Acute rheumatic fever in Indigenous people in North Queensland: some good news at last?

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ABSTRACT

Objectives: To ascertain whether changing from enhanced to routine surveillance had any deleterious impact on notification rates of acute rheumatic fever (ARF) among Indigenous people in north Queensland; and to determine whether initiatives to raise awareness about ARF among medical practitioners during the routine surveillance period were associated with any changes in the numbers of recurrences of the disease among Indigenous people in the region.

Design, participants and setting: Routine surveillance of all cases of ARF, and (to identify unrecognised prior episodes) retrospective checking of the medical records of Indigenous people with notified first cases of ARF from mid 2004 to mid 2009 in north Queensland, which has an estimated resident Indigenous population of about 68 400.

Main outcome measures: Rate of notifications of ARF during the routine surveillance period (mid 2004 to mid 2009) compared with that in the previous 5 years of enhanced surveillance; proportion of recurrent episodes of ARF that occurred from mid 2004 to the end of 2006 compared with the proportion in the following 2.5 years.

Results: There were 203 notifications of ARF in 194 Indigenous people in north Queensland from mid 2004 to mid 2009, and this was a 23% increase in the average annual incidence compared with that in the preceding 5 years. Of the 54 recurrences, 34 (63%) occurred between mid 2004 and the end of 2006 and 20 occurred between the beginning of 2007 and mid 2009 ($P < 0.01$). Of the 148 episodes that were not recurrences, 69 (47%) occurred in the first 2.5 years and 79 in the more recent 2.5 years ($P > 0.05$).

Conclusions: Changing from enhanced to routine surveillance in 2004 did not have a negative impact on notifications of ARF. The initiatives to raise awareness about ARF probably contributed to fewer missed cases and therefore to the considerable increase in the number of notifications, and ultimately to fewer recurrences.

MJA 2010; 192: 581–584

Acute rheumatic fever (ARF) became a notifiable disease in Queensland in 1999. Over the next 5 years, enhanced surveillance of ARF was undertaken in north Queensland, with multiple means used for case identification.[1] However, in 2004 the enhanced surveillance had to be discontinued because of competing priorities, and it was replaced by a more routine model of surveillance, relying on health care providers to notify cases spontaneously.

The high percentage of ARF cases documented during the period of enhanced surveillance that were recurrences raised concerns about the effectiveness of the ongoing management of Indigenous ARF patients in north Queensland.[1] However, in the latter part of 2004, it became apparent that there was another factor contributing to ARF recurrences — the failure of medical practitioners to recognise ARF at an initial presentation.[2] Obviously, individuals with unrecognised ("missed") episodes of ARF do not have the opportunity to receive regular antibiotic prophylaxis, and therefore remain at considerable risk of recurrences of ARF.[3] Two examples of missed cases are detailed in the Box 1.

A process for routinely looking for missed cases of ARF was established by Queensland Health at the end of 2004. This required undertaking a detailed "look-back" into the available past medical history of each patient with a notified new case of ARF. It soon became obvious that a considerable number of cases of ARF were being missed in north Queensland, either because: (i) ARF was considered, but either not followed up or the diagnosis was discarded for incorrect reasons (as in the first example in Box 1); or (ii) ARF was not considered at all (as in the second example in Box 1).[4]

As well as the look-back, more deliberate efforts were made to inform medical practitioners about: the essential features of the disease in north Queensland;[1] how to make the diagnosis;[3] how each case should be subsequently managed;[3] and how ARF was to be notified. These initiatives began in early 2005 (soon after the model of surveillance was changed), and were particularly intensive throughout the next 2 years. They included: hospital grand-round, ward-round and in-service presentations; orientation sessions and tutorials for junior hospital medical staff and medical students; newsletters;[2,4,5] and the development and distribution of several supporting resources (an example is shown in Box 2).

The initiatives to raise awareness about ARF among medical practitioners repeatedly emphasised several main points:

- school-aged Indigenous children (aged 5–14 years) in north Queensland are at extremely high risk of developing ARF;
- ARF usually presents as a rheumatological disorder, with the predominant presenting complaint being either monoarthritis or polyarthritis (which is classically, but not necessarily, migratory in nature);
- sudden onset of either refusal to bear weight or non-use of an upper limb (without an obvious cause) is an ominous presenting complaint in an unwell Indigenous child, and ARF must be considered as a very likely cause;
- carditis is not a mandatory criterion for the diagnosis of ARF;
- unless there is a very specific indication, there is no need for extensive laboratory investigations (such as screening tests for arboviruses, or serum levels of urate, serum complement, antinuclear antibody, and rheumatoid factor) in an Indigenous child in north Queensland who may have ARF, particularly if the child has only had a short illness. These investigations may divert the attention of the requesting practitioner away from ARF to make a spurious diagnosis; and
- any concerns should be discussed with a paediatrician or physician familiar with the disease.

