ON RHEUMATIC HEART DISEASE (RHD):
GLOBAL VOICES

Over a decade ago I was doing ultrasound scans at Groote Schuur Hospital, when I noticed that every second or third patient I saw had rheumatic heart disease. This shocked me to no end and led me to believe that we ought to do something about RHD.

Bongani Mayosi | University of Cape Town | South Africa

"The Ministry of Health in Sudan reported that nearly 37,000 cases of rheumatic fever are followed in outpatient clinics in 2011, mostly from Khartoum, Darfur, and Kordofan. There were over 500 hospital admissions for rheumatic heart disease, approximately 200 heart surgeries and 44 deaths. In Sudan's main Children's hospital, 735 cases of RHD were seen in the outpatient clinic in 2011, almost all with severe disease needing surgery. Surgery costs are very high and there are long waiting lists: about one in five of those who need surgery get it and for them, mortality is 15%. Even those who have gotten surgery still need expensive, complicated and costly medical followup. It is tragic that a condition that can be prevented through basic health services takes such a toll on the families, communities and health systems that can least afford it. Sudan has initiated an ASAP program (Awareness, Surveillance, Advocacy and Primary prevention) and it is already included in the Ministry of Health NCD plans, but we need technical and logistic assistance."

Sulafa K M Ali | Sudan Heart Institute | Sudan

"Having a child with rheumatic heart disease completely changes the life of the whole family. The parents have to spend a lot of time and money to take the child to hospitals that are usually far away… they may have to quit work or stay with relatives during hospitalizations so there are a lot of social problems that come along with the disease. It is hard to watch these children coming in again and again, progressing to heart failure, having strokes. When we see them with severe heart disease we know that we, and our health system, have failed to protect them from this preventable disease. The first thing I would do to improve the situation is to improve the training of doctors and of health workers. Unfortunately we are taught mostly about the diseases of Europe and North America. Only recently the African health community has started to look at its own problems and to implement research projects into specific cardiovascular conditions that affect people in this continent. We need to bring diseases like rheumatic fever to the attention of the public and of policymakers."

Ana Olga Mocumbi | Instituto Nacional de Saúde | Mozambique

"I came across RHD the first time when I was in medical school, accompanying a woman through labor. She had more and more trouble breathing, and then she went into cardiac failure. She had undiagnosed valve damage from RHD, had a precipitous delivery and had to have an emergency procedure for her mitral stenosis. She did well because she was in Groote Schuur Hospital, where we have a cath lab, but in many other places she probably would have died. We know that RHD is one of the top cardiovascular causes of maternal mortality.

It is right to call RHD a disease of social injustice. It has fallen between the cracks of different funding categories and specialties and with neither commercial interests nor dynamic action groups to drive intervention it remains a neglected disease. This has resulted in a lack of political will to improve awareness in communities, schools and hospitals. In South Africa the Department of Health is showing a growing commitment to tackling rheumatic heart disease."

Liesl Zühlke | University of Cape Town | South Africa

Rheumatic heart disease accounts for about 90% of the cardiac surgery we do in Cameroon. Each surgery costs about USD 9,000. For many, this is totally unaffordable. It is not a question of whether the Ministry of Health should invest in RHD: it does. It is more a question of how to make that investment so that it has the greatest benefit.

Samuel Kingue | University of Cameroon | Cameroon

"I see an average of 30–40 patients with RHD each month, with about 2–4 new patients a week; that is about 15 percent of my patients. We have cardiac surgery and a cath lab, but there is no insurance so they have to pay for it themselves, which is far too expensive for most RHD patients. If they are very poor, they sometimes can get support; I keep telephone numbers in my drawer to pass on. For those who don't find funding, there is little we can do. If they get surgery, then they often need anticoagulation and monitoring: we can do that here, but not in the villages. We can't really estimate overall compliance with secondary prophylaxis. We lose a lot of patients to follow up: they go home and don't come back and we really don't know what happened to them."

Nasir Moin | Islamabad | Pakistan

We knew that many of our RHD patients were lost to follow up, but we did not know what had happened to them. We assumed that many had moved, changed clinics, or chosen not to come back. When we did the REMEDY study and called to find out what had happened to them it was sobering to learn how many had died. The nurses making the calls were upset; we realized that we have to do something: we had not realized just how big the problem is.

