

Parental knowledge and participation in the management of Children with Chronic Rheumatic Heart Disease

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Table of contents

| Content | Page |
|--------------------------|-----------|
| Abbreviations | 3 |
| Operational definition | 4 |
| Abstract | 5 |
| Introductions | 6 |
| Back ground | 6 |
| Statement of the problem | 7 |
| Literature review | 8 |
| Objective of the study | 10 |
| General objective | 10 |
| Specific objective | 10 |
| Methodology | 11 |
| Results | 12 |
| Discussion | 17 |
| Work plan | 19 |
| Questioners | 20 |
| Reference | 24 |

Abbreviations

- ✓ WHO – World Health Organization
- ✓ RHD – Rheumatic Heart Disease
- ✓ ARF – Acute Rheumatic Fever
- ✓ CHD-congenital heart disease
- ✓ CHF-congestive heart failure

Operational definition

- **Knowledge:** *It refers to the information and understanding of parents on the nature and prognosis, treatment and prevention of the illness of their children.*
- **RHD:** *refers to the major long-term sequel of acute rheumatic fever, which involves the cardiac valves leading to stenosis or regurgitation with resultant hemodynamic disturbance.*
- **Children:** *It refers to an individual between the age group of 0 to 14 years*
- **Parents:** *It refers to mother, father or a guardian in-charge of caring for the children with RHD.*

Abstract

Background:-RHD is the most common cause of acquired heart disease in developing countries with prevalence being highest in sub-Saharan countries. It follows throat infection by Group A β hemolytic streptococcal infection. The high prevalence in these countries, including Ethiopia, could be attributed to the low socioeconomic status, overcrowding, poor health seeking attitude during early illness. And even after first diagnosis of Rheumatic fever/RHD there is a tendency to have a poor adherence to monthly benzathine penicillin which increases the risk of rheumatic recurrence and the severity of carditis.

Objective:-to assess the understanding and participation of parents/guardians about the nature and prognosis of their children's cardiac illness and to assess the degree of their involvement in the management of their children.

Methodology and material:-A quantitative, descriptive cross sectional study was done to assess knowledge of parents/guardian about the nature and prognosis of their children's cardiac illness and the extent of their participation in the management process. The study was conducted at the pediatric cardiac clinic of the Addis Ababa University hospital (Tikur Anbessa hospital). A structured, standardized and pretested questionnaire, which contains 35 questions, was used to assess 206 parents during the period from September 2013 to February 2014.

Results: -All parents answered the interview questions. The mean age of the attendants was 38 years with M: F ratio being 2.3:1. Half (51%) of the parents had educational level of elementary school and above. From the parents interviewed 91 % reported the child has heart disease and 18 % knew about the etiology, two parents (0.9%) knew about the chronicity of the disease and fourteen (6.8%) parents knew about the possibility of recurrence of the disease. When we look at the habit of reporting the problems faced during follow-up 21% reported their problems and 68% of the parents who reported found a solution. In this study attendant's educational level was significantly associated with parental knowledge about the disease and participation in the management of their child.

Conclusion: - While most parents know that their child has heart disease, parental knowledge of etiology, chronicity, possibility of recurrence and ultimate therapy was limited. So, intensified education and awareness programs are needed in order to prevent potential major morbidity and mortality for pediatric patients with Rheumatic heart disease.

1. Introduction

1.1 Back ground

Rheumatic Heart Disease (RHD) is a chronic heart condition caused by rheumatic fever that can be prevented and controlled. Rheumatic fever is caused by a preceding Group A streptococcal (strep) throat infection(1,2,3).

