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Published in:
Australian and New Zealand Journal of Public Health

DOI:
[10.1111/1753-6405.12737](https://doi.org/10.1111/1753-6405.12737)

Published: 01/02/2018

Document Version
Publisher's PDF, also known as Version of record

[Link to publication](#)

Citation for published version (APA):

Mitchell, A. G., Belton, S., Johnston, V., Read, C., Scrine, C., & Ralph, A. P. (2018). Aboriginal children and penicillin injections for rheumatic fever: How much of a problem is injection pain? *Australian and New Zealand Journal of Public Health*, 42(1), 46-51. <https://doi.org/10.1111/1753-6405.12737>

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Aboriginal children and penicillin injections for rheumatic fever: how much of a problem is injection pain?

Alice G. Mitchell,¹ Suzanne Belton,¹ Vanessa Johnston,¹ Clancy Read,² Clair Scrine,² Anna P. Ralph^{1,3}

Acute rheumatic fever (ARF) is still not controlled in Australia and occurs at disturbing rates, predominantly among Aboriginal children.¹ The condition requires long-term health care, and sometimes open-heart surgery, and is associated with premature deaths in this group. ARF is an autoimmune response occurring some weeks after an untreated infection with group A streptococcus (GAS). Historically, the GAS infection was thought to be only in the throat, but ongoing studies now suggest skin pyoderma, a common problem among Aboriginal children, is likely making a major contribution.²⁻⁴ The significant consequence of ARF is damage to the heart valves. Therefore, to protect children against further episodes of ARF and avoid compounding damage to their heart valves, a long-term regimen of penicillin injections is prescribed at initial diagnosis of ARF.⁵ The risk of ARF recurrence is known to be greatest in the first year after an initial diagnosis but persists for up to 10 years, so adhering to the penicillin injections during this first decade is most important.⁶ The injections are thought to provide blood and tissue levels of penicillin that prevent further GAS infection. They are given no later than every 28 days for 10 years after the last ARF episode, or until the child reaches age 21, whichever period is longer. For highly at-risk individuals with severe rheumatic heart disease (RHD), they are prescribed until age 35, or for life.

The penicillin injections (long-acting benzathine penicillin G) are invariably painful because of the large volume that is injected,

Abstract

Objective: To explore young Aboriginal people's and clinicians' experiences of injection pain for the 10 years of penicillin injections children are prescribed to prevent rheumatic fever recurrences.

Methods: Aboriginal children on the penicillin regimen and clinicians were purposively recruited from four remote sites in Australia. Semi-structured interviews and participant observations were conducted. Views were synthesised and thematically analysed.

Results: A total of 29 Aboriginal children and 59 clinicians were interviewed. Sixteen participants appeared to become accustomed to the injection pain, eight did not find pain an issue, and five found injection pain difficult. A further five believed the injections made them unwell. Patients expressed varying abilities to negotiate with clinicians about the use of pain reduction measures. Clinicians revealed good knowledge of pain reduction measures, but offered them inconsistently. All clinicians found administering the injections distressing.

Conclusion: Repeated painful procedures in children necessitate well-planned and child-focused care. Current practices are not in line with guidance from the Royal Australasian College of Physicians about effects of repeated painful procedures on children. Initiating the long-term injection regimen for rheumatic fever is a special event requiring expert input. A newly reported finding of a subset of young people feeling unwell after receiving the injection requires further investigation.

Implications for public health: Improvement of local and jurisdictional guidelines on use of pain reduction measures for children who have been prescribed repeated painful injections for rheumatic fever is needed.

Key words: rheumatic fever, Aboriginal children, penicillin injection pain, Australia

the viscosity and possibly the irritant nature of the solution. It is difficult to tell what impact this repeated painful procedure has on children. Australian guidelines provide advice on six techniques to reduce the pain of the injections, such as warming the syringe and injecting slowly. Applying pressure to the site before giving an intramuscular injection has been known as an effective pain reduction measure for two decades.⁷ This

was demonstrated again more recently in Turkey among 51 children with ARF receiving penicillin injections.⁸ Evaluation of measures to reduce pain of the penicillin injections in New Zealand by using local anaesthetic and a vibrating device with an ice pack was shown to improve patients' experiences, especially for children aged under 14 years.⁹ Measures such as these should be used at every injection episode, as intramuscular injections

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Submitted: April 2017; Revision requested: June 2017; Accepted: September 2017

The authors have stated they have no conflict of interest.

