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Missed Opportunities for Preventing or Diagnosing Acute Rheumatic Fever: A Retrospective Cohort Study of 20 Young Australians Diagnosed With Rheumatic Heart Disease on Screening Echocardiography

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ABSTRACT

Background and Aim: A cross-sectional echocardiographic screening study in a remote Aboriginal community in Australia identified hyperendemic levels of rheumatic heart disease (RHD). 20/613 screened were newly diagnosed with RHD, and 18/20 had no known history of acute rheumatic fever (ARF). Our aim was to explore the medical histories of those newly diagnosed with RHD for potential (1) missed opportunities for primary prevention of ARF through management of Group A Streptococcal (Strep A) infection, and (2) missed opportunities for diagnosis of ARF.

Methods: We assessed community clinic and tertiary hospital medical records of those children with new diagnoses of RHD ($n = 20$), and collected information regarding previous episodes of possible Strep A infection or its sequelae.

Results: All 20 participants had previous documented possible or confirmed Strep A infections, predominantly in the form of impetigo or infected scabies (range 1–17 episodes per participant). At least 15/20 participants had potential Strep A infections where treatment that was documented may not have adequately covered Strep A. 11/20 participants had scabies diagnosed without documented scabies treatment. 2/20 participants had previously diagnosed ARF, however these were diagnosed within the month prior to the community-wide screening for RHD. 2/20 participants had undiagnosed, probable or possible ARF when classified retrospectively from review of their case documentation. 13/20 participants had non-specific presentations with joint complaints that may have represented an ARF episode but with inadequate workup to fulfil diagnostic criteria on retrospective assessment.

1 | Introduction

The prevalence of rheumatic heart disease (RHD) in the Northern Territory of Australia is among the highest in the world [1]. In Australia, acute rheumatic fever (ARF) disproportionately affects Aboriginal and Torres Strait Islander people, accounting for almost 92% of cases diagnosed [1].

Addressing and improving the social determinants of health, such as poverty, housing and access to healthcare, has been

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credited as the main cause of reduction of ARF and RHD burden seen in many parts of the world; this 'primordial prevention' should be prioritised at all stages in the pathway from Group A streptococcal (Strep A) infection through to ARF and RHD [2, 3], and will have beneficial effects for health and well-being in general. Early identification and treatment of Strep A infections constitutes primary prevention of RHD by interrupting the abnormal immune response that leads to ARF [3]. Regular secondary antibiotic prophylaxis following ARF or RHD diagnosis prevents subsequent Strep A infection and the risk of recurrent episodes of ARF and progressive valvular disease [4].

People with mild valvular disease potentially have the most to gain from antibiotic prophylaxis [5, 6], however RHD is often diagnosed at an advanced stage with complications and without a recognised history of previous ARF [7–9]. The opportunity to commence regular antibiotic prophylaxis before valve disease is advanced may be missed if ARF is not diagnosed, which may be due to episodes being subclinical, patients having reduced access to healthcare, or health-workers lacking knowledge, exposure or completion of onward referral to make the diagnosis [5, 7, 10, 11].

A recent cross-sectional echocardiographic screening study in young people in the remote Northern Territory town of Maningrida detected an extremely high burden of RHD [12]. Definite RHD was detected in 32 of the 613 young people screened (5.2%; 12 known and 20 new cases); most had no known history of ARF. Of those newly diagnosed, 5 had severe RHD. We aimed to look for opportunities where RHD could have been prevented for those 20 children with newly diagnosed RHD. The focus was to retrospectively explore their medical histories for potential (1) missed opportunities for primary prevention of ARF (through management of Strep A infection) and (2) missed opportunities for the diagnosis of ARF.

2 | Design and Methods

We performed a retrospective cohort study, collecting data on all presentations to healthcare services for those 20 participants newly diagnosed with RHD, from the participant's birth up until the point of RHD diagnosis. Data collection occurred between June 2020 and January 2021. Data was obtained from the Primary Care Information System electronic medical record for community clinic visits, the tertiary referral hospital (Royal Darwin Hospital) medical records, and the Clinical Workstations electronic record for regional discharge summaries and correspondence. We checked with the Centre for Disease Control for any notifications of Invasive Strep A infection or post-Streptococcal Glomerulonephritis (PSGN) as these are notifiable diseases in the Northern Territory, and would also indicate prior Strep A infection.

