

# Challenging perceptions of non-compliance with rheumatic fever prophylaxis in a remote Aboriginal community

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In the past, non-compliance with medical treatments has been attributed to patient behaviour, characteristics of the therapeutic regimen, or a problem with the “doctor–patient relationship”.<sup>1</sup> More recently, a redefinition of the “problem of non-compliance” has been suggested, whereby it is understood to be one of many possible outcomes of socially contextualised health service delivery.<sup>2</sup> This broad approach removes some of the pejorative implications of non-compliance, and encourages the researcher to look beyond the clinical scenario to understand the structural factors leading to lack of treatment uptake.

Evidence for the role of patient education in promoting compliance is lacking.<sup>3-6</sup> Nevertheless, gross miscommunication between Aboriginal patients and non-Aboriginal health professionals has been demonstrated, and this may contribute to patients’ inability to comply with medical advice.<sup>7</sup>

Rising rates of recurrent rheumatic fever (RF) in the Top End of the Northern Territory of Australia in 2002<sup>8</sup> rekindled old debates about patient compliance. Patients with a history of RF should have monthly injections of benzathine penicillin for a number of years (depending on their age and the degree of cardiac involvement) to prevent recurrences and worsening of rheumatic heart disease (RHD). Clinicians believed that the increased rates of recurrence meant that patients were not receiving their secondary prophylaxis.

Our aim was to identify reasons for the failure of the RHD control program by investigating the factors that affect patient compliance with prophylactic penicillin injections.

## METHODS

The study was carried out in a remote Aboriginal community in North East Arnhem Land. The community was founded by missionaries and now has about 2200 residents. The Aboriginal people of many different clans and language groups in this region refer to themselves as *Yolngu*; the most common of several *Yolngu matha* languages spoken in this community is *Djambarrpuynu*.

The community was serviced by a health centre with a resident doctor, five non-

## ABSTRACT

**Aim:** To identify factors that affect rheumatic fever prophylaxis for remote-living Aboriginal patients, and to determine the proportion who received adequate prophylaxis.

**Design and setting:** Interview (with analysis based on principles of grounded theory) of patients with a history of rheumatic fever or rheumatic heart disease and their relatives, and health service providers in a remote Aboriginal community; audit of benzathine penicillin coverage of patients with rheumatic heart disease.

**Participants:** 15 patients with rheumatic heart disease or a history of rheumatic fever, 18 relatives and 18 health care workers.

**Results:** Patients felt that the role of the clinic was not only to care for them physically, but that staff should also show nurturing holistic care to generate trust and treatment compliance. Differing expectations between patients and health care providers relating to the responsibility for care of patients absent from the community was a significant factor in patients missing injections. Neither a biomedical understanding of the disease nor a sense of taking responsibility for one’s own health were clearly related to treatment uptake. Patients did not generally refuse injections, and 59% received adequate prophylaxis (> 75% of prescribed injections).

**Conclusion:** In this Aboriginal community, concepts of being cared for and nurtured, and belonging to a health service were important determinants of compliance.

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Aboriginal nurses and about 12 Aboriginal health workers. A second health service provided services to satellite outstations and employed two non-Aboriginal nurses and two Aboriginal health workers.

Community consent was obtained before starting the project. At the completion of the study the results were relayed to the participants at a meeting conducted in English and Djambarrpuynu.

The Human Research Ethics Committee of the Northern Territory Department of Health and Community Services and the Menzies School of Health Research approved the project.

## Interviews

Patients receiving RF prophylaxis, either currently or in the past, members of their families, and health care providers were invited to participate. Respondents were selected to represent a range of patient ages, levels of “compliance” and time since diagnosis of RF. Relatives were selected because they were parents of a young person with RF, or to discuss a male patient with RF, or as invited to participate by a patient. All health care practitioners working in the community were interviewed. Consent was

obtained in either English or Djambarrpuynu.

Information was collected about the few male patients with a history of RF through their relatives and carers. The viewpoints of multiple participants about some patients were available for comparison.

The profound shyness of young Yolngu women meant that they constantly deferred questions to their relatives, and the consensus was that it was not appropriate to interview them alone. Thus, where possible, we encouraged the participation of family groups, engaging the people who would be involved in making significant health-related decisions.

