

The Importance of Awareness and Education in Prevention and Control of RHD

Liesl J. Zühlke^{*,†,‡}, Mark E. Engel^{*}

Cape Town, South Africa

ABSTRACT

Acute rheumatic fever and rheumatic heart disease are diseases of poverty, low socioeconomic status, and inadequate access to health care. These preventable diseases remain largely ignored by the developed world while they continue to cause significant mortality and morbidity in the developing world. In the face of no existing cure, we need to focus on prevention and control methods. To this end, creating awareness of the disease and its effects on millions of people in the world is critically important. In this review, we will outline the importance of these efforts, discuss the barriers to awareness and education, and highlight some important models in this arena. We strongly support awareness-raising and health promotion strategies as an integral part of a rheumatic heart disease prevention and control program.

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are diseases of poverty, low socioeconomic status, and poor access to health care that remain endemic in developing and emerging economies while being largely ignored by the developed world [1]. It is conservatively estimated that there are over 15 million cases of RHD worldwide, with 282,000 new cases and 233,000 deaths annually. Until such time that far-reaching socioeconomic changes take place throughout the world, and in the face of no existing cure, we need to focus on prevention and control methods that can help to stem the tide of ARF/RHD. Thus, the importance of creating awareness of the disease and its sequelae cannot be underestimated, particularly in resource-limited conditions. The importance of these efforts needs to be recognized and barriers to awareness and education understood and overcome while health promotion research for ARF and RHD is prioritized.

IMPORTANCE OF AWARENESS AND EDUCATION

Over the last 2 decades, increasing emphasis has been placed on health communication strategies that are collaboratively designed, implemented, and evaluated [2]. Consequently, various successful strategic health communications campaigns have been developed, notably in the human immunodeficiency virus/acquired immune deficiency syndrome arena. However, as regards ARF/RHD, it is well known that as the incidence of ARF waned in the developed world, so did the awareness of and attention to this global public health problem. This has resulted in limited funding for RHD activities, decrease in research and publications, and reduced mention of RHD in textbooks published in more affluent parts of the world [3]. This is despite the reality that although ARF and RHD are almost exclusively restricted to developing countries, they have mortality rates

comparable to that of rotavirus, and about 50% of that of malaria, and they are still the most common cause of acquired heart disease in the world [4,5].

Establishing the true burden of disease of RHD and ARF is particularly important when considering methods to control RHD, assigning priority to specific efforts, and informing policy. A key element of establishing the true burden of disease lies in case detection of both ARF and RHD. Maximized case detection within a community implies that all members of that community are aware of the presentation and diagnosis of the disease, with the highest awareness needed among healthcare workers at the primary healthcare level. In South Africa, where disease notification is mandatory, a review of notifications has demonstrated that the legal requirement to notify has not been sufficiently stressed nor has notification been correctly implemented, resulting in poor capture of the burden of ARF [6]. Studies have shown that ARF is underdiagnosed in primary healthcare clinics in developing countries and that there is an increasing burden of RHD on autopsy in the same population [7]. It is feasible that these studies demonstrate the real possibility of multiple missed diagnoses and their tragic consequences.

Improving community awareness has been demonstrated by programs incorporating public education campaigns into their RHD control strategies as a vital element. It is critical that public awareness of the role of group A streptococcal (GAS) pharyngitis and its potential consequences are addressed, as this will result in increased health-seeking behavior regarding sore throat as well as earlier presentation with signs and symptoms consistent with ARF. School and educational institutions should be targeted, as the most vulnerable population for GAS infections are school-aged children. These institutions have tremendous potential to improve the reach of primary and secondary prevention and case detection.

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Despite the fact that RHD is the leading cause of acquired heart disease in the world and a key contributor to the burden of chronic cardiovascular diseases in the world today [8], there remains insufficient political incentive to control global cardiovascular disease, let alone address cardiovascular diseases limited to the poor. Yet, the burden of disease has major health, economic, and even sociodevelopmental consequences [9]. A key priority is creating political awareness around this disease and building organizational structures to promote control activities that will be supported by national funding and concerted political will.

