

UNDERSTANDING INDIGENOUS PEOPLE’S EXPERIENCES OF ACUTE HEALTH CARE WITH A FOCUS ON HEART HEALTH

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the degree**

Doctor of Philosophy

By

Vainess Banda Mbuzi

Registered Nurse Certification (Ndola School of Nursing),

Bachelor of Nursing -Post-registration (Deakin University),

Graduate Diploma in Intensive care (Queensland University of Technology),

Master of Nursing in Primary Health Care (Queensland University of Technology),

Master of Nursing in Health Professional Education (Griffith University)

School of Nursing and Midwifery

Faculty of Health Sciences

Australian Catholic University



AUSTRALIAN CATHOLIC UNIVERSITY

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Supervision team

Candidate: **Vainess Mbuzi**

Principal Supervisor: **Professor Paul Fulbrook**

[2012-2019] Professor of Nursing, School of Nursing, Midwifery and Paramedicine (Qld), Faculty of Health Sciences, Australian Catholic University; Nursing Director, Nursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane

Co-Supervisor: **Dr Sandra Miles**

[2017-2019] Lecturer, School of Nursing, Midwifery and Paramedicine (Qld), Faculty of Health Sciences, Australian Catholic University; Research Fellow, Nursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane

Co-Supervisor: **Professor Nereda White**

[2012-2014] Institute of Positive Psychology and Education, Australian Catholic University (Qld)

Associate Supervisor: **Dr Melanie Jessup**

[2013-2019] Lecturer, School of Nursing, Midwifery and Social Work, University of Queensland

Associate Supervisor: **Ms Natasha White**

[2019-2019] Manager, Indigenous Hospital Liaison Services and Cultural Capability Team, The Prince Charles Hospital

Thesis abstract

Overview

The program of research presented in this thesis was designed to increase understanding of the central issues related to Indigenous peoples' hospitalisation experiences. Emphasis was given to Indigenous peoples' cardiovascular health care. This area was chosen because cardiovascular disease has been described as one of the major contributors to the health disparity between Indigenous and non-Indigenous peoples in Australia. This was of interest to me because the main study setting is a cardiothoracic hospital. This hospital is the largest referral centre for cardiac conditions in Queensland, surrounding states, and neighbouring countries, including Papua New Guinea.

This program of research comprised four studies. The first study, a metasynthesis, was undertaken to gather a worldwide perspective of Indigenous peoples' experiences of acute care. In the second study, a narrative inquiry was undertaken. It focused on Indigenous Australians' experiences of acute cardiac care. The third study was a systematic review. It adopted a broader perspective to investigate the effectiveness of Australian Indigenous cardiovascular health programs. The final study, an autoethnography, utilised reflective inquiry to examine issues related to researching with Indigenous people.

Background

There are many explanations given to explicate sources of health disparities for Indigenous people. Most of the factors have their roots in past colonialism and its policies. Past practices by former Australian governments devalued the Indigenous culture, tortured individuals both physically and psychologically, and effectively marginalised the Indigenous population. Indigenous people still experience elements of tacit and overt discriminatory practices within the healthcare system. A range of cultural and Indigenous-specific factors also impact Indigenous health in a negative way. As a result, Australian Indigenous people encounter noteworthy health inequalities when compared to non-Indigenous Australians. In recognition and response to this disparity in health status, the Australian government launched a "Close the Gap" campaign in 2008. The campaign attempts to narrow the health differences and life expectancy, while also considering other factors that impact Indigenous health such as education and employment opportunities.

Coming to hospital is a challenge for most Indigenous Australians. In Australia, Indigenous people are often geographically isolated in scattered settlements, and living in relatively small communities, leading to fragmented services and support for health and social programs. They are isolated both geographically and culturally when they come to hospital. In most cases, they have to relocate in order to access the services they need. This experience can be overwhelming due to the different culture of hospital practices and world views of healthcare professionals, who are mainly from westernised backgrounds. In most healthcare settings, Indigenous peoples' culture and views of health have not been integrated into mainstream health. In a way, Indigenous people are forced to leave their way of life at home and adapt to western culture when hospitalised. This can cause discomfort for Indigenous people in many ways. As a result, some avoid accessing health services even when such services are needed and are available to them.

A few aspects of Indigenous culture may be presented in hospital settings but usually at tokenistic or symbolic levels. This includes items such as flags at the front of the hospital and Indigenous paintings on display. Health professionals' attitudes, as well as the hospital policies that guide their practice, do not usually accommodate Indigenous values into practice. Bedside manners and ward practices have remained the same for many years – fashioned and practiced in the ways of the dominant culture.

In Australia, cardiovascular disease is known to constitute one of the major single causes of ill health and death for Indigenous peoples. As a result, it contributes significantly to life expectancy differentials between this population and other Australians. Indigenous Australians suffer major gaps in health status even when compared with other Indigenous peoples in other first-class nations. This includes Indigenous peoples from Canada, New Zealand and the United States of America. Health practitioners, therefore, need to be aware and proactively act on the underlying causes of poor health outcomes among Indigenous people.

Methods

Four studies were conducted over the period of this program of research using qualitative and quantitative research methods. The first study was a metasynthesis of qualitative research studies. Its aim was to investigate current evidence of Indigenous peoples' hospital experiences in order to summarise current knowledge. Systematic procedures were employed to retrieve studies from the

period between 2000 to 2016. The review process was conducted following Joanna Briggs Institute (2014) guidelines for conducting systematic review and synthesis of qualitative data.

The second study utilised narrative inquiry, a qualitative methodology in which face to face interviews were used to enable participants to recount their experiences of hospitalisation. Narrative inquiry was selected specifically because it involves storytelling, which is culturally familiar to Indigenous people. The aim was to explore Indigenous peoples' experiences of hospitalisation of acute cardiac care. To accomplish this, data were collected using a purposeful sample of Indigenous cardiac participants: all Indigenous patient participants had been hospitalised for acute cardiac care.

The third study was a systematic review. Its aim was to investigate the effectiveness of cardiovascular health care programs designed for Indigenous Australians. Analysis of the strategies that were used to achieve successful outcomes was conducted. Studies that used experimental designs and reported interventions or programs explicitly aimed at improving Indigenous cardiovascular health were considered for inclusion. The search period was between 2008 to 2017.

The fourth study was an autoethnography. This study involved use of personal diary-based data and reflective inquiry to present a researcher perspective of the experience of conducting research with Indigenous people. The aim was to share the experience to inform others of aspects for consideration when conducting research with Indigenous participants. The purpose was to offer a true picture of conducting research from my perspective. The study enabled examination of the interplay of my personal, social, professional life and how these impact on my clinical and research practice,

Findings

The metasynthesis revealed that overall, Indigenous peoples, worldwide, have remained in a disadvantaged position when it comes to their health and wellbeing. Several factors were identified that contribute to widespread inequality in Indigenous healthcare. It was increasingly clear that current healthcare systems are not effectively working well in addressing Indigenous peoples' health needs.

The findings of the narrative inquiry indicated that three themes characterised Indigenous peoples' experiences of hospitalisation which were as follows: the impact of the past, reality of the present, and anticipating the future in Australia. Hospitalisation remains a challenge for Indigenous

peoples. This is due to a sense of dislocation and lack of cultural and spiritual aspects to care, as well as the persisting poor relational interactions encountered.

Quantitative research studies that implemented interventions targeted for management of cardiac conditions among Indigenous population within Australia were included in the systematic review. The results revealed that there were limited published studies targeted specifically towards Indigenous Australians' cardiac health improvement. However, positive outcomes were reported in terms of achieving clinical targets. Physical aspects such as blood pressure reduction, exercise attendance, and enhancing cardiac health knowledge in biomedical interventions for the Indigenous communities were the main focus.

The autoethnography revealed that with adequate preparation and involvement of Indigenous people the research process can be made easier. Again, because of past experiences which have led Indigenous people to be over researched with little feedback to them; researching this population group is challenging. Most researchers in the past have conducted research that has not effectively benefited the community. In some cases, research outcomes have misrepresented participants through use of methodologies that are not appropriate for Indigenous peoples. It is not unusual for Indigenous peoples to view the word "research" as a "dirty" word that brings uncomfortable feelings. In some instances, Indigenous participants have not seen its benefits of the research or understood the outcomes.

Conclusions

In summary, the program of research appraised current evidence. Further, it presented new knowledge that can inform and support practitioners in their quest to progress Indigenous peoples' healthiness and welfare. Highlighting issues from Indigenous peoples' perspectives can facilitate development of a better understanding of issues that impact their experiences with healthcare institutions. Such revelations can help in the identification of limitations faced by health professionals or constraints they encounter in the delivery of healthcare among Indigenous people. This could assist in revealing issues that are barriers to being effective in designing and implementing effective strategies to improve Indigenous health and wellbeing. Further research is warranted to follow up on the issues identified in this research.

Candidate's statement of sources

I declare that this thesis is my own work and contains no material published or extracted in whole or part from a thesis I have been qualified for or been awarded for another degree or diploma.

Information derived from published or unpublished work of others has been acknowledged in the main text of the thesis and reference list.

All research procedures reported in this thesis received approval of the relevant ethics committees.

Name: Vainess Banda Mbuzi

Student Number: S00139447

Signature:



Date: 17/01/2020

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Statements of Contributions to jointly published work

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Vainess Mbuzi

Overall contribution 75%

Study design; literature search and data extraction; analysis and interpretation of data; drafted and revised the article

Professor Paul Fulbrook

Overall contribution 15%

Study design; analysis and interpretation of data; critical revisions to draft versions for important intellectual content.

Dr. Melanie Jessup

Overall contribution 10%

Analysis and interpretation of data; critical revisions to the draft versions for important intellectual content

2. Statement of contribution for chapter four

Mbuzi, V., Fulbrook, P., & Jessup, M. (2017b). Indigenous cardiac patients' and relatives' experiences of hospitalisation: A narrative inquiry. *Journal of Clinical Nursing*, 17(23-24), 5052-5064.

Vainess Mbuzi

Overall contribution 80%

Study design; literature search and data extraction; analysis and interpretation of data; drafted and revised the article

Professor Paul Fulbrook

Overall contribution 10%

Study design; analysis and interpretation of data; critical revisions to draft versions for important intellectual content

Dr Melanie Jessup

Overall contribution 10%

Analysis and interpretation of data; critical revisions to the draft versions for important intellectual content

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Vainess Mbuzi

Overall contribution 75%

Literature search and data extraction; analysis and interpretation of data; drafted and revised the article analysis and interpretation of data

Professor Paul Fulbrook

Overall contribution 20%

Study design; analysis and interpretation of data; critical revision for important intellectual content

Dr Melanie Jessup

Overall contribution 5%

Critical revisions for important intellectual content

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Vainess Mbuzi

Overall contribution 80%

Literature search and data extraction; analysis and interpretation of data; drafted and revised the article analysis and interpretation of data

Professor Paul Fulbrook

Overall contribution 5%

Study design; analysis and interpretation of data; critical revision for important intellectual content

Dr Melanie Jessup

Overall contribution 10%

Study design; analysis and interpretation of data; critical revision for important intellectual content

Dr. Miles Sandra

Overall contribution 5%

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Peer reviewed publications in this thesis

Authors	Year	Title	Status	Journal
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Vainess Mbuzi, Paul Fulbrook, Melanie Jessup	2017	Indigenous cardiac patients' and relatives' experiences of hospitalisation: A narrative inquiry.	Published	Journal of Clinical Nursing. 2017. 26(23-24), 5052-5064. https://doi.org/10.1111/jocn.14005
Vainess Mbuzi, Paul Fulbrook, Melanie Jessup.	2018	Effectiveness of programs to promote cardiovascular health of Indigenous Australians: a systematic review	Published	International Journal for Equity in Health. 2018. 17, 153. https://doi.org/10.1186/s12939-018-0867-0
Vainess Mbuzi, Melanie Jessup Paul Fulbrook, Sandra Miles	2019	Researching with Indigenous people: an autoethnography	Under review	International Journal for Equity in Health

Conference and seminar presentations arising from this thesis

Authors	Year	Title	Type of presentation	Conference
Mbuzi V Fulbrook P, Jessup M	2012	Indigenous hospital experiences	Oral	Higher Degree Research Seminars Brisbane
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Mbuzi V Fulbrook, P Jessup M	2014	Indigenous hospital experiences	Oral	Higher Degree Research Seminars Brisbane
Mbuzi V, Martin J	2015	Indigenous patients in intensive care	Oral	Critical care in the vineyard Newcastle
Mbuzi V, Fulbrook P, Jessup M	2015	Indigenous patient in the intensive care unit	Oral	Indigenous Health Conference Cairns
Mbuzi V, Fulbrook P, Jessup M	2015	Indigenous patient experiences	Oral invited	Australian College of Critical Care Nurses seminar Brisbane
Mbuzi V, Fulbrook P, Jessup M	2015	Indigenous patient and family	Poster	The Prince Charles Hospital Foundation Brisbane
Mbuzi V, Fulbrook P, Jessup M	2016	Indigenous patient and family	Oral invited	World Federation of Critical Care Nurses International Congress Brisbane

Mbuzi V, Fulbrook P, Jessup M	2016	Researching Indigenous people: Researcher's experiences	Oral	Culturally and Linguistically Diverse workers conference Harvey Bay
Mbuzi V, Fulbrook P, Jessup M	2017	Indigenous cardiac patients	Oral	Australasian Cardiovascular Nursing College conference Brisbane
Mbuzi V, Fulbrook P, Jessup M	2017	Systematic review	Oral	The Prince Charles Hospital Research Forum
Mbuzi V, Fulbrook P, Jessup M	2018	Effectiveness of programs used to manage cardiovascular disease among Indigenous Australians: A systematic review	Oral	Australasian Cardiovascular Nursing College conference Sydney
Mbuzi V, Fulbrook P, Jessup M	2019	Effectiveness of programs used to manage cardiovascular disease among Indigenous Australians: A systematic review	Oral-Keynote speaker	Indigenous Health Conference

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Glossary of key terms and abbreviations

This section presents some key terms and abbreviations used in this thesis.

Aboriginal and Torres Strait Islander people are Indigenous peoples of Australia, descended from nations that existed in Australia main land and surrounding islands before British colonisation.

Aboriginal Health Workers are Indigenous Australians who are employed, in an Indigenous identified position and who is willing or has undertaken some form of training or education, for the purpose of providing flexible, holistic, and culturally sensitive health services to indigenous clients and the community to achieve better health outcomes and better access to health services for Indigenous peoples.

Acute care is the active short-term treatment or management for episodes of illness regarded critical, serious, severe or urgent requiring hospitalisation.

Autoethnography refers to a qualitative research method that uses a researcher's personal experience to describe and critique practices, beliefs, and experiences

Cardiovascular disease (CVD) refers to the medical condition affecting the heart's mechanical or electrical functions and its vasculature which may need medical, mechanical or surgical interventions.

Closing the Gap is a government strategy that aims to reduce health disadvantage among Indigenous Australians with respect to indicators such as life expectancy, child mortality, education and employment outcomes.

Credibility is a researcher's ability to demonstrate that the object of a study is accurately identified and described, based on the way in which the study was conducted

Culture refers to the idea, customs, beliefs, views and social behaviours of a particular people or society which encompasses a range of phenomena involving physical expressions, social organisation, spiritual beliefs and other intangible cultural heritage.

Interventions refers to action or process involvement used to intervene for the purpose of contributing positively towards improvement of a situation.

Metasynthesis is a qualitative research approach involving systematic processes to synthesise data across qualitative studies.

Narrative inquiry refers to the qualitative research approach and its processes that uses field text such as stories of experiences.

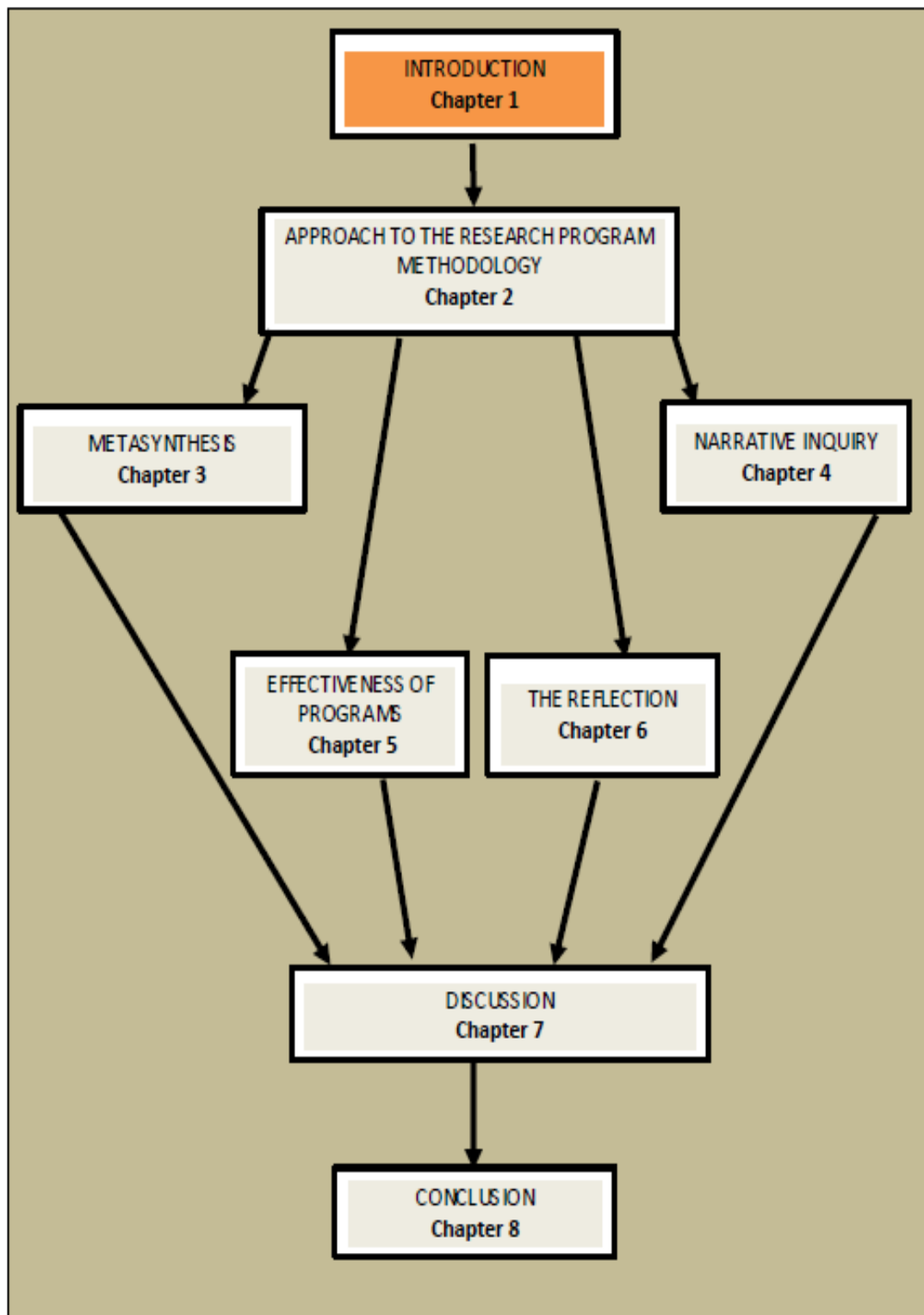
Purposive sampling is the selection of participants who have knowledge or experience of the area being investigated

Rigour is the degree to which research methods are scrupulously and meticulously carried out to recognize important influences occurring in an experiment.

Transferability is the ability to apply the results of research in one context to another similar context. Also, the extent to which a study invites readers to make connections between elements of the study and their own experiences.

Triangulation is the process by which the area under investigation is looked at from different perspectives. These can include two or more methods, sample groups or investigators. Used to ensure that the understanding of an area is as complete as possible or to confirm interpretation through the comparison of different data sources.

Chapter one: Introduction and background



Program of research structure.

Introduction

Thesis overview

This thesis presents a program of research designed to understand the significance and meaning of Indigenous peoples' experiences of health care. The purpose of the program of research was to explore Indigenous peoples' stories of their experiences with health care from both an international and Australian context. This document of eight chapters is presented as a *thesis with publication*. Chapters three, four, five, and six are presented in final manuscript form of published and pending articles. Chapters one, two, seven and eight are presented in traditional thesis format.

This research program involved four main studies. An initial metasynthesis investigated the worldwide status of Indigenous peoples' experiences of hospitalisation (chapter three). This was followed by a study exploring Indigenous participants' understanding of their hospitalisation experiences (chapter four), with a focus on cardiac health. A subsequent systematic review highlighted programs targeted to improve Indigenous cardiovascular health in Australia (chapter five). In recognition and acknowledgement of a story having multiple views, my own story of the experience I had in conducting the research program is presented as an autoethnography (chapter six). The project was designed to be understood in a holistic manner by considering historical, economic and socio-political contexts of experience of healthcare by Indigenous peoples. Storytelling was used as a theme, throughout the program of research. This ensured that stories from the of four perspectives participants informed the understanding of the Indigenous experience of healthcare in a holistic manner. The approach enabled revelation of issues surrounding Indigenous experiences of healthcare from different perspectives and contexts. The result was a comprehensive Indigenous experience story.

Thesis structure

Chapter one introduces the research program by placing it within the context of Indigenous health issues. It provides an overview of Indigenous health in general, focusing on cardiovascular health. The chapter starts by providing a background to the research problem, including my own story. This is followed by a presentation of the significance, aims and objectives of the study and the research questions that guided the investigation. The research conceptual framework that underpins the approach to this investigation is introduced. The chapter concludes with a synopsis of the key points contained in this current chapter (pages 23-51). Chapter two presents the methodology and research design of the four studies of the program of research. Focus was placed on the aspect of the methodologies that were not included in the chapters of the published papers (pages 52-83).

Chapter three presents the first of the linked studies that forms this program of research: a metasynthesis of qualitative studies on Indigenous people's experiences of hospitalisation. This chapter presents a detailed account of stories on Indigenous peoples' hospital experiences worldwide (pages 84-97). Chapter four presents a study undertaken to explore current hospitalisation experiences of Indigenous people related to acute cardiac care. This study used a qualitative narrative inquiry approach. It employed storytelling to investigate the experiences of Indigenous patients and their relatives with acute cardiac care (pages 98-113). Chapter five is a presentation of a systematic review conducted to evaluate the effectiveness of programs used for the management of cardiovascular health among Indigenous people in Australia (pages 104-133). Chapter six details the findings from the candidate's autoethnography. The chapter details some of the essential and critical events that were encountered by the candidate while conducting the research program (pages 134-157).

In chapter seven a discussion of the findings from the overall program of research is offered. The chapter positions the program of research within the wider healthcare and political context. Further, the chapter highlights the issues investigated in this research program regarding Indigenous healthcare experiences (pages 158-181). Chapter eight presents conclusions from the program of research. It sheds light on the significance of the program of research. A summary of insights into Indigenous healthcare and new knowledge gained in this program is presented. The chapter concludes by providing recommendations for health services practice and future research (pages 182-199).

Background

Personal context relevant to research purpose

I came from Zambia and commenced my nursing career in Australia in 1997. This was after completing a Master of Nursing program in primary health care. It was through this program of study that I was introduced to Indigenous health issues, primary health care principles, and the diversity of views of healthcare. Before then I had no idea of the difference in population groups in Australia and the profound impact this has on population health. I learned and discovered this through engaging with literature about the status of Indigenous health in Australia. My story and interest in Indigenous health started then.

As part of the Master of Nursing program I conducted a project investigating how primary healthcare principles were being implemented in Community Controlled Health Centres in Queensland. Primary healthcare core principles include the following: accessible healthcare, appropriate technology, health promotion, cultural sensitivity and cultural safety, intersectoral

collaboration, and community participation (Clendon & Munns, 2019). These principles guide healthcare providers to work towards equitable healthcare provision. They are interconnected in such a way as to enable provision of culturally appropriate health care to individuals (Clendon & Munns 2019).

After completion of my Master of Nursing program, I was employed at a cardiothoracic referral centre in Queensland. In my work there, I have witnessed how clinical expertise, pharmacology and technology have improved the health of many that I have cared for as an intensive care nurse. However, questions occurred to me as to why there was such a difference in health status between people of the same country: Indigenous and non-Indigenous Australians. With regards to hospital, one notable fact I discovered was that Indigenous people were described as having been alienated to hospital care. This was for various reasons such as experiences of discrimination and lack of relevant cultural approaches to health care. It felt like this status of events was accepted as normal although it continued to contribute to disparity in healthcare between Indigenous people and the rest of the Australian population.

My concern as a clinician about this ongoing disparity, which negatively affects the health of Indigenous people, ultimately led me to explore the issue further through a program of research. This thesis is the outcome of my inquisitiveness about Indigenous health issues. My longing to increase knowledge and understanding and provide information that can support transformation of health service delivery grew with time. My desire to provide information that can facilitate the work towards improvement of circumstances that Indigenous people experience on their hospital journey grew with time.

Most literature presents Indigenous health issues at a global or societal level. I think this can sometimes distance the impact such factors have on the individuals experiencing the issues. There is lack of evidence from Indigenous peoples' perspectives that explains the causes of their poor experiences with healthcare. Consequently the health disparity has mainly been examined from mainstream views. The questions I asked myself included: *What stories do Indigenous people hold about their experiences that influence formation of their perceptions about hospital, and healthcare in general? What actual issues from their perspective affect their healthcare experiences?* These questions needed to be answered by gathering information from the people affected. Statistics, by contrast, have limits on how much can be explained and, in most cases, cannot tell the individual experiences Indigenous peoples have with healthcare institutions, such as the hospital.

With current campaigns to practice patient-centred healthcare (Australian Commission on Safety and Quality in Healthcare, 2010; Delaney, 2018), it was important for me to elicit participant

perspectives in the ongoing search for a better healthcare experience for Indigenous Australians. I was looking for aspects of information that can have an impact on improved practices and health outcomes, especially within hospital settings. The starting point was, therefore, to ask Indigenous healthcare consumers or participants. It is from such a perspective that I hereby present the story of the experience of Indigenous peoples with healthcare in this thesis. I was able to look through different lenses that informed my understanding of the Indigenous experience, and my own story became intersected with theirs. I will continue to appreciate this story in my role as a health professional and in my personal life as a member of society.

