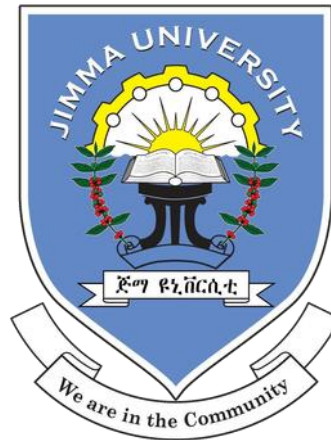


**PATIENT ADHERENCE TO SECONDARY PROPHYLAXIS FOR RHEUMATIC
HEART DISEASE AT HOSPITALS IN JIMMA ZONE, SOUTHWEST ETHIOPIA**



By:

ALINUR ADEM (M.D, MPH, MTM)

**A RESEARCH PAPER TO BE SUBMITTED TO JIMMA UNIVERSITY
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DECEMBER, 2019

JIMMA, ETHIOPIA

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BY

ALINUR ADEM (MD, MPH, MTM)

Email: alinur.adem@hotmail.com

Phone: +251911554534

ADVISORS:

- 1. DR. TADESSE DUKESSA (INTERNIST, CARDIOLOGIST)**
- 2. HABTEMU JARSO (BSc, MPH/EPIDEMIOLOGY)**

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Abstract

Background: Rheumatic heart disease continues to create havoc in the developing countries even decades after its discovery. It is entirely preventable through primordial, primary, and secondary level intervention. Secondary prevention is a reasonable treatment option in patients in Ethiopia, but good adherence to the treatment is essential to achieve the desired objective. Information regarding prevalence of good adherence and factors associated with poor adherence is limited in Ethiopia.

Objective: The aim of this study was to assess the prevalence of good adherence with secondary prophylaxis for rheumatic heart disease and identify factors associated with poor adherence among patients on treatment at hospitals in Jimma zone.

Methods: A hospital based cross sectional study was conducted from August –November, 2019 on selected rheumatic heart disease patients on follow-up at Jimma Medical Center, Shenen Gibe Hospital, Agaro Hospital and Seka Chekorsa Hospital. Data was collected by face-to-face interview and record review using semi-structured questionnaire and checklist respectively. Adherence of the last consecutive 12 months before the interview was assessed as outcome. The collected data was entered into EpiData, and cleaned and analyzed using SPSS 23.

Result: Results: A total of 253 patients with rheumatic heart disease taking Benzathine Penicillin were included in the analysis. One hundred seventy-eight (70.4%) of them were females. One hundred nine (43.1%) of them were in the age group of above 24 years. Our study showed that 36.8% of patients from the four hospitals in Jimma Zone receiving antibiotic prophylaxis for rheumatic heart disease had a rate of adherence <80% and were therefore at high risk of recurrence of acute rheumatic fever. The main reasons to miss their prophylaxis among Rheumatic heart disease patients were long distance from the treatment setting (56.9%) followed by lack of money (38%).

Conclusion and recommendation: Multivariable analysis showed that lower education of the patients, living in rural areas, and low knowledge about the disease were independently associated with poor adherence to medication. Further research and solutions directly targeting these barriers can improve patient adherence and decrease their overall risk of rheumatic heart disease.

Keywords: adherence, secondary prophylaxis, Rheumatic Heart Disease

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List of Abbreviations

AG= Agaro Hospital

AHA= American Heart Association

AR= Aortic Value Regurgitation

AS=Aortic Value Stenosis

AV= Aortic Value

CRP= C-Reactive Protein

ESR= Erythrocyte Sedimentation Rate

HF= Heart Failure

JMC= Jimma Medical Center

MR= Mitral Value Regurgitation

MV= Mitral Value

NYHA= New York Heart Association

RF= Rheumatic Fever

RHD= Rheumatic Heart Diseases

SCH= Seka CHEKORSA Hospital

WHO=World Health Organization

CHAPTER ONE

1. Introduction

1.1. Background

Acute rheumatic fever (ARF) and its sequel, rheumatic heart disease (RHD), remain important causes of morbidity and mortality in areas of socioeconomic deprivation [1,2, 3]. The Global Burden of Disease estimated in 2013 that there are 33 million cases RHD worldwide causing 275,000 deaths annually [4]. However, many echocardiographic screening studies put the prevalence of RHD at 8-57 out of 1000 children meaning that the true prevalence may rest closer to 62-78 million individuals worldwide with up to 1.4 million death each year [5,6].

The prevalence of RHD is estimated to be higher in developing than in developed countries, ranging from 24/1000 to 0.3/1000, respectively [3,8,9]. Rheumatic heart disease might occur following a single episode of acute rheumatic fever (ARF); however, it is most often the result of recurrent episodes [10]. Those diagnosed with ARF are at higher risk of suffering further episodes of ARF than the general population, with the incidence of rheumatic fever following streptococcal infection as high as 50% in those with previous ARF [11] compared to only 1-3% in the general population [12].

It is estimated that 95% of the cases of RHD and deaths related to this disease occur in developing countries [13]. Moreover, significant costs are associated with the treatment of RHD, including heart valve replacement [14]. The severity and prognosis of RHD depends on the extent of cardiac involvement and the frequency of recurrent events [9,15-18]. The risk of RF after an untreated group A beta-hemolytic streptococcal (GABHS) infection in healthy individuals is around 3% [7,9]; however, in individuals with a previous episode of rheumatic fever, this risk increases to more than 50%, emphasizing the importance of secondary prophylaxis [19].

Secondary prophylaxis, including the use of benzathine penicillin G, is therefore a critical cost-effective intervention for preventing morbidity and mortality related to RF [9,13,14,20,21]. However, ensuring adequate adherence to secondary prophylaxis for RF has been a challenging task, particularly in adolescents; as with most chronic treatments,

adherence is usually poor [22-25]. There is no reliable data available with regards to adherence to secondary prophylaxis and the rates of recurrent RF in many developing countries, including Ethiopia.

1.2 Statement of the problem

Considered one of the forgotten cardiovascular diseases, RF and RHD remain the common cause of cardiovascular morbidity and mortality in many low-income countries and across minority indigenous population. The Global Burden of Disease estimated in 2013 that there are 33 million cases RHD worldwide, majority come from low income countries like Sub Sahara Africa, south Asia and Middle East [4]. Rheumatic fever is a delayed sequel associated with infection by a group A-streptococcus, while easy curable through penicillin treatment, if left untreated can result in progressive and permanent valvular lesion known as RHD. Over the past 50 years, improved living condition and development of penicillin has been the larger contributor of decreased RF and RHD across high income countries [26]. However, both environmental and health system determinants contributing to progressive infection of group A streptococcus in resource limited settings resulted in more than 233,000 deaths per year [4, 26].

Additionally, RHD is the most common course of acquired heart disease in children and young adults. Children are the most susceptible as the peak age for the infection is between age 5-12 year with infection and re-exposure to the bacteria, the collagen in the heart valve eventually become inflamed resulting in impaired physical activity leading to chronic morbidity and in many cases early death before the age of 45 years [26].

One of the essential precursors of effective managed RHD is proper case detection, however, this has proved challenging for verities of reason given that the diagnosis of each stage of the disease has its particularities, strictly adhering to Jones criteria for detection of RF and RHD has often resulted in an under diagnosis and delaying treatment. The prevalence of RHD is higher in rural and remote area where case detection and treatment is low. Therefore, of the potential preventive measure for RHD, adopting secondary preventive strategy has been proven cost effective and practical in poor setting with limited diagnostic tools for early detection. For more than 20 years, the WHO has supported this

recommendation to be delivered most effectively within coordinated program using a registrant of patient. However, numerous health system constrains have imposed progress and implementation. Drug shortage for benzathine penicillin, lack of trained staffs for RHD detection, weak monitoring system and poor patient adherence to follow up have been some of the major contributor limiting effective management of RHD [26,27,28].

