Listen to the voice of the people: culturally specific consultation and innovation in establishing an Aboriginal health program in the west Pilbara

Lyn Dimer[1], Trevor Shilton[1], Anne Hayes[2], Shirley Hayes[2], Monteza Heard[2], Gina Turangi[2], Sandy Hamilton

[1]Heart Foundation WA

Abstract

Background: Cardiovascular disease remains the leading cause of morbidity in Aboriginal Australians, however only around 5% of eligible Aboriginal people attend cardiac rehabilitation (CR) heart health programs.

Through community consultation and strong collaboration between Heart Foundation, Karratha Central Healthcare (formerly Pilbara Health Network) and key stakeholder organisations in the West Pilbara a need was determined to provide culturally specific heart health programs for local communities in the region. These communities are Roebourne, Karratha and Onlsow.

Method: Consultation with local Aboriginal communities using snowball methodology, was followed by consulting with key community organisations/stakeholders. Oral interviews, were transcribed and fed back to all participating persons. Discussions included establishing community understanding and needs in relation to heart health logistics for program setup, recruitment of staff and aspects of implementation and sustainability. Yarning is an important part of Aboriginal culture, it was used throughout to discuss health messaging and support positive behaviour change through the diverse program activities and meetings.

Results: Since program commenced in September 2015, many changes have occurred including success in breaking down working in silos and establishing a more collaborative and partnership approach with stakeholder service providers the program can work alongside. Each town is different in size and access to service providers. Significantly through our program's processes, participants have experienced empowerment over their own health. Outcomes include improved self-esteem, increase knowledge of the benefits of healthy eating, physical activity and mostly cardiovascular health knowledge. Cross cultural learning between staff and community people has been beneficial and the program continues to evolve.

Background

Nearly one-third of the Australian population live in rural and remote Australia and although metropolitan and rural levels of cardiovascular disease are similar, cardiovascular outcomes for rural, remote and Aboriginal and Torres Strait Islander (Aboriginal) people are poorer.[1] Indeed in 2008, people living in very remote regions were 12 times more likely than metropolitan populations to die from cardiovascular disease.[2] These death rates are a reflection of the high Aboriginal populations living in remote and very remote regions, as the death rates for non-Indigenous Australians from remote regions were not significantly different from those in major cities.[2] Evidence also demonstrates that rural people have higher levels of risk behaviours, especially in regard to smoking, alcohol consumption, illicit substance use, overweight or obesity, sedentary behaviour (for males) and nutrition.[1,3]

Aboriginal people account for 12% of the Pilbara population, however, this figure masks with a higher proportion of Aboriginal people, such as Roebourne at 62%.[4] Aboriginal people are 1.3 times more likely to have cardiovascular disease compared with non-Aboriginal people despite their lower life expectancy, and this occurs at a much younger age than in non-Aboriginal people. Aboriginal females have a higher cardiovascular disease incidence and earlier onset compared to Aboriginal males.[5]

Poorer cardiovascular health in rural and remote populations may be explained by decreased or delayed availability of and access to health services, both acute and preventive services, including participation in cardiac rehabilitation programs.[6,7] The tyranny of distance in rural Australia escalates availability and access issues, including: difficulty in the recruitment and retention of health professionals; limited consultant specialist care, such as cardiologists; and distances travelled to receive or deliver health care. The availability of healthy and affordable foods and the ability to access these (food security) may also be reduced for people living in rural and remote regions.[3] A further consideration is the cost of accessing health care and/or access to medications and advice for a population whose incomes are generally lower than those of a metropolitan population.[7] People living in rural and remote regions are also less likely to seek preventive health advice and on average, their rate of GP attendance is less than city dwellers.[7,8]

Primary health care, especially in rural and remote regions, provides an ideal opportunity for preventive cardiovascular care.[9] However, gaps in cardiovascular risk management in rural and remote general practice remain evident.[9,10] To overcome these gaps, rural preventive cardiovascular care needs to focus on absolute cardiovascular risk[9] and to take an innovative and global approach.

In addition to the assessment and management of traditional risk factors, social and environmental factors that influence cardiovascular health in the rural population need to be considered. Culturally specific programs are required to encourage Aboriginal attendance for cardiovascular risk assessment and preventive cardiovascular care.[6] In more remote Aboriginal communities, employing a community development model may be beneficial for the management of chronic conditions.[11]

The Heart Foundation of Western Australia, in consultation with the communities of the West Pilbara, aims to develop and implement a sustainable local West Pilbara heart health care initiative. The initiative aims to provide a comprehensive, coordinated, integrated and culturally specific service to the Aboriginal people in the areas of Karratha, Roebourne and Onslow. The planning, development, implementation and evaluation of the Pilbara Aboriginal Heart Health Project will occur in three stages.