Research context

Indigenous health

Aboriginal and Torres Strait Islander people of Australia are known as Indigenous Australians, a term that has found acceptance since the 1980s (New South Wales [NSW] Department of Health, 2004). The term “First peoples” is also currently increasingly being used to refer to Indigenous Australians (Australian Indigenous HealthInfoNet, 2018a). Indigenous Australians were the first people in Australia (Hampton & Toombs, 2013) and yet they account for only 3.3% of the Australian population (ABS, 2017a). Records indicate that depopulation of Indigenous Australians started with the arrival of Europeans who settled and brought with them diseases that were not familiar to Indigenous people, such as smallpox (Booth & Carroll, 2005; Burnette, Sanders, Butcher, & Salois, 2011; Durey & Thomson, 2012; Eckermann, Dowd, Chong, Nixon, Gray, & Johnson, 2010). In addition, massacres by, and wars with, the new settlers contributed to further decimation of Indigenous people (Eckermann et al., 2010; King, Smith, & Gracey, 2009). Although relatively small in percentage, Indigenous Australians bear extremely poor health outcomes that justify a greater focus by the nation (Booth & Carroll, 2005; Taylor & Guerin, 2010; Vos, Barker, Begg, Stanley, & Lopez, 2009).

Among the many causes of poor health outcomes for Indigenous peoples in Australia is the fact that the health of Indigenous Australians was neglected by colonial powers (Middleton, 1977). In fact, early colonialists wished for extermination of the Indigenous population (Harris, 2013). Until recent years in Australia, little attention was paid to Indigenous health by the colonising authorities, as well as by successive Australian governments of more recent eras (Middleton, 1977; Vos et al., 2009). The struggles for justice started way back in the 1930s (Reconciliation Australia, 2016). However, it was not until the 1960s and mainly in the 1970s that Australian authorities of the time became aware of or started to respond to Indigenous people’s deteriorating health status. Efforts

were started towards addressing this health problem (Gracey, 2007; Middleton, 1977), though mainly by use of paternalistic approaches.

The magnitude of disparities in health among Australians is reflected in figures reported by the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW). For example, the life expectancy for Indigenous males was reported as 17.7 years less than non-Indigenous Australian males and 19.4 years less for Indigenous females in the 2005 ABS report (ABS, 2005). According to the ABS, these figures are equivalent to those of non-Indigenous Australians almost 100 years ago (ABS, 2005). Although the life expectancy gap has improved in 2018 reports to 10.6 years and 9.5 years for men and women, respectively (ABS, 2017a; AIHW, 2018a), the gap is still unacceptable. The difference is still far too high, especially in comparison to other first-class countries such as New Zealand, which has an overall estimated difference of 7.3 years (AIHW, 2011a; 2011b; Phillips, Daniels, Woodward, Blakely, Taylor, & Morrell, 2017).

Morbidity and mortality are no strangers in Indigenous communities and cardiovascular disease is one of the major contributors to their burden of illness. The following section provides an overview of the impact of cardiovascular disease on Indigenous Australians.

Indigenous people and cardiovascular disease

Indigenous people are overrepresented in hospitalisation statistics, especially for acute coronary syndromes, in comparison with other Australians (AIHW, 2008; Brown, 2010). They suffer death and disability at a disproportionately higher rate than that of the rest of the population (ABS, 2006; ABS, 2017b; AIHW, 2017b). Chronic conditions have been identified as major contributors to the disparity that exists. The high incidence of chronic diseases, including cardiovascular disease (CVD), accounts for 75% of the life expectancy gap (Human Rights & Equal Opportunity Commission, 2008; Brown, 2010).

Globally, CVD as a single disease, has been identified as one of the main sources of disability and mortality, especially among Indigenous people (World Health Organisation [WHO], 2011). The disproportionately high level of CVD among Indigenous Australians is a matter of health concern. There is an urgent need to develop effective strategies for early diagnosis and reduction of barriers for Indigenous people to access healthcare (Walsh & Kangaharan, 2017). Strategies that will facilitate improved Indigenous cardiovascular health outcomes are required. CVD is recognised within the chronic disease spectrum as the most significant health issue contributing to Indigenous people's mortality, accounting for 35% of deaths annually (ABS, 2005; ABS, 2017b; AIHW, 2017).

Indigenous Australians suffer from CVD at the rate of more than three times higher than other Australians, being over three times more likely to be hospitalised for CVD related issues (AIHW, 2017; Brown, Morrisey & Sherwood, 2006; Reading, 2015). CVD is, therefore, one of the main contributors to disproportion in health status between Indigenous people and non-Indigenous people. Indigenous Australians die out of hospital, from cardiac conditions such as coronary heart disease, at a rate of 1.4 times more in comparison with other Australians. When admitted to hospital, they suffer more than double the in-hospital coronary heart disease death rate (AIHW, 2017; Randall, Jorm, Lujic, Eades, Churches, O’Loughlin, & Leyland, 2014). Table 1.1 presents statistics of deaths from CVD from 2011 to 2015, suffered by Indigenous Australians.

Table 1.1. CVD deaths by Indigenous status 2011-2015

Type of CVD	Indigenous		Non-Indigenous	Rate ratio
	% of total CVD deaths	Age standardised rate (per 100,000)	Age standardised rate (per 100,000)	
Ischaemic heart disease	55	138	79	1.8
Cerebrovascular disease	22	58	39	1.6
Acute myocardial infarction	17	58	43	1.3
Stroke	14	46	33	1.4
Other heart diseases	17	45	34	1.3
Rheumatic heart disease	3.4	6.4	1.4	4.7
Hypertension	4.6	15	8.1	1.8
Other circulatory disease	3.3	9.3	8.4	1.1
Total CVD	100	271	173	1.6

Source: Australian Institute of Health and Welfare (AIHW), 2017

One explanation for this higher death rate is that Indigenous people shun hospitals and will delay presenting to the point of death or being too seriously ill to be saved (Brown, 2010). Post-acute care participation rates in cardiac rehabilitation are also low. This contributes to poor quality of life from lack of improvement in function, and contributes to low survival rates following a cardiac event (DiGiacomo, Davidson, Taylor, Smith, Dimer, Ali et al. 2010). Most Indigenous people have continued to face significant barriers to accessing and using health services. Although they have a higher number of hospitalisations and longer hospital stays than other Australians, the quality of care provided to them is behind the rest of population (Artuso et al., 2013; Roberts & Power, 2010).

Indigenous health disparity

According to the WHO (2007), healthcare is a human right and every citizen of a country should be able to access appropriate healthcare. However, in reality, there are disparities experienced by population groups within and across countries, especially for Indigenous people (AIHW, 2016a; King, Smith, & Gracey, 2009; Vos et al., 2009). Disparities are seen more between Indigenous and non-Indigenous people in countries that have a history of colonisation, such as Australia, Canada, New Zealand and the United States of America (Australian Human Rights Commission, 2008; King, Smith, & Gracey, 2009). The disparity is a matter of public concern (AIHW, 2018a; Genger, 2018).

Various programs have been implemented to tackle this health gap. One of the developments was the establishment of community controlled medical services in 1971 to allow for culturally safe environments for Indigenous people (Aboriginal Health & Medical Research Council, 2015). The definition of cultural safety refers to a holistic view of health care encounters where there is provision of “an environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning together” (Williams, 1999, p.213). This concept calls for understanding of the cultural belief systems of individuals and then development of skills that enable health practitioners to deliver such care to a diversity of population groups (Duke, Connor & McEldowney, 2009), which include Indigenous peoples. This thesis represents an attempt to highlight and address cultural safety in an acute hospital environment.

The latest nationwide strategy is the current ongoing *Closing the Gap* campaign which was launched in 2008 (Australian Human Rights Commission, 2008; Commonwealth of Australia, 2017). This indicates that improving Indigenous health has become a key priority for the Australian government (Australian Human Rights Commission, 2008; Commonwealth of Australia, 2013; Commonwealth of Australia, 2017). The following section attempts to explain why such a strategy is needed when the Indigenous health disparity has been recognised for so long.

The main factors for this health disparity are rooted in the history of colonisation and its policies that discriminated against Indigenous Australians at many levels, including healthcare (Dell, Firestone, Smylie, & Vaillancourt, 2016; Durey & Thompson, 2012; Eckermann et al., 2010). Colonisation superimposed its foreign values, such as healthcare models, culture, values, language,

food types, political, economic and spiritual beliefs. These affected every aspect of the way of life for Indigenous people (Eckermann et al., 2010; Genger, 2018; MacDonald & Steenbeek, 2015; Smith, 2012;). These superimposed values have hardly changed in that most health issues are viewed from mainstream perspectives. The dominance of the biomedical approach to healthcare still remains (Durey & Thompson, 2012). In order to increase understanding and provide insights for improvement, this program of research explored health care experience from Indigenous people's perspectives.

Colonisation

It is undeniable that colonisation has had a devastating impact on Indigenous people worldwide. Resources, such as land and food sources, were taken away from Indigenous peoples. This left them desolate and dependent (Eckermann et al., 2010; Smith, 2012). Colonisation policies discriminated against Indigenous people who were refused free access to many community venues and services, including hospitals (MacDonald & Steenbeek, 2015). A single, uniform White Australian culture was sought by the 1960s Australian government. Through assimilation policies, further devastation befell Indigenous people by prohibiting them from practicing their beliefs, traditions and values, including use of their own languages (Arthur, 1961; Harris, 2013; Jones, 2009). As a result, colonisation and its policies controlled every aspect of their lives (MacDonald & Steenbeek, 2015; Whitney, 1997).

In many ways Indigenous people were asked to abandon who they were as a people in preference for foreign cultures and values; an expectation that has continued (Eckermann et al., 2010). In hospital settings, insistence on these foreign cultures is still dominant and demonstrated through policies, practices, procedures, and processes that are used in the delivery of care. Expectations and ways of communication, even language is different from the normal interactions used in Indigenous communities (Eckermann et al., 2010; Li, 2017; Vallengia & Snoodgrass, 2015).

It is not only the technical biomedical aspects of health that have affected Indigenous health in Australia. Lifestyle, work, and other social aspects of living have also had an impact on health. This is coupled with issues such as discrimination, racism, cultural disconnection, and a lack of economic power (Eckermann et al., 2010; Henry, Houston & Mooney, 2004; Paradies, Harris, & Anderson, 2008). Indigenous Australians continue to struggle with health issues, and mainstream Australian culture has a role in the deterioration of their health through neglect and sidelining of Indigenous views and voices (Eckermann et al., 2010; Middleton, 1977; Sherwood and Edwards, 2006). Strangers who came into

their lands systematically disempowered Aboriginal and Torres Strait Islanders and took control of their everyday lives (Eckermann et al., 2010; Genger, 2018; Gracey & King, 2009; Henry et al., 2004).

Australian political history involves a clash of cultures in which Indigenous ways of life were changed at many levels (Eckermann et al., 2010). The experiences encountered have left Indigenous people traumatised with little trust in government institutions, even in settings such as hospitals. The past colonial experiences effectively oppressed their way of life and disregarded what they valued (Eckermann et al., 2010; Genger, 2018). The remnants of that paternalism, racism and disregard for Indigenous values have remained. These are displayed in subtle ways, such as the way the dominant culture still pervades policy and practice and is seen as the norm in mainstream health, such as use of English language, and a lack of outdoor environments and food types that meet Indigenous people's cultural needs (Durey & Thompson, 2012; Eckermann et al., 2010; Li, 2017; Sherwood & Edwards, 2006).

Acute hospital care

Hospitals are essential in the Australian health system because they are the major health service providers for the majority of the population. According to the 2018 *Australia's Health* report, Australians access hospital for births (97% births in 2015) through to management of chronic conditions (37% of hospitalisations), with a daily average of about almost 300,000 presentations (AIHW, 2018b). Hospitals are, therefore, essential because they provide a concentration of specialty health services for acutely ill patients (Hirshon, Risko, Calvello, Ramirez, Narayan, Theodosis & O'Neill, 2013). However, Indigenous Australians are more likely to report difficulty in accessing affordable health services that are nearby than non-Indigenous Australians (AIHW, 2018a). With regards to Indigenous people's hospitalisation rates, the report indicates a rate of 1:3 when compared to non-Indigenous people. This is with the exclusion of admission related to dialysis treatments (AIHW, 2018a; 2018b).

The people who use health services expect provision of effective and safe health services, especially those admitted to hospital. Provision of timely and appropriate preventive health services may reduce potentially preventable admissions (Li, Gray, Guthridge, Pircher, Wang, & Zhao, 2009; Li, 2017). With reference to renal disease, for example, early detection is vital to prevent late diagnosis, slow disease progression, and holds the potential to avoid dialysis altogether (Rix et al., 2015). For Indigenous people, healthcare service environments have not been culturally safe for them, so they will sometimes delay presenting until it is too late (Li, 2017).

Late presentation among the Indigenous population may have contributed to higher admissions at a rate of up to 3 times higher than the non-Indigenous population for potentially preventable hospitalisations (AIHW, 2018b). In 2017-2018 about 6.7% of emergency department presentations were for Indigenous Australians (AIWH, 2018b). For many Indigenous people, going to hospital is a stressful situation due to the added aspect of the historical experience of abuse (Dell et al., 2016).

Indeed, Indigenous people have had such poor experiences of hospitalisation that a significant proportion of them leave hospital against medical advice (Utz & Sheahan, 2014). Some will present to hospital in late stages of illness because of fear of coming into hospital (Shahid et al, 2009). Others leave hospital with unmet health needs and dissatisfaction with the care they received (Katzenellenbogen et al., 2013). The rate of self-discharge ranges from 2.4 to 4.5 times higher (Katzenellenbogen et al., 2013; State of Queensland, 2018) among Indigenous people in comparison to non-Indigenous counterparts.

There is more to be done to improve hospital journeys for Indigenous Australians. Cultural safety of Indigenous people within hospital settings is a challenge because of limited understanding of Indigenous beliefs and a history that has left the power differential between the patient and healthcare provider (Dell et al., 2016). The striking social, economic, and cultural trauma experienced throughout a collective history (Eckermann et al., 2010) still has an impact on them in contemporary times. Providing opportunities for Indigenous people to tell their stories may assist in gaining information that can assist in implementing changes in practice for better experiences for Indigenous people.

Unique healthcare challenges

Hospital journeys

A journey to the hospital has remained an uncomfortable experience for Indigenous people of Australia (Artuso, Cargo, Brown, Daniel, 2013; Brown, 2010). Government institutions, including hospitals, have been agents of discrimination and a source of pain and disadvantage for Indigenous people in many ways, including taking children away from their mothers and experiencing painful procedures and deaths (Eckermann et al., 2010; Henry et al., 2004). Institutional racism exists through lack of integration of Indigenous values in healthcare. In hospitals, institutional racism represents one of the greatest barriers to better healthcare for Indigenous people (Henry et al., 2004). Hospitals have an oppressive nature towards Indigenous beliefs and culture in their practices. Racism in health

institutions is demonstrated in many ways, including the building of a health system around values and beliefs that discriminate against the minority, such as lack of recognition of language barriers (Henry et al., 2004; Li, 2017).

Although hospitals are important health institutions, the domination and continued exclusive use of a biomedical model to deliver healthcare has limited the ability to consider other aspects of health, such as psychosocial factors. Deacon (2013) indicates that even though psychosocial factors are acknowledged by medical professionals, with the biomedical model as the centre of practice, there seems to be little consideration made for these aspects of health (Reading, 2016). The emphasis is on physical treatment, especially given that patients largely present to hospital with physical disorders. Despite the fact that spiritual care has been recognised as a significant aspect of health care provision (Holmes, 2018), there are limited interventions to that effect.

For Indigenous people, healthcare requires a holistic approach, in which the body, mind, spirit, land, environment, customs, and socioeconomic status are incorporated into care (Australian Nursing Federation, 2009; Booth & Carroll, 2005). Concentration on the dominant paternalistic approach to health makes services culturally inappropriate. In the Indigenous context, health cannot be determined by physical abnormalities alone, and, as a result of the shortcomings of the biomedical approaches, they struggle with negotiating their way through hospital culture and its expectation, procedures and therapeutic relationships that occurs in hospital settings (Li, 2017). It has been previously suggested that factors such as social determinants of illness and empowerment of families and individuals should be strengthened within the healthcare system (Dwyer et al., 2004; Markiewicz, 2012; Marmot, 2011). For Indigenous peoples, patient-centred care means considering their beliefs and values (Araki, 2019; Delaney, 2018; Queensland Health, 2014). Provision of health care therefore must evolve from a paternalistic approach to a patient-centred care approach (Green, Anderson, Griffiths, Garvey & Cunningham, 2018), and the development of partnerships between healthcare and health consumers (Araki, 2019; Delaney, 2018). Likewise, there is a need to shift from total dependence on the dominant western approach, with its linear spectrum of illness and disease, to give voice to Indigenous people and their views (Sherwood & Edwards, 2006) and exercising flexibility to accommodate patients' beliefs and values that promote their health (Delaney, 2018).

Clinical settings, such as intensive care environments, face unique challenges. Healthcare providers attempt to deliver care that is acceptable and appropriate to various populations and individuals. This is done while competing with a fast-paced curative approach to care in order to achieve survival of the patient (Kelleher, 2006). Expectations can be overwhelming. Constraints in terms of knowledge, resources, workload, stress, and time continually impede advancement to

practice patient-centred care in an environment that is based on biomedical approaches (Davidson, Powers, Hedayat, Tieszen, Kon, Sheppard, Spuhler et al., 2007; DeWalt, Callahan, Hawk, Broucksou, & Hink, 2010; Jakimowicz et al., 2017; Tuckett, Winters-Chang, Bogossian, & Wood, 2015).

There are many competing priorities in the clinical setting that make it impossible at times to work outside the box of biomedical processes to incorporate various cultural aspects while remaining consistent with professional demands (DeWalt et al., 2010; Jakimowicz et al., 2017; Kelleher, 2006; Tuckett et al., 2015). With standardised care being promoted in hospital settings, it is harder to provide care that is individualised, especially for marginalised populations. The pressure of everyday practices that are tailored toward demonstrable outcomes and efficacy means that attempts to comply with difference may remain elusive (DeWalt et al., 2010; Jakimowicz et al., 2017; Kelleher, 2006; Tuckett et al., 2015). Despite patient-centred care being advocated to address the issue (Sharp, Mcallister & Broadbent, 2018), implementation of such an approach is challenging. Understanding from an Indigenous people's perspective can illuminate what is priority from their perspectives. This can then facilitate the design, development, and implementation of more effective models of care. Most importantly, achievement of the promotion of individualised treatment for patients and their families that is reflective of Indigenous values.

Differences in worldviews and its impacts on health

As reflected in the long-standing definition presented by the WHO (1946), "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (p. 2). However, health is defined differently by different population groups based on a diversity of backgrounds such as cultures, religions, traditions, languages and histories worldwide (Helman, 2007). Each community, therefore, emphasises certain aspects of well-being to explain their health status. The different views are further influenced by education, experiences and other ethnic customs a person or community is exposed to (DeWalt et al., 2010; Marmot, 2011).

In Australia, therefore, another issue that may be ignored is the fact that Indigenous Australians do not belong to two groups of people. Aboriginal Australians and Torres Strait Islanders are further divided into countries, communities and language groups with diverse cultures (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2019). It is, therefore, not appropriate to assume that they are all one group with same cultural beliefs and values. These differences need to be understood and taken into consideration when caring for Indigenous people.

A biomedical view dominates western medicine while other cultures may value psychosocial well-being (Sharp et al., 2018; Li, 2017). This diversity is not acknowledged by mainstream health services when Indigenous people present to access healthcare, in terms that are satisfactory to them (Li, 2017; Markiewicz, 2012). As far as Indigenous Australians are concerned, good health is more than the absence of physical ailment or illness, therefore, it is a perception that embraces physical, communal, emotional, cultural, spiritual and environmental wellbeing, mutually for the individual and the public (National Aboriginal Health Strategy Working Party, 1989). This Indigenous view of the concept of health emphasises the connectedness that exists between individuals, community, and the universe, and goes beyond viewing body, mind, and society as separate entities. This view recognises the impact that each aspect of life, be it social, psychological or cultural, has as a determinant of health (Marmot, 2011; WHO, 2007).

Despite studies focusing on population health, mainstream health services have paid little attention to the different perceptions of health by promoting standardised care models, which has contributed to the marginalisation of Indigenous groups worldwide (DeWalt et al., 2010; McBain-Rigg & Veitch, 2011). By involving individual experiences, this program of research can highlight individualised concerns and reveal issues that cannot be counted or observed but only felt and perceived at individual level. Healthcare is, after all, provided at the individual level and its quality should also be evaluated at individual level by those who receive the care.

Indigenous views of health

There are limited data that explore Indigenous views of the healthcare they receive. Most studies focus on providers' views. Those that do address the Indigenous population are mainly observational and epidemiological in nature, which may deny the real Indigenous voice. Spiritual and emotional wellbeing are described as being at the heart of Indigenous cultures (Dudgeon, Milroy & Walker, 2014; McMahon et al., 2010).

Discovering the manner in which Indigenous people, present and relate with the healthcare systems on the whole can facilitate understanding of their views on healthcare. It has been suggested that Indigenous people exhibit a significant mistrust and decreased satisfaction for health systems in comparison to the mainstream population (Gerlach, Browne & Greenwood, 2017; Health Council of Canada, 2011). The possible reasons for this are due to different worldviews on the issues pertaining to health and health care (Carjuzaa & Ruff, 2010).

Most healthcare providers are non-Indigenous. This causes an experience that induces anxiety, fear and loneliness for Indigenous patients (Watson, 2002). There are limited studies that

specifically address Indigenous people's perspectives that can provide understanding and insights on how to improve care for Indigenous people. These are essential for transactional and relational facets of health services that hold values for the patient and their families.

Cultural influences on health (family, community, relationships, country-identity, and values)

Ethnic identity offers group membership with a sense of belonging as a result of individuals having a common ancestry, history, traditions, language, beliefs, and values (Cokley, 2007). Existing studies reveal that ethnic identity is a construct that is linked to strength within a people of the same ethnic background (Smith & Silva, 2011). In this study's conceptualisation, ethnic identity comprises primarily a sense of attachment or belonging to one's ethnic group, and identifying and engaging with its practices (Cokley, 2007).

In this program of research, culture is viewed as a shared system of values in not only behaviours and mindset learned and embodied through shared experiences, lives, and stories, but inclusive of political, economic, legal, ethical and moral practices (Napier et al., 2014). There is full recognition for much needed culturally appropriate healthcare because cultural differences impact greatly on health care. To continue neglecting Indigenous views or imposing foreign views on Indigenous people will only increase their disadvantage and continue to hurt this population group (Dudgeon et al, 2014). The differences cause a significant divide between individuals and the healthcare system. This is more so when patients are admitted to hospital where they encounter a different culture with which they are not familiar.

The disconnect between Indigenous and non-Indigenous healthcare is mainly as a result of a lack of significant involvement and governance by Indigenous people themselves through systematic exclusion by mainstream systems (Farmer, Kim, Kleinman & Basilico, 2013). As cultural barriers impact the care Indigenous people receive (Li, 2017), health providers are being encouraged to practice patient centred care which empowers the person/patient and their family. It recognises their cultural identity and their input (Browne et al., 2016; Green, et al., 2018).

Further, respect for a patient's background by considering integration of their culture may contribute to better care experiences (Freeman et al, 2014) for Indigenous peoples. Although there is emphasis on respect, this must be understood within cultures, and ultimately between individuals. Acts of respect are mostly recognised by individuals when enacted in clinical interactions. This can, be during hands on delivery of care or conduct of research. It has to do with how the concept is defined by the individual receiving it (Flickinger et al., 2016; Paternotte, Dulmen, Lee, Scherpbier & Scheele, 2015).

In addition, respect can be endorsed by intentionally recruiting Indigenous healthcare professionals through a systems level policy and practice. Such an approach is demonstrated in projects by Daws and colleagues (2014) and Taylor and colleagues (2009) in which Indigenous health workers were included as part of the treating team. Currently, Indigenous artworks displayed around hospital walls also communicates a commitment of respect that ensures representation. However, these symbols are not enough to communicate respect when other cultural views are ignored either at the bedside or organisational level through practice of appropriate cultural procedures.

Socioeconomics and Indigenous health

The relationship between social factors and health is well recognised (Anderson et al., 2016; Booth & Carroll, 2008). Respectful health is associated with a multifaceted set of fundamental influences that comprise behaviours, access to, and utilisation of available health services and health inheritance (AIHW, 2016a; Booth & Carroll, 2008). Although health disproportions faced in healthcare are the consequence of influences and processes that fall external to the straight forward domains of health (Shepherd, Li, & Zubrick, 2012), it is vital for health services to be designed in such a way that they reflect the community needs and that they respond appropriately through modification of standard approaches.

According to AIHW (2016a), “human health is sensitive to social environment” and elements such as income, education, conditions of employment, power and social support act to strengthen or undermine the health of individuals and communities’ (p. 1). For Indigenous Australians, social determinants that impact health include factors such as cultural distinctiveness, family, and access to land (AIHW, 2018a; McMahon et al., 2010). These social elements reflect and are determined by broader societal and political situations (AIHW, 2018a; McMahon et al., 2010).

Factors such as social exclusion and financial inadequacy due to unemployment, low education, and inadequate salary can lead to inadequate resources to meet daily needs such as nutrition, (McMahon et al., 2010). These have an impact on Indigenous health due to lack of choice (AIHW, 2016a; 2016b). It is well known that due to the past government policies, Indigenous people were disempowered and remained with limited authority to influence these factors that impact on their lives and wellbeing (Eckermann et al., 2010).