Despite the availability of some cardiology services for those with established Rheumatic Heart Disease as a sequel to Rheumatic Fever and effective antibiotic treatment and prophylaxis to prevent Rheumatic Fever, it remains major global problem especially in developing countries.(4) The high prevalence of rheumatic fever and RHD in developing communities is mainly related to poverty and overcrowding, which favors the transmission of group A streptococcal infection .But Improved living conditions, nutrition, access to medical care, and penicillin use have substantially changed the epidemiology of acute rheumatic fever and rheumatic heart disease in the developed world. (5, 6, 7)

Primary prevention of acute rheumatic fever (the prevention of initial attack) is achieved by treatment of acute throat infections caused by group A streptococcus. This is achieved by up to 10 days of an oral antibiotic (usually penicillin) or a single intramuscular penicillin injection (2, 21). People who have had a previous attack of rheumatic fever are at high risk for a recurrent attack, which worsens the damage to the heart. Prevention of recurrent attacks of acute rheumatic fever is known as secondary prevention. This involves regular administration of antibiotics, and has to be continued for many years (1, 2).

Secondary prevention programs are currently thought to be more cost effective for prevention of RHD than primary prevention and may be the only feasible option for low- to middle-income countries in addition to poverty alleviation efforts. Surgery is often required to repair or replace heart valves in patients with severely damaged valves, the cost of which is very high and a drain on the limited health resources of poor countries (1,2,5,6).

The knowledge of one's own disease is an important determinant of health related behavior. For children with Rheumatic heart disease, parents' knowledge about their child's heart disease, treatment, and prevention of complications may likewise promote a better health related behavior in their child by increasing the understanding of the cardiac problem, improving compliance with treatment, and avoiding risk taking behavior(8).

In Ethiopia, Studies in school children estimated the prevalence of RF/RHD to be in the range of 4.6 to 6.4 per1000 children, which is one of the highest prevalence in the world (9, 10). Not more than 15% of parents of these children know their children had some form of heart disease related with infection and only 22% were on regular prophylaxis showing low knowledge and level of awareness about the disease (11). Though sub-Saharan Africa has one of the highest burden of RHD in the world (3, 4), there are few studies on the understanding of

parents of children with RHD about the nature and prognosis of the disease and more importantly, their participation in the management of their children's cardiac condition.

1.2 Statement of the problem

Rheumatic heart disease causes at least 200, 000–250, 000 premature deaths every year, and is the major cause of cardiovascular death in children and young adults in developing countries (1, 3), but epidemiological data for Africa are scarce (2, 3,7). In areas of poor or no medical attention, the natural course of the disease prevails because patients have no access to treatment. Mortality rates in these areas can be as high as 20% at 6-year follow-up according to a Nigerian pediatric cohort study or 12.5% every year in rural Ethiopia (7, 12). Additionally, rheumatic heart disease causes substantial morbidity in children and adults, and can affect quality of life and economic growth. According to a 2004 WHO report, the number of disability-adjusted Life-years lost to the disease was as high as 5.2 million per year, worldwide (7).

Despite the wide spread availability of effective antibiotic treatment of prophylaxis to prevent Rheumatic Fever and cardiology services for those, with established Rheumatic Heart Disease, the recurrence rate of rheumatic fever tends to be high in some sub-Saharan countries which is as high as 4-6% in South Africa, which was mainly associated with poor adherence to the secondary prophylaxis (13).

Ethiopia, which is one of the sub Saharan countries, has a population size of around 83 million people of which 39% (look for current figures) live below the countries poverty line. It is one of the most prevalent areas in the world in RHD (7). A prevalence determined in Addis Ababa showed an overall prevalence rate of 6.4per 1000 (9).

So to decrease the morbidity and mortality associated with the disease and its complication (3,14), parental knowledge about the disease and management plays a major role in preventing recurrences and progression of the disease (5,6) . So the aim of the study is to assess the knowledge and participation of parents of children with rheumatic heart disease and to fill the gaps of knowledge of the parents during the data collection.

1.3 LITRETURE REVIEW

According to WHO, at least 15.6 million people have RHD and 300, 000 of about 0.5 million individuals who acquire ARF every year go on to develop RHD, and 233, 000 deaths annually are directly attributable to ARF or RHD (1, 3,4,7). However, these estimates are based on conservative assumptions, so the true disease burden is likely to be substantially higher (3). The incidence of ARF in some developing countries exceeds 0.5 per 1000 children. The prevalence of RHD in children aged 5–14 years is highest in sub-Saharan Africa (5.7 per 1000) (3), the Pacific and Indigenous populations of Australia and New Zealand (3.5 per 1000) (3), and south-central Asia (2.2 per 1000), and lowest in developed countries (usually 0.5 per 1000) (3,7).