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Aust NZ J Public Health. 2018; 42:46-51; doi: 10.1111/1753-6405.12737

are known to cause pain and distress in children. Australian guidelines indicate that the pain of the injections is not the main factor preventing patients' adherence to the treatment schedule, as does The World Heart Federation, which additionally admits to an incomplete understanding of the issue.^{5,10} In contrast, however, African doctors advise clinicians that "pain is one of the major problems when intramuscular BPG [penicillin] is given" and they urge clinicians to consider using lignocaine (local anaesthetic) as a diluent.¹¹ The manufacturer of the premixed formulation used in Australia does not recommend mixing lignocaine with their product, although it has been commonly used in Australia until recently, and continues to be used elsewhere.⁵ There is global effort to reformulate the penicillin product, largely to reduce pain and increase adherence to the regimen.¹²

Fourteen studies in a variety of settings explored barriers to adherence to penicillin injections for ARF. In seven of these, injection pain emerged as a barrier reported by children, their carers, or adults on the regimen. These sites included India,^{13,14} Egypt,¹⁵ Jamaica,¹⁶ Uganda^{17,18} and Nepal.¹⁹ Three Australian studies among remote Aboriginal patients on the regimen have been conducted. In one, children were not included, and injection pain did not emerge as a significant issue.²⁰ In the second study, there were seven participants and pain did not emerge as a significant issue, but the ages were not delineated apart from one teenage male and two parents of children with ARF.²¹ A third, recently published, Australian study included 11 patients/carers but did not specify all participant ages, although some children or parents of children were interviewed. The study revealed that clinicians found administering the painful injections distressing and also considered pain to be a major barrier to patients' uptake. However, the authors state that with regard to injection pain, "the evidence is not so clear from the patients'/parents'/care givers' perspectives".²² Injection pain lasting up to 48 hours was reported by caregivers in 46 out of 160 Aboriginal children who were treated with the penicillin injections for skin sores in a recent NT study.³

Adherence to rheumatic fever prophylaxis among many Aboriginal children is known to be inadequate.¹ Any missed injection is a major concern as it places children in danger of acquiring another episode of ARF.²³ Determinants of adherence to the regimen are multi-factorial and perceptions

of injection pain are subjective. Expression of pain and its interpretation by caregivers may be affected by the cultural lens of children or the clinicians,²⁴ and care needs to be taken in assessing pain when clinicians and children do not have the same primary language.²⁵ The issue of injection pain or fear of pain among children has not been explored in northern Australia. The aim of this qualitative study was to investigate the experiences of injection pain among Aboriginal children and young people with ARF along with clinicians' experiences and practices of administering the painful injection.

Theoretical frame

Decolonising theory, defined here as a determined response to the negatives of colonisation on research practices among indigenous peoples, along with a determination to prevent harm, was used to frame our approach to all study participants and all study activities.²⁶⁻²⁸ Whiteness studies emerged as a push back against a focus on black or native, or 'the other', and we additionally used this frame to intentionally avert a white stance – that of superiority, power and privilege simply due to ethnicity, (not white skin colour) – which is recognised as a strong driver of colonisation.^{29,30} This juxtaposing duo is appropriate for the study context because Aboriginal families of children with ARF remain strongly affected by colonisation and also must seek their care from health services where clinicians are predominantly privileged and powerful.

