Towards a uniform plan for the control of rheumatic fever and rheumatic heart disease in Africa – the Awareness Surveillance Advocacy Prevention (A.S.A.P.) Programme

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Over the last 150 years the developed world has experienced a dramatic decline in the incidence and prevalence of rheumatic fever and rheumatic heart disease (RF/RHD) through improved living conditions and the widespread use of penicillin for the treatment of streptococcal pharyngitis. Despite the proven effectiveness and availability of penicillin for both primary and secondary prevention of RF, developing countries continue to face unacceptably high rates of the disease.[1]

RF/RHD is the most common cardiovascular disease in children and young adults in the world, because 80% of the world's population live in developing countries where the disease is still rampant. Recent research estimates that RF/RHD affects about 15.6 million people worldwide, with 282 000 new cases and 233 000 deaths each year. There are 2.4 million affected children between 5 and 14 years of age in developing countries, 1 million of whom live in sub-Saharan Africa, making the continent the major RF/RHD hotspot.[2]

A recent systematic review of prevalence studies found exceptionally high rates of RHD in sub-Saharan Africa, with the highest level in Kinshasa, DRC at 14/1 000 school-aged children.[3,4] The only prevalence data available on RHD for South Africa are derived from two studies dating back to 1972 and 1984 which estimated the prevalence using clinical examination (no echocardiography) in Soweto (Johannesburg) and Inanda (Durban) at 7.1/1 000 schoolchildren and 1.0/1 000 schoolchildren, respectively.[5,6]

As a middle-income country South Africa would be expected to have more capacity than other countries in the region for developing and implementing a national RF/RHD intervention programme; however, South Africa has fallen short in its control efforts. A local assessment of the country's national guidelines[7] on the secondary prevention of RF found that as of 2004, little progress had been made towards implementing the guidelines which have been in existence since 1997.[7] Concerted efforts to control RF/RHD must be bolstered as soon as possible in the developing world so that progress can be made towards eradicating what is an entirely preventable disease.

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Programme description

The **A**wareness, **S**urveillance, **A**dvocacy, **P**revention (A.S.A.P.) proposal is a comprehensive programme for the control of RF and RHD that was adopted at the 1st All Africa Workshop on Rheumatic Fever and Rheumatic Heart Disease at the Champagne Sports Resort, Drakensberg, South Africa on 15 - 16 October 2005. The meeting was convened by the Pan African Society of Cardiology (PASCAR), sponsored by the national Department of Health of South Africa, the Medical Research Council of South Africa, the World Health Organization - Africa Office (WHO-AFRO), and the World Heart Federation, and endorsed by the South African Heart Association and the Paediatric Cardiology Society of South Africa. The workshop was attended by a total of 42 delegates, from Angola (1), Cameroon (1), Congo (1), Egypt (1), Ghana (1), Mozambique (2), Nigeria (3), South Africa (27), and Zimbabwe (2). There were also speakers from Australia (1), the Netherlands (1), and the USA (1).

The components of the A.S.A.P. model adopted at the workshop include: **A**wareness raising, a **S**urveillance system, an **A**dvocacy campaign, and a **P**reventio n programme.

The objective for developing A.S.A.P. is to create a simple, modular but comprehensive model for RF/RHD control in Africa, based on interventions of proven efficacy, which can be adopted in part or *in toto* by national departments of health or non-governmental organisations with a commitment to reducing the burden of disease attributable to RF/RHD in Africa. This document presents: (*i*) the rationale; (*ii*) barriers; (*iii*) best practice of what works; and (*iv*) action points (online) in relation to the four focus areas of A.S.A.P.

Awareness raising

Rationale

RF/RHD case detection is an essential component of the A.S.A.P. model. In the absence of adequate case detection, the magnitude of the RF/RHD burden cannot be estimated accurately and undetected cases will not receive treatment and antibiotic prophylaxis. Maximised case detection within a community requires that all key members of the community be aware and

alert to the risks and signs of both the preceding streptococcal pharyngitis and to RF. Awareness must be highest among child caregivers, teachers and health care workers, especially those likely to be the initial point of contact with the health care system.

