Good Heart: Telling Stories of Cardiovascular Protective and Risk Factors for Aboriginal Women



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Background	Aboriginal and Torres Strait Islander peoples' perspectives of health and cultural wellbeing encapsulate the spiritual, social and environmental health of individuals, their communities and country. Strategies designed to reduce the cardiovascular burden of Aboriginal and Torres Strait Islander people often fail to consider their unique knowledge and worldview.
Methods	This adapted, grounded theory study sought to explore Aboriginal women's views of cardiovascular protective and risk factors.
Results	Twenty-eight (28) women from five women's groups across Central and South Australia participated. Women distinguished the heart as core to their spiritual and physical wellbeing. Women identified six attributes that keep a woman's heart strong, four that can make the heart sick, and eight socio-ecological factors which affect a woman's capacity to care for their heart. Women described having a healthy heart when able to identify as Aboriginal women, being connected to family and community, having a healthy life and body, and being engaged in their health and health care.
Conclusions	There are gaps in the provision of cardiovascular risk assessment and management, gaps in the cultural safety of primary health care services, and gaps in the communication of the sex-specific warning signs of a heart attack, all of which must be addressed.
Keywords	Indigenous peoples • Women • Cardiovascular disease prevention and control • Health equity • Grounded theory • Australia

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Introduction

Aboriginal and Torres Strait Islander¹ women experience significant health inequities as a result of the unique interplay of racism and sexism from enduring oppression and discrimination [1,2]. Cardiovascular disease is the leading contributor to the gap in disease burden for Aboriginal women, substantially reducing women's capacity to fulfil long standing cultural obligations in their roles as leader, carer and nurturer of family and community [2,3]. It is important the responses of the health system are culturally relevant, and understand and meet Aboriginal women's unique identified needs to address cardiovascular inequities.

Current health promotion and disease prevention strategies in Aboriginal communities largely focus on clinical and behavioural cardiovascular risk factors [4–6]. Often, these strategies are framed within a deficit narrative of illness, disease, bad behaviour and loss, perpetuating "narratives of failure and inferiority" [7] and contributing to framing illness as part of Aboriginal identity [8]. This is in stark contrast to a strength-based Aboriginal conceptualisation of health which is centred on Aboriginal identity of strength, resilience and connectedness [8,9]. Aboriginal conceptualisation of health and wellbeing encompasses a person's spirit, community, environment, and the strength of culture and ceremony [10,11], and has been defined as:

"... the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life." [12]

As such, strategies fail to recognise and incorporate Aboriginal perspectives and understanding of cardiovascular health and disease in the development and delivery of models of care [13–15]. In doing so, our health system often falls short in caring for Aboriginal women's hearts in a way that meets their cultural needs within a holistic understanding of health and wellbeing.

To the best of our knowledge, there has been no published conceptualisation of Australian Aboriginal women's world-views of cardiovascular health. This paper explores Aboriginal women's understanding of cardiovascular protective and risk factors, with a view to informing health system responses to cardiovascular disease.

Method

The study was undertaken with Aboriginal women in Central and South Australia using a constructivist grounded theory method and led by an Aboriginal Women's Advisory Group. Seven (7) women's groups providing diversity in age and geography were approached to participate. Engaging with established women's groups was recognised as an acceptable approach and the majority member position of

