ማንኛውም መረጃ ለሌላ ለማንም አይሰጥም ።

መልስ ሰጪው “አዎ” የሚሉ ከሆነ ይቀጥሉ።

መጠይቁን ያደረገው ሰው ስም _____ ፊርማ _____

ቀን _____

የህጻናት ካንሰር ታማሚዎች የህይወት ጥራት መገምገሚያ በ አማርኛ

ተ.ቁ	ማህበረሰባዊ መረጃ	
101	የህፃኑ/ኗ እድሜ	_____
102	ፆታ	1. ወንድ 2. ሴት
103	ከ ህፃኑ/ኗ ጋር ያልዎት ዝምድና	1. እናት 2. አባት 3. ዘመድ 4.ሌላ/_____
104	የ ህፃኑ የት/ት ሁኔታ	1. ት/ት ያልጀመረ 2. ት/ት ያቋዋረጠ 3. መዋለ ህፃናት 4. 1-4ኛ ክፍል 5. 5-8ኛ ክፍል 6. 9-12ኛ ክፍል
105	የ እናት የት/ት ደረጃ	1. ማንበብ እና መጻፍ የማትችል 2. 1-8ኛ ክፍል 3. 9-12ኛ ክፍል 4. ዲፕሎማ ፣ ዲግሪ እና ከዚያ በላይ
106	የ አባት የት/ት ደረጃ	1. ማንበብ እና መጻፍ የሚችል 2. 1-8ኛ ክፍል 3. 9-12ኛ ክፍል 4. ዲፕሎማ፣ዲግሪ እና ከዚያ በላይ
107	የ እናት የ ስራ ሁኔታ	1. ስራ አጥ 2. የመንግስት ስራ 3. ነጋዴ 4. ግብርና 5. የግል ተቀጣሪ 6. የቀን ስራ 7. ሌላ
108	የ አባት የ ስራ ሁኔታ	1. ስራ አጥ 2. የመንግስት ስራ 3. ነጋዴ 4. ግብርና 5. የግል ተቀጣሪ 6. የቀን ስራ 7. ሌላ
109	አድራሻ/ነዋሪነት	1. ከተማ 2. ገጠር
110	ሀይማኖት	1. ኦርቶዶክስ 2. ሙስሊም 3. ካቶሊክ 4. ፕሮቴስታንት 5. ሌላ _____
111	የ ቤተሰብ የወር ገቢ	_____

112	የ ቤተሰብ መጠን	_____
113	የቤተሰብ መዋቅር	1. እናት፣ አባት እና ልጆች 2. ወላጆች፣ ልጆች እና ሌሎች የቤተሰብ አባላት/ዘመዶች 3. እናት ወይም አባት እና ልጆች

ስለ በሽታው እና ህክምናው		
114	በሽታው ሲገኝበት/ባት የነበረበት/ችበት እድሜ	_____
115	በሽታው ከተገኘበት/ባት ምን ያህል ጊዜ ሆነው	_____
116	የ ካንሰሩ አይነት	1. የደም እና ተያያዥ ካንሰር 2. “solid” ካንሰር 3. ሌላ
117	የሚሰጠው/ጣት ህክምና አይነት	1. ኬሞቴራፒ 2. ኬሞቴራፒ እና ጨረር 3. ኬሞቴራፒ እና ቀዶ ጥገና 4. ኬሞቴራፒ፣ ቀዶ ጥገና እና ጨረር
118	ህክምናውን ከጀመረ/ች ያለው ጊዜ	_____
119	በወር ምን ያህል ጊዜ ሆስፒታል ይመጣሉ	_____

የ ‹PedsQL™ 4.0 › አጠቃላይ የህፃናት ህይወት ጥራት ደረጃ መመዘኛ የህፃናት-የራስ ዘገባ

በሚቀጥለው ገጽ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል ። እባክዎ ካለፈው ወር ውስጥ እያንዳንዳቸው ምን ያህል ችግር እንደነበሩ ይንገሩን ፣ 0 -በጭራሽ ችግር ካልሆነ ፣ 1- በጥቂቱ ችግር ከሆነ፣2 -አንዳንድ ጊዜ ችግር ከሆነ ፣ 3 -ብዙውን ጊዜ ችግር ከሆነ ፣ 4- ሁልጊዜ ችግር ከሆነ።

		በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለአካላዊ እንቅስቃሴ (ችግሮች.....)						
1	ጥቂት መራመድ ለእኔ ከባድ ነው	0	1	2	3	4
2	መሮጥ ለእኔ ከባድ ነው	0	1	2	3	4
3	የስፖርት እንቅስቃሴ ወይም የአካል ብቃት እንቅስቃሴ ማድረግ ለእኔ ከባድ ነው	0	1	2	3	4
4	ከባድ ነገርን ማንሳት ለእኔ ከባድ ነው	0	1	2	3	4
5	በራሴ መታጠብ ወይም ገላ መታጠብ ለእኔ ከባድ	0	1	2	3	4
6	በቤቱ ዙሪያ የቤት ውስጥ ሥራ መሥራት ለእኔ ከባድ ነው	0	1	2	3	4
7	ያመኛል ወይም እሠቃየሁ	0	1	2	3	4
8	ዝቅተኛ ኃይል አለኝ/ አቅም ያንሰኛል	0	1	2	3	4
ስለ ስሜቴ (ችግሮች...)						
1	ፍራቻ ወይም ፍርሃት ይሰማኛል	0	1	2	3	4
2	ሀዘን ይሰማኛል	0	1	2	3	4
3	የ ንዴት ስሜት ይሰማኛል/እናደዳለሁ	0	1	2	3	4
4	ለመተኛት እቸገራለሁ	0	1	2	3	4
5	በእኔ ላይ ስለሚሆነው ነገር እጨነቃለሁ	0	1	2	3	4
ስለ ማህበራዊ መስተጋብር (ችግሮች...)						
1	ከሌሎች ልጆች ጋር ለመቀራረብ እቸገራለሁ	0	1	2	3	4
2	ሌሎች ልጆች ጓደኛዬ መሆን አይፈልጉም	0	1	2	3	4
3	ሌሎች ልጆች ያሾፉብኛል	0	1	2	3	4
4	በእኔ ዕድሜ ያሉ ሌሎች ልጆች ሊያደርጓቸው የሚችሏቸውን ነገሮች ማድረግ አልችልም	0	1	2	3	4
5	ከሌሎች ልጆች ጋር ስጫወት ከ እነሱ እኩል መሆን ለኔ ከባድ ነው	0	1	2	3	4
ስለ ትምህርት ቤት (ችግሮች ከ ...)						
1	በክፍል ውስጥ ትኩረት መስጠት /መከታተል ለኔ ከባድ ነው	0	1	2	3	4
2	ነገሮችን እረሳለሁ	0	1	2	3	4
3	የ ክፍል እና የቤት ስራ ለመስራት እቸገራለሁ	0	1	2	3	4
4	በሕመሜ ምክንያት ከት/ ቤት እቀራለሁ	0	1	2	3	4
5	ወደ ሆስፒታል ለመሄድ ት/ቤት እቀራለሁ	0	1	2	3	4

የ ‹PedsQL™4.0 › አጠቃላይ የህጻናት የህይወት ጥራት ደረጃ መመዘኛ የወላጅ ዘገባ

በሚቀጥለው ገጽ ላይ ለልጅዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል ። እባክዎን እያንዳንዳቸው ባለፈው አንድ ወር ውስጥ ምን ያህል ችግር እንደነበሩ ይንገሩን ፣ 0 -በጭራሽ ችግር ካልሆነ ፣ 1 በጥቂቱ ችግር ከሆነ ፣ 2- አንዳንድ ጊዜ ችግር ከሆነ ፣ 3 -ብዙውን ጊዜ ችግር ከሆነ ፣ 4- ሁል ጊዜ ችግር ከሆነ።

		በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
ስለ አካላዊ እንቅስቃሴ						
1	ጥቂት እርምጃ መራመድ	0	1	2	3	4
2	መሮጥ	0	1	2	3	4
3	በስፖርት እንቅስቃሴ ወይም የአካል ብቃት እንቅስቃሴ ውስጥ መሳተፍ	0	1	2	3	4
4	ከባድ የሆነ ነገር ማንሳት	0	1	2	3	4
5	በእራሱ / ራሷ ገላ መታጠብ	0	1	2	3	4
6	የቤት ውስጥ ሥራዎችን መሥራት	0	1	2	3	4
7	ህመም ወይም ስቃይ	0	1	2	3	4
8	ዝቅተኛ የኃይል ደረጃ/አቅም ማነስ	0	1	2	3	4
ስለ ስሜቶቹ/ቿ						
1	የፍርሃት ስሜት	0	1	2	3	4
2	የሐዘን ስሜት	0	1	2	3	4
3	የመናደድ ስሜት	0	1	2	3	4
4	ለመተኛት መቸገር	0	1	2	3	4
5	በእሱ ወይም በእሷ ላይ ስለሚሆነው ነገር መጨነቅ	0	1	2	3	4
ማህበራዊ መስተጋብር						
1	ከሌሎች ልጆች ጋር መቀራረብ	0	1	2	3	4
2	ሌሎች ልጆች የእሱ ጓደኛ መሆን አይፈልጉም	0	1	2	3	4
3	በሌሎች መሳለቂያ/ ማሾፊያ መሆን	0	1	2	3	4
4	በሱ/ኗ እድሜ ያሉ ልጆች የሚያደርጉትን ነገር ማድረግ አለመቻል	0	1	2	3	4
5	ከሌሎች ልጆች ጋር ሲጫወቱ ከ እነሱ እኩል መሆን	0	1	2	3	4
ስለ ት/ቤት						
1	በክፍል ውስጥ ትኩረት መስጠት	0	1	2	3	4
2	ነገሮችን መርሳት	0	1	2	3	4
3	የት/ ቤት ስራ መስራት	0	1	2	3	4
4	በህመም ምክንያት ከት/ቤት መቅረት	0	1	2	3	4
5	ወደ ሐኪም / ሆስፒታል ለመሄድ ት/ ቤት መቅረት	0	1	2	3	4

የ ‹PedsQL™ 3.0 › የህፃናት የህይወት ጥራት ደረጃ መመዘኛ ካንሰር ሞዱል የህፃናት ዘገባ

በሚቀጥለው ገጽ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል ። እባክዎ ካለፈው ወር ውስጥ እያንዳንዳቸው ምን ያህል ችግር እንደነበሩ ይንገሩን ፣ 0 በጭራሽ ችግር ካልሆነ ፣ 1 በጥቂቱ ችግር ከሆነ ፣2 አንዳንድ ጊዜ ችግር ከሆነ ፣ 3 ብዙውን ጊዜ ችግር ከሆነ ፣ 4 ሁልጊዜ ችግር ከሆነ ።

ድብርት እና ህመም	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም ይሰማኛል	0	1	2	3	4
2. ያመኛል/እሰቃያለሁ	0	1	2	3	4

ማቅለሽለሽ	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ህክምናው ሲሰጠኝ ያቅለሸልሸኛል	0	1	2	3	4
2. ምግብ ለእኔ ትሩ ጣእም የለውም	0	1	2	3	4
3. ስለ ህክምና ሳስብ ውስጤን ያመኛል	0	1	2	3	4
4. ለመብላት ውስጤን ህመም ይሰማኛል	0	1	2	3	4
5. አንዳንድ ምግቦች እና ሽታዎች ውስጤን ያሳምሙኛል	0	1	2	3	4

ስለ ምርምራዎች ጭንቀት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. መርፌ (ለምሳሌ -መርፌዎች ፣ የደም ምርመራዎች ፣ በደም የሚሰጡ ነገሮች) ያማል	0	1	2	3	4
2. የደም ምርመራ ሲኖረኝ/ሊደረግልኝ ሲል እፈራለሁ	0	1	2	3	4
3. በመርፌ - የደም ምርመራዎች፣ መዳኒቶች ሲሰጡ እፈራልሁ	0	1	2	3	4

ስለ ህክምና ጭንቀት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ሐኪሙን ለማየት በምጠብቅበት ጊዜ ፍርሃት ይሰማኛል	0	1	2	3	4
2. ወደ ሐኪም መሄድ ሲኖርብኝ ፍርሃት ይሰማኛል	0	1	2	3	4
3. ወደ ሆስፒታል መሄድ ሲኖርብኝ ፍርሃት ይሰማኛል	0	1	2	3	4

መጨነቅ/ማሰብ	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ስለህክምናው የጎንዮሽ ጉዳቶች/መድሀኒቱ ስለሚያመጣቸው ችግሮች እጨነቃለሁ	0	1	2	3	4
2. ህክምናዎቼ እየሠሩ /እያሻሉኝ ስለመሆናቸው እጨነቃለሁ	0	1	2	3	4
3. የእኔ ካንሰር /በሽታዬ ተመልሶ ይመጣ ብዬ እጨነቃለሁ	0	1	2	3	4

