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Madhab Ray
Tufts University

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Original Article

A questionnaire survey for improving awareness of rheumatic heart disease among school-aged children in India



Madhab Ray^a, Santanu Guha^b, Meghna Ray^c, Avik Karak^b, Basabendra Choudhury^b, Bipasha Ray^d, Prakash C. Hazra^e, Harry P. Selker^{a,*}, Robert J. Goldberg^f, Deepak L. Bhatt^g

^a Institute for Clinical Research and Health Policy Studies, Tufts Medical Center and Tufts University School of Medicine, Boston, MA, USA

^b Department of Cardiology, Kolkata Medical College, Kolkata, India

^c Dartmouth College, Hanover, NH, USA

^d Andover High School, Andover, MA, USA

^e Ministry of Health & Family Welfare, Government of India, India

^f Department of Population and Quantitative Health Sciences, University of Massachusetts Medical School, Worcester, MA, USA

^g Brigham and Women's Hospital Heart & Vascular Center, Harvard Medical School, Boston, MA, USA

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ABSTRACT

Objectives: We examined the level of awareness about Rheumatic Heart Disease (RHD) among school-aged children in a rural district of India and evaluated the effects of a questionnaire-based survey in improving the level of awareness.

Methods: The study involved 8,646 students aged 10–16 years from 20 schools in West Midnapore, India which was conducted in August 2017. We examined changes in the level of awareness of RHD using a 29-point scoring system in seven domains. The baseline questionnaire survey assessed students' knowledge and was followed by a multimedia presentation about RHD and a post-intervention survey using the same questionnaire. The questionnaire included 9 questions on different aspects of RHD including prevalence, nature of disease, symptoms, determinants, treatment options, impact of the disease and diagnosis.

Results: The mean age of the study population was 13 years and 46% were boys. At baseline, the mean level of knowledge about RHD was 42% (12.2 out of 29 points). After the school-based presentation, the score improved to a mean of 55% (15.9 points on the 29-point scale), a 31% relative improvement. Improvement in students' knowledge was noted across all seven domains, individually and combined ($p < 0.001$).

Conclusions: Awareness among children in rural India about RHD is modest. A school-based intervention could help in improving awareness about this chronic condition and may promote secondary prophylaxis to reduce the morbidity and mortality from RHD.

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1. Introduction

India is a low-middle income country and is the second most populous country in the world with a population of 1.3 billion.¹ The literacy rate among residents of West Midnapore, India is 78%, being higher in men than in women (85% vs. 71%).² Children are considered minors until the age of 18 years old, and decisions

related to their health and participation in their school studies are determined by their parents or legal guardians. Higher education is encouraged both at the family and the societal level with incentives from community and government authorities.³

Rheumatic fever and its sequelae of Rheumatic Heart Disease (RHD) is widespread in developing countries such as India, particularly among school-aged children.^{4–6} Rheumatic fever is a connective tissue disease affecting the cartilage of heart valves and joints secondary to molecular mimicry to streptococcal antigen.⁷ Persons with undiagnosed or inadequately treated rheumatic fever may develop RHD with progressive damage of the heart valves, hemodynamic compromise, rhythm disturbances, and

* Corresponding author. Institute for Clinical Research and Health Policy Studies, Tufts Medical Center, 800 Washington St, #63, Boston, MA, 02111, USA. Fax: +617 636 8023.

E-mail address: hselker@tuftsmedicalcenter.org (H.P. Selker).

predisposition to thrombus formation, all of which can lead to significant morbidity and premature death in a small percentage of individuals.

1.1. Burden of rheumatic fever and rheumatic heart disease in India

Using Global Burden of Disease Analytical Tools, it was estimated that in 2015 there were 33.4 million cases of RHD and 10.5 million disability-adjusted life-years due to RHD globally.⁸ India harbors the greatest number of patients with RHD in the world (13.7 million, 40% of the global burden).