Methods

Clinician interviews were conducted in the qualitative component of a mixed-methods community randomised trial seeking to improve delivery of penicillin injections in 10 health services providing care for Aboriginal patients in the Northern Territory (NT).³¹ Patient interviews were conducted in an ethnographical study embedded within the trial in four of the sites. Both parts were conducted concurrently but separately. Clinicians were asked about their views on injection pain and their clinic's practices as well as their own practices to reduce pain. Questions on pain were open and were part of a series of questions about care for children with ARF. Interviews were conducted by project officers in the first phase of the trial, commencing in December 2013 with the clinicians who administered the injections. All relevant clinicians working in the 10 sites were invited to voluntarily participate in interviews. Interviews were conducted in

English, which is the operational language of NT health services.

A focused ethnography was nested within the trial. A focused ethnography differs from conventional ethnography in that it explores a specific issue among a distinct group of people within a particular setting, in this case, Aboriginal young people on the penicillin regimen residing in remote communities in the NT.³² Semi-structured interviews and participant observations were carried out with Aboriginal children who were prescribed the injection regimen, or with young Aboriginal people who had commenced the regimen as children and were now between ages of 18 and 35. Among other topics to do with their care, interviewees were asked using open questioning to talk about the pain of the injections. Children were interviewed in the company of a close relative, such as parent, if they were younger than 15 years old. Interviews were carried out with an interpreter where possible, in the participants' language where that language was spoken by the interviewer, or in English. English was not the primary language spoken by any patients. Patient interviews were conducted in four of the 10 trial sites between December 2013 and November 2015. Participants between ages five and 35 years were purposively recruited using data from the NT RHD Register and local clinics. The number of eligible participants at the study sites was 119. Potential participants were located and invited to participate at a time that suited them. As adolescent males are least represented in the literature, interviews with this group were intentionally sought.

Consent was gained for all participants. Where possible, children were observed by the researcher after receiving their injection and were additionally interviewed at that time. Clinician's preparation of the injection was also observed by the researcher if practicable. Practices to reduce pain, either by clinicians or patients and their family, as well as the severity and duration of pain, were recorded. Some children were interviewed or observed on multiple occasions in the ethnography and some clinicians were observed on more than one occasion.

Interviews were audio recorded and transcribed verbatim or hand-written at the time, or shortly afterwards, if consent was not given for audio recording. Clinician and patient data were analysed separately by different team members: CR and CS analysed clinician data and AM conducted the nested ethnography and analysed patient data.

All responses were transcribed verbatim and field notes or project officer reports related to pain were collated. All data were analysed inductively in a thematic analysis. Patient findings were reviewed with a senior Aboriginal leader from a participating community and one 16-year-old Aboriginal participant on the injection regimen, while reports on clinician findings were supplied to participating health clinics and opportunity was provided to clinicians to comment on findings. Nvivo 10 (QSR International Pty Ltd, Victoria, Australia) software was used to assist with all data analysis. Collation of clinician and patient findings occurred towards the end of all analyses, with agreement on themes being reached by all the researchers.

Ethics approval

Ethical approval was provided by the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research HREC-2012-1756. The clinical trial was registered with the Australian New Zealand Clinical Trials Registry: ACTRN12613000223730.

Results

We interviewed the clinicians who provided the majority of penicillin injections for ARF delivered at each study site. A total of 59 clinicians voluntarily consented to be interviewed. The clinicians who responded to the question on pain of injections, among other questions about patient care, consisted of 13 doctors, 30 staff with 'nurse' in their title and 16 Aboriginal Health Practitioners across the 10 sites. Clinicians were predominantly female. A summary report synthesising clinicians' interviews conducted at baseline phase in the 10 health services was generated. Clinicians' views on injection pain within the report were collated for analysis, and original transcripts were reviewed to confirm meanings when required.

Twenty-nine patients with ARF were specifically asked about injection pain in interviews about their experiences of being on the regimen. This non-random sample comprised 13 males and 16 females, and participants' ages ranged from seven to 33 years. The sample included eight adolescent males aged between 11 and 15 years. Overall, 19 participants were aged ≤ 18 at the time of first interview; and a further seven participants, who had started the injections as children (≤ 18), were between 23 and 28 years old at the time of first interview. Three male participants had started the injection regimen

in their early twenties and were included due to their prolonged experience of receiving the regular injections (≥ 10 years). Ages of patients, sex and duration on the regimen were recorded at the time of first interview. Duration of injections varied and included: < 1 year ($n=4$); 1–5 years ($n=9$); 6–10 years ($n=6$); and ≥ 10 years ($n=10$).

