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Priorities for improved management of acute rheumatic fever and rheumatic heart disease: analysis of cross-sectional continuous quality improvement data in Aboriginal primary healthcare centres in Australia

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Abstract

Objective. This study investigated the delivery of guideline-recommended services for the management of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Australian primary healthcare centres participating in the Audit and Best Practice for Chronic Disease (ABCD) National Research Partnership project.

Methods. ARF and RHD clinical audit data were collected from 63 Aboriginal centres in four Australian jurisdictions using the ABCD ARF/RHD audit tool. Records of up to 30 patients treated for ARF and/or RHD were analysed per centre from the most recent audit conducted between 2009 and 2014. The main outcome measure was a quality of ARF and RHD care composite indicator consisting of nine best-practice service items.

Results. Of 1081 patients, most were Indigenous (96%), female (61%), from the Northern Territory and Queensland (97%) and <25 years of age (49%). The composite indicator was highest in the 0–14 year age group (77% vs 65–67% in other age groups). Timely injections and provision of client education are important specific areas for improvement. Multiple regression showed age >15 years to be a significant negative factor for several care indicators, particularly for the delivery of long-acting antibiotic injections and specialist services in the 15–24 year age group.

Conclusions. The results suggest that timely injection and patient education are priorities for managing ARF and RHD, particularly focusing on child-to-adult transition care.

What is known about the topic? The burden of rheumatic fever and RHD in some Aboriginal communities is among the highest documented globally. Guideline-adherent RHD prevention and management in primary health care (PHC) settings are critically important to reduce this burden. Continuous quality improvement (CQI) is a proven strategy to improve guideline adherence, using audit cycles and proactive engagement of PHC end users with their own data. Previously, such CQI strategies using a systems approach were shown to improve delivery of ARF and RHD care in six Aboriginal health services (three government and three community controlled).

What does this paper add? This paper focuses on the variation across age groups in the quality of ARF and/or RHD care according to nine quality of care indicators across 63 PHC centres serving the Aboriginal population in the Northern Territory, Queensland, South Australia and Western Australia. These new findings provide insight into difference in quality of care by life stage, indicating particular areas for improvement of the management of ARF and RHD at the PHC level, and can act as a baseline for monitoring of care quality for ARF and RHD into the future.

What are the implications for practitioners? Management plans and innovative strategies or systems for improving adherence need to be developed as a matter of urgency. PHC professionals need to closely monitor adherence to secondary prophylaxis at both the clinic and individual level. RHD priority status needs to be assigned and recorded as a tool to guide management. Systems strengthening needs to particularly target child-to-adult transition care. Practitioners are urged to keep a quick link to the RHDAustralia website to access resources and guidelines pertaining to ARF and RHD (https://www.rhdaustralia.org.au/arf-rhd-guideline, accessed 3 October 2019). CQI strategies can assist PHC centres to improve the care they provide to patients.

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Introduction

Rheumatic heart disease (RHD) manifests as permanent damage to heart valves resulting from repeated episodes of acute rheumatic fever (ARF), an autoimmune reaction to a Group A streptococcus (StrepA) infection.[1] The incidence of ARF in some Aboriginal communities is among the highest documented globally.[2,3] RHD can lead to heart failure, may require open-heart surgery for valve repair or replacement and often results in premature mortality. Therefore, guideline-adherent prevention and management are critically important.

There has been increased availability of ARF and RHD guidelines for Australian healthcare providers, including quick reference[4] and comprehensive online versions (https://www.rhdaustralia.org.au/arf-rhd-guideline, accessed 3 October 2019). Other guideline-related resources associated with rural practice,[5] antibiotic prescription[6] and rheumatology[7] all align with these ARF and RHD guidelines. However, knowledge about, and where to seek information on, ARF and RHD remains low among healthcare providers. Consequently, adherence to guidelines may be suboptimal, with patients missing out on much-needed care.[8] In particular, inadequate delivery of secondary prophylaxis with regular penicillin injections (long-acting benzathine benzylpenicillin G (BPG) once every 28 days) to prevent recurrences of ARF on re-exposure to StrepA infections, can mean that ARF recurrences occur, often progressing to RHD.

Continuous quality improvement (CQI) is a proven strategy to improve guideline adherence, using audit cycles and proactive engagement of primary healthcare (PHC) end users with their own data. For example, where a predetermined target proportion of prescribed penicillin injections is not met, the PHC service can introduce activities to improve the delivery of injections. Although this is challenging in remote Aboriginal community settings,[9] partly due to high staff turnover[10] and other factors, such as inadequate community engagement,[11] some successes with CQI have been seen in ARF and RHD care,[12] as well as in other chronic conditions.[13,14]

Australian PHC services are subsidised through Australia's universal health insurance scheme, Medicare. Aboriginal Medical Services receive additional resources for supplementary services for Aboriginal people to address additional cultural and logistical needs. Some of these more-comprehensive services are run by community-elected boards (community controlled[15]), whereas others are part of government services.

The Audit and Best Practice for Chronic Disease (ABCD) project uses participatory action research methods to develop CQI audit tools and processes for use in Aboriginal PHC services to strengthen local delivery systems and improve health outcomes.[16] The CQI tools are based on internationally accepted PHC models and locally developed clinical guidelines for the prevention and management of a range of conditions. Health centre participation in ABCD CQI activities is voluntary and based on local service priorities. Most health centres using ABCD CQI tools volunteered their deidentified data for analysis to the ABCD National Research Partnership (NRP) Project. An ABCD clinical audit tool was developed for capturing quality of care (QOC) indicators for ARF and RHD from participating PHC sites.[17] The availability of such CQI data provides the opportunity to obtain a rare snapshot of how well ARF and RHD are managed in PHC.

