

BROKEN HEARTS IN TIMOR-LESTE:

AN ECHOCARDIOGRAPHY-BASED PREVALENCE STUDY OF RHEUMATIC HEART DISEASE IN SCHOOL STUDENTS

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**EAST
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What is Rheumatic Heart Disease?

Rheumatic Heart Disease (RHD) is a preventable, treatable form of cardiovascular disease that affects more than 32 million people around the world, and claims 275,000 lives a year. RHD is an illness characterised by damage to one or more heart valves, following an episode of acute rheumatic fever (ARF).

ARF itself is an illness that begins with infection by strep bacteria, known formally as group A Streptococcus. Strep bacteria can cause many illnesses, but commonly cause sore throats and school sores, especially in children. Following this infection some children will have an abnormal response from their immune system, causing inflammation in different tissues, including the heart. After several weeks, the illness resolves but the damage to heart tissue can remain and be life-long. Repeated infections cause more episodes of ARF – this can cause even more damage to heart valves, resulting in RHD.

RHD can result in stretched, or scarred and stiffened valves. This means that the valves don't close properly (and are leaky) or don't open properly (stopping blood from passing through properly). If left untreated, this can lead to heart failure and death, including in children.

WHY WAS THE STUDY DONE?

The study was commissioned by East Timor Hearts Fund, with the support of project partners, to raise awareness about the need for more effective responses to RHD in Timor-Leste.

East Timor Hearts Fund's volunteer cardiologists have worked in Timor-Leste for almost 20 years. They and other health professionals in Timor-Leste diagnose many children and young adults with RHD every year, but with low access to healthcare, the true prevalence of RHD was unknown.

HOW WAS THIS STUDY DONE?

In October 2016, a volunteer team comprising cardiologists, paediatricians, nurses and support staff from around Australia and from Timor-Leste screened almost 1400 school students aged between 5 and 20 years, with an average age of 11. Just over half (53 per cent) were female and 37 per cent were from the capital Dili, with the rest from rural Ermera.

Students were examined for skin conditions known to be associated with RHD, including impetigo (school sores – a strep bacterial infection of skin) and scabies, a skin condition caused by a tiny mite.

The students then had their hearts examined using echocardiography. This is an ultrasound machine that can create an image of the heart and reveal the signs of RHD, such as damaged valves and abnormal blood flow through the valves. All abnormal scans were reviewed by paediatric heart specialists and classified as having 'borderline' or 'definite' RHD based on internationally accepted criteria.

All students with RHD were entered into a register and given a first dose of antibiotic, benzathine penicillin G (BPG). This is an antibiotic in a salt form that is given deep into the muscle. Because of the formulation, it is released slowly into the bloodstream over weeks. Injections given every 4 weeks are able to protect against new infections of strep bacteria, thereby lowering the risk of further damage to heart valves. The register is used to follow patients with RHD and to help make sure that they get a regular dose of BPG until they are out of the risky age group for strep infections. Most of the students with RHD will need regular injections for at least 10 years. Students with heart disease that might benefit from surgery or other procedures in Australia were referred on for assistance.

The study has been peer-reviewed and published in the Medical Journal of Australia.

What did the study find?

ONE OF THE HIGHEST RATES OF RHD IN THE WORLD

The study found that Timor-Leste has one of the world's highest rates of rheumatic heart disease, with 35 borderline and definite cases per thousand. By contrast, in Australia the RHD rate in high-risk indigenous communities is 25 per thousand, with lower rates in the broader population.

Of all those screened, 25 were found to have definite RHD, based on international criteria. A further 23 were found to have borderline RHD.

None of the students had been previously diagnosed with RHD and all the cases were classified as mild or moderate. All of the students with definite RHD have been commenced on BPG injections to prevent progression of RHD. There were 11 children found with congenital heart disease – that is, disease present at birth.

These findings may be conservative. The true prevalence could be even higher as some children may have been too unwell from RHD to attend school.