There were no patterns among patients' responses according to age group or length of time on the regimen. The youngest participant was aged seven years and clearly experienced distress (expressed as screaming) on receiving the injection. The next youngest were in a group aged 11–14 years and no trends were apparent. Some who had been on the regimen for years were experiencing the most pain or dislike of the injections. Children who were on the regimen less than one year either did not express pain as an issue or endured the pain, apart from the seven-year-old mentioned above.

Themes

Six themes relating to participants' experiences of receiving or of giving regular penicillin injections for ARF emerged in the analysis: 'stoic resignation'; 'neutral response'; 'negative encounters with the pain of the injection'; 'impact of the injections on wellbeing'; 'perceived control over pain reduction measures'; and 'inconsistent use of pain reduction measures'.

Stoic resignation to pain

Sixteen patients described how, while the injections were painful, they had become resigned to them. Many used the phrase "used to it" in their responses.

When I was 14 I just went for the injection without thinking about it. Then it got worse and worse and I couldn't walk. But you get used to it. It's not really a worry. [24-year-old male on regimen 10 years]

Similarly, a 15-year-old girl on the regimen for seven years stated, "they are painful but you get used to it. I don't mind getting them cos it helps me get better". One 15-year-old female, on the regimen for seven years, described the injections as "annoying" but said she was "used to it" and a 14-year-old male on the regimen for one year described the injections as "märr-ganga" in his language, meaning so-so.

Four parents perceived that their children had initially found the injections painful but were now used to it. While a mother stated her 12-year-old daughter, who had been on the regimen for 18 months, was used to it, the

researcher was given permission to remain in the room while the injection was given and the girl was observed to whimper, and tensed while receiving the injection.

While becoming resigned and willingly attending the clinic to receive injections, patients in this group still found the experience taxing, and their words revealed a simmering underlying stress.

Sometimes I hate it, sometimes it is okay. It hurts a lot. I just wanna find out when it stops. I feel fine now. [25-year-old male on regimen 10 years]

A 15-year-old female responded:

When I get it I don't hurt, like, but after, when I put pressure and stuff, it hurt. [On regimen for one year].

Some clinicians also stated that patients "got used to" the pain and that pain was not a significant issue. One nurse stated:

We have a lot of patients who are really compliant and have been for years and years, and obviously the older ones you know they're used to that routine of getting it and they just do it.

Another nurse said that "a lot of those kids have had the LA Bicillin [benzathine penicillin] all their lives for other things" and suggested this led to young people's resilience or resignation to the injection pain and, additionally, their adherence to the regimen.

Neutral response to the injections

Eight patients did not use negative descriptors of the injections during interviews even after probing by the interviewer. Some were observed just after receiving their injection and showed no negative signs. In some cases, the researcher met them over subsequent days and they stated that there was no ongoing pain. This group frequently used phrases such as "it's no problem", "they don't really hurt" and "it's okay" when asked about pain. When questioned about effects on sleep or walking post-injection, this group reported no ill effects.

Two patients in this group stated that they declined the offer of local anaesthetic by clinicians to help with pain. A 14-year-old female on the regimen for nine years was questioned just after receiving her injection: "Did they ask you if you want lignocaine?" She replied, "Yes, I didn't want it." Another 15-year-old male on the regimen for < 1 year stated, "I don't mind if it is given fast or slow, both ways". There were no patterns in the pain reduction measures offered, declined or accepted in this group. In contrast to these

neutral responses, while some clinicians thought patients got used to the pain, none believed that patients did not find the injections painful.

Negative encounters with pain of the injection

Five patients stated that the injection pain was difficult to bear.

