



## Lack of adherence to the national guidelines on the prevention of rheumatic fever

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**Objectives.** To explore the extent to which current practices for the secondary prevention of rheumatic fever (RF) in Cape Town adhere to those outlined in the national guidelines on the primary prevention and prophylaxis of RF and rheumatic heart disease (RHD) for health professionals at primary level.

**Methods.** A combination of qualitative tools was used to evaluate the four priority issues identified in the guidelines as fundamental elements of a comprehensive programme for the secondary prophylaxis of RF/RHD: (i) health education and promotion; (ii) case detection of RF and RHD; (iii) secondary prophylaxis every 3 - 4 weeks at primary level; and (iv) notification of acute rheumatic fever (ARF). The qualitative tools included parent/child interviews of cases diagnosed with ARF in the Cape metropole area during the period 1999 - 2003; a physician questionnaire focused on awareness and adherence to the national guidelines; and a review of the

records on acute rheumatic fever notification in the Cape metropole area from 1999 to 2003.

**Results.** The evaluation revealed four key findings. First, patient knowledge on the disease was almost non-existent. Despite this lack of knowledge, adherence to secondary prophylactic treatment was good. Second, the physicians most likely to encounter a case of rheumatic fever were least likely to be aware of and to comply with the national guideline. Third, the guidelines do not clearly state how increased detection of ARF will be achieved. Finally, the RF notification system is dysfunctional, with discrepancies in the reporting of cases at hospital, city and provincial levels.

**Conclusions.** Since the publication of the national guidelines in 1997, little progress has been made towards achieving the implementation of a comprehensive programme for the secondary prevention of RF/RHD.

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Rheumatic fever (RF) is currently the most important cause of acquired heart disease among children in South Africa.<sup>1</sup> A 2002 report from a paediatric cardiology workshop highlights the belief among clinicians that South Africa is currently in the midst of a RF epidemic.<sup>2</sup> While accurate epidemiological data are urgently needed to confirm this suspicion, efforts to address the situation have already been launched. In 1997, the South African Department of Health (DOH) released a set of national guidelines on the primary prevention and prophylaxis of rheumatic fever (RF) and rheumatic heart disease (RHD).<sup>3</sup> The guidelines were intended to facilitate a comprehensive programme for the primary and secondary prevention of RF. Targeting health workers at the primary care level, they cover interventions addressing education, living conditions, diagnosis, treatment, referral, notification, and follow-up.

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While these guidelines are comprehensive and evidence-based,<sup>4,5</sup> it is not clear what impact they have had on clinical practice or on the overall burden of disease associated with RF and RHD. The purpose of this study was to explore the extent to which current practices for the secondary prevention of RF at the primary level adhere to those outlined in the national guidelines.

### Methods

This study used various methodologies, primarily qualitative, to assess the extent to which the objective of implementing a comprehensive programme for the secondary prevention of RF/RHD has been achieved in the Cape metropole area. The evaluation focused on a set of four priority issues identified in the 1997 national guidelines. These priority issues include: (i) health education and promotion; (ii) case detection of RF and RHD; (iii) secondary prophylaxis every 3 - 4 weeks (referral back to primary level); and (iv) notification of acute rheumatic fever (ARF).<sup>3</sup> We obtained data from several sources: case/guardian interviews, physician questionnaires, and statistics on disease notification from hospital, metropolitan, and provincial records. The University of Cape Town Research Ethics Committee approved the study.

For priority issues 1, 2, and 3 (health education/promotion, case detection, and secondary prophylaxis) we conducted a retrospective qualitative case study of children aged 3 - 12



years, who had been diagnosed with ARF during the period 1999 - 2003. We identified cases from Red Cross Children's Hospital (RXH) using two discrete search techniques: a manual search of records from the RXH rheumatic fever clinic and an electronic search of the hospital's diagnosis database. We screened the medical records and applied the Jones criteria to include only definite cases of RF.<sup>6</sup> We then extracted relevant biographical and medical history data using a data extraction form.

Through a community health worker, we contacted the caregivers of all included cases ( $N = 8$ ) to arrange face-to-face interviews. The interviews were semi-structured, lasted approximately 20 minutes, and focused on the delivery of care at the time of diagnosis, adherence to secondary prophylaxis, and general knowledge of the causes and effects of RF/RHD. A single investigator (KAR) conducted the interviews in English and each interviewee was given the opportunity to ask questions about RF/RHD. We used a Xhosa translator when required.

A second data source for the evaluation of priority issues 1, 3 and 4 (health education/promotion, secondary prophylaxis, and RF notification) was a self-administered, structured physician questionnaire. Initially the evaluation was planned to target physicians working at the primary level, given that the national guidelines specifically target that level. However, patient/guardian interviews revealed that patients had little interaction with health care professionals at the primary level during visits for prophylactic treatment. Therefore, a broader sample of physicians was required, consisting of three groups: one from Groote Schuur Hospital (GSH), one from RXH, and a group of private general practitioners (GPs) from the Cape Town area. The group from GSH was a convenience sample of physicians working in areas most likely to encounter a case of RF (i.e. the emergency unit and the cardiac clinic in the Department of Medicine). The group from RXH was a convenience sample of physicians from the medical outpatient department. The group of private GPs was a non-random sample of physicians known to one of the investigators (BMM). All participating physicians were selected on the basis of their willingness to participate in the survey. The physician questionnaire focused on awareness of and adherence to the national guidelines (Appendix A).

Additional data for the evaluation of priority issue 4 (RF notification) were obtained through a review of hospital, city, and provincial records on disease notification. We reviewed records from RXH for notification statistics from 1999 to 2003 and obtained official government statistics from health information specialists at city and provincial level. Case information available from all sources included the date of diagnosis and the residential address at the time of diagnosis.

We analysed our findings by summarising the information gathered from the various sources, using these summaries as

the basis for evaluation of the four priority issues. Responses obtained through the case/guardian interviews and the physician questionnaires contained primarily factual information that could be summarised easily; therefore the investigators felt that a formal coding system of analysis was unnecessary. For the analysis of disease notification, we compared the number of cases reported from each level and cross-referenced each case based on the individual's address.

## Results

We identified 67 possible cases of ARF from the search of RXH's records. After reviewing the medical records and applying the Jones criteria, we excluded 54 cases and selected 13 cases for follow-up. The majority of excluded cases were either chronic RF/RHD cases that had visited RXH within the past 5 years or cases that did not fulfill the diagnostic criteria. Of the 13 cases selected, we were able to locate and interview 8 cases.

A total of 24 physicians responded to the questionnaire. Twelve physicians from GSH participated in the study, 5 medical registrars and 7 senior house officers. Eight physicians participated from RXH, all of whom were physicians working in the medical outpatient department. Five private GPs were contacted to participate, 4 of whom responded to the questionnaire.

### Health education and training of all personnel involved with children

Information gathered through the case/guardian interviews revealed high levels of ignorance concerning all aspects of the disease. Six of the 8 guardians said that they did not know what causes RF, 1 stated that it was caused by 'something in the air', and one stated that it was caused by a sore throat. None could explain how to prevent it, and none knew the purpose of the monthly injections. Seven of the 8 guardians had not heard of RF before the child's diagnosis, and the same number had not heard of the disease from any source other than the doctor. One parent claimed to have heard it mentioned on the radio.

The physician survey yielded conflicting results regarding awareness among physicians of the existence of the national guidelines. Seven of the 12 physicians sampled from GSH and 2 of the 4 private GPs were aware of the guidelines. None of the physicians sampled at RXH, the location most likely to see cases of ARF, was aware of the guidelines. Inquiry into the type of information provided to the patient and guardian at the time of diagnosis indicated that physicians from all groups stress the importance of adherence to prophylaxis. Many also commented on the causes, basic pathophysiology, and long-term consequences of the disease.



### Case detection of ARF

The guidelines do not state clearly how increased detection of ARF will be achieved. Specifically, the guideline does not stipulate whether new cases or recurrent attacks should be notified, and the level of diagnostic certainty required before notification. The Jones criteria for the diagnosis of RF apply to the first attack, and recurrences may be diagnosed without meeting all the criteria. The lack of clarity of the guideline on the method of case detection may contribute to the lack of effectiveness of the current notification system for RF.

### Secondary prophylaxis (with referral back to primary level)

Information used for the evaluation of this priority issue was gathered through the case/guardian interviews and physician questionnaires. The findings from the interviews suggest high levels of adherence to secondary prophylaxis, with 7 of 8 cases claiming that they have not missed a treatment. One patient, diagnosed in 2001, had not received any treatment for the past year. Six of the 7 cases reporting adherence received monthly treatments at primary care level (community health clinics) while 1 received all treatment at the RF clinic at RXH. Those receiving treatment at primary care level reported little or no discussion of their condition with health care personnel at the time of treatment. Six cases received treatment in the form of monthly intramuscular injections of penicillin, while 1 case received penicillin orally because of the pain of injection. Six of the 7 cases receiving treatment in the primary care setting also attended follow-up visits at the RF clinic every 3 - 6 months.

### Notification of RF

RF is a notifiable disease in South Africa (Health Act No. 63 of 1977). Legally, the responsibility for case notification falls on the 'first health care professional or facility with whom a patient presenting with [rheumatic fever] comes into contact'.<sup>7</sup> We evaluated the notification system for RF based on information derived from physician questionnaires, as well as incidence data collected at hospital, city and provincial level. Results from the physician survey and conflicting disease statistics found at various administrative levels indicate that the current notification system has not been implemented effectively and is not accurately capturing the burden of disease attributable to RF.

The physician survey revealed wide discrepancies in RF notification practices. Only five of the 12 physicians from GSH and 2 of the 4 private GPs said that they either notify cases of ARF or would if presented with one. Only 1 of the 8 physicians sampled from RXH reported notifying cases.

Table I gives a summary of the number of notifications for new cases of RF in the Cape metropole region during the period from 1999 to 2003 according to various sources. Records on reportable diseases from RXH indicate that the

hospital has notified the local health authorities of 39 new RF cases during this period, all with addresses within the metropolitan area. A review of these cases conducted by the investigator (KAR) found that 1 of these cases had been reported twice. There is currently no system in place at hospital or government level to identify double reporting. Data from the City of Cape Town's Department of Health and the Provincial Authorities of the Western Cape indicate that 17 and 28 cases of RF, respectively, were reported within the metropolitan area during the same period.

Table I. Discrepancies in statistics on ARF cases in the Cape metropolitan area from 1999 to 2003 (N)

Red Cross Children's Hospital reportable disease database	Municipal health authority	Provincial health authority
39	17	28

A further review of the records showed that of the 8 ARF cases identified for interview purposes, 6 were diagnosed at RXH. Of those 6, 3 were notified according to both hospital and city records. With regard to the non-RXH cases, 1 case was diagnosed at Tygerberg Hospital and was reported to health authorities, and the other was diagnosed at Eben Donges Hospital and was not reported to the health authorities. Therefore, according to the cohort of cases interviewed, the health department's reporting system identified only half the cases of ARF within the 5-year period.

### Discussion

This study revealed that little progress has been made towards establishing a comprehensive secondary prophylaxis programme for RF in Cape Town since the publication of the national guidelines in 1997. Given the shortcomings of the current RF notification system in South Africa, it is not feasible to obtain a reliable estimate of the impact of the national guidelines on disease incidence. However, the evaluation revealed four key findings that merit discussion. First, patient knowledge on the disease is almost non-existent. Yet despite this lack of knowledge, adherence to secondary prophylactic treatment was good. Second, physician awareness and compliance with the national guideline was unsatisfactory. Third, the method for case detection of RF was unclear. And finally, the RF notification system was dysfunctional.

The first key finding suggests that individuals most affected by RF and RHD know little about the disease, including methods for prevention and the potential long-term consequences. However the question-and-answer sessions held at the end of each interview frequently resulted in the guardian recalling one physician's explanation of the disease given at the time of the child's diagnosis. The inability of patients and guardians to retain the information provided at



the time of diagnosis could be attributable to the complexity and sheer volume of information needed to understand the illness. Our study therefore highlights the need for more effective methods for communicating knowledge to patients. The fact that 7 of the 8 cases interviewed had not heard of RF before diagnosis also suggests a low level of community awareness of the disease. Implementation of targeted health promotion programmes for RF/RHD (a priority issue identified by the national guideline), aimed at improving patient and community knowledge of the disease is therefore urgently needed.

Despite lack of patient understanding/knowledge of the disease and the specific benefits of treatment, adherence to prophylactic treatment was high. This finding does not fit the traditional 'knowledge, attitudes, practice' (KAP) model<sup>8</sup> of health promotion, founded on the premise that knowledge is required for individuals to change their behaviour. Other determinants of adherence may therefore be in operation in this setting and warrant exploration in future studies.

Our second major finding was that physicians most likely to encounter RF are not aware that it is a notifiable disease. To address this shortcoming, appropriate education and increased use of physician reminders for the requirement of notification are needed.

Our third finding highlights the failure of the guideline to address the issue of case detection adequately. The national guideline does not include strategic objectives for improving incident case detection, nor does it address procedures for detection and notification of recurrent RF cases. It also fails to address the issue of case detection for subclinical group A  $\beta$ -haemolytic streptococcus infection and its impact on the burden of RF/RHD.

The inconsistent data reports on RF incidence over the past 5 years at hospital, municipal and provincial levels leads to our last finding, namely that the current RF notification system is inaccurate and unreliable. Only 4 of the 8 cases that we interviewed had been reported to the health authorities. According to reports from the national Department of Health, there were only 7 and 11 notified cases of RF and no deaths attributed to RF in 2002 and 2003, respectively.<sup>7</sup> This is likely to be a gross underestimate of the incidence of RF in South Africa, and suggests that the findings of our study are likely to be generalisable to the rest of the country. Efforts are needed to address the current problems which appear to be both endogenous (problems with the actual system of reporting) and exogenous (failure to implement the system properly).

Some of the systemic problems in the notification system deserve special mention. From the point at which a suspected case first enters the health system (usually at primary care level), to the time the patient is diagnosed with RF (usually at a tertiary care centre), he or she has been seen by several health care professionals. The legal obligation of reporting currently

falls on the first health care professional to come into contact with the patient. This obligation seems misplaced in the case of RF as it would be preferable for the physician who is ultimately responsible for the diagnosis to assume responsibility. The system has been modified to correct for these shortcomings, evident through the observed reporting activity currently taking place at RXH. However, misconceptions among health care professionals on their legal responsibility to notify are still widespread.

This evaluation of the national guidelines on the primary prevention and prophylaxis of RF and RHD for health professions at primary level was not intended to be a comprehensive review. We conducted a preliminary assessment of the progress made in priority areas identified by the guidelines as central to the establishment of a comprehensive programme for secondary prevention of RF/RHD. Our review suffers from several potential shortcomings. The guidelines were designed to target health care professionals working at primary care level whereas most of the physicians who participated in the survey were practising at tertiary level. Assessing awareness and compliance levels at primary care level is especially important for evaluating the level of case detection and the effectiveness of the primary prevention system. An additional weakness of this study is the potential for bias introduced by our inability to obtain a random sample of physicians to participate in the survey. Lack of randomisation could result in either an over- or underestimation of physician awareness of RF/RHD guidelines and protocols.

## Conclusion

Our findings show that since the publication of the guidelines in 1997, little progress has been made towards achieving the implementation of a comprehensive programme for the secondary prevention of RF/RHD. Patient knowledge of RF/RHD is virtually non-existent; however, adherence to prophylactic therapy seems high, presenting a scenario that appears to contradict traditional models of health promotion and behaviour change. Physician knowledge and compliance with the guidelines is inconsistent. In addition, the guidelines do not clearly state how increased detection of ARF will be achieved. Finally, the notification system for RF is currently dysfunctional and probably does not provide an accurate depiction of the current burden of disease associated with RF in the Cape metropole area. The implementation of an effective notification system for RF is paramount to the health system's ability to assess the current burden of disease attributable to RF/RHD, and to monitor future progress towards reducing that burden.

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## Appendix A. Summary of physician questionnaire

Affiliated hospital (circle one)

RXH

GSH

Tygerberg

Department \_\_\_\_\_ OR Location of private practice \_\_\_\_\_

1. Are you aware of the existence of national guidelines on the primary prevention and prophylaxis of RF/RHD for physicians at the primary level? (If NO, skip to question 5)
2. When did you first become familiar with the guidelines?
3. Do you follow the clinical guidelines when diagnosing and treating cases of acute RF?
4. Do you believe these guidelines provide appropriate measures for the secondary prevention of RF/RHD? If not, why?
5. What information do you typically provide the patient/caregiver on RF at the time of diagnosis?
6. Do you believe the distribution of an informational pamphlet on RF/RHD at the time of diagnosis would be a useful tool for raising patient awareness of the disease?
7. Do you report cases of acute RF to the local health authorities?
8. Approximately how many cases of ARF have you diagnosed in the last year?