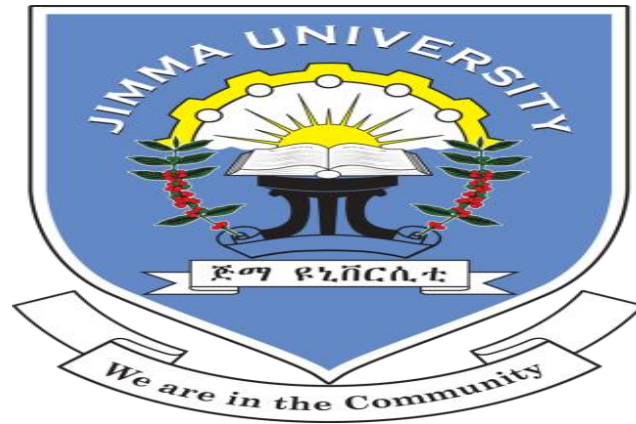QUALITY OF LIFE OF CHILDREN WITH RHD IN PEDIATRIC CARDIAC CLINIC, JIMMA UNIVERSITY MEDICAL CENTER, JIMMA ZONE SOUTHWEST ETHIOPIA

BASAZIN TASEW (MD, Pediatrics Resident)

RESEARCH THESIS TO BE SUBMITTED TO JIMMA UNIVERSITY, INSTITUTE OF HEALTH, FACULTY OF MEDICAL SCIENCES, DEPARTMENT OF PEDIATRICS AND CHILD HEALTH, AS PARTIAL FULFILLMENT FOR THE REQUIREMENT OF SPECIALTY CERTIFICATE IN PEDIATRICS AND CHILD HEALTH

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OCTOBER, 2020

JIMMA, ETHIOPIA

QUALITY OF LIFE OF CHILDREN WITH RHD IN PEDIATRIC CARDIAC CLINIC,
JIMMA UNIVERSITY MEDICAL CENTER, JIMMA ZONE SOUTHWEST ETHIOPIA

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ABSTRACT

Background*: RHD is one of the most common chronic illnesses encountered in children. But, very few studies have tried to Asses quality of life in children with RHD in developing country including Ethiopia, especially in study area*

Objectives*: This study aimed to asses Quality of Life of children with RHD in Pediatric cardiac clinic, Jimma University Medical center.*

Methodology: *The study was conducted at pediatric cardiac follow-up clinic of Jimma Medical Center, from April 20,to August 20, 2020.The study design was Descriptive cross-sectional study and children with RHD who have follow-up in study period were included in the study. Data were collected by trained medical person using structured questionnaire. After cleaning and coding, the data was interd and analyzed using Statistical Package for Social Sciences (SPSS) windows version 25.0. Relevant test of statistical association was employed*

Result*: A total of Fifty five children (55) were enrolled in this study. The mean age of the study participants were 12.2 years with the (+SD) age of ±2.34 years. About 12(21.8%) and 17(30.9%) of children have sever wasting and moderate wasting based on MUAC measurement respectively. Twenty six (47.3%) of study participants had good knowledge towards relationship of RHD with sore throat. The magnitude of the total quality of life among study participants with RHD attending their follow up in JUMC was (38.2%), (50.9%) and (10.9%) high, moderate and poor quality of life respectively. Among children with RHD about (32.7%) of them had bad QOL towards health and activities, whereas more than one-third (34.5%) had good quality of life. In this study care giver educational status ($X^2 =14.20$, P=0.031), level of family income ($X^2 =11.44$, P= 0.042), duration of illness before diagnosis($X^2 =9.93$, P=0.017) and type of medication used ($X^2 =9.97$, P= 0.027) a significant association with quality of life of children with RHD in the study area.*

Conclusion *:it was concluded that quality of life is affected in most children with rheumatic heart disease. The majority of the studied subjects had poor knowledge about rheumatic heart disease which consequently effect on their quality of life.the majority of the studied subjects had poor knowledge about Rheumatic heart Health educational program shoud be given to children who had RHD &their families, about nature of disease, periodic follow up and compliance with treatment to improve their quality of life.*

Key words*-Quality of life, Adolescent, Rheumatic heart disease.*

ACKNOWLEDGEMENT

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ACRONYMS AND ABBREVATIONS

ARF- Acute rheumatic fever

CD- Chronic disease

GAS-Group A Streptococcus

HL'QOL- Health related quality of life

JUMC- Jimma Medical Center

QOL-quality of life

RHD-Rheumatic heart disease

WHO- World Health Organization

Yr- year

No-number

RX-treatment

1. Introduction

1.1. Background

RHD includes spectrum of lesions from pericarditis, myocarditis and valvulitis during ARF to chronic valvular lesions that evolve over years following one or more episodes of acute rheumatic fever (1) which occurs 2 to 4 weeks following GAS pharyngitis (2). Carditis and resultant chronicRHD are most serious manifestations of ARF and account for essentially all morbidity and mortality. The valvular lesions begin as small verrucae composed of fibrin and cells along the borders of 1 or more of the heart valves. The mitral valve is affected most often, followed by aortic valve. Isolated aortic valve disease is rare and generally seen with concomitant mitral valve involvement. Right-sided heart manifestations are quite rare and are virtually only associated with left-sided valve disease.as the inflammation subsides, the verrucae tend to disappear and leave scar tissue (3)

Worldwide RHD remains the most common form of acquired heart disease in all age-groups, accounting for up to 50% of all cardiovascular disease and 50% of all cardiac admissions in many developing countries(3). Recent studies and estimates suggest that 62 to 78 million individuals worldwide may have RHD which may potentially be responsible for 1.4 million premature deaths per yrs(4)and causes highest cardiovascular-related disability (5).

The economic cost to countries with a persistently high incidence of rheumatic heart disease is significant. The most devastating effects are on children and young adults in their most productive years. It leads to increased school absenteeism and drop-out, and lost wages. In one example from Brazil, rheumatic fever cost the affected family annually about US$ 97/patient and, whereas a secondary prevention program cost US$ 23/patient annually(6).

WHO define Adolescent as any person between age 10-19 yr(7),which is a critical developmental stage for appositive course of future health and well-being(8).it is recognized that chronic disease can represent a major psychosocial burden, contribute to risk of psychosocial stress(9)and unhealthy psychosocial development(10)(11)(12)as well as poor QOL/health related

quality of life(13)(14)(15)(16)health and well-being(17).both disease and treatment processes can affect their appearance (18), and leading to isolation from the peer group(19).The participation in educational/social activities with peers and the connection with other people /institution are crucial as age increases. Particularly in adolescent, since it assumes a major importance in the socialization process (20), representing powerful positive protective factor and a key component for developing healthy youth (21)(22).Peer relationship and support from close friends can also play a special significant role when a CD exist constituting a great help to cope with the illness and with inherent psychosocial and life style changes(23).However these can be weakened due to having CD(24). Adolescent with Chronic disease are prone to develop neuropsychiatric disorder. Their risky behavior might compromise health, quality of life, or life itself (25).

Since RHD is one of chronic illness & most common chronic disease associated with cardiovascular problem in adolescent, it can result all above mentioned problem on this age group. In Ethiopia, The prevalence of RHD was lowest in children aged 6–9 years and is uniformly distributed in those aged 10–18 years (26). In jimma on those cardiac patient (10-14 yr),83% of these have acquired heart disease and RHD account for 74.1% of all acquired heart diseases(27) .In Egypt, Rheumatic fever had an impact on the most of the life style of children Majority of them had poor knowledge about Rheumatic fever, which moderately effect on their physical aspect of their quality of life as well as their academic achievement. Nearly two thirds of the studied children didn't participate in school activities, more than half of them didn't participate due to their frequent absenteeism from school (28)

Life style of children with RHD is affected by numerous factors including medical factors which are presented by perceived difficulties in adherence to rheumatic regimen, complications, duration and onset of disease. On the other hand, the social factors are presented by age; gender and nursing intervention also influence life style(29)(30).The primary outcomes for patients with RHD were progression to severe RHD, diagnosis of a serious complication (heart failure, endocarditis, stroke, or atrial fibrillation), or death. (31).