1.3 Significance of the study

Rheumatic heart disease (RHD) continues to create havoc in the developing countries even decades after its discovery. It is entirely preventable through primordial, primary, and secondary level intervention. Secondary prevention is a reasonable treatment option in patients in Ethiopia, but it suffers due to poor adherence which remains the main impediment to its implementation.

Compared to other regions of the globe, very few studies have evaluated the compliance of secondary prophylaxis for controlling rheumatic fever (RF) and rheumatic heart disease (RHD) in Sub-Saharan Africa, including Ethiopia. The aim of this study is to determine the compliance with benzathine penicillin as secondary prophylaxis in RHD patients and to identify the patient related factors for adherence and reasons for missing of doses. Furthermore, the findings of this study could be useful in planning health promotion and disease control programs for ARF/RHD.

CHAPTER TWO

2.1 Literature Review

Rheumatic fever is a multi-system inflammatory, chronic disease, which presents as delayed sequelae to group A β -hemolytic streptococcal pharyngitis in genetically susceptible individuals [29, 30]. In the course of the disease, the patient develops carditis, arthritis, chorea, subcutaneous nodules and erythema marginatum [29]. Rheumatic fever is a disease that occurs in every latitude, although its epidemiology is highly diverse. Currently, the annual incidence varies from $< 0.5/100\ 000$ in highly developed countries to $> 100/100\ 000$ in poor countries [31]. It is estimated that there are approximately 500 000 new RF cases and about 230 000 deaths caused by the disease annually on the global scale [32].

The most serious aspect of rheumatic fever is the development of chronic valvular disorders that produce permanent cardiac dysfunction' or rheumatic heart disease [33]. Acquired heart defects can be a consequence of RF. Estimates show that approximately 60% of RF patients in endemic countries develop chronic rheumatic heart disease, which is a complication of RF [34]. The risk of chronic rheumatic heart disease is 1.6–2 times higher in female patients [29].

Ethiopia is one of the African countries shares the burden of ARF. It is documented that the prevalence of RHD among Ethiopian cardiac patients in Addis Ababa city and in Jimma town was 39.6% and 32.8% respectively [35, 36]. Studies from other African countries have also showed higher rate of prevalence [37,38,39]. Report from teaching hospital in Addis Ababa showed that rheumatic heart disease accounted for 50% of cardiac admission [35]. The course of the disease is characterized by relapses, where after the first episode more may follow, thus increasing the risk of heart defects. The risk is the higher the younger the patient [40].

Research done in university of Tennessee college of medicine showed that mitral valve was the most commonly and severely affected (65-70%) and the aortic valve was second in frequency of affection (25%); the tricuspid valve was deformed in only 10% of patients and was almost always associated with mitral and aortic lesion [41]. The pulmonary valve was

rarely affected [41]. Similarly, according to report by Ethiopian Medical Journal 2004, mitral valve was the most commonly involved value by rheumatic heart disease and combined mitral and aortic value involvement accounted for 42.6%. Isolated mitral value stenosis or mitral value regurgitation was relatively low and aortic valve lesion without mitral valve involvement was rare (3.5%) [37,42].

Acute RF and its complication in the form of chronic rheumatic heart disease (RHD) remains an enormous health problem in poor countries [43]. A systematic review of the hospital-based and cause of death studies in Africa relating to RHD highlights RHD as the main cause of cardiac morbidity and mortality in children and young adults [43]. The clinical course of acute rheumatic carditis in Africa runs a fulminant course and seems more malignant [34].

In a retrospective study of deaths between 1995 and 2001 at the Tikur Anbassa Teaching Hospital, Addis Ababa, Ethiopia, Oli and Asmera reported that 26.5% of the cardiovascular deaths were due to RHD and 70% of patients with RHD died from congestive heart failure at a mean age of 25 years (11% died from systemic embolization and comorbid conditions) [44]. The majority had combined mitral and aortic valve regurgitation, and isolated mitral regurgitation or stenosis was relatively uncommon [44].

Contrary to the data in the developing countries, only isolated cases of RF are observed in the countries of Western Europe and North America [31]. This is confirmed by the experience of Clinic of Developmental Age Rheumatology (Poland). In the years 2005–2015, nine children were admitted to this clinic with a confirmed RF diagnosis. Since 2015, they have not recognized RF in any child [40]. This decrease in morbidity should be attributed to the improvement in economic conditions, hygiene, a better access to medical care and antibiotic therapy [31].

Rheumatic fever diagnostic criteria

The diagnosis of a first RF episode required a confirmation of 2 major criteria or 1 major and 2 minor criteria, along with evidence of antecedent group A β -hemolytic streptococcal infection. Rheumatic fever can also be diagnosed if the Jones criteria are not met, in the case of isolated chorea or carditis with an insidious onset, long-term course and inconspicuous

progression of lesions, after other causes have been excluded. In the revised 2015 Jones criteria (Table 1) [31], a low, medium and high-risk population was identified. A low risk population is one in which cases of acute RF occur in $\leq 2/100\ 000$ school-age children or rheumatic heart disease is diagnosed in $\leq 1/1000$ patients at any age during one year [29, 31, 32].

The modifications introduced in 2015 in the Jones criteria are as follows:

1. In the major criteria:

- Low risk population: clinical and/or subclinical carditis. AHA recommends that all the patients with suspected RF undergo Doppler echocardiographic examination, even if no clinical signs of carditis are present [31]. In doubtful cases it is recommended that echocardiography is repeated.
- Medium and high risk population: also clinical and/ or subclinical carditis and arthritis – monoarthritis or polyarthritis, possibly also with polyarthralgia [29, 31].

2. In the minor criteria:

- Low risk population: the parameters of inflammation and the level of fever were defined precisely.
- Medium and high-risk population: monoarthralgia, also with defined parameters of inflammation and the level of fever.

The diagnosis of RF in the whole population with evidence of antecedent group A β -hemolytic streptococcal infection requires a confirmation of two major criteria or one major and two minor criteria – the first episode of the disease. The diagnosis of subsequent episodes of the disease requires a confirmation of two major criteria or one major and two minor criteria or three minor criteria [29, 31].

Diagnostic criteria for rheumatic fever – modified 2015 Jones criteria [31]

Major criteria	
Lower risk population	High risk population
Carditis (clinical or subclinical)	Carditis (clinical or subclinical)
Arthritis – only polyarthritis	Arthritis – monoarthritis or polyarthritis
Chorea	Polyarthralgia

Erythema marginatum	Chorea
Subcutaneous nodules	Erythema marginatum
	Subcutaneous nodules

Minor criteria

Lower risk population	High risk population
Polyarthralgia	Monoarthralgia
Hyperpyrexia ($\geq 38.5^{\circ}\text{C}$)	Hyperpyrexia ($\geq 38.0^{\circ}\text{C}$)
ESR ≥ 60 mm/h and/or CRP ≥ 3.0 mg/dl	ESR ≥ 30 mm/h and/or CRP ≥ 3.0 mg/dl
Prolonged PR interval (after taking into account the differences related to age; if there is no carditis as a major criterion)	Prolonged PR interval (after taking into account the differences related to age; if there is no carditis as a major criterion)

Rheumatic fever treatment has not changed for many years. It covers: anti-streptococcal treatment (primary and secondary prevention), anti-inflammatory treatment [40]. Long-term treatment with penicillin is recommended to prevent infection with Group A streptococcus among those with a previous diagnosis of ARF, and it has been shown to significantly reduce the morbidity and mortality associated with both recurrent ARF and RHD [45,46].