These activities were reinforced from mid 2006 with the recruitment of a north Queensland Rheumatic Heart Disease (RHD) Program Coordinator (MFC). The key roles of the coordinator were to establish and update local disease registers, to improve ARF/RHD case management (eg, by using the

1 Examples of cases in which acute rheumatic fever (ARF) was missed

Case 1

A 9-year-old Indigenous boy was admitted to a hospital with polyarthritis (a major manifestation of ARF) and fever (a minor manifestation). His erythrocyte sedimentation rate (ESR) was 74 mm/h (a minor manifestation), and he had an antistreptolysin O titre (ASOT) of 100 IU/mL and an anti-DNase B titre of > 1600 IU/mL.

Despite the presence of one major and two minor manifestations of ARF, with serological evidence of a recent Group A streptococcal infection, his clinical notes stated that there was no evidence of carditis, and there were "insufficient criteria for RF".

He had an equivocal rheumatoid factor test, and was discharged with a diagnosis of juvenile rheumatoid arthritis. He was readmitted at 12.5 years of age acutely unwell with acute heart failure secondary to carditis affecting two valves; *de novo* ARF was notified this admission.

Case 2

An 11-year-old Indigenous girl presented to an emergency department with a painful, swollen right foot and fever (38.5°C). Her ESR was 100 mm/h, ASOT was 300 IU/mL and anti-DNase B titre was > 1600 IU/mL. She was admitted and therapy with intravenous antibiotics was commenced. The next day she had a "tender" right knee, but made a rapid "recovery" and was discharged on oral antibiotic therapy after 3 days.

She was seen again at the emergency department 18 months later with acute refusal to bear weight on her right leg because of a swollen and painful knee (with no history of injury) and fever (38.6°C). A diagnosis of osteomyelitis was considered; she was not admitted and oral antibiotic therapy was prescribed.

She was admitted again at 13 years, again with refusal to bear weight because of a painful left knee, several weeks after receiving a diagnosis of gout at a local medical service. Her ESR on admission was 110 mm/h, and the initial differential diagnosis included reactive arthritis (possible juvenile chronic arthritis or systemic lupus erythematosus) or septic arthritis. The knee was aspirated, revealing blood-stained synovial fluid. The observation "13 yo ♂ with L knee monoarthritis — cause?" was noted, but ARF was not diagnosed until the patient was seen on a ward round by a paediatrician. ◆

2 Prompt card designed to raise awareness of acute rheumatic fever in Indigenous children

registers for patient recall), to ensure notification of ARF cases, and to provide education to increase awareness about ARF/RHD among health staff in the region.

In this report, our objectives were: (i) to ascertain whether changing from enhanced to routine surveillance had any deleterious impact on notifications of ARF in Indigenous people; and (ii) to determine whether initiatives to raise awareness about ARF among medical practitioners were associated with any changes in the numbers of recurrences of the disease in Indigenous people in the region.

METHODS

Medical practitioners (and rural and remote community health nurses) were requested (including by means of the initiatives detailed above) to use the existing ARF case report form to notify any cases of ARF, even if the cases were initially only suspected. The ARF case definition and the ARF case report form were the same as those used when ARF surveillance began in 1999.[1,3]

From late 2004, on notification of each apparent first episode of ARF, public health personnel used Queensland Health's computerised laboratory database to determine if the patient concerned had ever had prior requests for throat swab culture, streptococcal serological testing, or any prior investigations for "rheumatic fever", "limb pain", "painful joints" or similar. If there was a potentially relevant prior laboratory investigation, the patient's past clinical records were examined to ascertain if there had been a prior missed episode of ARF. If so, the prior episode was notified (belatedly) as a first episode and the current episode was reassigned as being a recurrence.

Incidences of ARF during mid 2004 to mid 2009 were calculated using the 2006 Experimental Estimated Resident Populations (ERPs) derived by the Queensland Treasury (Office of Economic and Statistical Research).[6] These ERPs are based on 2006 national census data; the Indigenous ERP in north Queensland in 2006 was about 68 400 persons, which is 17% greater than the estimate in the 2006 national census. To enable comparisons to be made, the mid 1999 to mid 2004 average annual incidence rates for ARF[1] were recalculated using the 2001 ERPs.

