Formative evaluation of a community-based approach to reduce the incidence of Strep A infections and acute rheumatic fever

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Abstract

Objectives: To explore the acceptability of a novel, outreached-based approach to improve primary and primordial prevention of Strep A skin sores, sore throats and acute rheumatic fever in remote Aboriginal communities.

Methods: A comprehensive prevention program delivered by trained Aboriginal Community Workers was evaluated using approximately fortnightly household surveys about health and housing and clinical records.

Results: Twenty-seven primary participants from three remote Aboriginal communities in the Northern Territory consented, providing 37.8 years of retrospective baseline data and 18.5 years of prospective data during the study period. Household members were considered to be secondary participants. Five Aboriginal Community Workers were trained and employed, delivering a range of supports to households affected by acute rheumatic fever including environmental health support and education. Clinical record audit and household self-report of Strep A infections were compared. No association between clinical- and self-report was identified.

Conclusions: Ongoing participation suggests this outreach-based prevention program was acceptable and associated with improved reporting of household maintenance issues and awareness of prevention opportunities for Strep A infections.

Implications for public health: Biomedical, clinic-based approaches to the management of Strep A infections in remote communities can be usefully augmented by outreach-based supports delivered by Aboriginal Community Workers responding to community needs.

Key words: rheumatic fever, Aboriginal and Torres Strait Islander health, Group A streptococcus, community health workers, environmental health

Rheumatic heart disease (RHD) is the leading cause of cardiovascular inequality between Aboriginal and Torres Strait Islander people and non-Indigenous people in Australia.[1] RHD stems from group A streptococcal (Strep A) infections of the throat, and likely the skin, precipitating an abnormal immune reaction known as acute rheumatic fever (ARF). Severe or recurrent episodes of ARF cause permanent damage to the heart valves known as RHD, which progresses to heart failure and further complications.

There are four broad opportunities to intervene on the causal pathway from ARF to RHD: primordial prevention (focusing on addressing environmental risk factors), primary prevention (treatment of Strep A infections), secondary prevention (regular antibiotics to prevent another Strep A infection) and tertiary care (to minimise the complications for people who already have RHD). Australia's national Rheumatic Fever Strategy has historically focused on supporting the provision of secondary prophylaxis.[2] However, program evaluation and results from other research suggest that increasing focus on primordial and primary prevention is needed to prevent new cases of ARF.[2-4]

The RHD Endgame Strategy for Australia was published in late 2020, calling for far greater focused attention on prevention of Strep A infections and ARF.[5] However there are no established service delivery models for improving the delivery of primary and primordial prevention in practice. We developed a pilot approach to improving primordial and primary prevention of Strep A infections and ARF in three communities in the Top End of the Northern Territory to address this gap. Strategies explored in this study were determined from feedback from earlier studies,[3] consultation with communities and peak bodies and biologically plausible priorities.[6] An iterative process for refining, naming and

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understanding the scope of potential activities occurred via the circulation of diagrams through email and subsequent teleconferences. These coalesced into the activity domains in Figure 1.

The aim of this paper is to present a formative evaluation from the first twelve months of program implementation. It is intended to provide a foundation for further discussion and iteration with project partners.

Methods

This is a pragmatic intervention study with baseline and activity phases, seeking to build workforce capacity, deliver care navigation and work with community members to reduce the burden of Strep A and their consequences.

Community engagement

Communities were invited to participate on the basis of accessibility, presence of people with ARF/RHD, willingness to engage with the study and presence of Aboriginal community members available to be employed by the project. Once agreement was obtained, a partnership agreement was signed with local health services. The study budget provided an allowance for two to three clinics to be involved.

Within participating communities, Aboriginal community members were identified through discussions with clinic staff and other contacts and invited to be employed as Aboriginal community workers (ACW). People with existing relevant training such as completion of high school or a vocational education training certificate, including in health, were approached. The project aimed to employ two ACWs at each community site. ACWs received training in ARF and RHD health literacy including cause, treatment and prevention. This was provided in communities by the project manager with assistance at one site from the nurse educator from the RHD Control Program on one occasion. ACWs were also invited to Darwin for training workshops. Training included presentations on Strep A infection, the role of skin sores and sore throats, and facilitated discussion about data collection through household survey and consent processes.

ACWs additionally received on-the-job training in the conduct of research, especially confidentiality, and the forms and processes required specifically for this study. The chief form of data collection to be undertaken by ACWs during the first year of the study was a weekly survey of participating households to ascertain household occupancy, the occurrence of any syndromes consistent with streptococcal infection since the last survey, and functionality of home hardware.