Project stages

The planning, development, implementation and evaluation of the Pilbara Aboriginal Heart Health Project occurred in three stages:

- Stage 1: Scoping and evaluation
  - Phase 1: Feasibility Study (scoping)
  - Phase 2: Feedback Report to all stakeholders
  - Phase 3: Planning and Formulation of Proposed Initiative for testing
- Stage 2: Development and setup of proposed initiatives
  - Phase 1: Finalise proposed initiative with relevant stakeholders
  - Phase 2: Launch proposed initiative in community

- Stage 3: Management of the initiative
  - Phase 1: establish networks, collaborations
  - Phase 2: implement programs, three locations
  - Phase 3: evaluate program, three locations.

The Aboriginal Health Manager and various Heart Foundation staff made many visits to the West Pilbara with the aim of building trust, developing rapport and consulting with the community and service providers during Stage 1. The primary focus of these visits was to undertake a needs assessment to determine the need for a program, the type of program and method of program delivery. Consultations, interviews and focus groups were held with community and service provider in Karratha, Onslow and Roebourne.

Consultation process

Interviews

The Aboriginal communities, Aboriginal corporations and service providers of Karratha, Onslow and Roebourne were approached for interviews to gather the required information/data for the scoping and needs assessment of a heart health program in the West Pilbara region.

The following interview questions were utilised for all participants:

- Is there a need for a heart health program in your community?
- What are the important issues for your community for improving heart Health?
- What do you think is needed?
- Who else should be consulted?
- Who in your community can you recommend to work on this project?

A written project description was provided to inform interviewees of the Stage 1/Phase 1 activities. Interviews were recorded with permission following the signing the Heart Foundation's Use of Personal Information Consent Form—General. If the interviewee declined to have their interview recorded, permission was sought for the interview to be documented by hand written notes, scribed and later typed into a Word document. Recorded interviews were transcribed by a transcription service and returned to the interviewee for checking prior to analysis.

These interviews included individuals, couples and groups and were held in a place appropriate and comfortable for the interviewee. Interviewees ranged from Aboriginal men with a history of cardiovascular disease with or without their wife/partner present, an Aboriginal women's group, community women running a resource centre, women from the Bindi Bindi community in Onslow and two women outside the Roebourne café

Service provider consultations

Service provider consultations were held in Karratha, Onslow and Roebourne over a 6-month period. Interviews with service providers included Aboriginal Corporations, primary and secondary health services, a private physiotherapy centre, outreach health services to the Bindi Bindi community in Onslow, Not for Profit organisations, school programs in Roebourne and Onslow, Aboriginal Legal Services, PCYC, Community Health Teams and Aged Care.

Scoping and Evaluation: A total of 38 interviews and two focus groups were held with 88 community members and service providers involved in the interview /consultation process. Five feedback workshops were conducted in October 2014, two in Karratha and two in Roebourne, one in Onslow, information was provided on the processes taken to date and some key learnings. The veracity of the key learnings and further suggestions were also sought. The importance and success of the consultations with the community and service providers in Karratha, Roebourne and Onslow was seen through the warmth and support received by the team and the willingness of the community and service providers to engage in the interview process

With written consent, interviews were recorded and transcribed or hand written notes scribed at the time of interview. Qualitative data from interviews and group discussions were subjected to thematic analysis and the concepts and themes generated.

The report details the findings from this analysis and makes recommendations for the development, implementation, and sustainability of a Heart Health Program in the West Pilbara. There was overwhelming agreement by those community members and service providers involved in the consultation process that a heart health program was needed in the West Pilbara.

The key findings from the needs analysis.

Key findings

- A Heart Health Program is needed and wanted in the West Pilbara.
- Limited access to health services was identified as an important issue and need.
- Multiplicity of service provision and a lack of knowledge of what services are available and how to access them.
- A requirement for a Heart Health Program that covers the continuum of cardiac care, is inclusive of chronic disease management and self-management support and has a focus on care coordination/navigation.
- Comorbidities such as diabetes and renal disease were of equal concern.
- There is limited service capacity of cardiac rehabilitation and secondary prevention.
- Implement the Heart Health Program in alignment and synergy with current service provision.
- The importance of having health care in the West Pilbara and on-country.
- A wide and varied range of program content and methodologies were suggested.
- Program development, implementation, success and sustainability all need planning and ongoing consultation with Aboriginal elders and community. The formation of an Aboriginal Community Reference/Advisory Board should be considered.
- Community fragmentation, family feuds and violence impact on emotional and social wellbeing and health. These stressors contribute to poor mental health and increase cardiovascular risk.