women provided a balanced power relationship. A localised method of data collection, review of data, and communication of results and recommendations was co-developed with five groups who agreed to participate. All five groups chose yarning circles [16] to share knowledge, reflecting the cultural appropriateness of this technique. Semi-structured, open-ended questions exploring six constructs of Aboriginal women's understanding and conceputalisation of heart health and protective and risk factors were guided by story telling (Supplementary File 1). Yarning was undertaken in a time and place determined by the group; was led by a researcher, member of the Aboriginal Women's Advisory Group or social/health service employee; and data documented in written notes or voice recording, as determined by the group. Participants were women, aged 18 years and over, self-identified as a member of the group and self-identified as Aboriginal and/or Torres Strait Islander heritage. Line-byline in-vivo coding was undertaken for first-level analysis by one Aboriginal (CF) and one non-Aboriginal (KM) researcher and group member checking performed. Second level analysis involved development of theoretical memos which were reviewed thematically and line-by-line by the Aboriginal Women's Advisory Group. These memos were arranged by the Aboriginal Women's Advisory Group to form a story, with multiple layers of context and affect, of Aboriginal women's understanding of what makes a strong, healthy heart, with a visual depiction of the narrative drawn. Review of memos and development of the narrative occurred over a 3-day workshop. The quotes in this article are the direct voices of Aboriginal women and have not been changed. They are to be respected and must not be taken out of context.

Ethics approval was provided by the South Australian Aboriginal Health Research Ethics Committee (04-17-734), the Central Australian Human Research Ethics Committee (CA-18-3029) and the University of South Australia's Human Research Ethics Committee (200342).

Results

Twenty-eight (28) women from five women's groups participated, ranging in age from early 20s to 82 years and living across diverse geographic regions (Figure 1).

A narrative was developed from Aboriginal women's understanding of what protects and puts the heart at risk. The narrative describes 10 personal attributes which keep a woman's heart strong or can make the heart sick and eight socio-ecological factors which affect a woman's capacity to care for her heart. Figure 2 is a visual depiction of the narrative, and Table 1 provides a high level description of and an exemplar quote for each element. The high level description articulates the fundamental concept/s explored within each element as identified by the Aboriginal Women's Advisory Group. The narrative is provided in Supplementary File 2.

¹ Here on "Aboriginal" is used as an accepted term amongst Aboriginal and Torres Strait Islander communities where the study was conducted.

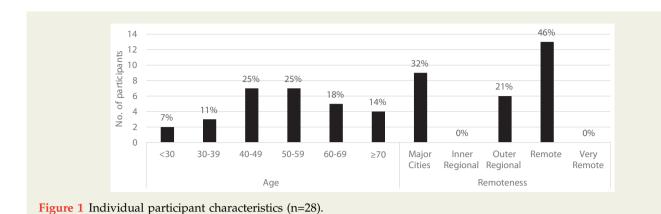


Figure 2 was designed by the Aboriginal Women's Advisory Group as they developed the narrative of women's understanding of a strong, healthy heart. The circular shape has been used as it depicts the relational worldviews of connectness and cyclical relationships of health and wellbeing. The core principle positions the woman's understanding of the heart as vital for health and wellbeing and as a giver of life. The core principle provides

context to the attributes and socio-ecological factors, and

for this reason, is placed at the centre of the visual depiction of the narrative. The 10 attributes surround the core and are within a circle. Women are symbolised sitting around this circle. A woman's personal attributes are influenced by the socio-ecological factors, these socio-ecological factors are visually depicted as surrounding and connected to the circle of women. The contrasting colours of the text represent the distinction between the strengthening and harmful attributes and socio-ecological

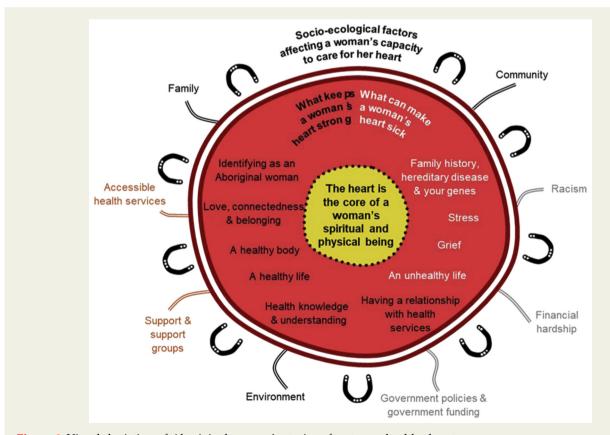


Figure 2 Visual depiction of Aboriginal women's stories of a strong, healthy heart.

