Volume 1 Issue 3
www.escientificlibrary.com
ES Journal of Cardiology

Relationship between Patient Understanding and Compliance with Rheumatic Heart Disease Prevention Programs in American Samoa

Research Article

Jennifer H. Huang MD[1*], Callia Elkhal MD[2], Ipuniuesea Eliapo-Unutoa[3], Laurie R. Armsby MD[4] and Erin J. Madriago MD[5]

[1]*Department of Pediatrics, Oregon Health and Science University, USA*
[2]*Department of Pediatrics, Oregon Health and Science University, USA*
[3]*Department of Health, American Samoa Government, Fagaalu, USA*
[4]*Department of Pediatrics, Oregon Health and Science University, USA*
[5]*Department of Pediatrics, Oregon Health and Science University, USA*

Received: May 14, 2020; **Accepted:** June 08, 2020; **Published:** July 22, 2020

***Corresponding author:** Jennifer Huang MD, Department of Pediatrics, Oregon Health and Science University, United States of America

Abstract

Objective: While mostly eradicated in developed nations, rheumatic heart disease (RHD), is still the leading cause of preventable cardiovascular disease in children. RHD and its antecedent acute rheumatic fever (ARF) remain endemic in many low to middle income countries, as well as in vulnerable communities in wealthy ones. Evidence-based interventions are particularly important in resource-poor settings. We sought to determine if efforts directed at patient and family education impact compliance with community based prevention measures, and with short term disease progression.

Materials and methods: We performed an observational, cross-sectional study of children with RHD aged 5-19 years, along with their parents, in American Samoa. A survey was administered in November 2016 to assess patient and parent knowledge of RHD. Scores were compared to compliance with penicillin prophylaxis via chart review.

Results: We collected a total of 70 surveys of child-parent dyads with a patient mean age of 14.28 years ± 2.71. An increased knowledge score was predictive of increased penicillin compliance for both children (12.70% increase in compliance per 1-unit increase in score (p=0.0004)) and parents (10.10% increase in compliance per 1-unit increase in score (p=0.0012)).

Discussion: Increased knowledge about RHD, and particularly treatment of RHD, was correlated with increased compliance with secondary penicillin prophylaxis. With a 12.7% increase in compliance for every 1-unit increase in the child's overall survey score and a 9.4% increase for every 1-unit increase in the parent-child combined overall score.

Conclusion: A clear relationship exists between patient and parent knowledge of rheumatic heart disease and compliance with penicillin prophylaxis. This study was the first to link patient understanding of RHD to compliance with preventative measures.

Keywords

Rheumatic heart disease, patient education, pediatric cardiology

Introduction

Acute rheumatic fever (ARF) and its sequelae rheumatic heart disease (RHD) have largely been eradicated in developed nations but continue to remain as the leading cause of preventable cardiovascular disease in children and young adults worldwide [1-5]. ARF is a delayed immunologic response to pharyngeal infection with Group A β-hemolytic streptococci, which causes cardiac disease through the deformation and rigidity of valve structures and subsequent valvar regurgitation and later stenosis.A previous diagnosis of ARF increases the risk of subsequent ARF episodes and ultimately RHD [6]. Recurrent and progressive valvar destruction ultimately lead to heart failure and even death.

Despite their status as a territory of the United States, the small islands of American Samoa have a particularly high (12.9%) prevalence of RHD placing them as one of the most endemic geographical regions in the world [7]. This prevalence is likely due toa combination of genetic factors,environmental exposure, a paucityof resources including specialty medical care and decreased accessibility to services. While RHD continues to pose significant morbidity and mortality across the world, there has not been significant decline in the prevalence of RHD in low and middleincome countries in the last 25 years [8]. For these often resource poor countries in particular, the efficacy of public health initiatives are critically important and thus evidence-based strategies should be prioritized.

Studies in other conditions have shown that individuals who have a better understanding of their disease tend to have better health outcomes, particularly for chronic conditions [9,10]. Secondary prophylaxis of RHD with penicillin is relatively inexpensive and effective,however there are significant barriers to compliance [11,12]. Given the high prevalence of RHD and its significant consequences, we sought to determinethe relationship between patient understanding of RHD, patient compliance with preventative measures and disease progression.