BARRIERS TO AWARENESS AND EDUCATION

It has been concerning to note from several reports that the level of awareness of ARF/RHD is low in the communities most affected by it. The vast majority of clinicians (87%) in a study from Tanzania felt that their patients and families were unaware of the consequences of untreated GAS infection [10]. Even patients with RHD had poor knowledge of the connection between GAS and RHD, a finding also prevalent in South Africa, and where most patients and their guardians had not yet heard of RHD until they were diagnosed with the condition, demonstrating a low level of awareness in the general community [11].

There are some possible explanations for this phenomenon. The countries dealing with RHD are, understandably, dealing with other serious health priorities. Only 38% of the respondents in the Tanzania study felt that their clinic prioritized the diagnosis and treatment of GAS infection; in fact, clinicians were in conflict over the possible inference with other priority health concerns such as malaria and tuberculosis [10]. Furthermore, the human immunodeficiency virus pandemic has inflicted untold mortality in sub-Saharan Africa. In addition, access to health care and healthcare resources are, almost by definition, restricted and under-resourced in these areas with endemic RHD. Faced with human resource and organizational crises in health in many parts of the world, it is clear that more resources in terms of staff and structure are needed to care for the millions of people living with RHD. In sub-Saharan Africa, it is claimed that the inadequacies in the health workforces are the greatest impediment to health, with a deficit of 2.4 million doctors and nurses [12]. Only 1.3% of the world's health workers care for people who experience 25% of the global disease burden. The consequences for some countries are dire, with completely inadequate services to rural and primary care settings, which are the very focus of an effective prevention and treatment program for ARF/RHD [13].

Another dichotomy is the high levels of ARF/RHD in the pockets of indigenous people living beside their more affluent neighbors. This stark disparity is evident in New Zealand and Australia [14,15], as well as in South Africa and Brazil, with high-income inequality rates among their populations [16]. Together with these disparities are gaps perpetuated in the training of medical personnel. Teaching

in the countries most affected by ARF/RHD tends to mimic that in developed countries and is unlikely to take into account differences in public, private, and primary healthcare strategies. It is crucial that medical education in developing countries be defined by the needs and services required by the majority of the people [17]. We have recently seen, though, that the importance of integrated primary healthcare services and management of chronic diseases is gaining momentum and the artificial dichotomy between diseases is slowly receding in favor of a combined approach that will benefit all conditions. This is of particular importance in 2013, following the U.N. Global Summit on Non-Communicable Diseases and as developing countries struggle with the impending (and rapidly approaching) burden of noncommunicable diseases [5,18]. This integration of comprehensive services, especially within existing and established primary and secondary healthcare structures, should be strongly supported by clinicians, policy makers, and the community.

Although physicians report attempts to educate patients on the causes of their disease, pathogenesis, and the importance of adhering to secondary prophylaxis, patients still have very low levels of understanding regarding the specifics of their disease. There are several coinciding factors involved. Although younger patients may not understand the complexity of the disease processes, this trend seemed to be evident in older patients as well. Also, caregivers accompanying patients are often different individuals on each visit to the clinic/hospital. Language also plays a very important role [19]. We need to recognize the importance of performing these explanations in the local language observing cultural observances and levels of literacy and understanding. Even complex concepts can be clearly understood, given appropriate communication strategies. Awareness of the patients' needs and cultural background should take precedence in the conversation around expectations of adherence and follow-up. It is known that physicians explanations and the level of patients' understanding significantly affect treatment adherence, treatment outcome, and patients' satisfaction [20]. We need to be critically aware of these issues when communicating with patients and their caregivers, select health information that is appropriate to the client's level of understanding, and employ a systematic approach utilizing a variety of mechanisms (e.g., printed material, displays, videos, and discussions) to educate and improve awareness in and stress motivating principles, cultural relevance, and feasibility.

Finally, RHD has not been called a disease "of social injustice" without good reason [21]. It has long fallen between the cracks, and without commercial interests or dynamic action groups to drive intervention, it remains a neglected disease. This has resulted in the lack of political will to significantly improve awareness and education of the disease in communities and schools. The onus thus falls on the medical community to take up the challenge of advocating for the return of diseases of the poor such as RHD to the political agenda.