For all episodes of care, we recorded date of presentation, location and final diagnosis. Successive presentations were grouped as a single episode of care if presentations were obviously related, or if presentations were within 2 weeks from each other. For episodes of possible Strep A infection or its sequelae, we recorded more detailed data on the clinical features, investigation results and treatments documented.

We defined 'possible Strep A throat infections' as presentations with sore throat or features of tonsillopharyngitis. We defined 'possible Strep A skin infections' as skin sores (impetigo), cellulitis or skin abscesses. We noted any episodes with scabies, as scabies is often associated with secondary Strep A skin infection [3]. Other possible manifestations of Strep A infection were included if Strep A was confirmed with culture. We determined adequate treatment based on current Australian guidelines [3, 13]—that is, for Strep A sore throat, intramuscular benzathine benzylpenicillin G (BPG), an oral penicillin for 10 days, or azithromycin for 5 days; for Strep A impetigo, BPG, or trimethoprim/sulfamethoxazole for 3 days.

We recorded detailed data on episodes involving relevant major or minor manifestations of ARF, and retrospectively assigned definite, probable or possible ARF diagnoses based on current Australian guidelines [3]. We also recorded detailed data on any episodes with joint complaints (whether a history of trauma was given or not), even where other diagnostic features of ARF were not present or tested for, because arthralgia is the most common presenting symptom of ARF [3].

3 | Results

There were 20 participants; 10 female and 10 male; median age of 12.5 (range 6–17) years at diagnosis (Table 1). All 20 participants had documented evidence of healthcare presentations that could have been associated with Strep A infection or its sequelae. Missed opportunities for primary prevention or diagnosis of ARF were identified in most participants (Figure 1).

3.1 | Strep A or Scabies Infections

All 20 participants had previous possible or confirmed Strep A infection (233 episodes; median 11 episodes per participant; range 1–29) in their lifetime prior to their RHD diagnosis. These presentations included: impetigo (including 'infected scabies') (165 episodes; range 1–17 per participant), skin abscess (38 episodes), cellulitis (6 episodes), ambiguous documented skin conditions (19 episodes; mainly 'healing' or 'old' sores documented) and sore throat or pharyngitis (17 episodes). Eighteen episodes had confirmed Strep A on culture (17/18 from skin swabs).

Appropriateness of antibiotic treatment was analysed for 174 episodes of possible or confirmed Strep A infection (42 excluded because of possible alternative bacterial aetiology; 17 excluded due to inadequate documentation). Of these, 36/174 (21%) did not have documentation of adequate treatment for Strep A infection (no documented systemic antibiotic, inadequate duration or delayed appropriate antibiotic treatment due to initial treatment with dressings only).

All participants had previous documented scabies (122 episodes; range 1–16). All participants had scabies co-infected with impetigo, or 'infected scabies' (77 episodes; range 1–11). Scabies was most commonly treated with topical permethrin (92/122). Eleven participants had scabies without documented scabies treatment (24/122 episodes).

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TABLE 1 | Summary of participant demographics and characteristics.

	All participants ($n=20$)	Mild or moderate RHD ($n=15$)	Severe RHD ($n=5$)
Sex			
Male	10	8	2
Female	10	7	3
Age at diagnosis			
5–9 years	3	2	1
10–14 years	13	10	3
15–19 years	4	3	1
History of scabies	20	15	5
History of possible Strep A infection	20	15	5
History of joint complaints	14	11	3
Definite ARF	2	1	1
Probable or possible ARF	2	1	1
Nonspecific joint complaints	13	10	3
PSGN	0	0	0
Previous echocardiogram	5	5	0

Abbreviations: ARF, acute rheumatic fever; PSGN, post-streptococcal glomerulonephritis; RHD, rheumatic heart disease; Strep A, Group A streptococcal.

3.2 | ARF or Presentations With Joint Complaints

Fourteen of the 20 participants had previous documented episodes involving joint complaints (26 episodes, range 0–3 per participant). One patient was diagnosed with ARF without carditis but then had developed carditis by the following month when they had an echocardiogram as part of community-wide screening. Another participant had presented 3 weeks prior to their screening echocardiogram with arthralgia, and had been referred for a formal echocardiogram to investigate the possibility of ARF, but the formal echocardiogram had not yet been performed. This participant had carditis detected on screening and received a confirmed diagnosis of definite ARF and severe RHD requiring cardiac surgery.

