



Challenges in Management of Pediatric Rheumatic Heart Disease in Indonesia: A Narrative Review

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Abstract. Rheumatic heart disease (RHD) is heart valve(s) damage as a long-term complication of Acute Rheumatic Fever (ARF). The ARF is preventable and the global mortality of RHD has significantly decreased due to the treatment advances. However, with the increase of patients' survival rate, it causes more children and young people with disabilities which leads to a severe health burden in developing countries, such as Indonesia. The objective of this study is to identify the challenges in childhood RHD management in Indonesia. Data were extracted from PubMed, Google Scholar, and Science Direct by employing several keywords and various combinations relevant to the topic. The literature search extended to articles published within the last 10 years. The identification of literatures was limited to the publication in English or Indonesian language with free-full text publications which can be accessed by our institution. Studies encompassing evidence of epidemiology, management, and life quality of pediatric RHD were included. Results: Management of pediatric RHD in Indonesia is problematic. There are inadequate nationwide data of the disease magnitude, lack of subclinical RHD data due to limited resources, low adherence of secondary prophylaxis treatment, and lower quality of life among surviving patients. Conclusion: RHD in children in Indonesia remains a health concern. It is crucial to develop the management system of childhood RHD in Indonesia.

Keywords: Rheumatic Heart Disease · Children · Management · Challenges · Indonesia

1 Introduction

Rheumatic heart disease (RHD) is damage of the heart valve(s) secondary to Acute Rheumatic Fever (ARF), an autoimmune response toward pharyngitis caused by Group-A Streptococcus (GAS). It is of the cross-reactive antigen antibodies effect, wherein anti-group A streptococcal antisera (ASTO) reacts with myocardial or skeletal muscle tissue. Meanwhile, the autoimmune response of ARF frequently resolves after a period of acute phase, the chronic damage of the valve(s) may persist, causing RHD [1]. After 1- and 5- year follow-up, a third of patients with carditis at the presentation of ARF

possessed persistent subclinical or clinical valvular changes. As children and adolescents are the most prevalent group, this condition is a potential cause for heart failure at young age, which causes disability and premature death in many countries [2].

The distribution of RHD is more frequent in developing countries, associated with the factors contributing to the GAS infection, such as poor sanitary, overcrowding households, lower socioeconomic level, and limited access to sufficient nutrition or health facilities [1, 2]. Thus, we conducted a narrative review to elaborate the situation of childhood RHD management in Indonesia.

2 Method

2.1 Literature Search

This study is a narrative review to explore information about the current situation of RHD management in children in Indonesia. A comprehensive electronic literature search was conducted employing several keyword terms TS = (“rheumatic fever” OR “rheumatic heart disease” OR “rheumatic valvulopathy” OR “subclinical rheumatic heart disease”) AND TS = (“childhood” OR “children” OR “pediatric”) AND TS = (“Indonesia”) AND TS = (“epidemiology” OR “incidence*” OR “prevalence*” OR “burden of disease*” OR “adherence” OR “compliance” OR “health knowledge” OR “patient*perspective*” OR “parents*perspective*” OR “patient*view*” OR “quality of life” OR “patient*clinical*feature*” OR “patient*characteristic*” OR “patient*clinical outcome*” OR “treatment” OR “surgical” OR “secondary*prophylaxis*” OR “penicillin*injection*” OR “environment*factor*” OR “screening” OR “management” OR “challenge” OR “barrier”.

2.2 Eligibility Criteria

The inclusion criteria were all studies with a full-text publication, written in English or Indonesian language, and published within the last 10 years. Studies with the type of case report or case series were excluded.

3 Result and Discussion

3.1 Epidemiology of Pediatric Rheumatic Heart Disease in Indonesia

As the world’s largest archipelago and one of the most populated developing countries, it is essential to consider Indonesia as one of RHD endemic areas. Three decades ago, Naim et al., discovered 73 cases of childhood ARF in North Sumatera in 1983–1985, with 60 among them accompanied by valvular disorders and developed RHD [3]. By contrast, to date, the nationwide data of RHD epidemiology in Indonesia -particularly in children, has not been established. Some small studies revealed a various number of RHD cases as a result of vast differences among study populations and settings.

There were 31 cases of RHD childhood and adolescent (0–10 years and 11–20 years), contributing to 57.4% of total RD cases in West Sumatra from January 2009 to December

2014 [4]. Another study from South Sulawesi uncovered that 80 children were diagnosed with RHD from January 2005–December 2009 [5]. In East Java, 50 new cases of RHD were diagnosed in 2014–2015 [6]. A retrospective study from 2012 to 2018 in the national cardiac center Jakarta revealed a higher rate, with 108 cases in children of 279 total patients with RHD [7]. The higher rate of childhood RHD in East Java or Jakarta might be affected by the setting as tertiary cardiac centers. However, those numbers were underestimated to be extrapolated as national data. The data were obtained from the higher center in urban areas, whereas the evidence revealed that the prevalence or incidence of childhood RHD in rural areas were higher than the observed one [8].