ስለ አእምሮአዊ ችግሮች	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. አንድ ነገር ሲረብሸኝ ምን ማድረግ እንዳለብኝ መወሰን/ማወቅ ለእኔ ከባድ ነው	0	1	2	3	4
2. የሂሳብ ጥያቄዎችን መስራት /መፍታት እቸገራለሁ	0	1	2	3	4
3. የትምህርት ቤት ስራ/ሪፖርቶችን/አሳይመንት የመፃፍ ችግር አለብኝ	0	1	2	3	4
4. ለነገሮች ትኩረት መስጠቱ/መከታተል ለእኔ ከባድ ነው	0	1	2	3	4
5. ያነበብኩትን ማስታወስ ለእኔ ከባድ ነው	0	1	2	3	4

ስለ ራሱ/ሷ አካላዊ ገጽታ ያለው/ያላት አመለካከት ያለ ችግር	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. እኔ ጥሩ መልክ እንደሌለኝ ይሰማኛል	0	1	2	3	4
2. ሌሎች ሰዎች ጠባሳዎቼን እንዲያዩ አልፈልግም	0	1	2	3	4
3. ሌሎች ሰውነቴን ሲያዩ አፍራለሁ	0	1	2	3	4

ስለ ግንኙነት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. እኔ ምን እንደሚሰማኝ ለዶክተሮች እና ነርሶች መንገር ለእኔ ከባድ ነው	0	1	2	3	4
2. ሐኪሞቹን እና ነርሶችን ጥያቄ መጠየቅ ለእኔ ከባድ ነው	0	1	2	3	4
3. ህመሜን ለሌሎች ሰዎች ማስረዳት ለእኔ ከባድ ነው	0	1	2	3	4

የ ‹PedsQL™ 3.0› የህፃናት የህይወት ጥራት ደረጃ መመዘኛ ካንሰር ሞዱል የወላጅ ዘገባ

በሚቀጥለው ገጽ ላይ ለ ልጅዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል ። ልጅ እባክዎን ላለፉት አንድ ወር ምን ያህል ችግር እንደነበረ ይንገሩን ፣ 0 በጭራሽ ችግር ካልሆነ ፣ 1 በጥቂቱ ችግር ከሆነ 2 አንዳንድ ጊዜ ችግር ከሆነ ፣ 3 ብዙውን ጊዜ ችግር ፣ 4 ሁል ጊዜ ችግር ከሆነ።

ድብርት እና ህመም	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. በመገጣጠሚያዎች እና / ወይም በጡንቻዎች ላይ ህመም ስሜት	0	1	2	3	4
2. ህመም /ስቃይ	0	1	2	3	4

ማቅለሽለሽ	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. በሕክምና ወቅት ማቅለሽለሽ	0	1	2	3	4
2. ምግብ ለእሱ / ሷ በጣም ጥሩ ጣእም የለውም	0	1	2	3	4
3. ስለ ህክምና እያሰበ/ች ማቅለሽለሽ መሆን	0	1	2	3	4
4. ለመብላት ሲያስብ/ ስታስብ በጣም የማቅለሽለሽ	0	1	2	3	4
5. አንዳንድ ምግቦች እና ሽታዎች/ ያቅለሽልሽዋል/ታል	0	1	2	3	4

ስለ ምርመራ ጭንቀት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. መርፌ (ለምሳሌ ፣ መርፌዎች ፣ የደም ምርመራዎች ፣ በ ደም ስር የሚሰጡ መዳኒቶች) ህመም ማስከተል	0	1	2	3	4
2. ለ ምርመራ ደም ሊቀዳለት ሲል መጨነቅ	0	1	2	3	4
3. ስለ መርፌመጨነቅ (ለምሳሌ ፣ መርፌ ፣ የደም ምርመራ)	0	1	2	3	4

ስለ ሕክምና ጭንቀት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ሐኪሙን ለማየት በሚጠብቁበት ጊዜ መጨነቅ	0	1	2	3	4
2. ወደ ሐኪም ለመሄድ መጨነቅ	0	1	2	3	4
3. ወደ ሆስፒታል ለመሄድ መጨነቅ	0	1	2	3	4

መጨነቅ/ማሰብ	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ስለህክምናው የጎንዮሽ ጉዳቶች መጨነቅ	0	1	2	3	4
2. ስለ ሕክምናው መስራት/ ማሻል መጨነቅ	0	1	2	3	4
3. ካንሰሩ እንደገና ይመጣብነኛል የሚል ስጋት	0	1	2	3	4