WHO defines Quality of Life as 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 (32).

Most HR'QOl measures have evolved from the World Health Organization's definition of health: a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (33). For patients with chronic health conditions, the goal of health care is to restore them to the fullest health possible by improving symptom management, treatment adherence, and their ability to cope with the impact of the condition. For this reason, HRQOL may be more important than biomedical measures when assessing patients with chronic health conditions .if we want to ensure that children receive the best possible health care in the most appropriate settings from the most qualified professionals, we need to assess their health status (34)

World Health Organization therefore establishes main strategies for prevention, control and elimination of rheumatic heart disease for countries where it is endemic on seventy-first world health assembly 12 April 2018.One of these strategies is improving standards of living; expanding access to appropriate care, development and implementing feasible programs for prevention and control of rheumatic heart disease, supported by adequate monitoring and surveillance, as an integrated component of national health systems responses (35)

But in our center, quality of life in Adolescent with rheumatic fever, rheumatic heart disease was not studied previously. So this study will assess Quality of life in Adolescent with rheumatic heart disease which is the most serious manifestations of acute Rheumatic fever

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1.2 Statement of the problem

ARF and RHD remain significant causes of cardiovascular diseases in the world today and it's most devastating effects are on children and young adults in their most productive years. It is also responsible for the highest cardiovascular-related loss of disability adjusted life years among 10–14 years old worldwide. It leads to increased school absenteeism and drop-out, and lost wages. The illness, treatment, hospitalization, all magnify concerns about a teens physical appearance, placing them at higher risk for poor educational ,vocational, and social outcome(18).).Chronically ill adolescent are more likely to develop psychiatric and behavioral disorder(36),may show higher prevalence of at least one psychiatric diagnosis(37) than healthy controls ,and are more likely to be depressed or have low self-esteem(38) Delayed growth and puberty is also common (39).Adolescents with disabilities are less exposed to protective factors (40) and   more exposed to bullying (41), have fewer contacts with peers and more emotional problems than healthy counterparts (42).

Patients experience severe difficulties due to complications caused by RHD such as atrial fibrillation(43) stroke(44)heart failure, endocarditis consequently have problems in maintaining normal daily activities.

CHAPTER TWO

2.1 Literature Review

Descriptive cross sectional, study was conducted in primary school children (aged 6-12 years) with rheumatic fever in the outpatient medical clinics of Tanta city, Egypt. Rheumatic fever affects dietary habits of the majority (82.9% and 87.8% respectively) of children less than 10 years. There is a statistically significant difference between the children aged <10 years, 10-12 years old and the children's preference of certain types of food. There was a statistically significant difference between frequency of follow up visits of the children and their age. More than half (58.6%) of children that their duration of illness <15 months had a school absenteeism < 3 days/month, furthermore the majority of them (87.9%) had good academic performance. Psychological state of most of the studied children was affected. Nearly two thirds of the studied children didn't participate in school activities, more than half of them didn't participate due to their frequent absenteeism from school. Of total family   47%of them had insufficient income and only 13% of them reported that it was enough and saving(29).

Cross-sectional study done on parents of 133 patients with rheumatic fever aged between 5 and 18 years in Brazil. The most common manifestation of the disease was articular symptoms associated with cardiac problems, present in 74 cases (56.1%). Most patients belonged to low-income families. Subjects had higher scores on: physical functioning, role/social-physical; role/social-emotional/behavioral; bodily pain; and family activities. The items with the lowest scores were: family cohesion; general health; global behavior; and parental impact-emotional. Girls had higher scores on: self-esteem; role/social-emotional/behavioral; and general health. Patients belonging to middle-income families had higher scores on: mental health; physical functioning; role/social-physical; and family activities. Children from the lowest social class had higher scores on bodily pain and psychosocial aspects(45).

This case-control study was conducted at the Gulab Devi Chest Hospital, Lahore, Pakistan, The mean age of cases was 33.77±12.19 years and that of the controls was 34.66±12.38 years. The patients had significantly reduced scores in all aspects QOL compared with the controls, indicating that there was a relationship between the two. The affected individuals reported significant impairment not only in total score but also in all domains, including general health, physical functioning role functioning/physical, role   functioning/emotional,

emotional well-being ,vitality , bodily pain , social functioning and health change . The most significant differences were observed in total score, general health subscale, physical functioning, role functioning/physical, role functioning/emotional, vitality and bodily pain. The lowest differences although significant were seen for emotional wellbeing, social functioning and health change .Subjective health-related QoL in RHD patients was significantly impaired and was much worse than the controls. Rheumatic heart disease imposes a substantial burden on QoL. The burden can be reduced through prevention, rehabilitation and other disease management strategies (46)

Study done in Texas, to assess quality of life in children with cardiovascular problem, by self-report, mean PedsQL scores for children with cardiovascular disease were significantly lower than healthy child norms for physical and psychosocial functioning. Psychosocial quality of life scores were classified as significantly impaired as reported by 21% of children >8 years of age. Even among children with less severe cardiovascular disease, 19.2% reported significantly impaired psychosocial quality of life. Children with more severe cardiovascular disease reported lower mean scores for physical functioning, but smaller differences in psychosocial quality of life scores were observed related to disease severity. Children with more severe cardiovascular disease have worse physical and psychosocial quality of life. One in 5 children with cardiovascular disease perceives impaired psychosocial functioning, including children with mild disease severity (47)

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2.2 Conceptual framework of the study

*Disease related

-duration of illness

-severity of disease

-no of admission

-Knowledge about

*Treatment related

- RX adherence

-No of medication

*Parent related

-income

-occupation

-educational status

-care taker

*QOL dimension

-Heart problem and RX

-Treatment II

-perceived physical appearance

-Treatment anxiety

-cognitive problem

Quality of life

*Sociodemograpic factor

-Age,sex

-lack of nearby health facility

Figure 1 Conceptual framework of quality of life of children with rheumatic heart disease.

2.3 Significance of the study

Information on the quality of life of adolescent with RHD is critical for the improvement of quality care. But, very few studies have tried to Asses quality of life in children with RHD and reported quality of life is impaired significantly. Children with RHD are treated at Jimma University Medical Center, pediatrics and child health department. However QOL of children with RHD treated at this hospital has not been assessed so far, so this study will assess their quality of life and subsequently we will have a plan to improve their quality of life .Therefore, the aim of this study is to assess quality of life of children and adolescent with RHD having follow-up at cardiac clinic, JUMC. The results of this study will be helpful in the evaluation of the health care needs of a community, and used to influence public policy decisions, including the development of strategic health care plans, identifying health disparities, promoting policies and legislation related to community health, and aiding in the allocation of health care resources. It also used as input to subsequent research question.

CHAPTER THREE

3. Objective

3.1. General objective
➢ To Asses quality of life in children with RHD in pediatric cardiac follow up clinic, Jimma Medical Center, Jimma, Southwest Ethiopia.

3.2. Specific objective
➢ To Asses quality of life of children with RHD in pediatric cardiac follow up clinic ,jimma medical center
➢ To assess factors associated with QOL of children with RHD in pediatric cardiac followup clinic ,jimma medical center
➢ To asses knowledge of children with RHD toward RHD in pediatric cardiac follow up clinic ,jimma medical center

CHAPTER FOUR

4. Methods and Materials

4.1. Study area

The study was conducted at Jimma University Medical Center (JUMC). JUMC is located in Jimma Zone, Oromia Region, Southwest Ethiopia, 350 Km from the capital city of Ethiopia, Addis Ababa. It has bed capacity of around 432 with a total of nearly 1,000 hospital staffs. It provides services for approximately 9,632 inpatients, 5,000 accident and emergency cases, and 80,000 outpatient attendants each year. Currently there are 334 children with RHD on follow up in pediatric cardiac clinic.