Semi-structured informal interviews were conducted in either Yolngu matha or English. Two researchers conducted most interviews together: a non-Aboriginal female doctor residing in the community (ZH) and a Yolngu woman with a background as a health worker (JB). Three interviews with health care providers were conducted by ZH alone in English. The interviews were recorded, translated and transcribed. In two cases, the interviews were directly transcribed, as the participants declined to have their interviews recorded. Interviews were

conducted between 1 April and 31 August 2003.

We analysed interview data using the principles of grounded theory.<sup>9,10</sup> In brief, this involves identifying concepts within the data, developing interrelationships between the concepts, and then building theory from the “ground” up. This form of analysis is well suited to an exploratory investigation. Unlike deductive research, it is not constrained by predetermined hypotheses. Our open-ended starting point was “the care of Yolngu patients with RHD”. We were particularly interested in the factors that affected the uptake of secondary prophylaxis for RF.

We optimised the rigour of our analysis by using researchers representing the two cultures examined in the study, checking our findings with respondents at a feedback meeting, triangulating interview data with an audit of patient records, and attending to cases that appeared to contradict the emerging argument.<sup>11</sup>

**Audit of benzathine penicillin injection records**

The health clinic maintains a list of all patients residing in the community with RHD or past RF, and records the penicillin injections administered. We audited benzathine penicillin coverage of patients with past RF from 1 January 2002 until 30 September 2003 and calculated the percentage of prescribed injections received by each patient. Adequate coverage was defined as more than 75% of injections received on time.

**1 Composition of study participants**

Participants	Female	Male	Total
Patients with rheumatic heart disease or a history of rheumatic fever	14	1	15
Relatives	17	1	18
Aboriginal health workers	8	1	9
Nurses	6	1	7
Doctors	0	2	2
<b>Total</b>	<b>45</b>	<b>6</b>	<b>51</b>

**RESULTS AND DISCUSSION**

There were 32 patients (eight male) in the community who either were receiving or had received RF prophylaxis. Fifteen of these participated directly (age range, 20–60 years; range of time since diagnosis of RF, 1–30 years). The total number of participants, including family members and health care workers, was 51 (Box 1). There was a sex imbalance (45 female, six male), in part resulting from the smaller number (8/32) of male RF patients. Overall, we conducted 23 interviews (with groups or individuals) involving 51 respondents and taking 14 hours.

In this article, we discuss five themes derived from the analysis that we believe are of the greatest clinical relevance: concepts of good care for patients with RHD; the process of giving and receiving RF prophylaxis; missing injections; how this process is affected by the patients’ knowledge and understanding of RHD; and the allocation of responsibility for health care. Our findings are summarised in Box 2.

**Good care for patients with RHD**

*Patient:* Like 10 or 15 years ago, the health workers used to go through the camps, so that we can feel the relationships and communication. There’s two-way communication... After a few years [the visits] stopped. A lot of people became sick, because of that.

Yolngu expressed a desire for a health service that not only provided medical care, but also performed a pastoral type of role — visiting people at home, talking to families, encouraging patients and caring for them emotionally, like a family member. “Good care” for patients with RHD was often discussed using the terms *djaka*, meaning to care for physically, and *gungga’yun*, translated as to encourage or to nurture. This finding highlights the fact that, although the physical care of a patient was valued, the emotional and spiritual components of care were equally important to Yolngu.

Many patients had relatives working in the health centre (including non-Aboriginal

**2 Summary of findings pertaining to uptake of secondary prophylaxis**

	Factors promoting uptake	Factors inhibiting uptake	Factors with no simple relationship to uptake
<b>Staff factors</b>	Appropriately trained staff	Negative perception of the secondary prophylaxis program	
	Socially and culturally competent staff	Conflicting priorities for staff	
	An active recall system	No effective strategy for dealing with absent patients	
	Staff willingness to treat the patient at home	Staff fatigue and frustration	
<b>Patient factors</b>	An appropriate location for receiving injections	Conscientious refusal of treatment	Biomedical knowledge of the disease
	Belief that the disease is chronic and serious	Inconvenience to the patient	Taking responsibility for health
	Confidence in the health service and a feeling of holistic care	Not “belonging” to the health service	Perception of the painfulness of the treatment
	Family support for the treatment	Lack of family support	
	Belief in the efficacy of the treatment	Lack of confidence in the treatment	◆

staff who had been “adopted” into Yolngu families). A sense of belonging to the clinic, like belonging to a family, was conveyed in a number of interviews. Conversely, not being a member of the community was implicated as a reason for receiving poorer care.