To ascertain whether the initiatives to improve awareness about ARF were associated with changes in the numbers of recurrences, we compared the first and second halves of the 5-year period of routine surveillance — the proportion of the recurrences that occurred from mid 2004 to the end of 2006 were compared with the proportion that occurred from the beginning of 2007 to mid 2009. Recurrences included cases notified as recurrences and those in patients determined by the Queensland Health look-back to have had a prior missed episode of ARF; a one-sample test of proportion was used for the comparison. Other proportions were tested as appropriate.

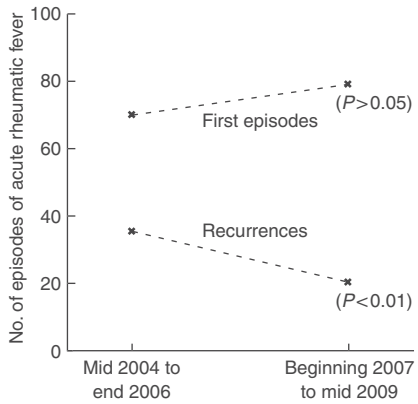
RESULTS

Over the 5 years from mid 2004 to mid 2009, there were 203 notifications of ARF in 194 Indigenous people in north Queensland; this was a 41% increase over the number in the preceding 5 years (Box 3). There was a 23% increase in the average annual incidence compared with that in the preceding 5 years ($P > 0.05$). There was also a 41% increase in the number of notifications among children aged 5–14 years, with a 29% increase in the annual incidence in this age group ($P > 0.05$). Increases in notifications were particularly evident in the Torres Strait and Northern Peninsula Area, Cape York, Tablelands and Mt Isa health service districts (data not shown). Indeed, in

3 The features of the acute rheumatic fever cases in Indigenous people in north Queensland notified from mid 1999 to mid 2004,[1] and from mid 2004 to mid 2009

Feature	Mid 1999 to mid 2004	Mid 2004 to mid 2009
Total notifications	144	203
Annual incidence per 100 000 population (95% CI)	48 (40–56)	59 (51–68)
Median age (years)	12.0	12.6
Female (% of total persons)	67 (50%)	111 (57%)
Recurrences (% of total cases)	33 (23%)	54 (27%)
Carditis (% of total cases)	61 (42%)	77 (38%)
Chorea (% of total cases)	12 (8%)	20 (10%)
Notifications in children aged 5–14 years (% of total cases)	93 (65%)	131 (65%)
Annual incidence per 100 000 children aged 5–14 years (95% CI)	120 (96–146)	155 (132–181)

4 Changes in the numbers of episodes of acute rheumatic fever (ARF) in Indigenous people in north Queensland between mid 2004 to the end of 2006 and the beginning of 2007 to mid 2009



one health service district (Mt Isa), the recent annual incidence of 95 cases (95% CI, 67–130 cases) per 100 000 Indigenous people was significantly higher than that in the previous 5-year period (40 cases [95% CI, 23–65 cases] per 100 000).

There was a recent 7% increase ($P > 0.05$) in the number of cases of ARF among females, but otherwise, the proportions of the key features of ARF remained very similar over the two 5-year periods (Box 3).

There were 54 known recurrences of ARF. It could not be determined if one episode of ARF (notified in 2005) was a recurrence or not. Box 4 shows that, of the 54 known recurrences, 34 (63%) occurred between mid 2004 and the end of 2006 and 20 occurred between the beginning of 2007 and mid 2009 ($P < 0.01$), and that, of the 148 episodes that were not recurrences, 69 (47%) occurred between mid 2004 and the end of 2006 and 79 occurred between the beginning of 2007 and mid 2009 ($P > 0.05$).

DISCUSSION

Our findings indicate that changing from enhanced to routine surveillance in mid 2004 did not have a negative impact on notifications of ARF. On the contrary, there was a 41% increase in the total number of notifications of ARF in the 5-year period during which only routine surveillance was used. Similarly, there was a (non-significant) 23% increase in the average annual incidence of ARF in Indigenous people in north Queensland in the recent 5-year period compared with that observed in the previous 5 years.

The recent annual incidence of ARF in school-aged Indigenous children in north Queensland (155 episodes per 100 000 Indigenous persons aged 5–14 years) is of particular concern. As "high risk" has been defined by an incidence of over 30 episodes per 100 000 persons aged 5–14 years,[3] this incidence indicates that these children are at an extremely high risk of developing ARF. A consequence is that there is a high prevalence of RHD in the region.[7,8]

It is quite plausible that the extra initiatives (to improve recognition of the disease) that were introduced from early 2005 contributed to fewer missed cases in the following 5 years, which in turn resulted in the considerable increase in the number of notifications.