This study investigated the delivery of services scheduled in current guidelines for the management of ARF and RHD in Australian PHC centres that participated in the ABCD NRP. Specific objectives were to describe the demographic and clinical profile of ARF and RHD patients whose clinic records were audited, determine the variation in quality of ARF and RHD care across age groups according to key indicators and identify health centre and individual patient factors that affect the quality of ARF and RHD care in participating centres.

Methods

Study design

The present cross-sectional observational study used ARF and RHD clinical audit data from 63 PHC centres in the Northern Territory (NT), Queensland (Qld), South Australia (SA) and Western Australia (WA) participating in the ABCD NRP Project.

Data collection

The ABCD ARF/RHD audit tool[17] was developed in consultation with disease experts and Aboriginal and Torres Strait Islander PHC centres with the aim of evaluating the quality of PHC services for RHD.[17] The tool allows assessment of actual

practice against best practice standards based on treatment guidelines.[4]

ABCD clinical audits were undertaken between 2009 and 2014 by health centre staff trained in the audit tools and supported by quality improvement facilitators. Between one and six audits (mean 3.3) were completed per health centre.

All patients living in the community for at least 6 of the previous 12 months with a suspected or definite diagnosis of ARF or a diagnosis of RHD were eligible for inclusion. Inactive patients (history of ARF, no RHD and secondary prophylaxis ceased) were excluded. Where the eligible service population was ≤30, all records were included. If the eligible population was >30, a randomly selected sample of patient records was audited, following guidance from the ABCD protocol.[16]

The most recent audit of ARF/RHD clinical service delivery conducted by each of the 63 PHC centres between 2009 and 2014 was analysed. Demographic variables collected included age, sex and ethnicity. Variables audited included: diagnoses (ARF, RHD, both), severity classification (Priority 1–4, corresponding to different levels of risk for RHD complications including death), the presence of a current and complete ARF or RHD management plan, penicillin prescription (or not), adherence to dosing regimen if prescribed penicillin, whether the patient received regular doctor and specialist review, alcohol and tobacco use, whether provision of education about ARF and RHD was documented and whether brief interventions regarding cardiovascular risk factors, including smoking, high-level alcohol intake, nutrition and physical activity, were documented.

QOC indicators

The main outcome measure was an overall quality of ARF and RHD care composite indicator consisting of up to nine best-practice service items within the audit tool. Not all patients required all nine items (e.g. 50-year-old patients with RHD may no longer require penicillin). The composite indicator comprised documentation of disease classification within the health summary, a current and complete ARF or RHD management plan, planned frequency of penicillin injections, ≥80% of planned penicillin injections received, active recall (if <80% of injections were received), guideline-compliant timing and nature of medical reviews, echocardiogram and client and/or family education on ARF. A service was recorded as delivered if there was a clear record of delivery within the recommended time frames.

Statistical analysis

Profiles of patients, types of services and QOC indicators were analysed using means, medians and proportions. Scores for the nine QOC indicators were calculated from the most recent audit occasion, representing the percentage of individuals receiving the respective service item. These scores were summarised by age group (<15, 15–24, 25–50, >50 years) and exact 95% binomial confidence intervals (CIs) reported. The overall QOC index was derived for each individual by dividing the number of service targets met by the number of targets for which the individual was eligible. Generalised linear mixed-effects logistic regression was used to analyse the determinants for each QOC indicator considering the following covariates: sex, age group, ARF and RHD status, remoteness of the clinic, number of years CQI cycles had been done and number of cycles. In addition to calculating the odds ratios (ORs) for the fixed effects, the model takes into account the clinic random effect due to the clustering of cases within a clinic. Statistical analysis was performed using R software version 3.6.0 (R Foundation for Statistical Computing, Vienna, Austria).

Ethics approval

Ethics approval for the study was granted by the human research ethics committees in all jurisdictions with participating health services,[16] including the NT, New South Wales and Qld, the SA Aboriginal Health Research Ethics Committee, Curtin University, University of Western Australia, WA Country Health Services and the WA Aboriginal Health Information and Ethics Committee.

Results

Clinical records of 1081 patients with ARF or RHD aged 2–81 years were audited. Almost all (97%) participating health centres were located in the NT or Qld, and 94% were in regional or remote areas (Table 1). The majority (88%) of the most recent audits were conducted between 2012 and 2014.

Profile of patients

Aboriginal and Torres Strait Islander people comprised 96% of eligible patients. Patients aged <25 years comprised 48.9% of the cohort, with 40.5% aged 24–49 years. Sixty-one per cent of audited patients were female, with the proportion of females increasing from 51% in the youngest age group to 67% in the oldest age group (Table 1). There were relatively more patients in the 0–14 year age group in regional areas, and relatively more patients in the ≥50 year age group in urban areas. A diagnosis of ARF only was recorded in 8% of patients; 36% had RHD only and 56% had both ARF and RHD. Over two-thirds of patients aged <25 years had both ARF and RHD recorded, with the percentage of RHD-only patients increasing with age.

Severity classification was recorded in 29.9% of patients; 138 patients (12.7%) were recorded as medium ($n = 88$) or high ($n = 50$) priority. High-risk status (Priority 1) increased (from 0.9% to 7.0%) and low-risk status (Priority 3) decreased (from 25.0% to 8.8%) with age as a percentage of all patients (Table 1). Among adults (those aged ≥15 years), 42.4% were recorded as smokers. Alcohol use was poorly recorded, although documentation of 'no alcohol use' increased with age.

Clinic attendance and clinical management

The median time between previous clinic attendance and audit date was 22 days (Table 2). The most common reason for attendance across all age groups was to receive a BPG injection (45%), being highest for those aged 0–14 (68.9%) and 15–24 (58.1%) years.