Figure 1: Activity domains of the outreach-based support model, additional activity descriptions in Supplementary File 1.

Enrolment procedures and study activities

Households were eligible if someone usually resident had been diagnosed with ARF or RHD and was currently prescribed secondary prophylaxis. Participants living with ARF or RHD were considered to be primary participants and household members were considered to be contact participants. Written, informed consent was sought from primary participants or their guardians.

Study activities are summarised in Figure 1 and detailed in the logical framework (log frame) model in Supplementary File 1. This framework was developed by investigators to help codify the activities that had been prioritised by ACWs. The majority of activities were conducted by ACWs during interactions with householders when service navigation and health literacy support was provided alongside data collection.

Quantitative data collection

Data on primary care presentations were collected for a cluster of clinical items. These included presentations consistent with likely or potential Strep A infection (sore throat, skin sores); presentations relating to ARF or RHD; and presentations related to environmental living conditions. This list of relevant infectious diseases was derived from previous audits in remote Aboriginal and Torres Strait Islander communities.[7-10] Manual clinical record audits were undertaken to extract these relevant clinical items for 12 months prior to the study period (baseline) and during the 12 months of study intervention (activity phase). New infections were defined as occurring >14 days after a previous presentation for the same condition or as considered clinically appropriate by study investigators. Skin sores were included when clearly described in clinical records; clinical descriptions consistent with boils, abscesses and fungal skin infections were excluded, being attributable to pathogens other than Strep A.

Data on disease priority and the delivery of secondary prophylaxis injections were provided for primary participants by the Northern Territory RHD Register.

Household data were collected during regular contacts between the ACWs and participating individuals using paper forms and including discussions about what skin sores and sore throats are. Hard copy data collection forms were transcribed into an MS Access™ database, subsequently updated to a REDCap (Research Electronic Data Capture) database hosted at Menzies School of Health Research.[11] Household occupancy data were collected using a previously-developed tool for describing household composition in remote communities.[12]

Data analyses

Data were examined on a per-household basis. Where primary participants lived in the same house, some duplicate data collection occurred for the same household on the same day. In each instance, duplicates were examined, reconciled through discussion with the project manager and duplicate records were dropped. Infections were counted as the same episode if occurring within a two-week period.

Analyses were done using Stata 14.2 (StataCorp. 2015. Stata Statistical Software: Release 14). Clinic and register data were summarised using descriptive statistics. Relationships between potential streptococcal infections (skin, throat, any) or RHD disease severity (priority 1: severe; priority 2: moderate; priority 3: mild or ARF only) and predictor variables (household occupancy, bed-sharing, household hot water availability, functioning shower and functioning toilet) were examined using scatter plots and tested using the chi-squared test or simple linear regression as appropriate. A multivariable model could not be constructed due to the small number of streptococcal infections and low frequency of positive outcomes in the predictor variables.

Person-years were calculated to account for the follow-up of primary participants. Household-years were also calculated since some households were occupied by >1 participant. The number of days of follow-up per household was calculated from the interval between the consent date and the date of the most recently completed household survey. The number of estimated person-years in the activity period contributed per household was calculated as median number of household occupants multiplied by number of days of follow-up contributed by that household, divided by 365. The number of times the primary participant was reported to be sharing a mattress with at least one other individual was expressed as the proportion of all interviews in which mattress sharing was reported.

Data on adherence to penicillin secondary prophylaxis were described as the proportion of people achieving >80% of scheduled injections (11 or more out of 13 annual injections administered every 28 days). Clinic presentations with and self-reported episodes of sore throat or skin sores were expressed as rate per person-year. The difference, if any, in the occurrence of sore throats and skin sores from self-report compared with clinic data was determined. Concordant infections between household surveys and clinical records were defined as infections recorded in both sources within a 30-day window to account for delays in health-seeking or in conducting household surveys.

Knowledge survey

At study enrolment and after 12 months, participants were asked about their knowledge of Strep A, ARF and RHD: *Why do you think you (or your child) get the penicillin needle every 4 weeks? What do you call this sickness? What do you think causes it? How can you stop it?* These questions were chosen based on previously identified knowledge gaps and to capture any change in disease prevention knowledge.[13] A comprehensive qualitative evaluation of the program was conducted alongside this study and a forthcoming paper outlines qualitative findings over the first two years.

Ethics

Approval was provided by the Human Research Ethics Committee of the Top End Northern Territory and Menzies School of Health Research (2017-2898). Authorisation to access Northern Territory RHD Register was granted by the Northern Territory Government Department of Health. Authorisation to access clinic records was provided by Sunrise Health Service Aboriginal Corporation and the Northern Territory Government Department of Health.