Rheumatic fever is common in areas of high poverty, poor living conditions and poor nutrition, among others. Overcrowded and unsanitary living conditions, especially during the rainy seasons in tropics and sub tropics foster transmission of streptococcal Infection and hence the development of rheumatic fever (14). Rheumatic fever tends to cluster in families. This may be due to contagious nature of throat infection as well as genetic predisposition (7, 15). In Ethiopia heart disease is said to account for nearly 35% of admissions to various hospitals of which rheumatic heart disease is the leading cause (14). Studies in school children estimated the prevalence of RF/RHD to be in the range of 4.6 to 6.4 per1000 children (9, 10,11).

Prevalence of RHD among school children was determined in Addis Ababa, and out of 10,053 school children selected 9,388(93%) were examined of which sixty were confirmed to have RHD giving an overall prevalence rate of 6.4per 1000 which is one of the highest prevalence in the world(3,9) .and among schoolchildren in rural town (Butajira) where 92.8% of the entire school children(n=3235) were screened fifteen children accounting for a rate of 4.6/1,000 were noted to have findings consistent with RHD (10). Surprisingly enough, not more than 15% of parents of these children know their children had some form of heart disease related with infection and only 22% were on regular prophylaxis showing low knowledge and level of awareness about the disease (11).

When we look at knowledge of parents of children about rheumatic diseases there are limited researches done, of which one was done in 2001 in Saudi Arabia (16). One hundred sets of parents, of children with established rheumatic diseases with mean duration of illness, (4.1 +/- 2.83), And a mean child age (9.9 +/- 3.15) years, were given questionnaire which addressed 4 main areas: parental awareness regarding their children's diagnosis and duration, source of information and parental satisfactions, general knowledge about rheumatic diseases and knowledge about medical and physical therapy. The total possible score was 23 and the overall mean score was11.6. The results showed that total knowledge is not affected by the parental education level and majority of parents have wrong beliefs regarding the disease. The treating physician is the main source of parental information and in majority of the parents this information is satisfactory (16).

In a study done on parents of 205 patients attending the pediatric cardiology clinic at King Khalid University Hospital, Riyadh from June 1999 to June 2000, the parents were

interviewed using questionnaire pertaining to their knowledge about child cardiac disease, medication & bacterial endocardial prophylaxis (BEP). The result of the study revealed that 201 (98%) parents knew the correct name of their child cardiac condition, and 48 out of 50(92%) knew the names of their child's current medication. 113 out of 176 (64%) parents with at risk children were aware of measures to prevent endocarditis. It was concluded that though the parents knew the names & current medication of their child heart lesions the knowledge of endocarditis and BEP was limited (17).

In one study done in Guilan province, Iran, with the aim of determining Mothers' understanding and co-operation as an important factor supporting primary prevention and secondary prophylaxis for controlling rheumatic fever and rheumatic heart disease. They evaluated 443 mothers through an interview about the different aspects of the disease and found out most mothers have good knowledge about the treatment (86%),but few had good knowledge in the epidemiology(34%),symptoms(4%) , route of infection(27%) and complications(10.5%) (18).

In another study done at a hospital in Dareselam,Tanzania, targeting at the assessment of parents' knowledge about their child's congenital heart disease, after interviewing 84 parents they found out that of the parents couldn't meaningfully explain the cardiac problem of their child while other 72% were unable to mention about the signs of deterioration of their child's cardiac condition. And they also found out that the parents understanding of the cardiac defect correlates with their educational level (19).

