Rheumatic heart disease: Social and economic dimensions

Rheumatic fever (RF) and rheumatic heart disease (RHD) are primarily diseases of childhood and young adulthood. As a result of this epidemiological pattern, RF and RHD negatively impact on society by decreasing the capacity of the most productive age groups, as well as limiting future capacity by thwarting the development of young people. Acute RF and RHD lead to increased school absenteeism and drop-out, and lost wages due to parental absenteeism from work. The patient and the family bear most of the brunt of these costs, which are shared to some extent by society as a whole.

The global burden of RF and RHD over the past century has shifted to fall almost entirely on people living in the developing world, who constitute 80% of the world population. The worldwide prevalence of RHD is estimated at 15.6 million, with 282 000 new cases arising each year, resulting in 233 000 deaths per year.[1] Ninety-five per cent of these cases and deaths occur in the developing world. Sub-Saharan Africa has the highest average prevalence of RHD of 30 per 1 000 schoolchildren, leading to the designation of this region as the 'hotspot' of RF and RHD in the world.[2] This geographical distribution of disease highlights the link of RF and RHD with poverty. RF and RHD are not only the result of conditions that exist in poverty; they also act to perpetuate poverty by crippling a significant proportion of the most productive members of society, thereby hindering economic growth. Understanding and defining the relationship between RF/RHD and poverty is an important step in building the political support, national and international, to fashion and implement a plan of action to combat the disease.

What is the socio-economic impact of RF and RHD?

At least two studies from Brazil and India have attempted to quantify the socio-economic impact of RF and RHD.[3,4] The Brazilian study provides a useful breakdown of direct and indirect costs that impact on the patient, family and society.[3] Direct costs to the family include medical consultations, laboratory tests, transportation, and lost wages. Assuming that most patients with RF/RHD receive publicly funded health care, direct costs to society include medical consultations not paid for by the family, hospital admissions, cardiac catheterisation and surgical costs, and medications and laboratory tests. Indirect costs to the family include lost wages because of work missed, while indirect costs to society encompass the production losses attributable to lost workdays. While these costs associated with RF and RHD are not exhaustive, they include most of the pertinent tangible costs. In Sao Paulo, Brazil, RF costs the affected patient and family about US$97/patient/year, and the disease costs society US$320/patient/year. The annual cost of a secondary

prevention programme is US$23/patient/year in Brazil. Compared with the cost burden on the family or the society for treating a case of RF, this analysis clearly confirms that secondary prevention is a cost-effective intervention.

The Indian study sets out to compare the cost-effectiveness of primary, secondary and tertiary prevention programmes for RF/RHD.[4] The investigators compared the input cost vs. the output cost for each form of prevention strategy. They found that primary and secondary prevention are both cost-effective interventions and while primary prevention is more expensive to implement, the outputs, or economic/social gains, of primary prevention exceed both secondary and tertiary gains. They also found that tertiary prevention (i.e. medical and surgical intervention for heart failure due to RHD) is least cost-effective. While this study has been criticised on methodological grounds,[5] it highlights the fact that leaving the disease untreated increases the economic cost to the patient, family and society.

In addition to tangible economic losses associated with RF/RHD, there are also intangible costs, or social implications that cannot be quantified. Patients disabled by RHD often face physical limitations, which can restrict their future educational and work opportunities. The Brazilian study found that children affected by RF/RHD have a 22% school failure rate, which can further limit future career options. And with respect to their parents, 5% reported losing their jobs because of absenteeism associated with the illness of their child.

What are the prospects for the eradication of RF and RHD?

The developing world faces a double burden of infectious diseases, which are associated with poverty, and chronic diseases associated with urbanisation and social change. RF and RHD comprise a unique disease entity that spans the infectious and post-infectious chronic disease paradigm. The antecedent stage of streptococcal pharyngitis is infectious, relatively simple to diagnose and inexpensive to treat.[6] As the disease progresses towards the chronic stage (RHD), it becomes expensive for the patient, the family and the society to diagnose and to treat by medical and surgical means.

It has been amply demonstrated in Cuba, Costa Rica and other countries that a comprehensive strategy of primary prevention (i.e. syndromic treatment of suspected 'strep' pharyngitis with penicillin), secondary prevention (screening for rheumatic heart disease in schoolchildren and use of penicillin prophylaxis for affected children), and tertiary prevention (i.e. medical and surgical treatment of patients with heart failure due to RHD) results in almost complete eradication of the disease within 10 - 20 years.[7,8]

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The Drakensberg Declaration of the Pan African Society of Cardiology (PASCAR) calls on national ministries of health in Africa to adopt the A.S.A.P. Programme for the prevention of RF and RHD. This programme seeks to emulate the Cuban and Costa Rican examples through the application of evidence-based approaches to the prevention of the disease on national and continental levels.[9,10] The occasion of national Rheumatic Fever Week, which was marked by the Minister of Health on 4 - 8 August 2008, provided us with an opportunity to rededicate ourselves to the fight for the eradication of RF and RHD … 'in our own lifetime'.[11]

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Rolling out male circumcision as a mass HIV/AIDS intervention seems neither justified nor practicable

Two articles[1,2] published in this issue address male circumcision (MC).