4.2. Study period

Study period was from April 20 to July 20, 2020.

4.3. Study design

Institutional based cross-sectional, study design was employed.

4.4. Population

4.4.1. Source population

Source population consists of all children aged from 8-18 years with RHD who had follow-up in pediatric cardiac clinic, JUMC.

4.4.2. Study population

Study population consists of all selected [Children (8-18yr)] with RHD who had follow-up in pediatric cardiac clinic, JUMC, during the study period.

4.4.3. Inclusion and exclusion criteria

Inclusion criteria

> ➢ All children (8-18yr of age) with RHD who had follow during the study period in pediatric cardiac follow up clinic, JUMC.

Exclusion criteria

> ➢ Children who are newly diagnosed with Acute rheumatic fever
>
> ➢ Children with other diagnosed chronic illness
>
> ➢ Children who are in critically ill condition

4.5. Sample size determination and sampling technique

The sample size is determined by using the following formula.

$$n= \frac{(Z\text{-}\alpha/2)^2 p q}{d^2}$$

Where:

- Z-α/2- is the standard normal variable with 95% accuracy and 5% margin of error and its Value equals to 1.96

- **p**- is   the prevalence of the problem to be studied is 0.5 since the similar studies on this problem were not done in this hospital previously.

- **q**- is 1-p

- **d**- is the margin of error which is 0.05 %

Therefore: - $n_o= \frac{(1.96)^2 0.5 \times 0.5}{} = 384$

(0.05) 2

No- is initial sample size (minimum sample size) = 384

The total numbers of children who had follow-up in pediatric clinic of JUMC are 10 per week on average. Thus, In 16 week is 160 patients had follow up.

- The **corrected sample size   (Ni)** is determined by the formula:
    - $n = no/1 + no/N$

Where: **n**-is the corrected sample size

       no-is initial sample size that is **384**

       N- is total number of children who will have follow up during data collection period that is 16 week is 160. So, Ni=384/1+384/160=112.

- The final sample size, (NF**)** including non-respondents (5%) will be determined by the following formula ;
    - NF=Ni+Nix5/100

NF =112+112x5/100=112+5=117

All patients having follow up was enrolled till sample size achieved

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4.6. Variables

- ➤ **Independent Variables**

  - Age
  - Sex
  - Height
  - Weight
  - Knowledge of child
  - Drug adherence
  - Educational status of the mother/caretaker
  - Occupation of mother or care taker
  - Family income
  - Duration of the illness

- ➤ **Dependent Variables**

  - Quality of life

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4.7. Data collection process

A structured interviewer administered questionnaire was administered to every recruited patient& patient card review to know severity of disease& precipitating factor for admission. QOL was assessed by using 11 different items which are included in Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales and 3.0 Cardiac Module. It is a validated multidimensional assessment tool for children aged 2 to 18 years. And encompasses 23 items that assesses physical (8 items), emotional (5 items), social (5 items), and school functioning (5 items). The 3.0 cardiac module is a disease-specific module and it has 6 subscales evaluating HRQOL related to heart problems and treatment (7 items), treatment barriers (3 items), physical appearance (3 items), treatment anxiety (4 items), cognition (5 items), and communication (3 items).

Measurement The data was collected by trained health personnel (Medical interns or BSc nurses) who can speak Amharic and a fan Oromo with strict supervision by Supervisor and principal investigator.

4.8. Data quality control

Data quality is checked by training of data collectors and supervisor, pretest and reliability of questionnaire. It was pre tested on 10% (12) patients and reliability of tool was assessed and it is 0.7 before the actual study. Reliability was checked by using pretest data.Collected data was sorted and checked for errors and completeness onsite daily. Patient's cards was boldly marked to avoid repetition. Overall activities was supervised by supervisor and principal investigator

4.9. Data Processing and analysis

The data collected was checked for completeness and consistency and then it was cleaned, coded, and entered into EpiData 4.4., exported to, cleaned and analyzed using Statistical Package for Social Sciences (SPSS) version 25.0. Descriptive analysis was employed. The numerical variable was expressed as the means and standard deviation (SD).The item assess quality of life in six domains, including heart problems and treatment (7 items), treatment barriers (3 items), physical appearance (3 items), treatment anxiety (4 items), cognition (5 items), and communication (3 items) on overall quality of life (QOL).The domain score was transformed into linear scale between 0 and 100 following the scoring guideline a mean score of $< 50\%$ in each domain denote high quality,(50-75%)indicates moderate and $> 75\%$ indicates poor quality

of life. Relevant test of statistical association was employed. The Significance level for each analysis was taken as $p < 0.05$.

4.9. Ethical consideration

Ethical clearance was obtained from ethical review board for human studies of Jimma University and permission was obtained from the authorities of the hospital. Written consent and assent (for older children) was obtained from each study participant. They had the right to refuse study and their refusal didn't interfere their routine medical care. Confidentiality was assured by collecting data anonymously using just card number of the records.

4.10. Plan for data Dissemination

The findings of the study will be presented to Jimma University Scientific community and submitted to department of Pediatrics and Child Health, faculty of medical sciences and institute of health, Jimma University. Recommendations will be forwarded to hospital staffs and other stakeholders based on the findings of the study. Efforts will be made to publish the findings on national and international scientific journals.

4.11. Operational definitions

➢ Quality of life -is An individuals' perceptions 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 which is divided in to three using tool derived from Pediatric Quality of Life Inventory (PedsQL)(48)

-High level of quality of life < 50%

-Moderate level of quality of life 50-75%

-POOR level of quality of life > 75%

➢ Adolescent as any person between ages 10-19yr(49)

➢ Adequate adherence to benzanthine penicillin was defined for each patient as receiving >80% of injections on time per year(50)

CHAPTER FIVE

5. Results

A total of 72 RHD were seen at pediatric cardiac follow up clinic during the study period. Out of this 17 children who didn't fulfill the inclusion criteria were excluded. Fifty five children (55) were enrolled in this study (Covid pandemic)

5.1. Socio demographic characteristics

Half of the study participants were 28 (50.9%) falls in the age group of 10-13 year while18 (32.7 %) were in the age group of 14-18. The mean (+SD) age of the study participants were 12.2 ±2.34 years. More than two third (69.1%) of the children were female. Similarly, nearly two third of the respondents were from rural area. About 24 (43.6%) of parents of the children have no formal Education. Around 36 (65.5%) of children are attending primary school, but 9(16.4%) of children have no formal education (Table 1).

Table 1: Socio demographic characteristics of Children with RHD in pediatric cardiac clinic, JMC Southwest Ethiopia, 2020 (N=55).

Variables	Categories	Frequency	Percent
Age (years)	8-9	9	16.4
	10-13	28	52.7
	14-18	17	30.9
Sex	Male	17	30.9
	Female	38	69.1
Place of Residence	Urban	18	32.7
	Rural	37	67.3
Educational level of the parents	No formal education	24	43.6
	Read and Write only	7	12.7
	Primary	18	32.7
	Secondary	4	7.3
	Above high school	2	3.6
Relation sheep of care giver to the child	mother	5	9.1
	Father	16	29.1
	Both	26	47.3
	Other	8	14.5
Occupation of parents	House wife	3	5.5
	Farmer	40	72.7
	Self employed	10	18.2
	Government/compa ny	2	3.6

Family monthly income	<1000	14	25.5
	1001-2000	26	47.3
	2001-3000	11	20.0
	>3001	4	7.3

5.1.1 Educational status

Regarding to educational status of children nearly two-third 36 (65.5%) of them attending primary education, nine (16.4%) of respondents have no formal education and 3 (5.5%) of study subjects attended secondary school (Figure 1).