Finally there are several explanations for the low levels of awareness of RF/RHD in communities often most affected by the disease(20).One of these barriers arises from the reality that communities at highest risk for RF/RHD are also frequently burdened with high rates of other major diseases such as HIV/AIDS and tuberculosis. These diseases inevitably receive higher priority from those in charge of distributing scarce resources for disease-control programs. Inadequate resources and the lack of prioritization of RF/RHD educational programs have effectively maintained a public that is largely ignorant of the causes, symptoms and risks associated with RF/RHD (5, 6,20).

2. OBJECTIVES OF THE STUDY

2.1 General objective

- ✚ To assess the knowledge and participation of parents of children with RHD about the disease and management.

2.2 Specific objectives

1. To determine the knowledge of the parents about the cause of the disease
2. To determine the knowledge of the parents about the complications of the disease
3. To measure the knowledge of the parents about the management and prognosis of the disease
4. To identify some of the barriers on the knowledge of the parents about the disease
5. To calibrate the participation of parents in the management of the disease

3. METHODOLOGY

3.1 Study Setting

Tikur Anbessa specialized hospital is located in the capital city Addis Ababa .It is the largest specialized referral teaching hospital for both undergraduate and postgraduate students in the country. In addition to teaching the hospital also gives both inpatient and outpatient services to patients referred from different parts of the country. Currently it is the only hospital where pediatric cardiac surgery is practiced in the country with a follow-up clinic for congenital and acquired heart disease in children.

3.2 Study design: a cross sectional descriptive study was conducted.

3.3 Source population: Parents of children with RHD attending pediatric cardiac follow-up clinics.

3.4 Study population: Parents of children with RHD who come To pediatric cardiac follow-up clinic on months September 2013 to February 2014

3.5 Sample size and sampling method:

Single population proportion formula for estimating sample size was used as follows:

$$n = \frac{z^2 p(1 - p)}{w^2}$$

Assumptions $Z=1.96$, $p=50\%$ (because we don't know the proportion), $w=0.068$

The estimated sample size based on the above assumption was 206. All parents accompany their children to the pediatric cardiac clinic during the study period were interviewed.

3.6 Inclusion Criteria-

1. Parents of children with RHD who are willing to participate in the study.
2. Parents of children with RHD who are available during data collection period.

3.7 Exclusion Criteria-

1. Parents of children who came for the first time to the clinic as a follow up of the disease.

2. Parents and guardians who are not willing to participate in the study.

3.8 Data collection process:

A Structured and standardized questionnaires was developed in English and Amharic language and pre tested for validity, then data was collected by trained nurses and the principal investigator.

3.10 Data quality assurance:

The data collectors were trained on how to collect data from parents .we used pretested questionnaire for data collection and the questionnaires were checked for completeness by the supervisor and principal investigator.5% of the data was checked for completeness. Then the data was cleaned, coded, entered and analyzed using SPSS version 20.

3.9 Data analysis:

Data was cleaned and entered using SPSS-20. The association of various parental and child characteristics with knowledge and participation in the management of RHD was analyzed using chi-square test and multivariate binary logistic regression.

3.12 Dissemination of results:

The interpreted results discussion and recommendations will be submitted to the department of pediatrics, policy makers and later on the article will be submitted to a reputable journal.

3.13 Variables

-Dependent variables: Knowledge and participation of the parents

-independent variables: Parental age, sex, clinical condition of the child, educational status, number of children, number of admission of the child, duration of follow-up

3.14 Ethical considerations

A written legal permission regarding the study was obtained from the department of pediatrics and child health and AAU-medical faculty institutional review board prior to the study.

Confidentiality of the patient and parents was kept during the study and during dissemination of the result. A written consent was prepared both in Amharic and English for the parents.