Element	Description	Exemplar Quote ^a
Core principle	A principle which is fundamental to Aboriginal women's narrative of heart health, providing context within which personal attributes and socio-ecological	
The heart is the core of a woman's spiritual and physical being	factors should be considered. Women identified the heart is critical for spiritual and physical wellbeing, and is the core of a person's emotions. The spiritual and physical are interconnected and must be considered together.	" your heart isn't just an organ in you human body, it's a very spiritual connection to your emotions. I don't set the human body as just a physical thing it's a huge, spiritual, the casing to our spiritual being." (P2.3)*
Attributes that keep a woman's heart strong Identifying as an Aboriginal woman	Attributes identified by Aboriginal women as keeping the heart strong and healthy. Aboriginal women discussed that women who identify with a strong and constant connection to their culture have a strong heart. Identity is strengthened through family connections, strong community and embracing life. Cultural knowledge is passed through the social structure of the kinship network. Women expressed concern for men and their heart hearlth, feeling that some men have lost some of their traditional roles as a concequence of significant changes in	" with your identity, with your heritage, your culture, your language, it makes you feel good. And when anything makes you feel good it has a positive effect on your heart." (P3.1)*
Love, connectedness and belonging	women discussed that when a woman experiences love and it is reciprocated, there is a feeling of wellbeing and a healthy heart. When there is a strong identification with culture, family, community and environment there is a true sense of connectedness, belonging and love. Being carers and nurturers of family and community is fundamental.	"When you think of love you think of the heart and when you're deprived of love, they know that it can actually impact on your heart." (P5.3)*
A healthy body	Women understood the body as a whole, not separate organs or parts, and the importance of caring for the whole body in order to nurture the heart.	"Your heart is connected to all the other parts of the body." (P3.6)*
A healthy life	Living a traditional life was recognised as a healthy life. Women discussed a healthy life as vital for the heart: eating healthily and drinking water, being physically active, having a healthy weight, having hobbies, and having good sleeping patterns and ample sleep.	"And so we can live long lives, but we need to choose that I think, we have to choose to be healthy and look after ourselves." (P3.3)*

Element	Description	Exemplar Quote ^a
Health knowledge and understanding	Women identified that to be able to take care of their heart they needed an understanding of their heart and knowledge of how to care for it. Women had a good understanding of stroke symptoms, however voiced concern over the lack of information on the warning signs of heart attack experienced by	"The doctor will check your blood pressure and your ears, but won't tell you the results." (P1)* "They never show the woman having a heart attack. And the way that the woman has a heart attack." (P3.1)*
Having a relationship with health services	women. Having a constructive relationship with health services was identified as important for women to engage in caring for their heart.	" the services, they need to have an understanding of the community, of Aboriginal people Having that understanding of Aboriginal cultures an understanding of me and be able to si down and listen, that would make my heart feel, oh, ever so happy and glad." (P5.1)*
Attributes that can make a woman's	Attributes that are recognised as causing ill-	
heart sick	health and can damage the heart.	WITH 11 1 0 11 0 11 11
Family history, hereditory disease and your genes	Women identified family history and genes as playing a part in determining a woman's heart health. Having knowledge could help women understand their risk of heart problems and other health conditions.	"Like diabetic complications, on this side of the family, the {surname} side, you know, and heart, and all of that as well, so to map out family health conditions is something that, I think, that all blackfellas should have, so we have a record of showing next generation what to be wary of, what runs in the family." (P3.1) ^b
Stress	Women identified stress as leading to poor spiritual and physical health. There are many sources of stress: about their own health, discord in family and the community, often separation from country, living with the daily presence of racism, and at times financial hardship. Women also talk about the many responsibilities they have, and express the stress in carrying such a load.	" you don't need the stress in your life but stress is one of the things that lead up to a lot of health problems." (P5.1) "Too much worry you get sick, end up ir hospital." (P4)
Grief	Women experienced grief which often caused spiritual and physical breakdown of the heart and often resulted from social and political factors in women's lives: the loss of loved ones; separation and breakdown of family, community; intrusion on culture and identity and; feeling a loss of control over one's life.	"In Aboriginal community we live with grief all the time, and it could be all sorts of grief, you know, where people die in our life or where things happen to us that are beyond our control, again like the Stolen Generation issue." (P3.3) "I believe that grief and loss can cause you to die of a broken heart." (P2.3)

