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Variability in disease burden and management of rheumatic fever and rheumatic heart disease in two regions of tropical Australia

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Abstract

Background: Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) contribute to Aboriginal Australian and Torres Strait Islander health disadvantage. At the time of this study, specialist ARF/RHD care in the Kimberley region of Western Australia was delivered by a broad range of providers while in far north Queensland (FNQ) a single provider model was used as part of a coordinated RHD control program.

Aims: To review ARF/RHD management in the Kimberley and FNQ to ascertain whether differing models of service delivery are associated with different disease burden and patient care.

Methods: An audit of ARF/RHD management. Classification and clinical management data were abstracted from health records, specialist letters, echocardiograms and regional registers using a standardised data collection tool.

Results: 407 patients were identified with 99% being Aboriginal and/or Torres Strait Islanders. ARF without RHD was seen in 0.4% of Aboriginal and/or Torres Strait Islander residents and RHD in 1.1%. The prevalence of RHD was similar in both regions but with more severe disease in the Kimberley. More FNQ RHD patients had specialist review within recommended timeframes (67% versus 45%, χ^2, p<0.001). Of patients recommended benzathine penicillin secondary prophylaxis, 17.7% received ≥80% of scheduled doses in the preceding 12 months. Prescription and delivery of secondary prophylaxis was greater in FNQ.

Conclusions: FNQ's single-provider model of specialist care and centralised RHD control program were associated with improved patient care and may partly account for the fewer cases of severe disease and reduced surgical and other interventions observed in this region.

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Introduction

Acute rheumatic fever (ARF) is a non-suppurative complication of infection with group A streptococcus (GAS). Its major chronic sequela is chronic heart valve damage associated with rheumatic heart disease (RHD). Rates of ARF and RHD in Aboriginal Australians and Torres Strait Islander peoples are among the highest documented in the world, but these conditions are very rare in non-Indigenous Australians.[1,2] Across the north of Australia the prevalence of RHD in the Aboriginal and Torres Strait Islander population has been reported at 1-2%.[3-6]

The development of national Australian guidelines for ARF and RHD diagnosis and management[7] have facilitated the standardisation of ARF/RHD care between Australian state health departments and they have been utilized to inform local management guidelines.[8-10] Management of ARF and RHD encompasses secondary antibiotic prophylaxis in the form of 3-4 weekly long-acting benzathine penicillin (BP) injections to prevent GAS infection and recurrent ARF, regular local primary healthcare review, echocardiography, specialist review and education.[7] Management of RHD also involves preventing and managing complications such as endocarditis, cardioembolism and heart failure, and assessing the need for valve related surgical procedures.[7]

Previous studies of ARF/RHD in the north of Australia have demonstrated suboptimal care: secondary prophylaxis coverage is inadequate, survival following heart valve surgery is

low, and monitoring of anticoagulation is variable.[11-13] This earlier work, and the demonstrated high burden of disease, has provided a focus for local initiatives which aim to improve access to, and quality of, care.

The processes and models of local service delivery for comprehensive ARF/RHD care remain variable. This is in part due to historic models of service delivery, geography, and population and health workforce distribution. The Kimberley region of Western Australia (WA) and Cape York and Torres Strait regions of far north Queensland (FNQ) (see Figure 1) illustrate such variability, with significantly different models of service delivery.

At the time of this review, ARF/RHD care in the Kimberley was based on a "multi-provider model" centred on primary health care with support and follow-up provided by community-based and outreach specialist service providers. These services included local regional physicians and paediatricians who visited large and small communities, and visiting cardiologists (paediatric and adult) and echocardiographers in larger centres. This involved public and private service providers from a number of different organisations with any required surgery being undertaken in one of three Perth hospitals. Individual primary health care sites maintained a variety of paper-based and electronic registers and recall systems with no single regional system.

In FNQ, ARF/RHD care was similarly centred on primary health care but with support and follow-up provided by a "multi-skilled single-provider model". This consisted of a single specialist outreach service of physicians (who also performed echocardiography) and paediatricians, with adult or paediatric cardiology review generally only provided when

surgery was planned at regional referral centres (Cairns or Townsville). Registration and recall of ARF/RHD patients was provided from a regional database supported and coordinated by a centralised ARF/RHD program.