The following key recommendations emerge from the thematic analysis of the community and service provider interviews for the Pilbara Heart Health Project.

Key recommendations

- That the Heart Health Program Pilbara office and Program Facilitator be based in Karratha with outreach services to Onslow and Roebourne.
- The program Facilitator should be a health professional with expertise in cardiovascular disease and Aboriginal health and if possible have local knowledge.
- The Heart Health Program should be aligned and work in synergy with current services and service providers.
- The Heart Health Program to be inclusive of the continuum of cardiac care and provided for kids, families and carers.
- Care coordination/navigation should be a key component of the Heart Health program.
- Owing to complexities within the three communities and the wide range of expressed needs, the program should be implemented incrementally over time.
- The program should aim to empower, upskill and mentor local Aboriginal community care coordinator/navigators and support workers in Karratha, Onslow and Roebourne.
- Sustainability needs to be planned and built into program development at the very beginning.
- That an Aboriginal Community Reference/Advisory Group is formed.

Aim

The overall aim of the Chevron Pilbara Heart Health project is to provide a comprehensive, coordinated, integrated and culturally specific service to the Aboriginal and Torres Strait Islander people in the areas of Karratha, Onslow and Roebourne.

Objectives

This aim will be achieved through the following objectives:

- To provide participatory interventions that contribute to improving the health of at-risk Aboriginal and Torres Strait Islander people and their communities in the region.
- To expand access to culturally specific programmes for at-risk Aboriginal and Torres Strait Islander people and their communities;
- To work with key community stakeholders to develop and strengthen individual health literacy and leadership capacity in a culturally specific way; and
- To increase and sustain the economic viability of the broader community through a comprehensive approach that builds family self-sufficiency and self-efficacy; and leads to the creation and sustainability of local jobs in local businesses for local people.

To ensure the Heart Foundation is committed to engage and develop the work post stage 1, in accordance with community findings, a set of principles was developed to define our work in progress. These principles are listed and are interdependent and of equal weight and importance.

The Pilbara Aboriginal Heart Health Project is committed to the following principles:

- community control
- holistic approach
- cultural safety
- equality
- reciprocity and inclusion
- best practice
- building community capacity
- accountability
- sustainability.

Stakeholders

- National Heart Foundation of Australia, WA Division
- Aboriginal and Torres Strait Islander (Aboriginal) and non-Aboriginal communities of the Pilbara, including Karratha, Onslow and Roebourne
- Service providers of the Pilbara, including Karratha, Onslow and Roebourne removing the silos
- Our funders Chevron

Comorbidities

Cardiovascular disease was not the only health issue identified throughout the consultations and interviews. Issues and needs around several other chronic conditions were identified. Many community members have more than one chronic condition or comorbidity, increasing the complexity of care and service provision. The conditions most frequently reported and given the most weight was:

- Type 2 diabetes (also a risk factor for cardiovascular disease)
- Chronic Kidney Disease
- Mental Health
- Drug and alcohol addiction
- Hypertension (also a risk factor for cardiovascular disease)
- Overweight and Obesity (also risk factors for cardiovascular disease)
- Chronic obstructive pulmonary disease
- Ear health

It will be necessary for a Heart Health Program to have a chronic condition management focus to encompass the complexity of an individual's (and their carer and family's) health needs with a holistic approach. This approach applies to both primary and secondary prevention and care coordination. Fortunately, most of the lifestyle interventions applicable to the prevention of cardiovascular disease also apply to most of the chronic conditions identified as a priority by the communities in the West Pilbara.

Presenter

Lyn Dimer is the Manager of the Aboriginal health program at the Heart Foundation in WA. Lyn is passionate about improving the health of her people; she works tirelessly to increase access to services and equality, which will lead to optimal care for her people who have, or are at risk of, cardiovascular disease. Lyn has dual qualifications in health and education, is a wife, mother and grandmother, her family is the most important blessing in her life, providing inspiration to remain true and loyal to the field of Aboriginal health sharing culture, health and wellbeing with people she meets.