The quality of management of rheumatic fever/ heart disease in the Kimberley

Christine M. Mincham
Department of Public Health, The University of Western Australia

Donna B. Mak
Kimberley Public Health Unit; Centre for International Health, Curtin University of Technology, and Department of Public Health, The University of Western Australia

Aileen J. Plant
Curtin University of Technology, Western Australia

Abstract

Objective: To evaluate the quality of management of Kimberley patients with rheumatic fever (RF) and rheumatic heart disease (RHD).

Methods: A retrospective analysis of medical records for 215 residents of the Kimberley region of Western Australia, diagnosed with RF or RHD during the years 1982 to 1996.

Results: Among patients prescribed intramuscular penicillin for secondary prophylaxis, 67% of prescribed doses were given, with individuals receiving 8-100% of doses prescribed. Of patients recommended visiting specialist or echocardiographic review, 78% and 64% attended respectively. Only 34% of patients with RHD in 1996 were recommended dental review in 1996 or 1997. Appropriate blood testing occurred in 34% of the months in which people had anticoagulant prescribed.

Conclusions: A clinical audit can be used to evaluate the management received by this population and hence identify areas to improve management. We found much room for improvement if optimal clinical outcomes are to be obtained.

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The advent of antibiotics and improved socio-economic conditions and health care have seen a decline in rheumatic fever (RF) and rheumatic heart disease (RHD) throughout the developed world.[1-3] Developing countries and Indigenous groups (including Indigenous Australians), however, still have unacceptably high rates of disease.[4-7] Compliance with clinical management can decrease the risk of recurrence and the risk of complications from rheumatic fever, and for this reason we undertook an audit of current practice in a remote part of Australia.[8,9] For the purposes of this paper, compliance refers only to whether a patient received the recommended health care intervention, without passing judgement on why the intervention was or was not received.

It is accepted medical practice that incident cases of RF be prescribed antibiotics, most commonly monthly injections of benzathine penicillin for at least five years after the last clinical episode, or until the person reaches 25 years, whichever is the sooner. People with RHD are usually referred for specialist cardiologist opinion and echocardiography of heart valves. It is also usually recommended that people with RHD have regular dental reviews (because of the risk of dental infection-related endocarditis). A small proportion of people with RHD are recommended valvular surgery. Many of those people undergoing surgery and some individuals with atrial fibrillation secondary to their valvular disease are recommended to be anti-coagulated.[10,11]

We aimed to evaluate the quality of management of Kimberley patients with RF and RHD.

Setting

The Kimberley region, in the far north of Western Australia, has a resident population of about 30,000 people scattered across an area of more than 420,000 square kilometres. Aboriginal people make up one-half of the resident population.

The landscape ranges from coastal subtropical areas to open savanna and semi-desert. Much of the terrain is rugged and accessible only by four-wheel-drive vehicle or light aircraft. There are six towns with populations ranging from 2,000 to 10,000 and more than 200 discrete Aboriginal communities, ranging in size from just a few families to more than 500 people.

Health care is provided predominantly by government and community-controlled organisations. Each of the towns has a hospital and one or more primary care services, whereas remote area clinics staffed by resident nurses and Aboriginal health workers are present in fewer than 15 Aboriginal communities.

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Correspondence to:
Donna Mak, Kimberley Public Health Unit, PMB 912, Derby, Western Australia 6728.
Fax: (08) 9193 1378; e-mail: donna.mak@health.wa.gov.au

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The unique cultural and demographic mix of the Kimberley, coupled with its geographic features and low population density, has considerable implications for health care delivery.

Methods

We identified all documented cases of RF and RHD between 1982 and 1996 and undertook a medical records-based retrospective audit of their management during a two-year period, 1 January 1996 to 31 December 1997. We chose indicators of quality of management that could be measured from patients' records. These included secondary prophylaxis with benzathine penicillin injections, attendance at visiting specialist and echocardiographic appointments for monitoring of RHD, the timing and types of surgical intervention, compliance with anticoagulant therapy and recommendation for dental review.

Cases included any Kimberley resident diagnosed with RF or RHD during 1982-96. We identified cases by surveying all Kimberley health services and by examining patient databases maintained by the regional hospital and visiting specialists.

We created an audit tool to collect information from the medical records of each case identified. We recorded patient identifying information (allowing patients to be followed between health services), data related to disease diagnosis between 1982 and 1996 and indicators of the management received by the patient during 1996-97. Estimated residential population data were obtained from the Health Department of WA for the relevant years. In accordance with ethical requirements of the Health Department of Western Australia and to protect patient confidentiality, only CMM and DBM had access to patient-identified information.