Results

In this study of 6 months period we were able to interview 206 Attendants .The mean age of the attendants was 38 years with M:F ratio being 2.3:1. 91.6% of the attendants live with the child. Half (50%) of the parents are from urban areas and the other half from rural areas. During the interview 77.2% of the children were attended by their family members (mothers (20%), Fathers (47%) and siblings (8%)) and the other children were attended by other relatives (21%) and 3 children were brought by non-relative. Sixty one percent of the attendants came more than three times for follow up with the child and the other 35 % came two or three times in the preceding 12 month period before the interview. Four percent of the attendants came once. (See table 1)

Table 1. Socio demographic data of the attendants

| characteristics | | Number | Frequency (%) |
|---|--------------------------------|--------|---------------|
| Age | Below 20 | 9 | 4.5 |
| | 21-35 | 69 | 34.7 |
| | 36-50 | 100 | 50.3 |
| | 51-65 | 20 | 10.1 |
| | >66 | 1 | 0.5 |
| Residence | Urban | 100 | 50 |
| | Rural | 100 | 50 |
| Relationship with the child | Mother | 42 | 20.9 |
| | Father | 97 | 48.3 |
| | Sibling | 16 | 8.0 |
| | Other relative | 43 | 21.4 |
| | Not related | 3 | 1.5 |
| Educational level | Illiterate | 50 | 24.9 |
| | Able to read & write | 46 | 22.9 |
| | Completed elementary education | 42 | 20.9 |
| | Completed high school | 42 | 20.9 |
| | Collage education | 21 | 10.4 |
| Accompanied child to clinic in the past 12 months | Once | 9 | 4.5 |
| | Twice | 30 | 14.9 |
| | Trice | 41 | 20.3 |
| | More than 3 | 122 | 60.4 |
| Lives with the child | Yes | 185 | 91.6 |
| | No | 17 | 8.4 |

The mean age of the children was 10 year and one month with M: F ratio of 1:1.2.the youngest child with RHD was 3 years old at the time of interview. Severe mitral regurgitation is present in 57.3% of patients and sever aortic regurgitation in 18.9% (see table 2)

Patients who are on at least two cardiac medications are 61.5% and the other 17.5% and 5.5% are on three and more medications respectively. Seven of patients (3.4%) are not on any cardiac medications Except 2 patients all were on monthly bezanthine peniciline. The interval of follow up was three monthly in 57% of the children and six monthly in 25% of patients the remaining were followed on monthly, two monthly or yearly basis.

During the period of one year prior to the interview 29% of the children had admission to the hospital at least once. The reasons for admission were rheumatic Recurrence and CHF precipitated by Drug discontinuation in 34.5% and 12.1% patients respectively. (See table 2)

The attendants' place of residence is Urban in half and rural part of the country in the others. During the interview 91% of the attendants remembered that they were told about the diagnosis and management of the children. The other 9% claim that they were never told about the diagnosis or management or do not remember. Of the attendants who reported to be told about the diagnosis and management, of the child 91 % reported the child has heart disease and 18 % know about the etiology. Two parents (0.9%) know about the chronicity of the disease and fourteen (6.8%) parents know about the possibility of recurrence of the disease.(see table 3)

Three forth (75%) of the attendants think they have adequate time to express the child's condition during each visit and 25% of them think the time that they get to discuss with the physician is inadequate. Sixty percent of them reported that the physicians always ask about the condition of the child during each visit while 25 % reported that they are asked intermittently and 15% reported that they were never asked about the child, only the medications were refilled. . More than half of the respondents were told about the child's medications, but 15% of the respondents don't remember being told about the child's medication at all. Fifty six percent of the parents don't remember physician advising them to go to health facility when the child gets sick .Ninety five percent of the attendants had a memo sent by a physician to their nearby health facility at least about the monthly injection (95%).

