RHEUMATIC HEART DISEASE

Sudan Rheumatic Heart Disease Control Initiative: achievements and challenges: 2012-2017. Sudan RHD Control Committee

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Introduction:

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) constitute significant public health problems in the Sudan with an incidence of 100 per 100000 per year and a prevalence of 10.2 per 1000 population in 1992. (1) The Federal Ministry of Health (MOH)-Sudan annual report in 2011 revealed that the total number of patients seen with ARF in out-patients clinics was 36877, with 11976 seen in Khartoum State followed by Western States [Darfur and Kordofan] (9170) (2). Pediatric referral hospitals reported that 95% of patients with RHD have severe forms of valve disease and 50% of patients were not compliant with secondary prophylaxis. Many patients are seen for the first time with adverse echocardiographic (echo) characteristic such as low ejection fraction and severe pulmonary hypertension, which lead to adverse surgical outcomes (3).

The World Health Organization (WHO) Program for RHD control in Sudan ended in1990 (4). From that time and up to 2012 there was no active program for RHD control. In 2012, a national initiative led by the RHD Control Committee in collaboration with the Ministry of Health was established.

This report summarizes the work of this committee in the period 2012-2017.

Establishment of the National Committee of RHD Control and Program Approval:

In June 16/2012 a group of pediatric and adult cardiologists, pediatricians, the Ministry of Health (MOH) head of Curative Medicine Department and representatives of the Sudan Heart Society and Sudanese Association of Pediatricians held a foundation meeting for RHD Control at Al Ribat University. Professor Abdelmoneim Elseed delivered a talk on RHD and the urgency to have a control program in Sudan. Professor Sulafa Ali presented a proposal for RHD Control based on the African experience of Awareness, Surveillance, Advocacy and Prevention (ASAP) (5).

The main outcomes of this meeting were:

1. It was felt that policy and advocacy are needed rather than money for the initial stage.
2. The concept of primary prevention was adopted. for the first time in the Sudan
3. A draft of the proposal needs to be submitted for evaluation and approval by the MOH.

On July 10/2012, the Advisory Committee on Cardiovascular Disease of the MOH approved the program that included primary and secondary prevention protocols and the program was launched. (6, 7)

Program Implementation: Achievements:

1. RHD Committee Work:

The committee was extended to include MOH departments of Non-communicable Disease (NCD) School Health, Health Promotion and Drug Supplies as well as nongovernmental organizations. The Committee meets 2-4 times per year at the NCD office of the MOH. Up to date, the Committee works on a voluntary basis with no dedicated funds or administrative assistance acting as a technical advisory group to the MOH- NCD Department and recognized by the World Heart Federation who visited the committee in 2014 (Photo 1)



Photo 1:The RHD Committee meeting with World Heart Federation RHD Program Director in July 2014. From right to left: Dr.Lamia Eltigani, Sudan WHO office, Alice G Gasser (WHF), Drs. Sulafa Ali, Ahmed Elsayed and Manal El Imam (authors and RHD Committee members)

In 2015, a proposal to give the committee an official status was presented to the MOH, director of Primary Health Care. The outlines of this proposal included the following: The mission and vision of the RHD Control Program, the objectives and tools, proposed hierarchy, reporting and accountability of the committee. Although the committee could not get an official nomination by the MOH, however, the MOH continued to provide technical support to the Committee.

2. RHD Training Materials:

A full package of training materials were designed and printed based on charity donations from the following organizations:

1. Sudanese Children's Heart Society (SCHS) (www.sudankidsheart.org)
2. Sudanese Association of Pediatricians
3. Sudan Heart Society
4. Federal and Khartoum Ministries of Health
5. Individual donations (artists and designers)

Training materials included the following: (can be found at www.sudankidsheart.org)

1. Acute Rheumatic Fever and Rheumatic Heart Disease: Sudan's Guidelines for Diagnosis, Management and

Prevention (authored by: Sulafa Ali, Mohamed S Alkhalifa and Siragedeen M Kheir,First edition 2015, second edition 2017)

2. Rheumatic Heart Disease for Health Personnel: simplified Arabic booklet
3. Posters on management and prevention: for physicians and nurses
4. Training modules: modules for physicians, nurses and medical assistants (Arabic) and health promoters (Arabic) updated in 2017 and include:
   A. Diagnosis and management of sore throat (primary prevention)
   B. Diagnosis and management of Acute Rheumatic Fever (secondary prevention)
   C. How to administer Benzathine penicillin G.

3. Training Workshops:

i. Physicians: About 40 workshops were conducted for physicians in Khartoum , Niyala, Al Obeid and Port Sudan with a total number of about 2500 participants. A few were funded by Khartoum Ministry of Health but most were funded by charities or affiliated to scientific conferences of Pediatrics and Cardiology.(Photo 2)



Photo2: Training workshop for physicians of target states. From left to right: Dr.Ahmed Elsayed, Professor Sirageldin M Kheir, Professor Mohamed S Alkhalifa and Professor Sulafa Ali (authors and RHD Committee members) with other physicians.

ii. Medical Assistants: in 2016, the World Health Organization (WHO) regional office donated 10 000 US Dollars to the program (through the MOH) for training of medical assistants in 3 states. The first trainer's workshop was conducted in February 2017 and included 35 physicians (from Khartoum and the targeted states) trained to train the medical assistants. (Photo3)The first medical assistant's workshop was held in Al Obeid-North Kordofan on February 28/2017. Two more workshops are planned to be in Al Fashir and Kosti targeting 120 medical assistants.



