

## *Letter from Ganiyari*

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### RHEUMATIC HEART DISEASE: A DISABLING CONDITION WITH SYSTEMIC ROOTS

Seema and her husband had been waiting all day for their turn to consult the doctor in our outpatient department at Jan Swasthya Sahyog (JSS). Seema had rheumatic heart disease (RHD) with mitral stenosis and her breathing had got worse. Requiring frequent breaks to catch her breath, she no longer could do her daily chores at home.

RHD is one of the most preventable chronic diseases in the world,<sup>1,2</sup> yet estimates of its prevalence in India range from 0.5 to 8 million.<sup>3-6</sup> It is almost exclusively a disease of poverty—this is especially evident in Australia where the disease prevalence is 122-fold greater among the poor indigenous populations than among mainland Australians.<sup>7</sup>

Prevention can be approached at many levels. Children who develop Group A streptococcal pharyngitis can be treated with penicillin before they develop acute rheumatic fever (RF), and those who develop acute RF can receive penicillin prophylaxis to prevent recurrent attacks.

An inspiring example of prevention of RHD is seen in Cuba where from 1986, with little extra cost, a primary and secondary prevention programme was implemented using the existing health systems. Personnel were trained to treat acute pharyngitis for primary prevention and provide penicillin for secondary prophylaxis. Patients with acute RF were registered so they could be followed up, and the community was educated through the media. In just 10 years, the prevalence of RHD decreased from 2.27 to 0.24/1000.<sup>1</sup>

Sadly, the healthcare system in rural India is not as organized as in Cuba, and for those who live 100 km from healthcare, penicillin is not readily accessible. Our patients often wait for end-stage symptoms to develop before seeking medical care, at which point palliative treatment and surgery are the only options. Mitral stenosis, which usually has a two-decade latent period, is the most common valvular lesion.<sup>8-10</sup> Mitral stenosis is debilitating: once the progressive stage begins, total disability occurs after an average of 9 years.<sup>11,12</sup> Forty per cent of patients with RHD also develop atrial fibrillation (AF), which contributes to further disability.<sup>13</sup> With medical treatment alone, patients with AF and the New York Heart Association Class II or III symptoms have a

10-year survival rate of 34%, and those with Class IV symptoms have a 10-year survival rate of 0%.<sup>14</sup>

Fortunately, we have options to help patients who reach this level of disease. Patients with mitral stenosis can get commissurotomies, valvuloplasties or valve replacements, and those with mitral regurgitation may be able to get repairs or replacements. There are government schemes to cover the cost of these procedures for patients who can make the trip to Delhi. For those who cannot make the journey or do not qualify, JSS can arrange surgeries in Chhattisgarh.

Why then, do we bring up RHD as an issue? If we have all the mechanisms in place for tertiary care, can we not ignore it in favour of the multitude of other issues in the developing world?

We examined Seema and found that she had an irregular pulse and a rumbling, diastolic murmur. We scrambled to get an electrocardiogram, as AF would be a near-death sentence for her. The development of AF in patients with mitral stenosis indicates a >50% mortality rate in 5 years<sup>11</sup> without intervention. Before that, it can cause worsening heart failure, stroke and systemic embolism. Some of these complications can be mitigated by anticoagulation using warfarin.

However, for someone like Seema who lived 100 km away from our centre, taking warfarin safely is close to impossible. Just to get to JSS and back, she had to leave her home and her children for at least 3 days. She and her husband walked several kilometres to the bus stop, took a bus to the closest train station, rode the train to Bilaspur and endured an 18-km rocky autorickshaw ride to finally arrive in Ganiyari. Arriving at dusk, she would sleep on the hospital grounds and wake up the next morning to wait in line for her turn in clinic. If it was not too late by the time her investigations were done and reviewed, she could start the journey back home. If she had to travel to Ganiyari biweekly, or even monthly, for warfarin monitoring, this would place an enormous burden on her family, who survived on daily wages. Seema is one of thousands who suffer like this. Looking at internal data from 2014 to 2016, 30% of our patients who took warfarin came from >150 km away, and despite our efforts, the median international normalized ratio (INR) was subtherapeutic at 1.7. Many women (as we have seen personally) face the threat of abandonment by their families because of the care they require.

Warfarin taken without proper monitoring is fraught with risks, including bleeding, drug interactions, stillbirth, birth defects and foetal and maternal haemorrhage, to name a few. Even among well-monitored patients in urban Canada, rates of haemorrhage with long-term warfarin are nearly 9%, and even higher in the first 30 days.<sup>15</sup> In many of our patients, risks are so high that we do not prescribe warfarin, and for good reason. A few months ago, we met Ram, a 30-year-old man with RHD on anticoagulation with warfarin who came to JSS with abdominal pain several days after a local pharmacist gave him diclofenac (a non-steroidal anti-inflammatory drug that interacts with warfarin). We found his INR to be 11 and haemoglobin 4 g/dl. He barely survived, and we can imagine many who would not make it in time.

Primary care is what we need in rural India to prevent near tragedies such as what happened to Ram, Seema and all those patients whose stories we have heard or will never hear. We tell you about them not only to point out how debilitating it is for a young mother to have mitral stenosis, or how difficult it is to monitor warfarin for patients who live hundreds of kilometres away but to call for help in preventing these situations from ever occurring in the first place.

In Chhattisgarh, each village subcentre is staffed with one community health worker for almost 5000 people. Primary health centres (PHCs), which are supposed to be 24/7 hospitals, are expected to serve an area of 30 000 people with just a single medical officer. Only 33% of these PHCs have regular supply of electricity, and <60% are open 24 hours a day.<sup>16</sup> Only 30% of the PHCs surveyed in one study even had a medical officer employed.<sup>17</sup> Only 412 of 947 required laboratory technician positions were filled in 2015,<sup>18</sup> and only minimal laboratory testing is available at the subcentre level.<sup>19</sup> Such is the state of primary healthcare accessible to the rural patients in Chhattisgarh.

The Government of Chhattisgarh is making strides to help the poor access healthcare by a state-wide insurance scheme covering up to ₹30 000 of medical bills a year. However, this bolsters tertiary level care and does not provide the outpatient visits and access to chronic medications that patients need.

At JSS, our mission to fill the healthcare gaps in rural Chhattisgarh has taken root in Ganiyari hospital, our three village subcentres and our 125 village health workers. Every month, we send our health workers out into the community to educate people about common chronic diseases, and we staff our subcentres with senior healthcare workers to manage patients who are diagnosed. While we see thousands of patients in a year, the need remains large, and we write this letter in an effort to urge the government to make primary care a priority. More health workers should be trained and more oversight provided so that existing health centres can be adequately staffed. Laboratory testing, though difficult to make available in the subcentres, should be provided in the PHCs, especially for monitoring of chronic conditions. The framework is in place, it is the implementation that needs to be tightened. We believe that Chhattisgarh can become a model for the rest of the country.

Thirty-five-year-old Seema listened patiently while we explained her surgical options and post-surgical care. Tears welled up in her eyes at the possibility of needing warfarin. Frequent monitoring would be difficult, she said. How ironic it is that complex, expensive surgery was more accessible than primary care. On the other hand, we considered the thousands of children who, as we give them better access to primary care, will avoid this situation altogether!

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