We obtained consent from the Human Rights Committee of The University of Western Australia and signed a Memorandum of Understanding with Kimberley Aboriginal Medical Services Council to conduct the study. One health service decided that, for reasons of confidentiality, consent from each individual was required before their records could be accessed for the purpose of the study. This service's study population was diminished to 39% of its RF/RHD patients due to the large proportion of individuals who could not be located to be asked for their consent. However, CMM was allowed access to the service's 'injection book' to collect data regarding benzathine penicillin injections. These data allowed us to calculate compliance with intramuscular secondary chemoprophylaxis for individuals who could not be located to ask for their consent and for individuals who had received some of their injections at this health service even when it was not their principal service provider. After developing, piloting and modifying a draft audit tool, data collection was completed by visiting each health service to examine the medical records. Data were recorded on a computerised database and analysed using SPSS.[12]

Results

A total of 217 individuals were identified as having been diagnosed with RF and/or RHD between 1982 and 1996, the 15 years prior to the study period. However, due to the death of one individual and a lack of clinical information for another, 215 cases were included in this audit of the quality of management for the years 1996-97. The incident rate between 1982 and 1996 for RF was 83.3/100,000 person-years and the prevalence of RHD in the Kimberley in 1996 was 440/100,000 population.

The various parameters used to measure management are summarised in Table 1. In general, the quality of management of patients with RF/RHD was far from ideal, with less than one-fifth of patients having benzathine penicillin injections within the recommended timing. Patients on anticoagulation had INRs (a measure of effectiveness of anti-coagulant therapy) measured infrequently and INRs were often outside the therapeutic range. Between 64% and 78% of patients recommended for echocardiographic or visiting specialist review were reviewed during the study period.

Discussion

The Kimberley population has high incidence rates of rheumatic fever and rheumatic heart disease and the clinical management received by individuals is critical for the prevention of further morbidity.[9,13]

Essential components of an audit are to have predefined objectives for that which is being audited and clear indicators that can be used to describe the quality of these objectives.[14,15] There was a limited amount of literature outlining the appropriate or ideal management of individuals with rheumatic fever or rheumatic heart disease. While it is difficult to evaluate the appropriateness of indicators chosen to reflect the quality of management, those chosen had clinical face validity.

Compliance with intramuscular secondary chemoprophylaxis was examined with reference to both frequency (by the proportion of prescribed injections received), and timing (by the intervals between consecutive injections). The compliance results showed less than half of those prescribed monthly benzathine penicillin were administered eight or more injections annually, compared with an ideal of 12.

Of those individuals not receiving benzathine penicillin, 31 individuals were not receiving benzathine penicillin (or any other secondary prophylaxis) for unknown reasons. These individuals may have been either non-compliant with their medication or recommended to stop medication, without the stipulation of either in their medical records. Hence the figure of 10 individuals not compliant with medication is likely to be an under-estimation. Unfortunately, there was no information for compliance available for the 27 individuals who were receiving oral secondary prophylaxis.

Review of patients by visiting specialist services involves a process of referral from local health services, organisation of the appointment, attendance at the appointment and planning for follow up. Of the population who should have been recommended for visiting specialist review during these years (i.e. those with recent rheumatic fever or current rheumatic heart disease[16]), only 66% had referral documented.

With regard to the time taken for patients to attend visiting specialist and echocardiography appointments, it is important to

note that these services visit the Kimberly approximately every three months. Hence, attending an appointment within six months means that the patient attended within two visits by the visiting specialist.

Once a patient was recommended for review, 78% attended visiting specialist review and 64% attended for echocardiography. Even though overall attendance at echocardiography was lower, all of the individuals that did attend did so within six months of the scheduled date, compared with only 64% of people attending their visiting specialist appointment within six months.

The timing of surgery may be an indicator of quality, however, it is difficult to ascertain what is optimal timing. The results indicate that on average most patients did have surgery performed within months of it being recommended and scheduled. Intuitively, the shortest time between scheduling and operating is optimal timing, however, delays that occur may not always be indicative of poor clinical management. The retrospective nature of this study meant that we were unable to examine the patient's pre-operative clinical and social circumstances to allow appropriate interpretation of the timing of surgery with respect to quality of management.

The results showed that most individuals receiving anticoagulants were not consistently having their coagulation status checked and the values that were obtained were often outside the therapeutic range. Too low a level of anticoagulation means the individual is at risk of morbidity from the very reason that they were anticoagulated in the first place, in this instance usually thrombo-embolism. On the other hand, levels that are too high risk complications such as haemorrhagic stroke.

The review of medical records showed that relatively few individuals were recommended for dental review. This is of some concern, especially when most of the recommendations for dental review were made by one visiting physician.

We recognise that our study had many limitations. The accuracy of the medical records-based research may have been compromised by lack of access to medical records, incomplete case finding or inaccurate information contained in the medical records. A review such as this may create a situation where those patients well known to health staff (and possibly were more likely to be receiving a high quality of management) were most likely to be recorded/remembered.