Secondary prophylaxis with regular intramuscular injections of benzathine penicillin G (BPG) is a key component of ARF and RHD control programs. This approach aims to prevent group A beta-hemolytic streptococci (GAS) infections and subsequent recurrent episodes of ARF [13]. The World Health Organization (WHO) recommends 3-4 weekly BPG continued for a duration dependent on factors including age, time since the last episode of ARF, risk of streptococcal infections in the area and presence of RHD [43]. According to WHO guidelines, secondary prophylaxis should continue for at least 5 years after the last episode of ARF or until the age of 18 years (whichever is longer) and for a greater length of time in cases of carditis or RHD [43, 47]. However, local health authorities give slightly varying recommendations for the frequency and duration of BPG injections [47]. Low adherence with secondary prophylaxis is one of the main challenges to effective control of

ARF and RHD [43]. A patient with rheumatic heart disease is expected to receive at least 80% of the annual prescribed injections. Receiving less than 80% of the injections places an individual at a higher risk of recurrent ARF and its complications (45).

Factors Associated with Lower Adherence

Adherence variability to three- or four-weekly injections of benzathine penicillin is well documented, both in the community setting and in hospital-based studies. Several factors could explain the non-adherence observed among these patients [10]. In underprivileged settings where ARF and RHD remain prevalent, there are a number of interrelated factors associated with low adherence to secondary prophylaxis. Rurality with limited access to health care was one important theme in four studies [48,49,50, 51], one involving logistic regression analysis (Bassili *et al.*) and three others including qualitative semi structured interviews. Bassili *et al.* reported non-adherence to be more common amongst children in semi-urban and rural areas, [48]. Mincham *et al.* found that living in a remote location was a negative influence on adherence [51] and two Indian studies identified lack of local services and long distances of travel as reasons for non-adherence [49, 50]. For patients living in rural and remote areas with lesser access to health care, adhering to secondary prophylaxis regimens may be more difficult [49,50]. Negative patient, staff and health service interactions were also reported as contributors to non-adherence in three studies [48,51, 52]. Bassili *et al.*'s found non-adherence to be more common among children whose families were not satisfied with the health care provided [48], and qualitative semi-structured interviews performed by Mincham *et al.* and Harrington *et al.* highlighted that negative patient-staff interactions, limited confidence in the treatment and a lack of sense of “belonging” to the health service could reduce adherence [51, 52]. These studies also discussed transient nature of staff in remote settings, a negative perception of the secondary prophylaxis program, conflicting health priorities, and lack of effective strategy for dealing with absent patients leading to staff frustration and fatigue [51, 52]. These findings may be most relevant to Australian Indigenous populations and other minority groups in developed countries, where a difference in cultural values, attitudes and beliefs between the patient/ caregiver and health care provider may exist. In Mincham *et al.*'s study, lack of an effective reminder system for due injections additionally led to non-adherence to secondary prophylaxis [51].

Other factors associated with non-adherence included lack of family support [50, 52], a disinterest in or conscientious refusal of treatment [50, 52] and inconvenience of the treatment or treatment interference with personal priorities [51, 52]. Intramuscular injections of benzathine penicillin are painful and may sometimes be associated with allergic reactions [10]. Among asymptomatic or minimally symptomatic patients, this might prove to be a deterrent, particularly if the links to future recurrence of rheumatic fever are not repeatedly reiterated [11]. Furthermore, practitioners in the community might be reluctant to administer penicillin injections for fear of anaphylaxis [11].

CHAPTER THREE

3. Objectives

3.1 *General objective*

The aim of this study is to assess the prevalence of good compliance with secondary prophylaxis for RHD and identify factors associated with poor adherence among patients on treatment at hospitals in Jimma zone.

3.2 *Specific objectives*

- To determine the prevalence of good adherence with secondary prophylaxis for RHD
- To identify factors associated with poor adherence to secondary prophylaxis for RHD
- To establish the patient reported reasons for missing monthly benzathine penicillin injections

CHAPTER FOUR

4. Method and Materials

4.1 Study area and period

The study was conducted at four public hospitals in Jimma zone namely Jimma Medical center, Shenen Gibe Hospital, Agaro Hospital and Seka Chekorsa Hospital which are located in Oromia region, Southwest of Ethiopia. Jimma Medical Center (JMC) and Shenen Gibe Hospital are located in Jimma town, 354 km from Addis Ababa. JMC is one of the teaching hospitals in the country which serves as a referral hospital for south western part of Ethiopia including Jimma zone. Among the different service units in JMC, chronic illness clinic is worth mentioning which has Cardiac as a sub-unit. Cardiac clinic runs every Friday and serves about 60 patients daily on average. The activities are accomplished by a cardiologist, internist, three to four residents who rotate every month and nurses.

Agaro Hospital (AH) is a district hospital located in Agaro town, 45 km from Jimma town in the West direction. Seka Chekorsa Hospital is a district hospital located in Seka Chekorsa town, 20 km from Jimma town in the South direction.

The study was conducted at chronic illness referral clinic on scheduled dates of cardiac clinic of the four hospitals from August, 2019- November, 2019.

4.2 *Study design*

A hospital based cross sectional study was used. Data on adherence and associated factors was collected at the same time.

4.3 *Source population*

The source population for the study was all patients clinically diagnosed with rheumatic heart disease and confirmed by echocardiography and on treatment follow-up at the cardiac clinic of the selected hospitals during the study period.

4.4 Study population

The study population was all patients clinically diagnosed with rheumatic heart disease and confirmed by echocardiography and visiting cardiac clinic of the selected hospitals during the study period and who fulfilled inclusion criteria.

4.4.1 Inclusion criteria

- Patients on benzathine penicillin for at least one year before the date of interview (all age groups).

4.4.2 Exclusion criteria

- 1- Patients whose medical record was not complete
- 2- Repeat visits during the study period

4.5 Sampling

4.5.1 Sample size

Sample size was calculated using the formula

$$n = \frac{Z^2 (1-\alpha) / 2 \cdot P (1-P)}{d^2}$$

$$d^2$$

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

$$(0.05)^2$$

Where, n = sample size

Z= confidence level (1.96) p= estimated prevalence (0.5)

d= Margin of error to be tolerated (0.05).

Since the total population is <10,000 the finite population correction formula was used to determine the final sample size.

$$N_f = n / (1 + (n/N))$$

n = sample size, N_f = actual sample size

N = total number of adult RHD patients who attend cardiac clinic of zonal hospitals, (N= 743).

Therefore, the sample size was: N_f = 384 / (1+(384/743)) = 253

By adding 10% contingency a total of 278 patients were be sampled.

4.5.2 Sampling technique

Patients who met the inclusion criteria were consecutively recruited over a period of three months until a total of 278 patients were reached.

Measurements

4.6.1 Variables

4.6.1.1 Dependent Variables

- Adherence status

4.6.1.2 Independent variables

- **Socio-demographic characteristics**
 - Age
 - Sex
 - Religion
 - Ethnicity
 - Educational status
 - Marital status
 - Residency (urban or rural)
 - Distance from the hospital
 - Family income (monthly)
- Disease and treatment related characteristics
 - Condition of the patient (disease class)
 - Duration on treatment
 - History of hospitalization
- Knowledge and attitude

4.6.2 Data collection procedure

Data was collected from patients' medical records and through a standardized questionnaire administered face to face by a single interviewer. For very young children, one of the parents at least was interviewed. For children aged less than 16 years old and able to understand the questions, we interviewed the child and one of his parents at least. We collected information about demographic and socio-economic characteristics, health care

team and system-related factors, condition-related factors, therapy related factors and patient related-factors, according to WHO recommendations [53].