Educational status of the study participants
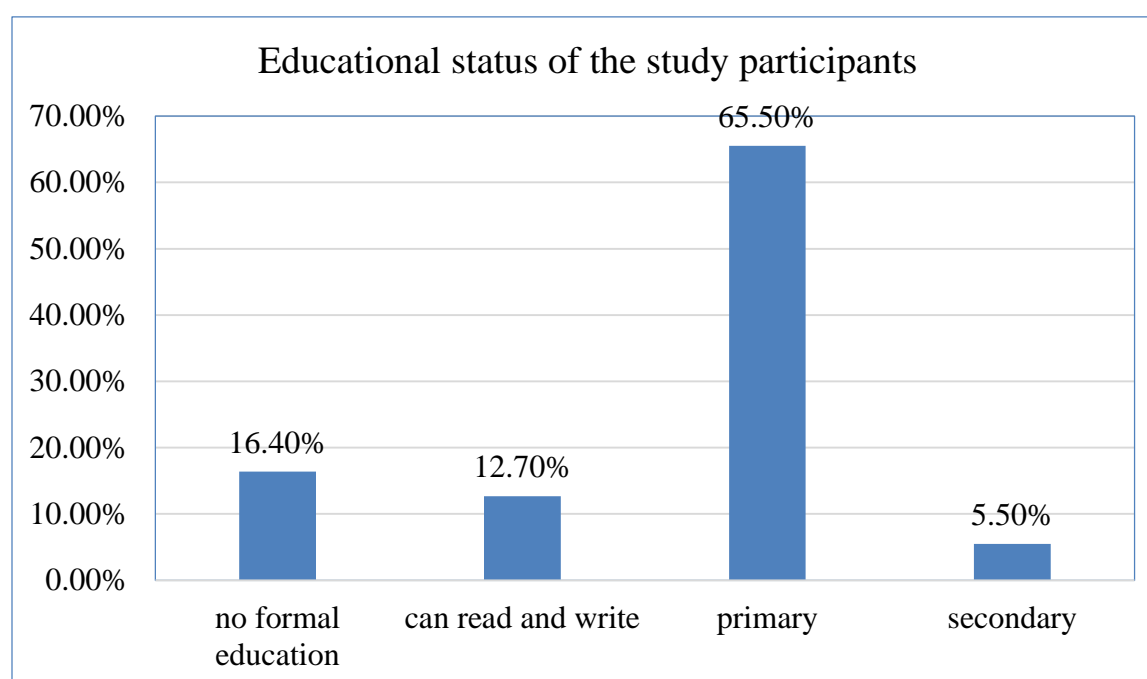
Figure 2: level of educational status of the study participants among children with RHD attending cardiac follow up clinic at JUMC, 2020.

5.2 Anthropometric characteristics

About 12(21.8%) and 17(30.9%) of children have sever wasting and moderate wasting based on MUAC measurement respectively. But based on BMI only 5(9.1 %) have sever wasting.(Figure 2).
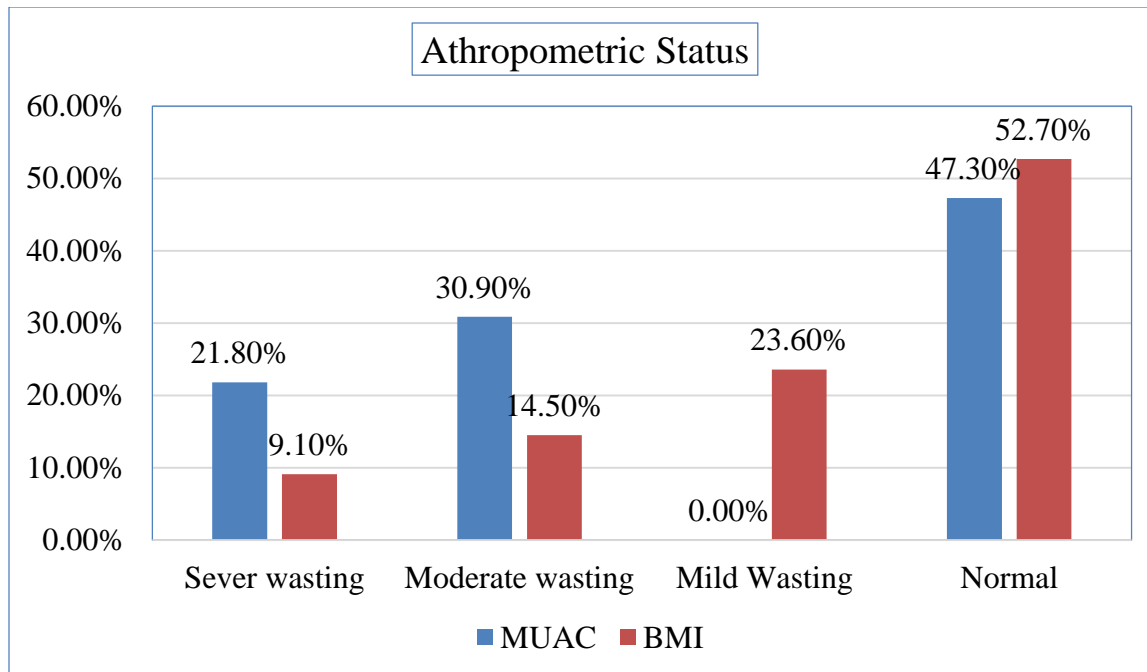
Figure 3 : Anthropometric characteristics of the study participants attending their follow up at cardiac clinic in JUMC 2020.

5.3 Clinical assessment of children with RHD

This study revealed that more than half 29 (52.7%) of the study participants had greater than 24 months duration of illness, whereas 23 (41.8%) of study participants had 12-24 months of illness. Similarly, nearly three-fourth (76.4%) of study participants had less 12 months of duration of illness before the date of diagnosis. The vast majority 49 (89.1%) of study participants had regular follow up. fourty three(78.2%) of study participants had history of admission, from this 17(30.9%) had repeated admission (Table 2).

Table 2: Clinical assessment of among children with RHD attending their follow up at cardiac clinic in JUMC 2020

Variables	Categories	Frequency	Percent
Total duration of illness (month)	<12	3	5.5
	12-24	23	41.8
	>24	29	52.7
Duration of illness before diagnosis (month)	<12	46	83.6
	12-24	5	9.1
	>24	4	7.3
Do you have regular follow up	Yes	49	89.1
	No	6	10.9
Among regular follow up frequency of follow up(n=49)	1 month	28	57.2
	2 month	5	10.2
	3 month	15	30.6
	6 month	1	2.0
No of medication used	1	17	30.9
	2	8	14.5
	≥3	30	54.5
History of drug discontinuation	Yes	10	18.2
	No	45	81.8
Type of medication discontinued (n=10)	Po	4	40.0
	IM	1	10.0
	Both	5	50.0
Number of admission	<=2 times	26	47.3
	>2 times	17	30.9
	No history of admission	12	21.8
Involved valve	Mitral	24	43.6
	Aortic	2	3.7
	M&A	18	32.7
	M,A&T	4	7.2
	M&T	7	12.8
Lesions	Regurgitant	29	52.7
	Stenosis	15	27.3
	Both	11	20.0

5.4 Knowledge status of the study participants towards RHD

About 25 (45.5%) of study participants know sore throat could be related to their heart problem. Similarly, almost half (50.9%) study participants reported that poorly treated of sore throat can exacerbate their heart problem. In the same fashion more than half (56.4%) of study participants reported that IM monthly medication will decrease their heart problem. Generally 26 (47.3%) of study participants had good knowledge towards relationship of RHD with sore throat (Table 3).