Two other participants had undiagnosed probable or possible ARF when classified retrospectively from review of their case documentation. One participant with probable or possible ARF that was not diagnosed had been admitted to hospital with monoarthralgia, fever, elevated c-reactive protein (CRP) (three minor criteria) and positive streptococcal serology, but did not have other investigations including echocardiography and electrocardiogram (ECG) to investigate for ARF. A second participant was reviewed in clinic with migratory polyarthropathy (hip arthralgia, followed by toe arthritis) and fever (one major and one minor criteria), but did not have further investigations for ARF.

There were 22 episodes (in 13 patients) of non-specific joint complaints (including monoarthritis, monoarthralgia or polyarthralgia) for which ARF could not be diagnosed or excluded, due to insufficient workup. Blood tests were done for two of these episodes (including one who was admitted to hospital). An ECG was requested for one episode but was not done. Echocardiography was not done in any of these cases.

3.3 | Previous Echocardiography

Five participants had previous documentation of a normal echocardiogram. One was the case described above with development of RHD from an episode of ARF. Four other participants had normal echocardiograms ranging from 18 months to 13 years prior to their RHD diagnosis, referred for indications other than ARF (three for incidentally noted cardiac murmur, one for osteomyelitis).

3.4 | Post Streptococcal Glomerulonephritis

Six participants had episodes with features of possible PSGN (mainly microscopic haematuria or hypertension), however there were no episodes that were notified to the public health register as confirmed PSGN.

4 | Discussion

Missed opportunities for the primary prevention of ARF were identified for almost all participants with screening-detected RHD. Missed opportunities of presentations that may have been episodes of ARF that warranted additional investigations for ARF were identified. Treatment of Strep A infection is important

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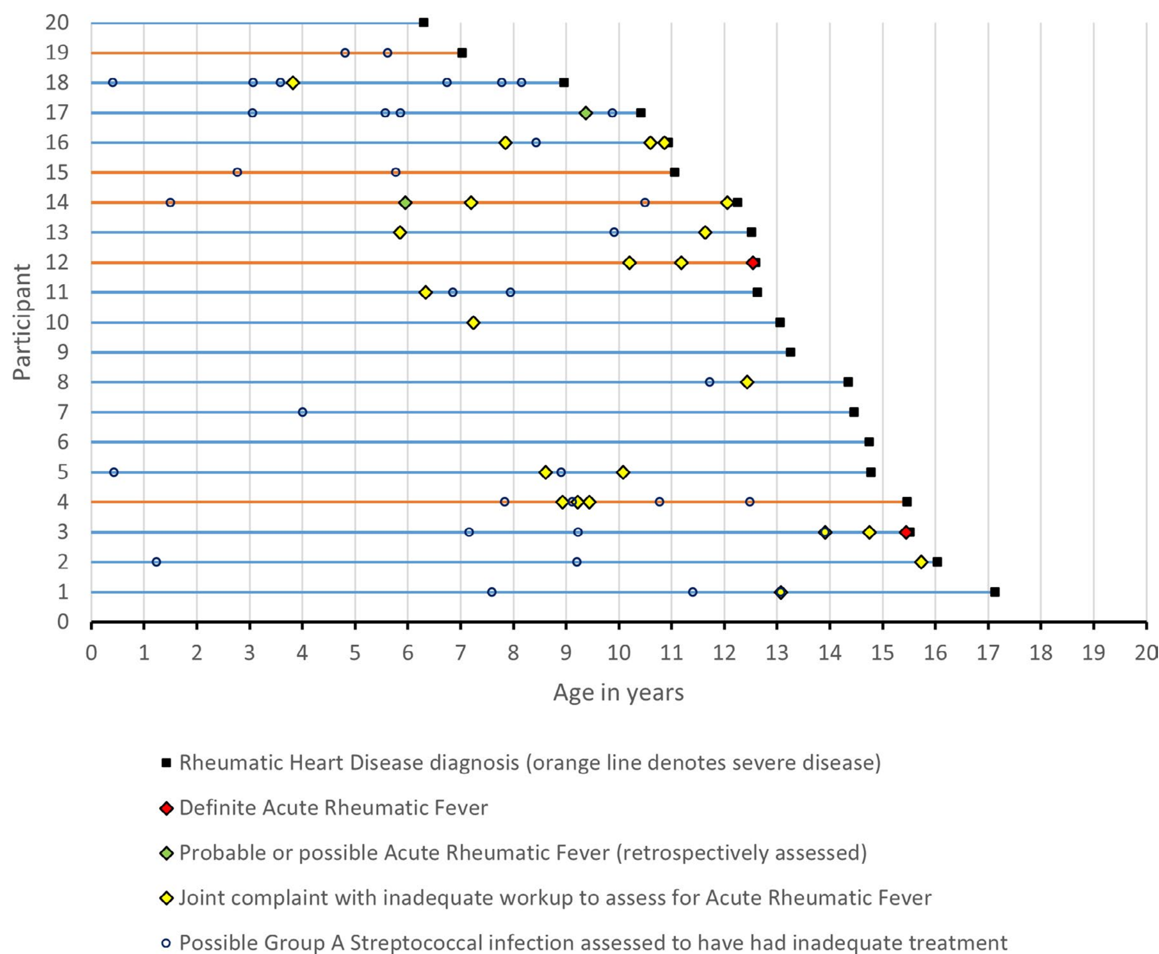