BEST PRACTICE MODELS

Several programs have reshaped the landscape in terms of RHD control and achieved remarkable successes. The programs of the 1950s based in Baltimore and New York not only set the scene for RHD control activities, but they also gathered important epidemiological evidence to document important trends. A comprehensive community program was suggested by Griffith in 1949 [22] that stressed the importance of community organization to combat the disease, especially in the face of the socioeconomic, psychological, and epidemiological aspects of the disease. The importance of education in early case detection is emphasized, as well as utilizing lessons learned from other infectious diseases programs such as tuberculosis interventions. Although this community was experiencing a gradual decline in the incidence of ARF, these and other similar initiatives resulted in a precipitous fall in the incidence of ARF.

A remarkable model has been implemented by Martinique Guadeloupe and Cuba [11,23]. Here, a comprehensive 10-year plan was initiated with education, with awareness strategies at all levels, and with primary and secondary prevention delivered through a registry as the mainstays of the program. Communication efforts were strengthened by a multichannel approach, targeting several areas, as well as mass media, to reach as many people as possible. All health messages were coordinated centrally to ensure consistency, which also offered synergy to the campaign. In the French Caribbean Islands, a rapid decline in ARF incidence was achieved at modest cost and an overall reduction of ARF by 78% in Martinique and 74% in Guadeloupe. In Cuba, similar reductions in incidence of ARF, prevalence of RHD, and cost were followed-up for 5 years subsequent to the study. Years after the project ended, most of the measures initiated at the start of the program were still in place and occurrence of ARF/RHD remained low.

More recently, 2 programs initiated in and by communities affected by RHD have established important programs in their regions. The Pacific Rheumatic Heart Disease Control Program has focused on health education and promotion while stressing secondary prevention delivered through an effective register-based system [24]. Importantly, this program is now self-supporting and run by individuals from the Pacific Islands. Critical to the success of this program was identification of key priorities a priori and setting realistic and focused goals. This is key to eventual evaluation of such intricate community interventions. Education has been directed at all levels, and multiple channels have been used to disseminate information. Clinical care has also been addressed with the incorporation of clinical care coordination, standardized delivery methods, and case-finding activities [24,25].

The Pan-African Society of Cardiology convened a meeting of cardiologists from all over Africa in 2005 that resulted in a uniform plan for the control of RF and RHD in

Africa. That plan, the ASAP (Awareness Surveillance Advocacy Prevention) program, details the 4 pillars imperative in the goal to eradicate RHD “in our lifetime” [26,27]. The primary objective of this program was to create a simple, modular, but comprehensive model for RF/RHD control in Africa, building on the best evidence-based interventions, to be adopted by national departments of health and countries/organizations with a combined commitment to reducing the burden of disease attributable to RF/RHD in Africa. This program has galvanized efforts in Africa and the world [28] and has led the way to establishing demonstration sites across Africa [29]. Currently, a large multicenter study, coordinated from Cape Town and involving sites all over Africa and including India, the middle East, and South America, is seeking to collect prospective data and document the course of morbidity and mortality of this neglected disease [30]. Like the example of Boston and Baltimore in the 1950s, this study will be a source of valuable information for governments as they formulate policy and guidelines for the control and treatment of RHD.

STRATEGIES TO IMPROVE AWARENESS AND EDUCATION AROUND ARF/RHD

The key element in successful health program is strategic design. To improve health in a lasting and significant way, it is critical to initiate health promotion strategies that are collaboratively designed, locally adapted, implemented on multiple levels, and comprehensively evaluated [31]. Although it was initially thought that medical communication related only to the doctor addressing the patient, the medical monologue, we now see the limited reach this strategy has had. We have moved into the era of strategic communication characterized by multichannel integration, multiplicity of stakeholders, attention to evaluation, and evidence-based programming, and the use of mass media, social networks, and a conversational communication process [32].