When I get the injection, it is painful for two to three days. I limp and it sometimes keeps me awake at night. It leaves a lump in buttock that is painful to touch. [18-year-old female on regimen 7 years]

The father of a seven-year-old child who had been on the regimen for six months found the experience harrowing, saying: "She screams when she gets the injection. I have to leave the room; I can't stand to hear her scream". One mother described her 12-year-old son, on the regimen for four years, as "cripple next day" and "usually he just lies there crying".

Most clinicians expressed degrees of anguish about the injections and used strong descriptors revealing their distress. Comments included: "That needle is horribly painful, it's a nasty needle" [nurse]. One nurse described it as "repeatedly hurting people" and another stated that patients were "tortured" with the injection. One doctor felt that giving the injection could be viewed as "actually assaulting the child". Clinician's negative experiences led to their reluctance to administer the injections. For instance, one nurse stated, "I don't want to give the nasty needle". Other clinicians expressed angst at not having the time needed to give the injection well: "We don't have that luxury of time to waste hours giving one injection". Additionally, some clinicians expressed a lack of confidence working with adolescents, with a doctor reporting "[a lack of] understanding from the health professionals about how you work with adolescents, it's very poorly developed, and yet it's critical in this type of scenario".

Perceived impact of the injection on wellbeing

Five patients reported unwellness that they believed resulted from the injections. They reported fevers, malaise and site soreness.

Two days I get like sick, like dizzy like. I feel heavy when I get it, after it. [12-year-old female on regimen for 6 years].

A relative reported about her 12-year-old niece, "She has trouble walking around after the injection and stays home from school on

the day". A 13-year-old male stated, "It always paining then I feel hot and sick at night when I get the injection. I get the injection ... then I go home and get sick." When questioned about the frequency of these symptoms one year later, he stated that they did not occur with each injection but, "sometimes happen". A 25-year-old male on the regimen for 10 years reported, "It makes me feel sleepy, I can't work, I feel lazy" [lethargic] while a mother reported that the injections always make her 11-year-old son sick [on regimen for 3 years]. In contrast, one young woman believed the injections made her feel well:

I feel weak and lazy without the injections. When I have the injections I feel strong and walk around. [28-year-old on regimen 10 years].

Similarly, a 29-year-old male on the regimen for 10 years stated that "I can feel when it is time for the injections. It makes me feel better". No patient reports such as those just described were provided by clinicians.

Perceived control over pain reduction measures

Seven patients showed some ability to negotiate about the pain of their injection with clinicians, such as declining an offer of lignocaine, while thirteen demonstrated either lack of ability or opportunity to negotiate. A 23-year-old woman, on the regimen 10 years, stated that the nurses decide about pain relief: "They don't ask me. Some give it, some don't". One 12-year-old girl was observed asking for her penicillin to be injected fast but the nurse overrode this preference without discussion stating, "I don't give it fast". An 18-year-old girl stated that she did not like it when the nurses "jab it in" but would prefer the needle to be inserted slowly. When a 15-year-old girl was asked: "Does the nurse do anything to stop it hurting? Like give you panadol or...?" she responded in the negative, "Nuh" [no]. Being able to negotiate was linked with having a trusting relationship with clinicians. A 28-year-old male, on regimen for 11 years, explained his reason for not advising a new nurse at his home clinic that he preferred pressure to the injection site as: "But I don't know this nurse". This conversation occurred just after he received his injection and was limping.

Most clinicians discussed how determining a patient's preference for pain reduction measures was a normal part of their practice. Two different nurses spoke about use of local anaesthetic: "So I will always ask the person if they want it, some people don't

but most do", and "Everybody gets offered local anaesthetic". One nurse expressed that having a good relationship with at least one clinician in a health service facilitated patients' abilities to negotiate: "If they've got the one person who is kind, respectful, has a good behaviour and has that relationship ... just has a nice way about them".

Clinicians demonstrated good knowledge of measures to reduce injection pain and collectively reported 20 measures that either they used personally or were used in their clinic. These included standard measures as well as others such as use of nitrous oxide gas and supervising a young patient to give their own injection.

Clinicians felt that good injection technique was an important skill to master to reduce pain and stress for patients as well as influencing adherence to the regimen.