Apart from experiencing a disproportionate burden of illness, Indigenous people are also socioeconomically underprivileged and marginalised (Gorman, 2017; Hajizadeh, Hu, Bombay & Asada, 2018). Colonisation is implicated in many of these problems including the socioeconomic consequences faced by Indigenous people (Hajizadeh et al., 2018). Examples of the disparities in this

instance are revealed in the gaps in income, educational attainment, employment, and levels of participation in policy making (Gorman, 2017; Shepherd, Li, & Zubrick, 2012).

Healthcare is a social event because different parties interact in order to address health issues (Kappas, Gross, & Kelleher, 2012). At the clinical interface, for example, individual sensitivities of prejudice are usually linked to poorer results for preventative health behaviours (Helman, 2007). In Australia, there has been a growing recognition that health disparities experienced by Indigenous people are largely as a result of socioeconomic and political dispositions (Booth & Carroll, 2008).

The socioeconomic disparity in Australia is evidenced by education and income statistics (AIHW, 2016a; 2016b). The monitoring of socioeconomic differences in health plays a significant role in assessment of development in the direction towards achievement of obligations by government (Booth & Carroll, 2008). On the other hand, it highlights issues faced by the population in terms of hardships resulting in poor lifestyles, particularly to explain health disparities (Booth & Carroll, 2008). Identifying factors that account for socioeconomic inequalities in health can enable implementation of effective interventions and policies to address health issues associated with it (Valeggia & Snodgrass, 2015). The significance of addressing these differences can progress not only quality of life and reduction of the burden of illness but promote economic and justice-based care for Indigenous Australians (Anderson, Robson, Connolly et al., 2016; Kirmayer, 2016).

Socioeconomic status disparities produce disease because of their effect on self-esteem and effects of discrimination which negatively impact on health (Anderson et al., 2016; McMahon et al., 2010). The effects of discrimination on health are underrated because of a failure to precisely quantify collective effects of trauma based on acute and/or chronic discrimination. It is impossible to assess or quantify the impact of blocked opportunities as a result of racism and other discriminatory acts such as stereotyping and prejudice (Helman, 2007; Wylie, & McConkey, 2017). The multidimensional state of discrimination creates a barrier to correctly measuring this concept (Hausmann, Jeong, Bost & Ibram, 2008; Shavers et al., 2012).

Further research is suggested into these elusive factors that have a stronghold on Indigenous peoples' health outcomes. Patient satisfaction has been related directly to interpersonal interactions. This includes the honesty and respect displayed by health providers, how much patients and family are involved in treatment plans, and how they are provided with suitable information (Calabro, Raval, & Rothstein, 2018; Chen, Zou & Shuster, 2017). Although at a clinical level economic issues may not be the priority for the healthcare professional, these may be the key issue that may impact individual patients or their relatives in managing their health (AIHW, 2016a; 2016b).

Power differences

Power can be defined as something that enables a person or a group to achieve goals; giving individuals or groups the potential for changing attitudes and the behaviours of others (Luthans, Luthans, & Luthans, 2015). Power is always present in all person to person interactions (O’Leary, 2013). Power is therefore, present in all interactions without exceptions within healthcare (Luthans, Luthans, & Luthans, 2015; Sepasi, Abbaszadeh, Borhani, Rafiei, 2016). Although this is the level that most individuals accessing healthcare experience power differences, organisational power relations matter and have major influences on how healthcare processes and procedures are carried out (Eckermann, et al., 2010; Wright, Lin, & O’Connell, 2016).

Healthcare institutions should make Indigenous health issues a priority in order to improve their health outcomes. Power is a complex and extensive concept in healthcare settings and can have positive or negative effects depending on how it is exercised. This can be at both individual and institutional levels (Nimmon & Stenfors-Hayes, 2016; Sepasi et al., 2016). Organisations and government agencies, such as those that deliver health services, educational providers, or policy makers must, therefore, work in partnership with Indigenous people. This can progress strategies that inform and empower staff to practice culturally safe healthcare and make Indigenous people feel welcome (Hunter, et al., 2013). Institutions must work towards strengthening the contribution of Indigenous leaders in the development of policy and practice affecting Indigenous people. The recognition and acceptance of Indigenous peoples’ cultures and perspectives of health and wellbeing must remain high on the agenda of healthcare reform (Dudgeon et al. 2014) at all health system levels.

Indigenous people have been marginalised in many ways and have been left in a powerless position (Alfred, 2009; Eckermann et al., 2010) causing power differentials at every level. This has an impact on their independence and autonomy that affects their wellbeing (Sepasi et al., 2016). In healthcare delivery it was acceptable to segregate Indigenous people and practice paternalistic ideologies which widened the power differences. Health professionals, such as nurses, accepted the practice (Forsyth, 2007; Hayman, White & Spurling, 2009) and incorporated the policies into their practices.

Paternalism was the underlying philosophy of protection policies, reinforced by prevailing attitudes that Indigenous peoples were childlike, and dependent. Although colonialism’s obvious marginalisation and domination is seen as a thing of the past (Forsyth, 2007), remnants of it continue to yield silent messages that perhaps are as destructive as unconcealed subjugation (Alfred, 2009; Eckermann et al., 2010; Forsyth, 2007). It is not uncommon to experience communication which

privileges health professionals and not patients (Eliassen, 2015; Koeck, 2014). In most cases the information provided by patients gets disregarded, undervalued, and is not effectively utilised in the pursuit for management directions suitable to that patient (Koeck, 2014). This state of affairs is worse among Indigenous patients because of widespread stereotyping against them (Wylie, & McConkey, 2017).

Indigenous clients value storytelling and yarning to influence fostering of relationships that are based on faith, to reinforce engagement, and facilitate yielding of helpful conclusions in their experiences with healthcare (Jennings, Bond & Hill, 2018). Yarning can be formal or informal conversation that occurs between people with a purpose of conveying or receiving information (Bessarab & Ng'andu, 2010; Geia, et al., 2013). Yarning is a special way of communication and is used "in the telling and sharing of stories and information" and "can entail the sharing and exchange of information between two or more people socially or more formally" (Bessarab & Ng'andu, 2010, p. 38). Yarning is a two-way communication between speakers and provides a dialogical process that is reciprocal and mutual. Storytelling on the other hand has a storyteller and a listener to that story. In this situation the storyteller has the information which is transferred to the listener for purposes of teaching, informing, sharing knowledge, expressing and validating experiences (Iseke, 2013). Yarning and storytelling are used interchangeably although differences between the two terms can be drawn (Geia, Hayes & Usher, 2013).

An interaction between health service providers and Indigenous patients can strengthen helplessness, through condemnatory down-talk, use of medical jargon, or concealment of information. It can also empower patients, through good talk, delivered at the patient's level of understanding (Alfred, 2009; Jennings, Bond & Hill, 2018; Wilson, Kelly, Magarey, Jones & Mackean, 2016). Effective communication is, therefore, an essential element to improving Indigenous engagement with healthcare services (Browne et al., 2012). Effective communication has the ability to minimise the power gaps between Indigenous clients and the healthcare system (Jennings et al., 2018).

Hospital settings are the best places where close encounters are experienced by patients and their healthcare professionals. Communication, verbal or non-verbal, can build or break the therapeutic relationship between healthcare and Indigenous people seeking healthcare (Browne et al., 2012). The problems and barriers as a result of cultural differences within healthcare are described repetitively across clinical settings. This is more so when dealing with Indigenous people due the history with government institutions, as well as difference in health views (Eckermann et al., 2010). Clinicians exert their influence through their positions, use of jargon words, corporal position,

knowledge, and familiarity with hospital processes. These issues are often above most patients' positions in this context (Browne et al., 2012; Koeck, 2014). Power differentials matter in delivery of healthcare to Indigenous people and need to be considered.

Both clinical and institutional leadership is key to identification of areas of care that are exemplary or requiring additional resources. Such changes are more likely to be effective when clinical leaders and senior members of the healthcare teams promote and foster these changes (Hoffmann, Bennett, & Del Mar, 2017). Clear, unambiguous and explicit role modelling and direction from these leaders may encourage and promote changes to practice. An implementation of teams of role models and mentors throughout the health system is vital for sustainability of impact of changes in the organisation (Melnyk & Fine-Overholt, 2019). Change that is aimed towards improved healthcare provision to Indigenous peoples is essential. Outcome measures of quality and best practice in providing culturally safe healthcare need to be developed. These can include implementation of continuous quality improvement; creating culturally welcoming environments for Indigenous people and their families. Implementation of compulsory cultural competency for all health professionals and staff could be a start (Ewen, Paul, & Bloom, 2012; Gwynne & Lincoln, 2017).

Researching with Indigenous people

Researching with Indigenous people has been a challenge due to past research activities that were not sensitive to Indigenous people's ways (Fredericks, 2008; Smith, 2012). Earlier research studies among Indigenous people have been described as being full of abuse, and that they focused on researching the participants rather than with the participants. These activities disregarded their views as a community (Fredericks, 2008; Rigney, 1999; Wilson & Neville, 2009). Thus, some research outcomes were not of any benefit to the participants or their communities.

Indigenous Australians have been widely researched by non-Indigenous researchers (Bond, Foley, & Askew, 2016; Fredericks, 2008). On many occasions research has resulted in the misuse of Indigenous knowledge and the use of culturally insensitive and inappropriate research methods (Fredericks, 2008). Incorporating the voices of Indigenous people is an important link in promoting culturally appropriate and safe healthcare, including research and policies. Their stories and voices need to be heard.

Current strategies

From a social and political perspective, it has been recognised that for significant improvement in the health disparities between Indigenous and non-Indigenous Australians to occur, a process of reconciliation needs to be adopted (Davis, 2014; Jackson & Ward, 1999). The Australian government has continued with efforts to find a common ground for its people in terms of uniting the two cultures for the benefit of all (Reconciliation Australia, 2016). Colonialism stripped Indigenous Australians of everything by devaluing their identity and what they stand for as a people (Eckermann et al., 2010; Smith, 2012). Their health was neglected until the late 1970s (Middleton, 1977), but the journey for justice and equitable health service provision for Indigenous people continues (Reconciliation Australia, 2016).

Some interesting landmarks of this journey for justice have been noted; starting from the 1932 petition calling for the preservation of the Indigenous race from extinction to current campaigns towards constitutional recognition of Indigenous Australia (Reconciliation Australia, 2016). The Closing the Gap campaign launched in 2008 (Australian Human Rights Commission, 2008; Commonwealth of Australia, 2017) makes a strategy that is inclusive of many aspects that impact health. Appendix 1 has some details of events that have taken place so far.

An apology was delivered to the Stolen Generation and their families, in 2008 which indicated the fact that the government acknowledged and owned past injustices and recognised them as bad policies that had negative outcomes for Indigenous people (Australian Human Rights Commission, 2008; Commonwealth of Australia, 2017). The sorry speech by the then Prime Minister of Australia, Kevin Rudd, formally acknowledged the hurt Indigenous Australian experiences as a result of past government policies especially the assimilation policy and forced child removal from their homes (Reconciliation Australia, 2016). A national Sorry Day is an annual event that commemorates the history of forced removal and its continued effects (Reconciliation Australia, 2016).

Acknowledgement of Indigenous people as equal citizens with a right to vote and be included in decision making marked acceptance of Indigenous people's identities and in a way respect for them as a people (Reconciliation Australia, 2016). Reconciliation Australia has led in advancing issues for development of unity between Indigenous and non-Indigenous people at many levels including campaigns such as "Recognise". Reconciliation affects health service delivery in terms of its importance towards overcoming barriers to healthcare experienced by Indigenous people, such as racism (Reconciliation Australia, 2016; Reconciliation Australia, 2018). Reconciliation as a process acknowledges the past in the light of the present and needs to be adopted across all sectors of society,

including the healthcare sector (Jackson & Ward, 1999). A lot of activities and campaigns continue but in most cases healthcare services appear to fall short of interventions to reflect incorporation of Indigenous culture into practice.

As a result of such efforts, the Australian healthcare has continued to show interest in demonstrating health equity for Indigenous peoples. Recent work continues on activities or programs that address equity in Indigenous health including introduction of compulsory competence training/education for all staff (Ewen, Paul, & Bloom, 2012; Gwynne & Lincoln, 2017), development of guidelines such as the National Safety and Quality Health Service Standards Users Guide for Aboriginal and Torres Strait Islander Health (ACQS) and growth in research interest addressing Indigenous peoples' experiences of healthcare services (Anderson, Cunningham, Devitt, Preece, & Cass, 2012; Artuso, Cargo, Brown, & Daniel, 2013; Green, et al., 2018, McGrath, 2006; McGrath & Rawson, 2013; Worrell-Carter et al., 2016).

The Community Controlled Medical services initiatives have remained strong since initiation in the 1970s (Aboriginal Health & Medical Research Council, 2015). The only limitation is that cultural concepts that have made these institutions popular have not been integrated effectively within mainstream health services. In addition, the services are only at the primary health care level with none that are community controlled at the tertiary level of care.

Other reported programs demonstrate commitment by communities to improve Indigenous health (Australians for Native Title & Reconciliation, 2007; Tibby et al., 2010). The only limitations are that such programs lack evaluation to demonstrate effectiveness. Some lack processes and means to publish the success stories witnessed by local programs as they work to improve Indigenous peoples' experiences within healthcare.

Conceptual framework

The conceptualisation of Indigenous health as holistic has been the underpinning principle in the design of this program of research. According to Indigenous health views, every aspect of life is interconnected with no demarcations (body, spirit, emotional, social, cultural, personal and community aspects of an individual work together), because health is traditionally a holistic concept (Dudgeon, Milroy & Walker, 2014; McMahon et al., 2010; Queensland Health, 2014). Smith (2012) states that Indigenous people have stories that represent another perspective to that of mainstream health perspectives.

A conceptual framework assisted in the identification of the research focus and the lens through which the problem at hand is being explored (Creswell & Poth, 2018). It is a representation

of the researcher's synthesis of literature on how to explain the issues under investigation (Regoniel, 2015). It maps out the actions required in the course of the study. This was in view of previous knowledge of other researchers' points of view and observations on the subject of research. As stated by Maxwell (2005), a conceptual framework is not found but constructed.

Through use of a storytelling method, participants have an opportunity to tell their story in ways that privilege their worldviews (Smith, 2012). This program of research recognises that Indigenous culture is dynamic and considers culture as a set of both objective and personal values, resulting in continuity of human diversity in society (Napier et al., 2014). Storytelling enables renewal of cultural concepts and redefinition of viewpoints to enable adaptation to the present.

The overarching direction and focus of this study is value based and considers the values that Indigenous people place on health experiences. The perspective through which this investigation was viewed is based on constructing an understanding of Indigenous people's assumptions and beliefs. It was important for the program of research to incorporate the values and ethics regarding researching with Indigenous people which include: "reciprocity, respect, equality, responsibility, survival and protection", and "spirit and integrity" (Australian Institute of Aboriginal and Torres Strait Islanders Studies [AIATSIS], 2012; National Health and Medical Research Council [NHMRC], 2018a; NHMRC, 2003). These values are the result of progress that has been made to protect Indigenous people and their interests and needs during the planning and conduct of research through to research outputs. The imperative to protect Indigenous people and their culture, interests and needs throughout the research process underpinned this program of research through creation of a culturally safe environment. Use of storytelling provided that safe environment and empowerment for participants.

There must be a genuine commitment by healthcare providers to not compromise the cultural rights, values, expectations, and practices of Indigenous people. They need to construct and provide culturally appropriate health services that are acceptable to them. The core values, although addressing research practice, are transferable to any health care situation, whether clinical or policy making. These values point to the fact that healthcare should focus not only on procedural rules but on values and relationships (Laycock, Walker, Harrison, & Brands, 2011).

The core values are central to the conceptual framework because as individuals encounter experiences, they share them through storytelling, and these become a collective story from which to engage others to understand Indigenous distinctive cultural identity (Fig. 1.1). Individuals share what they experience in reference to their beliefs and values. In using storytelling the storyteller reflects these values and drives the narrative in their own voices, creating knowledge and about Indigenous

peoples' views (Geia, et al., 2013). The following section explain the values and represents how storytelling and the standards work together in the conceptualising of this program of research.

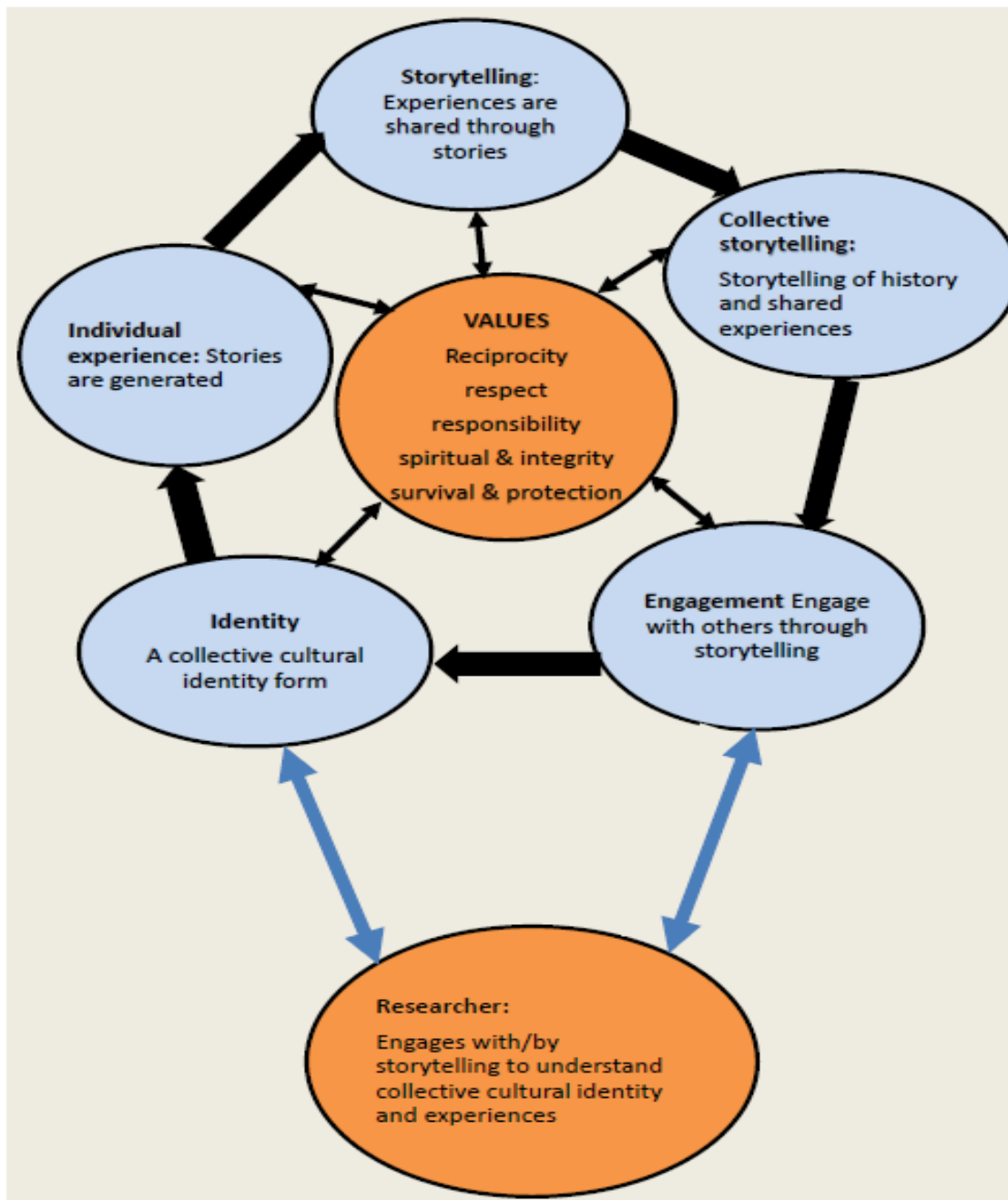


Figure 1.1. Conceptual Framework: Storytelling.

Spirituality and integrity

For Indigenous people there is always a link between ancient, contemporary and upcoming ways of living and beliefs within Indigenous beliefs (Poroch, Arabena, Tongs, Larkin, Fisher & Henderson, 2009). Every aspect is connected, living or non-living, and all have an impact on health.

Aspects such as smoking ceremonies, welcome to country ceremonies and paintings are all an expression of spirituality (AIATSIS, 2012; Laycock et al., 2011; NHMRC, 2018; Porocho et al., 2009). It is a respectful and honourable behaviour to hold together the values and cultures that make up their communities and lives. This means that healthcare providers are required to recognise and respect this belief and practice. Decisions made in the process of receiving treatment must be consistent with values held by individuals and their communities (Laycock et al., 2011). Progressions must respect the fullness and honour of the cultural inheritance of past, present and upcoming generations and of the associations that bind the generations together (Laycock et al., 2011). Spirituality and integrity of Indigenous people must, therefore, be considered along with physical treatment (AIATSIS, 2012; Laycock et al., 2011; NHMRC, 2018).

Reciprocity

For Indigenous people, reciprocity is significant because it influences relationships with other people (Porocho et al., 2009). Reciprocity involve sharing benefits to keep relationships strong. There is a mutual obligation in maintaining health for Indigenous peoples which calls for inclusion. Engagements must be equitable and respectful. Focus should be placed on advancing the interest voiced by Indigenous people and their communities who are part of a service or research project (Markiewicz, 2012).

Reciprocity can be achieved through active listening to priorities stated by Indigenous people. This may call for clinicians or researchers to be willing to change their approach in order to respond relevantly to individual or community values and aspirations (Markiewicz, 2012). Reciprocity also addresses issues such as being transparent in sharing information about the patient's condition, plan of treatment or research results so that participants can appreciate outcomes and be equally engaged. This communicates care for the individual or community. (AIATSIS, 2012; Laycock et al., 2011; NHMRC, 2018).

Respect

A respectful rapport inspires faith and co-operation in those involved. Durable values and acceptable ways of dealing with each other in any relationship are built on respect and trust (Laycock et al., 2011). Such a solid attitude towards one another encourages dignity and recognition of the importance of their views, beliefs and way of life (Markiewicz, 2012). This approach offers a considerate and sharing atmosphere that results in therapeutic outcomes (Laycock et al., 2011).

Respectful relationships acknowledge and uphold the rights of people to have diverse principles, standards and ambitions (Markiewicz, 2012).

Respect for somebody is regarding them, and their background, and keeping an open mind about how they view life. It involves recognising and acknowledging in actions that we are all different and no one knows everything. Accepting that their opinions on issues, as individuals, though different, matter (Markiewicz, 2012). Such an attitude may even reveal new aspects that can be beneficial to arriving at a new understanding (AIATSIS, 2012; Laycock et al., 2011; NHMRC, 2018). Respect helps in creating a healthy relationship and environment in which Indigenous people feel cared for, engaged, and experience collaborative service.

Survival and protection

It is important to protect Indigenous peoples' cultures and identity because this contributes to the strengthening of shared values. Survival and protection means being considerate and taking into account how vital values-based cohesion is to Indigenous people (AIATSIS, 2012; Laycock et al., 2011). Indigenous people have a strong social cohesion which builds special personal and collective bonds within their families and communities. They need to be in a safe environment that is free from discrimination or negativity in order for them to enjoy their cultural distinctiveness (AIATSIS, 2012; Laycock et al., 2011). a balance of individual and collective identity is critical. Indigenous peoples are not homogenous, and it is important to counter the negative stereotypes often depicted within general society (AIATSIS, 2012; Laycock et al., 2011; NHMRC, 2018).

Responsibility

Indigenous communities' responsibilities involve issues such as land and its forms, family relationship ties and consideration for other people. The preservation of traditional obligations, and having a divine responsiveness is central (AIATSIS, 2012). It is their belief to harm no one or any place, and this is in addition to other shared responsibilities. In health, as in the general public, no harm should be done to individuals and this is especially central within the traditional and societal extents of Indigenous life (Markiewicz, 2012). Clinicians and researchers need to be open and take steps to explain and maintain communication with patients or participants to minimise consequences of lack of information which might brew into mistrust and misrepresentation (AIATSIS, 2012; Laycock et al., 2011; Markiewicz, 2012; NHMRC, 2018). It is the responsibility of all healthcare professionals and their organisations to uphold and support Indigenous patients and their families.

Clinical problem

The main problem, providing the impetus for this program of research is that although records indicate higher rates of hospital admissions for heart disease, Indigenous people still have poorer health outcomes in comparison to other Australians (Queensland Health, 2017). There is limited information for use by clinicians on how to address the problem of health disparity between Indigenous Australians and other Australians. One observation is that there is a lack of Indigenous voices to inform healthcare services about what Indigenous peoples see as their needs, and how they experience healthcare. Clinicians want to know: what interventions or strategies can be employed to address the gap in health that disadvantage Indigenous people? The central questions were: How is it that Australia is failing to address health problems of a very small population percentage? Can Indigenous peoples themselves provide the answer to enhance understanding for healthcare services?

There are unacceptable levels of health disparity between Indigenous Australians and other Australians, and cardiovascular disease is one of the main contributors to morbidity and mortality. Indigenous people are more likely to receive fewer suitable hospital treatments for CVD (Queensland Health, 2017) because many find it hard to access healthcare and follow management plans. This is due to various reasons, such as lack of appropriate information for them to understand processes, lack of monetary ability to afford the cost, encountering issues that contradict their cultural values, and factors regarding the physical distance to health service centres (Queensland Health, 2017). The problem of being able to provide health services that are acceptable and culturally appropriate to Indigenous Australians has continued to challenge health service providers. This program of research investigated the Indigenous experience through listening to their stories, with an aim to extend knowledge and to better understand their experiences from their perspectives.

Research rationale

This program of research was designed to use storytelling to better understand how Indigenous people experience healthcare. Although patients in general may have a dislike of hospitals, Indigenous people have a history of traumatic experiences with hospitals and other government institutions because of different cultures and previous stressful encounters. Investigating how Indigenous people experience the hospital journey is a suitable purpose for gaining insights into how to design and deliver appropriate and effective health care for the Indigenous population. The focus is on what might be learned from specific narratives of their experiences. Through such an understanding, more effective ways to engage and work with indigenous peoples may be identified and implemented into practice (Markiewicz, 2012).