*Relative:* But I remember in the past . . . one health worker . . . said “Why do we have to treat this boy if he is from another community?”

A previous study in the Kimberley also found that a close relationship between the patient and the health service provider was associated with treatment compliance. However, only two of the seven participants were living in remote communities, and their particular concerns were with confidentiality and the transience of the non-Indigenous staff.<sup>12</sup>

### The process of giving and receiving RF prophylaxis

The community health service provided an active recall system for RF prophylaxis. Patients could elect to receive their benzathine penicillin injections at home or at the clinic. The appropriate person to administer each needle was selected according to the sex and kinship ties of the patient. Aboriginal health workers reported both their satisfaction with administering the injections, as well as the occasional frustration with difficulties in locating a patient or convincing a patient of the necessity of the injection. Non-Aboriginal staff were more circumspect about the intrusiveness of home visits to administer the injections, which was the preferred venue for many patients.

Patients, on the whole, spoke positively of their monthly RF prophylaxis injections. Injections were considered to be more powerful than tablets, and the pain associated with the injections was not reported to be a deterrent. Patients knew that the injections were intended to protect the heart, and even reported feeling better as a result of the injections.

*Relative:* Because inside his body he can tell if he misses injections or tablets. His body can tell there is something happening to him, and then he asks me to get him some tablets or an injection. “Can you ask the health workers for an injection?” he says. “Because I think my body needs an injection.” When he takes this, he feels happy.

### Missing injections

A simple audit of the benzathine penicillin coverage for the 27 patients in the community requiring RF prophylaxis indicated that 11 of those patients (41%) did not receive

adequate prophylaxis (>75% of prescribed injections on time). This was almost the same as the findings of another recent Top End study and within the wide range of results reported from other countries.<sup>13,14</sup>

The most striking association with missing injections that arose from the interviews was time spent away from the community. Patients hesitated to interact with unfamiliar health services, and when required did this through family members and the home clinic.

*Interviewer:* Did you miss your injections?

*Patient:* No. But I missed all my injections when I was over in Darwin.

*Interviewer:* Why? Too busy? Your home was too far from the clinic?

*Patient:* My sister used to ring the [home] health centre to transfer the injection to [a Darwin Aboriginal health service]. No one from there contacted us and let us know if the injection is ready or not.

*Interviewer:* How long was that for?

*Patient:* A few years. When I came back home, I saw the doctor who started the injections straight away.

Obstacles to attending other health services included transportation, the lack of an active recall system and lack of familiarity with the other health centre. Staff at the home clinic were unable to fulfil patients’ expectations of facilitating health services beyond their jurisdiction. In cases when a patient was absent from the community, an effort was made to ring the relevant health centre to notify them of the requirement for RF prophylaxis, but no attempt was made to ensure that this had been administered.

In contrast, various reasons were given for missed injections by patients remaining in the community. Treatment refusal was uncommon, and often overcome by repeated visits from the health workers.

### Knowledge and understanding of the disease

Disease education resources have been a focus for the Top End RHD control program.<sup>15</sup> While there is a lack of evidence of any effect of patient education on treatment uptake, it does make intuitive sense and has popular support from people working in the field.<sup>16,17</sup> In our study, staff and patients believed that knowledge and understanding of the disease was an important factor in treatment uptake. However, few staff and even fewer patients could provide a clear biomedical explanation of the disease,

despite recent efforts to provide education about RHD in the local language. Nevertheless, most patients accepted their injections.

*Interviewer:* Did they tell you that you have heart disease?

*Patient:* No. I didn’t know.

*Interviewer:* Until when?

*Patient:* Until 1991, then I knew. I asked them, “Why did I get all these injections, what for?” Then the doctor told me, “It’s for your heart that you are getting this injection.”