There is no national registry of RHD in India or other South East Asian countries. Although different studies suggest a declining trend in the prevalence of RHD, it is difficult to estimate changes in the prevalence rates of this condition over time.⁹ Most of the descriptive epidemiologic data about RHD are derived from hospital records or small community-based studies showing wide regional differences.^{5,10–13}

While the availability of portable echocardiography has significantly improved the sensitivity and specificity of detecting RHD, variations in study design and diagnostic methods have made it difficult to interpret available data. Different school-based studies have reported significant variation in the prevalence rates of RHD ranging from less than 1 per thousand in Gorakhpur in Uttar Pradesh to 51 per thousand in Ballavgarh in Rajasthan.¹⁴ Some of these school-based studies involved the clinical screening of all 10–16-year-old school children followed by echocardiography of suspected cases.^{9,15} Other studies performed echocardiographic screening of children aged 10–16 years old without any prior clinical screening.¹⁶ Each of these methods, however, are time consuming and labor intensive and necessitate a considerable amount of clinical and technical resources. As a result, there is no national screening program for the early detection of RHD in India, related in part to infrastructural and financial limitations.¹⁷

Lack of awareness is an important barrier in reducing the burden of RHD.¹⁸ The objectives of this large observational study were to examine the current level of awareness about rheumatic fever and RHD in school-aged children living in rural India and the effects of a brief educational intervention on students' knowledge and awareness about RHD.

2. Methods

This study was conducted in the district of West Midnapore, West Bengal, India in August, 2017. The study was approved by the Institutional Review Board of Tufts University and the Ethics Committee of Calcutta Medical College.

2.1. Study population

Twenty schools from the rural district of West Midnapore, West Bengal, India participated in this questionnaire survey. Selection of participating schools was based on study logistics and feasibility, as well as previous experience of the study team in conducting a study on cardiovascular health awareness of school children aged 10–16 years in 2014 in this district.¹⁹ Participation was entirely voluntary. Informational handouts were circulated in the schools to the students approximately one month prior to the study. Students were provided with information regarding the purpose, benefits, and risks involved in the study and participating students did not receive money, gifts, or other incentives for completing the in-class questionnaire survey.

2.2. Development of survey tool/questionnaire

A questionnaire was developed with groups of 10–15 students randomly selected from different schools using cognitive laboratory testing to ensure students' understanding in the study population of 10–16 years old children. To ensure that the children had no fear of sharing their symptoms, it was emphasized that their responses would remain confidential and the data would be analyzed in an unidentified manner. It was also explained that the survey was not an examination and students' individual responses would not be published nor shared with parents or school authorities.

The primary objective of this study was to assess students' knowledge in seven domains about rheumatic fever and RHD. A total of nine questions were asked about the following seven topics: 1) disease prevalence; 2) nature of the disease; 3) symptoms; 4) determinants; 5) treatment options; 6) impact of the disease; and 7) diagnosis. The domain of symptoms had a maximum score of five points and the six remaining domains had a maximum score of four points for a total of 29 points. The final questionnaire survey was developed after multiple iterations to establish internal validity and reliability.

From these nine questions, two questions asked for information about the respondents' personal experience with regards to the symptoms or signs relevant to the clinical suspicion of RHD. The remaining seven questions each addressed a specific and different domain. For the question regarding symptoms, there were five expected correct statements out of twelve choices. Each correct statement chosen was scored as one point with a maximum of five points for the domain. For disease prevention, there was one correct answer out of four choices, and participants scored zero or four for this question; the question regarding nature of the disease was scored in the same manner. For the questions about determinants of RHD, treatment options, and impact of the disease, each of the four statements were correct and a participant could score between zero and four points depending on how many choices were selected. For the diagnosis of RHD, three choices were correct out of four options and partial credit was offered for each correct response. There were no negative marks for any incorrect answer.

2.3. Survey administration

Students who were present in school on the day of this cross-sectional study were eligible, and informed consent from parents and assent from participating students were collected prior to the study. The questions on the survey were asked in the local language, namely Bengali. The version utilized was validated by translation and back translation by the IRB at Tufts University. Approximately one hour was allocated for the study: 20 minutes for completion of the baseline survey; 20 minutes for an informational multimedia presentation on RHD; and 20 minutes for completion of the post-intervention survey.