The impact of the problem is seen in the fact that many Indigenous people die before they reach hospital, or present late to hospital. For those who reach hospital, a significant number die in hospital or they discharge themselves against medical advice. Discharge against medical advice rates are higher for Indigenous people than other Australians (ABS, 2012). While, it is beyond the scope of this study to understand whether those who make it to hospital are different from those who do not, it could be that those who do not make it are part of the group that discharge themselves against medical advice. Regardless of the causes of delay to present or dying on country, all of these events have been associated with fear of hospitals. Significantly, some Indigenous people choose to die at home rather than be treated in hospital (Eckermann, et al., 2010). Therefore, investigation into hospitalisation experiences of Indigenous Australians is crucial to inform improvement of their hospital experiences and their access to hospital services.

It is crucial for healthcare providers, whether in the clinical setting, education or research, to appreciate the factors hindering Indigenous people from having improved health care experiences that would contribute to better health outcomes for them. Patient-centred care is one of the pillars of quality healthcare and is important to patients' experiences (Australian Commission on Safety and Quality in Healthcare, 2010; Delaney, 2018). In-depth data from participants may inform development of care models that are effective, safe and appropriate to Indigenous patients and their families. Thus, the rationale and motivation for the program of research arose from the need to increase understanding of Indigenous people's experiences of healthcare. This was in order to make recommendations for development and improvement of health services, and to promote research into Indigenous healthcare. Development of effective strategies that may go a long way in achieving improved health outcomes for Indigenous people is essential. In this context of investigating healthcare experience, several informal research questions were considered:

- What is the perception of Indigenous people of their hospitalisation experiences worldwide?
- What are the challenges that Indigenous people face during healthcare encounters?
- What do Indigenous people value in health care and how can their experience be improved?
- What are the better aspects of their experiences and specific issues that need to be promoted?

The purpose of asking questions like these was to enable the program to elicit Indigenous voices and enhance understanding for healthcare providers. In the face of the need to improve healthcare for Indigenous patients and support health outcomes, the research presented in this thesis is particularly significant. It is relevant to health services provision, Indigenous communities, health professionals, educators, and researchers. From these informal questions an overarching research question was developed.

Research question

What are Indigenous people's experiences of acute health care?

Aim

The overall aim of this program of research was to explore experiences via participants' stories of acute healthcare with a focus on cardiac health from the perspectives of Indigenous people to gain understanding and insights to inform future health service developments and improvements.

Objectives

This was achieved by:

- Designing a program of research to address the question
- Appraising current evidence on Indigenous peoples' experiences of acute care
- Exploring current hospitalisation experiences of Indigenous peoples related to acute cardiac care
- Investigating the effectiveness of current programs designed for improvement of cardiovascular health of Indigenous Australians
- Reflecting on the experience of researching with Indigenous peoples
- Providing recommendations for practice.

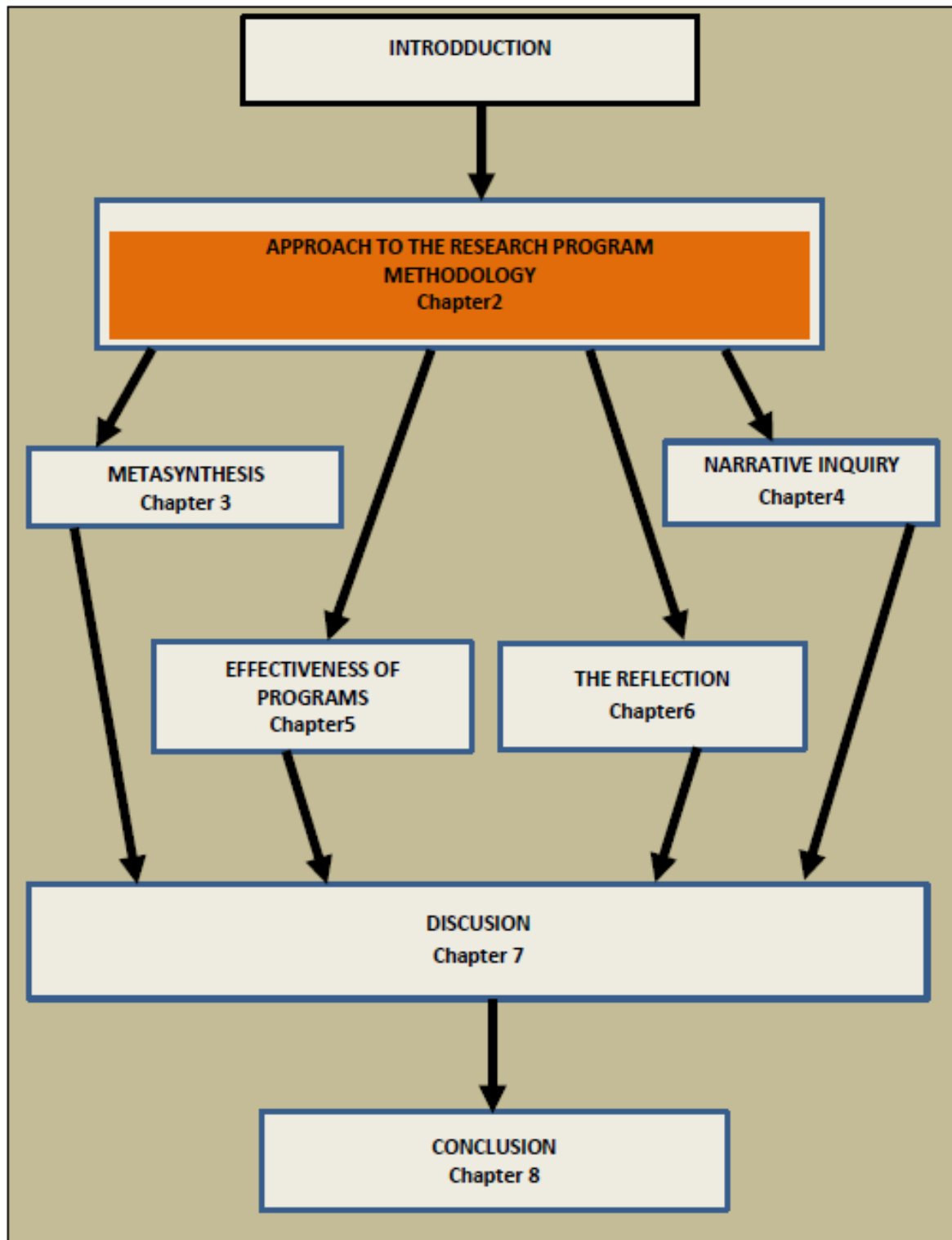
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Chapter summary

This chapter has presented an overview of issues surrounding Indigenous people and healthcare concepts. The research focus has been outlined to point to the basis for the investigation in this thesis. An explanation of the research significance, aims and research questions that will be addressed in this thesis has been presented. A conceptual framework based on Indigenous values and the studies that make up the program of research have also been introduced.

The rest of the thesis continues to tell the story of Indigenous people's experiences of healthcare in detail. Each chapter is arranged to address objectives that have been introduced in this chapter, and to reflect the progression of the story contained within this thesis. The chapter that immediately follows presents the plan and strategies on how the story collection will take place and flow, to ensure rich and significant data that represent the Indigenous experience of acute health care.

Chapter two: Methodology



Introduction

Chapter overview

This chapter presents the overall research approach and design utilised in this program of research. The research problem and contextual background has been presented in Chapter one. The program of research presented in this thesis was designed to address the aim and objectives developed from the identified research problem. The four studies in this program of research have used different approaches to investigate the issues of interest, and each study has contributed to the construction of an Indigenous story of healthcare experiences. While the details of research designs and the methods used have been presented in published studies, included as Chapters three to five, and a submitted manuscript in chapter six, this chapter provides an overview of the research approaches and adds any further details which were not included in the manuscripts, thus cross-referencing to following chapters is used. It should be noted that the program of research has a major qualitative focus because of the nature of the question being investigated.

This chapter explains the guiding concepts, planning, and implementation of the program of research (Burns & Grove, 2011; Liamputtong, 2013). It was important to choose an appropriate methodological approach that would enable the obtaining of appropriate answers to suit the type of research question for this program of research (Liamputtong, 2013). Further, the methodology chosen provided a systematic way to address the research question within each study addressing a specific research objective in a methodological way, in terms of data collection methods, the data analysis techniques used, synthesis of findings and why these choices were made (Liamputtong, 2013). This chapter commences with a reminder of the research question and proceeds to present the four methodological approaches used in the program of research.

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The overall aim of this program of research was to explore experiences via participants' stories of acute healthcare, with a focus on cardiac health, from the perspectives of Indigenous peoples to gain understanding and insights to inform future health service developments and improvements.

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This was achieved by:

1. Designing a program of research to address the question
2. Appraising current evidence on Indigenous peoples' experiences of acute care
3. Exploring current hospitalisation experiences of Indigenous peoples related to acute cardiac care
4. Investigating the effectiveness of current programs designed for improvement of cardiovascular health of Indigenous Australians
5. Reflecting on the experience of researching with Indigenous people
6. Providing recommendations for practice.

The focus of this chapter is on how this program of research was designed to address the overall research question, and addresses the uncovering objective, which is to design a program of research. It, therefore, presents how the case of the Indigenous acute health experience story was planned.

Methodology

Research Design

Qualitative approach

This program of research is mainly informed by a qualitative approach, because of its emphasis on personal perspective from the standpoint of participants (Hammarberg, Kirkman, & de Lacey, 2016). It is an approach used to answer questions about experience, meaning and perspective (Burns & Grove, 2011; Hammarberg et al., 2016; Holloway & Galvin, 2017), therefore, fits with the research question. In recognition that each individual experiences the world in essentially distinctive ways (Peck & Mummery, 2018), qualitative approaches seek to investigate issues through a person's perspective within a specific context (Denzin & Lincoln, 2005; Holloway & Galvin, 2017). The special aspect of qualitative research is that it offers an invitation to researchers to inquire about the human condition by allowing exploration of the meaning of experiences and making it possible for change to occur by acquiring a new awareness on issues, and driving the desire for purposeful action (Taylor, 2013a). Since a quantitative research approach cannot capture the unique elements of experiences,

lives, thoughts, and feeling of individuals, this heralded the need to mainly utilise a qualitative research approach for this program of research (Peck & Mummery, 2018). As qualitative methods are used to observe, analyse, and interpret what people do and make, and how they describe and enact their cultures, these fit with research relating to health care experiences of Indigenous people.

There are a variety of research approaches that come under the term of qualitative inquiry such, ethnography, grounded theory, narrative research, and phenomenology (Creswell & Poth, 2018; Denzin & Lincoln, 2018; Holloway & Galvin, 2017; Holloway & Wheeler, 2010; Taylor, 2013a). These qualitative research approaches, although different, share some common characteristics (Holloway & Galvin, 2017), including: primacy of data; context bound research; thick descriptions; participant-researcher close relationship; and explicit stance of the researcher through reflexivity (Holloway & Galvin, 2017). Qualitative research is personal (Patton, 2015), both for the researcher and researched, because what moves the researcher to engage in certain matters in research is mainly personal interest and values, while the participants tell what their personal experiences/perspectives are on the matter, and together they co-construct outputs that reveal shared understandings that influence future actions (Patton, 2015).

Research participants hold an important presence in qualitative research (Bhattacharya, 2016; Holloway & Galvin, 2017), as by presenting their perspectives, understanding is developed that can influence transformation in the larger societal structures and principles surrounding the research problem (Bhattacharya, 2016). It is through the personal stories of people's experiences and the perceptions, therefore, that society gets shaped by individual stories (Bhattacharya, 2016; Petty, Jarvis, & Thomas, 2018). Experience and meaning are considered to be crucial concepts for reaching a deeper understanding of participants' perspectives (Bhattacharya, 2016; Holloway & Galvin, 2017; Gergen, 2001). This facilitates improved comprehension of the cultural, physical, psychological and social aspects of the subject being studied (Holloway & Galvin, 2017). When researching with Indigenous people, these issues cannot be viewed as separate units without being interrelated to the whole (Australian Indigenous Doctors' Association [AIDA], 2010).

A contemporary Indigenous model of holistic health should include cultural, spiritual, social, emotional physical and psychological dimensions (AIDA, 2010). Thus, this program of research takes the understanding that experiences and their meanings are always embodied in a person and interwoven in their everyday lives. Use of a storytelling strategy enabled a holistic outlook of the Indigenous experience of acute healthcare. This way, the research interest was not only on the physical events or behaviours that take place in participants' experiences, but on how they make sense of every aspect, and how their understanding then influences their behaviours (Holloway & Wheeler,

2010; Maxwell, 2013). As a result of all these characteristics and qualities of qualitative research, it is described as a form of social inquiry, mainly because of its focus on the way people interpret their experiences and issues surrounding their lives (Holloway & Wheeler, 2010). Qualitative research uses an inquiry process, based on interpretivism and constructionism (Creswell & Poth, 2018; Guba & Lincoln, 1994), focusing on the interpretation and meaning of human experiences (Holloway & Galvin, 2017; Pope & Mays, 2006). Qualitative approaches allow the question to inform the choice of method in the study. The next section presents an overall ontological and epistemological underpinning aligned with this program of research.

Underpinning philosophies

Research approaches exist to assist in acquiring knowledge to answer questions that perplex humans and an ever-present question is how that knowledge is generated and the nature of its existence (Roberts & Taylor, 2002). The philosophical foundations of research are the belief system and assumptions about development of knowledge (Liamputtong, 2013). Ontology and epistemology are the two main ways of seeing a study's viewpoint (Pernecky, 2017; Polit & Beck, 2012; Roberts & Taylor, 2002). At the start of the program of research, these issues were considered because an approach to research is not only about procedures such as sampling, data collection or data analysis. An underpinning philosophy explains how the study deliberations should be viewed with regards to a belief system that is used to view the nature of reality (ontology), and source of information (epistemology). Researchers identify with particular viewpoints to guide choice of approaches and procedures that are most likely to gather the type of information essential for the study. It is the ontological and epistemological assumptions that shape how the question is formulated, methods chosen and how findings are interpreted (Polit & Beck, 2012; Taylor, 2013a).

Ontology

Every approach is rooted in particular ideas about the world and the nature of knowledge about social reality (Holloway & Wheeler, 2010; Polit & Beck, 2012; Taylor 2013a). "Ontology refers to the question of whether or not there is a single objective reality" (Liamputtong, 2013, p. 10). The researcher for this program of research adopts a research approach that enables gaining of understanding of experiences of other people. In so doing the researcher acknowledges subjectivities in belief, values, emotions and general perspectives of individuals (Liamputtong, 2013). This research was thus guided by the recognition of multiple realities and acknowledgement that people's

experiences and perspectives differ according to where they are positioned, thus, “...all tenable statements about existence depends on a worldview and no worldview is uniquely determined by empirical or sense data about the world” (Patton, 2015, p. 112), but that it is all relative. In this program of research, the view that different experiences of people are interrelated and can be obtained to inform understanding was adopted.

Epistemology

Epistemology focuses on the nature of information and how knowledge is obtained (Liamputtong, 2013), thus, defining what knowledge is possible and legitimate (Roberts & Taylor, 2002). Further, epistemology provides understanding and explanation about how and what is known (Roberts & Taylor, 2002). This program of research is supported by a constructionist epistemology.

A constructionist epistemology is appropriate for this study as it contends that reality and sense are not objective, but created from engagement with the world (Creswell, 2012; Karnilowicz, Ali, & Phillimore, 2014; Patton, 2015). Further, the investigator is also part of the exploration process and is not objective (Patton, 2015). A constructionist view points to the fact that our unique individual experiences are influenced by the culture in which we grow up (Creswell & Poth, 2018; Patton, 2015). Therefore, within the constructionist epistemology, an interpretivism approach was adopted to enable generation of knowledge that would inform understanding of the Indigenous experience of acute healthcare. In this case, how Indigenous people interpret the world has been informed by their cultures and through social interactions with society (Karnilowicz, Ali, & Phillimore, 2014; Liamputtong, 2013). Therefore, the constructionist view expects that every individual participant will have had different experiences and perceptions of healthcare. By capturing these differences and examining them, a new understanding and insight will be gained (Liamputtong, 2013). From within a constructionist epistemology, the interpretive approach to research was adopted. This was founded on the principle that social connections between humans and context are foundational for knowledge generation (Karnilowicz, Ali, & Phillimore, 2014).

This program of research aimed to facilitate transformation of acute health experiences for Indigenous people. By gaining improved understanding and insights from Indigenous people’s perspectives on their health care experiences, better strategies may be developed to integrate their needs and improve their experiences. The ontological and epistemological views were merged to co-create findings of the inquiry.

Study designs

For this program of research, four specific studies were designed to address each of the research objectives stated in the introduction. Each study required a specific research approach; thus, a multimethod design was used, with an overarching qualitative focus. Figure 2.1 represents the research design of this program of research that was used to gather evidence to build up the story of the Indigenous experience of acute healthcare. The underpinning philosophies of the researchers and participants informed the data gathering methods, which, in turn, influenced the choice of research design and methods (Figure 2.1). Completing this design addressed the first objective of the program of research.

A qualitative metasynthesis was undertaken for Study One to ascertain current knowledge of Indigenous peoples' hospitalisation experiences worldwide, addressing the second objective of the program of research. A desire to include participants and use interviews to draw out people's experiences led to the use of a qualitative methodology, narrative enquiry, for Study Two, addressing the third research objective. To explore the effectiveness of Indigenous cardiovascular health programs in Study Three, a systematic review was used to address the fourth research objective. Informed by the underlying principles and immersed in the research, a fourth study was planned as an autoethnography to address the fifth research objective. The sixth objective was achieved through identification of the new understanding and provision of recommendations for practice. The different approaches used in this program of research enriched the story of Indigenous experiences of healthcare, and the issues impact their experiences. This program of research was planned to use different approaches to address the research question to ensure provision of a holistic and comprehensive perspective that can enrich and facilitate a deeper understanding of the issues and provide insights on which to base recommendations.

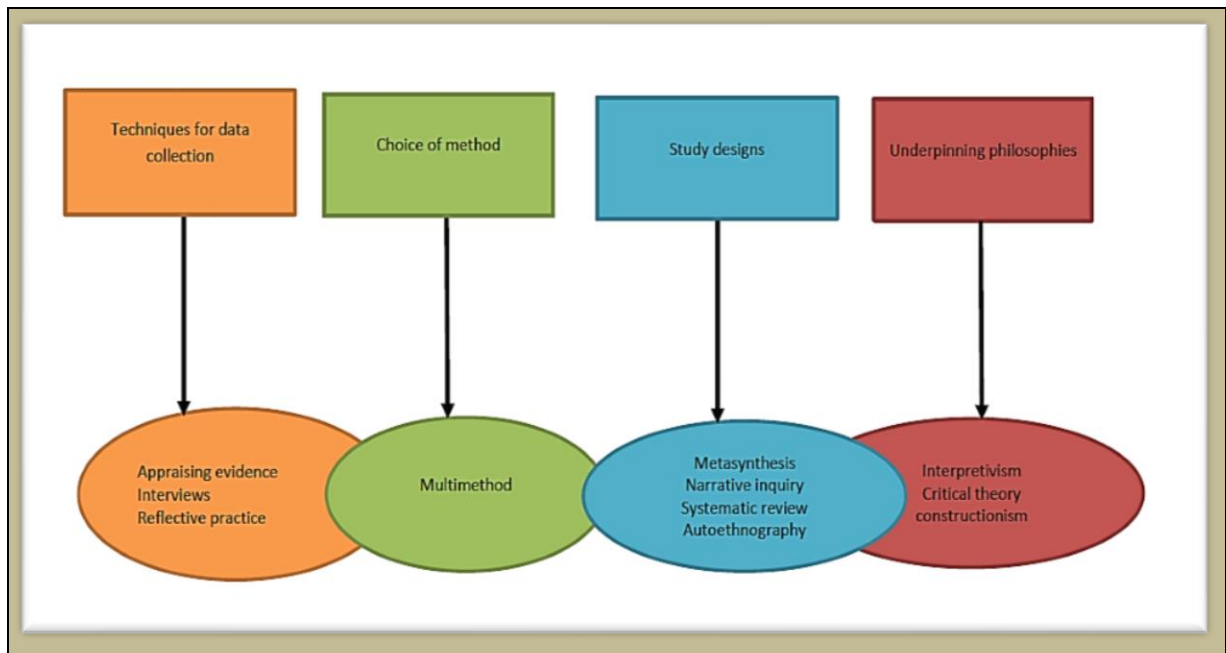


Figure 2.1. Research design

The structure of the program of research

The studies conducted for this program of research were undertaken firstly from an international Indigenous peoples' perspective, then from an Australian Indigenous peoples' perspective (Figure 2.2). Following this, a local perspective was explored with experiences from the researchers' own hospital and then the researcher's own auto-ethnographical exploration. This journey of exploration is represented in Figure 2.2 and specifics for each study are detailed in the following sections.

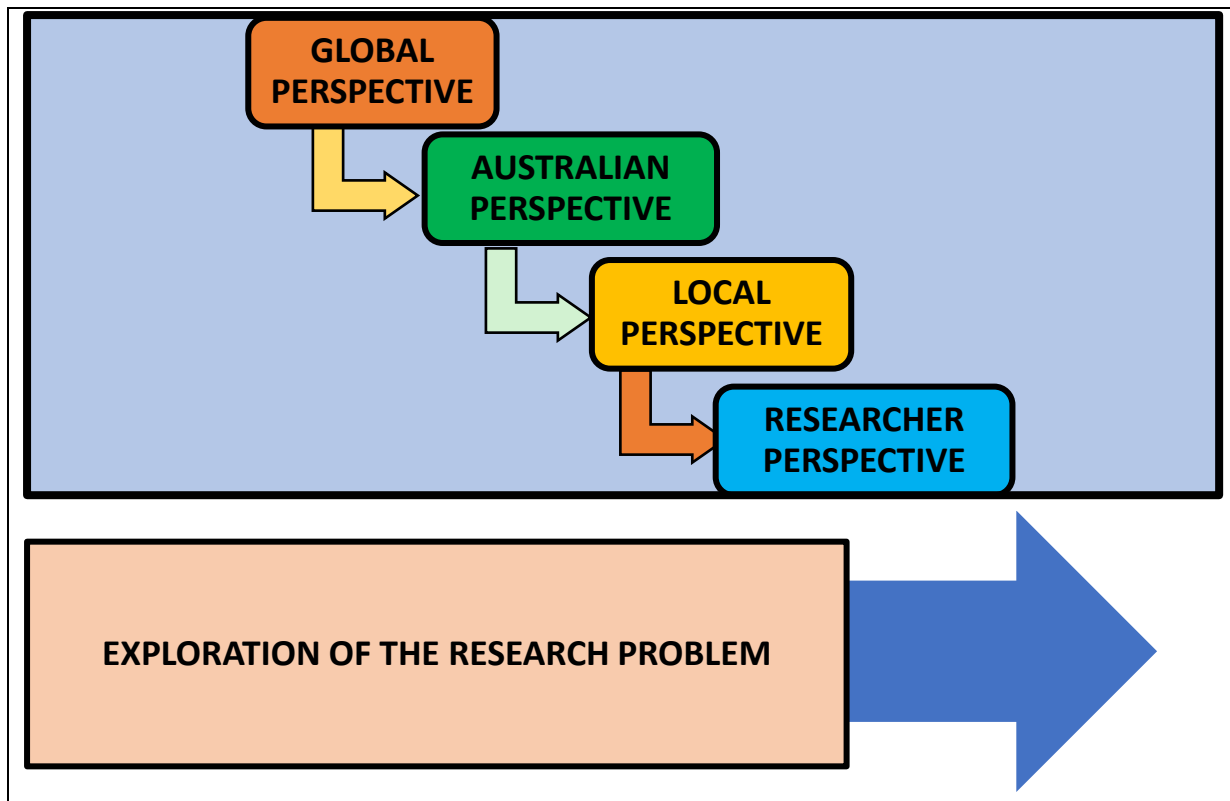


Figure 2.2. The structure and sequence of the research explored

Study one design- metasynthesis

Indigenous peoples' experiences and perceptions of hospitalisation for acute care: A metasynthesis of qualitative studies (Chapter three).

The patient perspective of health care has been recognised as a vital aspect to the delivery of quality care (Australian Commission on Safety and Quality in Healthcare, 2010; Delaney, 2018; Greaves et al., 2013; Grondahl et al., 2013; Tsianakas et al., 2012). Therefore, understanding the needs and values of Indigenous patients and their relatives is crucial for the delivery of high-quality healthcare. It is imperative to investigate what Indigenous patients and families encounter while in hospital, in order to provide effective care that addresses their unique needs and supports positive health outcomes. Stories influence our understanding of central matters associated with Indigenous peoples' health care experiences and can positively impact their health practices as well as healthcare practice (Bhattacharya, 2016). It was thus important to determine if there already are published stories of Indigenous patient experiences that could inform this program of research. The purpose of this first study then was to seek answers from the literature for the research question: How do Indigenous

patients and their relatives experience hospitalisation or acute care? Given that there are Indigenous peoples' worldwide, this study was designed to explore this question from a global perspective (Figure 3.1). As well, given that stories were being sought, the review focused on literature that addressed qualitative studies of Indigenous people's experiences (stories) of acute care. A systematic way of reviewing literature was planned to ensure quality of appraisal to address the second research objective for this program of research. Thus, the main aim of Study One was to conduct a qualitative metasynthesis of Indigenous peoples' experiences of hospitalisation to facilitate an understanding of their perceptions, beliefs, and expectations at an international level.