FIGURE 1 | Selected episodes by age.

to interrupt the abnormal immune response that leads to ARF [3]. Impetigo is the most common source of possible Strep A infection in the Australian Aboriginal and Torres Strait Islander population [3], and scabies is an important association [14, 15]. This is reflected in our data, where the most common presentations of possible Strep A infection were impetigo or infected scabies. Some episodes of skin infection received inadequate antibiotic treatment. This could reflect clinician awareness and knowledge of treatment protocols, but is also influenced by changes in treatment recommendations over time. For example, earlier recommendations for treatment of impetigo included an approach of only using topical treatment if fewer than five lesions were present [3, 13]. Studies have found that carers of patients with skin infections prefer that treatment options are discussed with them, and this could lead to improved uptake of effective treatment [16]. In some cases, the lack of laboratory testing might have made clinicians less likely to treat for Strep A. It is possible that innovative approaches to point of care Strep A testing may help to improve recognition and treatment of infections in remote settings [17].

In addition to documented cases of inadequate treatment of possible or confirmed Strep A infections, it is likely that there were more episodes of infections that were not documented. This can happen when patients present for clinical review for other reasons, if a concurrent Strep A infection is overlooked by the healthcare provider and/or patient. Normalisation of skin infections has been identified in hospital settings [18], and it is possible that this may occur in primary healthcare settings as well. Normalisation can also occur for patients and their families, making them less likely to seek medical care [19]. In a similar way, patients may not always access healthcare during ARF episodes, particularly when symptoms are mild and self-limited. Improved community understanding of the pathway from Strep A infections, to ARF and RHD, may have an impact on increased presentations [20].

Missed cases of ARF represent a missed opportunity for commencing secondary prophylaxis, increasing the risk of recurrent ARF and cumulative heart valve damage [3]. Most participants did have previous episodes with joint complaints that may have been ARF, but most episodes did not get investigations specific to ARF, including echocardiography. The Jones criteria have had multiple revisions, but current internationally accepted criteria still rely on recognition of clinical findings and investigations, some of which are readily available in remote settings (such as electrocardiogram, CRP and streptococcal serology) but also include tests that may not be readily accessible in remote locations (such as echocardiogram, erythrocyte sedimentation rate and work up for differential diagnoses) [21]. Access to echocardiography may be improved by training non-expert practitioners in abbreviated screening echocardiography protocols using hand-held ultrasound devices, which has been shown to achieve good diagnostic accuracy [22]. Ongoing research may

14401754, 2025, 5, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jpc.16797 by Edith Cowan University, Wiley Online Library on [30/06/2025]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

also help to identify a biomarker that could be used in the future to aid diagnosis of ARF [23]. In many remote clinics there can be a high turnover of staff and a high reliance on locum staff who may be coming from urban settings and who may not be as well-versed in ARF recognition or management. In settings where ARF/RHD burden is high, ensuring that staff are trained to recognise features of ARF and refer for appropriate investigations is an important priority [11, 24].