What seemed to be important was that patients (and their families) believed that the condition was serious and chronic, rather than having a more detailed medical understanding of the condition.

*Relative:* That’s why she was missing all these injections. She thought that it was a *garramat* [superficial] sickness. But sometimes I was concerned. I told her it wasn’t a *garramat* sickness, “It’s inside your heart, it will stop your heart all at once”.

This message had to come from a trusted source. Gaining trust and respect as a health practitioner was facilitated by good communication with patients, but it was more the process of communication than the disease-specific details that was valued. Knowing how much and what sort of information to convey to patients was unclear to non-Aboriginal health staff, many of whom have little local cultural experience.

*Nurse:* . . . because I am not one hundred per cent sure of the culture, how much people understand. And the stories that we tell them . . . whether that is really what they want to hear? Or how much understanding they have of the story, and how pertinent and important it is to them at that time of life anyway?

### Allocation of responsibility for health care

For non-Aboriginal staff, there was a tension between providing comprehensive health care and respecting patients’ autonomy. Apart from the RHD program, the clinic provides active recall in many areas such as antenatal care, vaccinations, contact tracing for sexually transmitted infections and depot medications for the mentally ill. There is a long history of clinic “maternalism” and community passive (or otherwise) acceptance of the service provided. Health staff described the difficulty of resolving the balance of responsibility for health care.

*Nurse:* It’s a challenge to take responsibility for your own health, and it’s a chal-

lenge for the staff of a health service to follow that through. And where do you start, and where do you stop? And where do you — you often juggle this in your mind — where do you think that people have to own their illness? You know. Sometimes I feel we disempower people, you know, by pushing them to do things that they would rather not do, you know, like the Bicillins. I wonder about that.

Indeed, the nearest urban Aboriginal medical service provides fewer active recall programs because of its much larger and more mobile client base and resource constraints: it relies on patient initiative in seeking health care. Remote-living patients often fail to make the transition from the “support” provided by recalls from their home clinic to the requirement to initiate their own care at urban clinics. This is not to argue that all Aboriginal health services must provide active recall systems for chronic disease but rather that there be a common understanding of the roles and expectations of the patients and health care providers. It is possible that elements of the health care interaction other than patient recalls and home visits will be the crucial indicators of care (*djaka*) and nurturing (*gungga'yun*) for patients of an urban health service.

## CONCLUSION AND IMPLICATIONS

We found that the process of RF control relied on a professional, motivated and efficient health service and strong relationships between patients and health care providers, as well as a shared understanding of the roles and responsibilities of the parties involved in health care. Yolngu expressed a desire for a holistic health service that not only cared for them physically, but also nurtured and encouraged them. Without glossing over the inherent blemishes, the strong ties between health staff at the home clinic and Yolngu patients create a sense of belonging. The corollary of this is the sense of estrangement patients expressed in their interactions with other health services. Issues that turned out to have a lesser impact on the uptake of treatment were a biomedical understanding of the disease, the painfulness of the injections or a sense of personal responsibility for health care (for a patient residing within the community).

Strengths of this study are the use of socially comfortable groups of respondents, interviews conducted in the local language and the participation of a local researcher. Its major weakness is the reduced represen-

tation of men. As most patients and nearly all health care providers in the community are female, this was not unexpected. The fact that both interviewers were female might have negatively affected the participation of Aboriginal men, particularly relatives of the researchers. As it has been suggested that men from a community such as this have worse rates of uptake of treatment for RHD, it would be important to pursue men's perspectives further.<sup>13</sup>

There is no reason to believe that our conclusions pertain only to patients with RHD. Chronic disease, pregnancy and mental illness have their own complexities and all require ongoing cooperation between patients and health care staff, and often involve issues of compliance with medical treatments.

We cannot generalise beyond the community studied. Although it is tempting to generalise our findings to the people of Arnhem Land based on the similarity of languages and traditions, Yolngu tend to emphasise their differences. Nevertheless the concepts of care (*djaka*), nurturing (*gungga'yun*) and belonging to a health service have an intuitive veracity that might prove to be generally relevant.

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## COMPETING INTERESTS

None identified.

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