Connolly *et al.*[1] show in a national survey that MC, whether pre-pubertal or post-pubertal, has no protective effect on acquisition by males of HIV infection as measured by prevalence.

Sidler *et al.*[2] state that neonatal MC continues to be promoted without adequate justification as a medicalised ritual, via an HIV prevention rationale. They caution that for MC to be a therapeutic as opposed to a non-therapeutic procedure, it is necessary to gather more corroborative and consistent evidence of its benefit, consider the potential harms (psychological, sexual, surgical and behavioural/disinhibition), examine the ethical implications, and examine effectiveness and efficiency (costs and benefits) at the population and societal levels. They point out that MC is not just a technical surgical intervention – it takes place in a social context that can radically alter the anticipated outcome. At the 2008 International AIDS Conference[3] in Mexico cultural, political and educational issues raised by the intervention, such as decreased condom use and marginalisation of women, were hotly debated. Some cultural interpretations may view MC as a licence to have unprotected sex. A case in point is Swaziland, where men are flocking to be circumcised with the understanding that this means they no longer need to use other preventive methods (e.g. wear condoms or limit the number of sexual partners).[4]

The 2003 Cochrane review[5] of observational studies of MC effectiveness concluded that there was insufficient evidence to support it as an anti-HIV intervention. Three randomised controlled trials (RCTs) from South Africa, Kenya and Uganda in 2006 - 2007 show a protective effect of MC. However, Garenne[6] has subsequently shown from observational data that there is considerable heterogeneity of the effect of MC across 14 African countries. Despite the South African RCT showing a protective effect, he reports for the nine South African provinces that 'there is no evidence that HIV transmission over the period 1994 - 2004 was slower in those provinces with higher levels of circumcision'. Interestingly, in both Kenya and Uganda, where two of the RCTs were done, a protective effect of MC was observed, but a harmful effect was observed in Cameroon, Lesotho and Malawi. The other eight countries showed no significant effect of MC.

These somewhat discordant findings are difficult to interpret. While RCTs are theoretically strong designs, it is conceivable

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that their findings are not generalisable beyond their settings. Furthermore, there have been no trials of neonatal MC. Study flaws such as inability to obtain double blinding, and loss to follow-up in RCTs, may effectively degrade their quality to that of observational studies. Meanwhile other disturbing findings referred to by Sidler *et al.* are emerging, including the reported higher risk for women partners of circumcised HIV-positive men, disinhibition, urological complications, relatively small effect sizes of MC at the population level, and relative cost-inefficiency of MC.

Not all objections to MC as an HIV intervention have to do with evidence of effectiveness or cost. Sidler *et al.* raise ethical objections. Owing to the current climate of desperation with regard to the HIV epidemic, evidence in favour of MC frequently seems overstated. This reduces the scope for informed consent and autonomy for adult men considering the procedure. Further problems arise in the case of neonates whose parents may be considering the procedure. Whereas informed consent is at least possible for adult men, it is clearly not possible for neonates. Parents can only guess what the child's wishes would be if he were presented with the information they have at their disposal. If it could be shown that circumcision was necessary in the neonatal period, parental consent on behalf of the neonate would be justified. But since no valid surgical indications for circumcision exist in this period, and the future benefit to the child in respect of HIV avoidance is not relevant before sexual debut, the duty of parents may well be to err on the side of caution, and defer the procedure until the child can make an autonomous decision. In the absence of compelling indications, a procedure such as circumcision could also be seen as a violation of the child's right to bodily integrity. Furthermore, the ethical principle of non-maleficence cannot be upheld as there are clear harms attached to this practice, to which Sidler *et al.* refer in their article. Lastly, at a societal level MC may be unjust insofar as it could compete for resources with more effective and less costly interventions[7] and disadvantage women.

Despite a strong pro-circumcision lobby driven by enthusiasts who have been promoting MC as an (HIV) intervention for many years, and impatience expressed by protagonists about the long delay after the 2006 - 2007 RCT results and the UNAIDS/WHO policy recommendations[8] of March 2007, few mass campaigns have been launched in African countries.

Given the epidemiological uncertainties and the economic, cultural, ethical and logistical barriers, it seems neither justified nor practicable to roll out MC as a mass anti-HIV/AIDS intervention.

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