Most patients (80.4%) had disease management plans recorded. Current prescription for regular BPG injections varied by age group. Approximately 83% of patients aged <50 years (97.8% of those aged <15 years and 26.3% of older patients) were prescribed regular BPG injections. The program target of receiving ≥80% of injections within the appropriate time frame was met in 46.7% of patients, varying from 64.1% in people aged 15–24 years to 13.2% in people >50 years of age. Only

Table 1. Demographic and health characteristics of clients included in the most recent audit cycle

Data are given as the number of people for whom records were audited, using the most recent audit per person (*n*), with percentages in parentheses. ARF, acute rheumatic fever; RHD, rheumatic heart disease

	Age group (years)				Total (*n* = 1081; 100%)
	0–14 (*n* = 228; 21.1%)	15–24 (*n* = 301; 27.8%)	25–49 (*n* = 438; 40.5%)	≥50 (*n* = 114; 10.5%)	
Patient characteristics					
Male sex	112 (49.1)	123 (40.9)	153 (35.9)	38 (33.3)	426 (39.4)
Indigenous					
Yes	219 (96.1)	288 (95.7)	420 (95.9)	112 (98.3)	1039 (96.1)
No	3 (1.3)	0 (0.0)	4 (0.9)	2 (1.8)	9 (0.8)
Not recorded	6 (2.6)	13 (4.3)	14 (3.2)	0 (0.0)	33 (3.0)
Remoteness of clinic attended					
Remote	187 (82.0)	260 (86.4)	381 (87.0)	93 (81.6)	921 (85.2)
Regional	30 (13.2)	22 (7.3)	33 (7.5)	8 (7.0)	93 (8.6)
Urban	11 (4.8)	19 (6.3)	24 (5.5)	13 (11.4)	67 (6.2)
State					
Northern Territory	117 (51.3)	148 (49.2)	286 (65.3)	81 (71.1)	632 (58.5)
Queensland	105 (46.1)	149 (49.5)	134 (30.6)	27 (23.7)	415 (38.4)
South Australia	0 (0.0)	0 (0.0)	4 (0.9)	3 (2.6)	7 (0.6)
Western Australia	6 (2.6)	4 (1.3)	14 (3.2)	3 (2.6)	27 (2.5)
Year of audit					
2009	4 (1.8)	4 (1.3)	8 (1.8)	4 (3.5)	20 (1.9)
2011	20 (8.8)	35 (11.6)	49 (11.2)	7 (6.1)	111 (10.3)
2012	46 (20.2)	51 (16.9)	59 (13.5)	14 (12.3)	170 (15.7)
2013	110 (48.2)	149 (49.5)	192 (43.8)	45 (39.5)	496 (45.9)
2014	48 (21.1)	62 (20.6)	130 (29.7)	44 (38.6)	284 (26.3)
Health status					
ARF and RHD status					
ARF only	31 (13.6)	30 (10.0)	24 (5.5)	2 (1.8)	87 (8.0)
ARF with RHD	163 (71.5)	197 (65.4)	211 (48.2)	35 (30.7)	606 (56.1)
RHD only	34 (14.9)	74 (24.6)	203 (46.3)	77 (67.5)	388 (35.9)
Risk classification (severity of disease)					
High	2 (0.9)	12 (4.0)	28 (6.4)	8 (7.0)	50 (4.6)
Medium	8 (3.5)	21 (7.0)	48 (11.0)	11 (9.6)	88 (8.1)
Low	57 (25.0)	72 (23.9)	46 (10.5)	10 (8.8)	185 (17.1)
Not determined or recorded	161 (70.6)	196 (65.1)	316 (72.1)	85 (74.6)	758 (70.1)
Smoking status					
Smoker	3 (1.3)	107 (35.3)	211 (48.2)	44 (38.6)	365 (33.8)
Non-smoker	64 (28.1)	85 (28.2)	148 (33.8)	63 (55.3)	360 (33.3)
Not recorded	161 (70.6)	109 (36.2)	79 (18.0)	7 (6.1)	356 (32.9)
Alcohol use					
RHD higher risk	0 (0.0)	23 (7.6)	59 (13.5)	12 (10.5)	94 (8.7)
RHD low risk	2 (0.9)	34 (11.3)	49 (11.2)	11 (9.7)	96 (8.9)
RHD risk level not stated	1 (0.4)	20 (6.6)	33 (7.5)	4 (3.5)	58 (5.4)
No alcohol use	61 (26.8)	79 (26.3)	148 (33.8)	62 (54.4)	350 (32.4)
Not recorded	164 (71.9)	145 (48.2)	149 (34.0)	25 (21.9)	483 (44.7)

12.7% of those patients failing to meet the target had a documented follow-up action plan.

In terms of scheduled reviews, 48.6% of patients at high or medium risk of RHD complications and 71.4% of low-risk patients had a record of general practitioner consultation within the recommended time frame (6 and 12 months respectively). Approximately 40% of high- and medium-risk patients were seen by a specialist (cardiologist, physician, paediatrician or specialist registrar) or received an echocardiogram within 6 and 12 months respectively. In contrast, 75.1% of low-risk patients received echocardiograms according to guidelines.

In terms of overall delivery, the youngest age group received the highest level of care with an average of 77% delivery for items in the composite indicator (Fig. 1; see Table S1, available as Supplementary Material to this paper).