Table 3 : Knowledge status of the study participants towards relationship of RHD with sore throat

Variables	Categories	Frequency	Percent
Do you know sore throat could be related to your heart problem	Yes	25	45.5
	No	30	54.5
Do you know poorly treated sore throat exacerbate your heart problem	Yes	27	49.1
	No	28	50.9
Do you know as monthly IM medication will decrease your heart problem	Yes	31	56.4
	No	24	43.6
Knowledge status	Poor knowledge	29	52.7
	Good knowledge	26	47.3

5.5 Magnitude of quality of life of children with RHD

The quality of life of study participants with RHD attending their follow up in JUMC was 21(38.2%), 28(50.9%) and 6(10.9%) high, moderate and poor quality of life respectively (figure 4).
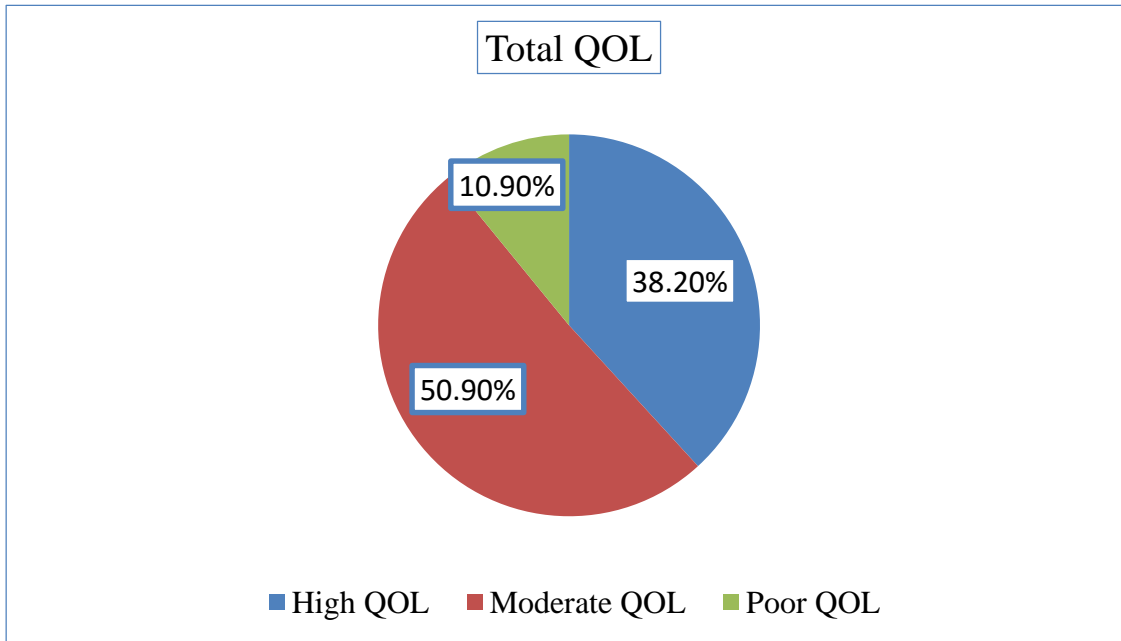
Figure 4 : The magnitude of QOL among children with RHD attending their follow up at Cardiac clinic in JUMC, 2020.

5.6.1 General health status

Regarding to the general perception of children with RHD about their health status, 18 (32.7%) of respondents explained their health status as good. In the same way 3 (5.5%), 6(10.9%), 12 (21.8%) and 16(29.0) of individuals perception about their general health was bad, fair, very good and excellent respectively.
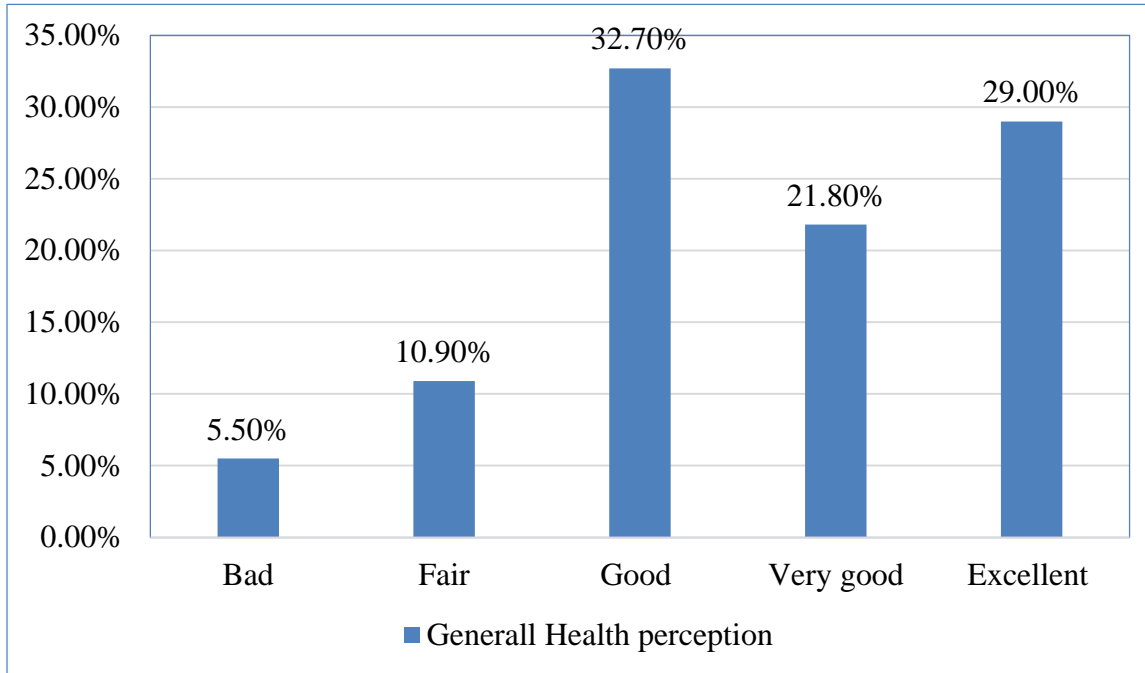
Figure 5 : The general perception about their health among children with RHD attending their follow up at cardiac clinic, JUMC, 2020.

5.7 The distribution of QOL for each parameters or items which measured total QOL

According to this study among children with RHD about 18(32.7%) of them had poor QOL towards health and activities, whereas more than one-third 19 (34.5%) had high quality of life. In the same manner almost half the study subjects with RHD had high QOL regarding to their emotional status. Additionally, 25 (45.5%) of study participants with RHD was had poor QOL for self- perception. Nearly half of the study participants with RHD had high QOL for treatment anxiety and 19 (34.5%) of children had moderate QOL. Similarly, nearly two-third of the study

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participants had high QOL regarding to communication, the rest 14 (25.5%) and 6 (10.9%) had moderate and poor QOL for communication respectively (Table 5).

Table 4 : the distribution of QOL for each items which measured total QOL

Items	Categories	Frequency	Percentage
physical activities	High	19	34.5
	Moderate	18	32.7
	poor	18	32.7
Emotional status	High	27	49.1
	Moderate	13	23.6
	poor	12	27.3
Relationship with others	High	32	58.1
	Moderate	10	18.2
	Poor	13	23.6
About school activities	High	30	54.5
	Moderate	12	21.8
	poor	13	23.6
Personal feeling	High	8	14.5
	Moderate	22	40.0
	poor	25	45.5
Heart problem	High	28	50.9
	Moderate	18	32.7
	poor	9	16.4
Treatment	High	30	54.5
	Moderate	12	21.8
	poor	13	23.6
Perceived physical appearance	High	38	69.1
	Moderate	10	18.2
	poor	7	12.7
Treatment anxiety	High	27	49.1
	Moderate	19	34.5
	poor	9	16.4
Cognitive problem	High	22	40.0
	Moderate	18	32.7
	poor	15	27.3
Communication	High	35	63.6
	Moderate	14	25.5
	poor	6	10.9

5.8 The relationship between total QOL and socio demographic variables among children with RHD attending follow up at cardiac clinic in JUMC, 2020.