In order to explore optimal models of care for people with ARF/RHD living in the north of Australia we undertook an assessment of these two differing systems. This included an assessment of the locally recognised burden of disease, an audit of the care received by patients, and benchmarking care against local management guidelines. This process focused on the performance and coordination of care across each region rather than on individual providers.

Materials and Methods

We reviewed the management of ARF/RHD patients who had accessed primary and specialist health care services in the Kimberley region of northern WA and in the Cape York and Torres Strait regions of FNQ (see Figure 1). In the Kimberley, these services were provided by Aboriginal community-controlled health services and/or state health department primary health care clinics and hospitals. In FNQ they were predominantly provided by health department primary health care clinics and hospitals.

Inclusion criteria were a clinician-recorded diagnosis of either (1) ARF and/or (2) RHD in patients considered by the local health service to be "regular" clients. A diagnosis of ARF required health record documentation of ARF (irrespective of time of diagnosis and whether ARF currently actively managed) or the use of an ARF care plan and, where available, no evidence of RHD on the most recent echocardiogram report. A diagnosis of

RHD required documentation of RHD by the local health service with an associated abnormal echocardiogram, or a history of prosthetic valve replacement/valve repair/valvuloplasty, or an echocardiogram report consistent with RHD. Consistent echocardiography findings included: mitral stenosis, mitral regurgitation with thickening and/or distortion of the valve leaflets, or mitral valve and aortic valve regurgitation or stenosis.

Eligible patients were identified at local health services through interrogation of health information management systems (i.e. searching for clients assigned to an ARF/RHD "care plan", or generating ARF/RHD "problem" lists), accessing BP recall lists, and through questioning of local health service staff. In FNQ the regional ARF/RHD register was also accessed to identify potential clients for inclusion. Finally, electronic copies of specialist letters and echocardiography reports were searched for terms that may indicate the client had ARF/RHD (e.g. rheumatic, mitral, aortic, valve, regurgitation, stenosis) and the health records of clients identified through these methods checked for diagnoses .

Data were collected in the Kimberley between August and November 2007 at 17 primary health care sites and in FNQ between November 2008 and March 2009 at 12 sites (Figure 1). Data on clinical management were abstracted from local health records (paper-based and electronic), specialist letters, echocardiogram reports, and local and regional registers and recall databases. A standardised data collection tool was utilised with a manual providing standardised definitions for patient selection and service delivery.

Data collected and quality measures assessed included: patient demographics; echocardiogram timeliness and results; severity of ARF/RHD based on the classification system proposed by the national guidelines[7] (see Table 1); prescription and uptake of secondary prophylaxis in the 12 months prior to audit; timeliness of specialist review (cardiologist, physician, paediatrician); uptake of immunisations (influenza vaccination within past 12 months, pneumococcal vaccination within last 5 years); and appropriateness of anticoagulation. The delivery of health services was benchmarked against local standards of care as outlined in the Kimberley chronic disease protocols[9] and Queensland chronic disease guidelines[10] (see Table 2). For those clients receiving secondary prophylaxis, the proportion achieving >=80% of scheduled doses in the 12 months prior to audit was calculated and any episodes of recurrent ARF for that period recorded.

Population denominators were based on 2006 Australian Bureau of Statistics census data.[14] Disease prevalence in the Kimberley was based on the entire Aboriginal and Torres Strait Islander population of the region as clients from all possible health care sites were included. Disease prevalence in FNQ was based on population statistics for Local Government Areas (LGAs) associated with those sites audited. Data from Thursday Island were excluded as accurate population denominator data were not available.

Data were analysed using SPSS (v15.0 for Windows, SPSS Inc, Chicago, IL, USA) and Intercooled Stata 12 (Stata Corporation, Texas, USA). All statistical tests were two-sided with a p-value < 0.05 taken to indicate statistical significance.

This project was approved as a clinical audit by the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC), the Western Australia Country Health Service Board Research Ethics Committee, and the Human Research Ethics Committee of the Cairns and Hinterland Health Service District, Queensland Health.