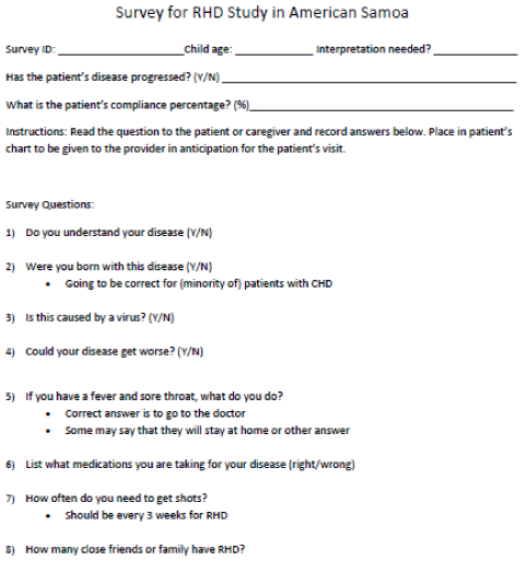
Materials and Methods

Study Design

We performed an observational cross-sectional study of American Samoan school children aged five to nineteen years and their parents/guardians. We surveyed patients awaiting their pediatric cardiology appointments from 11/7/16 -11/11/16at Lyndon B. Johnson Medical Center in Pago Pago, American Samoa. Patients were included if they had previously diagnosed rheumatic heart disease. Patients were excluded if they lacked a previous diagnosis, hadadditional congenital heart disease or if they or their parents did not wish to take part in the survey. Parental consent and child assent (if older than 8 years of age) were obtained in person with interpreters as needed. This study was approved by the institutional review boards of Oregon Health and Science University and the Lyndon B. Johnson Tropical Medical Center.

Knowledge Survey

An 8-question basic knowledge survey was developed by study authors utilizing prior knowledge surveys found in the literature. Based on important factors in managing RHD, questions were adapted to meet the needs of our study population (Figure 1). Survey questions were asked in person using a local interpreter if necessary. In order to independently identify a knowledge score for children without the influence of their parent's responses (and vice versa), children and parents were asked to participate in the survey separately.



Survey for RHD Study in American Samoa

Survey ID: _____Child age: _____ interpretation needed? _____

Has the patient's disease progressed? (Y/N) _____

What is the patient's compliance percentage? (%)_____

Instructions: Read the question to the patient or caregiver and record answers below. Place in patient's chart to be given to the provider in anticipation for the patient's visit.

Survey Questions:

1) Do you understand your disease (Y/N)
2) Were you born with this disease (Y/N)
   - Going to be correct for (minority of) patients with CHD
3) Is this caused by a virus? (Y/N)
4) Could your disease get worse? (Y/N)
5) If you have a fever and sore throat, what do you do?
   - Correct answer is to go to the doctor
   - Some may say that they will stay at home or other answer
6) List what medications you are taking for your disease (right/wrong)
7) How often do you need to get shots?
   - Should be every 3 weeks for RHD
8) How many close friends or family have RHD?

Figure 1: Knowledge Survey administered to patients and parents.

Disease Progression

Following the survey, study subjects proceeded to their pediatric cardiology appointment. One of two physicians evaluated the patient and determined overall disease progression compared to the most recent visit one or more

years prior. Disease progression was based on symptoms, physical exam signs, and echocardiographic changes.

Bicillin Compliance

We reviewed the Lyndon B Johnson Tropical Medical Center's electronic health record to determine medication compliance. Local practice for RHD is intramuscular Bicillin every 21 days given either at the hospital orvia the American Samoa Department of Health with dates recorded in the medical record. Of note, due to access issues the island did not receiveintramuscular Bicillin for approximately 2 months in the summer of 2016. Participants instead received an oral form of Bicillin at either 21 or 30-day intervals. Compliance with the oral version of this medication was determined by evidence of medication refill from the pharmacy. Medication records were pulled for each participant from 1/1/16 through 11/11/16. Calculation of compliance was made using the formula

$$\frac{Total\ \#\ Days\ -\ Days\ Missed}{Total\ \#\ Days}\ x\ 100 = Percent\ Compliance$$

Days missed was defined as the number of days beyond 21 days since their last Bicillin injection or number of days beyond the prescribed supply of oral penicillin that they retrieved their new prescription.

Statistical Analysis

Composite and sub-grouped knowledge scores were compared to disease progression and Bicillin compliance. Data analysis was performed with SPSS software (SAS version 9.4) using linear regression, correlation coefficients, and analyses of variance as indicated.