Results

Three communities with a combined population of 824 participated in the study.[14]

Community and Aboriginal Community Worker engagement and role

Community engagement for this project began in July 2017 and included meetings with clinics, community groups and prospective project staff. This study was not initiated by communities who became final participating sites. However, conversations about exploring the acceptability of an ACW role grew from a community-led project at another site and was informed by Aboriginal investigators and consultants as part of the END RHD Centre of Research Excellence.[5,15] Participating community sites, project staff and investigators provided the foundation for the model (Figure 1), which in turn informed the study activities by ACWs.

ACWs were employed and trained from November 2017 (Figure 3) before they approached eligible participants to seek consent. Sites A and B began project activities in February 2018; Site C began in November 2018.

At Site A, three female ACWs were employed (one then retired and was replaced by a new recruit, one resigned, and the other stayed employed throughout). At Site B, two ACWs (one male, one female) were employed, with one male subsequently ceasing employment. After eight months, a third community (Site C) adjacent to Site B elected to join, staffed by the same ACW servicing Site B. In total, five ACWs were employed over 12 months, each at 0.3–0.4 full-time equivalent. The median length of employment was eight months (range 1–12 months).

Study activities by the ACWs included regular household data collection, opportunistic household/family education about Strep A infections, support for secondary prophylaxis adherence delivery by reminding people of upcoming due doses and using informal networks to escalate housing maintenance needs.

Recruitment

Over the first 12 months of the study, 36 people with a history of ARF or RHD currently receiving penicillin secondary prophylaxis were identified as potential participants. Potential participants were identified primarily in consultation with clinic staff. Clinic lists of people receiving secondary prophylaxis are maintained; these sometimes differ from data provided by the RHD register, although corrections to reconcile discrepancies are made. Although it is not possible to identify a firm denominator of possible participants, we believe that all or the majority of eligible participants were approached to be part of the study.

Twenty-seven primary participants consented to participate, outlined in Table 1. Three pairs of individuals were relatives living in the same house, providing 24 households overall (11 at Site A, 10 at Site B and three at Site C). In total, 3.3% of the census population across three communities participated in this study, reflecting a very high burden of ARF and RHD. Eight participants withdrew within the first year of study because they moved away (5), completed secondary prophylaxis (2) or did not wish to continue (1).

Data collection

Fidelity to the planned data collection strategy is shown in Table 2. The intention was for ACWs to collect surveys at households on a weekly basis. However, data collection needed to fit within the schedules of ACWs who had other paid and unpaid responsibilities, and the schedules and desires of household members. As a result, data collection occurred less than weekly, and in a neutral meeting place rather than within households, since visiting households was felt to be too intrusive by participants and ACWs.

A total of 534 household surveys were eligible for analyses after removing duplicate records of two primary participants living in one household, each of whom completed a household survey on the same day. Participating individuals completed a median of 21 household surveys (range 1–43) over a median of 274 days of participation (range 22–339).

For primary participants, there were 32.8 person-years of data in the baseline period and 18.5 person-years of data in the activity period. Accounting for household occupancy, there were 80.5 household-years of data.

Skin sore and sore throat infections

In the 12-month baseline period preceding study activities, a clinic record audit identified nine skin sores and six sore throats over 33 person-years of data for primary participants. This is a baseline rate of 0.45 infections per person-year. Two skin sores and three sore throats were recorded in clinical records during the 12 months of the activity period. This is a rate of 0.27 infections per person-year for 18.8 person-years of primary participant data.

Table 1: Participant demographics. Disease priority is defined by the 2020 Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (3rd edition).[16]

	n = 27 participants
Gender	
Female	15 (55%)
Male	12 (44%)
Median age at enrolment (years)	15.8 (6.9 – 76.3)
Site	
A	12 (44%)
B	12 (44%)
C	3 (11%)
Disease priority	
Priority 1 (Severe RHD)	5 (19%)
Priority 2 (Moderate RHD)	0 (0%)
Priority 3 (History of ARF or RHD requiring secondary prophylaxis)	21 (78%)
Priority 4 (Inactive disease not requiring secondary prophylaxis)	1 (4%)

In the 12-month activity period, household survey data on self-reported infection occurrences identified 23 potential Strep A infections (skin [n=17] or sore throats [n = 6]). Nine of these occurred among primary participants and 14 among household members. All reported infections were at Site B, with three households accounting for 17 (74%) occurrences.

