Rebuilding the Rheumatic Heart Disease Program in Sudan

This is a story of my country. I became a pediatric cardiologist to help the children in Sudan. I was trained in Saudi Arabia and had a good job, a good salary, and a big, nice apartment, but I wanted to come back to Sudan and help the children here. When I came back, I was focusing on high-tech things—we set up the center here with echocardiography and interventional cardiac catheterization. We always considered rheumatic heart disease (RHD) as a chronic pain with no remedy! The only program for RHD control in 1986 was a World Health Organization campaign involving 16 countries including Sudan that was conducted in collaboration with the Ministry of Health (MOH). The campaign was aimed at screening and raising awareness with an emphasis on secondary prophylaxis. Screening of 13,322 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.

When I attended the 2012 World Congress of Cardiology in Dubai, it was to present a paper about pediatric arrhythmias. However, I happened to meet the World Heart Federation RF/RHD Working Group, and this meeting has changed my concepts about RHD to a disease that attracts the attention. I found myself part of a big family caring about RHD.

In fact, some of us were trying to forget RHD! We go to other countries and learn about all of these fancy cardiac technologies and we come back home only to find these hopeless, pitiful cases. We collect a lot of money to get these patients surgery—valve replacement costs about $5,000—but they come back a few months later with a hemorrhage, because the anticoagulant levels were not controlled, or a stroke, because they did not take the anticoagulants at all. Moreover, after a marvelous repair by our surgeon, the disease recurs in the same or other valves. In the end, it is just untreatable.

I was fascinated when I was in Dubai and met the RHD group there. Right after the meeting all that I was doing was writing—I was writing the proposal for a RHD control program in Sudan. The program is mainly based on the ASAP Program proposed by the Pan African Society of Cardiology.

When I came back to Sudan, I talked to everyone, and I got help from many people, including my colleagues and our scientific societies (Sudan Heart Society and Sudanese Association of Pediatricians) as well as the MOH officials—we wanted to join all efforts to make a strong case. We presented the proposal to the MOH Advisory Council on Cardiology 2 months after Dubai, and they gave input and accepted it and then passed it to the vice minister of Health for his review.

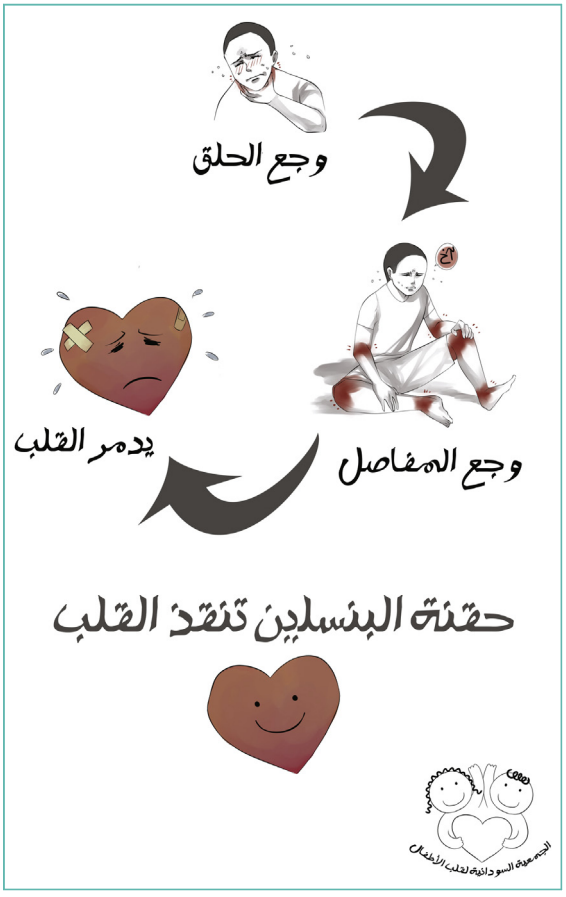

FIGURE 1. Brochure in Arabic for public awareness.

We started collecting some money through our charity group—The Sudanese Children's Heart Society [1]—and started publishing brochures for public awareness (Fig. 1). We distributed them through medical students when they made their rural rotations. As the program was inserted in their academic courses, students were very keen to share; many of them had chosen to conduct their fifth-year research on RHD awareness. We also utilize the website of our society as a resource for health education for both parents and physicians about RHD.

Once the vice minister had accepted the proposal, Khartoum state organized its first training workshop for 50 health professionals in the MOH, including primary care physicians and pharmacists in February 2013. We met with the school health department in Khartoum state. They have a health education program for teachers.

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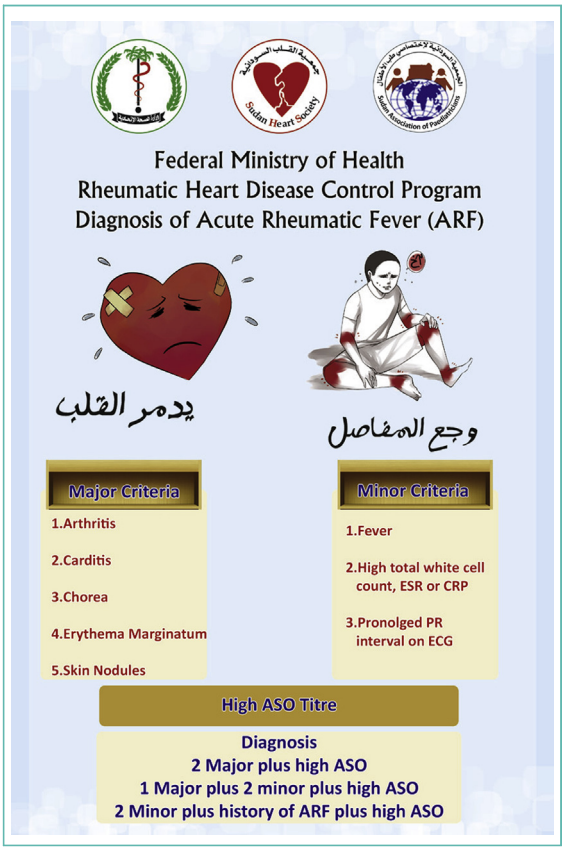

FIGURE 2. Flow chart included in manual for secondary care physicians.

We developed a manual for teachers and the ministry inserted a 2-h session on RHD into that course; 200 teachers have taken it so far.

We talked to the World Health Organization office here, and at the last minute, they integrated the RHD program into their PEN (Package of Essential NCD interventions for primary care in low-resource settings) pilot for Darfur. They were very helpful. In June 2013, the ministry had the first train-the-trainer course for 20 physicians from Darfur, using the manuals we developed for primary and secondary care (Fig. 2). These trainers will in turn train fellow physicians and nurses. They were also given special manuals in Arabic made to train paramedical staff.

We also have trainee doctors to deliver lectures on RHD at secondary and tertiary hospitals around Khartoum and distribute the manuals there. They are also gathering information on the level of knowledge of health professionals, and they are finding that it is very low because there has been no active program for RHD in the last 12 years.

Very recently, we sat with the director of Therapeutic Medicine Department at the MOH, and we planned the roll-out of the program to the remaining states: train-the-trainer workshops for 20 physicians in each state. After that, we need an awareness campaign. We have made some broadcasts here and there but not really a full campaign.

Sudan Heart Institute has started a simple register based on RHDnet [2]. We need someone to do data entry; we physicians have collected about 400 cases so far, and although the data are not complete, it is a start. Sometimes it is hard for us to be patient because we are thinking only about RHD, and the MOH has many other things to think about, but the ministry has really listened and things are moving. We are making good progress!

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