ስለ አእምሮአዊ ችግሮች	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. አንድ ነገር ሲረብሸው/ሻት ምን ማድረግ እንዳለበት/ባት ለይቶ ለማወቅ መቸገር	0	1	2	3	4
2. የሂሳብ ጥያቄዎችን መፍታት/መስራት መቸገር	0	1	2	3	4
3. የትምህርት ቤት ስራ ፣ሪፖርቶችን፣አሳይመንት መጻፍ ላይ መቸገር	0	1	2	3	4
4. ለነገሮች ትኩረት መስጠት ላይ መቸገር	0	1	2	3	4
5. ያነበበውን/ችውን ማስታወስ አስቸጋሪ ነው	0	1	2	3	4

ስለ ራሱ/ሷ አካላዊ ገጽታ ያለው/ያላት አመለካከት ያለ ችግር	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. እሱ ጥሩ ቁንጅና እንደሌለው ሆኖ ሊሰማው ይችላል	0	1	2	3	4
2. ሌሎች ሰዎች የእሱን/ሷን ጠባሳዎች እንዳያዩ አይፈልግም/አትፈልግም	0	1	2	3	4
3. ሌሎች ሰውነቱን/አካሉን ሲያዩት ማፈር	0	1	2	3	4

ስለ ግንኙነት	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
1. ለሐኪሞቹ እና ለነርሶቹ ምን እንደሚሰማው/ማት መንገር አስቸጋሪ ነው	0	1	2	3	4
2. ሐኪሞችን ወይም ነርሶችን መጠየቅ መቸገር	0	1	2	3	4
3. በሽታውን/ዋን ለሌሎች ሰዎች ማስረዳት መቸገር	0	1	2	3	4

የ PedsQL™ 3.0 ድካም መመዘኛ የህጻን ዘገባ

በሚቀጥለው ገጽ ላይ ለእርስዎ ችግር ሊሆኑ የሚችሉ ነገሮች ዝርዝር ይገኛል ። እባክዎን እያንዳንዳቸው ባለፈው ወር ውስጥ ምን ያህል ችግር እንደነበሩ ይንገሩን። 0 በጭራሽ ችግር ካልሆነ 1 በጥቂቱ ችግር ከሆነ 2 አንዳንድ ጊዜ ችግር ከሆነ፣ 3 ብዙውን ጊዜ ችግር ነው ፣ 4 ሁልጊዜ ችግር ከሆነ

	በጭራሽ	በጥቂቱ	አንዳንድ ጊዜ	ብዙ ጊዜ	ሁልጊዜ ማለት ይቻላል
አጠቃላይ ድካም (ችግሮች ከ...)					
1. ድካም ይሰማኛል	0	1	2	3	4
2. የአካል መድከም ይሰማኛል (ጠንካራ ያለመሆን ስሜት)	0	1	2	3	4
3. ማድረግ የምፈልገውን ነገር ለማድረግ በጣም ድካም ይሰማኛል	0	1	2	3	4
4. ከጓደኞቼ ጋር ጊዜ ለማሳለፍ በጣም ይደክመኛል	0	1	2	3	4
5. ነገሮችን ለማጠናቀቅ እቸገራለሁ	0	1	2	3	4
6. ነገሮችን ለመጀመር እቸገራለሁ	0	1	2	3	4
እንቅልፍ / በ እረፍት ጊዜ ድካም (ችግሮች ከ...)					
1. ብዙ እተኛለሁ	0	1	2	3	4
2. ሌሊት መተኛት ለእኔ ከባድ ነው	0	1	2	3	4
3. ጠዋት ከእንቅልፌ ስነሳ ድካም ይሰማኛል	0	1	2	3	4
4. ብዙ አርፋለሁ	0	1	2	3	4
5. ብዙ ጊዜ ብዙ የቀን እንቅልፍ እወስዳለሁ/እተኛለሁ	0	1	2	3	4
6. አልጋ ውስጥ ብዙ ጊዜ አጠፋለሁ/አሳልፋለሁ	0	1	2	3	4
የአእምሮ ድካም (ችግሮች ከ...)					
1. ትኩረቴን በነገሮች ላይ ማድረጉ ለእኔ ከባድ ነው	0	1	2	3	4
2. ሰዎች የሚነግሩኝን ማስታወሱ ለእኔ ከባድ ነው	0	1	2	3	4
3. የሰማሁትን ለማስታወስ ይከብደኛል	0	1	2	3	4
4. በፍጥነት ማሰብ ለእኔ ከባድ ነው	0	1	2	3	4
5. እያሰብኩት የነበረውን ነገር ማስታወስ ከባድ ነው	0	1	2	3	4
6. በአንድ ጊዜ ከአንድ ነገር በላይ የማስታወስ ችግር አለብኝ	0	1	2	3	4