Data was collected by trained medical interns and nurses working at cardiac clinic follow-up clinic. The data collection procedures were supervised by an Internal Medicine Resident. The data collection was conducted by reviewing each patients' register chart and patient interviewing with supervision of the whole activity by the investigator. The necessary data on associated factors was obtained by careful review of the chart and interviewing of the client.

4.7 Data quality control

The measures that were undertaken to ensure quality of data include Pre-testing of the data collection instrument three weeks ahead of data collection at Cardiac clinic of Jimma Medical Center on five percent of the sample population (15) patients (charts). Training on data collection for data collectors before data collection was started and supervision of the data collection process, data storage and management were done by principal investigator.

4.8 Data processing and analysis

Data was entered in Epidata 3.1, backed and cleaned to prevent data loss and then exported to SPSS windows version 23 for analysis. Continuous variables were summarized using means \pm standard deviation or median and interquartile range (IQR). Frequencies of potential factors between good-adherent and poor adherent patients were compared by Fisher's exact test. All statistical tests were two-tailed, and p values of less than 0.05 was considered to indicate statistical significance. We used logistic regression to examine the association between potential factors and the likelihood of a favorable outcome. Odds ratios (OR) and 95 percent confidence intervals (CI) were used to quantify the strength of the associations. Multicollinearity was checked in linear regression with collinearity diagnostics and none was found (the largest VIF was 1.86). Model fitness was checked by Hosmer and Lemeshow test and the p-value was 0.492 indicating good fitness. The classification table also correctly classified 70.8% of the variables which indicated good fit model.

Results were presented in text, tabulation and figurative presentations from which conclusions and recommendations were made. In addition, results were also compared with other studies and discussed.

4.9 Ethical consideration

Institutional ethics approval was obtained from the Research and the Ethics Committee of Institute of Health, Jimma University. We obtained informed consent for all the patients and informed assent for those unable to give consent. Patients' initials and study numbers were put on the questionnaires instead of full names to ensure confidentiality. Patients were informed that they have the right to withdraw at any point during the study period. Confidentiality and privacy were maintained. Patients found to be poor adherent were linked service providers for enhanced counseling.

4.10 Dissemination plan

After research completion and finalizing report, it will be submitted to department of internal medicine, Jimma Medical Center, the ministry of health and other concerned institutions and stake holders for possible application and publication of the study.

4.11 Operational definitions

- **Adherence status:** Adherence with rheumatic fever prophylaxis was measured. Patients were classified as “good-adherent” when the rate of adherence was $\geq 80\%$ of the expected injections and as “poor-adherent” when it was $< 80\%$ [54].
- **Illiterate:** can't read and write and haven't attended formal education.
- **Income:** estimated average amount of cash money an individual earns monthly in terms of Ethiopian currency. For those without monthly salary their raw materials were estimated in terms of Ethiopian birr.
- **NYHA Class I:** No limitations of physical activity; no symptoms of HF.
- **NYHA Class II:** Slight limitations of moderate or prolonged physical activity (e.g., symptoms after climbing 2 flights of stairs or heavy lifting); comfortable at rest.
- **NYHA Class III:** Marked limitations of physical activity (symptoms during daily activities like dressing, walking across rooms); comfortable only at rest.
- **NYHA Class IV:** Confined to bed, discomfort during any form of physical activity; symptoms present at rest.

CHAPTER FIVE: RESULTS

5.1 Demographic and socio-economic characteristics of the participant or attendant

Out 278 expected patients, 253 participated in the study giving a response rate of 91.0%. More than three-fourths (77.9%) patients were from Jimma Medical Center. A total of 253 patients with RHD taking Benzathine Penicillin were included in the analysis. One hundred seventy-eight (70.4%) of them were females. One hundred nine (43.1%) of them were in the age group of above 24 years. Majority of the patients (73.1%) are Oromo in ethnicity. Majority of the patients (75.5%) are Muslim. Eighty-nine (35.2%) of the patients were illiterate, whereas 96 (37.9%) and 58 (22.9%) of the respondents has completed primary and secondary school respectively. Sixty-nine (76.9%) of them were married. Majority of the study participants (43.5%) were students, followed by farmers (28.1%). Two third of the patients (66%) were from rural areas. The mean annual income is 1500 ETB (Table 1).

Table 1. Socio-demographic characteristics of patients with rheumatic heart disease who are on monthly Benzathine Penicillin at four hospitals in Jimma zone from August to November 2019

		Number	%
Hosp Name	Jimma	197	77.9
	Agaro	8	3.2
	Shenen Gibe	37	14.6
	Seka Chekorsa	11	4.3
Age of patient (in years)	<15	47	18.6
	15-24	97	38.3
	>24	109	43.1
Sex of the patient	male	75	29.6
	female	178	70.4
Ethnicity of the patient	Oromo	185	73.1
	Amhara	30	11.9

	Kafa/Dawuro	19	7.5
	Gurage	14	5.5
	Silte	4	1.6
	Kimant	1	0.4
Religion of the patient	Muslim	191	75.5
	Orthodox	41	16.2
	Protestant	21	8.3
	Wakefata	0	0.0
Marital status of the patient/attendant	Single	157	62.1
	Married	84	33.2
	Divorced	5	2.0
	Widowed	7	2.8
Residence of patient	rural	167	66.0
	urban	86	34.0
Distance from health facility (in km)	1-5	62	24.5
	6-10	10	4.0
	11-20	49	19.4
	21-30	37	14.6
	>30	95	37.5
Education of the patient	Illiterate(not educated)	89	35.2
	Primary(grade 1-8)	96	37.9
	Secondary(grade 9-12)	58	22.9
	University/College	10	4.0
Occupation of the patient/attendant	Student	110	43.5
	Farmer	71	28.1
	Government employee	6	2.4
	Merchant (business man/woman)	11	4.3
	Unemployed	16	6.3
	Daily labor	17	6.7
	House wife	22	8.7

Family size	≤ 5	72	28.5
	>5	181	71.5
Monthly household income (ETB)	≤ 1000	85	38.1
	1001-2000	88	39.5
	>2000	50	22.4

5.2 Clinical characteristics of the participants

Almost three-fourths (74.3%) patients had history of hospitalization for RHD. More than half (56.5%) were in NYHA Class II. No other cases of RHD in the family in 94.5% and only 14 (5.5%) reported that family member, suffering from similar illness (Table 2).

Table 2. Clinical characteristics of the participants with rheumatic heart disease who are on monthly Benzathine Penicillin at four hospitals in Jimma zone from August to November, 2019.

Any hospitalization history for RHD?	yes	188	74.3
	no	65	25.7
Duration on medication (in year)	≤ 5	144	56.9
	> 5	109	43.1
Condition of patient (NYHA class)	NYHA class I	89	35.2
	NYHA class II	143	56.5
	NYHA class III	13	5.1
	NYHA class IV	8	3.2
Other cases of RHD in the family?	yes	14	5.5
	no	239	94.5

5.3 Knowledge of study participants

With regard to knowledge about the disease and treatment, the proportion of patients with good and poor knowledge is nearly comparable (51% vs 49%). Almost three-fourths (74.7%) of the study participants responded that curing from RHD is possible. Nearly half (49%) knew that the treatment for RHD is lifelong. Nearly all (95.3%) knew that the

treatment is taken every month. Six out of seven respondents think that missing the doses treatment affects the outcome of disease and seven out of eight patients knew that treatment prevents complication or death (Table 3).

Table 3: Knowledge of the patients towards their disease condition and treatment among RHD patients having follow-up in the four hospital in Jimma zone, August - November, 2019.