Metasynthesis allows for integration of individually conducted research study findings (Walsh & Downe, 2005), which provides an improved understanding of the experiences that different settings provide to Indigenous people and their families. A metasynthesis was used as a way of isolating issues that are encountered in different health environments within and across countries (Finfgeld, 2003). The use of a worldwide lens on the issues that impact Indigenous peoples' experiences and how this informs the formation of their collective stories about healthcare enables revelation of important influences in the experience of healthcare by Indigenous people. This provides an extended understanding of and insights from a worldwide perspective and the identification of issues that are common overall.

Metasynthesis methodology

The purpose of using metasynthesis for this study was to gather evidence of Indigenous peoples' experiences of acute healthcare from a worldwide perspective. Metasynthesis is an analytical process of synthesising findings of qualitative research on specific issues (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). Synthesis of primary research allows the transmission of accumulated knowledge in an area (Sandelowski, Docherty & Emden, 1997). Through metasynthesis, individual qualitative research results, which otherwise might be isolated and have little impact on practice (Finfgeld, 2003), are made accessible and user friendly for practice. Specific experiences investigated by numerous authors are merged into a meaningful whole (Thorne et al., 2004). Synthesis of multiple study findings makes the results more accessible for use by health providers, such as clinicians, policy makers, researchers, and also enables theory building, theory clarification, and clearer understanding of the issues under consideration (Finfgeld, 2003).

One of the main issues for metasynthesis is to ensure the quality of the studies that are included in the review (Walsh & Downe, 2005). Use of quality markers is said to be crucial for the credibility of a metasynthesis study (Cooke, Smith, & Booth, 2012; Walsh & Downe, 2005). On the

other hand, other scholars believe that controlled judgement, by use of a formal appraisal tool, of the studies to be included in a metasynthesis may not offer reliable benefits (Dixon-Woods, Agarwal, Jones, Young &, & Sutton,2005). They state that parameters of the appraisal tool may prevent important and relevant findings from being included (Dixon-Wood et al., 2005; Sandelowski & Barroso, 2007). This is because most quality tools are designed in line with quantitative views and may disregard or miss details of qualitative aspects of research, which are targeted for interpretive synthesis, in contrast to quantitative statistical amalgamation (Cooke et al., 2012; Dixon-Woods, Sutton, Shaw, Miller, Smith, Young, Bonas, Booth, & Jones, 2007).

Since there is no consensus about the issue of quality, it is up to the researcher to follow numerous tactics concerning the choice of key studies that meet the criteria and the quality level (Barnett-Page & Thomas, 2009; Walsh & Downe, 2005). Several factors influence the choices that a researcher makes and these mainly address the overall purpose of the synthesis, and anticipated outcomes from the process (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2007). Nonetheless, the use of prescribed evaluation criteria or specifications is advised to enhance validity and reliability of the appraisal process (Cooke et al., 2012; Walsh & Downe, 2005). Therefore, this study used a formal checklist, the Critical Appraisal Skills Programme (CASP, 2013) to assess the quality of studies to be included.

Methods

Specific methods for this study are located in Chapter Three, including the search strategy and search terms (Section 2.2, p. 88), study selection and appraisal (Section 2.3, p. 88) and metasynthesis approach (2.4, p. 88). Further details not included in Chapter Three are provided here.

Search Strategy

Data were collected by identifying published studies relevant to the topic and using the findings from these studies as data. A search of electronic databases was conducted over a nine-month period and the search strategy is detailed in chapter three (p. 87). The search trail was kept using the search flow chart of studies. This involved recording of total number of citation hits from searches, number of those rejected, number of full text articles that were assessed, how many were excluded, and, finally, how many studies were appraised and included in the synthesis study. The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow chart was used to facilitate

the process of transparency and good reporting (Liberati, Altman, Tetzlaff, Mulrow, Gotzsche, Loannidis, Clarke et al., 2009), as presented in Chapter Three (p. 88).

Study Selection and Appraisal

Details of the selection process is presented in chapter three (p. 88). Studies were limited to those published on Indigenous patients, and their families' experiences. The studies had to be in a peer reviewed journals, available in English, and most of all, be qualitative or with a significant qualitative component. The purpose of the study had to be an interpretive explanation and not prediction; therefore, the sample had to be purposive rather than exhaustive (Barnett-Page & Thomas, 2009; Cooke et al., 2012; Dixon-Woods et al., 2007). Attention was placed on original qualitative research studies focused on Indigenous people's hospital or acute care experience, use of individual interviews to emphasise individual experiences, Indigenous participants, and care provided within hospital or acute care settings. Search terms included hospital experiences for Indigenous patients. On the other hand, quantitative studies, literature reviews, and studies focusing on professionals' perspectives were excluded. Further, community focused studies, such as those addressing primary health care were also excluded.

The studies included in the metasynthesis were assessed for reasonable quality in terms of transferability, dependability, conformability and credibility. The Critical Appraisal Skills Programme (CASP, 2013) checklist was used for appraising the research papers prior to being included in the study. This tool contains a list of questions to assist in the consideration of specifying what the results are, whether the results are valid, and whether they are useful. Ten screening questions with prompts are listed to assist in making sense of the studies. The questions address issues which include demonstration of aims of the research, design, methods, recruitment strategies, data collection, researcher/participant relationship, ethical considerations, data analysis, findings, and how valuable the research is (CASP, 2013) (Appendix 2). The CASP was found to be suitable because it is comprehensive and sufficiently generic to be applicable to different qualitative methods (Masood, Thaliath, Bower, & Newton, 2011). Details of the quality appraisal results are presented in chapter three (p. 83).

Metasynthesis

The metasynthesis was informed by the procedures presented by Thomas and Harden (2008) as detailed in Chapter Three (p. 85). The process involved use of a thematic approach to analyse and

synthesise the data into new concepts (Jensen & Allen, 1996; Sandelowski & Barroso, 2007). As stated by Jensen and Allen (1996), the process of synthesis started following data retrieval. Focus was on portraying all relevant individual findings through paying extensive attention to details of each individual account and comparing and contrasting these individual study findings in order to construct new concepts in which there is consensus, while maintaining the central concepts of each account in related to other accounts (Jensen & Allen, 1996). The process of reciprocal translation ensures achievement of holistic interpretation (Jensen & Allen, 1996). Initial concepts were refined to come up with final themes to represent original individual descriptions. Themes isolated across the studies were finally presented (chapter three, p. 91).

Study Two Design: Narrative inquiry

Indigenous Cardiac patients' and relatives' experiences of hospitalisation: A narrative inquiry (Chapter Four).

The hospital is an environment that is filled with complexities, hopes, dreams and intentions for those who journey through it. Accounts of patients' and their relatives' experiences are important to ensure continuous improvement in response to their needs and expectations. The depth of focus of the study query required a method that emphasised co-construction and interpretation of the experiences within hospitalisation context. Through a qualitative approach, the study was intended to capture the interpretive essence of the hospital experience of the participants in order to reveal the hidden issues which are not normally obvious to clinical practitioners and the healthcare service as a whole; the participants' perspectives (Barton, 2004; Green & Thorogood, 2009; Maxwell, 2013).

This approach is used in studies that aim to understand more about the phenomenon rather than measure it (Green & Thorogood, 2009). The study used a narrative method in which participants were invited to take part by telling their story about their hospital experience. Narrating one's story is a great technique for communicating about one's own personal values and identity perceptions to someone else (Larson and Sjoblom, 2010; Petty, Jarvis, & Thomas, 2018). The narrator imparts knowledge to the listener and no assumption is made that stories are told as they really happened. The narrator holds the power to represent how their world came to be in regard to the subject under study. The approach was suitable for this study because of the ability to put emphasis on the participants and their views (Larson and Sjoblom, 2010; Taylor, 2013b).

Study Two addressed research objective three, which is the exploration of current hospitalisation experiences of Indigenous people in relation to acute cardiac care. This study was

conducted using a qualitative research approach to develop a holistic understanding of the issues faced by Indigenous people while hospitalised for acute cardiac care. Narrative inquiry was used to explore the specific experiences of Indigenous patients and their families during admission to hospital for acute cardiac care. Storytelling is one of the oldest communication styles and has been widely accepted as a method for sharing experiences (Iseke, 2013; Larson and Sjoblom, 2010). “Indigenous peoples engage in oral traditions, historical/ancestral knowledges, and cultural resources to examine current events and Indigenous understandings in ways consistent with traditional worldviews ...” (Iseke, 2013, p. 559). Therefore, unstructured face to face interviews were used to ask participants to tell their stories of health care experiences. Storytelling is an important approach because it is flexible and nurtures relationships and provides opportunities for sharing knowledge, teaching lifelong lessons, counselling, and teaching culture (Iseke & Brennus, 2011; Kovach, 2009).

Narrative Inquiry Methodology

Narrative inquiry is the study of everyday experiences (Clandinin & Connelly, 2000; Larson and Sjoblom, 2010). Stories or narratives are reflections of people’s experiences and the meanings those experiences have for them, therefore, inquiring into people’s narratives is a useful way of gaining access to participants’ feelings, thoughts and beliefs (Holloway & Wheeler, 2010). The story, the teller and the listener are all important in narrative inquiry because they encompass narrated life experiences from which to learn about human knowledge and existence (Taylor, 2013b). The telling of narratives is empowering because it allows participants to construct who they are and how they want to be known and the researcher becomes the listener (Taylor, 2013b). To explore experiences of hospitalisation for the participants of this current study, it was vital to empower the participants to exercise their choice of content and approach to their stories of their experiences. Through stories, people can depict the ways they experience the world, which enables others to have insights into understanding other people (Larson and Sjoblom, 2010; Taylor, 2013b).

Narrative inquiry does not seek to answer questions; rather it adds understanding of a phenomenon within a specific context (Duffy, 2012; Larson and Sjoblom, 2010). Thus, the aim of Study Four was to gain understanding of hospitalisation experience from the participants’ perspectives. It was anticipated that the understanding gained through this study would enable stakeholders in Indigenous health to review issues in a different way that will enhance designing and implementation of effective healthcare provision. Agius and Hamer (2003) describe the narrative approach as “holistic” because it works with all aspects of a person’s experience, including how all characteristics of the

individual's story interconnect (Stock, Mares & Robinson, 2012). In this case, spiritual meanings, physical indicators, family and community hopes and emotional responses can all be brought together in a story (Stock et al., 2012). Further, Indigenous people are rooted in traditions of storytelling, both in everyday societal life and in the rearing and provision of instructions to their young family members (Agius & Hamer, 2003; Stock et al., 2012). Information is transmitted from one generation to another through stories.

Despite the positive comments about a narrative approach, it has also been criticised as lacking rigour or having some omissions in the details of the method (Bird, Wiles, Okalik, Kilabuk, & Egeland, 2009). This is because critics attempt to adopt the same evaluation tools as those used in positivist approaches (Morse, 2012). Morse (2012) believes that such misuse of evaluation tools, such as the Cochrane criteria, impede qualitative health research. This criticism of narrative inquiry carries weight only if viewed with the lens of quantitative orientation. For example, positivists and post-positivists refer to bias in research, while in the context of narrative, this concept is redundant, because narrative inquiry embraces subjectivity (Bird et al., 2009; Lather, 1986; Vezeau, 1994). In that case, interest-free knowledge is logically impossible, and, therefore, attempts to produce value-free science are increasingly being abandoned (Lather, 1986). In terms of narrative rigour, assessment is based on the question of when a story is a story and not the determination of whether a story is truthful (Vezeau, 1994). Narrative research should be seen considering its strength to enable co-construction of information that builds respect between the investigator and the participant (Galbin, 2014; Taylor, 2013b).

As Sandelowski (1991) explains, narrative truth is different from the truths obtained through prescribed and conventional science methods because its focus is on the life-like, understandable, and believable story. Further, Sandelowski (1991) clarifies that stories should be anticipated to evolve with time and from telling to telling, and therefore, the concept of confirming them empirically is totally unfamiliar within narrative truth. Storytelling invites the teller to not only include personal knowledge, but to base their whole story on personal knowledge. According to Vezeau (1994 p.59), "storytelling, by definition, is personal". Thus, a "true" story relates obvious facts and themes, but its meaning will always be individually interpreted and valid (Duffy, 2012; Petty, Jarvis, & Thomas, 2018; Sandelowski, 1991; Vezeau, 1994). Particularly within the context of Indigenous knowledge and power, the concept of "understanding" merits exploration. Therefore, with narrative, there will always be multiplicity of interpretations, and narratives should always be able to stimulate debate, and thus engender disagreement or agreement among readers (Patton, 2015). By including their individual voices,

Indigenous patients and their relatives are placed in a position of power to influence knowledge development that could benefit them and their communities.

In this study, data collection was conducted using face to face interviews to elicit stories from participants about their hospital experiences. Storytelling was chosen on the premise that it is the basic mode of human interaction and a familiar way of exchanging information. Healthcare has used storytelling in various ways, such as for health education, promoting better-quality clinical care, and community health efforts (Tsui & Starecheski, 2018). Stories, when placed in the context of one's life experience, allow others to see what influences individual experience and the connections to the larger community's past, communal, cultural and structural forces that impact their everyday life (Tsui & Starecheski, 2018). Storytelling facilitates refinement of experience into focused and shareable information (Briant, Halter, Marchello, Escareno, & Thompson, 2016; Njeru et al., 2015; Tsui & Starecheski, 2018). Stories are dynamic, and they change as experiences and perceptions evolve with passage of time and acquisition of new insights.

Study Two framework

This study resonates with a social constructionist stance – reflecting the fact that reality is socially constructed (Galbin, 2014; Gergen, 2001; Patton, 2015). Each person creates their story from perceptions of the actual world (Galbin 2014). Further, a constructionist view acknowledges a multiplicity of meanings (Hair & Fine, 2012; Walker, 2015), focuses on relationships and maintains the person's position in the social construction of realities (Galbin, 2014). The experiences of the participants become alive due to the interactions and relationships they encountered in the process of receiving health care within the hospital confines, as well as everyday life encounters; thereby valuing many voices (Hair & Fine, 2012). Individual stories are told which become collective stories and when these are shared, an identity or recognition of particulars is validated, elevating story to the primary technique of understanding the lived world (Lewis, 2011).

The connection between the investigator and participants also facilitates the capturing and description of lived experiences of participants (Chase, 2017). The shared understanding between the investigator and those participating in the study develops, which enables co-construction of research outcomes (Chase, 2017; Chase 2005). Knowledge production is, therefore, viewed as a collective process and each party's worldview influences the way meanings and understanding is constructed (Gergen, 2001). As a result, narratives produce multiple understandings and the focus is not to reach

a correct explanation of the story told but an understanding of the world of lived experiences from the viewpoints of persons who live it (Bhattacharya, 2016; Walker, 2015). Narrative investigation involves exploring different traditions of knowing with an open mind because truths are viewed as subjective and only shared meanings and understandings can be achieved (Bhattacharya, 2016). Knowledge in this case is positioned in the context of the investigator and the participants in the study, with both owning a degree of influence over how the narrative is formed, organised, and represented (Bhattacharya, 2016). The sanctity of narratives is in the association that storytellers make between historical, contemporary, and impending events (Bhattacharya, 2016).

Justification of method

Qualitative approaches to research enable strengthening and broadening the types of evidence to inform practices. Healthcare research has usually been dominated with inquiry into effectiveness of interventions because of its focus on biomedical approach. However, health systems are complex and create challenges for both clinicians and consumers of health services (Lewin & Glenton, 2018; Miller et al., 2010). It is important to seek the best type of evidence on which to inform decisions on how to move forward and provide effective and acceptable health service to all. Enquiries regarding impact of healthcare, patients' perspectives, appropriateness of interventions, and how patients and their family value different outcomes are better addressed using qualitative approaches to research (Lewin & Glenton, 2018; Miller, 2010). Without integration of qualitative research outcomes, major information gaps will persist in understanding the setting and opportunities for healthcare systems and translation of knowledge (Lewin & Glenton, 2018; Mihalicza et al., 2018; Miller, 2010). Narrative research allows sharing of perspectives which enables creation of new understanding and information (Barton, 2004). Since this program of research aims to gain deep understanding and meaning embedded in the participants' first-person stories (Holloway & Freshwater, 2007), the narrative methodology has been chosen as a suitable approach. It is an interpretive research method that allows participants to voice their ideas on issues under study (Duffy, 2012; Holloway & Freshwater, 2007). It is a legitimate interpretive research method, which is gaining increased recognition (Duffy, 2012), and, with regards to healthcare, it has been of interest to psychologists for many years (McCance et al., 2001).

Use of narrative research methods opens opportunities to co-constructing and co-participation in ways that are respectful because the participants' perspectives are preserved. It is known as a relational approach to research because recollection of stories makes it possible to

discover historical, cognitive and ethical aspects of participants' experiences through conversation with another (Barton, 2004; Bhattacharya, 2016). These communications are valuable because they facilitate highlighting of understanding and insight through the individual and societal experiences that are shared, and they provide prospects for immediate interpretation of the presented issues in the stories (Barton, 2004). The method also promotes maintenance of a holistic nature of issues that participants are experiencing (Barton, 2004) because the narrative research approach enables recognition of insights, fundamental aspects, and the quality that accompany each person's principles and cultural expressions and desires (Barton, 2004). These characteristics make the narrative research approach appropriate for use in Indigenous research.

Stories were used as data because the method was found to be a traditionally affirming approach which is fitting when working with Indigenous peoples (Gorman & Toombs, 2009). Australian Indigenous cultures value storytelling and it is used to pass on important information from one generation to the next in a way that is conducive for them due to their use of culturally familiar methodology of information sharing (Gorman & Toombs, 2009). Barton (2004) supports the use of narrative research because it is congruent with Indigenous epistemology. Story, in this case, is a special kind of narrative that is a mode of knowing by connecting qualities of lives, making them sources of knowledge (Barton, 2004; Bhattacharya, 2016; Duffy, 2012). Patients and their families are stakeholders in the health service. Human beings have capacity to narrate their own experiences. They gain enthusiasm from telling as well as listening to stories, sustain a sense of community, and they are also encouraged to act by stories that give optimism (Block & Weatherford, 2013). For patients and their relatives, it is vital to provide them with an opportunity to contribute to discussions about their care and general experience while receiving the care. Healthcare providers must be motivated to act in ways that promote care.

The significance of using narrative research in this study lies in the value that is placed on involving key players in the creation of evidence (Bird et al., 2009; Duffy, 2012). To ensure non-directive participation, the study participants were asked to tell the story of their hospital experience without using pre-determined research questions and this positioned power with the participants (Block & Weatherford, 2013). In so doing, the method gives respect to the individuality of experience. It also provides the means to individualise therapeutic responses because participants are given the opportunity to express themselves (Block & Weatherford, 2013). A partnership is developed between researcher and participants through the interpretive activities which result in a deeper understanding of the experience (Barton, 2004). A narrative approach to research respects the ethics of justice and

supports the potential to include Indigenous people as genuine contributors in the construction and distribution of information (Bird et al., 2009).

Research trustworthiness

Rigour is an important issue in the practice of research and the ability to demonstrate that the research presented is trustworthy and, therefore, meaningful (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). The notion of trustworthiness continues to be discussed in relation to qualitative enquiry, but the main view that influenced this study was that rigour is critical to research because it demonstrates the quality of being thorough and accurate in the conduction of research (Maxwell, 2013). Qualitative research carries different criteria for evaluating rigour or quality to those used in quantitative research approaches. Quantitative approaches achieve this through use of standardised measures and statistical analysis, and qualitative researchers, on the other hand, establish trustworthiness of their work through development of confirmability, credibility, dependability, and transferability of their research process and resultant product in form of findings and conclusions drawn (Lincoln & Guba, 1985). This is referred to as trustworthiness, and is a concept that describes quality and authenticity, in relation to the confidence readers may have in the findings of the study (Cypress, 2017).

To achieve rigour of this study some objectives were considered, and these included:

- Ensuring transparency
- Ensuring rigorous research procedures
- Adherence to evidence.

Ensuring transparency

Qualitative approaches depend on organisation, description, and interpretation of textual, verbal or visual data, and, due to the subjectivity that is inherent in qualitative research (Cypress, 2017), demonstration of rigour was seen as a vital aspect to this study. Being transparent in the study processes creates a dependability because consumers of the research findings are able to evaluate and judge the study and how it was conducted (Cypress, 2017). Presentations to peers and other external agencies was conducted to provide for constructive feedback on the research procedures followed, and interpretations and conclusions reached. Participants' quotes were used in the presentation of findings (Houghton, Casey, Shaw & Murphy, 2013; Maxwell, 2009). Use of participants' quotes enables the participating population and readers to recognise and identify with the experiences described in the study (Koch, 1994). Specific processes are presented in chapter four.

Ensuring rigorous research procedures

The research process was adhered to as presented in the research proposal that underwent ethics review. The strength of the selected strategy and its suitability to answer the posed question was described, and this strengthened the rigour of the study (Cypress, 2017). Data were processed systematically from data gathering, data examination and final synthesis of data and presentation (Creswell, 2009). Descriptions of the population group under study, procedures for data collection and analysis, and the context of the study enabled the possibility of transferability of findings to other appropriate situations (Koch, 1994). The descriptions further provided for confirmability by describing the research processes followed in the study. This study used purposive sampling and provides thick description, which enhances transferability of findings (Cypress, 2017).

Adherence to evidence

To adhere to evidence, the original transcripts were kept for reference to guarantee consistency of findings with the data (Koch, 1994). Verbatim transcripts of the interviews were used to enable storage of the transcripts in their original state (Maxwell, 2013). This study was conducted using a team of investigators (research supervisors) and this provided triangulation, which strengthened credibility of the evidence presented by confirming the data and ensuring that data was complete (Houghton, Casey, Shaw & Murphy, 2013). The process of cross checking of the data was achieved by having the team of three researchers. Participants' voices in words were used in the presentation of findings as a way of adhering to evidence. To provide further credibility, presentations were made to Indigenous audiences at Indigenous health-specific conferences and positive feedback was that the findings were compatible with the perceptions of the population group under study. This provided an external peer debriefing to support credibility of the findings (Houghton et al., 2013). The researcher ensured that findings were compatible with the perceptions of the participants (Holloway & Gavin 2017), in order to establish relevance and credibility of the study.

Further, seven months were spent interacting with various participants as they gave their story. The prolonged engagement with the participating population provided credibility to the study (Cypress, 2017), by providing opportunities to collect different kinds of data; rich data which enabled confirmation of observations and inferences of the study findings (Maxwell, 2013). Peer review in terms of conference presentations, seminars, and article publication process was planned into the

research process (Houghton et al., 2013; Shenton, 2004). Throughout conduction of this research program staff from the Indigenous Unit at the research site were involved through meetings and discussions to allow questions and critique of the research process and its findings. Summary of how rigour was achieved in this program of research is presented in Table 2.1. Further description of rigour is presented in chapter four (4.6, p. 98)

Study Two Methods

Setting

The setting for this study was The Prince Charles Hospital (TPCH), which is part of the Metro North Hospital and Health Service, in Queensland. Ethical approval (Appendix 3) and site-specific approval (Appendix 4), was obtained from TPCH Human Research Ethics Committee, and this was registered with the Australian Catholic University Human Research Ethics Committee (Appendix 5).

The Prince Charles Hospital is the largest cardiac referral centre in Queensland and the leading cardiac service provider for Queensland and northern New South Wales. This hospital offers health programs in intricate interventional cardiology, structural cardiac ailments, heart electrophysiology and adult congenital heart disease (Queensland Health, 2019; The Prince Charles Hospital Foundation, 2018). Although the hospital offers other services, such as general surgery and general medicine, its core business is cardiothoracic health services with a unique position as a cardiothoracic referral centre for the state, interstate and overseas.

Further, it is also the centre of one of Australia's heart imaging services, the Queensland Heart Failure and Transplant Unit (QHFTU), and the base for a statewide Indigenous Cardiac Outreach Program (ICOP) (Queensland Health, 2019). As a result, Indigenous patients and their families often leave their communities to access healthcare for their cardiac condition at this hospital and may have follow up management through ICOP. Thus, this is an appropriate site to conduct such a study because the hospital offers a variety of cardiac procedures and management options to cardiovascular patients and serves a large Queensland state-wide population of Indigenous people, as well as those from the northern New South Wales area. Further information on the study setting is presented in chapter four (4.2, p. 102).

Table 2. 1. Ensuring rigour of the program of research

Source: Cypress, 2017; Houghton et al., 2013; Maxwell, 2013

	CRITERIA	MEANING	TECHNIQUES	ACHIEVED
1	Credibility	The findings make sense. To create assurance that the results (from the standpoint of the participants) are accurate, trustworthy and authentic.	Prolonged time in the field. Triangulation. Peer debriefing.	Practiced interviewing before commencing study Interviews were done for over 7 months One interviewer used to collect data and was familiar with process Debriefing meetings with supervising team regularly Conference /seminar/in-service/publication of results Use of multimethod/team of researchers Publication of results
2	Dependability	The research has been conducted in a dependable way that can be audited. To ensure the conclusions of this qualitative investigation are repeatable if the investigation happened within the similar settings.	Audit trail of decision making throughout the research process. Rich descriptions	Prepared detailed study protocol Rich description used in the reports Interviews transcribed verbatim and kept as reference Peer reviews
3	Transferability	There is potential for findings to be transferred to another setting. To extend the degree to which the results can be transferred to other situations or locations.	Use of purposive sampling Rich description of the setting and participants	Purposive sampling was used Rich descriptions of participants and settings Use of worldwide, national and local data/ settings
4	Confirmability	Confirmation of the researcher's position and influence. To range the assurance that the results would be confirmed or validated by other investigators.	Reflexivity – reflective journal	Use of multimethod to collect data Use of a team of researchers Presentation at conferences and seminars for peer briefing Researcher reflective process used to be transparent of researcher assumptions

Sample

Indigenous patients admitted to the hospital for management of cardiovascular problems and their relatives were invited to participate in the study. The exclusion and inclusion criteria were as follows:

Inclusion criteria

All Indigenous cardiac patients and their relatives aged 18 years and above were potential participants. The patient must have been admitted to hospital, able to speak in English and able to narrate their experiences. All adult Indigenous cardiac patients and their relatives who met the inclusion criteria were invited to take part.