Fidelia Bode-Thomas | Jos University Teaching Hospital | Nigeria

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"I follow about 250 cardiac patients and I would say about 30% of them have rheumatic heart disease. When visiting surgery teams come, about 30% of the cases they operate on have rheumatic heart disease: most of them are kids. On top of the costs of surgery we estimate that proper follow up will cost over $400/year. My gut feeling is that these are only the tip of the iceberg. The ones who are not sick yet and who would benefit from prevention, I don't see them. We have no organized system of prophylaxis. We have penicillin but there is still a lot of work to do: we need to organize, train and raise awareness. What we need most is awareness and that does not cost much. Then we need baseline statistics, a national registry. There already is a system that takes care of HIV management in the country using internet and mobile phone and it works well; maybe we could use a similar model."

Joseph Mucumbitsi | King Faisal Hospital | Rwanda

More than half of the cardiac patients we see have rheumatic heart disease. In some ways it is harder on the health professionals who provide care than it is for the patients themselves – psychologically, at least. The patients think their pain and loss is inevitable, but we know that it is not. We know what could be done.

Dejuma Yadata | Tikur Anbesa Hospital | Ethiopia

"When I came back to Tonga from medical school abroad, I could not believe how many children I saw with RHD. There had been a World Health Organization RHD programme earlier, but the funding stopped and no one could find the register. When I first had the chance to do RHD screening, I was afraid. I didn't want to find more children who needed surgery: the waiting lists were already so long. But when I thought about how so many could be spared all of that by getting penicillin injections, I knew we had to do it. Sometimes it is hard to convince the system to invest in RHD because there are higher priority conditions, like diabetes, but preventing RHD will actually liberate funds that are already being spent. We were sending many RHD cases abroad for surgery every year. In a few years we expect to recuperate the costs of RHD control through savings from reduced surgery. We follow over 1,100 people who are on secondary prophylaxis. Since 2008, prevalence has gone down from 72/1000 to 48/1000, and while it is too early to tell for sure, it looks like we are beginning to see a reduction in need for surgeries."

Toa Fakakovikaetau | Ministry of Health | Tonga

"In Nepal we estimate that about 1000 children die each year from RHD. About 25% of the cases we admit in the National Heart Centre are from RHD: about 30% of our cardiac surgery is for RHD. In 2011 we screened children for RHD in Nepal and found 1.1 cases of RHD/1000; there have been six studies done since 1994 and they have shown little change in prevalence. Working with the Ministry of Health, the Nepal Heart Foundation launched a national RHD program in 2008, a register-based programme focusing on secondary prevention. The program involves 38 hospitals, and follows over 9,000 patients with RHD; it monitors distribution of benzathine penicillin G to health facilities, provides patient-held injection records, maintains and electronic register, trains doctors and paramedics in secondary prophylaxis, conducts program evaluation and monitoring and screening of school children, and engages communities and schools in advocacy and public awareness activities. In 2013 we are piloting primary prevention."

Prakash Regmi | Nepal Heart Foundation| Nepal

"When I went to Northern Australia, I saw one boy who had presented with what they thought was an infection in the hip joint. He wasn't properly diagnosed with rheumatic fever and came back 8 months later in severe heart failure from RHD. That was in a health system that was supposed to be one of the best in the world. We began by documenting how big the RHD problem was and showing that there were deficiencies in how we were caring for and preventing it. Now the Australian government has funded a national program: in places where there is a big RHD problem we run control programs with a single unit to coordinate. Now we're starting to see more people getting penicillin, starting to see the rates of recurrence of rheumatic fever come down. It isn't something you change overnight, but it is happening."

Jonathan Carapetis | Telethon Institute | Australia

Rheumatic fever is a barometer of the delivery of healthcare. Preventing rheumatic fever is about basic human rights. We need these kids for the future.

Diana Lennon | Auckland University | New Zealand

"With other heart conditions now coming to the forefront, even the attention of the cardiologists and cardiac surgeons dedicated to rheumatic heart disease is decreasing because they are concentrating on coronary heart disease, which is more common and importantly, more lucrative. Many would rather run after the wealthy patient with ischemic heart disease than look after a poor children or young women who may not be able to pay for the services they need. So many diseases come and occupy public attention, policy space and claim resources and in the competition we sometimes forget the diseases of the poor. We must ensure that RHD is not forgotten by policymakers, health professionals and by those who fund health programs. This is an eminently treatable problem that kills poor young people; we cannot let it be forgotten."

K. Srinath Reddy, President | World Heart Federation

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