Knowledge items	Response	Number	%	
Overall knowledge	good	129	51.0	
	poor	124	49.0	
Is curing from RHD possible?	yes	189	74.7	
	no	64	25.3	
For how long should the treatment of RHD be taken?	Few months	7	2.8	
	One year	2	0.8	
	Ten years	98	38.7	
	20 years	22	8.7	
Lifelong		124	49.0	
	How frequently should the treatment be taken?	Every month	241	95.3
	Every two months	12	4.7	
	Do think missing the doses affects the outcome of disease?	yes	217	85.8
	no	36	14.2	
	Treatment prevents complication/death	true	221	87.4
	false	32	12.6	

5.4 Attitude of study participants

Regarding attitude of patients towards treatment, services and prognosis, majority of the patients (85.8%) had good attitude towards their illness and the treatment approach. Nearly half (48.6%) and 44.3% of the respondents graded the pain of injection as moderate and mild respectively. Nearly two-thirds (62.8%) respondents were somewhat satisfied with services while 70% were somewhat satisfied with prognosis. More than six out seven respondents believe that the treatment is important (Table 4).

Table 4: Attitude of the patients towards their disease condition and treatment among RHD patients having follow-up in the four hospital in Jimma zone, August - November, 2019.

Attitude	Response	Number	%
How do you grade the pain of injection?	mild	112	44.3
	moderate	123	48.6
	severe	18	7.1
How much are you satisfied with services during previous visits?	not satisfied	8	3.2
	somewhat satisfied	159	62.8
	very satisfied	86	34.0
How much are you satisfied with the prognosis of condition?	not satisfied	11	4.3
	somewhat satisfied	177	70.0
	very satisfied	65	25.7
What is your belief about the importance of this treatment?	somewhat important	35	13.8
	very important	218	86.2
How do you feel about the behavior of service providers?	not welcoming	13	5.1
	somewhat welcoming	122	48.2
	very welcoming	118	46.6
Overall attitude	negative	16	6.3
	neutral	20	7.9
	positive	217	85.8

5.5. Adherence to medication

From a total of 253 RHD patients who received secondary prophylaxis, 167 (65.2%) of them missed their regular injection at least once in the past one year. One hundred sixty (63.2%) had good adherence to their medication, while 93 (36.8%) had poor adherence to monthly Benzathine penicillin injection (i.e. they missed more than two times within a year).

The main reasons to miss their prophylaxis among RHD patients were long distance from the treatment settings 144 (56.9%), followed by lack of money 41 (38%), unaffordability (30.8%), and their inconvenient work schedule (22.5%) (Figure 1).

No nurse was designated for ARF prevention program in any of the four hospitals in the zone.

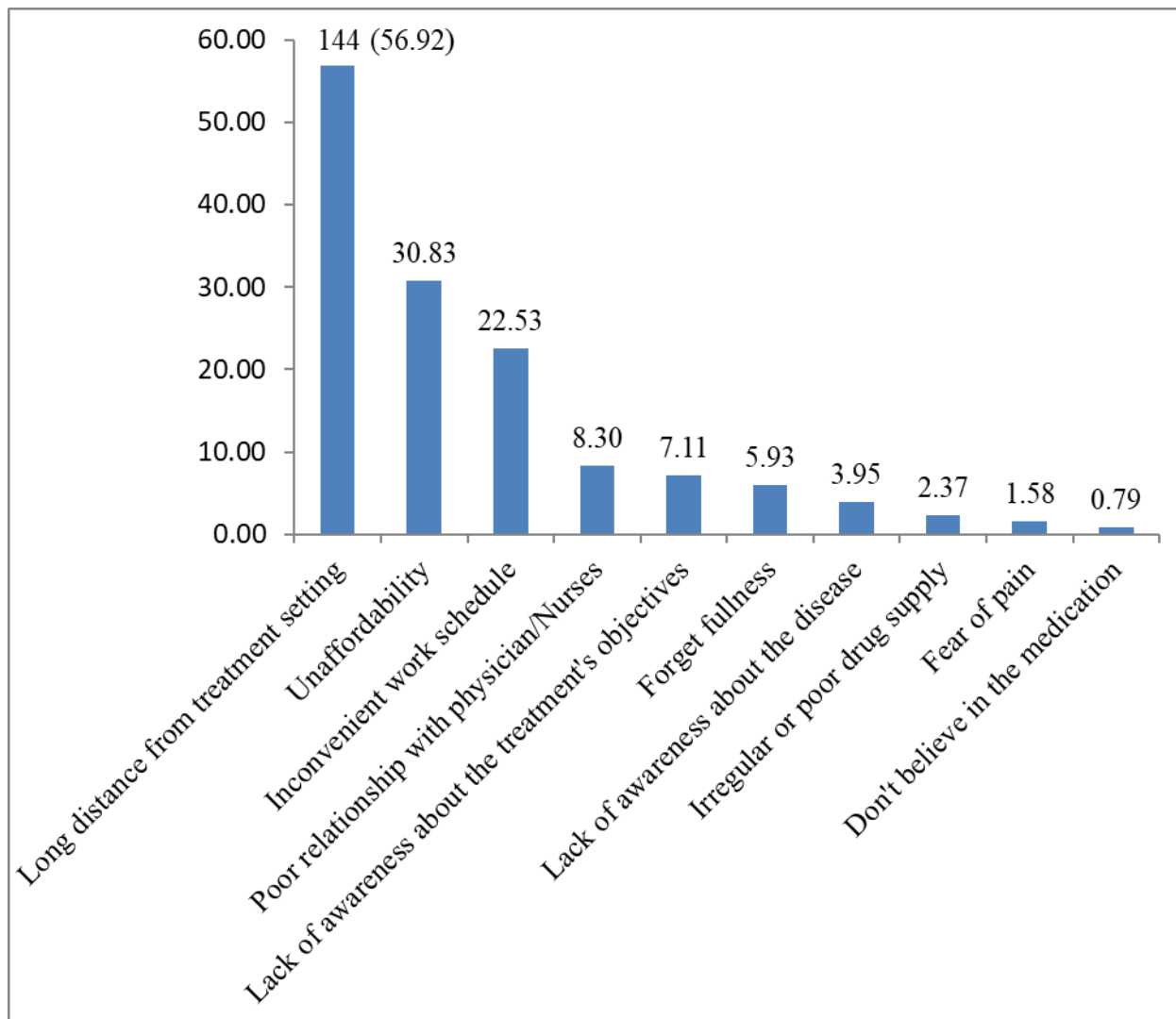


Figure 1: Distribution of reasons for missing monthly Benzathine Penicillin injection among RHD patients having follow-up in the four hospital in Jimma Zone, August - November, 2019.

5.6. Valves affected

The most commonly affected valve in patients with RHD on follow up in the four hospitals in Jimma zone was mitral valve (Figure 2).