3.2 Limited Data of Subclinical Pediatric Rheumatic Heart Disease

A recent concern is globally being directed toward the emerging cases of subclinical RHD due to the extensive implementation of echocardiography for screening. A guideline for RHD classification employing echocardiography-based diagnosis was published in 2012 by the World Health Federation, consisting of definite, borderline, and normal RHD. The classification is determined by assessment utilizing advanced tools 2D, color Doppler, and continuous-wave echocardiography. Due to its high sensitivity compared to stethoscope auscultation, echocardiography has been intensively implemented for subclinical RHD screening in healthy children [9]. However, it will be a challenge to be performed in a limited resource setting, which is unavailable competent physicians or advanced tools.

There is limited data to demonstrate the epidemiology of subclinical pediatric RHD in Indonesia. The only study was conducted in South Sumatera which revealed that subclinical RHD was discovered in 8% out of 250 healthy children screened [10]. This rate is higher than that uncovered in Uganda (2.7% out of 4869) in 2012 [11]. The limited data in Indonesia is associated with scarce number and uneven distribution of cardiologists. According to data from the George Institute for Global Health in 2016, there were merely 1.5 cardiologists to serve the 1 million population with half of 30 cardiac centers are centered in Java island, contributing to a gap of health service coverage in rural areas [12].

Strategies for closing this gap were investigated in some developing countries. In Timor-Leste, non-specialist health practitioners were briefly trained and supervised by cardiac sonographers and cardiologists which expertise is in the RHD diagnosis. When compared with the assessments from the experts, the accuracy of the non-experts tests employing single parasternal-long-axis view with a sweep of the heart (SPLASH) echocardiography in the detection of any MR and/or AR were 70.4% for sensitivity, 78.1% for specificity, and 78.2% for kappa agreement [13]. It is also comparable to those discovered by [14, 15], which presented good agreement between non-experts' assessment and cardiologists for any RHD, and notably higher sensitivity for definite RHD or when conducted by two views.

These findings corroborate a promising opportunity to train non-expert operators in facilitating RHD screening in limited-resources areas. However, the extensive variability of scans resulted among non-expert operators, and fact that trainees conducting more scans demonstrate better accuracy suggest improvement of training system with the needs of longer and more under supervision scans [13]. Therefore, regular monitoring, continuing training program, building facilities for confirmatory diagnosis and management, is also crucial to ensure the screening program quality.

3.3 Clinical Features and Long Term Outcome of Pediatric Rheumatic Heart Disease in Indonesia

A study at the tertiary cardiac center in Indonesia reported that most patients possessed left ventricular hypertrophy (35.19%) and atrial fibrillation (27.7%) on electrocardiography. Almost one-third of heart valve abnormality is mitral regurgitation (30.4%), and 36.8% of it with a severe grade of damage. Congestive heart failure was more prevalent in children (11.11%), whilst young adults were generally suffered from pulmonary hypertension (19.5%) [7]. This finding corroborate [16] that the most valve abnormality in children with RHD is mitral regurgitation (43%) compared to mitral stenosis in young adults.

Long-term follow-up involving 921 children of 3343 subjects (15–52 years, median age 28 years) in 14 countries (12 African countries, Yemen and India) revealed 16.9% died and 64.6% of that occurring within the first year of follow-up. The higher mortality rates of RHD were discovered in the lowest-income countries, and there were significantly different mortality rates among countries in accordance with the countries' income. The complications occurring after 2 years of follow-up are congestive heart failure, atrial fibrillation, the surgery need, and stroke or transient ischemic attack [17].

Severe valve damage is more prevailing in groups of lower adherence to secondary prophylaxis [18]. A similar result was uncovered in Egypt that noncompliant patients displayed more severe clinical features [19]. Literature revealed that secondary prophylaxis on enrollment possessed significant protective effects toward complications of RHD (OR 0.86; CI 0.70–1.09, p 0.17) [20].

A prospective study discovering long-term clinical progression of RHD patients in Indonesia is still limited, particularly associated with the outcome after surgery procedures. A retrospective study based on medical records in the Indonesian national cardiac center unveiled the pediatric RHD clinical outcome after surgery. However, this study owns limitations which are a small number of subjects and a short period of follow-up. Between 2003–2008, 28 children underwent surgical procedures. All subjects presented signs of heart failure, with most being in level III or IV as per NYHA. The most surgical procedure was mitral repair, followed by mitral replacement, tricuspid annuloplasty, and double valves replacement [21].

Follow-up within 7 days post-surgery revealed no significant difference of both left ventricular ejection fraction (LVEF) and ventricular shortening fraction (LVSF) in comparison with preoperative, nevertheless, left ventricular end-diastolic dimension (LVEDD) presented improvement. Three of 28 subjects owned complications of pleural effusion, postoperative bleeding, and sepsis. One child with severe heart failure, severe mitral stenosis, and refractory atrial fibrillation passed away soon after the emergency operative [21].