For all older age groups, overall delivery of care was substantially lower, at 67%, 66% and 65% for those aged 15–24, 25–49 and ≥50 years respectively. The main weaknesses were found in delivering at least 80% of BPG injections in a timely manner and documentation of provision of client education. Without taking these two indicators into account, the overall composite score increased to between 87% (for those aged <15 years) and 79%

Table 2. Profile of clinic attendance and management of acute rheumatic fever (ARF) and rheumatic heart disease (RHD)
Unless indicated otherwise, data are given as *n* (%). BPG, benzathine penicillin G; ECG, echocardiogram

	Age group (years)				Total (*n* = 1081)
	0–14 (*n* = 228)	15–24 (*n* = 301)	25–49 (*n* = 438)	50+ (*n* = 114)	
Days since last attendance					
Median no.	25	27	20	12	22
≤28	130 (57.0)	161 (53.5)	265 (60.5)	85 (74.6)	641 (59.3)
≤90	204 (89.5)	259 (86.0)	385 (87.9)	104 (91.2)	952 (88.1)
≤365	226 (99.1)	298 (99.0)	432 (98.6)	114 (100.0)	1070 (99.0)
Reason last attended					
Acute care	32 (14.0)	58 (19.3)	118 (26.9)	38 (33.3)	246 (22.8)
BPG injection	157 (68.9)	175 (58.1)	147 (33.6)	7 (6.1)	486 (45.0)
Oral prophylaxis	1 (0.4)	1 (0.3)	5 (1.1)	2 (1.8)	9 (0.8)
Wellness check	8 (3.5)	7 (2.3)	18 (4.1)	4 (3.5)	37 (3.4)
Specialist review	11 (4.8)	12 (4.0)	19 (4.3)	1 (0.9)	43 (4.0)
Other	19 (8.3)	48 (15.9)	131 (29.9)	62 (54.4)	260 (24.1)
ARF and RHD management					
Management plan given ARF or RHD					
RHD diagnosis only	27 (79.4)	56 (75.7)	167 (82.3)	55 (71.4)	305 (78.6)
ARF diagnosis only	25 (80.6)	22 (73.3)	15 (62.5)	0 (0.0)	62 (71.3)
Overall	195 (85.5)	247 (82.1)	345 (78.7)	82 (71.9)	869 (80.4)
Cardiac surgery undertaken if Priority 1					
Yes	1 (50.0)	10 (83.3)	17 (60.7)	4 (50.0)	32 (64.0)
No	1 (50.0)	2 (16.7)	11 (39.3)	3 (37.5)	17 (34.0)
Prescribed regular BPG injections					
Overall	223 (97.8)	273 (90.4)	308 (70.3)	30 (26.3)	833 (77.1)
ARF diagnosis	190 (97.9)	206 (90.7)	163 (69.4)	13 (35.1)	572 (82.5)
RHD only	33 (97.1)	66 (89.2)	145 (86.8)	17 (22.1)	261 (67.3)
Recurrent ARF	5 (100)	6 (85.7)	6 (66.7)	0 (0.0)	17 (81.0)
Planned BPG injections received					
<80%	99 (43.4)	193 (64.1)	198 (45.2)	15 (13.2)	505 (46.7)
BPG action plan if <80% of injections received					
Yes	17 (17.2)	23 (11.9)	22 (11.1)	2 (13.3)	64 (12.7)
Oral antibiotic use (instead of BPG)					
Yes	1 (0.4)	7 (2.3)	10 (2.3)	1 (0.9)	19 (1.8)
Doctor review within 6 months (RHD risk = high or medium)					
Yes	4 (40.0)	14 (42.4)	36 (47.4)	13 (68.4)	67 (48.6)
Doctor review within 12 months (RHD risk = low)					
Yes	45 (78.9)	44 (61.65)	36 (78.3)	7 (70.0)	132 (71.4)
Cardiac review within 6 months (RHD risk = high)					
Yes	2 (100)	6 (50.0)	9 (32.1)	3 (37.5)	20 (40.0)
Cardiac review within 12 months (RHD risk = medium)					
Yes	3 (37.5)	5 (23.8)	22 (45.8)	7 (63.6)	37 (42.0)
ECG within 6 months (RHD risk = high)					
Yes	1 (50.0)	3 (25.0)	8 (28.6)	3 (37.5)	15 (30.0)
ECG within 12 months (RHD risk = medium)					
Yes	3 (37.5)	3 (14.3)	22 (45.8)	7 (63.6)	35 (39.8)
ECG (RHD risk = low)					
<15 years old, 2 yearly; ≥15 years old, 3 yearly	46 (80.7)	53 (73.6)	32 (69.6)	8 (80.0)	139 (75.1)
Influenza vaccination (yearly if RHD risk high or medium)					
Yes	2 (20.0)	17 (51.5)	53 (69.7)	13 (68.4)	85 (61.6)
Pneumococcal vaccination (if RHD risk high or medium)					
First	4 (40.0)	17 (51.5)	53 (69.7)	12 (63.2)	86 (62.3)
Second	2 (20.0)	4 (12.1)	19 (25.0)	11 (57.9)	36 (47.3)
Third	3 (20.0)	1 (3.0)	4 (5.3)	7 (36.8)	14 (10.1)
Education provided about RHD					
DVD or video	68 (29.8)	39 (12.9)	41 (9.3)	8 (6.8)	156 (14.3)
Written information	83 (36.4)	69 (22.8)	58 (13.1)	9 (7.6)	219 (20.1)