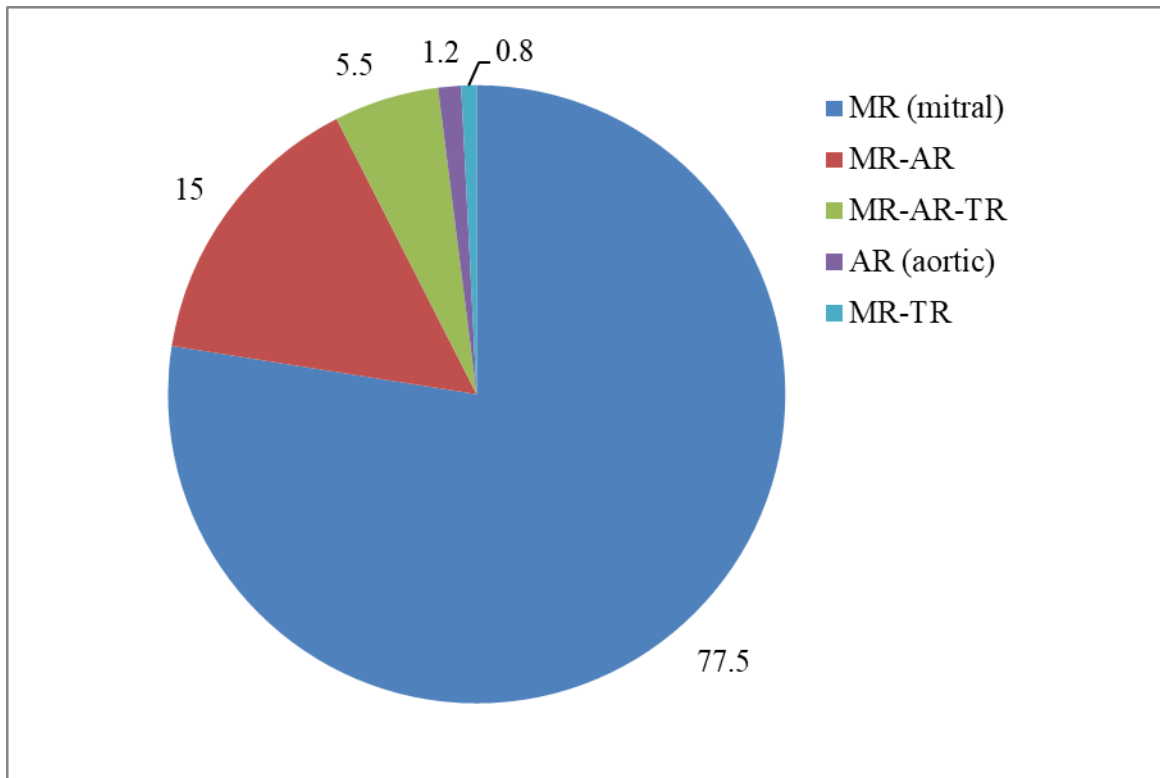


Figure 2: Valves affected by RHD among RHD patients having follow-up in the four hospitals in Jimma Zone, August - November, 2019 G.C

5.7. Factors associated with adherence to medication

We have performed chi-square test of independence for the variables that satisfy the Pearson's chi-square test assumption. We found that residence, distance from health facility, education, family size, income, duration on medication, condition of the patient (NYHA class), overall knowledge, patient knowing that missing the doses affects the outcome of disease, patient knowing that treatment prevents complication/death and patient's feeling about the behavior of service providers, are significantly associated with adherence to medication at p-value < 0.05 (Table 5).

Table 5. Chi-square test of association between medication adherence and characteristics of RHD patients having follow-up in the four hospitals in Jimma zone, August - November, 2019.

Characteristics of the respondent		adherence to medication		P-value
		poor	good	
Age category	<15	12	35	.198
	15-24	37	60	
	>24	44	65	
Sex of the patient	male	22	53	.112
	female	71	107	
Residence of patient/attendant	rural	87	80	.000
	urban	6	80	
Distance from health facility (in km)	≤ 5	3	59	.000
	6-10	5	5	
	11-20	22	27	
	21-30	14	23	
	>30	49	46	
Education of the patient	Illiterate(not educated)	52	37	.000
	Primary(grade 1-8)	28	68	
	Secondary(grade 9-12)	13	45	
	University/College	0	10	
family size	≤5	18	54	.014
	>5	75	106	
income category	≤ 1000	38	47	.001

	1001-2000	37	51	
	>2000	7	43	
duration on medication (in year)	<=5	42	102	.004
	>5	51	58	
Condition of patient (NYHA class)	NYHA class I & 2	91	141	
	NYHA class III & IV	2	19	.007
Other cases of RHD in the family?	yes	8	6	.104
	no	85	154	
Knowledge	poor	63	61	
	good	30	99	.000
Do think missing the doses affects the outcome of disease?	yes	73	144	.012
	no	20	16	
Treatment prevents complication/death	true	70	151	.000
	false	23	9	
Attitude	negative	9	7	.161
	neutral	9	11	
	positive	75	142	
How do you feel about the behavior of service providers?	not welcoming	6	7	.000
	somewhat welcoming	59	63	
	very welcoming	28	90	
Number of valve affected	one	75	124	.556
	more than one	18	36	

We did bivariate binary logistic regression to identify variables candidate for multivariable analysis. Accordingly, place of residence, distance from health facility, family size, duration on medication, condition of the patient (NYHA class), and overall knowledge were found to be candidates (Table 6).

Table 6. Bivariate logistic regression of factors associated with medication adherence among RHD patients on follow-up in the four hospitals in Jimma zone, August - November, 2019.

Characteristics of the respondent		Medication adherence		COR (95%CI)	P-value
		poor	good		
Residence of patient/attendant	rural	87	80	1	.000
	urban	6	80	0.069 (0.029,0.167)	
Distance from health facility	≤ 5	3	59	1	.001
	6-10	5	5	19.67 (3.60,107.41)	
	11-20	22	27	16.03 (4.41,58.18)	
	21-30	14	23	11.97 (3.15,45.57)	
	>30	49	46	20.95 (6.14,71.52)	
Education of the patient	Illiterate	52	37	1	.000
	Grade 1-8	28	68	0.29 (0.16,0.54)	
	Grade 9-12	13	45	0.21 (0.097,0.43)	
	University/ College	0	10	NA	
Family size	≤5	18	54	0.47 (0.26,0.87)	.016
	>5	75	106	1	
Income category	≤ 1000	38	47	1	.724
	1001-2000	37	51	0.90 (0.49,1.64)	
	>2000	7	43	0.20 (0.08,0.50)	
Duration on medication	≤5	42	102	1	.004
	>5	51	58	2.14 (1.27,3.60)	
Condition of patient (NYHA)	I & 2	91	141	1	.016
	III & IV	2	19	0.163 (0.037,0.717)	
Knowledge	poor	63	61	3.41 (1.99,5.84)	.000
	good	30	99	1	
Missing the doses affects the outcome of disease	yes	73	144	1	.013
	no	20	16	2.47 (1.21,5.04)	

Treatment prevents complication/death	true	70	151	1	
	false	23	9	5.51 (2.43,12.53)	.000
Feeling about the behavior of service providers	not welcoming	6	7	2.76 (0.86,8.88)	.090
	somewhat welcoming	59	63	3.01 (1.73,5.23)	.000
	very welcoming	28	90	1	

After adjusting for the confounding effect of other variables, place of residence, duration on medication, condition of the patient (NYHA class) and overall knowledge were found to be independently associated with adherence to medication. Urban residents were nearly 84% lower (AOR = 0.162; 95%CI: 0.054,0.489) likely to have poor adherence compared to rural residents. Patients on treatment for more than five years were more two times higher (AOR = 2.45; 95%CI: 1.28,4.70) at risk of having poor adherence compared to those on treatment for at most five years. Patient with disease condition NYHA class III or IV were more than 86% lower likely to have poor adherence compared to patients with NYHA I or II (AOR = 0.134; 95%CI: 0.028,0.65). Patients having poor overall knowledge about the disease or treatment were more than twice higher (AOR = 2.24, 95%CI: 1.14,4.39) likely to have poor adherence compared to those who had good overall knowledge (Table 7).