Our results compare to a retrospective study of 25 Torres Strait Islanders with screening-diagnosed RHD [25] with a few differences. Similarly few had prior ARF (3/25), and 5/7 ARF episodes were retrospectively diagnosed. They reported more sore throats (11/25) but fewer skin sores (18/25), with higher microbiological confirmation (17/25). Among 50 patients (including 25 controls), 56% of sore throats and 15% of skin sores were undertreated, with lower rates in those who went on to develop RHD.

Systemic barriers to accessing healthcare services also exist. Staffing availability and volume of presentations can sometimes lead to longer wait-times for patients to be seen in clinic, and 'minor' presentations requiring less urgency could be delayed. Patients may not present to clinic when travelling or fulfilling cultural obligations. Inter-generational trauma and lack of culturally appropriate care may also be important factors preventing patients accessing adequate care [26]. Optimal patient care requires effective communication between healthcare providers, patients and carers [27]. The lens through which Aboriginal and Torres Strait Islander peoples view health and disease can be very distinct from the understanding from a Western biomedical view, and various terms and concepts may be absent in peoples' home languages [28, 29]. Communicating in someone's home language, for example through the use of interpreters for patients for whom English is not their first language, can reduce feelings of disempowerment and improve health outcomes [30, 31]; whereas poor communication reduces health care utilisation [20]. Working towards delivering culturally safe health services requires staff and organisations to critically self-reflect on their own culture, attitudes, biases and structures, and address those which may affect the quality of care provided [32–34]. For remote Aboriginal communities, building the local Aboriginal health workforce is one of the most powerful ways to improve cultural safety and access to healthcare.

Within Maningrida, work is ongoing to improve health care delivery and strengthen connections within community. The local Aboriginal Community Controlled Health Service, Mala'la, has created a school nurse position to make access to care easier for children attending school. There is an RHD program with dedicated male and female staff, including a team of Aboriginal health workers, so that patients can develop a trusting relationship with a regular team supporting their care, and the team members get to build their own clinical expertise. There are environmental health officers who work alongside to support and advocate for families to maintain healthy home environments. There is a collaboration with Orange Sky mobile washing machines with the aim of improving access to health hardware for clean clothing for families and reducing the burden of Strep A and scabies. For the last 2 years, Mala'la have led a community-wide Healthy Skin Week, with a mantra of 'Healthy Skin, Healthy Home, Healthy Heart'. Mala'la are also working in partnership with Ninti One to deliver Aboriginal health worker certificate training in community, such that trainees do not need to leave their community, family and cultural ties to obtain further education. These initiatives have a long-term goal of improving access to culturally safe care that may result in improved prevention, as well as recognition and treatment of Strep A infections, ARF and RHD.

4.1 | Limitations

This study was limited by not capturing illness for which no care was sought, which may often occur for skin and joint symptoms. The study relied on review of the medical documentation, and thus there may have been additional episodes of Strep A infection and its sequelae that we did not capture. It is possible that treatment may have been given for episodes of scabies or suspected Strep A infection and not documented. The study size was small, and findings cannot necessarily be extrapolated to other populations. Presentations to other health services (where electronic medical records are not linked) would not have been captured. As this is not a case control study, we cannot report on whether the occurrence of potential Strep A infections or ARF-like presentations were more common in those found to have RHD than those not found to have RHD.

4.2 | Conclusion

Children diagnosed with RHD on echocardiographic screening in this high burden setting had multiple missed opportunities for primary prevention (through treatment of Strep A infections) and possible recognition of ARF, which would have facilitated earlier commencement of secondary antibiotic prophylaxis. Patient, health service and other systemic factors may all have contributed to missed opportunities for treatment and prevention. It is essential that health services in remote settings implement strategies for improved prevention, recognition and treatment of Strep A infections, and improved recognition and investigation of the symptoms of ARF. These strategies should involve community engagement and education, in addition to addressing health service factors to improve cultural safety and communication, and to increase trust in the health system.

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The authors have nothing to report.

Ethics Statement

Full ethical approval was granted for this study by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC Reference Number 2020-3656), in accordance with the NHMRC "National Statement on Ethical Conduct in Human Research 2007".

Conflicts of Interest

The authors declare no conflicts of interest.

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