Results:

407 patients were included in the study. Patient demographics, disease prevalence and severity, and valve surgery/procedures are presented in Table 3. There were no significant differences in the demographics of Kimberley and FNQ patients. The prevalence of a previous diagnosis of ARF (with no progression to RHD) and RHD was similar in the two study areas but with more severe disease in the Kimberley. Significantly more RHD patients in the Kimberley had undergone valve surgery or associated procedures.

A history of ARF without associated RHD was seen in 24.5% (52/212) of Kimberley patients and 27.7% (54/195) of FNQ patients. Median age was 22.4 years (IQR 17.2 – 32.4) and women were overrepresented, accounting for 60.2% of patients. There was no significant difference in age or gender between Kimberley and FNQ ARF patients.

In people with a history of ARF it is recommended that an echocardiogram be performed at the time of diagnosis (to assess for carditis and pre-existent RHD) and prior to ceasing prophylaxis. FNQ ARF patients were more likely to have had any echocardiogram performed with 96% (52/54) having a record of an echocardiogram compared with 85% (44/52) of Kimberley patients (χ^2, $p < 0.05$).

Evidence of RHD was seen in 75.5% (160/212) of Kimberley and 72.3% (141/195) of FNQ participants. Median age was 30 years (IQR 20 to 43) and women were again overrepresented, accounting for 71.8% of patients.

Overall 55.1% (166/301) of RHD patients had had a specialist review by a paediatrician, physician or cardiologist in concordance with timeframes recommended in local management guidelines. Timely specialist review was more likely for FNQ RHD patients (66.7%, 94/141) compared with Kimberley patients (45.0%, 72/160) (χ^2, p<0.001).

Echocardiography was delivered to 60.5% (182/301) of RHD patients within recommended timeframes with no overall difference between regions. However, RHD patients in the Kimberley who had a history of valve surgery or other procedures were more likely to have received a timely echocardiogram than comparable patients in FNQ (31/44 (70.5%) versus 9/23 (39.1%), χ^2, p<0.001).

The delivery of secondary antibiotic prophylaxis to ARF/RHD patients is outlined in Table 4. The proportion of patients receiving BP prophylaxis was significantly higher in FNQ than in the Kimberley (χ^2, p<0.001) as was the median number of doses given in the twelve months prior to audit (Wilcoxan Mann-Whitney test, p<0.0001). Ten patients in FNQ and two in the Kimberley with a recommendation for benzathine penicillin prophylaxis had an episode of recurrent ARF in the 12 months prior to the study (Fisher's exact test, p<0.05). All of these cases were preventable with no patient receiving adequate secondary antibiotic prophylaxis in the 2 months prior to their episode of recurrent ARF.

One in five RHD patients was receiving warfarin anticoagulation (see Table 5). Based on a recommended frequency of INR monitoring of six weekly[15], 36.7% of these had inadequate monitoring. Of all recorded INR results 65.1% were outside the recommended range.[7] No significant differences were observed between FNQ and the Kimberley.

Influenza and pneumococcal vaccinations were recommended for all patients with ARF/RHD. Influenza and pneumococcal vaccination was more likely to be up-to-date in FNQ patients (influenza 54.4%, pneumococcal 47.7%) compared with Kimberley patients (38.6%, 37.3%) (χ^2, p<0.01 and p<0.05 respectively).

Discussion

This study is the first to highlight differences in the nature and burden of ARF/RHD, and the quality of care received by ARF/RHD patients in different northern Australian regions.

