The National Rheumatic Heart Consortium: A nationwide initiative for the control of rheumatic heart disease in India

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CHALLENGES OF RHEUMATIC FEVER AND RHEUMATIC HEART DISEASE CONTROL IN INDIA

Rheumatic fever (RF) and rheumatic heart disease (RHD) continue to be important public health issues in many low- and middle-income (LAMI) countries affecting children and young people living in conditions of poverty, poor sanitation and overcrowding.¹,² These conditions have been nearly eliminated in the high-income countries, but continue to be common in Africa, Asia and the Pacific.³–⁵ Over 15 million people around the world suffer from RHD, resulting in approximately a quarter million deaths every year. RHD is the most commonly acquired heart disease found among children and young people in LAMI countries including India.³

There is a perception that the disease burden has declined in parts of India where human development indices have improved.⁶–⁷ Though epidemiological data are limited, RHD may have declined in some of the major cities of India, especially in southern India.⁸ However, in many parts of India with poor human development indices, the high disease burden may not have declined.⁹,¹⁰ There is a paucity of epidemiological data from poorly served rural populations, urban slums and tribal pockets.⁶ The loss of productivity and costs of care of the large number of currently affected patients with established valvular RHD in India is likely to be formidable.

There are vertical disease-specific national programmes for tuberculosis, malaria and HIV infection, but RF and RHD have not received the same attention from policy-makers.¹¹ This has contributed to the ‘neglect’ of RF and RHD in India. Other important reasons include the widespread perception among cardiologists, cardiac surgeons and key opinion leaders in cardiovascular medicine that RF and RHD are no longer important public health issues. These perceptions are formed because the population most affected by RF and RHD is getting increasingly marginalized and may not be in the consciousness of cardiovascular professionals. Most cardiologists and cardiac surgeons practise in tertiary centres in urban areas. It is difficult for the population affected by RHD to seek treatment at these centres. Besides, there are competing priorities for overworked cardiologists and cardiac surgeons that include the coronary artery disease burden which has acquired the status of an epidemic. Paediatric cardiologists and heart surgeons are now looking after an increasing number of children with congenital heart defects that have come to notice as advanced cases.¹²,¹³

The consequences of the neglect of RF and RHD are potentially devastating. A good example is the unfortunate situation with penicillin in India. The majority of patients with RHD do not receive adequate secondary penicillin prophylaxis. A number of issues relating to the manufacture and distribution of penicillin relate to the decline in quality of primary health services in India. There is a need for strong and sustained advocacy to encourage manufacture and distribution of penicillin.

The main challenges relating to RF and RHD in India are:

1. Lack of appreciation among the general public and many health professionals that RF and RHD are still important public health issues.
2. Suboptimal functioning of public health systems in regions with probably the highest burden of the disease, resulting in poor surveillance, and poor primary and secondary prophylaxis.
3. The absence of any national policy: RF and RHD are not notifiable diseases in India.
4. Suboptimal data: Comprehensive disease registers represent only a small proportion of India’s vast population, with little data from regions that are likely to be worst affected.
5. Erratic supply of good quality penicillin and absence of guidelines for administration of penicillin; poor acceptability among medical professionals.
6. Poor engagement of most stakeholders such as government and non-governmental organizations (NGOs), professional societies and civil society representatives.

These challenges get amplified when one considers the large population of India together with its sociocultural, economic and geographic diversity.

The National Rheumatic Heart Consortium (NRHC) has been established in India in recognition of the need for a concerted effort towards prevention and management of RF and RHD. It has been constituted by a group of professionals committed to the cause of RF and RHD in India. The members belong to a diverse group and include caregivers, public health experts and other stakeholders, and represent different regions of the country.

GOALS AND PURPOSE OF THE NRHC

The main goals of the consortium are:

1. Awareness and education. This will involve formulation of guidelines for the diagnosis, prevention and management of RF and RHD on the basis of contemporary evidence and practical challenges. Specific efforts will be directed towards increasing awareness among practising physicians and paediatricians regarding optimal care of patients and among the community at large. Creating awareness on selected issues relating to RF and RHD among the general public is also a goal but this will require partnership with civil society organizations and NGOs, particularly in high-prevalence regions.
2. Advocacy. The NRHC will be the primary advocacy body for RF and RHD. Advocacy will be targeted at the following key stakeholders: Central and state governments, research agencies, key organizations of health professionals, and the pharmaceutical industry (focus on making high-quality injectable and oral penicillin widely available).
3. Surveillance. The NRHC will work towards creating systems for surveillance of RHD. This will potentially involve creation...
of a common national registry for RHD. Specific efforts will be
directed at obtaining prevalence data in regions with poor
health infrastructure.

4. **Patient and family empowerment** will be a focus area for the
NRHC. This will involve creation of support groups for
patients affected with RHD. Active partnerships with NGOs
and international agencies will also be pursued.

5. **Research.** Besides translational research, this will involve
cooperation with industry to explore low-cost solutions at all
levels of the patient care continuum.