Table 2- Clinical baseline data of the children

| | | Frequency | Percent |
|--|------------------------|-----------|---------|
| Duration of illness | 1 - 5 years | 118 | 57.3 % |
| | 5 - 10 years | 31 | 15.0% |
| | greater than 10 years | 5 | 2.4% |
| | less than one year | 51 | 24.8% |
| Duration of follow up | less than one year | 57 | 27.7% |
| | 1 - 5 years | 120 | 58.3% |
| | 5 - 10 years | 25 | 12.1% |
| | greater than 10 years | 3 | 1.5% |
| NYHA class | I | 58 | 28.2% |
| | II | 67 | 32.5% |
| | III | 67 | 32.5% |
| | IV | 8 | 3.9% |
| Cardiac medications | monthly | 25 | 12.1% |
| | three months | 113 | 54.9% |
| | six months | 49 | 23.8% |
| | yearly | 2 | 1.0% |
| | four monthly | 7 | 3.4% |
| | 2 months | 3 | 1.5% |
| Cardiac medications | single | 25 | 12.1% |
| | double | 113 | 54.9% |
| | triple | 49 | 23.8% |
| | more than 3 | 2 | 1.0% |
| | no medication | 7 | 3.4% |
| Hospital admission in the past 12 months | yes | 59 | 28.8% |
| | no | 143 | 69.4% |
| Reason for admission | Rheumatic Recurrence | 20 | 34.5% |
| | Drug discontinuation | 7 | 12.1% |
| | Infective endocarditis | 2 | 3.4% |
| | Pneumonia | 4 | 6.9% |
| | Anemia | 2 | 3.4% |

Sixty five percent of the parents were told that their child needs exercise modification at least once during their follow up. The remaining 35% were never told about exercise modification, and of the parents who received the advice on exercise modification 94% had similar information from the physicians, the remaining 6% had contradictory advice. When asked about dietary restriction 67 % reported that they had advice but dietary restriction and 33% did not. Of those who were told about the dietary restriction 97% had similar advices. When asked about the problems they faced during medication 13% of the children had occasional drug intolerance. The other 21 % were having problems with benzantine penicillin monthly injection for the health professionals refused to give it.

Table 3- Knowledge about the different characteristics of the disease and management plan.

| | Number of parents who know | Frequency (%) |
|---|----------------------------|---------------|
| Diagnosis of the child | 188 | 91.2 |
| Etiology | 39 | 18.9 |
| Chronicity | 2 | 0.9 |
| Possibility of recurrence | 14 | 6.8 |
| Importance of compliance with benzanthine penicillin | 99 | 48 |
| Ultimate modality of treatment | 34 | 16.5 |
| Need for antibiotics prophylaxis during dental of invasive procedures | 56 | 27.2 |

When we look at the habit of reporting the problems faced during follow-up 21% reported the problems and 68% of the parents who reported found a solution. Thirty seven percent of the parents reported that the major problem they faced was their child evaluated by different doctors at different follow-up time. The other 15% think they can't communicate freely.

Forty four percent of the children were referred to the cardiac surgical center for surgical repair, and of these one third (30 %) don't know why they were referred. In this study we found out that attendants education level was significantly associated with knowledge of the parents and participation in the management of their child ($p < 0.05$, CI 95%)

Discussion

Most of the children have severe forms of valvular lesions the commonest being Severe Mitral Regurgitation (57.3%), followed by Severe AR (18.9%) and severe AS (12.6%).

In this study which was done from September, 2013 to February, 2014 we were able to interview 206 parents and guardians of children with rheumatic heart disease. Most of the children had severe forms of rheumatic valvular heart disease and 44% of them were referred to the cardiac surgical unit for possible surgery. Similar to the other studies done in Tanzania and India, most of the parents had little knowledge about the disease and also the management.

Although majority had follow-up more than 1 to 5 years, only few knew beyond the diagnosis of their children. Majority of the parents (91%) knew their child had cardiac problem which when compared with 98% of parents of children with congenital heart disease in Al-Jarallah et al study in Saudi Arabia(14) is lower, but greater than lower than the Tanzanian study where 56% of the parents meaningfully explained the cardiac condition of their child(16). The other parameters of knowledge assessment also showed that only few parents had knowledge about the chronicity of the disease(0.9%), the Etiology(18.9%), the possibility of recurrence(6.8%) and also the need for compliance of the monthly benzantine penicillin(48%). This knowledge gap might have contributed to the higher rate of admission to the hospital secondary to congestive heart failure. We have seen that one third of these children had admission to the hospital at least once in the preceding one year before the interview. The commonest reasons for admission were rheumatic recurrence and drug discontinuation which can be prevented by a good adherence of the drugs. These findings reflect the poor knowledge on the need for compliance of the drugs.