Barriers

There are several explanations for the low levels of awareness of RF/RHD in communities often most affected by the disease.[7] One of these barriers arises from the reality that communities at highest risk for RF/RHD are also frequently burdened with high rates of other major diseases such as HIV/AIDS and tuberculosis. These diseases inevitably receive higher priority from those in charge of distributing scarce resources for disease-control programmes. Inadequate resources and the lack of prioritisation of RF/RHD educational programmes have effectively maintained a public that is largely ignorant of the causes, symptoms and risks associated with RF/RHD.[7]

Another barrier was identified through interviews with children who have suffered an acute attack of RF and their family members in the Western Cape of South Africa.[7] It is assumed that patients and their parents receive extensive information on the causes, course of disease, and importance of adhering to secondary prophylaxis from the treating physician at the time of diagnosis. Yet the interviews revealed high levels of ignorance among this group suggesting that they either had not received the appropriate information, or had not understood the information when it was given to them.[7] The complex aetiology and pathogenesis of this disease make knowledge transfer to the patient difficult but no less essential.

Best practice

Community awareness has been found to be essential for case detection. A 10-year educational programme, undertaken in two French Caribbean Islands beginning in 1981 which sought to reduce the incidence of RF, provides evidence for the link between awareness and case detection.[8] One year after implementing an educational campaign that consisted of widely distributed pamphlets and posters, television advertisements and educational videos, the reported cases of RF increased 10 - 20%. This increase was entirely attributed to an increased awareness of the disease in the community. The study[8] also found that over the course of the 10-year educational intervention, the incidence of RF progressively declined on both islands by 74 - 78%. These findings support the argument that a community-based educational programme aimed at raising awareness of RF is essential for case detection and may be a critical first step in a comprehensive plan for RF/RHD control.

The Bach study[8] also highlights the importance of addressing the elements of RF/RHD control not as discrete entities but as interconnected principles with efficacy levels reliant on the successful execution of activities in all areas. The example above illustrates the importance of raising community awareness to improve incidence reporting. The reciprocal relationship also holds, whereby incidence reporting is a valuable tool for monitoring and evaluation of the effectiveness of an educational programme in reducing the burden of RF/RHD. In order to take advantage of this reciprocal relationship, community RF/RHD control programmes should combine the efforts of raising awareness with incidence reporting.

Awareness among health care workers of the importance of treating streptococcal pharyngitis with antibiotics, the appropriate method for diagnosing RF (using the revised Jones criteria),[1] and the obligation of case reporting to local authorities, where RF is a notifiable condition (such as in South Africa), is also needed for a functional RF/RHD control system.

Awareness action plan

See www.pascar.org

Surveillance

Rationale

As highlighted by the 2001 World Health Organization (WHO) Report on RF and RHD,[9] collection of epidemiological data is a crucial step in planning and implementing a national programme for the prevention and control of RF and RHD. Epidemiological data allow policymakers and practitioners to identify groups or locations that are most affected by RF/RHD in order to direct and concentrate control efforts appropriately. Ongoing surveillance of the incidence of RF and the prevalence of RHD is therefore the second pillar of the A.S.A.P. model, which has a symbiotic relationship with an awareness-raising campaign, the critical first step.

The current state of RF/RHD surveillance programmes in countries most affected by the disease is deficient.[1] The aforementioned systematic review[4] of RHD prevalence studies highlights the lack of quality prevalence data and the absence of reports on RF outbreaks from developing countries. The scarcity of reliable surveillance data has been one of many barriers preventing developing countries from mounting an appropriate and effective response to combat RF/RHD. Therefore, an immediate priority for getting the A.S.A.P. programme off the ground is to bolster surveillance programmes in a step-by-step fashion to achieve the establishment of a sustainable comprehensive surveillance system.

Barriers

Barriers to effective surveillance of RF/RHD are multiple but tend to be rooted in the following: (*i*) lack of surveillance capacity; (*ii*) lack of awareness among health professionals regarding their obligation to report cases;[7] (*iii*) lack of

awareness among the public to ensure accurate case detection;[7] and (*iv*) lack of political will on the part of national departments of health.

Best practice – the stepwise approach to surveillance

The stepwise approach to RF/RHD surveillance advocated in the A.S.A.P. programme is modelled after the 'WHO STEPwise approach' used to collect epidemiological data on risk factors for non-communicable diseases in developing countries.[10] The approach is based on the premise that in resource-constrained settings the collection of a small amount of accurate data is more valuable than large quantities of inaccurate data or no data at all. The ultimate goal of the stepwise approach is to eventually create a sustainable comprehensive national and continental surveillance system by achieving smaller, more realistic goals one step at a time.