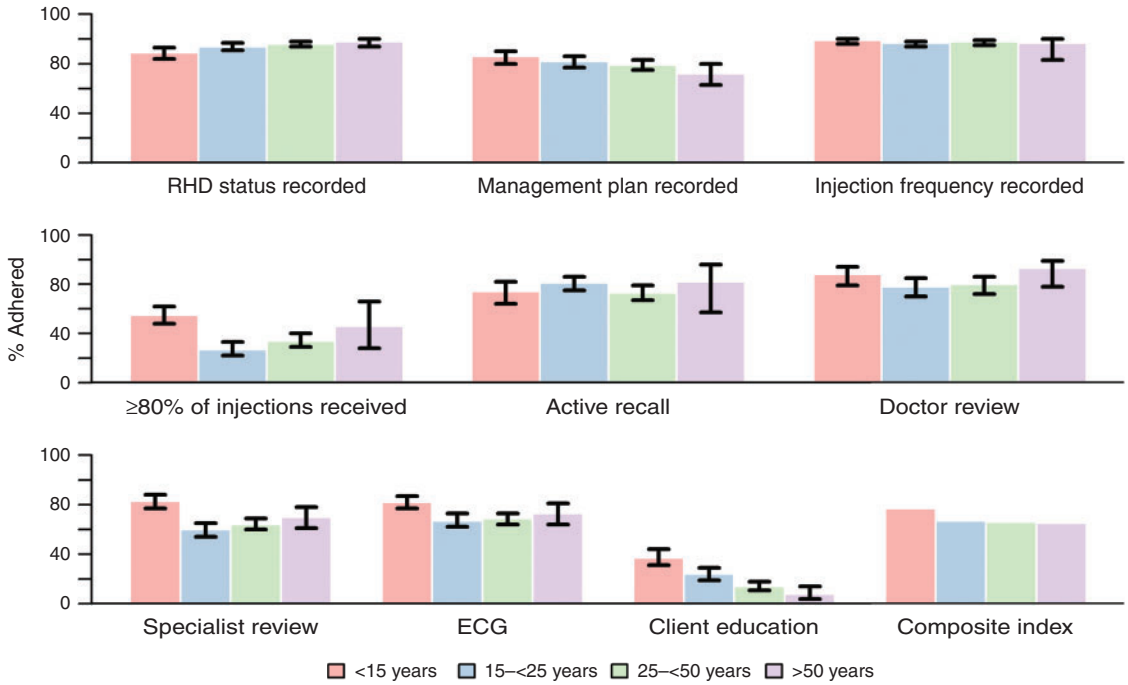

Fig. 1. Guideline adherence of healthcare providers on acute rheumatic fever (ARF) and rheumatic heart disease (RHD) quality of care indicators by age group in the most recent Audit and Best Practice for Chronic Disease (ABCD) cycle (2010–14). Data are the percentages ± 95% confidence intervals. ECG, echocardiography.

(for those aged 25–49 and ≥50 years) across age groups. Moreover, the lower level of service delivery for those aged 15–24 years was less pronounced.

Determinants of QOC indicators

The results of the regression analyses are given in Table 3, with each column representing a separate model undertaken for each QOC indicator.

Compared with patients aged <15 years, older age was found to be a significant negative factor for several indicators, in particular the 80% BPG injections target (OR 0.3 and 0.47 for those aged 15–25 and >25–50 years respectively), timely specialist review (ORs 0.27, 0.29 and 0.37 for those aged 15–25, >25–50 and >50 years respectively), timely echocardiogram (OR 0.42, 0.44 and 0.15 for those aged 15–25, >25–50 and >50 years respectively) and client education (OR 0.47, 0.33 and 0.37 for those aged 15–25, >25–50 and >50 years respectively). The effect was particularly strong for the young adult group (15–24 years) for delivering BPG injections and specialist services. As expected, patients with RHD (with and without documented ARF) had a significantly higher odds (ORs 1.79 and 3.05 respectively) of receiving timely specialist visits compared with ARF-only patients.

Health centre-level factors varied substantially across indicators, accounting for between 10% and 74% of the variation in service delivery to patients (Table 3). The centre effects capture the residual clinic-specific variability that is not explained by the fixed effects included in the models in Table 3 (i.e. a large percentage of variance explained by clinic effects means that the included fixed effects were less important in explaining the outcome (QOC measure) than other unmeasured factors). Conversely, a small percentage of variance explained by clinic effects means that the fixed effects explain a large part of the variability in the data. A large percentage of variance explained by clinic effects is not related to the degree of difference in QOC measures between clinics. Health centre factors were particularly pronounced for having patients' RHD classification recorded (clinic effects = 81.5%) and were weak for access to specialists (clinic effects = 10.6%), echocardiograms (clinic effects = 11.2%) and 80% BPG injections received (clinic effects = 24.1%).

Discussion

This study provides important insights into patient profiles and management of ARF and RHD across PHC clinics participating in ABCD audits predominantly around remote northern Australia. With over 80% of ARF and RHD patients having a management plan in place and regular BPG prescribed (>90% of those aged <25 years), clinic staff show guideline awareness in managing the disease. However, the relatively low achievement of the 80% benchmark of adherence to BPG and only 12% of poor adherers having action plans indicate that insufficient systems are in place to translate these secondary prevention guidelines into quality care. In addition, only 30% of patients had their priority status recorded, suggesting that this classification was rarely used to guide other management. Some guideline targets were relatively well achieved for Priority 3 patients (>75% having an echocardiogram within the past 2–3 years) compared with much lower guideline concordance in this domain for Priority 1 and 2 patients with moderate and severe

Table 3. Adjusted odds ratios (ORs) and 95% confidence intervals (CIs) for each of nine acute rheumatic fever (ARF) and rheumatic heart disease (RHD) indicators of quality of care received by ARF and RHD patients in primary care

Each column represents a separate model including an intercept (not reported). The dependent variable is listed in the column header. Statistically significant associations are bolded. BPG, benzathine penicillin G; ECG, echocardiogram