Results from this study confirm that in northern Australia ARF/RHD remains almost exclusively a disease of Aboriginal and Torres Strait Islander people with 99% of identified ARF/RHD patients being of Aboriginal and/or Torres Strait Islander ethnicity). The observed prevalence of RHD in Aboriginal and Torres Strait Islander people in the Kimberley (1.02%) and FNQ (1.14%) was comparable to earlier studies of Aboriginal Australian and low income country populations.[2, 3, 6, 16] This is in contrast to the waning burden of disease among other Australians (0.2% in the Top End of the Northern Territory and less than 0.1% in Central Australia)[6] and most other high income nations.[16, 17]

The relatively young median age of RHD patients in this study is presumably related to premature mortality of people with RHD in this setting. This is supported by evidence from the Northern Territory where the mean age at death of Aboriginal people with RHD is 35.7 years compared to 67.3 years in non-Aboriginal RHD patients.[1]

The predominance of female patients has been noted previously.[2, 6] Whilst the cause of this remains unclear it has been suggested that a greater exposure to GAS associated with the care of children, enhanced diagnosis accompanying more frequent health care utilisation and a gender-related propensity to autoimmune disease may all contribute.[18]

While the overall prevalence of ARF/RHD was similar in both regions we demonstrated a greater proportion of severe RHD and higher levels of valve related procedures in the Kimberley. This difference may be explained by regional differences in the pattern of ARF/RHD, differences in diagnosis and monitoring, and uptake of secondary antibiotic prophylaxis.

ARF/RHD is associated with economic and environmental disadvantage[19, 20] and incidence of infection with GAS[21]. The available data do not suggest differences in housing, employment, degree of remoteness or income between the Kimberley and FNQ[22] and there is no obvious reason to suspect that the natural history of ARF/RHD differs between the two regions.

It is possible that cases of ARF and/or mild RHD were not as readily identified in the Kimberley as in FNQ. In FNQ we observed a significantly greater proportion of ARF/mild RHD which may indicate that cases were being identified earlier here. Earlier identification

would enable earlier intervention, including delivery of secondary prophylaxis to prevent the development or worsening of RHD, thereby ensuring that fewer patients progress to severe disease or require heart surgery. In Queensland there was a centralised RHD control program and a regional ARF/RHD database in place at the time of this study. This program incorporated an ARF notification system, a centralised coordination unit, regular reminders to health providers about individuals requiring BP prophylaxis and specialist follow-up, and ongoing training and support for health staff in relation to the management of ARF/RHD. In contrast, at the time there was no such program or regional ARF/RHD database in the Kimberley. This difference in the coordination of care may be associated with the differences in observed service delivery and disease severity between the two regions. An ARF/RHD enhanced surveillance system similar to the one in place in FNQ has since been implemented in the Kimberley.

While we did demonstrate lower levels of echocardiography in ARF patients without RHD in the Kimberley, the use of echocardiography (and thus diagnosis and monitoring of severity) in those with RHD was comparable between regions. Differences in monitoring of disease severity alone do not explain the differences in disease severity observed.

More severe disease was associated with less delivery of secondary antibiotic prophylaxis and less specialist review in the Kimberley compared to FNQ. Even if the greater use of less effective oral antibiotic secondary prophylaxis[23] in FNQ was excluded, 16% more patients were prescribed BP prophylaxis and the median number of BP doses delivered was 75% greater in FNQ. Greater delivery of secondary antibiotic prophylaxis in FNQ would be expected to have led to fewer episodes of recurrent ARF and hence less disease

progression. The recorded rate of recurrent ARF was, however, significantly higher in FNQ. At the time, ARF was a notifiable disease in FNQ but not in the Kimberley suggesting that episodes of recurrent ARF were more likely to be reported in FNQ and that significant under-reporting and perhaps under-recognition was occurring in the Kimberley.

The delivery of specialist services observed in both the Kimberley and FNQ was less than optimal with only 55.1% of RHD patients being reviewed within recommended timeframes and 60.5% receiving a timely echocardiogram. An earlier study in the Kimberley reported that of those patients recommended visiting specialist or echocardiographic review, 78% and 64% attended respectively.[11] Similarly, in the Northern Territory, while RHD patients with severe disease were usually receiving follow-up, approximately half the people with moderate and mild disease had been inadequately investigated and/or had not received follow-up.[12]