3.4 Adherence of Secondary Prophylaxis

Secondary prophylaxis with intramuscular benzathine penicillin-G (BPG) once per 3–4 weeks is the standard guideline in preventing recurrent infection of GAS, thus inhibiting the extent of valvular damage. The prophylaxis injection should be sustained for at least 5 years after the last episode of ARF or until age 18 years (depending on the longer one) [1]. However, in areas with limited access to health care, the situation of long-term treatment adherence is challenging.

The rate of patients' adherence to the secondary prophylaxis in Indonesia was 57.4% [18]. It is higher than that revealed in India (42.8%) [22], West Ukraine (40%) [17] and comparable to similar studies in Egypt (64.6%) [23], and eastern Nepal (58.3%) [24]. Many factors have contributed to the low adherence of RHD secondary prophylaxis in Indonesia. The most barrier was pain and injection disliking (31/63), followed by lack of family support (22/63) [25]. Kevat et al. discovered that lack of family support was more common in non-compliance groups. However, pain or disliking injections owned an unclear association with noncompliance [26]. A suitable protocol to produce a more comfortable process of drug administration in Indonesia is warranted to increase the compliance level.

The lower levels of parental education and occupation, fair or poor parental knowledge of the secondary prophylaxis significance, living in the rural or suburban area, and less satisfaction toward health care was revealed as the significant factors for noncompliance of penicillin injection [23]. This finding was also corroborated by evidence that 70% of RHD patients in Indonesia live in rural areas [4], with monthly family income less than minimum regional standard and a low level of patients' parents' education [27, 28]. However, limited access to the hospital and healthcare insurance is considered less associated with lower adherence in Indonesia [25]. It may be an advantage of universal health implementation in Indonesia. Hence, the accessibility of BPG injection for all patients is guaranteed. It is in accordance with [29] that adequate health care coverage possessed a protective effect toward the adherence of penicillin injection prophylaxis.

To our knowledge, there is limited data pertaining to parents' understanding level of childhood RHD in Indonesia. However, a study encompassing parents of healthy children in Central Java demonstrates that all respondents owned a low level of knowledge about ARF and RHD. Effective individual counseling employing questionnaires, flipcharts, and leaflet provides a significant increase of parents' knowledge about the diseases and require long-term prophylaxis [30]. This finding corroborates the importance of utilizing knowledgeable terms and effective methods to deliver education about the course of the disease to the patients' families.

3.5 Impaired Quality of Children Life with Rheumatic Heart Disease

The improvement of the RHD survival rate in children provides the consequences of increasing morbidity along with the problems associated with the quality of life (QoL). With its debilitation consequence, RHD reduces the school attendance of children and decreases the employability of youth. Medical and operative treatment, recurrent hospitalization tremendously burdened the health cost, which may lead to more complexity of cultural and socioeconomic impact [31].

The assessment employing Pediatric Quality of Life Inventory (PedsQL) 4.0 displayed that physical and school functions were the most impaired aspect in all groups of age. All subjects owned problems with intense physical movements whereas the function of sedentary activities is not affected [32, 33]. Additionally, children with RHD imposed problem of exercise tolerance due to the impaired strength of respiratory muscle, as presented by lower score on the six-minute walk test (6MWT) than expected, even if they were considered clinically stable [34].

The social function of older children (8–12 years old and 13–18 years old) possessed more impaired compared to the younger age group (5–7 years old) since they were not able to perform common activities like children of their age. Older children also owned lower school function, obtained by self-report or parents demonstrating the loss of attending school because of not feeling well or not having routine visits to the physician [32, 35]. Their emotional function is also more affected by the course of the disease, as illustrated with a feeling of scared, anger, and worry, compared to no one in the group of age 5–7 years old [32].

The assessment employing both PedsQL 4.0 and PedsQL 3.0 Cardiac Module revealed that children's self-report and parents' proxy report perceive lower levels of psychosocial, emotional and social domain compared to the physical domain, and the lowest score on school function domain. The nonphysical domains encompassing the treatment anxiety, perception about the physical appearance, cognitive and communication problems, affected more rather than physical domain (heart problems and treatment, problems with treatment) [36].

The evidence displays the important roles of communities to establish the empowering environment for people with chronic diseases, encompassing cardiac diseases. Children with RHD (clinical and definite latent RHD) in Uganda who regularly attend peer group meetings for 6 months owned a significant improvement score of QoL, Hawthorne friendship scale, and knowledge level regarding their disease. However, this study possesses some limitations because there are no control groups, which involve only subjects with definite RHD, owned access to healthcare, and were compliant to monthly injection of penicillin prophylaxis [37].

This finding concerns on the importance of support from the community as part of the pediatric RHD comprehensive management of. The Australian has experienced in raising community awareness by delivering the RHD concept into the indigenous metaphors or wisdom, and recruiting local societies presented the effective result. Strategies involving local values help the community more comprehend the disease [38, 39].

4 Conclusion

Management of childhood RHD is a complex problem. Therefore, it requires a multi-aspect approach. The data in this narrative review allow us to comprehend the management problem of childhood RHD in Indonesia. What we understand about pediatric RHD in Indonesia is still far from sufficient. The finding of this study still requires further research to represent more situations on problems of this disease, so that effective strategies can be maximized.

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