There was no concordant reporting of infections on household surveys and in clinical records, meaning that none of the Strep A infections reported by primary participants in the household survey were recorded in clinical records, nor were any of the clinical record events reflected in household surveys.

Household occupancy and hardware

The median number of people per house reported across all surveys was five (range 2–16). The primary participant was reported as sharing a mattress with at least one other person 29% of the time and two or more people 6% of the time.

One household reported not having soap (one occasion), two reported having no hot water (one house in each community), and one reported that the shower and toilet were not working. In each instance, repairs were facilitated within 14 days of the problem being reported to the respective ACW.

The numbers of times household hardware malfunctions were reported were too low to examine for associations with streptococcal infections. There was a positive (directly proportional) relationship between maximum household occupancy and bedsharing, but this was not statistically significant.

Association between clinical outcomes and household measures

No association was apparent between numbers of reported total infections and the proportion of time that bedsharing of the primary participant was reported, nor median household occupancy. When restricting data to Site B only (the only site to report infections) there was no association with mattress sharing but there was an association between median household occupancy and number of reported infections (p=0.0025).

Of the 23 skin and throat infections reported on household surveys, all occurred at Site A and three households accounted for 74% of these infections. Two of these households were distinguished by higher levels of crowding (median occupancies of 8 and 9.5 people respectively) but not by mattress sharing or household maintenance issues (no health hardware issues reported) or disease priority (all four residents of the high burden households having Priority 3 disease).

There was no association between crowding and the severity of RHD; residents of the two most crowded households (median occupancies of 8 and 9.5 people, respectively) all had Priority 3 disease.

Secondary prophylaxis adherence

Nineteen participants received secondary prophylaxis injections in both the baseline and activity periods recorded in the NT RHD Register (Communities A and B only). Others received oral penicillin or had their prophylaxis ceased during the study. In both the baseline and activity period, 14/19 (74%) of people received >80% of scheduled secondary prophylaxis injections.

Table 2: Data sources and fidelity to data collection protocols.

Data source	Reporting	Planned frequency	Actual frequency	Baseline data	Project data
Household surveys on household occupancy and infrastructure	Self-reported by household member	Weekly	Approximately Fortnightly (n=534)	N	Y
Household surveys on household skin sores/sore throats	Self-reported by household member	Weekly	Approximately Fortnightly	N	Y
Clinic data on incidence of skin sores and sore throats	Recorded by clinic, collected by researchers	Continuous	Continuous	Y	Y
RHD Register data on secondary prophylaxis injection administration	Provided by RHD register	Continuous	Continuous	Y	Y
Surveys of ARF/RHD knowledge	Self-reported by household member	At recruitment and 12 months	At recruitment (n=21) & 12 months (n=9)	Y	Y

Twenty-one participants completed the knowledge survey on enrolment (Table 2). Ten repeated the survey after approximately 12 months of study participation (Supplementary Table 2). These small numbers indicate more familiarity with the words rheumatic fever, rheumatic heart disease and strep germ and a clearer sense of skin sores and sore throats as the cause of disease.

Discussion

This study demonstrates that in three remote Aboriginal communities where at least 3.3% of people are living with a history of ARF or RHD, recognising and responding to antecedent skin and sore throat infections is an ongoing challenge. A comprehensive, community-based approach to this issue appears to be acceptable and have the potential for ongoing development.

This was the first study to use an outreach-to-household approach for supporting people living with ARF and RHD and this model was largely embraced by participants, ACWs and communities. Acceptance was broadly demonstrated by the retention of participants, staff and sites: only one person chose to withdraw from the study, two ACWs remained employed throughout the first year of the project and a third community site requested to join the study. Acceptability was enhanced by the capacity to iterate the data collection model. For example, ACWs initially reported that the planned weekly visits were too much and that sometimes it was more convenient to meet with people near the local shop. After reducing to an approximately fortnightly schedule and adopting a flexible approach to the location of survey completion, ACWs reported a greater ease of engaging participants in conversation and data collection. ACWs report that other elements of the program were welcomed by participants; support to escalate housing maintenance needs and school visits were particularly well received. Acceptability will be further explored a qualitative evaluation of this project over the first 2 years of implementation.