Photo3: Trainers workshop: 35 physicians were trained to train medical assistants in 3 target states, funded by the World Health Organization.

iii. Health Promoters: In Niyala and South Kordofan, pediatricians championed the insertion of RHD in the packages of Integrated Management of Childhood Diseases (IMCI) and Mother and Child Health programs and managed to train 200 promoters and distributed over 50000 posters.

4. Training of Physicians in Echocardiography:

Hospital registry had shown that RHD is mainly prevalent in Kordofan and Darfur States rather than Khartoum, therefore, we called a pediatrician from South Darfur who had a focused course for 2 months on RHD echo using standard and hand held machine. She managed to establish an RHD clinic in Niylala. Another pediatirician from North Kordofan received 6 month training in Pediatric Cardiology and echo and is now running a clinic in Al Obeid.

5. Public Awareness:

Public awareness materials were designed and printed by charities (see 2 above). They include posters, teacher pamphlets and promotional video and can be accessed at www.sudankidsheart.org. The RHD Control Committee requested the MOH to dedicate a National Day for RHD Control (Juy 17) and 2 campaigns were carried on that day in 2014 and 2015 (Photo 4) which was targeted to poor communities in inner Khartoum.



Photo 4: The National Day of RHD Control celebration in July 2015 at Mayo area, Khartoum

In 2017, the Minister of Health of North Kordofan was approached through the Sudanese Association of Pediatricians during their annual conference in Port Sudan, he agreed to fund an awareness, screening and training campaign in 25 villages in North Kordofan. The campaign screened 3300 people (4-40 years) by hand held echo machines donated to the SCHS by the Sudanese American Medical Association (SAMA- see below). For the first time, the screening included both children and young adults. Eighty one medical assistants were trained and given a manual on diagnosis and management of RHD.



Photo5: Medical assistants trained in North Kordofan village carrying posters and manuals. Trainer is Dr.Sara Domi (sitting on right) February 2017

6. Advocacy:

To strengthen public, political and medical attention to RHD, a drama film was produced by the SCHS (http://sudankidsheart.org/index.php/2014-06-11-11-15-50/rhd-film.html). Two documentary films were produced that stress the importance of echo screening using hand held machines.(Rheumatic Heart Disease: a Silent Killer: (https://www.youtube.com/watch?v=rBiwAhWn8Ro).

7. Collaboration with Regional and International Organizations:

I. Pan African Society of Cardiology (PASCAR):

i. **The Primary Prevention Workshop:**
PASCAR in collaboration with the World Heart Federation (WHF), donated 2000 US dollars to the SCHS for primary prevention advocacy. A workshop was carried at Corinthia Hotel in Khartoum in January 2015 with participation of PASCAR president, Professor Bongani Mayosi, Egyptian President of RHD Program Dr.Alaa Al Ghamrawi. Sudanese Association of Ear, Nose and Throat , Pediatric and Heart Societies, MOH departments of IMCI ,non-communicable disease, and drug supply were all present. Recommendations of this workshop helped to introduce sore throat in IMCI and to highlight the need to supply good quality benzathine penicillin in Sudan.(photo 6). Letters were written to Primary Health Care and Drug Supplies Departments asking for inclusion of benzathine penicillin in the free drug list (it was already in the essential drug list) and for importing good quality Penicillin. Consequently, the drug was included in the free drug list.



Photo 6: The Sore Throat workshop, January 2015. From right to left: Professor Bongani Mayosi, President of PASAR, Professor Abdelmoneim Elseed (author, RHD Committee), Professor Siragedeen M Khair (author, RHD Committee), Dr. Abdullah Al Amin, Cardiothoacic (Medani Heart Center), Dr.Mohamed Al Amin (Pediatric Cardiologist (Medani Heart Center). Front: Dr.Satti Abdelrahim, President of Sudanese Association of Pediatricians author, RHD Committee and Professor Sulafa Ali (author, RHD Committee)

ii. **PASCAR-African Union Joint Meeting: The Addis Ababa Communiqué**:
PASCAR invited 2 of the RHD Committee members (Sulafa Ali and Ahmed Elsayed) to attend the Addis Ababa Communiqué on RHD , a joint activity with the African Union. Three episodes were carried in 2015 ,2016 and 2017 where 7 key actions were proposed for RHD Control (8).Sulafa Ali was appointed as a lead for Action Group 2 which deals with Benzathine Penicillin availability and use in Africa. She was also asked to design a training module for ARF/RHD and Benzathine Penicillin Administration to be implemented for training of African health workers.