Quality of care measure	Model 1: RHD severity or priority classification recorded in health summary		Model 2: record of current and complete management plan		Model 3: record of planned frequency of BPG injections	
	OR	95% CI	OR	95% CI	OR	95% CI
Sex						
Male	1.00		1.00		1.00	
Female	0.94	0.45–1.95	1.23	0.83–1.84	0.97	0.38–2.48
Age group (years)						
≤15	1.00					
>15–25	1.68	0.66–4.3	0.79	0.43–1.45	0.38	0.1–1.46
>25–50	1.32	0.52–3.37	0.67	0.38–1.2	0.58	0.14–2.45
>50 years	1.35	0.22–8.16	**0.4**	**0.19–0.86**	0.37	0.03–4.0
Location						
Non-remote	1.00					
Remote	53.17	1.59–1777	4.99	0.87–28.78	2.59	0.66–10.11
Audit year	0.34	0.06–1.94	0.59	0.31–1.12	0.94	0.53–1.68
No. cycles	1.80	0.68–4.77	1.51	0.96–2.38	1.05	0.72–1.54
ARF and RHD status						
ARF only	1.00					
ARF and RHD	1.70	0.62–4.64	1.66	0.78–3.54	0.51	0.06–4.59
RHD only	2.81	0.87–9.06	1.6	0.72–3.55	0.54	0.05–5.38
% Variance clinic effects[A]	81.5		53.3		12.2	
	Model 4: record of ≥80% BPG injections received		Model 5: record of active recall if <80% injections received		Model 6: timely doctor review	
Sex						
Male	1.00		1.00		1.00	
Female	0.97	0.69–1.35	0.98	0.6–1.61	2.05	0.98–4.25
Age group (years)						
≤15	1.00		1.00		1.00	
>15–25	**0.3**	**0.2–0.47**	1.7	0.87–3.3	0.69	0.26–1.87
>25–50	**0.47**	**0.31–0.71**	1.12	0.58–2.19	1.17	0.42–3.25
>50 years	0.83	0.34–2.03	1.99	0.44–8.98	0.83	0.13–5.19
Location						
Non-remote	1.00					
Remote	0.52	0.18–1.47	2.86	0.44–18.71	0.06	0–4.19
Cycle date	0.87	0.61–1.23	0.55	0.27–1.09	0.74	0.25–2.19
No. cycles	1.02	0.79–1.31	1.19	0.76–1.85	1.23	0.42–3.62
ARF and RHD status						
ARF only	1.00		1.00		1.00	
ARF and RHD	1.36	0.68–2.7	2.17	0.84–5.57	0.95	0.33–2.74
RHD only	1.45	0.69–3.09	2.55	0.91–7.17	1.16	0.33–3.99
% Variance clinic effects[A]	24.1		45.2		56.3	
	Model 7: timely specialist review		Model 8: timely ECG		Model 9: record of client education	
Sex						
Male	1.00		1.00		1.00	
Female	1.28	0.96–1.7	1.00	0.74–1.33	1.17	0.8–1.71
Age group (years)						
≤15	1.00		1.00		1.00	
>15–25	**0.27**	**0.17–0.41**	**0.42**	**0.27–0.65**	**0.47**	**0.29–0.75**
>25–50	**0.29**	**0.19–0.44**	**0.44**	**0.29–0.68**	**0.33**	**0.2–0.53**
>50 years	**0.37**	**0.2–0.66**	**0.53**	**0.29–0.96**	**0.15**	**0.06–0.38**
Location						
Non-remote	1.00		1.00		1.00	
Remote	1.19	0.6–2.33	1.07	0.53–2.14	1.27	0.23–7.01
Cycle date	1.04	0.82–1.31	0.96	0.76–1.23	**0.47**	**0.26–0.83**
No. cycles	0.88	0.74–1.04	0.85	0.71–1.01	0.99	0.64–1.51

(*continued next page*)

Table 3. (*continued*)

Quality of care measure	Model 1: RHD severity or priority classification recorded in health summary		Model 2: record of current and complete management plan		Model 3: record of planned frequency of BPG injections	
	OR	95% CI	OR	95% CI	OR	95% CI
ARF and RHD status						
ARF only	1.00		1.00		1.00	
ARF and RHD	**1.79**	**1.03–3.09**	1.32	0.75–2.33	1.09	0.54–2.19
RHD only	**3.05**	**1.69–5.52**	1.83	1.0–3.37	0.75	0.34–1.65
% Variance clinic effects[A]	10.6		11.2		48.5	

[A]This is the percentage of variance attributed to the clinic random effects. The remaining variance stems from the fixed effects captured by the covariates listed in the table.

RHD. Documentation of provision of health education was low, even among people aged <25 years, in whom secondary prevention has the most potential to improve outcomes.

The relative youth of ARF and RHD patients (approximately half <25 years of age) highlights that this chronic disease has its roots in childhood but can affect survivors into adulthood. Consistent with findings in other populations,[1] females comprised an increasing proportion of cases from early adulthood. Moderate and severe RHD (13% over all ages) peaked in early and mid-adulthood.

Most patients <25 years of age (88.5%) had RHD, with 20% having RHD without a documented history of ARF and a relatively small proportion with a history of ARF only. This suggests that although missed diagnosis of ARF could be due to subclinical symptoms, in many instances ARF is being misdiagnosed by health personnel. The high proportion of patients with RHD also suggests that increased surveillance through opportunistic screening of youth from populations at high risk of RHD could identify undiagnosed RHD, offering opportunities to prevent further progression, although careful consideration of targeting screening to maximise cost-effectiveness is needed.[18]

Of major concern is the drop in QOC for young adults 15–24 years compared with children <15 years of age across multiple indicators, including receipt of scheduled BPG injections, management plans, educational sessions and medical and other specialist reviews within guideline-recommended times. This is consistent with other previous reports and highlights the need for transition care that is increasingly being used for chronic paediatric conditions to support children through adolescence and to adulthood.[9,19–21] Engagement of adolescents and young adults urgently needs to be addressed to improve ARF and RHD outcomes.