Table 7. Multivariable logistic regression of factors associated with medication adherence among RHD patients on follow-up in the four hospitals in Jimma zone, August - November, 2019 G.C

Characteristics of the respondent		COR (95%CI)	AOR (95%CI)
Residence of patient/attendant	rural	1	1
	urban	0.069 (0.029,0.167)	0.162 (0.054,0.489)
Distance from health facility	≤ 5	1	
	6-10	19.67 (3.60,107.41)	5.75 (0.75,44.06)
	11-20	16.03 (4.41,58.18)	3.03 (0.61,15.21)
	21-30	11.97 (3.15,45.57)	2.69 (0.53,13.63)
	>30	20.95 (6.14,71.52)	5.29 (1.17,23.98)
Education of the patient	Illiterate	1	
	Grade 1-8	0.29 (0.16,0.54)	

	Grade 9-12	0.21 (0.097,0.43)	
	University/ College	NA	
family size	≤ 5	0.47 (0.26,0.87)	0.52 (0.24,1.11)
	>5	1	1
income category	≤ 1000	1	
	1001-2000	0.90 (0.49,1.64)	
	>2000	0.20 (0.08,0.50)	
duration on medication	≤ 5	1	1
	>5	2.14 (1.27,3.60)	2.45 (1.28,4.70)
Condition of patient (NYHA)	I & 2	1	1
	III & IV	0.163 (0.037,0.717)	0.134 (0.028,0.65)
Knowledge	poor	3.41 (1.99,5.84)	2.24 (1.14,4.39)
	good	1	1
missing the doses affects the outcome of disease	yes	1	
	no	2.47 (1.21,5.04)	
Treatment prevents complication/death	true	1	
	false	5.51 (2.43,12.53)	
Feeling about the behavior of service providers	not welcoming	2.76 (0.86,8.88)	
	somewhat welcoming	3.01 (1.73,5.23)	
	very welcoming	1	

CHAPTER SIX: DISCUSSION

A patient with rheumatic heart disease is expected to receive at least 80% of the annual prescribed injections. Receiving less than 80% of the injections places an individual at a higher risk of recurrent ARF and its complications (45).

In our study, an adherence level of at least 80% was found among 160 (63.2%) patients, compared to 93 (36.8%) with adherence levels less than 80%. This means that 36.8% of these patients with a previous history of ARF or RHD and receiving Benzathine Penicillin injections were at high risk of recurrence of ARF. This was almost similar to the adherence level determined by Harrington in an aboriginal community in Australia, in which 59% of patients had received more than 75% of their prescribed injections during an interview (52). However, the level of adherence we determined in this study was considerably higher than that found among RHD patients on follow-up at JMC in previous study where the mean adherence level was 55.2% (55). On the other hand, this level of adherence was considerably less than that found in several other studies such as the study done in Haryana district in India, which found that 90% of the patients had received over 80% of their benzathine injections over the previous eight years (24)

The variability in levels of adherence may reflect the different systems in which these studies were done, duration of follow up, the different factors that may influence adherence, the individual study designs, and the different cut-off points for defining adherence in the different studies.

The wide range of indicators used in these different studies makes comparison particularly difficult and highlights the necessity of standardized indicators to evaluate adherence.

Analyzing the association of patient factors with adherence levels provides insight into those groups at particular risk of recurrence through poor adherence.

In our study, poor-adherence to secondary prophylaxis was 36.8% in the total sample of patients (253). In other studies, this rate varies from 10% to 65.7% (8,19,24,48,52, 56,58-62). Although high, the rate reported in our centers corresponds to rates found in other centers (51, 55).

In the present study, the commonest reason reported for missing monthly benzathine prophylaxis injections was the long distance from hospitals (56.9%). This finding could be

supported by a study done by Mincham *et al.* found that living in a remote location was a negative influence on adherence (51). The second commonest reason reported for missing the dose in our study was lack of money (38%). These factors have also been described by WHO expert consultation in Geneva (38).

A **limitation** of the study is that register data in some instances are incomplete

Conclusion and recommendation:

After adjusting for the confounding effect of other variables, place of residence, duration on medication, condition of the patient (NYHA class) and overall knowledge about the disease or treatment were found to be independently associated with adherence to medication.

The key point to improve adherence among RHD patients should include interactive education workshops targeted at patients as well as their families to provide accessible knowledge about RHD.

We also recommend that the nurse designated for the ARF prevention program in the hospitals coordinate an active recall system based on an updated local register.

Further research and solutions directly targeting these barriers can improve patient adherence and decrease their overall risk of RHD.

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ANNEX 1: CONSENT FORM
TOPIC: DETERMINANTS OF POOR ADHERENCE TO SECONDARY
PENICILLIN PROPHYLAXIS FOR RHEUMATIC HEART DISEASE AT
HOSPITALS IN JIMMA ZONE.

Principal Investigator: Alinur Adem (MD, MPH, MTM)

Organization: Jimma University, College of Health Sciences

Sponsor: JU, College of Health Sciences

Purpose of the Research Project

The aim of this study is to assess the compliance with benzathine penicillin as secondary prophylaxis in RHD patients and to establish the patient-related factors for adherence and reasons for missing of doses.

Procedure

The study involves patients on follow up at cardiac clinic. Trained hospital staff, clinical nurses, general practitioner and residents will be included for this purpose.

Benefits, Risk and /or Discomfort

There is no risk from being involved in the study as there will not be any invasive procedure and patients may benefit from this project if results suggest need for further investigation or follow up.

Incentives/Payments for Participating

The participants will be provided 20 ETB for compensation of time they spend.

Confidentiality

The personal information collected from the individual participants will be kept confidential and stored in a file, without their names by assigning a code number to it.

Right to Refusal or Withdraw

Participants have the full right to refuse participating and withdraw at any time from this research.

Person to contact

This research project will be reviewed and approved by the ethical review committee of Jimma University. If you have any question, you can contact the following principal investigator at any time.

Dr .ALINUR ADEM (Internal Medicine Resident) Tel No – +251911554534, Email address: alinur.adem@hotmail.com

Annex 1.1. Information to the Participant

Interview code no. _____

Greeting self-introduction and consent

Greeting: - Good morning/afternoon.

My name is DR ALINUR ADEM. We are conducting a scientific research to assess the determinants of poor adherence to secondary penicillin prophylaxis among RHD patients on follow up at cardiac clinic of JMC. Therefore, I am happy to inform you that you are selected as one of the participants in this study. By participating in this research project, you may feel some discomfort in wasting your time. However, your participation is definitely important in identifying patterns of compliance to the treatment and factors associated with poor adherence to Benzathine penicillin in RHD patients in our hospital. The interview may take 20-25 minutes and the information gathered will be used for writing a research paper for partial fulfilment of a specialty certificate in Internal Medicine at Jimma University.

Here, I want to assure you that any information obtained from you will remain confidential and even there is no need of writing your names or any personally identifiable information. There is no risk or direct benefit in participating in this research project. Your participation is determined only by you. It is only if you are willing, I will proceed to ask you some information. Finally, you are kindly requested to give your genuine response in the interview.

Certificate of Consent

Do you wish to participate in the study? A. Yes B. No

If the participant agrees to participate in the study, let him/her to sign consent and proceed with interview.

I have adequate information about the research and I have decided to participate in the study.

Signature -----

If the participant says “No, I don’t want to participate in the study”, thank him (her) and proceed to the next participant.