The technique of giving the needle is important because when you've got staff turnover and you've got inexperienced people, someone's only got to have a really nasty experience with a needle blocking and having to have it stuck in three or four times, put in too quickly or you know, then they go "Oh I don't think I'm going to go back there again". [Doctor]

Some clinicians were felt to be less skilled at giving the injections, such as new clinicians and midwives, who may give them less often were described as: "So, they don't want to give it because they're scared or they've had bad experiences or whatever. They don't feel comfortable". Some clinicians suggested that 'skilled injectors' be recognised and promoted in each health service for the regular penicillin injections.

Inconsistent use of pain reduction measures

Patients were not consistently offered pain relief. A Buzzy Bee™ device, which uses cold and vibration to reduce needle pain, has recently been introduced in the NT. While one adolescent mentioned that use of this device helped her, it was not always offered.³³ While application of cold externally can distract from pain, the penicillin solution itself is less painful when warmed to body temperature. Only four clinicians were observed by the researcher preparing the injection. All warmed the syringe prior to administration. In two of these instances, the clinicians were heard talking soothingly to the young person while the researcher remained in the room (with patient privacy maintained). Some parents reported their efforts to help

their children with the pain. The mother of an 11-year-old boy said: "I tell him, if you cry, muscles go hard. I talk to him to relax". Other parents mentioned use of paracetamol for "after pain", with one young woman stating that she would buy it from the local shop to help with her "after pain". Paracetamol was commonly dispensed after the injection was administered. There were varying responses to the pain-relieving measure of lignocaine mixed with the injection and oral paracetamol: some patients reported it worked for them; for others, these measures did not reduce the pain substantially.

Discussion

There is little literature on the issue of injection pain for ARF in the Australian context. Three Australian studies containing patient views on the injection are inconclusive as they either contain few children's comments or pain did not emerge in interviews.²⁰⁻²² The injection regimen constitutes repeated episodes of procedural pain for Aboriginal children. Procedural pain management is known to be underutilised and poorly managed in children³⁴⁻³⁹ as well as for Aboriginal patients.⁴⁰ Aboriginal patients may under-report pain leading to the erroneous assumption that they feel pain less or are more tolerant and stoic.^{41,42}

Stoicism and resignation to injection pain appeared to be a common patient trait and the view of some clinicians in this study. However, the Royal Australasian College of Physicians states that it is a myth that children get used to repeated painful procedures: "Most do not get used to having them without psychological and/or pharmacological intervention".³⁴

The College recognises stoic resignation and cooperation as an outward response to repeated painful procedures but maintains that internal responses are not necessarily obvious, and it is difficult to predict which children are the most vulnerable. Recognising and predicting internal vulnerabilities is even more difficult when working with different cultural groups such as Aboriginal children, and even more so when the operational language of the health service is different from that of patients.^{25,43} The fact that it is predominantly Aboriginal children requiring the injections, and the majority of clinicians who give the injections are white, and thus represent the dominant and the privileged (non-Aboriginal), means the repeated painful episodes have potential to deepen already felt inferiority and lack of power among

Aboriginal families.⁴⁴ For these reasons, a decolonising stance would ensure that pain reduction measures are mandated for every instance.³⁴ The hinted underlying stress among those who stated they were "used to" the injections highlights the difficulty in determining just what possible negative effects children on the regimen are experiencing. In a well-articulated patient's story on the website of RHD Australia (the Australian national coordinating unit for RHD), a young Aboriginal man states, "Now that I'm a little older, I'm quite comfortable telling my doctor how I prefer my needle", emphasising the need to recognise children's vulnerabilities in this regard.⁴⁵

Clinicians demonstrated good knowledge of the range of measures that can be used to reduce penicillin injection pain but did not always offer them. It is difficult to postulate the reasons for this omission, especially when so many clinicians stated that they always offer pain reduction measures. Time pressure is a possible explanation. This study revealed the distress that clinicians feel with having to repeatedly give the painful injections to children as seen in their use of strong descriptors such as "torture" and "horrible, nasty needle". In starting from a position of distress, a flow-on effect could be overall poor management of the event. However, not providing pain reduction measures every time is substandard and unethical practice.³⁹