Regarding to the relation between total quality of life of the study participants with RHD and their socio demographic data, the present study was revealed that there was a statically significant relationship between total quality of life of the study subjects with RHD and care givers educational status (X^2 =14.20, P=0.031). Similarly, this study was revealed that there was a significant difference between study subjects with RHD and the level of income of the family (X^2 =11.44, P= 0.042) (Table 6).

Table 5: The relationship between total QOL and their clinical characteristics among children with RHD

Variables	Categories	Total QOL			X^2	P value
		Good (%)	Moderate (%)	Bad (%)		
Sex	Male	9(52.90)	5(29.40)	3(17.60)	4.79	0.071
	Female	12(31.60)	23(60.50)	3(7.90)		
Age of the child	8-9	3(33.3)	4(44.40)	2(22.20)	2.03	0.78
	10-13	12(41.4)	14(48.30)	3(10.30)		
	14-18	6(35.30)	10(58.8)	1(5.90)		
Residence	Urban	6(33.30)	8(44.40)	4(22.3)	3.27	0.232
	Rural	15(40.5)	20(54.1)	2(5.40)		
Educational status of the parents	No formal education	9(37.50)	15(62.50)	0(0.00)	14.20	0.031*
	Read and write only	5(71.40)	2(22.60)	0(0.00)		
	Primary	4(22.20)	8(44.40)	6(33.30)		
	Secondary	2(50.00)	2(50.00)	0(0.00)		
	Above high school	1(50.00)	1(50.00)	0(0.00)		
Educational status of children	No formal education	3(33.30)	6(66.70)	0(0.00)	6.73	0.26
	Read and write only	3(42.90)	4(57.10)	0(0.00)		
	Primary	15(41.70	17(47.2)	4(11.1)		
	Secondary	0(0.00)	1(33.30)	2(66.70)		
Level of income	<1000	5(35.70)	7(50.00)	2)14.30)	11.44	0.042*
	1001-2000	7(26.90)	18(69.20)	1(3.80)		
	2001-3000	6(54.50)	2(18.20)	3(27.30)		
	>3001	3(75.00)	1(25.00)	0(0.00)		

Key *indicates variables associated with QOL among children with RHD at p <0.05 by X^2

5.9 The relationship between total QOL and their clinical characteristics among children with RHD attending follow up at cardiac clinic in JUMC, 2020

Regarding to the relation between total quality of life of the study participants with RHD and their clinical data, the present study showed that there was a statically significant relationship

between total quality of life of the study subjects with RHD and total duration of illness (X^2 =9.93, P=0.017). Additionally, this study was revealed that there was a significant difference between quality of life among study subjects with RHD and the level of no of medication used (X^2 =9.97, P= 0.027) (Table 7).

Table 6 : The relationship between total QOL and their clinical characteristics among children with RHD

Variables	Categories	Total QOL			X^2	P value
		Good (%)	Moderate (%)	Bad (%)		
BMI	Severe wasting	3(60.00)	1(20.00)	1(20.00)	9.01	0.12
	Moderate wasting	3(35.50)	5(64.50)	0(0.00)		
	Mild wasting	3(23.10)	6(46.20)	4(30.80)		
	Normal	12(41.40)	16(55.20)	1(3.40)		
MUAC	Severe wasting	6(50.00)	5(41.70)	1(8.30)	2.00	0.77
	Moderate wasting	7(41.20)	9(52.90)	1(5.90)		
	Mild wasting	0	0	0		
	Normal	8(30.80)	14(53.80)	4(15.40)		
Total Duration of illness (months)	<12	3(42.90)	3(42.90)	1(14.20)	1.45	0.93
	12-24	16(40.00)	20(50.00)	4(10.00)		
	≥24	2(25.00)	5(62.50)	1(12.50)		
Duration of illness before diagnosis	<12	16(34.80)	25(54.30)	5(10.90)	9.93	0.017*
	12-24	5(100.00)	0	0		
	≥24	0	3(75.00)	1(25.00)		
Types of medication used	1	4(23.50)	8(47.10)	5(29.40)	9.97	0.027*
	2	3(37.50)	4(50.00)	1(12.50)		
	≥3	14(46.70)	16(53.30)	0		
Number of admission	≤2 times	11(42.3)	12(46.2)	3(11.5)	1.41	0.52
	>2 times	5(29.4)	11(64.7)	1(5.9)		
Lesions	Regurgitant	10(34.50)	13(44.80)	6(20.70)	5.20	0.25
	Stenosis	7(46.70)	8(53.30)	0		
	Both	4(36.40)	7(63.60)	0		
Knowledge status	Poor	9(31.00)	16(55.20)	4(13.84)	1.45	0.50
	Good	12(46.20)	12(46.20)	2(7.70)		

Key *indicates variables associated with QOL among children with RHD at p <0.05 by X^2

CHAPTER SIX: DISCUSSION

6. Discussion

In the present study, quality of life of children with RHD attending follow up in JUMC had High, moderate and poor(38.2%), (50.9%) and (10.9%) quality of life respectively .study done in

Egypt(29,53.7%)(23 ,42.6%)(2 ,3.7%) had high, moderate and poor total quality of life respectively. The reasons for this could be the difference in method used, study subjects and the background characteristics. Study in Pakistan shows that likelihood of an RHD patient having poor QoL was greater than a healthy individual(p<0.001). In order to compare with other studies, no other studies that I have tried to found that asses total QOL including in Ethiopia.

Regarding specific dimention of QOL of children with RHD,(18(32.7%) and18(32.75%) had moderate and poor quality towards physical activities respectively. Study done in Brazil, 50.5% had higher quality on the physical state, but in Egypt 72.2% had moderate quality .Almost half the study subjects had high quality in their emotional status and 32(58.1%) had high quality in relationship to other. In Egypt 88.9% had high level of quality on their psychosocial state. Regarding school activities, more than half (54.5%) and 13(23.6%) had high and poor quality respectively. More than half, 29(52.7%) had poor knowledge towards rheumatic fevers. But in Egypt, their academic achievement was moderately affected in 59.3% and 94.4% had poor knowledge. Reasons for this could be the difference in method used, study subjects and the background characteristics, sample size and cutoff point for age group.(29,45,46)

Factors associated with quality of life in this study were educational statuse of parents(X2 ,14.20,p=0.031),level of income(x2,11.44,p=0.042) duration of illness before diagnosis(x2,9.93,p=0.017),No of medication(x2,9.97,p=0.027).Age, frequency of follow up visits , their level of education ,crowding index and socioeconomic status were associated Factors in Other studies.

6.1 Limitation of the study

➢ Unable to achieve calculated Sample size due to international epidemic(corona)
➢ Since tool asses activity over past one month ,it was difficult to asses school activity so that it was changed to over past 1 year.
➢ Since the study design was cross-sectional, cause and effect relationship couldn't be established

CHAPTER 7: CONCLUSION AND RECOMMENDATION

7.1 Conclusion

Based on the present study findings, it was concluded that quality of life is affected in most children with rheumatic heart disease. The majority of the studied subjects had poor knowledge about rheumatic heart disease which consequently effect on their quality of life. Factor significantly associated with quality of life were educational status of parent, level of income, duration of illness before diagnosis and No of medication.