Many older individuals in this study were found to be prescribed penicillin, in contrast with guidelines, which recommend cessation of penicillin in most people at 35 or 40 years of age, depending on RHD severity.[4] This problem has recently been explored elsewhere.[22] Therefore, the lower penicillin adherence in this age group is less cause for concern. Timely review of penicillin-cessation rules is required, and will be clarified in the upcoming 2020 revision of the existing Australian guidelines.

What might be the priorities needing attention for the PHC management of ARF and RHD? The data suggest that the important areas for improvement include adherence to BPG and provision of patient education. The requirement for culturally appropriate education, provided in vernacular, on many occasions, has been well documented.[23] Many health literacy resources on ARF and RHD have been developed in Aboriginal languages, but greater implementation is needed.[24] Surgery delays need attention. System issues and an exerted effort to engage young adults remain overarching challenges. There is increasing recognition that secondary prevention of ARF and RHD comprises not just penicillin and regular follow-up, but also proactive efforts to support primordial[25] and primary prevention[26,27] among affected individuals. The present data do not address this, because primordial and primary care indicators were not included in the audits.

Strengths and limitations

Our reliance on appropriate documentation within PHC records may have underestimated service delivery due to a lack of documentation in client records, and crucial RHD severity classification information, on which priority levels and thus service provision are based, were often missing. Further, despite the collection of comprehensive data, we would need additional data points to run the complex models needed to refine the findings. The lack of significance of many analysed factors may be because key factors affecting service delivery are truly hard to quantify and highly variable across individual patients and clinics, requiring a mix of quantitative and qualitative methods to get a more detailed understanding.[28] Alternatively, they may be attributable to insufficient high-quality data available for analysis. Although the data are not necessarily representative of all Aboriginal people with ARF or RHD attending PHC clinics in regions where the disease is endemic, comprehensive PHC data focusing on ARF and RHD are rare and registers do not capture all cases or variables accurately.[29] Service delivery was highly variable, making it difficult to pinpoint key determinants of weaknesses in QOC. Differences in outcomes seem to be attributable to the characteristics of both the patient population and the health centres. Further research that collects data focusing on the interaction between patients and health workers is required to explore this in depth, as has been done by the ABCD project on CQI in other diseases.[14,28]

Currently research is being undertaken as part of a quasi-national RHD study[30] to describe the burden of ARF and RHD and to identify primary health system barriers and facilitators to the management of ARF and RHD. Results emerging from these studies, as well as the present ABCD analysis, will feed into the development of policy to address RHD. The End RHD coalition

has been formed to drive policy innovation and change to significantly reduce the extremely high rates of the disease in the Indigenous population.[27] Given the centrality of PHC to these initiatives, the results reported here provide a good source of baseline data for future monitoring of QOC indicators and PHC practice in our study settings over time.

Competing interests

The authors have no competing interests to declare.

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References

1 Carapetis JR, Beaton A, Cunningham MW, Guilherme L, Karthikeyan G, Mayosi BM, Sable C, Steer A, Wilson N, Wyber R, Zuhlke L. Acute rheumatic fever and rheumatic heart disease. *Nat Rev Dis Primers* 2016; 2: 15084. doi:10.1038/nrdp.2015.84

2 Australian Institute of Health and Welfare (AIHW). Rheumatic heart disease and acute rheumatic fever in Australia: 1996–2012. Canberra: AIHW; 2013.

3 Australian Institute of Health and Welfare (AIHW). Australian burden of disease study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. Canberra: AIHW; 2016.

4 National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand. The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition). 2012. Available at: https://www.rhdaustralia.org.au/sites/default/files/resources/quick_reference_guides_0.pdf [verified 3 October 2019].

5 Centre for Remote Health. CARPA standard treatment manual, 7th edn. Alice Springs: Centre for Remote Health; 2017. Available at: https://docs.remotephcmanuals.com.au/review/g/manuals2017-manuals/d/20318.html?page=1 [verified 27 September 2019].

6 Antibiotic Expert Group. Therapeutic guidelines: antibiotic. Melbourne: Therapeutic Guidelines Limited; 2014.

7 Rheumatology Expert Group. Therapeutic guidelines: rheumatology, 3rd edn. Melbourne: Therapeutic Guidelines Limited; 2017.

8 Gramenz E. Rheumatic heart disease going undiagnosed by NT's fly-in doctors, cardiologist warns. *ABC News* 3 October 2018. Available at: https://www.abc.net.au/news/2018-09-30/rheumatic-heart-disease-awareness-interstate-doctors-nt/10320902 [verified 27 September 2019].

9 Ralph AP, de Dassel JL, Kirby A, Read C, Mitchell AG, Maguire GP, Currie BJ, Bailie R, Johnston V, Carapetis JR. Improving delivery of secondary prophylaxis for rheumatic heart disease in a high-burden setting: outcome of a stepped-wedge, community, randomized trial. *J Am Heart Assoc* 2018; 7: e009308. doi:10.1161/JAHA.118.009308

10 Russell DJ, Zhao Y, Guthridge S, Ramjan M, Jones MP, Humphreys JS, Wakerman J. Patterns of resident health workforce turnover and retention in remote communities of the Northern Territory of Australia, 2013–2015. *Hum Resour Health* 2017; 15: 52. doi:10.1186/s12960-017-0229-9

11 Read C, Mitchell AG, de Dassel JL, Scrine C, Hendrickx D, Bailie RS, Johnston V, Maguire GP, Schultz R, Carapetis JR, Ralph AP. Qualitative evaluation of a complex intervention to improve rheumatic heart disease secondary prophylaxis. *J Am Heart Assoc* 2018; 7: e009376. doi:10.1161/JAHA.118.009376