Exclusion criteria

Non-Indigenous patients and their relatives, non-cardiac patients and their relatives, and those under 18 years of age or with cognitive impairment were excluded from participating. Further information on sample is presented in chapter four (4.3, p. 102).

Recruitment

Recruitment and consenting of participants' commenced following ethical approval (detailed in Chapter Four, (p. 102). Following identification through the admission process, participants were approached by the researcher. The Hospital Indigenous Liaison Officer was present for the initial contact to provide an introduction as well as provide a sense of cultural safety for the participants. The NHMRC (2007) and AIATSIS (2012) guidelines were followed with regard to recruitment.

An invitation package containing a letter inviting eligible participants, information about the study and consent forms was provided. A Plain English Statement and consent form, based upon the AIATSIS (2012) template, was used to facilitate understanding of what the study was about, and the role the participants were to play. Participants were advised of their right of choice to withdraw from the study, if they wished, at any stage of the project process without jeopardising their health care. Enough time was given to participants to familiarise themselves with the study by reading and understanding the information provided. Written consent was obtained from all participants as recommended (NHMRC, 2007). Details of the sample recruited are included in Chapter Four (p. 102).

Sample size

Samples for qualitative research are generally much smaller than those used in quantitative studies, but this contributes to more meaning and in-depth understanding (Holloway & Freshwater, 2007). The guiding principle for sample size in qualitative inquiry is usually the concept of saturation, though this is still debatable (Boddy, 2016). The determination of sample size for Study Two was contextual (Boddy, 2016); since the sample included two groups, patients and relatives, it was important to get perspectives from both groups and a sample that would be representative of the two groups. Further, the participants came from a variety of regions and it was considered important to represent these regions to gain further understanding. As result, the sample size in this study was on the higher side of the qualitative approach (Boddy, 2016; Mason, 2010).

A total of 33 participants were recruited of which 24 were patients and 9 were relatives. The high number allocated to participants allowed for multiple relatives to participate in the study. A study by Mason (2010) revealed a mean sample size of 31 for PhD studies using a qualitative research approach and qualitative interviews as a method of data collection. Researchers are aware that larger samples are labour intensive, time consuming, and may not be practical (Mason, 2010). Since Study Two is about a collective of stories, the higher number was chosen in order to facilitate inclusion of diversity in participants.

Ethical considerations

Ethical approval for Study Two was obtained from The Prince Charles Hospital Human Research and Ethics Committees (HREC/13/QPCH/316) and registered with that of the Australian Catholic University (201477N). Since there have been past problems with researching on instead of with Indigenous people, the research process was governed according to the Australian Institute for Aboriginal and Torres Strait Islander (AIATSIS) *Guidelines for Ethical Research in Indigenous Studies* (AIATSIS, 2012). These guidelines are based on fundamental principles of rights, respect and reciprocity, as well as mutual understanding, participation and partnership among other principles (AIATSIS, 2012). The process was also informed by the Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research as outlined by the National Health and Medical Research Council (NHMRC) (2003, updated 2018). Further information was obtained from the Australian Code for the responsible conduct of research (NHMRC, 2007), and the National Statement on Ethical Conduct in Human Research (NHMRC, 2007 (updated in 2018)).

Participation was voluntary, and participants gave written consent to tell their stories. The benefit to participants was an opportunity to be able to tell how they understand and perceive hospital care from their experiences. The researcher was aware that some participants may experience emotional discomfort in revisiting their unpleasant moments of their stories. The benefits of telling the story, however, were considered to outweigh the potential for discomfort. According to Pennebaker and Seagal (1999) storytelling can be therapeutic because it provides an opportunity for one's voice to be heard, thus there is value in encouraging people to express themselves.

Data collection

Unstructured qualitative interviews were chosen as a suitable method to collect data for this study to enable gaining of the views, attitudes, and feelings from the participants' perspective (Brinkmann, 2018; Green & Thorogood, 2009). Participants were encouraged to talk freely and be flexible and responsive to their own standpoints, which was achieved through limited use of open-ended questions (Kim, 2016; Morse, 2012). Interviews lasted between 10 to 45 minutes, which is usual for qualitative studies, although in some studies interviews have lasted between 60 to 80 minutes (Liamputtong, 2013). The interview schedule was unstructured, and the investigator's role was to be listener to the story of the participants (Brinkmann, 2018; Kim, 2016). To keep the researcher's influence to a minimum, no set of directive questions were prepared, but a few prompting questions were used for the purpose of sustaining the storytelling (Kim, 2016). An opening question to this study was:

Can you please tell me about your experience while you have been in hospital?

Supportive and encouraging questions were used including:

- What happened next?
- How has it been for you?
- What things do you remember?

Interviews were arranged one to two days before discharge from hospital and were scheduled during quiet periods of the ward, between 1500-1700 hours. The times were planned in consultation with the ward staff and negotiated with the participants in order to avoid disruption to their treatment activities and care. A private room was used for most of the interviews to provide privacy during the interviews to ensure confidentiality and a relaxed environment (Green & Thorogood, 2009). An arrangement with the ward was made prior to conducting interviews on the day, to ensure availability of the room and prevent disruption of the interviews.

Interviews were conducted in English and digitally recorded then transcribed verbatim. Notes were made immediately following the interview for later referral. These notes were to capture first impressions of the interview and were not taken during the interview to reduce disruptions (Kim, 2016). Personal notes were recorded as reflections throughout the program of research process. These personal reflections have been used in the autoethnography study, which is the fourth study in this program of research.

Data analysis

The aim of data analysis in narrative inquiry is to represent participants' narratives in a coherent and meaningful way, and the process is ongoing from the first data collected through to the last (Kim, 2016). Stories are unplanned and informal and require additional theoretical and operational progression to become narratives (Boje, 2001; Petty, Jarvis, & Thomas, 2018; Wiltshire, 1995). People are always in the middle of living their storied lives (Boje, 2001). In the telling of the story, the storytellers necessarily organise the story in a way, which for them, makes sense (Boje, 2001; Petty, Jarvis, & Thomas, 2018). Thus, narrative inquiry transforms events into historical facts that function as elements of a complete story (Hayler & Edmonds, 2013), with an opening, a central and a finishing aspect, giving it coherence (Boje, 2001). A narrative requires a plot to make it meaningful (Czarniawska, 1997) and part of the work of developing coherence in narrative inquiry is to construct a sequence of events in time (Vezeau, 1994).

Data analysis draws upon ideas from different writers. The focus for analysis was to use individual stories to understand collective and shared meanings of hospital care experience for participants (Holloway & Freshwater, 2007). Initial analysis is guided by the approach presented by Murray (2003), where the story form is highlighted in the three parts; beginning, middle and end. Further analysis is guided by structural approaches suggested by Labov and Waletzky (1967), as presented by Riesman (2008), in order to highlight what is happening in the story and provide sequence. Analysis involves construction of a sequence of events that make up the story of participants' hospital experiences (Duffy, 2012; Vezeau 1994). Further analysis involves emplotment as presented by Polkinghorne (1988). Plots were identified across the stories which demonstrated the essential and significant parts of the stories collected and main themes were identified, as detailed in chapter four (p. 99).

Study Three design: Systematic review

Effectiveness of programs to promote cardiovascular health of Indigenous Australians: a systematic review (Chapter Five).

To meet research objective four and further increase understanding of issues in relation to Indigenous people's health care experiences, the effectiveness of current programs designed for Indigenous cardiovascular health was explored by systematic review. This review was designed to enhance understanding of current program interventions and identify issues that influence program success, as well as identify barriers and facilitators in the delivery of healthcare services to Indigenous people. Given that results from program studies are mostly quantitative, a quantitative method of review was used. Nonetheless, a story line was maintained to locate and identify issues that impact Indigenous people's experiences of health care.

Systematic review methodology

A systematic review design was used to conduct a review which sought to find scholarly work within literature that was peer reviewed and focused on application of strategies targeted explicitly for Indigenous Australians and intended for heart health. Gough, Oliver and Thomas (2017) extol the sense of gathering and examining what is already identified from current investigations. A systemic review method allows use of rigorous approaches to synthesise prior investigation data in a systematically comprehensive way, by preparation of a question to address; outlining of procedures to find, choose, critically evaluate, extract and analyse data; and presentation of combined conclusions of the studies that are included in the review (Gough et al., 2012; Liangputtong, 2013; The Cochrane Collaboration, 2005). The bringing together and analysing of what is already known from research, through a systematic process, allows us to know what is already known and assists in the planning of what more needs to be done (Gough et al., 2017). The study protocol for this review is registered with Prospero International (number CRD42016046688). The protocol enabled adherence to a scientific process in the methodological approach (Liangputtong, 2013).

A systematic review facilitates the determination of what is known and is a powerful tool for determining knowledge gaps in literature. Identified gaps can be used to design future research, clinical interventions or formulation of policies; therefore, systematic reviews are "described as the most reliable source of evidence to guide clinical practice" (Clarke, 2011, p. 64). Having collected

stories from a worldwide perspective and local Australian contexts, it was essential to appraise literature to determine what is already known about the effectiveness of health service delivery through programs that were designed specifically for cardiovascular health improvement among Indigenous Australians. A systematic review was chosen for its systematic and rigorous approach, in comparison to use of a traditional or narrative literature review (Clarke, 2011; Gough et al, 2017).

The systematic process for this study involved activities, such as formulation of a question, focusing the study by creating eligibility criteria, designing a search strategy, preparation of a study protocol, study selection, quality appraisal through to data extraction and synthesis of the selected study findings (Clarke, 2011). Gough et al. (2017, p.4) group the review activities into four stages:

- Clarifying the question being asked
- Identifying and describing the relevant research (mapping the research)
- Critically appraising research reports in a systematic manner, bringing together the findings into a coherent statement known as synthesis
- Establishing what evidence claims can be made from the research

The specific methods used in this review are detailed in Chapter Five (p. 117-119).

Study Four design: Autoethnography

Researching with Indigenous people: An autoethnography (Chapter Six)

Researcher engagement

Study Four, which is presented in chapter six, addresses research objective five, which was to reflect on my experience of researching with Indigenous people. As a researcher across a program of research with Indigenous people, I chose to explore my own subjective experiences to bring to the research insights that I had learnt that may have otherwise remained silent. This was an opportunity to draw directly from my inner conversation or dialogue as I critically attempted to understand my position as a clinician, researcher and co-participant in this program of research, and the impact I had on the research process and on Indigenous people's experiences of acute healthcare, and how I was impacted by the process. The aim was to shed some light on how my personal experience was connected to the study. This was a demonstration of my attachment to the research, and my engagement with the question I had planned to investigate.

This study details assumptions held prior to undertaking the program of research and the learning that took place after completion of each and all studies. Humans are the tools of choice for

qualitative research because they have the capacity to interrelate with the situation (Patton, 2015) even without saying a word. In this program of research, I played the role of researcher, which included tasks such as preparation and submission of research protocol for ethics approval, preparation of protocols for systematic reviews, obtaining consent from participants, data collection, analysis, compiling of findings, through to presentation of the research findings through oral presentations and journal publications. Throughout the processes I was involved in making decisions and also critiquing the way issues were handled regarding Indigenous health, and the care they received in acute settings, research projects and other venues. I reflected on my own assumptions and influences that drive my perspective, beliefs, culture and approaches to my practice with regards to Indigenous healthcare and its outcomes. The journey was both challenging and enlightening at the same time.

In the beginning my assumption was narrow in that I assumed that my job would be complete if I carried out the set tasks of collecting data, analysing and preparation of research reports. It was up to the readers then to change their behaviour and consider appropriate ways of providing health care to Indigenous people. After going through the research process, it had an impact on me that motivated me to share my experience. This was to make the program of research story complete by including my own story in which I narrate how I brought my own biases into the research program, and how the lesson learned on my research journey have enriched my personal and professional story. I am a co-participant in this program of research (Wang, 2016), and the fact that I am one of the health professionals with direct contact with patients in the clinical area, made the stories I was told real and the impact on me was powerful. I planned to use the autoethnographic approach because of its focus on personal experience as data (Jones, Adams, & Ellis, 2016).

Study Four design

Autoethnography

Autoethnography comes under the umbrella of qualitative research. Approach. It enables examination of an investigator's subjective and embodied experiences (Chang, 2016; Hokkanen, 2017). The autoethnography was based on my (the research candidate) personal narratives in relation to my research experience with Indigenous people. Autoethnography accepts and accommodates subjectivity, emotionality, and the investigator's effect on the inquiry, rather than hiding from these matters or being presumptuous that they can be set aside as if they do not exist (Wang, 2016). Within this method the researcher is given authority to be the designer and implementer of the research

process (Chang, 2016; Creswell, 2012). I reflected on what I observed, and how my personal being was affected by the participants and the research process. I became aware that I was an integral part of the investigation process, as well as the practice that is carried out in both research and clinical areas. My values as an individual, my judgements, feelings, identity, and actions affect the research process and the way I practice. I decided to use journal and field notes I had kept as I listened to Indigenous stories about their hospital experiences, as data. I realised that I needed to critique my perspective reflexively to enable sharing of insights from this process.

Autoethnography has been described as a research method that has three parts; auto (self), ethno (culture), and graphy (research process) (Chang, 2016). Therefore, autoethnography is a research method focused on investigating how the person is situated in the world by viewing it within a culture they are experiencing (Grant, 2010). Autoethnography enables focusing externally on social and cultural aspects of a researcher's individual experience and then inward to expose a susceptible individuality that is stimulated by cultural interpretations (Duffy, 2012; Winkler, 2018). This connects the self with the social (Chang, 2016). A balance between self and culture is maintained by emphasising the extent to which the cultural setting and the self-accounts are linked (Winkler, 2018). It involves sharing the stories that individuals generate with other connections of the social setting to enable such stories to go beyond the self (Hayler & Edmond, 2013) because without that aspect, then the accounts are but autobiographic stories (Winkler, 2018). It is vital, therefore, to always question to what degree a personal story empowers the researcher and the readers to understand culture (Winkler, 2018). According to Hayler and Edmond (2013, p. 5), we are encouraged to "imagine autoethnography as a particular collection of tools within the qualitative research workshop which focus upon the memories of events, feelings, thoughts and emotions which contribute through varying methods of recall, collection and analysis, towards different types of systematic introspection in order to illuminate and to facilitate understanding".

There are two ways to approach autoethnography, and these are the evocative and analytic views (Chang, 2016; Colyar, 2013; McIlveen et al., 2010). The difference between the two approaches lies in the degree by which emphasis is put on either self (auto) or culture(ethno). The analytic approach has more emphasis on culture, whilst evocative approach leans more towards self (Chang, 2016). The evocative approach concentrates more on the "auto" element by focusing on storytelling than elements of culture and research process (Chang, 2016; Colyar, 2013). However, evocative and analytic approaches to autoethnography are not mutually exclusive (Hayler & Edmond, 2013). The separation comes about to define the emphasis with which the study can be designed. In this program of research, emphasis was on storytelling, but within the culture that participants experienced health

care and within which the researcher experienced the research process, with the aim of developing an improved understanding. The balance of self and culture was appropriate, presenting a primarily evocative approach to present my story with purpose. Sharing of the stories was in acknowledgement and recognition that everyone lives a connected to each other, in various community groups, such as professional, family or social groups that share common norms (Hayler & Edmond, 2013; Muncey, 2010). A sociocultural point of view was adopted in recognition of the importance of sociocultural aspects in knowledge building and implementation of real-world strategies to understand and appreciate Indigenous health experiences of healthcare and research (Banks, 2012; Chang, 2016; Fox, Thayer, & Wadhwa, 2017).

Use of a reflexive process prompts the investigator to be observant and mindful of the culture, political, societal, language and philosophical roots of their standpoint and voice in relation to those being interviewed, therefore it involves reflection in a deeper sense that is systematic in approach (Patton, 2015). While constantly being aware of how I influenced the research process, I was also attentive to how the investigation progression affected me. Autoethnography enabled me to use my personal experience and personal writing to critique practices, make contribution to existing research, embrace vulnerability with purpose or to make an attempt at creating reciprocal relationship with an audience for the purpose of providing insights that could compel a reaction or response (Jones et al., 2013). The process offered me an opportunity to review my own assumptions and expectations (Woodthorpe, 2009).

Listening to stories that inform a program of research entails knowledge co-construction (Barkhuizen, 2011; Duffy, 2012), and an ongoing sharing of the story between researcher and participants develops. A caring relationship develops that enables participants to feel safe to disclose their story (Lee, Hunter, & Franken, 2013). In this way, the research process becomes a collaborative inquiry between researcher and participants involving mutual storytelling and re-storying (Lee et al., 2013). My values and assumptions developed a link with those of the participants that influenced the shaping of this program of research.

The reflective process is another avenue for me as a researcher to situate myself within the study, demonstrating the bidirectional association that I experienced taking part in the program of research. By disclosing self, I reinforced the notion of intersubjectivity and reciprocity which are vital in a researcher-participant relationship and I acknowledged my respect for my participants by researching with instead of researching on my participants. A transparency was established by including my voice. Various forms of data were sourced to conduct this autoethnography, including field notes, diary entries, memory recall, comments and reflections drawn from the data. The major part of the data was reflections and insights gained from the research experience (Winkler, 2018) and

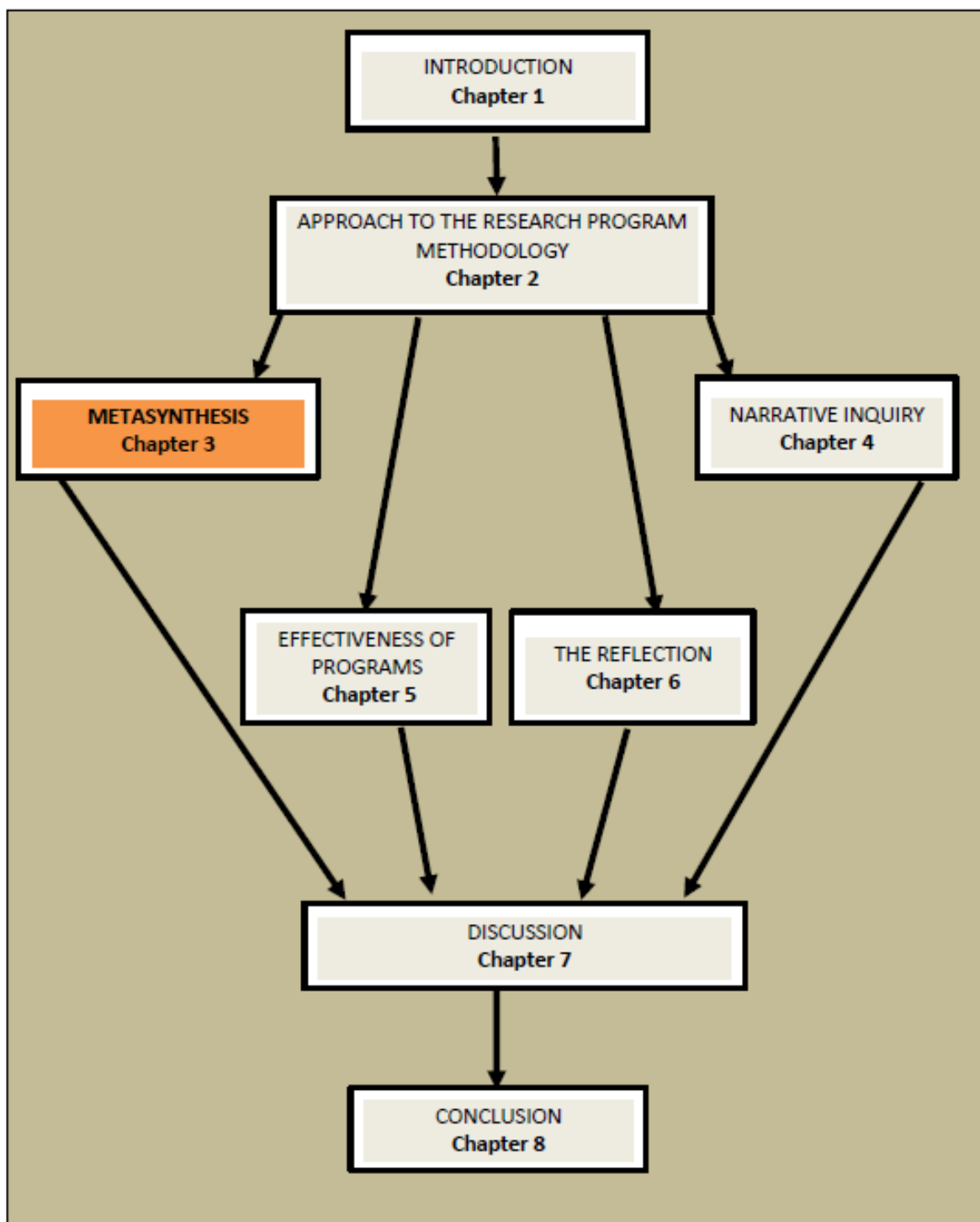
I present the study in a storytelling format (Lewis, 2011). Further details of the research methods and process are presented in Study Four in Chapter Six (p. 141-144).

Chapter Summary

In this chapter, an overview of the methodology used in this program of research has been presented. The research design, methodology and methods used in the four studies have been identified and summarised and cross-referenced to appropriate chapters where details are presented in published articles. The assumption for using this combination of methods was that the stories by participants and researcher reflections would be made visible, thereby revealing an understanding that can impact practice. The proceeding four chapters detail the four specific studies conducted in this program of research.

The next chapter is the beginning of the Indigenous experience story form a worldwide perspective. This will lead to other formats of stories that will contribute to a collective story of how Indigenous people experience acute health care, as told from their perspectives.

Chapter three: Metasynthesis – study one



Chapter overview

Chapter one introduced the program of research by providing a context for the studies and the concepts that inform this program, and chapter two provided the methodological context in which this study sits. This chapter presents a qualitative systematic appraisal of literature on Indigenous peoples' hospitalisation experiences. This was partly to achieve the first objective, which was to appraise current evidence on Indigenous peoples' hospitalisation experiences. It is presented in an article format and permission was sought to include this in this thesis (Appendix 6).

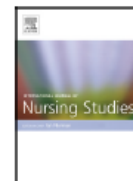
The overall goal was to evaluate previous research on hospitalisation experiences of Indigenous people. Evaluation of previous research enables identification of gaps in knowledge as well as providing rationale for the program of research. The following pages (85-96) present the published version of the metasynthesis verbatim, hence it is in the style of the journal in which it was published.

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Review

Indigenous peoples' experiences and perceptions of hospitalisation for acute care: A metasynthesis of qualitative studies

Vainess Mbuzi^{a,b,*}, Paul Fulbrook^{b,c}, Melanie Jessup^{b,c}^aAdult Intensive Care Services, The Prince Charles Hospital, Brisbane, Australia^bSchool of Nursing, Midwifery and Paramedicine, Australian Catholic University, Brisbane, Australia^cNursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane, Australia

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ABSTRACT

Objective: The objective of this study was to explore Indigenous people's experiences and perceptions of hospitalisation and acute care.

Methods: Systematic procedures were used for the literature search covering the period from 2000 to 2016. Final search was conducted in early September 2016. Quality of the selected studies was assessed using the Critical Appraisal Skills Program. Data extraction was conducted using the data extraction tool from the Joanna Briggs Institute. A thematic approach to synthesis was taken. Statements were assembled to produce aggregated data of the findings, which were then categorised based on similarity of meaning, and the categories were used to produce comprehensive synthesised findings.

Data sources: The literature search was conducted in the following databases: Cumulative Index to Nursing and Allied Health Literature, Google scholar, Medline, Psychology and Behavioural Sciences, and PsycINFO. Manual searches of the International Journal of Indigenous Health, Menzies website and references of reviewed papers were also conducted. Inclusion criteria were qualitative articles, published in English from across the world, in peer-reviewed journals, that investigated acute health care experiences of Indigenous people.

Review methods: A metasynthesis of qualitative research studies was conducted following Joanna Briggs Institute guidelines.

Findings: A total of 21 primary studies met the inclusion criteria. Three themes emerged from the metasynthesis: *Strangers in a strange land*; *Encountering dysfunctional interactions*; and *Suffering stereotyping and assumptions*. These themes emphasised the importance of meaningful relationships for Indigenous people and highlighted their cultural marginalisation in hospital settings.

Conclusion: The findings indicate that healthcare experiences of Indigenous patients and their relatives in acute settings can fall well short of their expectations and needs. It behoves healthcare professionals to firstly be aware of such discrepancies, and secondly to implement strategies that enable inclusive and individualised care.

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What is already known about the topic?

- Hospital admission can threaten Indigenous people's identity and compromise their health and recovery from disease.
- Hospital settings are foreign environments to most Indigenous people.

What this paper adds

- The relationship between health staff and Indigenous people during hospitalisation has a vital role in the determination of negative or positive experiences.
- Relationship-centred approaches to care are likely to enhance the wellbeing of Indigenous people and comfort their relatives.

* Corresponding author at: The Prince Charles Hospital, Adult Intensive Care Services, Rode Road, Chermiside, Queensland 4032, Australia.

E-mail addresses: vainess.mbuzi@health.qld.gov.au, vainess@hotmail.com (V. Mbuzi).

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1. Introduction

Indigenous people are defined as those that inhabited a country or geographical area before different cultures arrived and became

dominant through conquest, occupation, settlement or other means (United Nations, 2009). Indigenous people are more identifiable in countries such as Australia, Canada, New Zealand and the United States because they are the population that inhabited the land in pre-colonial times (United Nations, 2009). They represent a variety of cultures, religions, traditions and languages, and are referred to by other terms such as First peoples/nations, Aboriginals, ethnic groups, natives or tribes (World Health Organisation, 2007). In this paper the term 'Indigenous' is used. Effectively, most Indigenous peoples may be considered minority groups. The terms are not synonymous but both Indigenous people and minority groups tend to be poorer, marginalised and discriminated against, and have less access to social support systems such as education and health care (Grant, 2015).

