Yarning about 'that heart problem': RHD in pregnancy

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Rheumatic heart disease (RHD) is a preventable condition resulting in damage to cardiac valves with added risk in pregnancy. Overall a rare disease, it is prevalent among (particularly remote dwelling) Aboriginal and Torres Strait Islander peoples in Australia. Each year, two to three per cent of Aboriginal women in the Northern Territory (NT) journey through pregnancy with RHD.

During 2012–16, Australian Maternity Outcomes Surveillance System (AMOSS)* conducted population-based research on the pregnancies of women with RHD in 300 maternity units across Australia and New Zealand, and a qualitative study exploring NT women's experiences of RHD. The NT research team walked with eight women as they interacted with health services throughout their pregnancy, birth and the postnatal period.

This is a case study drawn from the experiences of two women who participated in the study. 'Sylvia' is a pseudonym to represent the shared lived experiences of some Aboriginal NT women with RHD during their pregnancy.

The researchers used the yarning methodology to understand the women's experiences and explore how biomedical phenomena impacted on their lives.[1]

Sylvia

Sylvia is a 22-year-old Aboriginal primiparous woman living remotely, about 600 km from an NT regional centre. She speaks two Indigenous languages and English as a third language. Sylvia lives with her mother-in-law and more than 10 other adults and children in a three-bedroom house. This is a typical remote community in that it has extremely limited access to fresh food, specialised health services, schooling and employment opportunities. The community health centre has a high staff turnover and a resident medical officer visits every four weeks.

Sylvia is a heavy smoker. Early in pregnancy, she developed a persistent cough. At 18 weeks, the resident medical officer detected a heart murmur and referred her for cardiac review. However, the four-monthly visiting echocardiogram service had just occurred, so it was 14 weeks before Sylvia had an ECG. By this stage, she was 32 weeks pregnant and very unwell. The doctors decided to fly her immediately to the regional referral hospital.

Sylvia's story

Sylvia arrived at hospital very breathless. Severe RHD with pulmonary oedema was diagnosed and she was commenced on frusemide, beta blockers and LABicillin injections ('secondary prophylaxis' every 21–28 days to prevent a recurrence of rheumatic fever [RF]). She was propped up in bed with pillows and given oxygen. A nurse arrived to provide information about RHD. She stood next to Sylvia, and used a mixture of medical jargon and metaphors: heart valves are 'doors'; streptococcus is a 'bug'. During the 30-minute consultation, Sylvia leant forward, struggling to breathe and her eyes were closed. The nurse left behind an information brochure about RHD, written in English. Sylvia is illiterate.

After four days, Sylvia was discharged, but was advised by her doctor to stay in town at the government-funded hostel. Sylvia's mum and partner, Steven, joined her. The hostel was basic. Meals lacked nutrition, there was no air-conditioning despite the extreme humidity of the Dalirrgang (the build-up to the rainy season), no kitchen to prepare food, no activities or educational opportunities and the rooms were overcrowded. It was a 30-minute walk to the nearest bus stop and a $25 taxi fare to the shops. The women played cards; they were bored. Gangs of youths from nearby housing estates intimidated the women, 'humbugging' them for money to buy food and drugs.

Understanding Sylvia's heart

The research team met with Sylvia, her mum and her partner at the hostel, and talked with Sylvia about her experience.

Sylvia said: 'My feet have been swollen for a few weeks. My heart was beating fast. I had to get an x-ray of my chest. (She moved her hand to her chest, upset.) I didn't know what was wrong with my heart – they didn't tell me. I had a kidney problem when I was a baby. Now I have RHD. But I don't really know what that means. A lady tried to explain it to me but I don't know what that needle [LABicillin] does. I don't feel breathless now because I take my tablets.'

Sylvia's mum described why Sylvia is sick: 'Because the blood and the water didn't really go in through the valve to her heart. You can't stop RHD because of, ah, like, sometime Aboriginal people get White People's sickness. Her heart didn't pump properly. You know, like, if that's what is wrong with her leg, everything is swelling up, because of that, um – I think she's got a fluid. She only had that, ah, kidney problem. Not really a heart problem but now she's got that, um, heart problem. She has exactly the same like her Aunty.'

Sylvia's partner, Steven, commented: 'Yeah yeah. Like you can get that from generation to generation, passing it down. It's in our family.'

Bush tucker and meat pies

Sylvia was very hungry. She ate the meat pie that the hostel had heated up for lunch. Fish, iron-rich wallaby and bush food/medicine are brought to pregnant mums back home, but that was not possible for Sylvia here in the regional centre.

Sit down time, waiting for baby

Sylvia was booked for a routine antenatal visit at the hospital in the regional centre. She was woken at 6am and driven to the hospital without breakfast. She waited in the clinic. It was full of pregnant women and their children. Most were Indigenous. There was no health information that she could understand and she chatted with distant relatives and neighbours to pass the time. At 10 am, a doctor called her name. By then she was really hungry. Her Basics card (to buy food) was back home in the community.