RHD patients in FNQ were more likely to have been seen by a specialist within recommended timeframes. This was confined to patients with RHD who had not undergone heart valve surgery (data not shown). More frequent specialist review in FNQ may have enhanced the uptake of secondary antibiotic prophylaxis and thus impeded the progression of disease, but it is not possible to confirm this. Despite more frequent specialist review in FNQ, by a workforce who provided contemporaneous echocardiography, and a centralised recall system, there was no difference in the delivery of echocardiography services to RHD patients in the Kimberley and FNQ. Indeed Kimberley RHD patients with a history of valve surgery or other procedures were more likely to have received a timely echocardiogram compared with FNQ patients. Specialist-provided echocardiography in FNQ, while

apparently more frequently available, may have been deferred in busy clinics with other clinical priorities. A dedicated echocardiography service such as that used in the Kimberley is not subject to similar distraction and appears to have ensured those with more advanced disease had echocardiography performed as scheduled.

Many patients with advanced RHD, in particular those who have a mechanical valve *in situ*, require anticoagulation. Delivery of anticoagulation therapy to RHD patients was suboptimal. The lack of concordance between INR targets recommended by national guidelines[7] and those recorded in patient notes is concerning, as is the finding that 1/3 of patients on warfarin did not receive adequate monitoring and that almost 2/3 of recorded INR results were outside recommended targets. A study in non-remote Australia found therapeutic anticoagulation in 57.6% of tests compared with 34.9% seen here.[24] It is vital that initiatives be developed to address this issue in these remote Australian settings. Newer oral anticoagulants which do not require INR monitoring have been developed, however evidence of their effectiveness in RHD, atrial fibrillation related to valvular disease, and mechanical valves is lacking.[25] Given the difficulties associated with anticoagulation and INR monitoring demonstrated here, balloon valvuloplasty, valve repair or bioprosthetic valve replacement are clearly preferable (where they are an option) for patients living in remote northern Australia.

While the differences in delivery of health services observed in this study, particularly the higher levels of BP prescription and delivery and the more timely specialist review observed in FNQ, may be associated with the differing models of service delivery in the two regions, it is important to note that data was collected in the Kimberley in 2007 while

data was collected in FNQ in 2008-2009. The national Australian guidelines for ARF and RHD diagnosis and management[7] were published in 2006 and it is possible that one reason for improved concordance in FNQ was that the extra time between publication and audit in FNQ may have enabled the implementation of awareness programs, education initiatives and system changes to align more closely with the guidelines.

Conclusion

This study has documented the nature, burden and management of ARF/RHD in two regions of northern Australia. We have demonstrated differences in disease severity that may, at least in part, be explained by differing levels of secondary prophylaxis uptake, differing specialist access and the presence or absence of a centralised ARF/RHD control program. In both regions specialist and echocardiography services, secondary prophylaxis and the management of anticoagulation have changed little over the last decade.[11, 12] Coordinated systems for ARF/RHD management supported by centralised database and recall systems and a consolidated specialist health care team were associated with improved patient care and may partly account for fewer cases of severe disease and a reduced number of surgical and other interventions observed in FNQ.

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(v) Figure Legends

Figure 1: Study sites in the Kimberley (Western Australia) and far north Queensland.

(vi) Tables

Table 1: Protocol-based classification of severity of acute rheumatic fever and rheumatic heart disease[7]

Classification	Criteria
Mild	ARF with no evidence of RHD; or trivial to mild valvular disease.
Moderate	Any moderate valve lesion in the absence of symptoms and with normal left ventricular function; or mechanical prosthetic valves.
Severe	Severe valvular disease; or moderate to severe valvular lesions with symptoms – shortness of breath, tiredness, oedema, angina or syncope; or tissue prosthetic valves and valve repairs.

Table 2: Recommended timeframe for delivery of health services to clients with ARF/RHD based on local standards of care as outlined in the Kimberley chronic disease protocols[9] (KIMB) and Queensland chronic disease guidelines[10] (QLD).