Worldwide, it is evident that current health care systems are not working well for Indigenous people (Gracey and King, 2009). Researchers have described long-standing inequalities and barriers in access to healthcare between Indigenous and non-Indigenous populations (Peiris et al., 2008), which are demonstrated in higher rates of morbidity and mortality among Indigenous people (Pan et al., 2010; Prabhu et al., 2013). Their experiences within health systems are commonly negative and frequently attributed to colonialism (Eckermann et al., 2010), which effectively marginalised them and their cultures (Browne et al., 2011; Eckermann et al., 2010). It is common for Indigenous peoples to experience clinical encounters that still carry elements of tacit and overt discriminatory practices (Kurtz et al., 2008). Additionally, hospital policies may contribute to discriminatory culture by not reflecting Indigenous views (Cunningham, 2010; Durey and Thompson, 2012; McCall et al., 2009). It is therefore unsurprising that they continue to avoid access to health services, even when they are required and are available (Katzenellenbogen et al., 2013).

Despite widespread acknowledgement of inequality in Indigenous healthcare and outcomes, research on their experiences in hospital is scarce. What is known has largely been drawn from surveys, such as satisfaction surveys, which usually provide simplistic responses to standardised questions, and statistically based clinical outcome data. Further, epidemiological studies, have tended to focus mainly on highlighting how bad the situation is for Indigenous people in terms of the prevalence of disease. Whilst such studies are helpful, they provide insufficient information on

which to judge the quality of healthcare provided to Indigenous consumers. They do not provide adequate insight into the reasons why they do not access healthcare nor do they provide sufficiently detailed information – from an Indigenous perspective – to inform strategies to improve healthcare. Differences in culture, beliefs, and views about health between Indigenous people and those of the dominant mainstream culture demand a better way of researching Indigenous experiences of hospitalisation (King et al., 2009). In this context, there is a need to include the Indigenous person's voice by exploring how they experience healthcare, particularly regarding hospitalisation as it usually forces them to leave their communities to access it.

Qualitative research facilitates a better understanding of people's experiences. The focus of this study was to review qualitative research that investigated Indigenous patients' and their families' experiences of hospitalisation, with the aim of gaining insight and understanding of their distinct perspectives. For the purpose of this metasynthesis, 'hospitalisation' was defined as healthcare received in an acute setting outside of participants' homes. The focus of the review was on hospital care experiences because in this setting there is a concentration of specialists and most staff are non-Indigenous. In Australia for example, it is recorded that Indigenous people attend hospital more than twice the frequency of other Australians, and yet their health outcomes remain poorer than the rest of the population (Australian Indigenous HealthInfoNet, 2016).

2. Methods

2.1. Design

A metasynthesis approach was chosen because of its unique contribution to answering complex questions in areas such as healthcare service delivery, and experiences of healthcare consumers (Sandelowski and Barroso, 2007). It enables understanding of the interplay between people and their environment. Its main strength lies in its ability to allow interrogation and presentation of findings from multiple studies to produce new interpretations of the data (Gewurtz et al., 2008; Sandelowski et al., 1997; Walsh and Downe, 2005), that may ultimately inform clinical practice,

Table 1
Search and search terms Search.

Search terms	Articles found (n)
S1 TI (Aborigin*OR First nation* OR Indigen* OR Inuit OR Maori OR Metis OR Native* OR Oceanic ancestry OR Torres Strait Islander*) OR AB (Aborigin*OR First nation* OR Indigen* OR Inuit OR Maori OR Metis OR Native* OR Oceanic ancestry OR Torres Strait Islander) OR (Aborigin*OR First nation* OR Indigen* OR Inuit OR Maori OR Metis OR Native* OR Oceanic ancestry OR Torres Strait Islander*)	281,916
S2 TI (Content analysis OR Descriptive OR Discourse OR Ethno* OR Exploratory OR Grounded theory OR Interpretive OR Interview* OR Mixed method* OR Multi* method* OR Narrative OR Phenomenolog* OR Qualitative OR Thematic* OR Theme*) OR AB (Content analysis OR Descriptive OR Discourse OR Ethno* OR Exploratory OR Grounded theory OR Interpretive OR Interview* OR Mixed method* OR Multi* method* OR Narrative OR Phenomenolog* OR Qualitative OR Thematic* OR Theme*) OR SU (Content analysis OR Descriptive OR Discourse OR Ethno* OR Exploratory OR Grounded theory OR Interpretive OR Interview* OR Mixed method* OR Multi* method* OR Narrative OR Phenomenolog* OR Qualitative OR Thematic* OR Theme*)	2,212,195
S3 TI (Attitude* OR Belief* OR Experience* OR Opinion* OR Perception* OR Perspective* OR Satisfaction OR Value* OR View*) OR AB (Attitude* OR Belief* OR Experience* OR Opinion* OR Perception* OR Perspective* OR Satisfaction OR Value* OR View*) OR (Attitude* OR Belief* OR Experience* OR Opinion* OR Perception* OR Perspective* OR Satisfaction OR Value* OR View*)	6,519,142
S4 TI (Acute care OR Emergency care OR Hospital OR Hospital admission OR Hospital care OR Hospitalisation OR Inpatient* care) OR TI (Acute care OR Emergency care OR Hospital OR Hospital admission OR Hospital care OR Hospitalisation OR Inpatient* care) OR (Acute care OR Emergency care OR Hospital OR Hospital admission OR Hospital care OR Hospitalisation OR Inpatient* care)	4,202,208
S5 S1 AND S2 AND S3 AND S4	1497
S6 Filter: English; Peer reviewed	623

education, policy formulation, and research (Finfgeld-Connett, 2010).

The concept of synthesising qualitative research evidence is based on the premise that integration of current evidence in the area of interest has the optimum power to guide practice, compared to a single study (Finfgeld, 2003; Sandelowski and Barroso, 2007; Sandelowski et al., 1997). Metasynthesis enhances the value of qualitative research through integration of evidence, which facilitates a fuller understanding of the phenomenon, context or culture under consideration (Jensen and Allen, 1996).

We employed a structured approach to the metasynthesis based on guidelines for a systematic review and synthesis of qualitative data by Joanna Briggs Institute (2014). The review process involved systematic literature search, selection of studies, appraisal of included studies, data extraction and synthesis of findings.

2.2. Search strategy

Systematic procedures were used for literature search covering the period from 2000 to 2016. The research question that guided the focus of the literature search was: *How do Indigenous people describe their experiences of hospitalisation or acute care?*

Qualitative articles, published in English, peer reviewed, and investigating hospitalisation experiences of Indigenous people were identified using computerised searches. The following databases were searched for relevant articles: CINAHL, Google scholar, Medline, Psychology and Behavioural Sciences and

PsycINFO. To formulate a search strategy that was both sensitive and specific, terms were divided into four categories: Indigenous people, personal experience, hospitalisation, and qualitative methodology, which formed the basis for the literature search, as shown in Table 1. The inclusion criteria for this review were a) qualitative studies (or mixed method studies with a significant qualitative component) that were focused on Indigenous patients' and relatives' hospital or acute care experience, b) use of interviews to emphasise individual experiences of participants, c) published in peer-reviewed journals, and d) involving significant Indigenous patients and relatives participation if a study had mixed participation. Studies were excluded if they were quantitative or were focused on health professionals' (including Indigenous) perspectives.

2.3. Study selection and appraisal

First, titles and abstracts were reviewed to isolate and exclude duplicate studies, those that did not focus on Indigenous people in acute care or hospital settings, and those whose focus was on health professionals' perspectives. The remainder was subjected to full text assessment and those that did not meet the inclusion criteria were excluded.

Studies that met the inclusion criteria were appraised for quality using a checklist from the Critical Appraisal Skills Programme (CASP) for evaluating qualitative research, which comprises 10 items concerned with rigour, credibility and relevance (CASP, 2013). Excluding the final question about the

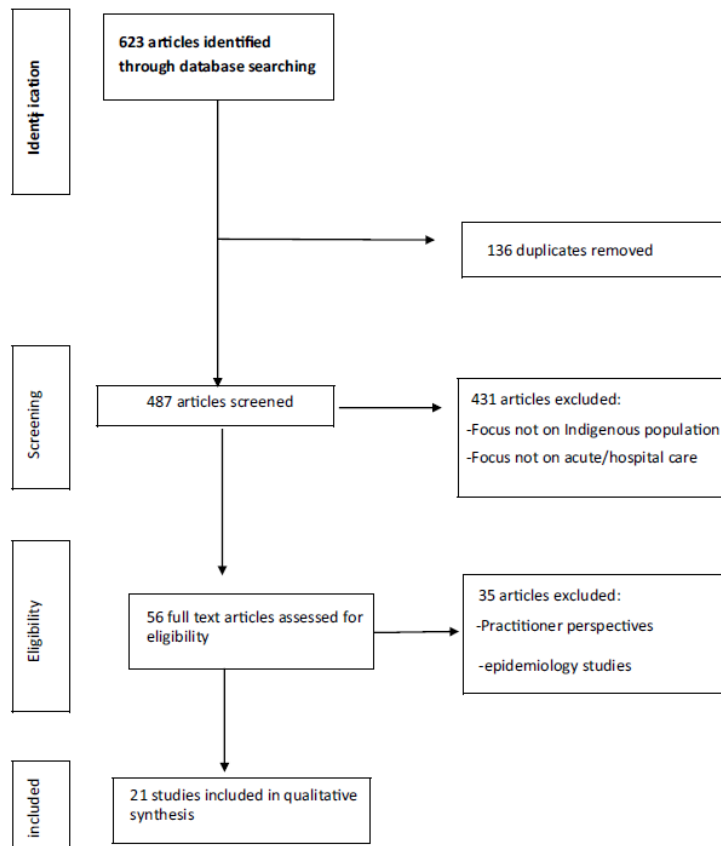


Fig. 1. Search flow diagram.

Table 2
Included articles: Indigenous people's experience of hospitalisation.

Author, year, country	Aim	Qualitative approach	Participants (n)	Method/ data source	Approach to analysis
Anderson et al. (2012), Australia	To gain understanding of how demands of dialysis impact the lives of Indigenous patients	Descriptive	Indigenous (146) and non-Indigenous (95)	Semi-structured interviews	Thematic analysis
Arlidge et al. (2009), New Zealand	To explore and describe the experiences of indigenous Maori families when their children were admitted to hospital	Exploratory	Maori (23)	In-depth interviews	Thematic analysis
Arnaert and Schaack (2006), Canada	Explore the experiences of the Inuit patients with emergency nursing	Exploratory	Inuit patients (4)	Semi-structured interviews	Content analysis
Brown et al. (2016), Australia	To explore the lived experiences described by Indigenous women accessing labour and birth care in the standard hospital care system at a tertiary public hospital	Phenomenology	Aboriginal women (14)	Interviews	Thematic analysis
Burnette and Kickett (2009), Australia	To explore the experience of Aboriginal people undergoing treatment for end stage renal disease	Ethnography	Aboriginal people (6)	Unstructured Interviews	Thematic analysis
Chapman et al. (2014), Australia	To identify the perceived barriers and enablers to accessing healthcare at a Victorian Emergency department for local Indigenous community.	Exploratory	Aboriginal participants (16)	Focus groups/yarns	Thematic analysis
Corbett et al. (2006), New Zealand	To understand the experiences of Maori in accepting responsibility for care of whanau member following a stroke	Exploratory	Maori (3) plus 7 focus groups)	Semi structured interviews and Focus group interviews	Thematic analysis
Kelly et al. (2009), Canada	To understand cross-cultural hospital based end of life care from the perspective of bereaved First Nations family members	Phenomenology	Recently bereaved family members (10)	In-depth interviews	Crystallisation and immersion techniques
McGrath (2006), Australia	To explore indigenous people's experience of relocation for medical treatment during end of life care	Exploratory	Indigenous (40) [plus 32 others]	Interviews	Thematic analysis
McGrath and Rawson (2013), Australia	To explore the experience of relocation for specialist care for Indigenous women	Exploratory	Indigenous women (12), health professionals (28)	Interviews	Thematic analysis
Mulemi (2008), Kenya	To explore how adult cancer in-patients feel about and make sense of their condition and therapy	Ethnography	Patients (42), nurses (11), relatives (11), doctors (3)	Observations and in-depth interviews	Thematic analysis (Maximum Qualitative Data Analysis)
Rix et al. (2014), Australia	To describe the experiences of Aboriginal people receiving haemodialysis in rural Australia	Indigenist and community based participatory approach	Aboriginal participants (18)	Storytelling and yarning approaches	Thematic analysis
Salvalaggio et al. (2003), Canada	To explore the experiences of health and illness among First Nations dialysis patients	Descriptive	First Nations (12)	Interviews	Thematic analysis
Sambrano and Cox (2013), Australia	To explore how three Indigenous people experienced the controversial practice of seclusion	Phenomenology	Indigenous (3)	In-depth interviews	Gadamer's phenomenology guided analysis
Shahid et al. (2011), Australia	Investigating experiences and barriers to access cancer services	Descriptive	Aboriginal participants (30)	In-depth interviews	Thematic analysis
Tanner et al. (2004), Australia	To develop a clearer understanding of the hospitalisation experiences of Indigenous families from remote areas of Australia	Exploratory/ Dadirri method	Indigenous (3) others (6)	Interviews	Thematic analysis
Treloar et al. (2014), Australia	To explore the cancer care experiences of Aboriginal people in NSW using a social inclusion lens	Exploratory	Aboriginal people (18), healthcare workers (16)	Interviews/ Narratives	Thematic analysis
		Descriptive	Indigenous (12)	Interviews	Thematic

value of the research, we assigned a score in the range 1–9 based on assessments of the first 9 questions (*Can't tell or No*: score = 0; *Yes*: score = 1). The studies scored between 7 and 9/9 which indicated high quality (1–3/9 = low quality; 4–6/9 = medium quality; 7–9/9 = high quality). One study scored 7/9, sixteen scored 8/9 and four scored 9/9. Seventeen studies scored 0 for question 6 which addresses researcher and participant relationship. Given the importance of relationship for Indigenous people, this was a significant oversight (Flicker and Worthington, 2012). Further evaluation of trustworthiness of each study was undertaken using the Rosalind Franklin Qualitative Research Appraisal Instrument (RF-QRA) (Henderson and Rheault, 2004), and they all met various aspects of the confirmability, credibility, dependability, and transferability strategies. The four main ones used across the studies were multiple investigators, inclusion of quotes, method description, and sample description respectively. However, we did not use the appraisal results as an additional method to exclude studies, on the basis that even low quality studies may contribute to findings because they do represent participants' views (Sandelowski et al., 1997; Thomas and Harden, 2008). As noted by Dixon-Woods et al. (2007), appraisal tools tend to focus more on procedural aspects of research rather than research findings and their relevance.

2.4. Metasynthesis approach

A thematic approach to synthesis of qualitative studies by Thomas and Harden (2008) guided the analysis process. Three stages were adopted. First, the studies were read several times to enable a clear picture of the findings and to gain an understanding of the themes and concepts of each study. Focus was placed on sections labelled 'results' or 'findings' to extract statements which were then assembled to produce aggregated data of the findings for each study. The statements were categorised based on similarity of meaning and these facilitated formation of themes within each study. Secondly, themes were transferred across the different studies to form categories. This was done by repeatedly examining and comparing data from one study against other data. Finally, themes isolated across the studies led to formation of three final themes which were used to produce comprehensive synthesised findings as described below.

3. Findings

The search found 623 studies of which 602 were removed. Fig. 1 demonstrates the selection process that led to the final studies

included in the synthesis. The 21 studies included in the metasynthesis are summarised in Table 2. The findings of this metasynthesis provide a rich and detailed contribution to the understanding of Indigenous people's experiences of care in a range of acute settings, which included dialysis centres (non-community based), emergency departments, maternity units, oncology wards, paediatric units, palliative care centres, and other hospital-based wards. Studies retrieved came from a variety of countries (Australia: 13; Canada: 4; Kenya: 1; New Zealand: 3). Several key features emerged consistently across the studies reviewed, which led to construction of the following three themes: *Strangers in a strange land*, *Encountering dysfunctional interactions*, and *Suffering stereotyping and assumptions*, which are presented below.

To enhance credibility, quotes are presented to illustrate each theme, and Table 3 illustrates how each study relates to each theme. The overarching message that Indigenous people gave voice to was that they were faced with a lot of difficulties when accessing healthcare in hospital settings. These were exacerbated by poor communication, environmental restrictions, superficial relationships, isolation, and ingrained negative attitudes towards them.

3.1. Strangers in strange land

This theme reflects the finding that for many Indigenous people, coming to hospital meant leaving their unique way of life and being exposed to a new experience and foreign culture (Brown et al., 2016; McGrath and Rawson, 2013). They had left their families and familiar community to come and dwell among strangers that were largely non-Indigenous, and who cared for them with little understanding or knowledge of cultural protocols, which impacted on the perceived quality of their care experiences. It was a frightening and stressful situation, especially for those experiencing hospitalisation for the first time.

3.1.1. Communication challenges

Good communication was an anchor for implementing effective care but it was challenging because of language barriers and lack of recognition of cultural differences (Arnaert and Schaack, 2006; Brown et al., 2016; Watson et al., 2002). Participants came from different language backgrounds and it was sometimes hard to find interpreters, as reflected in this quote:

Table 2 (Continued)

Author, year, country	Aim	Qualitative approach	Participants (n)	Method/data source	Approach to analysis
Watson et al. (2002), Australia	To develop educational resources through information and experiences provided by Aboriginal and Torres Strait Islander women and healthcare professionals				
Wiebe and Young (2011), Canada	To describe and record patient families and experiences	Exploratory	Mixed race participants (21)	Interviews	Thematic analysis
Wilson and Barton (2011), New Zealand	To explore Maori experiences of hospitalisation	Case study, mixed methods	Maori (11)	Semi-structured interviews/data triangulation	Thematic analysis
Worrall-Carter et al. (2016), Australia	To explore Aboriginal patients' lived experiences of cardiac care at a metropolitan hospital	Phenomenology	Aboriginal patients (10)	In-depth interviews	Thematic analysis

Table 3

Relationship between studies and themes (✓ = contributed to theme, × = did not contribute to theme).

Study	Strangers in a strange land		Encountering dysfunctional interactions		Suffering stereotypes and assumptions	
	Communication challenges	Environmental restrictions	Interpersonal relationships	Isolation of individuals	Socioeconomic disadvantage	Indigenous status
Anderson et al. (2012)	✓	✓	✓	✓	✓	✓
Arlidge et al. (2009)	✓	✓	✓	✓	✓	✓
Arnaert and Schaack (2006)	✓	✓	✓	×	✓	✓
Brown et al. (2016)	✓	✓	✓	✓	✓	✓
Burnette and Kickett (2009)	✓	✓	✓	✓	×	✓
Chapman et al. (2014)	✓	✓	✓	✓	×	✓
Corbett et al. (2006)	✓	✓	✓	✓	✓	✓
Kelly et al. (2009)	✓	✓	✓	✓	×	✓
McGrath (2006)	✓	✓	✓	✓	✓	✓
McGrath and Rawson (2013)	✓	✓	✓	✓	✓	✓
Mulemi (2008)	✓	✓	✓	✓	✓	✓
Rix et al. (2014)	✓	✓	✓	✓	✓	✓
Salvalaggio et al. (2003)	✓	✓	✓	✓	✓	✓
Sambrano and Cox (2013)	✓	✓	✓	✓	×	✓
Shahid et al. (2011)	✓	✓	✓	✓	✓	✓
Tanner et al. (2004)	✓	✓	✓	✓	✓	✓
Treloar et al. (2014)	✓	×	✓	✓	✓	✓
Watson et al. (2002)	✓	✓	✓	✓	✓	✓
Wiebe and Young (2011)	✓	✓	✓	✓	✓	✓
Wilson and Barton (2011)	✓	✓	✓	✓	×	✓
Worrall-Carter et al. (2016)	✓	✓	✓	✓	×	✓

There are not always interpreters here. It would be nice to have an interpreter ready for . . . who don't understand English. (Relative: Arnaert and Schaack, 2006)

In most cases, family members were relied upon for interpretation. This was a challenge because most participants had relocated and travelled away from family for treatment. This strategy was also only effective if the family interpreter understood the information that was presented. Again, sometimes the participant consented to a procedure because they felt pressured by a family member, as illustrated by the following participants:

'Mum, they are putting a thing in you to drain water.' That is all I could say, that's all I understood it to be, I didn't really know why. (Relative: Wilson and Burton, 2011, p2320.)

I blame my daughter . . . she . . . let (the doctor) put that catheter on . . . I didn't want it in. I told them I don't want it in right now . . . (Patient: Salvalaggio et al., 2003, p22.)

Participants frequently reported that hospital staff were too busy to make time to communicate effectively with patients and families. In this context, participants expressed gratitude for those that found time to check on them individually and explain issues to them:

They took good care . . . of me. They even went to check on me at night . . . (Patient: Arnaert and Schaack, 2006)

I was grateful that she [nurse] took time to explain this [why an intravenous catheter was needed] to me (Patient: Arnaert and Schaack, 2006)

It was also noted that even when explanations were given, participants felt they were not well understood due to the use of complicated medical terms. This was reflected in the following statement from a relative:

When doctors and staff explain things to Aboriginal patient, I found what they do; they talk in university words, big jaw breakers, instead of just talking plain English so they can understand it. (Relative: Rix et al., 2014)

Most instructions were in written form, and included hospital directions and information for patients and their families (Arlidge et al., 2009; Worrall-Carter et al., 2016). Receiving written information was foreign to some participants that had a predominantly oral tradition and expected face-to-face interactions. Furthermore, some were unable to read or understand the language in which the material was written. Even for those able to read, there was an expressed desire for face-to-face interaction (Brown et al., 2016), as illustrated below:

Sometimes they give you a pamphlet; you don't have time, and you need someone there to say it out. Like there are services that are available for you and your child, you know. But they should have some people like these based in hospital that can inform people about these services that can help them. (Relative: Arlidge et al., 2009)

I wanted someone to tell me what to do. (Relative: Corbett et al., 2006, p259.)

They don't prepare you for when you go home. They tell you some of the things that are available, but for real nitty, gritty, they don't. I was looking for them to say to me, 'Here are some services to help you when you get home'. (Relative: Corbett et al., 2006)

The majority of participants experienced significant communication challenges. Some of these are demonstrated in the following quotes:

. . . Yeah, shocked because nobody had ever said anything to me about [kidney disease] . . . I went to the hospital . . . late at night . . . and the next day . . . they were looking at my -you know- . . . which side they're gonna put [the fistula]. And they didn't say anything [to explain] that they was getting me ready [for dialysis]. (Patient: Anderson et al., 2012, p3.)

I don't know what he was . . . he brought the consent form around; he didn't check it was . . . consent form for the operation. I signed it, but I didn't see . . . sterilisation on it. But, the doctor . . . she brought it around to me and said, 'Hey, you're going to get sterilised.' . . . I said, No, I don't do anything about sterilisation. (Patient: Watson et al., 2002)

The communication challenge was compounded by cross-culture situations in participants' interactions with staff, as described in the following statement:

... they think differently, than us. Different lifestyles to us. (Patient: Burnette and Kickett, 2009)

It was found that Indigenous people were in a disadvantaged position due to language barriers, when compared to those who understood English and were of the same culture as that promoted in hospitals (Anderson et al., 2012; Burnette and Kickett, 2009; Watson et al., 2002).

3.1.2. Environmental restrictions

Participants found the hospital environment to be foreign and a journey to hospital was like travelling to another country:

... going away to hospital isn't an option for most people, it's foreign. (Patient: McGrath, 2006)

I was terrified in hospital ... Unknown territory. (Patient: McGrath, 2006, 104.)

Participants reported having a lack of personal and family space, prison-like dictates and also painful experiences in terms of physical pain and loss. It was hard to maintain privacy because of the forced sharing of spaces with strangers and most of the time discussions were held within hearing distance of other patients (Arlidge et al., 2009; Arnaert and Schaack, 2006; Watson et al., 2002), as stated by one participant:

The other patients were looking and listening to what we were talking about, you know there was no confidentiality, no privacy. (Relative: Arlidge et al., 2009)

Further, the environment was lacking in space that was appropriate for Indigenous families (Kelly et al., 2009; Worrall-Carter et al., 2016). Restriction of the number of people allowed at the bedside was difficult for larger Aboriginal families to manage, and it was hard to adhere to specific visiting times. The lack of an appropriate space was particularly difficult when a relative was dying, as reflected below:

... in our culture, towards the end you need more people. We want not just family, but friends there too. Not just immediate family. (Relative: Kelly et al., 2009, p e5.)

Mixed gender bed allocation in hospital was another source of distress for some participants (Burnette and Kickett, 2009). It was especially foreign to their culture of practising men's and women's business. There is normally a reserved relationship between men and women, with physical separation, especially those not known to them. The following example was recalled by a female participant:

There was men in there. Just lay there and cover ourselves, cover our body. I was telling all the nurses. They say 'We got no room.' I said, 'I want to go to another room'. (Patient: Burnette and Kickett, 2009)

In general, hospitals were described as unhappy environments that were associated with physical discomfort as a result of symptoms of disease processes, treatments, psychological distress and death (Anderson et al., 2012; Arlidge et al., 2009; Chapman et al., 2014; Corbett et al., 2006; McGrath, 2006; Salvalaggio et al., 2003; Shahid et al., 2011; Watson et al., 2002; Worrall-Carter et al., 2016). The concentration of sick and sad people was alien to participants' cultural practices in which sick people were not gathered together in one place to be cared for. This was reflected upon by one of the patient participants:

Hospitals are a place of sickness and death. So you do not want to be around that if you want to be well. There is energy about hospitals, there is a sickness to it and you don't want to be in the middle of that ... (Patient: Wilson and Barton, 2011, p2320.)