It is also possible that children in poorer families (who would be expected to have a higher risk of RHD) may not attend school and were therefore missed from screening. Cases of severe RHD were not found on screening, despite visiting heart specialists previously noting severe RHD in children that had died. There is a need for further studies to understand the true burden

of RHD on child disease and deaths.

GIRLS OVER-REPRESENTED

The study found significantly more girls than boys with RHD. Of all the girls screened, 5 per cent (one in 20) had RHD, compared to 2 per cent of boys (one in 50).

Taking into account other factors that might influence more girls being identified with RHD, they were still found to be 3.5 times more likely to have definite RHD.

WHAT DOES THIS ALL MEAN?

The paper recommended that efforts to tackle RHD in Timor-Leste should focus on all levels of prevention. This includes primordial prevention, which addresses the underlying risk factors such as poverty and household crowding. Primary prevention (treating strep infections as they occur) and secondary prevention (giving regular penicillin to prevent future strep infections) were also recommended. Finally, the role of surgery for patients with established heart disease was highlighted, noting that surgery is not currently available in Timor-Leste.

The fact that the majority of RHD cases were found in girls is an unusual finding that has been noted in some other settings. RHD can be particularly dangerous for mothers and babies during pregnancy and childbirth, and addressing the high burden of RHD in females in Timor-Leste is an urgent priority.

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Next steps



East Timor Hearts Fund commissioned this study as part of an effort to focus the attention of non-government and government organisations on the need for greater funding and resources to effectively tackle this devastating disease.

In response to the findings of this research East Timor Hearts Fund is doing the following:

- RHD awareness-raising and outreach (Primordial prevention): Culturally appropriate community awareness-raising materials are being developed and community education sessions are being held. Given the disproportionate impact of RHD on women and girls in Timor-Leste a gendered approach to community awareness-raising will be a focus area of expansion.
- Capacity-building for health care professionals (Primary prevention): East Timor Hearts Fund has already invested in supporting the training of Timor-Leste's only cardiologist. Support for capacity building of nurses, doctors, biomedical engineers and other health professionals is another planned area of expansion.
- Working with local health workers and community partners on the delivery of penicillin (Secondary prevention): This project is currently ongoing and is expected to expand as more cases are of RHD are discovered.
- Saving lives through conducting life-saving surgery (Tertiary prevention): East Timor Hearts Fund has and will continue to bring Timorese patients to Australia for life-saving surgery. Over the coming years more surgeries will be held at the Hospital Nacional Guido Valadares in Dili, Timor-Leste.
- Conducting further research: East Timor Hearts Fund will be seeking further funding to conduct research into the disproportionate prevalence of RHD among girls in Timor-Leste.
- Advocacy and advice: East Timor Hearts Fund will work to provide information and advice to the Ministry of Health and Hospital Nacional Guido Valadares in helping to strengthen the health system of Timor-Leste. East Timor Hearts Fund will also bring its voice and experience to bear on the global stage in working with partners to end RHD globally.

THANK YOU TO OUR STUDY PARTNERS

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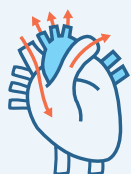
Fast facts

Snapshot of RHD in Timor Leste

1 in 20 girls

1 in 53 boys

1 in 28 people



Rheumatic Heart Disease (RHD) is an illness characterised by damaged heart valves, caused by infection (and sometimes repeated infections) with strep bacteria



This prevalence is as high as many of the highest burden countries in the world



This study investigated the burden of RHD in Timor-Leste, where little was known



Girls were found to have 3.5 times the risk of definite RHD, for unclear reasons



1365 students aged 5 to 20 were screened using ultrasounds of the heart



The study showed that finding early RHD was possible on screening and that putting patients on a register for follow-up and preventive antibiotic treatment is possible



More research is required to determine whether screening and establishing a register can change outcomes from RHD in a setting such as Timor-Leste