The other striking finding in this study was only few parents had knowledge on the importance of the medications (14%) and also the ultimate mode of treatment (5.8%). Surprisingly only 11% of them understood the need and justification for frequent follow up of the child, which contradicts with the fact that most claimed that they had adequate time with the treating physician during each follow up.

We have also seen the rate of rheumatic recurrence was high (10%), although 99% Of the parents claim that their children are taking the monthly benzantine penicillin. This also contradicts with the fact that 27 parents reported their child was not injected benzantine penicillin because the health professionals refused to do so. From our experience the reason for this refusal of injection could be the fear of risk of anaphylactic reaction while giving benzantine penicillin.

When we look at the factors that might have affected their knowledge, we found out that more than one third of the parents reported their child was evaluated by a different physician at

each follow up. The other 15% claimed that they can't freely communicate about the child's problem, probably because there are 2 to 3 physicians treating the same number of patients in the same room at the same time. This problem was also evidenced by only 21% reported about problems with benzantine penicillin injection and drug intolerance to their treating physician. One third of the parents reported that the physicians don't discuss the problems of the child in detail which might have affected their knowledge about the disease. Only few reported that the physicians don't listen to them when they try to explain the child's problem.

In this study Parental knowledge was significantly associated with parental educational level which was also seen in the Tanzanian study where the knowledge of the parents was significantly associated with parental educational background.

The other important finding was the contradictory advices given to the parents by different physicians about exercise restriction and dietary restriction which may affect the thrust of the parents on the health care and follow-up.

Conclusion

In this study we have seen that the parents have very little knowledge about the disease and also little participation in the management which might have contributed to the children's health condition. so we recommend the physicians to give a thorough explanation to the parents during each visit and also for them to have a guideline about supportive management of children with RHD including exercise and dietary recommendations. On this study we have tried to narrow the knowledge gaps by teaching the parents during the interview but this wouldn't be enough so we recommend the cardiac unit to prepare a parent guiding manual in local languages to be given during the initiation of follow up which may include disease etiology, cause, management, complication and prevention.

4. Work plan (the work plan, questionnaire etc can now be attached only as an annex.

| s.no | EXPECTED ACTIVITIES | DURATION(MONTHS) 2013 | | | | | |
|------|---|-----------------------|----------------|-----------------------------|------------|------------|--|
| | | August 2013 | September 2013 | October2013 toFebruary 2014 | March 2014 | April 2014 | |
| 1 | Preparation Submission of First draft | | | | | | |
| 2 | Submission of Final proposal | | | | | | |
| 3 | Obtaining ethical clearance | | | | | | |
| 4 | Securing fund for research | | | | | | |
| 5 | Selection & recruiting data collectors | | | | | | |
| 6 | Training of data collectors and supervisors | | | | | | |
| 7 | Pre-testing | | | | | | |
| 8 | Conducting data collection | | | | | | |
| 9 | Data entry and analysis | | | | | | |
| 10 | Report writing | | | | | | |
| 11 | Submission of first draft | | | | | | |
| 12 | Final submission of thesis | | | | | | |
| 13 | Defending thesis | | | | | | |
| 14 | Finalizing financial report | | | | | | |

Annex 1.