7.2 RECOMMENDATION

- ➢ Health educational program should be given for children who had rheumatic heart disease and their families about nature of disease.
- ➢ Educational program for school health team and teachers about the effect of RHD on students' physical activities
- ➢ Further studies are needed for more investigations about the effects of RHD on students' academic achievement

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Annexes

Annex 1

Information sheet, consent form, Assent Form and questionnaire

Jimma University, Institute of Health

Faculty of Medical Sciences

Department of Pediatrics and Child Health

An interviewer guided questionnaire prepared for Assessment of Quality of Life of children with RHD in Pediatric cardiac clinic, Jimma University Medical Center, Jimma, Southwestern Ethiopia

Research title: Assessment of Quality of Life of children and Adolescent with RHD in Pediatric cardiac clinic, Jimma University Medical Center, Jimma Zone Southwest Ethiopia

Name of the investigator: Basazin Tasew (MD, Pediatrics Resident)

Email:elyana21bz@gmail.com

Advisors:

Tsion Tilahun (MD, Assistant Professor of Pediatrics and Child health)

Tilahun Fufa (MSc)

Consent form

My name is Dr Basazin Tasew .I am final year Pediatrics and Child health resident at Jimma University.I am conducting a study on assessment of Quality of Life of children and Adolescent (8-18 yr) with RHD in Pediatric cardiac clinic of JMC.Your child's name or personal information is kept Secret. Exept for persons that are involved in study, nobody knows about your child's information. But your genuine answer is very important for this study. But your

child treatment is not affected by not involving in this study. It would take 10 minutes to complete the question. would you be willing to participate in the study?

1. Yes, I want to participate in the study.

Signature_____ date_____

> Name of data collector _____Signature _____
> Name of supervisor_____signature_____

2. No, I don't want to participate in the study.

<div align="center">Thank you!</div>

Informed assent form

Information Sheet

My name is Dr Basazin Tasew .I am final year Pediatrics and Child health resident at Jimma University.I am conducting a study on assessment of Quality of Life of children and Adolescent

(8-18 yr) with RHD in Pediatric cardiac clinic of JMC. I am going to give you information and invite you to be part of a research study.We asses quality of life of children only with RHD who are in your age –between 8-18 years old .you will be asked questions including list of things that might be a problem for you and will tell me how much of a problem each one has been for you during past one year .if you have any question you can ask .you can stop at any time if you are not interested. But your treatment is not affected by not involving in this study 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.

 Certificate of Assent:

would you be willing to participate in the study?

1 yes, I agree

   Name of child _____signature_____date_____

2 No, I don't agree

የፍቃደኝነት መጠየቂያና የመረጃ ቅፅ

እኔ ዶ/ር ባሳዝን ጣሰው አባላለሁ፡፡ በጅማ ዩኒቨርሲቲ ሆስፒታል የህስተኛ እና የመጨረሻ ዓመት ተማሪ ነኝ፡፡በዚህ የህፃናት ክትትል ከፍል ውስጥ ዕድሜያቸው ከ8-18 ዓመት ባሉ የልብ ህመምተኛ ልጆች ላይ አጠቃላይ የጤንነታቸው እና የአኗኗራቸው ሁኔታ በተመለከተ ጥናት እያደረኩ ነው፡፡የልጆት ስም እና ግለሰባዊ መረጃ ሚስጥራዊቱ የተጠበቀ ነው፡፡ ስለእርሶ ልጅ መረጃ ጥናቱ የሚያካሂደው ሰው ውጪ ሌላ ሰው አያውቅም ነገር ግን የእርሶ ትክክለኛ መልስ ለዚህ ጥናት

በጣም አስፈላጊ ነው:: ፍቃደኛ ባለመሆኖ ልጆት በሚያገኘው ማንኛንም የጤና ዕርዳታ ላይ ምንም አይነት ተፅዕኖ አይኖረውም:: ይህን ጥያቄ ለመጨረስ 10 ደቂቃ በቂ ነው:: በዚህ ጥናት ላይ ለመሳተፍ ፍቃደኛዎት?

1. አዎ ተስማምቻለሁ

    ስም --------------------- ፊርማ ---------------------   ቀን---------------------

    ➤ የጠያቂ ስም--------------------- ፊርማ ---------------------

    ➤ የተቆጣጣሪ ስም---------------------   ፊርማ ---------------------

2. አይ አልስማማም

<center>አመሰግናለሁ::</center>

የፍቃደኝነት መጠየቂያና የመረጃ ቅፅ

እኔ ዶ/ር ባሳዝን ጣሰው አባላለሁ:: በጅማ ዩኒቨርሲቲ ሆስፒታል የሦስተኛ እና የመጨረሻ ዓመት ተማሪ ነኝ::በዚህ የህፃናት ከትትል ከፍል ውስጥ ዕድሜያቸው ከ8-18 ዓመት ባሉ የልብ ህመምተኛ ልጆች ላይ አጠቃላይ የጤንነታቸው እና የአኗኗራቸው ሁኔታ በተመለከተ ጥናት አያደረኩ ነው:: በመጀመሪያ የዚህ ጥናት አባልእንድትሆን/እንድትሆኚ በመጋበዝ አንዳን ስለጥናቱ ጠቃሚ መረጃ እስጥሃለዉ/ሻለሁ ይህ ጥናት የሚሰራዉ በአንተ/ቺን የዕድሜ ክልል ውስጥ(8-18 ዓመት) ባሉ የልብ ህመምተኛ ልጆች ላይ ነው:: ስለዚህ ባለፈው አንድ ወር ውስጥ ላንተ /ቺ ችግር ሊሆኑ ይችላሉ ያልኳቸውን ጥያቄዎች አጠይቅሃለዉ /ሻለሁ እንተም/ቺም ምን ያህል ላነተ/ቺ ችግር እንደሆን ትነግረኛለህ/ለሽ ይትኛዉንም ጥያቄ ካል መጠየቅ ይቻላ:: በየትኛዉም ሰዓት ጥያቄዉን ማቆም ከፈለክ/ግሽ ማቆም ትችላለህ/ያለሽ በዚህ ጥናት ላይ ባትሳተፍ /ተፈ

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እንኳን ሊሰጡህ/ሽ የሚችለውን ህክምና ሊጎዱል እንደማይችል አረጋግጣለሁ፡፡ ስለዚህ ጥናት ከቤተሰብዎ /ሽ ጋር ተነጋግረንበታል፡፡እናም አንተን /ቺን ልናስፈቅድ ነግረውኛል፡፡ጥናቱ ላይ ምትሳተፍ/ፊ ከሆነ ቤተሰብህም/ሽም መስማማት አለባቸው ግን አንተ/ቺ ካልተስማማህ/ሽ ያለመሳተፍ ትችላለል/ለሽ፡፡ምንም እንኳን ቤተሰቦችህ/ሽ ቢስማሙም፡፡ በጥናቱ ላይ ለመሳተፍ ተስማምተሃል/ሻል?

1. አዎ ተስማምቻለሁ

   ስም -------------------- ፊርማ -------------------- ቀን--------------------

2. አይ አልስማማም

   አመሰግናለሁ፡፡

Guca Heyyama maatii Daa'immanii

Maqaan Koo Dr Baasazin Xaasawu jedhama. Hospitaala Yuniversitii Jimmaa Keessatti Kutaa Yaalumsaa fi Fayyaa Daa'immanii keessatti barattu waggaa sadaffaa fi isa xumuraati. Daa'imman umuriin isaanii waggaa 8-18 ta'e, dhibee Onnee qaban irratti waa'ee waliigala fayyaa isaanii fi akkaataa jireenya issanii ilaalchisee qorannoo gaggeessan jira. .Maqaan daa'ima keessanii fi odeeffannoo isin naaf kennitan icitiin isaa kan eegame dha..Odeeffannoo kana nama qorannoo kana gageessun alatti qaamni biraan beeku hinjiraatu. Yoo hirmaachuuf fedhii hinqabaanne tajaajila fayya daa'imni kun argachuu malu irratti homaa dhiibbaa hinqabu. Gaaffii deebisuu hinbarbaanne yoo jiraate deebisuu dhiisuuf mirga qabda. Haata'u iyyuu malee yoo fedhii kee ta'ee nuuf deebiste qorannoo kanaaf bu'aa guddaa qaba. .Gaaffii kana deebiisuuf daqiiqaan 10 ga'aadha. Qorannoo kana irratti Hirmaachuudhaaf .fadhi qabduu?