The initial survey was followed by a 20-minute multimedia presentation that provided information on RHD in each of the seven targeted domains. During this presentation, students were informed about the number of children affected by RHD, the symptoms and signs of this condition, how the affected heart valves look, how it can impact one's life, how the disease can be diagnosed and prevented, and treatment options if one has RHD. Technical terms such as Coronary Artery Disease (CAD) and Rheumatic Heart Disease (RHD) were explained at the time of obtaining consent and assent as well as during the in-class presentation to reduce the possibility of biased answers from the participants. It was emphasized that if any participants had or developed symptoms of

rheumatic fever or RHD, he or she should get an evaluation by the local physician and have an echocardiogram performed for the possibility of RHD. Echocardiography testing was offered free of cost to survey respondents by the study team. After the in-class presentation, a post-intervention survey was completed using the same questions as baseline for purposes of assessing changes in student's awareness and knowledge of RHD (see the electronic supplements for the survey questionnaire). In case any child was found to have symptoms or signs of the disease, he or she was advised to follow up with the local health facility for further evaluation and treatment.

2.4. Statistical analysis

We collected demographic information on survey participants, including their age, sex, grade, parental education, and number of people sharing a room for sleeping. Continuous variables were presented as means, medians, and interquartile range (IQR), and categorical variables were presented as counts and percentages. Baseline and post-intervention survey scoring was done for each participant and was analyzed according to the seven domains using a cluster sample design with the survey package in R (Table 2). Changes in test scores were evaluated by the Wilcoxon paired sample signed rank test. Regression analyses were performed to examine the role of age, parental educational level, and room sharing as a surrogate of overcrowding on the performance of the students in the survey.

3. Results

3.1. Study population

A total of 8,646 students participated in the study (55% response rate from the total student population in grades 5–10). The mean age of the study sample was 13 years, 46% were male, and 41% were in grades 9 and 10 (Table 1). Among the students who responded, 46% of their mothers had an elementary school education, 45% had a secondary education, 9% had a higher education. For fathers' education, corresponding figures for the different levels of education were 40%, 43%, and 17%, respectively. Six out of every ten

respondents shared a room for sleeping with three or more people in the family.

3.2. Signs and symptoms of rheumatic heart disease

We studied students' awareness of the different signs and symptoms of rheumatic fever and RHD including fever, shortness of breath, joint pain and swelling, palpitations, seizures, leg swelling, skin rash, sore throat, chest pain, skin nodule, easy tiredness, and dizziness. Fever was the most commonly reported symptom of rheumatic fever and RHD followed by easy tiredness and sore throat (Fig. 1).

3.3. Level of awareness of rheumatic heart disease

Performance in the survey was graded as per the local grading system in each participating school (A+ 90–100, A 80–90, B+ 60–79, B 45–59, C 25–44). At baseline, the overall level of knowledge of the students about RHD was modest; students correctly answered 42% of the questions asked. Their knowledge about the nature of the disease and its determinants was poor, 29% and 38%, respectively. Students were most aware about the impact of the disease, for which 55% had correct responses. In the other three domains including disease prevalence, treatment options, and diagnosis, their knowledge was suboptimal at approximately 43%.

After the educational presentation there were varying degrees of improvement in different domains. The greatest degree of improvement was noted in knowledge of the symptoms of RHD (87%), followed by prevalence of the disease (49%). Overall, there was an improvement of 31% across all domains ($p < 0.001$).

Analysis of the student responses by linear regression revealed a small but significant improvement in the students' performance with age and level of maternal education. For each additional year of age there was a slight improvement in their performance by 0.19 (95% CI 0.11–0.27). When the role of parental education was examined, we found that maternal, but not paternal, level of education had a positive influence on the children's performance (coefficient 0.82, 95% CI 0.41–1.2). Although overcrowding is known to be a risk factor for recurrent sore throat and RHD, no association

Table 1
Baseline characteristics of the study population.