Overall, there were fewer skin and throat infections reported in household surveys or in clinical records than anticipated. Although there was no baseline estimate of Strep A infection incidence in participating communities, a high burden of Strep A skin infections among young Aboriginal and Torres Strait Islander children in Northern Australia has been repeatedly described.[8,17,18] A recent publication from the region of Site B confirms high frequency of clinic presentations for <2 year-olds with skin infections.[19] The apparently low incidence of skin sores in this study may reflect a genuinely low burden of disease or an interplay of other factors. Clinic attendance for skin sores among very young children is frequent but may decline with age, as infections may be less symptomatic in a heavily exposed and hence partially immune population or as skin sores become normalised or, conversely, stigmatised.[9,17,20] Primary participants in this cohort (ranging from 6.9–76.3 years) may have passed the peak incidence of symptomatic skin sores. The sores burden may have been reduced by the relatively high levels of secondary prophylaxis adherence among primary participants. However, sores were also rare among household contacts who were wider in age range and were not receiving secondary prophylaxis. Recall bias may contribute to low reportage of infection in household surveys if people had overlooked sores that occurred between surveys. Finally, paper-based data collection without the capacity for real-time validation could have introduced recording errors. Despite being conducted by ACWs in local languages, household surveys may also have been subject to conceptual barriers with regards to both the nature of the infections, and the importance of data accuracy. It is not possible to assess the completeness of the recording of skin sores by clinic staff in clinical records. There is some evidence from tertiary settings that health staff may not document skin sores; it is unclear whether this normalisation also occurs in primary care.[21]

The clustering of risk among some households suggests there are opportunities for environmental health approaches to risk reduction. ACWs in this study were able to support households to report housing issues, including problems with hot running water, and to have these resolved within two weeks. This offers an important avenue to improve access to healthy living practices, including daily handwashing with soap and water, which can reduce the incidence of skin sores by 34%.[22]

Delivery of scheduled secondary prophylaxis is challenging throughout the Northern Territory with only 46% of people receiving more than 80% of their scheduled doses.[23,24] However, secondary prophylaxis delivery in communities A and B was significantly higher than this with 74% of people receiving more than 80% of scheduled doses in the baseline period. This high level of prophylaxis delivery was maintained in the activity period. This study did not have a demonstrable effect on secondary prophylaxis adherence.

The brief knowledge survey on enrolment demonstrated that almost all participants knew that they had a heart problem and needed medication/injections for it – but many people remained unsure about the cause of RHD. This is consistent with reports from ACWs, and prior research that knowledge about skin sores and sore throats relating to ARF and RHD was low.[13] Attitudes and beliefs about skin sores are also likely to influence reporting of skin sores to clinics and in household surveys, including both stigma and normalisation of skin sores.[20] This may contribute to the lack of association between infections recorded by clinics and by ACWs visiting households. Qualitative research is needed to explore whether health professionals communicate effectively with people seeking care and manage the issues of stigmatisation and normalisation of skin sores.

There were a number of other limitations to this study. The small number of participants and Strep A infections precluded exploration of risk factors for Strep A infection or measurement of the impact study activities on infection incidence. Implementation challenges included a high degree of ACW staff turnover in Site A, limited options for formal ACW training and career progression and low baseline awareness of Strep A, ARF and RHD.

Limitations of this study are indicative of structural barriers to improving health outcomes in remote Aboriginal communities. Within the health systems, high rates of health worker turnover and limited opportunities for training are well-recognised impediments to sustained, community-led, programs.[5] For people and families affected by ARF and RHD, these conditions are experienced in the context of colonisation, racism, powerlessness and poverty.[5,25] Each of these influence education opportunities, health literacy and engagement in biomedical approaches to disease management and prevention. At a community level, the effects of colonisation contribute to disempowerment and marginalisation, which affect the allocation of resources for housing and healthcare.[26]

ACW employment and out-of-clinic supports in this study offer some new approaches to primary and primordial prevention of ARF. However, far more substantive efforts are required to achieve sustained changes in health outcomes for a wide range of conditions in remote Aboriginal and Torres Strait Islander communities. For this study, operational leadership from within the health service rather than a research institution could support sustainable, integrated approaches to the environmental, socioeconomic and biomedical approaches to reducing ARF.

Conclusion

This ambitious program in three remote Northern Territory communities is among the first to attempt to operationalise primordial and primary prevention of RHD and measure outcomes on Strep A rates. Tailoring of the original project plan has resulted in a project concept that is feasible and acceptable to ACWs and community members. This trajectory should continue, with new mechanisms for greater community ownership and integration with routine delivery of primary care and other services. This next phase will be guided by ACWs and community leaders, including reflections on whether education on the pathophysiology of disease should remain a priority and how formal partnership with other community service providers and organisations (schools, the health clinic, environmental health and housing) can work most effectively. This program has provided new implementation experience to operationalise community empowerment and offers important lessons for delivering on community-based recommendations of the national RHD Endgame Strategy.[5]

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary File 1: Program Logic Model.

Supplementary File 2: Knowledge assessment.