Title: OUTCOMES FOR SCHOOL CHILDREN WITH SCREENING DETECTED RHEUMATIC HEART DISEASE IN TIMOR-LESTE

Authors: Juliana dos Santos Sarmento

Background & Aims: Rheumatic heart disease (RHD) is endemic in Timor-Leste. Many children present to hospital with severe RHD in late stages and often with heart failure. Hospitals do not have sufficient resources to perform the required operations, only being able to provide palliative treatment. Echocardiographic screening can detect latent cases, and secondary prophylaxis can prevent latent RHD from progressing. This cohort study will evaluate the treatment and clinical and echocardiographic outcomes of students diagnosed with RHD through echocardiographic screening in Timor-Leste, in the context of an established program for delivering secondary prophylaxis to those with definite RHD detected on screening.

Methods: This cohort study will include all screening-detected borderline and definite RHD cases from three separate school screening studies conducted across three different municipalities (Dili, Bobonaro, Ermera) in Timor-Leste (2016, 2018, 2019). Echocardiogram results, history of acute rheumatic fever (ARF) episodes and rates of concordance with secondary prophylaxis will be collected from a prospective RHD register maintained by Maluk Timor, an NGO that works in collaboration with the Ministry of Health on RHD in Timor-Leste. Cardiac outcomes are described as stable, regression or progression according to World Heart Federation criteria (2012) for echocardiographic diagnosis of RHD. Annual rates of concordance with secondary prophylaxis from year of diagnosis are calculated, and described as <50%, 50-79% or >=80% required injections received. The relationship between clinical outcomes and concordance with secondary prophylaxis, sex, location, age at diagnosis and time since diagnosis will be analyzed using multivariate logistic regression.

Results: There were 204 cases of RHD identified during the three studies (105 definite, 98 borderline, and 1 ARF no RHD). The cohort comprised 76.0% (155) girls and 24.0% (49) boys, aged 5 to 20 years old. Of the 204 cases, 59% (121) were initially prescribed secondary prophylaxis (105 definite, 15 borderline, and 1 ARF no RHD). 60.8% (124/204) of study participants have received a follow-up echo after initial diagnosis (>90% of those diagnosed before 2019). Comparison of the initial and most recent echo indicates that 40.3% (50/124) showed RHD regression, 50.0% (62/124) remained stable and 9.7% (12/124) progressed. Of those that had RHD regression, 54.0% (29/50) showed resolved RHD. Of those prescribed secondary prophylaxis, 41.3% (50/121) had 80% or higher concordance with secondary prophylaxis, 30.6% (37/121) had 50-79% concordance, 28.1% (34/121) had less than 50%. Of the 12 people whose RHD progressed, 6 (50%) progressed from borderline RHD, and five of these were subsequently commenced on BPG. Of the six who progressed despite being on secondary prophylaxis, concordance was below 50% for three of them, and between 50-79% for the other three. COVID-19 has significantly impacted on both follow-up screening and concordance with secondary prophylaxis, and concordance rates were lower in those diagnosed in 2019.

Conclusions: This is the first study to review clinical outcomes of screening detected RHD in Timor Leste. The evidence helps to understand the importance of early detection and early treatment of RHD in Timor-Leste, and contributes to the evidence base of RHD research in Timor-Leste and globally. The Ministry of Health continues to invest in development of national strategies for implementation of RHD detection and treatment in Timor-Leste, in line with national guidelines that were launched in 2021.