Baseline Characteristics of the Study Population			N
Age (years)	Mean	13.3	
	Median	13.0	
	IQR	12–15	
Sex	Male	45.5%	3900
Grade	5	9.5%	808
	6	14.5%	1231
	7	17.4%	1472
	8	16.5%	1398
	9	23.2%	1965
	10	18.5%	1564
Mother's Education	Elementary	45.8%	3506
	Secondary	45.0%	3445
	College	6.4%	491
	University	2.8%	229
Father's Education	Elementary	40.0%	2908
	Secondary	43.3%	3150
	College	11.9%	862
Room Share (person per room)	University	4.8%	347
	Mean	2.8	
	1–2	42.0%	3510
	3	26.9%	2248
	>3	31.0%	2445

Table 2
Changes in students' awareness of Rheumatic Heart Disease after the educational intervention.

Domain	Maximum Possible Score	Pre-test	Post-test	Mean Change (SD)	Change in %
Symptoms	5	1.7	3.2	1.5 (2.72)	87.3
Disease Prevalence	4	1.8	2.7	0.9 (2.42)	48.9
Nature of the Disease	4	1.1	1.6	0.5 (2.26)	46.0
Determinants	4	1.5	1.8	0.3 (1.11)	15.7
Treatment Options	4	1.9	2.2	0.3 (1.30)	14.6
Diagnosis	4	1.9	2.1	0.2 (1.30)	12.8
Impact of the Disease	4	2.2	2.3	0.1 (1.25)	4.1
Overall	29	12.2	15.9	3.7 (6.37)	30.9

Wilcoxon signed rank test $p < 0.001$ for all comparisons.

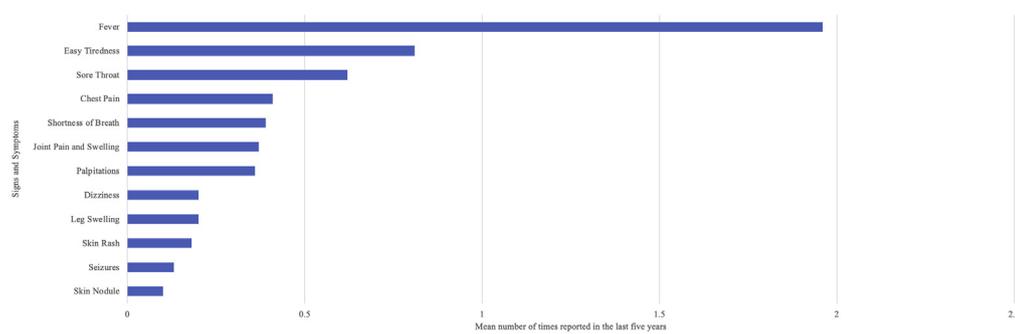


Fig. 1. Relative frequency of different signs and symptoms suggestive of RHD as reported by the children in the last five years.

between room sharing and students' performance on the survey questionnaire was observed.

4. Discussion

Inadequate awareness about RHD remains an important barrier to the more optimal primary and secondary prevention of this disease. Different prejudices, social and cultural beliefs, low educational levels of parents, and poor socioeconomic conditions complicate this picture. Awareness among school-aged children is particularly important since school-based health education has the advantage of early detection of the disease and addressing the different risk factors involved. Few studies have examined the role of school-based programs for improving the level of awareness about RHD among school-aged children in India or any other developing countries.

Increasing awareness about RHD in the population should be a low resource-intensive intervention, and could result in improved recognition of the symptoms of RHD. This, in turn, may help in identifying students at risk for developing RHD by administration of questionnaire surveys and assessing symptoms for rheumatic fever and RHD and subsequent screening by echocardiogram. More widespread implementation of this strategy may identify students with RHD at an early stage with a resultant increase in the receipt of effective secondary prophylaxis.²⁰

A relatively brief and inexpensive intervention used in this study showed significant improvement in the level of knowledge about RHD in this student population. The results of this study warrant further research on a larger scale. If validated, the methodology of this study may offer insights into a strategy to develop a nationwide program for health education in developing countries.