12 Ralph AP, Fittock M, Schultz R, Thompson D, Dowden M, Clemens T, Parnaby MG, Clark M, McDonald MI, Edwards KN, Carapetis JR, Bailie RS. Improvement in rheumatic fever and rheumatic heart disease management and prevention using a health centre-based continuous quality improvement approach. *BMC Health Serv Res* 2013; 13: 525. doi:10.1186/1472-6963-13-525

13 Burgess CP, Sinclair G, Ramjan M, Coffey PJ, Connors CM, Katekar LV. Strengthening cardiovascular disease prevention in remote indigenous communities in Australia's Northern Territory. *Heart Lung Circ* 2015; 24: 450–7. doi:10.1016/j.hlc.2014.11.008

14 Matthews V, Schierhout G, McBroom J, Connors C, Kennedy C, Kwedza R, Larkins S, Moore E, Thompson S, Scrimgeour D, Bailie R. Duration of participation in continuous quality improvement: a key factor explaining improved delivery of type 2 diabetes services. *BMC Health Serv Res* 2014; 14: 578. doi:10.1186/s12913-014-0578-1

15 Panaretto KS, Wenitong M, Button S, Ring IT. Aboriginal community controlled health services: leading the way in primary care. *Med J Aust* 2014; 200: 649–52. doi:10.5694/mja13.00005

16 Bailie R, Si D, Shannon C, Semmens J, Rowley K, Scrimgeour DJ, Nagel T, Anderson I, Connors C, Weeramanthri T, Thompson S, McDermott R, Burke H, Moore E, Leon D, Weston R, Gorgan H, Stanley A, Gardner K. Study protocol: national research partnership to improve primary health care performance and outcomes for Indigenous peoples. *BMC Health Serv Res* 2010; 10: 129. doi:10.1186/1472-6963-10-129

17 One21seventy National Centre for Quality Improvement in Indigenous Primary Health Care. Acute rheumatic fever and rheumatic heart disease clinical audit protocol: 2013 release. Darwin: Menzies School of Health Research; 2013. Available at: https://www.menzies.edu.au/icms_docs/253288_Acute_rheumatic_fever_and_rheumatic_heart_disease_clinical_audit_protocol.pdf [verified 3 October 2019].

18 Roberts K, Cannon J, Atkinson D, Brown A, Maguire G, Remenyi B, Wheaton G, Geelhoed E, Carapetis JR. Echocardiographic screening for rheumatic heart disease in Indigenous Australian children: a cost-utility analysis. *J Am Heart Assoc* 2017; 6: e004515. doi:10.1161/JAHA.116.004515

19 Edwards K. Days at risk for acute rheumatic fever recurrence. *NT Disease Control Bulletin* 2013; 20: 24–6.

20 Eissa S, Lee R, Binns P, Garstone G, McDonald M. Assessment of a register-based rheumatic heart disease secondary prevention program in an Australian Aboriginal community. *Aust N Z J Public Health* 2005; 29: 521–5. doi:10.1111/j.1467-842X.2005.tb00243.x

21 Mitchell AG, Belton S, Johnston V, Ralph AP. Transition to adult care for Aboriginal children with rheumatic fever: a review informed by a focussed ethnography in northern Australia. *Aust J Prim Health* 2018; 24: 9–13. doi:10.1071/PY17069

22 Holland JV, Hardie K, de Dassel J, Ralph AP. Rheumatic heart disease prophylaxis in older patients: a register-based audit of adherence to guidelines. *Open Forum Infect Dis* 2018; 5: ofy125. doi:10.1093/ofid/ofy125

23 Mitchell AG, Belton S, Johnston V, Gondarra W, Ralph AP. 'That heart sickness': young Aboriginal people's understanding of rheumatic fever. *Med Anthropol* 2019; 38: 1–14.

24 RHD Australia. Resources. 2018. Available at: https://www.rhdaustralia.org.au/resources [verified 3 October 2019].

25 Coffey PM, Ralph AP, Krause VL. The role of social determinants of health in the risk and prevention of Group A streptococcal infection, acute rheumatic fever and rheumatic heart disease: a systematic review.

PLoS Negl Trop Dis 2019; 12: e0006577. doi:10.1371/journal.pntd.0006577

26 Cannon JW, Jack S, Wu Y, Zhang J, Baker MG, Geelhoed E, Fraser J, Carapetis JR. An economic case for a vaccine to prevent Group A streptococcus skin infections. *Vaccine* 2018; 36: 6968–78. doi:10.1016/j.vaccine.2018.10.001

27 Wyber R, Katzenellenbogen JM, Pearson G, Gannon M. The rationale for action to end new cases of rheumatic heart disease in Australia. *Med J Aust* 2017; 207: 322–3. doi:10.5694/mja17.00246

28 Schierhout G, Hains J, Si D, C K, Cox R, Kwedza R, O'Donoghue L, Fittock M, Brands J, Lonergan K, Dowden M, Bailie R. Evaluating the effectiveness of a multifaceted, multilevel continuous quality improvement program in primary health care: developing a realist theory of change. *Implement Sci* 2013; 8: 119. doi:10.1186/1748-5908-8-119

29 de Dassel JL, Fittock MT, Wilks SC, Poole JE, Carapetis JR, Ralph AP. Adherence to secondary prophylaxis for rheumatic heart disease is underestimated by register data. *PLoS One* 2017; 12: e0178264. doi:10.1371/journal.pone.0178264

30 Katzenellenbogen JM, Bond-Smith D, Cunneen R, Dempsey K, Cannon J, Stacey I, Nedkoff L, Sanfilippo FM, Ralph AP, De Klerk N, Hung J, Geelhoed E, Williamson D, Wyber R, Bessarab D. The End Rheumatic Heart Disease in Australia Study of Epidemiology (ERASE) Project: data sources, case ascertainment and cohort profile. *Clin Epidemiol* 2019; in press. doi:10.2147/CLEP.S224621