The following steps are recommended to implement a RF/RHD surveillance system. The achievement of each subsequent step requires increased surveillance capacity so the plan should be followed in a progressive manner. Each step requires the establishment of several sentinel sites that capture high-risk populations living in a variety of environmental conditions. In order to evaluate the effects of various environmental conditions on the risk of developing RF, sentinel sites should capture rural, peri-urban and urban populations: Step 1: Creation and maintenance of RF/RHD registers, Step 2: Prospective RF incidence surveys, Step 3: Cross-sectional RHD prevalence surveys, and Step 4: Epidemiology of streptococcal throat and skin infections.

Step 1. The creation and maintenance of a register or database of RF/RHD cases is a proven strategy for the secondary prevention of the disease.[11] It can also be used as a tool for case management to track cases and ensure that they are receiving appropriate prevention and treatment. Registers have been implemented successfully in several developing countries at low cost using existing infrastructure. The establishment of registers is a minimum requirement that can be achieved in almost any setting where the will to establish a RF/RHD control programme exists. The registers may be used as a basis for incidence (step 2) and prevalence (step 3) studies of RF/RHD.

Step 2. Owing to their intrinsic relatedness, prospective RF incidence studies should be incorporated into a health education campaign aimed at raising awareness of RF/RHD. The incidence studies will monitor and evaluate the efficacy of the awareness campaign, while the awareness campaign will improve the level of case detection thereby improving the quality of incidence data.

The A.S.A.P. model recommends as step 2 of the surveillance initiative, the implementation of a medium-term pilot programme (e.g. 5 years) that combines community awareness building with incidence surveillance at a sentinel site. Elements of the programme that are continuous over several years include health education activities and passive incidence reporting through pre-existing reporting systems. Every 3 years, beginning 1 year after the implementation of the education programme (to maximise case detection), a formal prospective incidence survey relying on active surveillance activities should be undertaken. The goals of this intermittent active surveillance are: (*i*) to obtain more accurate incidence data (including baseline data); (*ii*) to improve existing reporting practices by highlighting discrepancies between active and passive surveillance datasets; and (*iii*) to more accurately monitor and evaluate the impact of the awareness campaign on RF incidence.

Following completion of the initial cycle of the pilot programme at a sentinel site, a permanent system should be implemented at national level for maintaining community awareness of RF/RHD and for maintaining the accuracy of passive disease reporting.

Step 3. A prevalence study is an important element in the progression of surveillance activities as it provides a snapshot view of the burden of disease in a defined population. The recommended study design is one that utilises echocardiography to detect clinical and subclinical evidence of RHD in school-aged children in a defined population. The resources needed for executing a prevalence study are substantial owing to the required investment in echocardiography machines and trained staff.

Step 4. The fourth step is to monitor the epidemiology of streptococcal throat and skin infections in the population. Patterns of streptococcal infection, related to infection rates and serological typing, exhibit seasonal and geographical variations. Describing these variations provides a more complete understanding of the epidemiology of RF/RHD, thereby improving the capacity to identify high-risk populations and increasing the likelihood of detecting outbreaks. This information is vital for the development of effective vaccines for streptococcal infection.

According to the revised Jones criteria, laboratory confirmation of RF requires evidence of a preceding group A streptococcal (GAS) infection – indicated by at least 1 elevated antibody titre. The most common antibody tests include anti-streptolysin-O (ASOT) and antideoxyribonuclease B, with serum levels peaking 3 - 4 weeks after an acute RF attack.[9] Therefore, laboratory services needed to support a GAS monitoring programme include the ability to test for antibodies to streptococcus, ability to culture throat swab samples, and the capacity to provide GAS serological and genetic typing. Because of the absence and/or inadequate capacity of the microbiological infrastructure in developing countries, the fulfillment of this step will require significant improvements in all other surveillance areas and discrete investment to improve laboratory capacity at all service levels.

The 2001 WHO report on RF/RHD[9] highlights the critical role that microbiological laboratories play in both primary and

secondary RF/RHD prevention programmes. The report also provides recommendations for the establishment of laboratory capacity at each level of care. Recommended levels range from peripheral laboratory facilities capable of immediate testing to international reference laboratories capable of co-ordinating regional GAS epidemiological information.