Priority	Low		Moderate		High	
	KIMB	QLD	KIMB	QLD	KIMB	QLD
Specialist review	2 years	2 years	1 year	6 months	6 months	3 months
Echocardiography review	2 years	1 year	1 year	1 year	1 year	6 months
Dental review	2 years	1 year	1 year	1 year	1 year	1 year

Table 3: Demographics, ARF/RHD severity (see table 1) and prevalence and type of valve surgery/procedure in patients included in this study. († Inter-quartile range, $^*\chi^2$, p<0.0001, $^{**}\chi^2$, p<0.05)

	All patients (n = 407)	Kimberley (n = 212)	FNQ (n = 195)
Age, median years (IQR†)	29.1 (18.7 – 40.2)	29.4 (19.2 - 41.0)	27.4 (18.3 – 39.5)
Female, n (%)	280 (68.8%)	141 (66.5%)	139 (71.3%)
Aboriginal and/or Torres Strait Islander, n (%)	403 (99.0%)	211 (99.5%)	192 (98.5%)
Disease prevalence in Aboriginal and/or Torres Strait Islander population, %			
ARF (no progression to RHD)	0.36%	0.33%	0.41%
RHD	1.07%	1.02%	1.14%
Disease severity, n (%)			
ARF / Mild RHD	237 (58.2%)	101 (47.6%)	136 (69.7%)*
Moderate RHD	66 (16.2%)	38 (17.9%)	28 (14.4%)
Severe RHD	104 (25.6%)	73 (34.4%)	31 (15.9%)*

Valve surgery or procedures,

n (% RHD patients)

Any valve surgery/procedure	67 (22.3%)	44 (27.5%)	23 (16.3%)[**]
Mechanical valve	36 (12%)	24 (15%)	12 (8.5%)
Bioprosthetic valve	13 (4.3%)	9 (5.6%)	4 (2.8%)
Valvuloplasty/repair	18 (6%)	11 (6.9%)	7 (5.0%)

Table 4. Recommendation for, and delivery of, secondary antibiotic prophylaxis in the 12 months prior to review. (*χ^2, p<0.001; **Wilcoxan Mann-Whittney test, p < 0.0001; *** Fisher's exact test, p<0.0001; †benzathine penicillin)

	All patients (n = 407)	Kimberley (n = 212)	FNQ (n = 195)
Recommendation or prescription for BP[†]	293	136	157*
n (%)	(72.0%)	(64.2%)	(80.5%)
$\geq$ 80% doses BP given	52/293	20/136	32/157
n (% of those recommended BP)	(17.7%)	(14.7%)	(20.4%)
Number of doses of BP	6	4	7**
median (IQR[†])	(2-8)	(1.5-8)	(4-9)
Recommendation for oral antibiotics	21/407	0	21/195***
n (%)	(5.2%)	(0%)	(10.8%)

Table 5: Anti-coagulation therapy and RHD in the Kimberley and FNQ ([†]national guideline INR recommendations[7]: atrial fibrillation without mechanical valve replacement 2 to 3; mechanical mitral valve 2.5 to 3.5; mechanical aortic valve2 to 3. [‡] Based on a minimum recommended monitoring interval of 6 weeks[15])

	All (n=301)	Kimberley (n=160)	FNQ (n=141)
RHD patients on warfarin, n (%)	60/301 (19.9%)	37/160 (23.1%)	23/141(16.3%)
Primary indication for warfarin, n (%)			
Mechanical valve	35/60 (58.3%)	24/37 (64.9%)	11/23 (47.8%)
Atrial fibrillation	19/60 (31.7%)	10/37 (27.0%)	9/23 (39.1%)
Mitral valve disease	6/60 (10.0%)	3/37 (8.1%)	3/23 (13.1%)
Target INR, n (%)			
Documented in medical record?	49/60 (81.7%)	29/37 (78.4%)	20/23 (87.0%)
Concordant with national guidelines?[†]	19/49 (38.8%)	8/29 (27.6%)	11/20 (55.0%)
INR tests in previous 12 months			
Number, median (IQR)	11 (5 – 21.5)	15 (5 – 26)	9 (6.5 – 12)
Adequate testing[‡], n (%)	38/60 (63.3%)	23/37 (62.2%)	15/23 (65.2%)
Results above recommended range, n (%)	180/758 (23.7%)	129/517 (25.0%)	51/241 (21.2%)
Results below recommended range, n (%)	314/758 (41.4%)	232/517 (44.9%)	82/241 (34.0%)

(vii) Figures

Figure 1: