



Notification of rheumatic fever in South Africa – evidence for underreporting by health care professionals and administrators

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Objective. To determine whether under-reporting of rheumatic fever occurs at hospital, municipal, provincial and national levels of the South African health system.

Background. Information on the incidence of rheumatic fever (RF) and the prevalence of rheumatic heart disease (RHD) is required for the prevention of valvular heart disease in developing countries. In South Africa, RF was made a notifiable condition in 1989. It has recently been suggested that the reporting of RF cases may be incomplete, possibly because of underreporting by health care professionals and deficient administration of the disease notification system in South Africa.

Method and results. We assessed whether underreporting of RF cases occurs by comparing the numbers of RF cases reported per year at hospital, municipal, provincial and national levels from 1990 to 2004. There was a fall in the number of RF cases reported per year at national and provincial level over the 15

years of observation. A detailed analysis of the number of RF cases reported at hospital, municipal and provincial level for a 5-year period showed that more cases were diagnosed in one hospital (serving a smaller population) than were captured at municipal and provincial level (serving a larger population), suggesting underreporting by health care professionals. There were discrepancies in the number of cases reported at municipal, provincial and national level, suggesting poor administration of the notification system.

Conclusion. There appears to be underreporting of RF cases by health care professionals, and poor administration of the RF notification system. Health care professionals need to be educated about the statutory requirement to notify all RF cases in South Africa. An effective national disease notification system is required.

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Rheumatic fever (RF) is the most common cause of acquired heart disease in children and young adults in the world, with at least 400 000 deaths per year from rheumatic heart disease (RHD) globally.^{1,2} The annual incidence of RF in many poor countries is as high as 100 per 100 000, whereas in the industrialised world the incidence is 1 - 2/100 000.³ In developing countries such as South Africa, where RF remains endemic, national prevention programmes are required to control RF and RHD.³ An important part of a prevention programme is a surveillance system to monitor the incidence of RF and prevalence of RHD.⁴

The official notification of RF is regarded as a vital component of a surveillance system for the monitoring of trends and control of RHD.⁴ In South Africa, RF and the initial diagnosis of RHD were added to the list of notifiable

conditions in 1989, and notification commenced in 1990.⁵ However, in 1991 the initial diagnosis of RHD was removed from the list of notifiable diseases for reasons that are not apparent to us.⁶ Nevertheless, the importance of RF notification has been highlighted in the South African guideline for the prevention of RF and RHD of 1997.^{7,8}

We have recently observed deficiencies in the RF notification system in South Africa, possibly leading to the underreporting of RF cases.¹ In this article, we assess whether such underreporting occurs by comparing RF reporting rates at hospital, municipal, provincial and national levels for the first 15 years of RF notification in South Africa (1990 - 2004).

Methods

We used information obtained from one hospital in the Western Cape (Red Cross Children's Hospital), its municipal health department (the Cape Town City Health Department), the Western Cape provincial Department of Health (DOH), and the national DOH. The hypothesis was that the number of RF cases reported per year should increase in a step-wise manner from one hospital to a municipal health department (which collects statistics on notifiable conditions from several hospitals in its jurisdiction), to the provincial health department (which collects statistics on notifiable conditions from all the municipalities in a province with a population of 4.7 million), to the national DOH (which collects statistics on notifiable

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conditions from nine provinces with a total population of 46.9 million).⁹

We conducted a two-stage retrospective comparison of the number of RF cases reported per year at national, provincial, municipal and hospital levels. The first stage was a comparison of the number of RF cases (living and dead) notified per year to the Western Cape provincial DOH and the national DOH for the period 1990 - 2004 (i.e. provincial v. national comparison). Data on the number of cases reported per year were obtained from government personnel in charge of notifications at provincial and national level. We also conducted a hand search for all government notices of notifiable medical conditions in the national DOH journal, *Epidemiological Comments*, from 1977 to 2004. However, the notification information published in *Epidemiological Comments* was not used in this study because the data were inconsistent from year to year, and incomplete compared with the departmental records.