While all indicators chosen described important areas of management, some were less appropriate for use in a medical records-based study. Indicators for which information was easily collected and interpreted include compliance with secondary prophylaxis, attendance for visiting specialist review and echocardiography and compliance with anticoagulation. Additional clinical and social information would allow further interpretation about quality of timing of surgery. As the audit was medical records-based there were important management issues that could not be

Table 1: Summary of indicators of management of rheumatic fever and rheumatic heart disease.

Indicator of management	No. eligible	Result
Secondary chemoprophylaxis (1996-97)		
Evidence regarding chemoprophylaxis	164	96 (59%) prescribed benzathine penicillin; 27 (16%) prescribed oral chemoprophylaxis; 10 (6%) non-compliant; and 31 (19%) unknown
Compliance with benzathine penicillin (no. received/no. months prescribed	96	78 (81%) with sufficient data to calculate; median compliance 67% (range: 8-100%); and median 5.2 weeks (range: 0.85-50.11 weeks)
Median time interval calculable (i.e. >1 injection received)	94	19% (18/94) people had a median injection interval of 3.5-4.5 weeks
Visiting specialist review (1996-97)		
Total population recommended review	120	94 (78%) attended
Diagnosis of RF from 1994 onwards recommended review	136	90 (66%) attended
Documented date for review	71	50 (70%) attended
Time interval calculable	36	23 (64%) attended within six months of scheduling
Echocardiographic review (1996-97)		
Recommended review	70	45 (64%) attended
Documented date for review	59	38 (64%) attended
Time interval calculable	31	31 (100%) attended within six months of scheduling
Surgery (1982-97)		
Population recommended surgery	29	23 individuals had surgery, plus one recommended too late for study, i.e. assume 24/29 (83%) satisfactory
Time interval between surgery being recommended and performed calculable	19	Mean 11.7 months, median 3.0 months, range 0-43 months
Anticoagulation (1996-97)		
Percentage of people prescribed anticoagulants who had anticoagulation level assessed (no. of months tested/no. of months prescribed)	17	Mean 39%, median 42%, range 0-94%
Percentage of tests in therapeutic range (no. months in therapeutic range/no. months checked)	17	Mean 34%, median 37%, range 0-76%
Dental review (1996-97)		
Population with RHD in 1996	113	39 (34%) documented as requiring dental review

assessed, for example whether patients were receiving dental review and culturally appropriate education.

The large number of cases involved in this audit made it very time consuming; subsequent audits may need only include a sample of cases or could be performed within individual health services.

The potential for audit of the management of these patients was restricted by the lack of standards or protocols on which to base the audit.[17] It was difficult to know whether the indicators chosen to describe quality in this study are the best indicators, given the topic of the audit and the location of the study. In retrospect, however, the indicators chosen were consistent with those recommended for Aboriginal primary health care settings.[11] It is difficult to make conclusions about the appropriateness of the audit and to interpret the results obtained, as there is no existing benchmark. However, this study has value as a preliminary audit and, after modification, has potential for being repeated. The results obtained in this audit instantly become a benchmark for the next. The reuse of the audit tool is of value when evaluating the effectiveness of any changes in management that may be implemented as a result of this study.

The results raise issues that must be addressed by health services and staff, and others that are more relevant for patients. However, the need for systems to follow-up patients and their management plans has been identified and these systems must be able to function optimally and separately from individuals, who may come and go.[18] Another issue that needs to be addressed is the relative shortage of staff compared with other similar settings, such as the Northern Territory, where staffing levels are well below acceptable standards.[19]

In light of the results of this study, and additional studies involving health staff and patients, action to improve the management of RF/RHD has occurred.[20] Standard RF/RHD management guidelines have been distributed to health services in the Kimberley. This was accompanied by a modified audit tool that staff were encouraged to use in the future to re-audit the patients accessing their service, and an education package to be used when interacting with patients with RF/RHD. Health staff were encouraged to attend a RF/RHD workshop, conducted by local public health staff and a specialist, that visited major Kimberley centres.

Conclusions

The high incidence of rheumatic fever and rheumatic heart disease in the Kimberley and the resultant long-term management issues provide an ideal situation for an audit of management. However, it has been limited by the lack of standard management protocols and baseline data on which to base this audit. Despite this, a number of indicators were examined to describe quality of management. These indicators successfully described some characteristics of both occurrence and timing of clinical management events.

This audit has been a valuable preliminary evaluation of clinical management and has allowed some simple suggestions about the improvement of management for RF and RHD in the Kimberley to be made. As such, it is one step on the road to the better long-term management of rheumatic fever and rheumatic heart disease in the Kimberley.

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