Some important characteristics to consider follow:

- Integrated services with, for example, RHD and maternal and child health serviced by noncommunicable disease staff: Other aligned programs such as integrated management of childhood illnesses lends itself to incorporating important RHD messages such as sore throat diagnosis and management [33].
- Integrated communication messages: “Heart health for kids” includes not only RHD, but also healthy eating habits, exercise, and nonsmoking.
- Mobile phones and health: Africa’s mobile usage has been growing by almost 50% annually, which is faster than any other region of the world. Cellphone usage in Africa has jumped from 63 million users 2 years ago to 152 million today. This provides us a unique opportunity to educate people at a fraction of the cost of individual efforts while being language-, culture-, and age-sensitive [34,35].

- Role of electronic media and social networks such as Twitter and Facebook: Video sites such as YouTube have also made connections with the younger generation, the ones most at risk [36,37].
- Involvement of the local community is mandatory with a strong consultative process: It is particularly important in indigenous communities such as Aboriginal Australians or Yoruba tribes in Africa to respect cultural differences and observe religious and cultural practices [38].
- Increased attention to evaluation and evidenced-based programming: Finally, increased attention to evaluation and evidenced-based programming will provide much needed data to inform and strengthen the process. Evaluations of complex interventions are not without their problems, especially if the intervention has not been fully defined and developed. Therefore, it is essential to create a framework for the design and evaluation of such complex interventions de novo [39].

The overarching component of an effective health communication program, however, remains a powerful, well-articulated, long-term vision. This needs to reflect the core values and beliefs of the team and the shared scenario for the future. It should stimulate teamwork and inspire a concerted, committed effort in creating constructive conversations around the core messages.

RESEARCH PRIORITIES

In order to strongly advocate for the widespread adoption of strategies employed in other countries, it is essential that evaluation, particularly to determine cost, cost-effectiveness, practicality, sustainability, and cultural acceptance be performed prior to scaling-up these programs. To date, there have been only 2 economic analyses of RHD control, based on data collected in the United States in the mid-20th century and few robust analyses of RHD awareness and education programs [40,41]. There is a strong need for these analyses to determine disease estimates (using disability- and quality-adjusted life-years) and for cost-benefit and cost-effectiveness analyses to model the most appropriate approach for RHD control in developing countries.

RHD falls squarely within the 2 major disease paradigms (i.e., infectious and noninfectious), and disease control activities have suffered from this unusual position. Yet, this is an artificial distinction in many ways, and it is increasingly clear that there is a need for diagonal models of integrative health rather than horizontal or vertical silos. RHD control programs lie mainly within primary health care, both for effective management of GAS infections and delivery of secondary prophylaxis. We need to examine the role of centralized community-based care structures incorporating community-health workers/noncommunicable disease nurses/health officers in effecting RHD control. This promises to be the most sustainable model in resource-poor settings where task-shifting and differently trained cadres of medical personnel carry a large burden of the preventative activities [42].

The importance of increased awareness in patients, caregivers, and the community is clear and will have far-reaching effects. By raising awareness within the community, we in turn will influence case detection, raise the profile of the disease, advocate effectively for our patients, and, hopefully, mobilize political will. Therefore, it is important that communities' efforts be designed effectively to achieve the desired health outcomes. To date, the best methods to do this have not been systematically evaluated. For communication strategies to succeed, they need to be science- and research-based with a focus on the formative data and to have identified the solutions, audience, and mechanisms necessary to evaluate the outcomes.

With all communication and promotional strategies, consideration should always be given to the possibility of expansion to scale and sustainability. Mass media campaigns are easier to scale up than community interventions are, and this should be part of the initial design if it would be required at a later stage. Health promotion and communication strategies need a long-term goal, and, therefore, they need a vision for sustainability with commitment from significant role players to achieve longevity and continuity in the program.

SUMMARY

ARF/RHD is a disease of poverty, social deprivation, and inequality. Yet, it is entirely preventable using simple cost-effective measures. We have evidence from past and current initiatives, instituted in various parts of the world, that comprehensive programs incorporating awareness-raising, surveillance, and prevention can not only control RHD but also create a global RHD agenda and construct a platform for collaboration. Communication and health promotion is an essential part of an effective RHD control and prevention program. The key construct is a strong, shared, long-term vision, which is evidence-based, results-oriented, and that strengthens all elements of the program to allow for scalability. Translational research, incorporating these constructs, will serve to bring the needed attention back to this neglected, yet devastating illness [31,41].

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