The second stage of the study involved a comparison of numbers of cases reported to the Western Cape provincial DOH with records from the Cape Town City Health Department, and the Red Cross Children's Hospital, for the period 1999 - 2003 (i.e. provincial v. local comparison).¹ This comparison was designed to establish whether all the cases diagnosed in one hospital were captured at municipal and provincial level.

In the review of state records no attempt was made to verify the diagnosis of RF according to the modified Duckett Jones criteria because the case notes were not available for verification of diagnosis.³ In the assessment of the records from Red Cross Hospital, case notes were reviewed to confirm that the cases met the modified Duckett Jones diagnostic criteria for RF.^{1,3}

Results

Provincial versus national comparison

The number of cases reported to the Western Cape provincial DOH is illustrated in Fig. 1. A total of 23 cases (22 alive, 1 dead) were reported in 1990, compared with 5 cases (no deaths) in 2004. The number of cases notified at provincial level appears to be dropping, particularly for the last 8 years of the period of observation. Similarly, the number of cases notified at national level appears to be falling, although there is some variability from year to year (Fig. 2). Eighty cases were reported in 1990 compared with 24 in 2004. The single death reported in the Western Cape in 1990 was not reflected in the national statistics. It is also of interest that the Western Cape, which has 10% of South Africa's population, accounted for 31% of all cases notified in 1990 and for a disproportionately higher share of the numbers notified in subsequent years. The poorer provinces of South Africa might have been expected to have a greater occurrence of RF than the Western Cape. The discrepancy in the reporting of deaths, and the

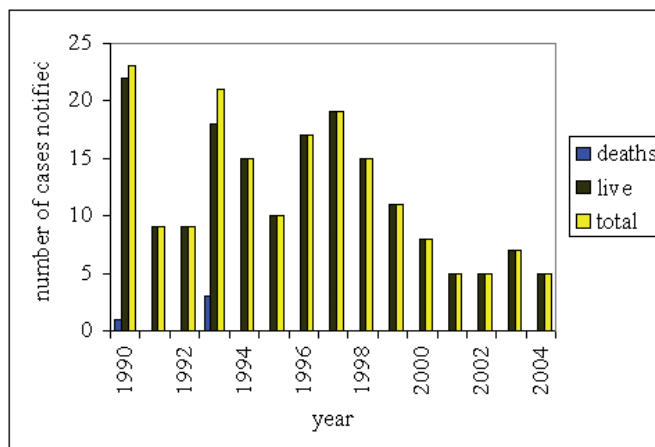


Fig. 1. Number of rheumatic fever cases notified per year to the provincial Department of Health, Western Cape, South Africa.

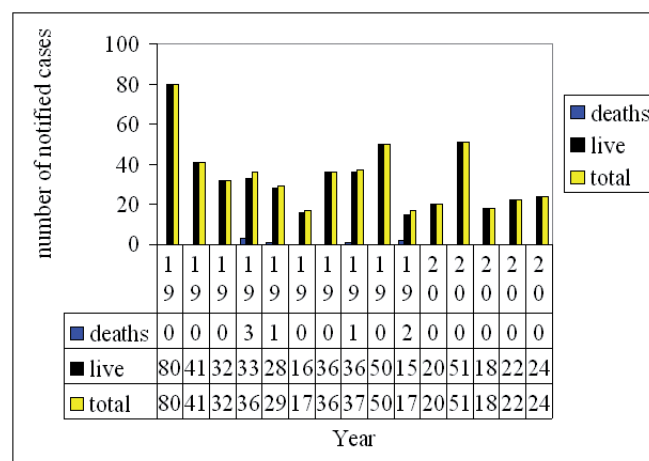


Fig. 2. Number of rheumatic fever cases notified per year to the national Department of Health, South Africa.

disproportionately higher share of RF cases in the Western Cape suggest that there may be incomplete capturing of the cases by administrators at the different levels of health system in South Africa, resulting in the underestimation of RF cases.