Study Questionnaire

Part I (to be completed from medical records)

1. Patient Identification

Card No _____ Age _____ Gender _____

2. Diagnosis

1. _____

2. _____

3. _____

4. _____

5. _____

3. NYHA Class I II III IV

4. Duration of Illness 1. < 1 year 2. 1-5years 3. 5-10years 4. >10years

5. Duration of follow up at TAH

1. < 1year 2. 1-5 Years 3. 5-10years 4. > 10 years

6. Cardiac medications

1. Single 2. Double 3. Triple 4. More than 3

7. Monthly benzathine penicillin 1. Yes 2. Not all 3. Defaulter

8. Appointment interval in the last 12 months 1. Monthly 2. Three monthly 3. Six monthly
4. Yearly

9. Hospital admission the past 12 months 1. Yes 2. No

10. If yes to Q9, reason for admission _____

Part II (to be completed by a non-uniformed interviewer)

11. Attendant's data Age _____ Gender _____
12. Attendant's Relationship to the child 1. Mother 2. Father 3. Sibling 4. Other relative
5. Not related
13. Does the attendant live with the child? 1. Yes 2. No
14. Attendant educational level 1. Illiterate 2. Able to read & write 3. Completed elementary education 4. Completed high school education 5. College education
15. How often in the last 12 months did the attendant accompany the child to the clinic? 1. Once 2. Twice 3. Trice 4. More than 3
16. Attendant's residence 1. Urban 2. Rural
17. Have you ever been told the diagnosis and treatment of the child at any time during your clinic visit? 1. Yes 2. No 3. I was told but do not remember
18. If yes, what information were you told? Circle all that apply
 1. Diagnosis
 2. Etiology
 3. Chronicity
 4. Possibility of recurrence of the etiology
 5. Importance of compliance with benzathine penicillin
 6. Need for antibiotic prophylaxis during dental procedure or invasive procedures
 7. The importance of the medicines the child is taking (if on medication)
 8. The need and justification of the follow up appointments for the child
 9. Ultimate modality of treatment
19. How do you rate the time and opportunity you are given to express the child's condition and your concern's on each visit? 1. Very good 2. Adequate 3. Inadequate 4. Not given at all
20. How do you rate the time and opportunity you are given to ask questions on the diagnosis and treatment of the child during each visit? 1. Very good 2. Adequate 3. Inadequate 4. Not given at all

21. Do your doctors ask you whether your child has any problems with the medicines or monthly benzathine penicillin injection? 1. Yes, always 2. Yes, most of the time 3. Yes occasionally 4. No, not all
22. Do your doctors advise you on the clinical condition of your child and his/her treatment?
1. Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. No, not all
23. Do your doctors advise you to contact your local health professional in case your child gets sick on your clinic visits? 1. Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. No, not at all
24. Have you ever received a memo or feedback or referral from your doctors at the clinic to your local health professional? Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. No, not at all
25. Do your doctors at the clinic tell you that you can bring the child back to the clinic out of your appointment schedule in case of problems? 1. Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. Not at all
26. Do your doctors at the clinic tell you whether your child needs exercise modification or not?
1. Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. No, not at all
27. If the answer to #26 is yes, was the information from the doctors similar? 1. Yes 2. No, it was contradictory
28. Do your doctors at the clinic tell you whether the child needs dietary restriction or not? 1. Yes, always 2. Yes, most of the time 3. Yes, occasionally 4. No, not all
29. If the answer to #28 is yes, was the information from the doctors similar? 1. Yes 2. No, it was contradictory
30. Which of these problems have you encountered in the past?
1. Inability to find prescribed medicines
2. Health professionals refusing to give benzathine penicillin injection
3. Medications not tolerated by the child
31. If you have encountered one or more of the above problems, how often have you informed you doctors at the clinic? 1. Always 2. Most of the time 3. Occasionally 4. Not at all

32. If you have informed the above problems to your doctors at the clinic. How often have they been helpful to you in anyway? 1. Always 2. Most of the time 3. Occasionally 5. Not at all
33. In your opinion, which of the following has been a major problem to you during the follow up of the child? Circle all that apply.
1. Doctors change every time I come
 2. I cannot freely communicate with the doctors because of language barrier
 3. Doctors do not listen to me when I try to tell the problems relating to the child
 4. Doctors do not discuss the problem of the child
 5. Doctors give me frequent appointment without justification
 6. I don't believe the doctors are helping the child
34. Has the child been referred to the cardiac center? 1. Yes 2. No
35. If referred, have you been told why he/she was referred? 1. Yes 2. No 3. I don't remember

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