Element	Description	Exemplar Quote ^a
An unhealthy life	It was discussed that an unhealthy life can make women's hearts' sick: poor diet, being overweight, drug use and gambling. These are often driven by social and political factors in women's	" it's only because some of the options of the junk food or the things with sugars are cheaper. Which is bad, 'cause fruits and all that, vegetables and that are a lot more expensive " (P3.1)*
Socio-ecological factors affecting a woman's capacity to care for her heart	lives. Social and ecological factors identified as impacting on the attributes which keep a woman's heart strong or can make it sick, and which increase or limit a woman's	
Family	capacity to care for the heart. Family was discussed as providing women with love, connectedness, belonging and identity. The responsibility of caring for family was a key driver for women to look after their heart. Women could experience challenges within family life that often	"If your heart is happy knowing where you fit in with your family and your community, you make, makes you realise how content you are around about who you are and where you're from." (P5.1)*
Community	caused stress and worry. Women identified that community provides a strong sense of connectedness, belonging, love, and identity. A community provides a sense of culture that enables women to be involved and participate. Government policies and a lack of funding often led to the loss of self-determination for	" our communities exist, Aboriginal communities, because of the women. Women are the ones who are strong, women are the ones that get up and do everything. You know. They look after their family, they look after their community" (P3.3)*
Racism	communities. Women often experienced daily, ongoing racism which had a cumulative effect on spiritual and physical health and wellbeing. Experiences of racism occured within both the health system and the	"So much stereotype" (P1)*
Financial hardship	wider community. Women discussed how financial hardship is a worry and causes stress for many Aboriginal women because often they are the providers. For women who experienced financial hardship, there was frustration at the lack of finances often connected to a scarcity of government funding, that could limit control over their life.	" if you only got that money to shop for two weeks, you can't spend it all on the perishable foods, 'cause they're going to go off within a couple of days, so you're looking, you're buying all the yucky foods 'cause it lasts longer." (P3.7)*

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Element	Description	Exemplar Quote ^a
Government policies and government	Women identified that historical and	"We want money when we're alive, we
funding	current government policies and	want money to spend, to buy things, I
	government funding significantly	don't mean go out and buy a new car
	influenced the self-determination of	but to have a better life. To look after our
	women and autonomy of communities.	old people in a better way have good
	This resulted in women feeling a lack of	housing that people can live in that
	support for and strength in communities,	belongs to them have good services
	reduced connectedness and stress and	that are provided with funding, that they
	grief.	can do better programs for all of our
		people in our community." (P3.3)*
Environment	The physical and social environment	"It's your cure there." (P1)*
	were identified as important for spiritual	
	and physical health. Connection to	
	country enabled women to connect with	
	their identity and culture and maintains	
	and regenerates health.	
Support and support groups	Having support within the kinship	"I think groups like this are good for me,
	network and professional support of	good for my heart, good for my stress
	services was identified as enabling	levels. I feel comfortable here. I can talk
	women to be connected, seek	" (P2.4)*
	information, gain new skills and manage	
	grief and stress.	
Accessible health services	Women discussed the importance of	"I ask them [new doctors] questions
	access to information and care from	before I tell them problems." (P4)*
	health services which were close to	
	home, affordable, and provide a safe,	
	comfortable environment.	