6. **Policy.** The NRHC has established links with key stakeholders
in the government. One of the tasks will be to draft a
comprehensive policy for prevention and management of RF
and RHD in India, which can be integrated with the existing
health systems. It will be necessary to identify specific areas in
health systems that need to be strengthened to deliver effective
preventive and curative services for RHD.

### ACTIVITIES AND MEETINGS

The first meeting of NRHC was held in 2012, in New Delhi and
the second in 2013, in Agra. It was agreed by the group that RF and
RHD remain public health issues in India, and measures towards
their prevention and control are warranted. At the meetings,
several community- and school-based surveys were presented
from different parts of India. A high prevalence was also found in
echocardiographic screening of school children from one site.

Similar screening at multiple sites was recommended, since
the prevalence of RF and RHD varies from region to region. The
problem of the availability of good quality benzathine penicillin
and possible solutions were also discussed. Optimal strategies for
treatment of chronic cases were discussed to improve patient care.
It was realized that valve repairs rather than prosthetic valve
replacements should be encouraged, as anticoagulation monitoring
is often poor. The group agreed that advocacy with the government
was crucial for creating awareness about prevention; however, no
concrete plans were put in place.

The third meeting of NHRC, held on 2–3 November 2014 in
New Delhi, specifically aimed to develop strategies for the
prevention and control of RF and RHD in India. It was perhaps for
the first time that participants from diverse disciplines from all
over India gathered in a 2-day brain-storming session to develop
an action plan (Table I) for the future. This meeting had experts
from the Ministry of Health and Family Welfare, Government of
India, Indian Council of Medical Research (ICMR), NGOs and
penicillin manufacturing industry (the list of participants is given
in Annexure I).

### Consensus statement of the third NRHC meeting

1. **RHD is a significant public health problem in India.** Surveys
for clinical and subclinical RHD have consistently shown
disease prevalence high enough to classify RHD as a public
health problem. Based on the prevalence data from the ambitious
Jai-Vigyan Mission Mode Project, which was conducted at 10
sites involving about 10 million population, it is estimated that
about 1.5–2/1000 people in all age groups in India are suffering
from RHD. This translates into a national burden of 2 to 2.5
million patients of RHD. The evidence from the Jai-Vigyan
study and other surveys in India suggests that RHD is related
to poverty, poor sanitation and lack of access to healthcare, i.e.
it is closely related to the human development index (HDI).

There is a gradient across various sites in India with the lowest
prevalence reported from sites with the best health and HDIs. Therefore, RHD is likely to be much more prevalent in states
with low HDI such as Bihar, UP, Chhattisgarh, Jharkhand,
though clear data are lacking from these regions. These ‘hot
spots’ need immediate attention.

2. **Treatment of sore throat.** More than 80% of sore throats are
viral in origin and do not lead to RF or RHD. Antibiotics are
therefore not recommended routinely for sore throat. However,
certain clinical features may indicate streptococcal sore throat
and such patients may be given antibiotics after confirming the
diagnosis.

3. **Creating awareness.** Creating awareness about RF and RHD
is important for its control. None of the existing public health
projects have incorporated awareness programmes for RF and
RHD. The link between sore throat and future development of
RF is largely unknown to the community. The NRHC group
strongly recommended working towards creating awareness
among parents, teachers, health workers and society in general.
This can be achieved by collaborating with village health
workers (accredited social health activists—ASHAs and
auxiliary nurse midwives—ANMs) and NGOs working in
rural areas, so as to integrate awareness in their existing
activities. Professional bodies such as the Indian Academy of
Pediatrics and Indian Medical Association could play a major
role and need to be persuaded to take up this cause.

4. **Ensuring availability of penicillin and its administration.**
Penicillin, both oral (penicillin V) and long-acting injectable
(benzathine penicillin) are an integral part of any control
programme for RF and RHD. Several countries have shown a
systematic decline in the burden of RHD by successfully using
injectable penicillin for secondary prophylaxis, in addition to
other measures. The NRHC acknowledged the problem of
availability of penicillin in the market and in most hospitals,
especially in some states of southern India. The NRHC
recommended engaging pharmaceutical companies and related
governmental offices to ensure availability of good-quality
penicillin for patients with RF and RHD all over India including
in rural areas. In view of the possible allergic reactions associated
with the use of injectable penicillin, the NRHC decided to
prepare a handbook containing guidelines for safe delivery of
injectable penicillin.

5. **Optimizing care of patients with RHD.** Patients who already
have RHD with valve involvement need long-term

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<td>12. Developing models for timing of valve surgery and care of postoperative valve surgery patients</td>
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**RF** rheumatic fever  **RHD** rheumatic heart disease
comprehensive care. The NRHC recommends setting up of registries for such patients, which will ensure regular supply of medicines and injectable penicillin to them. The timing of surgery (valve replacement or repair) is also crucial and such decisions are best taken by a group of specialists; to facilitate this task the NRHC will recommend a list of specialists to the ministry. The consortium will formulate guidelines for anticoagulation monitoring by regular check-ups of blood samples for those who have received metallic valves.

6. Research priorities. Translational research should continue in parallel with the control programme. The prevalence data and that from registries need to be tabulated for time-related changes. Such information will be of value in improving care of RHD patients in the future.

REFERENCES


ANNEXURE I

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