II. The World Heart Federation (WHF):

WHF staff visited Sudan in 2014 and attended the National RHD Control Day and the committee meeting (Photo1). In 2014 WHF invited Sulafa Ali to present Sudan's RHD Program at the World Congress on Cardiology in Melbourne. In May 2015, Sudan Minister of Health chaired a side event on RHD at the World Health Assembly in Geneva organized by WHF and Dr. Sulafa Ali gave a presentation on the Sudanese program. In 2016, WHF invited Sulafa Ali to participate in writing a document: Roadmap to RHD Control (in press) and in 2017, they asked the RHD Committee to lead an advocacy campaign in support of the proposed RHD Resolution , planned to be discussed by WHO in June 2017.

III. The Sudanese American Medical Association (SAMA):

SAMA expressed their interest in collaborating with a charity organization to support the Sudanese RHD Program and donated 2 hand held echo machines for the SCHS. The machines were used by the society in 3 projects:

a. Screening of children in Niyala camps : in collaboration with the Sudan Heart Society, a mission to Niyala was conducted and pilot study in camps for internally displaced people revealed that there is a high frequency of subclinical rheumatic heart disease. An Echo screening study including 4515 school children revealed an echo prevalence in Khartoum of 0.3 per 1000 and in Niyala of 33 per 1000.(unpublished data)
b. Establishing a sentinel site for RHD Control in Al Gazirah State-Sudan: this is a research project aiming to measure the echo prevalence of RHD in Al Gazirah. Echo screening was conducted for 1300 school children; health education at schools. Phase 1 finished in February 2017. (photo 7)



Photo 7: Dr. Mohamed Hassan performing hand held echo screening for a school child from Al Managil, Gazirah, Sudan.

c. Echo screening, health awareness and training of health personnel in North Kordofan villages: this is a project funded by North Kordofan Ministry of Health conducted in February 2017 (see photo 5 above) where 3300 people were screened.

A 3rd hand held echo machine was donated by the Sudanese Doctors in Abu Dhabi to the SCHS in January 2017.

8. RHD Registry:

A proposal to initiate a Registry for RHD was submitted to the Sudan Heart Society in 2016. An Electronic database was established, so far implemented in Jafar Ibn Ouf Children's Hospital and Sudan Heart Centers. The total number of patients registered is about 900. The registry helped mapping RHD hot spots and revealed that White Nile, Kordofan, Sennar, Darfur have the heaviest burden of RHD, followed by Al Gazirah and Blue Nile states.(Table 1 Ref 9)

State	Population	No. of Cases	Cases /100,000
White Nile	1,730,588	54	3.1
Kodrofan	4,327,396	120	2.8
Sennar	1,285,058	23	1.8
Darfur	7,515,445	125	1.7
Al Gazira	3,575,280	56	1.6
Blue Nile	832,112	13	1.6
Other states		5-10	<1.5

Table 1: RHD frequency per 100 000 population according to patients' residence for 478 patients

9. Integration of RHD into MOH Programs:

A proposal has been submitted to the MOH Child Health Department to insert treatment of sore throat into the IMCI program, and RHD has been inserted into the PEN (Package of Essential Non communicable Disease). However, these programs have yet to be implemented and the integration has not yet been indorsed to the concerned departments.
The RHD Committee recognizes the need to insert RHD package into Mother and Child Health (MCH) programs since RHD is an important cause of maternal mortality. A subcommittee on RHD in Pregnancy was formed and posters and pamphlets have been designed for training of midwives and physicians.
The program was included in the Introductory Course that is delivered to newly appointed house-officers.

10. Introducing RHD Control Guidelines in Medical and Health Schools Curricula:

An Arabic RHD Module have been submitted to the Academy of Health Sciences (Federal Ministry of Health) to be inserted in their curriculum. Updated English modules of RHD diagnosis, management and prevention based on the updated Sudan's guidelines were offered to many Medical Colleges in Khartoum and states through personal communications in order to be included in undergraduate curricula.

11. Informal Communications:

A WhatsApp group that includes the RHD Committee members as well as a network of physicians working in Sudan's remote states where RHD is endemic was formed.
The group consists of 23 doctors; most of them received RHD prevention training in Khartoum. The group shares educational materials, workshop news and also shares patients'
data for registration.

Challenges Facing RHD Control Program:

1. The lack of official nomination, administrative assistance and a dedicated office.
2. How to secure regular and sustained funds sufficient for the backbone activities and marketing of time limited programs
3. How to activate and implement integration of RHD into the running MOH programs to ensure programs sustainability.

Priorities for Future Directions:

National Level:

1. Nomination and recognition of the RHD Committee as expert higher forum leading the strategic success for RHD control program
2. Continue communication with partners, to involve patients and families and more political and financial support.
3. Sharing experience and knowledge as well as replication of best practices (e.g. Niayla, Al Gazirah and Kordofan projects) in other areas.
4. Active implementation of RHD Module integrated into IMCI, MCH, PEN and other related MOH programs

Regional and International Levels:

1. Continue working with regional and international organizations to promote RHD in the global health community aiming to get WHO technical support, hopefully, a resolution on RHD.
2. Work with PASCAR and African Union to secure sustainable RHD Programs in Africa

3. Generation of knowledge by high-standard research and publications for sound ,evidence- based practice

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