^aThe reference at the end of each quotation represents the group and individual identifier number of each participant. Where there is only one number, the individual participant was not identified in the transcript of the yarning circle, and the number represents the group identifier number.

^bThis is a direct quote from an Aboriginal woman, who used the language of "blackfellas". This language is widely accepted when used by Aboriginal people within the Aboriginal community, but is not accepted when used in the broader community and by non-Aboriginal people. The voice is to be respected and must not be taken out of context.

factors. The attributes and socio-ecological factors were described and arranged by their significance and relation to one another.

Discussion

Maintaining a strong, healthy heart is important for Aboriginal women within a holistic understanding of health and wellbeing centred on culture and knowledge. When a woman's heart is unhealthy, it affects her ability to carry out her role as leader, carer and nurturer of family and community.

Women identified multiple, complex, multi-layer and multi-directional relationships between the biological, cultural, pyschological, behavioural, community, social, economic, political and environmental drivers of cardiovascular disease [17,18]. These findings are consistent with the Aboriginal worldview of health and wellbeing [10–12], and

with conceptualisations of the social determinants of health [6,17]. The socio-ecological factors identified by women, including racism, government policies and funding and community connectedness influence the personal attributes of cardiovascular health and illness. These findings reiterate the importance of addressing social, political and economic determinants of health in order for a reduction of the impact of cardiovascular disease in Aboriginal communities.

Women acknowledged being strong in culture, cultural identity, strength and resilience as key protective factors against cardiovascular disease, and narratives conveyed perserverance and survival even in the face of adversity. Whilst Aboriginal women participating in this study had a sound knowledge and understanding of the biomedical and behavioural risk factors [4], there was greater importance placed on the cultural, spiritual, psychological and social protective and risk factors. Models of health promotion and disease prevention fail to address these factors, leaving a

substantial gap between women's identified needs and the health system's response. The focus on cultural, spiritual and psychological factors and their drivers is consistent with the findings of conceptualisation of psychosocial cardiovascular mediators, and of depression and cardiovascular disease in Aboriginal men [14,15,19]. In order for health promotion and disease prevention strategies to meet the needs of Aboriginal women, models and delivery of care should be re-designed in partnership with communities. These models will not necessarily be focussed on the individual's cardiovascular health, instead models which foster spiritual and physical health and connect families and communities may better resonate with women's priorities and responsibilities [2].

For Aboriginal women to keep their heart strong, participants placed great value on the accessibility of health services, quality of care, and effective communication to enhance their knowledge of cardiovascular health and care. Women identified they often did not receive care according to evidence-based guidelines on cardiovascular health assessment and management in primary health care. These findings confirm the importance of good communication by health advocacy groups, health promotion, disease prevention and primary health care services. Opportunities exist to enhance the way information is provided. For example, Aboriginal women understand that there is variation in warning signs by sex, however participants sought clearer messaging by health care professionals.

Limitations

This study purposefully sampled members of women's groups. This approach enabled collective story telling and facilitated balanced participant-researcher power relationships. Because of this, it is not unexpected that a socioecological factor of cardiovascular health identified in this study was having support groups. Additional research should explore the importance of supports with women who choose, or are unable, to be involved in such groups.

There was diversity in participant experiences of cardiovascular disease, most women had lived experience through family or community and were therefore informed on the topic; analysis by personal experience would provide additional insights into service provision.

Conclusions

This research is unique in terms of exploring Australian Aboriginal women's conceptualisation of heart health. Aboriginal women have identified what is important for a healthy heart; this is not matched in the delivery or quality of services to meet cultural, spiritual and psychological health needs. There is an urgent need for the health system's responses to improve the knowledge and provision of cardiovascular risk assessment and management for women; address the emotional and cultural safety of primary health care services and; effectively communicate the warning signs of myocardial infarction to and with Aboriginal women. Further to this,

addressing social, economic and political drivers are fundamental for enabling Aboriginal women to care for their heart.