We found that the overall level of knowledge of these school-aged students who lived in rural India about RHD was modest. Students had fair knowledge about the impact of the disease but very little knowledge about the nature of the disease, its

prevalence, determinants, symptoms, treatment options, and diagnosis. There was significant improvement in the short-term knowledge level of students after the study intervention, which consisted of a brief presentation and discussion about RHD.

The prevalence of RHD in low-medium income countries, such as India, is 2–3 per thousand school-aged children with wide regional variation.^{10,13,21} Globally there are areas where the prevalence of RHD is much higher than in South East Asian countries, such as India. Overcrowding, poor access to health care, and poverty remain the major determinants of RHD.²² Although the prevalence of RHD is decreasing among the school-aged children in India and in other parts of the developing world, RHD remains an important public health concern.^{9,23} It affects young children by interfering with their growth and development, reducing their performance and productivity, increasing loss in disability adjusted life years, and sometimes leading to premature death. The magnitude of this condition has prompted experts in the field and professional bodies such as the World Heart Foundation to develop a roadmap to deal with the magnitude and impact of RHD with an emphasis on actionable preventive measures including increasing awareness and knowledge on the part of all the stakeholders including educational institutions, school-teachers, parents and school-aged children.^{24–26}

There has been some concern about the benefits and potential harms of screening for RHD since the screening process may generate considerable anxiety in screened individuals, especially among those who are determined to be positives.²⁷ However, awareness about the disease is seen as a pre-requisite for any effective prevention program, and an educational presentation has been shown to reduce some of the apprehension related to screening studies.²⁸ In a study conducted in Gulu, Uganda, 4,773 students in the age group 5–15 from five schools underwent echocardiographic screening for RHD. A subsequent planned follow up study involving 255 students (4.8%) eight months later found mixed perception of the students about the screening process: 48%

felt nervous and 35% were scared during the screening. Pre-screening educational presentation explaining the painless nature of the screening and ensuring privacy of the test results were recommended while close collaboration between school teachers and school officials were advised to minimize disruption.

Our study showed that the students' knowledge about RHD was modest, but there was significant improvement in their knowledge level after the simple intervention of a standardized educational presentation by the study team.

There are few studies in the published literature that have assessed students' awareness about RHD and even fewer that have shown improvement in the awareness of this prevalent and impactful condition by a simple intervention.^{29,30} After a health awareness survey conducted by the Indian Council of Medical Research in 74 villages near Varanasi in Uttar Pradesh, the study team demonstrated a significant increase in respondents' knowledge about most of the symptoms, causes, consequences and preventive measures of sore throat, rheumatic fever, and RHD.³¹ A public service video entitled "A Sore Throat Can Hurt Your Child's Heart" with Hindi subtitles was shown in four villages and an urban slum in the Indian state of Chhattisgarh.³² Awareness of RHD increased by 90% in the population prompting them to involve local women and health workers to expand the program.³² We believe that increased knowledge of rheumatic fever and RHD will motivate students to seek medical help if they encounter any symptoms or signs suggestive of rheumatic fever and RHD.

4.1. Study strengths and limitations

The strength of our study stems from its simplicity and its easy replicability. With limited resources, we visited 20 schools in a rural district of India and surveyed a large number of students, assessed their level of understanding about Rheumatic Heart Disease, and improved their knowledge about RHD with a simple intervention. However, our study has some limitations that must be kept in mind in the interpretation of our results. Although our study population involved nearly 9,000 students between 10 and 16 years old, the schools were selected purposively from one area of the district of West Midnapore for ease of access to the study team rather than random selection from the entire district. One needs to be careful in generalizing the results of this study to the nation as a whole or to other developing countries due to differences in culture, socioeconomic strata, and education. Further, our study could not explore other important factors which can affect students' awareness about RHD. These factors include, but are not limited to, social attitudes about the disease, governmental policies, infrastructural support, and socioeconomic status. Although the attitudes of the students towards this study were positive, and the students were very receptive in the educational process, their behavioral responses to different symptoms associated with RHD were beyond the scope of this study.