Results

159 participants were identified, consented, and assented to the study. Of those, ten were later determined to be new to the clinic and therefore had no prior echocardiographic images to compare and determine disease progression. Four participants were excluded due to having both RHD and a congenital heart disease which confounded disease progression. One pair of participants was excluded as the patient was allergic to Bicillin and was taking an alternative medication which was tracked differently and therefore affected medication compliance documentation. Finally, three subjects were excluded from data analysis because they did not have acomplete parent-child data set; two were late-aged teenagers who chose to come to their appointments without a parent or guardian and one subject was a non-verbal child. Of the remaining 140 study subjects (70 parents/guardians and 70 children), the mean child agewas 14.28 ± 2.71 yearsand 15% neededSamoan language interpretation.

Overall knowledge survey scores were individually calculated for child and parent on a scale of 0-5 based on the number of correct answers. Scores were distributed in a parametric fashion with a mean child score of 3.31 and a mean parent score of 3.00 (Figure 2). 12.86% of subjects experienced disease progression. Median compliance with penicillin prophylaxis was 74.84% (Figure 3).

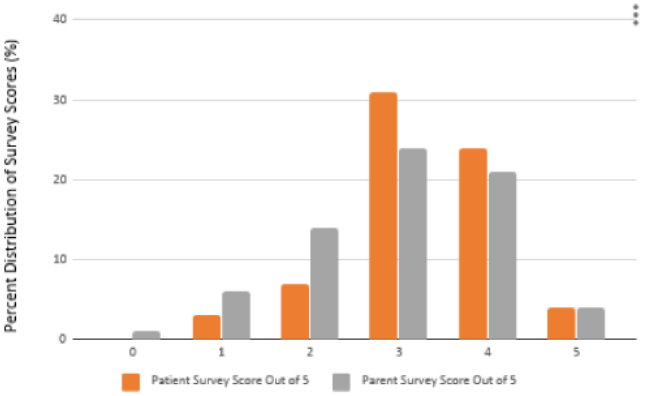


Figure 2: Knowledge Survey Score Distribution

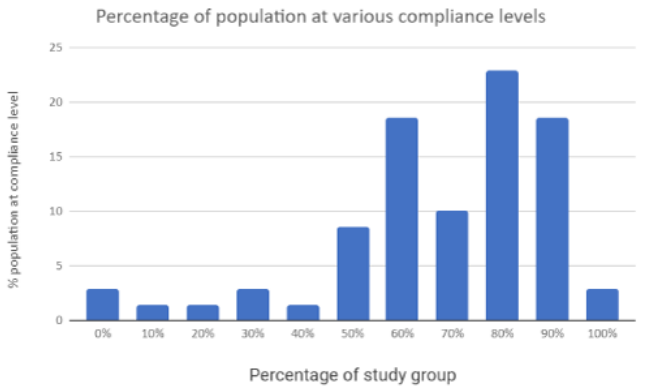


Figure 3: Compliance with Penicillin Prophylaxis

Using linear regression, a 1-unit increase in the child's overall knowledge survey score resulted in a 12.7% increase in compliance (p= 0.0004), a 1-unit increase in the parent/guardian survey score resulted in a 10.1%

Table 1: Summary of statistical analysis on compliance in relation to survey score, both overall and specific to treatment knowledge

	Compliance % Increase	Standard Error (%)	P-value
Patient overall survey score: 1-unit increase	12.70%	3.4	P=0.004
Parent overall survey score: 1-unit increase	10.10%	2.9	P=0.0012
Combined overall survey score: 1-unit increase	9.40%	1.9	P<0.001
Patient treatment-specific survey score: 1-unit increase in 2 survey questions	52.7%	19.8	P=0.0096
Parent treatment-specific survey score: 1-unit increase in 2 survey questions	49.8%	21.0	P=0.0206
Combined treatment-specific survey score: 1-unit increase in 2 survey questions	-30.4%	26.4	P=0.253

increase in compliance (p= 0.0012), and a 1-unit increase in the parent-child combined overall knowledge survey score resulted in a 9.4% compliance increase (p<0.0001). In further sub-analysis, for every 1-unit increase in the 2 survey questions specific to treatment (treatment-specific) for children and parents, there was an average increase in compliance of 52.7% ± 19.8% (p=0.0096) and 49.8% ± 21.0% (p=0.0206), respectively. The relationship between disease progression and knowledge survey scores were not statistically significant though they trended towards negative correlation (Table 1).