Competing Interest Statement and Conflicts of Interest

The authors report no competing interest associated with the work reported in this manuscript. The authors have no conflicts of interest to disclose.

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Appendices. Supplementary Data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.hlc.2020.09.931.

References

- Daylight P, Johnstone M. Womens Business: Report of the Aboriginal Women's Task Force. Canberra: Department of the Prime Minister and Cabinet Office of the Status of Women; 1986.
- [2] McBride KF, Rolleston A, Grey C, Howard NJ, Paquet C, Brown ADH. Māori, Pacific, Aboriginal and Torres Strait Islander women's cardio-vascular health: where are the opportunities to make a real difference? Heart, Lung Circ. 2020. In press.
- [3] Eades A, Hackett ML, Liu H, Brown A, Coffin J, Cass A. Qualitative study of psychosocial factors impacting on Aboriginal women's management of chronic disease. Int J Equity Health. 2020;19:8.
- [4] National Vascular Disease Prevention Alliance. Guidelines for the Management of Absolute Cardiovascular Disease Risk. Canberra: National Vascular Disease Prevention Alliance; 2012.
- [5] Australian Institute of Health and Welfare. Cardiovascular Disease, Diabetes and Chronic Kidney Disease - Australian Facts: Risk Factors. Canberra: AIHW; 2015.
- [6] Pearson TA. Public policy approaches to the prevention of heart disease and stroke. Circulation. 2011;124:2560–71.
- [7] Fogarty W, Lovell M, Langenberg J, Heron M-J. Deficit Discourse and Strengths-based Approaches: Changing the Narrative of Aboriginal and Torres Strait Islander Health and Wellbeing. Lowitja Institute; 2018.
- [8] Fforde C, Bamblett L, Lovett R, Gorringe S, Fogarty B. Discourse, deficit and identity: aboriginality, the race paradigm and the language of

- representation in contemporary Australia. Media International Australia. 2013;149:162–73.
- [9] Brough M, Bond C, Hunt J. Strong in the city: towards a strength-based approach in indigenous health promotion. Health Promot J Austr. 2004;15:215–20.
- [10] Commonwealth of Australia. National Aboriginal and Torres Strait Islander health plan 2013-2023. Canberra: Department of Health; 2013.
- [11] Lutschini M. Engaging with holism in Australian Aboriginal health policy a review. Aust New Zealand Health Policy. 2005;2:15.
- [12] National Aboriginal Health Strategy Working Party. A national Aboriginal Health Strategy. Canberra: National Aboriginal Health Strategy Working Party; 1989.
- [13] Aboriginal Health Council of South Australia. Next Steps for Aboriginal Health Research. Adelaide: AHCSA; 2015.
- [14] Brown A. Kurunpa [spirit]: Exploring the Psychosocial Determinants of Coronary Heart Disease Among Indigenous Men in Central Australia. 2009

- [15] Reilly RE, Doyle J, Bretherton D, Rowley KG, Harvey JL, Briggs P, et al. Identifying psychosocial mediators of health amongst Indigenous Australians for the heart health project. Ethn Health. 2008;13:351–73.
- [16] Bessarab D, Ng'Andu B. Yarning About Yarning as a Legitimate Method in Indigenous Research. Int J Crit Indig Stud. 2010;3(1):37–50.
- [17] Marmot M, Wilkinson RG. Social Determinants of Health. 2nd ed. Oxford: Oxford University Press; 2006.
- [18] Whitehead M. Policies and Strategies to Promote Social Equity in Health. Background Document to WHO - Strategy Paper for Europe. Institute for Futures Studies. 1991.
- [19] Brown A, Mentha R, Howard M, Rowley K, Reilly R, Paquet C, et al. Men, hearts and minds: developing and piloting culturally specific psychometric tools assessing psychosocial stress and depression in central Australian Aboriginal men. Soc Psychiatry Psychiatr Epidemiol. 2016;51:211–23.