Name of interviewer _____

Date ____/____/____

Annex 1.2. Informed Consent in Amharic

ለተሳታፊ የሚሰጥ የጥናት ውል ማስገንዘብያ

እኔ ዶ/ር አሊኑር አደም የተባልኩ የወስጥ ደዌ ህክምና ት/ት ክፍል የመጨረሻ አመት ሬዝደንት የመመረቅያ ፅሁፌን ለመስራት ለምያስፈልገኝ ጥናት እርስዎ መመረጠዎን ሳሳወቅ በታላቅ ደስታ ነዉ። ጥናቱ የሚካሄደዉ በቃለ መጠየቅ መሳሪያ ሲሆን በእርሶ ላይ ምንም አይነት ጉዳት አይደርስም። ከጥናቱ መዉጣት ከፈለጉ በማንኛዉም ሰአት አቋርጠዉ መዉጣት ይችላሉ። ይህም በማድረግዎ ምንም ተፅኖ አያደርስብዎትም።

ከጥናቱ የሚገኘዉ ዉጤት ወደፊት የሚካሄዱ ሌሎች ጥናቶች መነሻ ከመሆኑም ባሻገር የተፈለገዉ ጥናት በዞናችን ምን እንደሚመስል ያስገነዝባል።

የእርስዎን ስምና ሌሎች የእርስዎን ማንነት የሚመለከቱ ነገሮች በጥናቱ ላይ አይገቡም።

የተሳታፊዉ ፊርማ _____

የጠያቂዉ ስም _____

ቀን: _____

አመሰግናለሁ።

ተሳታፊዉ በጥናቱ ለመሳተፍ ካልፈለጉ አመሰግነዉ ያሰናብቷቸዉ።

በየትኛዉም ጊዜ ጥያቄ ካለዎት ዶ/ር አሊኑር አደምን ይጠይቁ።

ስ.ቁ: +251-911554534

ኢ.ሜል: alinur.adem@hotmail.com

Annex 1.3. Informed consent in Afaan Oromoo

Oddeffanoo Qoratamaaf kennamu

Ani **Dr Alinuur Aadam** jedhama. Karoora barreeffama eebbaa irratti hirmaataa akka naaf taatan kabajaan isin gaafadha. Qorannoon kun kan adeemsifamu waa'ee dhukuba Onnee ilaalchise yoo ta'u ,hamma muudannoo dhibeen kana fi wantoota isaan wal qabaataan addan baasu fi baruu dha. Qorrannoon kun daqiiqaa 20- 25 fudhachuu danda'a. Ooddeffanoon qorranoo kanarraa argamu hojii fuuldurraati adeemsamuuf gargaarsa guddaa kenna. Qorrannoo keessaa yeroo barbaadanitti ba'uun mirga kessan yoo ta'u qoranno kana irratti hirmachuu dhabunis wanti isinirra dhaqqabsisuu hin jiru.

Qo'anna irrati qooda fudhachuuf yoo waligaltan bakka armaan gadii irrati mallattoon mirkaneessaa.

Mallattoo qoratamaa_____

Galatoomaa!

Maqaa Qorataa-----Guyyaa-----

Yoo qo'annaa irratti qooda fudhachuu hinbarbaadne galateeffadhaa dhiisaa .

ANNEX : 2

Questionnaire

Data collection instrument on treatment adherence and associated factors among RHD patients on follow up at four hospitals in Jimma zone.

Instructions: Dear data collector, the aim of this study is to assess the compliance with benzathine penicillin as secondary prophylaxis in RHD patients and to establish the patient related factors for adherence and reasons for missing of doses. The results of the study will help us to see the magnitude of adherence to treatment, establish the patient related factors for adherence and reasons for missing of doses. Furthermore, the findings of this study could be useful in planning health promotion and disease control programs for ARF/RHD. So, you are kindly requested to revise each chart thoroughly, interview the respective clients carefully and record on the designed check list.

General information

1. Name of Hospital.....
2. Code

Part one: Demographic and socio-economic characteristics of the participant or attendant

1. Age.....(years)
2. Age of the child (if the patient is child).....yrs (for > 1 year)months (for < 1 year)
3. Sex: 1. Male 2. Female
4. Sex of the child (if the patient is child): 1. Male 2. Female
5. Ethnicity: 1. Oromo 2. Amhara 3. Kaffa/Dawuro 4. Gurage 5. Tigre 6. Other (specify).....

6. Religion: 1. Muslim 2. Orthodox 3. Protestant 4. Wakefata 5. Other
(specify).....
7. Marital status: 1. Single 2. Married 3. Divorced 4. Widowed
8. Residence: 1. Rural 2. Urban
9. Estimated distance from hospital _____ (km) OR _____(minutes)
10. Education: 1. Illiterate (not educated) 2.Primary (grade 1-8) 3.Secondary (grade 9-12) 4.University/college
11. Education of the child (if the patient is child): 1. Illiterate (not educated) 2.Primary (grade 1-8) 3.Secondary (grade 9-12) 4.University/college
12. Occupation
 1. Student 2. Farmer 3. Government employee 4. Merchant (business man/woman)
 5. Unemployed 6. Daily labor 7. House wife 8. Other
(Specify).....
13. Number of persons in the household
14. Monthly income:..... (In Birr)

Part two: Clinical characteristics of the participants

15. Duration of RHD diagnosis (Years)
16. Any hospitalization history for RHD? 1. Yes 2. No
17. For how long have you been taking this medication? _____ (years) & _____ months
18. What is the condition of the patient during the follow-up?
 1. NYHA Class I
 2. NYHA Class II
 3. NYHA Class III
 4. NYHA Class IV

19. Other cases of RHD in the family? 1. Yes 2. No

Part three: Knowledge and attitude related factors

a) Knowledge

20. Is curing from RHD possible? 1. Yes 2. No

21. For how long should the treatment of RHD be taken? 1. Few months 2. One year
3. Ten years 4. 20 years 5. Life long

22. How frequently should the treatment be taken? 1. Every month 2. Every two
months

3. Every year 4. Just once in one's life

23. Do you think missing the doses of treatment affects the outcome of disease? 1. Yes
2. No

24. Treatment taken without interruption prevents complication of RHD and death

1. True 2. False

b) Attitude

25. How do you grade the pain of injection? 1. Mild 2. Moderate 3. Severe

26. How much are you satisfied with services of previous visits?

1. Not satisfied 2. Somewhat satisfied 3. Very satisfied

27. How much are you satisfied with the prognosis of your condition OR your child's
condition?

1. Not satisfied 2. Somewhat satisfied 3. Very satisfied

28. What is your belief about the importance of this treatment?

1. Not important 2. Somewhat important 3. Very important

29. How do you feel about the behavior of service providers at this health facility?

1. Not welcoming 2. Somewhat welcoming 3. Very welcoming

Part four: Treatment

30. Did you ever miss your regular injection? 1. Yes 2. No

31. If yes to question 30 above, how many times did you miss the injection? _____

32. What was the reason for missing the dose? (**Multiple answer possible**)

1. Forgetfulness 2. Inconvenient work schedule
3. Unaffordability 4. Don't believe in the medication
5. Fear of pain 6. Fear of side effect (allergic reaction)
7. Lack of awareness about the disease
8. Lack of awareness about the treatment's objectives
9. Poor relationship between patient and physician/Nurses
10. Irregular or poor drug supply
11. Long distance from treatment setting
12. Other (specify)_____

33. **Is there a nurse designated for the ARF prevention program in your hospital (for Medical Director)?**

1. Yes 2. No

Questions to be filled from patients record:

34. Valves affected by RHD:

1. Mitral 2. Aortic 3. Tricuspid 4. Pulmonary

35. Prosthetic Valve: 1. Yes 2. No

36. Valve repair: 1. Yes 2. No

Thank you very much!

Name and signature of data collector

Name and signature of principal investigator

ASSURANCE OF PRINCIPAL INVESTIGATOR

The undersigned agrees to accept responsibility for the scientific ethical and technical conduct of the research project and for provision of required progress reports as per terms and conditions of the Institute of Health in effect at the time of grant is forwarded as the result of this application.

Name of the student: Alinur Adem (Internal Medicine Resident)

Date. _____ Signature _____

APPROVAL OF THE ADVISOR

Name of the first advisor: Dr. Tadesse Dukessa (MD, Cardiologist)

Date. _____ Signature _____

Name of the second advisor: Mr. Habtemu Jarso (BSc, MPH/Epidemiology)

Date. _____ Signature _____