It is not possible to state what proportion of the recurrent episodes that occurred before the end of 2006 was a consequence of a prior missed episode of ARF. This is because cases where ARF was not considered may not have had any "indicator" laboratory tests, and not all relevant past clinical records were able to be accessed by the public health personnel; besides, not all untreated ARF cases necessarily have recurrences. Nevertheless, extrapolating from those episodes where the past history was known with some certainty, it would seem that, overall, about 30% of the recurrent episodes that occurred before the end of 2006 had a prior missed episode of ARF. The remaining recurrences were probably all a consequence of suboptimal ongoing management of persons known to have had a prior episode of ARF.

The significant decline in recurrences between the periods mid 2004 to the end of 2006 and the beginning of 2007 to mid 2009 is striking. Again, the most plausible explanation is that the initiatives to raise awareness about ARF among medical practitioners (and other health care workers) in north Queensland made a considerable contribution to this decline. Not only would any backlog of missed cases have been cleared within a couple of years of commencing the initiatives, but the patients concerned in these previously missed cases would also have had the opportunity to receive antibiotic prophylaxis once their illnesses had been recognised as ARF. The non-significant changes in the proportion of episodes that were not recurrences between the two 2.5-year periods support this explanation: that raising awareness about the disease led to fewer cases of ARF being missed, and ultimately to fewer recurrences.

This report provides circumstantial evidence that misdiagnosis of ARF made a considerable contribution to recurrent ARF in Indigenous people in north Queensland. However, on the positive side, we found that raising awareness about ARF, among medical practitioners in particular, is likely to lead to fewer cases of ARF being missed, and to fewer recurrences of the disease.

The national guidelines on the diagnosis and management of ARF and RHD state: "Many medical practitioners in Australia have never seen a case of ARF, because the disease has largely disappeared from the populations among which they train and work. It is very important that health staff receive appropriate education about ARF before postings to remote areas."[3] Although we agree, in reality there is no mechanism in north Queensland to deliver such an orientation to rural and remote staff in a routine

and sustainable way. Fortunately, as part of a national initiative, an RHD Register and Control Program was recently established in Queensland. This program has four coordinators situated throughout north Queensland, whose role is to expand further the initiatives to raise awareness and improve ARF/RHD case management strategies that have been implemented in the region since 2005.

ACKNOWLEDGEMENTS

We thank Fiona Tulip for providing the Estimated Resident Populations and Alexandra Raulli for helping with the analyses. Special thanks to Margaret Young for her helpful comments on an earlier draft of the manuscript.

COMPETING INTERESTS

None identified.

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REFERENCES

1 Hanna JN, Heazlewood RJ. The epidemiology of acute rheumatic fever in Indigenous people in north Queensland. *Aust N Z J Public Health* 2005; 29: 313-317.

2 Acute rheumatic fever in north Queensland: mid-2004 to mid-2005. *Tropical Public Health Unit Network Communicable Disease Control Newsletter* 2005; (51): 1-3.

3 National Heart Foundation of Australia (RF/RHD guideline development working group) and the Cardiac Society of Australia and New Zealand. Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia — an evidence-based review. Canberra: NHA, 2006. http://www.heartfoundation.org.au/SiteCollectionDocuments/PP-590%20Diagnosis-Management%20ARF-RHD%20Evidence-Based%20Review.pdf (accessed Apr 2010)

4 Why are medical practitioners in north Queensland missing cases of acute rheumatic fever? *Tropical Population Health Unit Network Communicable Disease Control Newsletter* 2007; (55): 1-4.

5 Three more missed cases of acute rheumatic fever. *Tropical Population Health Unit Network-Communicable Disease Control Newsletter* 2008; (57): 1-2.

6 Australian Bureau of Statistics. Australian Demographic Statistics September quarter 2009. Canberra: ABS, 2010. (ABS Cat. No. 3101.0.) http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/26D01CDE59A47371CA2576F0001C7F50/$File/31010_sep%202009.pdf (accessed Apr 2010).

7 Rothstein J, Heazlewood R, Fraser M. Health of Aboriginal and Torres Strait Islander children in remote Far North Queensland: findings of the Paediatric Outreach Service. *Med J Aust* 2007; 186: 519-521.

8 McLean A, Waters M, Spencer E, Hadfield C. Experience with cardiac valve operations in Cape York Peninsula and the Torres Strait Islands, Australia. *Med J Aust* 2007; 186: 560-563.

(Received 10 Feb 2010, accepted 14 Mar 2010) ❑