In a firm voice the doctor said: 'The community can't manage your heart problems. You are to stay here until the baby is born', which was in about five weeks. The doctor made no eye contact with Sylvia.

This meant Sylvia would give birth away from Country. Sylvia was silent and then sighed. She wiped her eyes and murmured quietly: 'That a long time nine weeks, long time. I don't feel sick. I don't feel sick back home. Yeah, because of that bush medicine. Yeah, and I got my grandmother like, cook for a person when they're sick. With the medicine from the tree, yeah.'

Sylvia's heart medications ran out. She could not read the pieces of paper that the hospital had given her, but knew it was important to take the medicine. It was a week until her next antenatal appointment. Sylvia waited.

Having baby and returning home

At 38 weeks' gestation, Sylvia had an emergency caesarean as a result of her heart failure and gave birth to a baby boy. She had a postpartum haemorrhage requiring a blood transfusion.

The research team visited her after the birth. Sylvia was distressed: 'I have to go home by myself. The police came and took him (partner Steven) to the station, he is in trouble. He missed court.' Sylvia sobbed.

As Sylvia went into labour, Steven was arrested and jailed for assaulting her earlier in the pregnancy. This serious assault was documented in the case notes, but no health staff had discussed it with Sylvia or made a safety plan for her and the baby.

One week after the birth, Sylvia was flown home. The discharge summary was sent to the wrong community, Sylvia's medications were not provided and no postnatal recall appointments were set up. The primary healthcare team was not aware she had arrived home. Her next LABicillin secondary prophylaxis injection was late.
Back home, Sylvia was breastfeeding her baby. She was surrounded by aunties and cousins who played with him. He had big eyes and snuggled into his mum. He had crusted scabies on his feet and legs.

Desired outcomes

The authors hope that this study will add to the growing literature around culturally appropriate healthcare services and health education for Aboriginal women living in remote regions of Australia who are using cardiac and maternal health services to manage their RHD, and more fundamentally, eradicate this preventable disease.

Further reading

Brown A, McDonald MI, et al. Rheumatic fever and social justice. *MJA*. 2007;186(11):557-8.
Cass A, Lowell A, Christie M, et al. Sharing the true stories: improving communication between Aboriginal patients and health care workers. *MJA*. 2002;176(10):466-70.

True/False statements

1. Rheumatic heart disease (RHD) is a common congenital heart condition that is equally prevalent in all levels of society and in all geographical areas.
   False: RHD is a serious complication of acute rheumatic fever (ARF), where a Group A streptococcal (GAS) bacterial infection (upper respiratory tract /skin) leads to acute illness with fever, polyarthritis, carditis and chorea. Recurrent episodes of ARF usually lead to RHD, which damages heart valves and reduces cardiac function. RHD was prevalent in developed countries until 50 years ago, when improved living conditions, medical care and antibiotics resulted in a strong decline in its incidence. Although ARF and RHD have virtually disappeared from the affluent Australia and New Zealand population, Aboriginal and Torres Strait Islanders (particularly remote dwelling) and Maori and Pacific Islander peoples have among the highest documented rates of RHD in the world. It is a disease of overcrowding, poverty and inequity.

2. Sylvia has had ARF in the past; she should understand the causes and consequences of RHD.
   False: ARF/RHD may have been explained to her and her mother but she did not have ongoing LABicillin secondary prophylaxis that prevents RHD. Despite her history of ARF, Sylvia was only diagnosed with RHD in the third trimester – with attendant serious cardiac burden and risk. There were no appropriate health-promotion resources that she could understand or relate to, no interpreter service and she did not understand the Western biomedical cause of her disease. She linked her history of kidney disease (another condition disproportionate among Aboriginal peoples) with RHD. Health information was given to Sylvia when she was severely ill and during a time of crisis. There were missed opportunities for health education while she waited in town or at the antenatal clinic. Health promotion strategies need to draw on Indigenous expertise in developing and delivering appropriate resources.

3. Health services need to consider psycho-social needs rather than just medical needs to improve patient outcomes.
   True: Other needs to be considered include safe housing; food security; appropriate translator/interpreter support; referral to a social worker or appropriate professional Indigenous service for domestic violence; and assistance with orientating to the town and travel. In Sylvia's case, coordination and communication between the cardiac and the maternity team were poor, given the multiple appointments, and the issue of domestic violence was not addressed.

4. In Sylvia's case there are multiple issues impacting on her care and health outcome that the healthcare team should address.
   True: These include delayed diagnosis of RHD and treatment of heart failure; access to medication; smoking reduction and cessation strategies; isolation from family; lack of properly informed consent with treatment; interpreter assistance; gaps in referral to Aboriginal liaison officers and/or social workers; and risk to the baby of rheumatic fever/RHD. There were several gaps in Sylvia's care, including inadequate history and awareness by health services of the importance of the escalated risk and burden of RHD in pregnancy; inadequate access to cardiac (and other) services; errors in information transfer; and poor access to patient transport services.