Discussion

In our study increased knowledge about RHD, and particularly treatment of RHD, was correlated with increased compliance with secondary penicillin prophylaxis. With a 12.7% increase in compliance for every 1-unit increase in the child's overall survey score and a 9.4% increase for every 1-unit increase in the parent-child combined overall score. This observation is consistent with findings in other disease-states that show a relationship between increased patient understanding and better disease outcomes.

While our overall numbers were too small to make conclusions about the impact ofpatient understanding on disease progression, there was a trend towards an association and these results point to a need for further studies to explore that relationship. We know from previous studies that improved penicillin compliance leads to better disease outcomes [11] and thereby efforts to improve compliance should result in better patient outcomes as well. In addition, our study shows that educating children diagnosed with RHD is as important as educating parents only.

The main limitations with this study include the small number of subjects recruited as well as the small number of subjects with disease progression. Additionally, given that subjects were chosen from those attending clinic, selection bias in the form of increased understanding of the importance of medical care cannot be ruled out. Finally, given the island's access issues to bicillin, two months of compliance with oral medications could only be extrapolated based on refills of medications rather than direct observation of treatment [12].

Conclusions

Our study showed a strong correlation between patient understanding of the etiology, characteristics, and particularly treatment of RHD with patient compliance with penicillin prophylaxis. This relationship held true for individual patients, parents, andpatient-parent dyads. The efficacy of penicillin prophylaxis in decreasing morbidity and mortality of RHD is well-described, and so a natural conclusion is that increasing treatment compliance should significantly improve patient outcomes. While our study was not able to show this due to under-powering with low rates of disease progression, we did show a trend towards negative correlation that we think would bear out with a larger dataset. More research on disease progression as well as other factors affecting compliance is needed to determine the most effective ways to improve patient knowledge and delivery of prophylaxis and medical care.

National and global efforts to eradicate acute rheumatic fever and rheumatic heart disease are often limited by local resources. This study aimed to understand the relationship of patient and family understanding of disease with medication compliance and resulting disease progression. Given the correlation between patient knowledge and compliance, efforts in education of individual patients,

families and the broader community should remain a priority. Further exploration of the structure and design of educational initiatives may help prioritize effort for this global epidemic.

References

1. Seckeler MD, Hoke TR. The Worldwide Epidemiology of Acute Rheumatic Fever and Rheumatic Heart Disease. Clinical Epidemiol 2011;22:67-84.
2. Global Burden of Disease Study C. Global, Regional, and National Incidence, Prevalence, and Years Lived with Disability for 301 Acute and Chronic Diseases and Injuries in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. Lancet 2015;386:743-800.
3. Watkins DA, Johnson CO, Colquhoun SM, et al. Global, Regional, and National Burden of Rheumatic Heart Disease, 1990-2015. N Engl J Med 2017:377:713-22.
4. Carapetis JR, Steer AC, Mulholland EK, et al. The Global Burden of Group A Streptococcal Diseases. Lancet Infect Dis 2005;5:685-94.
5. Ralph AP, Carapetis JR. Group A Streptococcal Diseases and their Global Burden. Curr Top Microbiol Immunol 2013;368:1-27.
6. Chagani HS, Aziz K. Clinical profile of acute rheumatic fever in Pakistan. Cardiol Young 2003;13:28-35.
7. Huang, JH, Favazza M, Legg A, et al. Echocardiographic Screening of Rheumatic Heart Disease in American Samoa. Pediatr Cardiol 2018. 39;38-44.
8. Watkins DA, Johnson CO, Colquhoun SM, Karthikeyan G, Beaton A, Bukhman G, et al. Global, regional, and national burden of rheumatic heart disease, 1990-2015. N Eng J Med 2017;377:713-22.
9. Volk ML, Fisher N, Fontana R.J. Patient Knowledge about Disease Self-Management in Cirrhosis. Am J Gastroenterol2013;108:302-5.
10. Zhang, NJ, Terry A, McHorney CA. Impact of health literacy on medication adherence: a systematic review and meta-analysis. Ann Pharmacother 2014; 48: 741–51.
11. Tompkins DG, Boxerbaum B, Liebman J. Long-Term Prognosis of Rheumatic Fever Patients Receiving Regular Intramuscular Benzathine Penicillin. Circ 1972;45:543-51.
12. De Dassel JL, de Klerk N, Carapetis JR, Ralph AP. How Many Doses Make a Difference? An Analysis of Secondary Prevention of Rheumatic Fever and Rheumatic Heart Disease. J Am Heart Assoc 2018; 7:e010223.