Combating Rheumatic Heart Disease in Sudan: an affordable target

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Sudan has the highest incidence of RHD in the African and Arab regions (100 per 100000/year) and the prevalence had been reported as 10.2 per 1000 compared with 2.3 per 1000 in Saudi Arabia and 5.1 per 1000 in Egypt.(1)

The Ministry of Health (MOH) annual report in 2011 (2) revealed that the total number of patients seen with ARF in outpatient clinics in the whole Sudan was 36877, out of them (11976) were seen in Khartoum state followed by Western States (Darfur and Kurdofan) (9170) while the least number was seen in River Nile State (195) patients. The same report showed that 509 cases of RHD were admitted to hospitals, including 176 children between (5-14 years) . RHD caused 44 deaths in 2011(9%).

Another report from Gaafar Ibn Oaf Paediatric cardiology clinic (3)showed that total number of cases with acute rheumatic fever (ARF) seen in 2011 were 81 patients while patient presented with RHD were735 the majority were from Khartoum state but most of them were originally from Western States (Darfur and Kordufan) (3).

In the main Children's hospital, RHD represent the most common cause of admission to cardiology ward (55% of admissions) and the most common cause of death due to cardiac disease. In the same hospital, 95% of patients with RHD seen have severe forms of valve disease needing surgical intervention. Ninety % of those with RHD do not have history of ARF indicating that the first episode passed unnoticed and 50% of patients were not compliant with secondary prophylaxis .Many patients are seen for the first time with adverse echocardiographic characteristics such as an ejection fraction <60% or an end-systolic diameter >45 mm and severe pulmonary hypertension which lead to adverse surgical outcomes, similar to observations of other centers (4).

RHD surgery constitutes the most common type of cardiac surgery in children and young adults in Sudan in all cardiac centers (Sudan Heart Center, Ahmed Gasim, Al Shaab and Medani Heart Centers). The average number of operations performed in *each* of these 4 centers is 120-150 operations per year; valve surgery constitutes about 60 operations in each center.

Only 10% of those who need surgery get access to operations because of technical and financial constrains. The average cost of cardiac surgery is 4000 US Dollars, unaffordable both to families as well as to the Sudan's economy resources. The most commonly performed valve surgery is prosthetic valve replacement ; while valve repair is performed by few surgeons for mitral valves and scanty cases of aortic valve disease.

Even after successful valve repair we encountered many cases of recurrence of RHD in spite of strict adherence to penicillin prophylaxis. We documented that patients with chronic RHD have persistently elevated inflammatory markers (cytokines and C-reactive protein) which indicate an ongoing inflammation that leads to failure of their valve repair.(4,5) Similar observations have been reported from other African countries which has shown that prosthetic valve replacement in the presence of poor socio economic conditions, and the presence of chronic inflammation together with preceding poor echocardiographic indices like low ejection fraction , all lead to a poor outcome.(6) Late mortality related to prosthetic valve dysfunction, endocarditis, bleeding and cerebrovascular events are not uncommon.
Patients who underwent valve surgeries need lifelong follow up which constitutes a large burden on the families (which are mostly of low socioeconomic state) as well as on tertiary care centers in Sudan.

Previous RHD Control Programs:

In 1985, a World Health Organization (WHO) campaign involving 16 countries including Sudan was conducted in collaboration with the Sudanese MOH. The campaign aimed at screening and raising awareness with emphasis on secondary prophylaxis. Screening of 13322 children was done and 146 cases of RHD were reported in Khartoum Town. In this campaign Secondary prophylaxis coverage was found to be 72%. . Phase II was planned to extend the program to other states, however more financial and technical support was needed in terms of logistics, surveillance and basic research; therefore this program stopped in 2000. (Data from a report by Dr.Nawal Kurdufani, director of the project).

Lessons Learned from the Previous Program:

1. RHD control programs need to be modified to involve primary as well as secondary prevention.
2. More advocacy is needed, namely by involving local and international nongovernmental organizations (NGOs), the public and the patients.
3. More internal will and cooperation with regional organizations from countries with similarly high RHD prevalence are needed in order to assure continuity.

The New RHD Control Program: ASAP

In 2012 a new program for RHD control: Awareness, Surveillance, Advocacy and Prevention (ASAP) adopted from the Pan African Society of Cardiology (PASCAR) and the World Heart Federation was initiated by the working group on pediatric cardiology of the Sudan Heart Society in collaboration with the Sudanese Association of Pediatricians and the Ministry of Health.

Features of ASAP Program:

1. Adoption of Primary Prevention based on clinical diagnosis of bacterial pharyngitis for the first time in contrast to previous programs which only adopted secondary prevention
2. Cooperation with African , Indian, Australian and other countries with similarly high prevalence of RHD in close collaboration with the World Heart Federation.
3. More internal advocacy through national nongovernmental organizations and scientific societies.

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Objectives of ASAP:

General Objective: (adopted from the World Heart Federation)

To decrease the mortality of RHD in Sudan by 25% by the year 2025 in patients less than 25 years of age.

Specific Objectives:

To establish an Awareness, Surveillance, Advocacy and Prevention (ASAP)program for RHD in Sudan through the following:

1. Establishing an awareness program about RHD in Khartoum and States:

2. Training of health personnel on the new management polices including physicians, nurses, medical assistants.

3. Establishing a national registry for RHD.

4.Establishing screening programs for RHD for school children in Khartoum and States.

5. Establishing strong advocacy through social, political and media channels.

6. Adoption of diagnostic policy for bacterial pharyngitis based on the clinical findings of:

Sore throat in the absence of runny nose in patients 4-18 years of age.

The treatment of these patients will be a single intramuscular injection of benzathine penicillin after sensitivity testing.

What has been actually executed in ASAP-Sudan?

1. A board for RHD control is formed, chaired by Professor Abdulmonuem al seed and includes in addition: Dr.Saad Subahi (President of Sudan Heart Society), Dr.Elsadig Mohamed (Ministy of Health), Professor Mohamed S Alkhaleefa,Dr.Ahmed Ali Sulaiman (Al Shaab Teaching Hospital) and the author.

2. Protocols of the program has been written and approved by MOH to be included in School Health and Noncummnicable Disease (NCD) programs.

3. Manuals, brochures and teaching material had been designed and printed funded by charity groups including Sudanese Children Heart Society (http://sudankidsheart.com/en/index.html) and Sudan Heart Association.(Figure 1)

4.The program was discussed with the World Health Organization (WHO)-Sudan office and it was inserted into the NCD Plan of Darfur State. WHO funded the workshops (training of trainers) and educational materials. The workshop was conducted in May 2013.

5. The program is implemented by the MOH-Khartoum State: workshops for physicians and for school teachers were conducted in February 2013 (Figure 2).

6. The program is included in the curriculum of medical students at University of Khartoum.

7.Awareness materials were printed and distributed by medical students and media in limited rural areas.

9. School awareness days were conducted in collaboration with the Cardiac Care Organization, printed awareness material as well as lectures given to pupils and teaschers.

ASAP-Sudan Future Plans:

1.Fund raising activities targeting local and international organizations.

2. Seeking technical help in order to initiate a registry.

3. Conducting awareness campaigns through media.

4. Establishment of RHD Clinics and Control Offices in Khartoum and States.

5.Survelance programs including clinical and echocardiographic screening in highly endemic states.

Conclusion:

RHD control program based on awareness, surveillance, advocacy , primary and secondary prevention is established. Continuity of the program needs financial, technical and logistic support from scientific societies, governmental and non governmental organizations.

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