5. Conclusions

RHD remains prevalent in developing nations and awareness among children is crucial for effective secondary prophylaxis. We found that the level of awareness of RHD among school-aged children was modest (mean baseline correct answers of 42%). A brief educational intervention was modestly effective in increasing students' awareness about RHD (overall improvement in awareness level of 31%). Our study may be helpful in developing a strategy to enhance the level of awareness about RHD among school-aged children in India and other developing nations.

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Healthy Heart Initiative, Inc., Andover, MA, USA.

Conflicts of interest

Dr. Deepak L. Bhatt discloses the following relationships - Advisory Board: Cardax, CellProthera, Cereno Scientific, Elsevier Practice Update Cardiology, Level Ex, Medscape Cardiology, PhaseBio, PLx Pharma, Regado Biosciences; Board of Directors: Boston VA Research Institute, Society of Cardiovascular Patient Care, TobeSoft; Chair: American Heart Association Quality Oversight Committee; Data Monitoring Committees: Baim Institute for Clinical Research (formerly Harvard Clinical Research Institute, for the PORTICO trial, funded by St. Jude Medical, now Abbott), Cleveland Clinic (including for the ExCEED trial, funded by Edwards), Contego Medical (Chair, PERFORMANCE 2), Duke Clinical Research Institute, Mayo Clinic, Mount Sinai School of Medicine (for the ENVISAGE trial, funded by Daiichi Sankyo), Population Health Research Institute; Honoraria: American College of Cardiology (Senior Associate Editor, Clinical Trials and News, ACC.org; Vice-Chair, ACC Accreditation Committee), Baim Institute for Clinical Research (formerly Harvard Clinical Research Institute; RE-DUAL PCI clinical trial steering committee funded by Boehringer Ingelheim; AEGIS-II executive committee funded by CSL Behring), Belvoir Publications (Editor in Chief, Harvard Heart Letter), Duke Clinical Research Institute (clinical trial steering committees, including for the PRO-NOUNCE trial, funded by Ferring Pharmaceuticals), HMP Global (Editor in Chief, Journal of Invasive Cardiology), Journal of the American College of Cardiology (Guest Editor; Associate Editor), K2P (Co-Chair, interdisciplinary curriculum), Level Ex, Medtelligence/ReachMD (CME steering committees), MJH Life Sciences, Population Health Research Institute (for the COMPASS operations committee, publications committee, steering committee, and USA national co-leader, funded by Bayer), Slack Publications (Chief Medical Editor, Cardiology Today's Intervention), Society of Cardiovascular Patient Care (Secretary/Treasurer), WebMD (CME steering committees); Other: Clinical Cardiology (Deputy Editor), NCDR-ACTION Registry Steering Committee (Chair), VA CART Research and Publications Committee (Chair); Research Funding: Abbott, Afimmune, Amarin, Amgen, AstraZeneca, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, Cardax, Chiesi, CSL Behring, Eisai, Ethicon, Ferring Pharmaceuticals, Forest Laboratories, Fractyl, Idorsia, Ironwood, Ischemix, Lexicon, Lilly, Medtronic, Pfizer, PhaseBio, PLx Pharma, Regeneron, Roche, Sanofi Aventis, Synaptic, The Medicines Company; Royalties: Elsevier (Editor, Cardiovascular Intervention: A Companion to Braunwald's Heart Disease); Site Co-Investigator: Biotronik, Boston Scientific, CSI, St. Jude Medical (now Abbott), Svelte; Trustee: American College of Cardiology; Unfunded Research: FlowCo, Merck, Novo Nordisk, Takeda. All other authors have none to declare relevant to this study.

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