Provincial versus local comparison

To examine the possibility that there is underreporting of RF by health care professionals at hospital level, we analysed the records at Red Cross Children's Hospital for the period 1999 - 2003, and compared the numbers reported in 1 of 5 hospitals in the Cape Town metropole with the municipal and provincial figures (Fig. 3). There were wide discrepancies between the numbers reported at hospital, municipal and provincial levels. Unlike the expected step-wise increase in numbers from hospital, to municipal, to provincial levels, it is apparent from Fig. 3 that this relationship is inverted, especially in the hospital v. municipal comparison. The total number of cases diagnosed at Red Cross Children's Hospital (one of many hospitals in the province) over the 5-year period was higher ($N = 39$) than the numbers reported at municipal ($N = 17$) and provincial levels ($N = 36$).

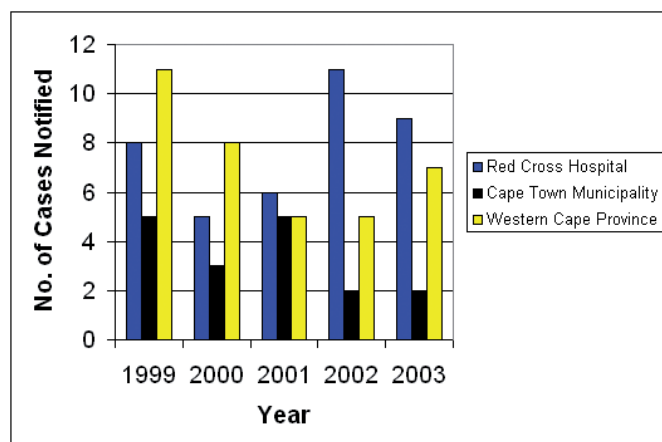


Fig. 3. Number of rheumatic fever cases reported at Red Cross Children's Hospital, Cape Town City Health Department, and the provincial Department of Health, Western Cape (1999 - 2003).

Discussion

To the best of our knowledge we present the first comprehensive audit of the number of RF cases that have been notified per year at different levels of the health system in South Africa since the advent of official notification 15 years ago. The study shows three key findings. First, there appears to be a fall in the numbers of RF cases that were notified per year over the past 15 years. Second, there were more RF cases diagnosed at one of the hospitals in the Western Cape than were reported to municipal and provincial authorities over a 5-year period, suggesting underreporting by health care professionals. Finally, there are discrepancies between the number of RF cases reported at municipal, provincial and national level, suggesting poor reporting by health administrators at all levels of the health system.

A 2002 report from a paediatric cardiology workshop highlights the belief among clinicians that South Africa is currently in the midst of an RF epidemic.¹⁰ By contrast, the national DOH has suggested that the incidence of RF and prevalence of RHD are declining steadily in many parts of South Africa.¹¹ While our data appear to support the latter observation, there is reason to believe that there may be significant under-counting of RF cases in South Africa. It is therefore premature to pronounce on the demise of RF/RHD until we have a reliable system for the surveillance and reporting of the disease.

It is of interest that the initial diagnosis of RHD was dropped from the list of notifiable conditions in 1992. It is not clear why this was done. We believe that there is merit in reporting

of the initial diagnosis of RHD in order to provide a more complete epidemiological picture of the disease and to improve the enrolment of affected patients in secondary prevention programmes and RF/RHD registers.⁴ For this reason we call on the national DOH to consider reinstating the initial attack of RHD on the list of notifiable conditions.

Implications for policy and practice

The results of this retrospective observational study have implications for clinicians, administrators and policy makers in the health service. First, the hospital, municipal and provincial authorities need to co-ordinate efforts to establish a seamless system for the accurate reporting of RF and other notifiable conditions. Second, adequate funds are needed to support the design, implementation and maintenance of a national surveillance system capable of detecting the incidence of RF and prevalence of RHD. Lastly, the revised surveillance system must prioritise ongoing efforts to educate clinicians and health care workers on the necessity of RF surveillance and the procedures to follow for reporting RF cases to the appropriate authorities.

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