Some children and young people were not provided opportunity or did not feel able to discuss the pain of their injections with clinicians. Power to hold these discussions seemed to depend on their relationships with individual clinicians. The high turnover of clinicians in remote NT health services, who are therefore unfamiliar with the clients, may exacerbate this issue. Without power to be heard or to negotiate, Aboriginal children and young people may use the only power they have, which is to refuse or avoid injections. The most worrying finding in this study is instances of children not being offered any pain reduction measures.

Conclusion

The study findings indicate that further development of supportive policy and guidelines is needed to improve the experiences of Aboriginal children and young people requiring the regular painful injections, as well as for those who deliver the injections. Substandard management of injection pain can be addressed by integrating guidelines into service delivery,

i.e. clinicians are prompted through their electronic medical record system every time they treat a patient with ARF.⁴⁶ This can be strengthened by adoption of a philosophy reflecting high priority of pain management and the creation of specific guidelines on repeated procedural pain in children and adolescents in the NT hospitals. Children with suspected ARF are currently admitted to hospital for confirmation of diagnosis and initiation of the injection regimen. Currently, such guidelines are not in place in the guideline repositories of the regional hospitals. In recognition of Aboriginal children's vulnerabilities, increased multi-disciplinary and relevant cultural input at the time of initiating the injections, such as Aboriginal language interpreters, child psychologists and cultural experts, is recommended. Deeper attention at the critical time of initiating injections may foster children's and families' sense of control and confidence, and better prepare them for the coming years of this repeated painful procedure.

A decolonising approach to primary health care in remote services is needed in order to improve shared decision making and alleviate power imbalances between clinicians and Aboriginal patients as revealed in this and other studies.⁴⁷⁻⁴⁹ White clinicians can find the complexities of working in remote Aboriginal communities daunting and self-reflection about practice is recommended for improving health care that is acceptable to Aboriginal patients.⁵⁰ Improved connecting with Aboriginal patients and focusing on patient-centred care may also assist with hearing patients' voices.⁵¹ Valuing local Aboriginal people's input and views will likely uncover better strategies for assisting children to cope with the years of injections.⁵²

For those young people who find injection pain a strong deterrent, seeking supportive relationships within the stable local community population to increase self-efficacy in their health care is recommended. These young people are at increased risk of permanent heart valve damage. Investigating local Aboriginal people's views on how to find long-term local support for this group to enable them to cope with the injection pain may reduce this risk. Additionally, supportive mentors from other agencies such as schools, clubs, church groups and ranger programs could be explored on an individual basis. While injection pain was reported as being intolerable in some children in this study, every injection is a repeated painful event for

Aboriginal children and young people and needs the best and most informed care for every child, every time.

Further research on the effect of lignocaine and other measures such as the Buzzy Bee™ device in this population is recommended. Additionally, given the newly reported finding here of a subset of people feeling unwell after receiving the injection, further research into medical non-allergic adverse effects or psychological adverse effects, and how to mitigate these, is required. Ultimately, alternative treatments such as new penicillin formulations are needed.

Limitations

Aboriginal participants were interviewed in keeping with cultural protocols and where possible in their first language. However, due to non-availability, it was not consistently possible to use interpreters or Aboriginal co-researchers to assist with interviewing as envisaged. Limitations in interpreting meaning in qualitative data when interviews are conducted across cultures and not in participants' first languages are acknowledged.⁵³ In conducting research in a post-colonial setting such as the context of this study, we acknowledge that power imbalance may hamper participants speaking freely about perceptions and difficulties.

Acknowledgements

We thank all participants and their families. We thank project officers, Melita Donohoe, Sagen Wilks and Jane Poole for qualitative data collection in the trial. AGM was supported by an Australian Postgraduate Award to conduct the ethnographic component of the trial. APR is supported by an Australian National Health and Medical Research Council fellowship (1113638).

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