Eyyee_____   Lakkii_____

Maqaa maatii hirmaatee _____   mallattoo_____

Maqaa nama gaafatee_____   mallattoo_____

Maqaa to'ataa_____   mallattoo

Guca heyyama Hirmaataa

Maqaan Koo Dr Baasazin Xaasawu jedhama. Hospitaala Yuniversitii Jimmaa keessatti kutaa Yaalumsaa fi Fayyaa Daa'immanii keessatti barattu waggaa sadaffaa fi isa xumuraati. Daa'imman umuriin isaanii waggaa 8-18 ta'ee dhibee Onnee qaban irratti waa'ee waliigala fayyaa isaanii fi akkaataa jireenya isaanii ilaalchisee qorannoo gaggeessan jira. .Qorannnno kana irratti akka ati hirmaattuf sin affeera. Qorannnon kun haala ji'a tokkoo darbe keessetti wantoota fayyaadhaaf rakkoo ta'uu danda'an jedhee yaade irrattin sigaafedha. .Rakkoon kun ammoo siif haangam rakkoo akka ta'e naaf himta. Waa'ee qorannno kanaa ilaalchisee maatii kee waliin haasofne jira. Isaanis siin akkan heyyemsiisu natti himani jiru. Qorannno kana irratti yoo hirmaachuuf fedhii qabaattee maatiin kees irratti walii galu qabu. Yoo hirmaachuuf fedhi hinqabdu ta'e garuu mirga keeti. Maatiin kee irratti walii galanii ati garuu yoo hinbarbaanne

hindirqisiifamtu. Yeroo barbaaddettis addaan kutuu dandeessa. Qorannno kana irratti hirmaachuu yoo hinbarbaanne tajaajila fayyaa argachuu maltu irratti homaa dhiibbaa akka hinqabne siifan mirkeneessa. Yoo hirmaachuuf irratti walii galtte isa armaan olitti dubbisatte ykn siif dubbifame hubachuu kee fi irratti walii galuu kee mallattoo keetiin naaf mirkaneessita. Kanaaf iyyuu qorannoo kana irratti hirmaachuuf fedhii qabdaa?

Eyyee_____   lakkii_____

Maqaa hirmaataa_____

Mallattoo_____

                    Guyyaa_____

Annex II

QUESTIONAIRES

I Socio Demographic characteristics

1. Card no._____ Code_____
2. Age (month/year)_____
3. Sex: A. Female   B. Male
4. Residence of the parents/care givers _____
5. Educational status of mother/care giver
A. No formal education
B. Read and Write only
C. Primary
D. Secondary
E. Above high school (college and higher)
6 Who is care taker, mother_____father_____Both_____other?
7 Educational statuse of, child
   A. No formal education
   B. Read and Write only
   C. Primary
   D. Secondary

8 .Occupation of mother/care giver:
   A. House wife
   B. Farmer
   C. Self employed
   D. Government/company

9. Family monthly income (estimate):_____(birr)

II Anthropometric Measurements

1. Wt. (kg) _____
2. Ht(cm)_____
3. W/H_____
4. MUAC _____
5. BMI for age _____

III Clinical Evaluation

a.   History
1 How long is the duration of illness _____

2 when was diagnosis made_____

3 do u have regular follow up, yes____, No_____
   If yes how frequent is the follow up_____
4 if no, why_____

5 No of medication used_____

6 history of drug discontinuation, No_____yes_____

7 if yes, which drug, Po or IM_____how many times____ for how
   Long (each) 1st_____   Why 1st_____
2nd___   2_____
3rd____   3_____
4th………   4t………….
8 No of admission_____precipitating factor_____

9which valve is involved_____regurgitant/stenotic_____

10 do you know sore throat coud be associated your heart   problem
, yes_____no____

11 doyou know poorly treated sore throat coud exacerbate your heart
Problem yes_____no_____

12 do you know your monthly IM medication will decrease your heart
   Problem yes_____No
13-is there any other acute illness now   yes_____no____

14-if yes what is diagnosis made_____

15-is there any previous history of the same compliant yes_____No___,if
yes ,how many times____

PedsQL 4.0 generic core scales(8-18 yr)

About my health and activities	Never	Almost never	Some times	often	Almost always
It is hard for me to walk high land	0	1	2	3	4
It is hard for me to run	0	1	2	3	4
It is hard for me to do sport activities	0	1	2	3	4
It is hard for me to lift something heavy	0	1	2	3	4
It is hard for me to take shower by myself	0	1	2	3	4
It is hard for me to dodaily routine activities	0	1	2	3	4
I ache	0	1	2	3	4
I have low energy	0	1	2	3	4
About my feeling					
I feel afraid	0	1	2	3	4
I feel sad	0	1	2	3	4
I feel angry	0	1	2	3	4
I have difficulty in sleeping	0	1	2	3	4
I worry about what will happen to me	0		2	3	4

How I get along with others					
I have difficulty in getting along with other kids	0	1	2	3	4
Other kids do not want to be my friends	0	1	2	3	4
Other kids tease me	0	1	2	3	4
I cannot do things that other kids my age can do	0	1	2	3	4
It is hard to keep up when I play with other kids	0	1	2	3	4
About school					
It is hard to pay attention in class	0	1	2	3	4
I forgot things	0	1	2	3	4
I have difficulty keeping up with my schoolwork	0	1	2	3	4
I miss school because of not feeling well	0	1	2	3	4
I miss school to go to the doctor or hospital	0	1	2	3	4

About me					
I feel happy	0	1	2	3	4
I feel good about my self	0	1	2	3	4
I feel good about my health	0	1	2	3	4
I get support from my family and friends	0	1	2	3	4
I think good things will happen to me	0	1	2	3	4
I think my health will be good in the future	0	1	2	3	4
In general	bad	fair	good	Very good	Excellent
In general how is your health	0	1	2	3	4

Heart problem and treatment	never	almostnever	sometimes	often	almostalways

I get difficulty of breathing when I do sport activities	0	1	2	3	4
My chest feels tight when I do sport activities	0	1	2	3	4
I get colds easily	0	1	2	3	4
I feel my heart beating fast	0	1	2	3	4
My lips turn blue when I run	0	1	2	3	4
I wake up at night difficulty of breathing	0	1	2	3	4
I have to rest more than my friends	0	1	2	3	4
Treatment II					
I refuse to take my heart medicine	0	1	2	3	4
It is hard for me to take my heart medicine	0	1	2	3	4
I forget to take my heart medicine	0	1	2	3	4
My heart medicine makes me feel sick	0	1	2	3	4
I woory about side effects from my medicine	0	1	2	3	4
Percived physical apearance					

I feel I am not good looking	0	1	2	3	4
I don't like other people to see my scars	0	1	2	3	4
I am uncomfortable when other see my body	0	1	2	3	4
Treatment anxiety					
I get fearful when I am waiting to see the doctor	0	1	2	3	4
I get fearful when I have to go to the doctor	0	1	2	3	4
I get fearful when I have to the hospital	0	1	2	3	4
I get fearful when I have to have medical treatment	0	1	2	3	4
Cognitive problem					
It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
I have difficulty solving math problem(if get school only)	0	1	2	3	4
I have difficulty in writing school papers or reports	0	1	2	3	4
It is hard for me to pay attention to things	0	1	2	3	4

It is hard for me to remember what I read	0	1	2	3	4
communication					
It is hard for me to tell the doctors how I feel	0	1	2	3	4
It is hard for me to ask the doctors questions	0	1	2	3	4
It is hard for me to explain my heart problem to other people	0	1	2	3	4

PedsQL 3.0 Cardiac module scales (8-18 yr)