Surveillance action plan

See www.pascar.org

Advocacy

Rationale

Effective methods of RF/RHD prevention have been available for over 50 years, yet the developing world has not succeeded in controlling the disease.[12,13] Conversely, the developed world has succeeded in nearly eradicating the disease, resulting in the unfortunate side-effect of de-emphasising the persistent toll it takes on populations around the globe. Advocacy is needed to reverse this trend and to spotlight the devastating effects of RF/RHD on the health of the majority of children worldwide.[2]

A population affected by RF/RHD that requires immediate attention and resources is the current cohort of patients with RHD who require medical and surgical intervention to repair or replace faulty heart valves.[14] There is also a need to provide facilities for monitoring of anticoagulation in patients who have received mechanical heart valves. The latter facilities are woefully inadequate in developing countries.[15]

Proper treatment for existing RHD must be prioritised alongside enhanced prevention efforts. Increased surveillance is urgently needed to quantify the burden associated with RHD in order to support the advocacy efforts needed to persuade governments to increase resources for the management of patients with rheumatic valve disease.

Barriers

The barriers preventing an adequate level of government prioritisation for RF/RHD include: (*i*) competition with larger-scale health problems; (*ii*) lack of reliable epidemiological data that can be used to quantify the burden of RF/RHD; (*iii*) lack of public demand for increased prioritisation because of low levels of awareness; and (*iv*) a drop in prioritisation of RF/RHD on the international health agenda.

Advocacy action plan

See Annex C www.pascar.org

Prevention

Rationale

The prevention of RF/RHD can be achieved through two discrete strategies, namely primary and secondary prevention. Primary prevention works by treating the preceding streptococcal infection with antibiotics. Secondary prevention is used after the initial RF attack to prevent the recurrence of RF and progression to RHD. Secondary prevention requires the prolonged or life-long administration of regular antibiotic injections. Both primary and secondary prevention strategies have been shown to be efficacious and cost-effective for the prevention of RF.[12,13]

Barriers

Some of the barriers that can make primary prevention programmes difficult in the developing world include: (*i*) lack of awareness among the public and health care providers with regard to the link between streptococcal infection and RF; (*ii*) lack of policy for the prevention of RF based on use of antibiotics in the appropriate setting; and (*iii*) the high prevalence of subclinical GAS infection.[1]

Some of the barriers to effective secondary prevention programmes include: (*i*) the burden of making regular trips to the clinic for penicillin injections; (*ii*) migration of patients in developing country settings, making continuity of care difficult; (*iii*) patient fear of intravenous injections; and (*iv*) perceived risk on the part of health care providers of inducing anaphylactic shock.[12]

Best practice

The prevention strategy recommended in the A.S.A.P. model is grounded in the evidence on efficacy and therefore advocates for the implementation of both primary and secondary prevention programmes in the developing country setting.[12,13] Because the A.S.A.P. model includes as one of its core principles the implementation of an education programme to increase awareness of RF/RHD, including primary prevention as one of its key messages does not require much additional investment. It is logical to implement all proven strategies to prevent the occurrence of RF whenever possible. The additional benefits gained through primary prevention add minimal costs to the programme yet yield the added benefit of preventing the burdensome and prolonged nature of secondary prevention for its benefactors.[13]

Prevention action plan

See www.pascar.org

Moving forward

Implementing national A.S.A.P. programmes

The first step to implementing a national A.S.A.P. programme is to create a National Advisory Committee on RF/RHD under the auspices of the Ministry of Health. The Committee would serve as the primary decision-making body of the programme and would be responsible for designing, implementing and adapting the A.S.A.P. model to fit the needs of the country. Committee members would consist of key stakeholders in the programme such as nurses, family physicians, paediatricians,

cardiologists, microbiologists, epidemiologists, policymakers, administrators and planners.

The initial task for the National Advisory Committee should be to perform an assessment of the current state of RF/RHD control in the country. This assessment should include: (*i*) the identification of specific barriers to control efforts; (*ii*) a review of the current investment and pattern of resource allocation for RF/RHD control; (*iii*) an assessment of the health infrastructure available to support programme activities; and (*iv*) any other situation analysis the Committee deems valuable. Once these assessments have been made, the Committee should then proceed with the design and implementation of specific elements of the A.S.A.P. programme. A timeline for the progressive implementation of programme activities will be an essential element to ensure an objective-led plan for RF/RHD control.

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