Some participants were also afraid of the hospital environment because of its perceived similarity to that of a prison because people were isolated, and a certain way of behaving was dictated (Sambrano and Cox, 2013). This was illustrated in the following quotes:

... every time I sit here there are tears, I sit here, I just go back and forwards, inside, outside, I come out, one o'clock, two o'clock ... It's like being in a prison ... (Patient: Brown et al., 2016, p6.)
In isolation they drug you up ... you can't even talk properly ... (Patient: Sambrano and Cox, 2013, p527.)

Participants felt like strangers in a strange country due to their lack of a common language and practices, but one great difficulty was being separated from their own community for long periods of time and also being afraid to die 'off country' as many believed it was important for their spirit to return 'to country' when they die.

3.2. Encountering dysfunctional interactions

The relationships encountered by participants in hospital were found to be superficial and perfunctory, which is counter to the personal relationships they practice culturally. Thus, it was hard to establish meaningful relationships with staff and other patients. This resulted in a boundaried therapeutic relationship that was viewed as being functional, contractual or mechanistic, that lacked trust or genuine meaning.

3.2.1. Interpersonal relationships

Participants described a desire to relate to staff positively but found that relationships were guarded due to a lack of trust and genuineness. Although some reports were positive about staff/patient relationships, in general, Indigenous people felt patronised and marginalised in most of their encounters (Anderson et al., 2012; Chapman et al., 2014; Sambrano and Cox, 2013; Treloar et al., 2014), as illustrated below:

Every time [my partner] goes into hospital, he is treated like a piece of dirt. And then he ends up discharging himself because he doesn't get proper treatment. (Relative: Treloar et al., 2014, p376.)

How the nurses talk to them up there, very, very, very, rude. They can have just a question and they get a bad response back. A real bad response like 'don't mess with us coz I work here' you know? (Patient: Sambrano and Cox, 2013, p527.)

The hospital setting was also perceived to have a medical hierarchy and patients felt that less attention was paid to patients' perspectives (Mulemi, 2008). As one patient stated:

To be quite honest I was a bit uncomfortable in going there ... I felt like I was just a statistic, they didn't get to know you ... (Patient: Rix et al., 2014)

Hospital staff conducted their practice focusing on western ways and culture, therefore, there was a strong perception among participants that staff made little or no effort to get to know them, believing that staff had minimal understanding of Indigenous concepts, as reflected in the following quotes.

Everything is done in a kind of Western way ... I just distrust them, it's just rituals and stuff – it's their belief system. (Relative: Wilson and Barton, 2011)

I think they need to go back to school ... learn about Aboriginal issues and cultural values. Because half the time their attitude towards Aboriginal issues and values keeps Aboriginals away. (Patient: Rix et al., 2014)

Participants felt that the ambience in the ward was busy most of the time (Watson et al., 2002; Worrall-Carter et al., 2016), and this sometimes left them feeling that they should not disturb staff or interfere with their work by asking for help. At times they felt that

staff were unhappy with them for calling for help, as one participant described:

We'd ring the bell . . . they'd come in and they're just grumpy that you've rung them. I don't know if it's because we're Maori or we are a nuisance. (Relative: Wilson and Barton, 2011, p2321.)

Participants felt that everything was conducted mechanically, at specific times, and felt they were not allowed to disturb the scheduled flow of events. For example, participants felt they were not given an opportunity to explain why they were late for or had missed an appointment. Rather, they felt as if lateness was classified as noncompliance and was associated with a sense of disobedience (Burnette and Kickett, 2009; Sambrano and Cox, 2013). These sentiments are illustrated by the following quotes:

When I come to dialysis, they're "hurry, hurry, hurry, hurry" . . . Sometimes I feel stressed when they're telling me to hurry up, at dialysis . . . Doesn't matter if I'm late, neither here nor there for me, so long as I get dialysed. I know there's other people besides me, but that's how I am. Slow . . . Noongar time. (Patient: Burnette and Kickett, 2009, p116.)

You are just a puppet . . . (Patient: Burnette and Kickett, 2009)

Relationships with healthcare staff were therefore guarded on the part of participants in fear of negative reactions (Mulemi, 2008). This limited relationship restrained participants from participating actively in their own care, especially when considering questions or saying something that might be construed as being contrary to what staff had suggested. Some were fearful of retribution if they did not conform as expected, as stated by the following patient participant:

What people fear most is that . . . this person [hospital staff] can even kill me! If I speak against you and you are the dakitari [doctor]. (Patient: Mulemi 2008)

Although mostly negative relationships were described, there were some accounts of caring relationships. In such cases, a sense of security and safety was engendered, as one participant reflected:

They looked after our baby like their own child . . . made us feel safe. (Relative: Wiebe and Young, 2011)

Participants wanted to be involved as part of the team and acknowledged as individuals with unique needs, but this was rare. However, when relationships were meaningful, a significant connection was felt, which demonstrated recognition of human equity despite cultural differences.

3.2.2. Isolation of individuals

Despite having other people around, participants felt isolated in hospital. Relocation for treatment tore apart their connectedness with family and home land (Anderson et al., 2012; Burnette and Kickett, 2009; Corbett et al., 2006; McGrath and Rawson, 2013; Salvalaggio et al., 2003) and they were confronted with marked cultural shock, especially those that had not previously been away from their community (McGrath, 2006; McGrath and Rawson, 2013; Salvalaggio et al., 2003). Leaving family and familiar surroundings was stressful enough (McGrath and Rawson, 2013), but facing life-threatening occasions alone impacted greatly on their experiences (Anderson et al., 2012; McGrath, 2006; Salvalaggio et al., 2003). The need for family presence in times of acute illness was important especially in situations where patients were dying (Kelly et al., 2009). Participants reflected as follows:

We was by ourself . . . and we couldn't hardly see people from [home region]. (Patient: Tanner et al., 2004)

. . . I get very homesick when I go to hospital, for my family. I miss my house, but mostly my family, or even another Aboriginal person not being in the ward. (Patient: Burnette and Kickett, 2009)

While a few made friends with other patients, their relationships were temporary, and they were lonely again when their new friends were discharged or died:

Unfortunately, my immediate friend here died two days after I came here. Then I was left . . . At night I am alone here because this one has gone [died]. (Patient: Mulemi, 2008.)

. . . it does get lonely in the hospital you know sick people everywhere, doctors walking everywhere, it's a very busy place. (Patient: Tanner et al., 2004)

The hospital was also lonely because other patients were sick and the staff were busy or the language spoken by the majority was not familiar (Tanner et al., 2004; Worrall-Carter et al., 2016). Ultimately, participants felt isolated from the relational network of their community and culture.

3.3. Suffering stereotyping and assumptions

Participants sensed they were judged simply because they were Indigenous. They felt looked down upon and blamed for their misfortune and illness, and for not taking care of themselves. They perceived that healthcare staff held an ingrained negative belief about them.

3.3.1. Indigenous status

Participants' perceptions were that staff held negative views about them and did not respect their views (Brown et al., 2016; Mulemi, 2008; Rix et al., 2014), as illustrated in the following quotes:

. . . I think that they think Aboriginals don't understand, but we're not stupid. (Patient: Burnette and Kickett, 2009)

The doctors were very busy, especially the specialists in the city. There was one that would come in and then leave without telling us what he found. . . ?I thought he probably thinks that we don't have a good grasp of English that we wouldn't understand . . . and that he thought his time would be wasted on us. That bothered me. (Relative: Kelly et al., 2009)

Apart from their medical conditions, participants suffered hardships as a result of potential or actual stereotyping and assumptions. All they wanted was to be treated as individuals and in accordance with their culture. These feelings are emphasised in the following quotes:

. . . it's kind of like when you go in there you just feel that stigma. I think that's me more my personal . . . feeling about it all was just the stigma of being a Pacific Islander . . . (Patient: Arlidge et al., 2009)

. . . the doctor, he gave me a hard time about it, like I was a neglectful, mother. And that's the other thing . . . they interrogate you because you're brown. (Patient: Wilson and Barton, 2011)
I had that many blues in hospital; I just think some of the staff in hospital don't understand where we come from. They misinterpret what we're saying, and all this sort of stuff, you can end up with a bit of a blue on your hands and I have been there before. (Patient: Burnette and Kickett, 2009)

Furthermore, coming to hospital engendered feelings of embarrassment (Chapman et al., 2014) and fear of being chastised (Rix et al., 2014; Sambrano and Cox, 2013). For example, as reflected in the following quotes, they felt they were being judged as bad parents or as patients that had brought the situation upon themselves:

I started getting a bit paranoid because I think I was thinking I wonder if these . . . nurses are looking at me going, 'I wonder if this is one of those cases . . . where the mother's broken the (child's) arm'. (Relative: Arlidge et al., 2009, p176.)

... in hospital about three or four times, um, I was questioned as to whether I did something else. And I whole heartily told the truth ... I even got taken out of my room and into another room and sat down with a doctor who said 'you can tell me no one is here' ... I cried, I was very, very upset, I felt like they were judging me ... it meant a lot to me to tell the truth ... it really, really upset me ... I felt, um, judged, really judged. (Patient: Brown et al., 2016)

At times, participants felt they were not in a position to stand up for themselves, even when they had reason to complain, as reflected below:

I had found out I could make a complaint if I wasn't happy with some of the care ... I spoke to my older sister ... she said just to leave it because she felt Mum might get alienated next time. (Relative: Wilson & Barton, 2011; p2321.)

Some participants did not understand why they were asked the same questions repeatedly by different staff (Mulemi, 2008). This was a source of stress and suspicion for some as they reflected upon past experiences, from childhood when children were taken away from their parents during healthcare consultation (Rix et al., 2014). Without offering an explanation, repeated questioning distressed some participants and caused anger, as expressed in these quotes:

I felt there were ... spies in there, marking down everything I did ... (Relative: Wiebe and Young, 2011)

... that really ticked me off ... I was answering the same questions all the way through, to every person I spoke to from nurse, doctor, to whatever intern ... don't you people write all this information down on paper, just pass the piece of paper along? (Patient: Arlidge et al., 2009)

Some participants found it difficult to answer questions about their improvement because they expected the doctor to know that information and are knowledgeable about all the tests that had been done (Mulemi, 2008). There was also reluctance to ask questions, even when they did not understand information, because they were shy or too frightened, as illustrated below:

But the majority of our people are very shy, they (are) frightened to ask questions of anybody, specially a white person and that's why they find they got a few problems because they (are) frightened to ask for some advice. (Relative: Rix et al., 2014)

People [indigenous patients] will go along and shake their head and agree to things to get away from that person [clinician] that is firing all these big questions at them ... they can't understand all that. (Relative: Anderson et al., 2012.)

3.3.2. Socioeconomic disadvantage

Participants described financial hardships of coming into hospital. Most were unable to access the financial assistance available due to the complicated application process (Corbett et al., 2006; McGrath and Rawson, 2013; Treloar et al., 2014), while some were not aware of its existence. For some the process brought about feelings of shame and made them feel like 'beggars', as expressed in this quote:

They say in the information there's financial assistance available, but they don't explain that you'll be assessed. ... I was never assessed and because I stayed working in the community sector ... I am one of the lucky ones too I suppose to have the knowledge. But you know ... it's like you're begging, for like, financial help and them not listening. I think you just get stereotyped as like ... you know, it's not fair. (Patient: Treloar et al., 2014, p377)

Financial hardship was an important consideration especially for those that had relocated temporarily in order to access health services (Anderson et al., 2012; Arnaert and Schaack, 2006;

Burnette and Kickett, 2009; Kelly et al., 2009; McGrath, 2006; Mulemi, 2008; Rix et al., 2014; Salvalaggio et al., 2003; Shahid et al., 2011; Tanner et al., 2004). Furthermore, participants were likely to be younger and with family responsibilities causing hospital admission to be harder for them financially (Anderson et al., 2012; Salvalaggio et al., 2003). The financial burden affected participants in a unique way mainly because of relocation and the extra resources required when their family was separated, as illustrated in the following quotes:

My other half he's ... ringing up four times a day you know to see how we are and when we're coming back ... It's hard on everyone really ... (Patient: Tanner et al., 2004)

My work does not give me benefits and so when I have to come down ...? I am not paid and my family suffers from this (Patient: Arnaert and Schaack, 2006)

Not all staff recognised the financial burden of hospitalisation on Indigenous people and it was not seen as a priority issue (Treloar et al., 2014). Daily visitations and personal items for care were expected to be provided regardless of the financial position of the patient or family. Such routine expectations caused participants discomfort and embarrassment when they were unable to afford these expenses, as expressed in the following quotes:

When I come in I got told to stop running around, visit her every day and I told them I have got no money (Relative: Watson et al., 2002)

I asked them [for sanitary pads]. [They said] 'You've got to buy your own. You got any money to buy them?' ... she made me feel shame ... (Patient: Watson et al., 2002)

4. Discussion

The findings provide a rich but consistent appreciation of the difficulties experienced by Indigenous patients and relatives when accessing hospital care. In summary, participants' experiences were found to be largely negative and very difficult on several fronts. Hospitalisation felt threatening and, for some, was associated with significant feelings of fear. It affected their sense of identity and cultural safety, and impacted their interpersonal relationships. In most cases there was a sense of displacement due to relocating away from family and country/community in order to access needed health services.

Relationship issues were central to the experiences of participants. The findings highlighted that Indigenous people put a high priority on relationships which demonstrate shared respect, meaning, knowledge and experience, and revealed that this is given little attention within western biomedical models of healthcare. As a result, participants reported difficulty in establishing genuine and meaningful relationships due to the fragmented, episodic and impersonal care delivery. Indigenous people sought a relationship that gave attention to each person and their particular complexities (Coyle and Williams, 2001). Better understanding of relational aspects by health professionals and integration of this into their approach to care may improve hospital experiences for Indigenous people through provision of a sense of security, and enhanced sense of significance.

The first theme, *Strangers in a strange land*, highlights the importance of family, familiar environment and culture. Relocation for treatment took away the sense of security and identity participants had within their families and communities: they were faced with a different culture and felt alienated by language, environment, relationships and general outlook on life. Participants did not report any evidence of health professionals' awareness of their culture within the hospital care setting.

The notion of cultural safety is both a theoretical and practical orientation to healthcare services that aims to meet the needs of Indigenous people (Brascoupe and Waters, 2009; Garneau and Pepin, 2015; Hole et al., 2015; National Aboriginal Health Organisation, 2008). Diminished cultural safety was reflected in participants' perceptions of a lack of cultural aspects and sensitivity in practice, such as lack of family space, and lack of cultural knowledge demonstrated by staff. Going beyond cultural awareness, competence and sensitivity, cultural safety also includes recognition and analysis of power imbalances, recognition of discrimination and patronising relationships, and acknowledgement of the impact these have on the beneficiaries of healthcare (National Aboriginal Health Organisation, 2008). Actions that demean, diminish or disempower an individual's identity and wellbeing are considered to be unsafe (Artuso et al., 2013). All people feel comfortable in environments that recognise and acknowledge them as individuals, demonstrated in the way that environment reassures them by reflecting something of them. This can be culture, language, customs, beliefs, attitudes or the ways things are done (Eckermann et al., 2010; Tanner et al., 2004). Safe environments for Indigenous people should encompass physical, emotional, social and cultural wellbeing of the whole person, their family, and community (Eckermann et al., 2010).

The second theme, *Encountering dysfunctional interactions*, emphasises the centrality of relationships to Indigenous people. Personal encounters provide the building blocks for therapeutic relationships yet participants mainly perceived a lack of respect and dignity in this regard. Literature reflects that interaction between staff and patients at a personal level have a major influence on the latter's experience (Cass et al., 2002; Coyle and Williams, 2001), and that relational approaches may underpin more positive experiences of acute care (Cass et al., 2002). It is important that staff provide personalised and dignified care that enhances Indigenous people's experiences (Coyle and Williams, 2001). The reality, however, is that in most cases Indigenous people are met with negative stereotyping (Ly and Crowshoe, 2015), typified in the third theme, *Suffering stereotyping and assumptions*, describing the discriminatory and negative targeting that participants encountered. Participants perceived feelings of being stereotyped and treated with negative assumptions. The reality of negatively stereotyping Indigenous people is acknowledged in the literature and may be socially influenced from an early stage in health professionals' careers. For example, a study identified that medical students were exposed to negative views about Indigenous people in medical school (Ly and Crowshoe, 2015). As well as disease, health professionals are charged with prevention and reduction of health inequalities, prompting an ethical reflection on their social mandate (Garneau and Pepin, 2015).

There are issues which can be common to both Indigenous and non-Indigenous people during hospitalisation, such as the financial difficulties suffered by participants. Timmons et al.'s (2013) study of cancer patients reported financial distress among non-Indigenous people, the difference is that, in most cases, Indigenous people were affected by disease at a younger age in comparison to their counterparts (Rix et al., 2014). This is highly relevant, as chronic conditions such as cancer and renal failure are more prevalent among Indigenous people. Themes may be applicable to anyone who encounters healthcare but the difference lies in how these two groups perceive, and understand or interpret the issues they are faced with in that encounter. For Indigenous people, many aspects may be foreign to them such as language, care models, and hospital culture. The history or past experiences between them and the health systems has an impact on how Indigenous people uniquely experience same environments and conditions as non-Indigenous people, and their response to issues.

4.1. Limitations

This review did not explore staff experiences in hospital/acute care settings, which is an area for further research. Staff may need support to effectively engage with Indigenous patients and their families, and education to dispel any adverse stereotypes. Hospitals are dominated by technical-based care and to shift such a focus is a challenge (Bridges and Meyer, 2007; Fitzgerald et al., 2006). An organisational and service wide commitment is required to create appropriate, inclusive service delivery for Indigenous patients and their families within hospital settings.

The majority of the studies were from Australia. This could be as result of lack of identification of Indigenous groups in other countries or lack of use of the terms in the studies' titles and focus. An initial search using terms of Indigenous peoples around the world provided by UN was conducted but did not retrieve any extra studies. Further study may investigate a comparison to determine whether the themes found in this study are similar to those identified for minority groups.

5. Conclusion

This metasynthesis highlights meaningful relationships as a central issue underpinning positive hospital experiences for Indigenous people. The fact that this review involved studies from a variety of settings indicates that the findings may be widely transferable across diverse domains. The need to care holistically by incorporating individual complexities such as financial needs and language barriers has been underscored, along with the impact that these issues have on Indigenous patients' and relatives' hospital experiences. Deliberate efforts should be made to incorporate their views and understanding into existing hospital cultures and practices to improve health experiences for Indigenous people.

Conflict of interest

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Ethical approval

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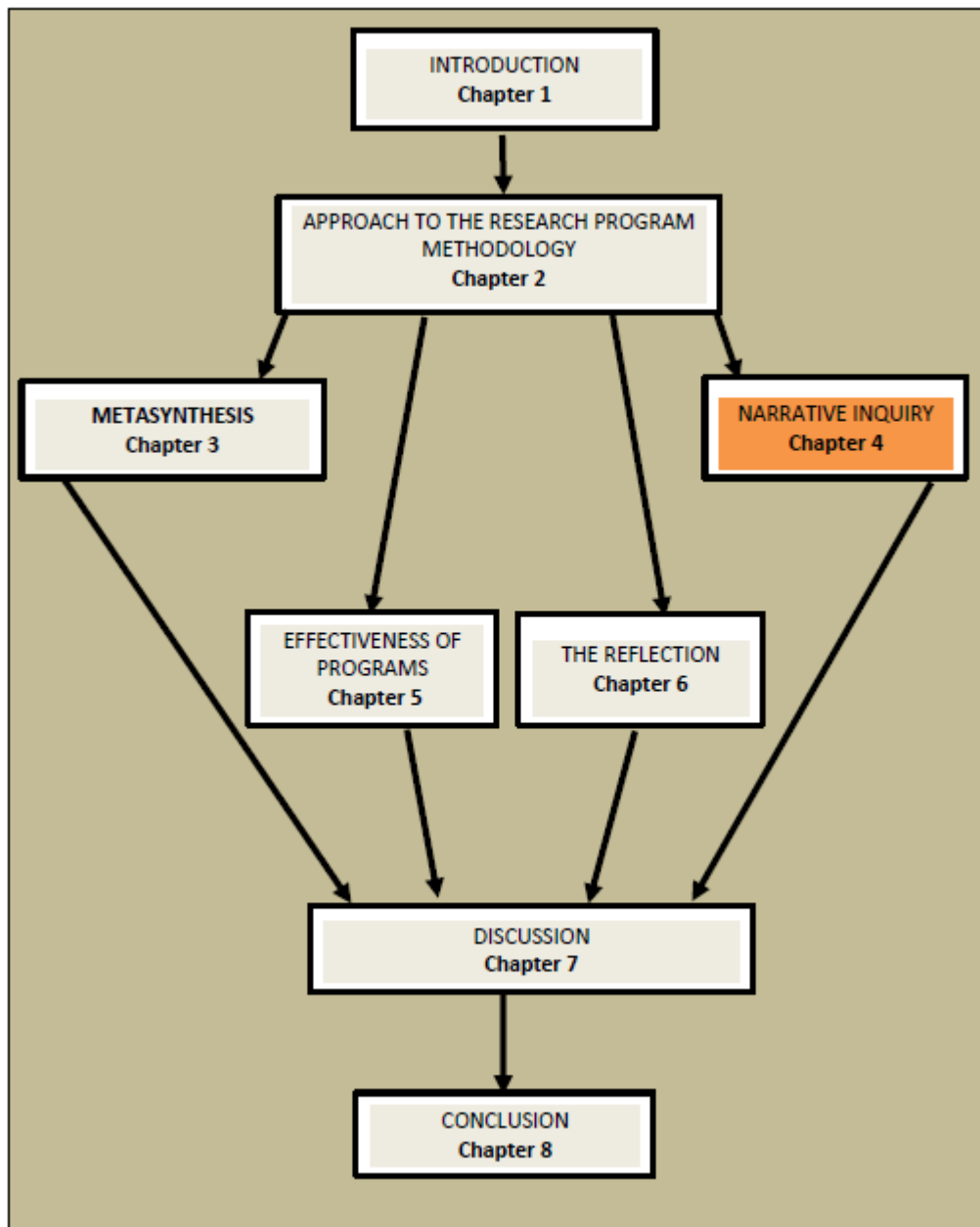
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Chapter summary

This chapter presented findings that reveal issues faced by Indigenous peoples while hospitalised for acute care on a worldwide level. Studies came from a variety of settings and countries. The findings show that there are several persisting barriers and difficulties across and within healthcare settings and countries. The chapter therefore provided current evidence appraisal that place the program of research within the existing literature. Cardiovascular disease is preventable and Indigenous people bear the higher burden of illness and CVD is one of the main contributing factors. The question comes as to these issues continue, and how relevant they are in the area of acute cardiac care settings within Australia.

The current study, therefore, which is presented in chapter four investigated current Indigenous people's experiences of acute health care. This provides an Indigenous experience story within an acute cardiac setting, and within local Australian context.

Chapter four: Narrative inquiry - Study two



Chapter overview

This chapter is a presentation of Indigenous people's perspectives on hospitalisation experiences. The data collected and analysed in this chapter addressed objective 2 which was to explore current hospitalisation experiences of Indigenous people related to acute cardiac care. It is presented here in its published form from the Journal of Clinical Nursing, with permission (Appendix 7).

The following section of this chapter presents the published version of the narrative study, which is presented verbatim in the style of the journal in which it was published.

Journal metrics: Journal of Clinical Nursing [Scimago Q1, Impact Factor 1.757, SJR ranking: 18/140 Nursing, Nursing (Miscellaneous)]

Indigenous cardiac patients' and relatives' experiences of hospitalisation: A narrative inquiry

Vainess Mbuzi BN, MNurs, PhD Candidate, Clinical Nurse^{1,2} | Paul Fulbrook RN, PhD, MSc, Professor of Nursing, Nursing Director Research and Practice Development^{2,3} | Melanie Jessup PhD, BN Hons, RN, Clinical Associate Professor, Research Fellow^{2,3}

¹Adult Intensive Care Services, The Prince Charles Hospital, Brisbane, Qld, Australia

²School of Nursing, Midwifery and Paramedicine, Australian Catholic University, Brisbane, Qld, Australia

³Nursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane, Qld, Australia

Correspondence

Vainess Mbuzi, Adult Intensive Care Services, The Prince Charles Hospital, Brisbane, Qld, Australia.
Email: vainess.mbuzi@health.qld.gov.au; vainess@hotmail.com.au

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Aims and objectives: To explore Indigenous people's experiences of hospitalisation for acute cardiac care.

Background: Indigenous Australians suffer a higher burden of cardiovascular ill health and hospitalisation rates in comparison with other Australians, but there is little research that explores their perspectives of hospitalisation.

Design: Narrative inquiry.

Methods: Interviews were undertaken using storytelling to facilitate participants' descriptions of their hospital experience. Data were collected during 2014–2015. A purposive sample of Indigenous cardiac patients that were admitted to hospital and their relatives participated.

Findings: The narrative revealed three linked themes that characterised Indigenous people's hospitalisation experiences: *The impact of the past*; *The reality of the present*; and *Anticipating the future*. Hospitalisation was challenging for participants due to their sense of dislocation and disorientation, a lack of cultural and spiritual aspects to care practices, and the poor interpersonal relationships they experienced. **Conclusions:** Findings revealed that there were many unmet needs during hospitalisation for Indigenous people. Past experiences and future expectations were connected in a way that impacted on participants' current hospitalisation experience. Understanding this context, with incorporation of cultural and spiritual aspects of care may help nurses and other healthcare professionals to provide more positive interactions that in turn may contribute to improved cardiac care experiences of Indigenous people during hospitalisation. Healthcare professionals need to be aware and focused on person-specific and contextualised aspects of Indigenous people's experience of hospitalisation for cardiac care in order to impact outcomes.

Relevance to clinical practice: Healthcare professionals need to understand Indigenous people's perspectives that contribute to improved health outcomes. Stories of participants' experiences may assist in the identification of aspects which might further the development of culturally appropriate continuity models that could effectively provide support throughout Indigenous people's hospital journeys, and beyond the hospital, and help improve associated health outcomes.

KEYWORDS

hospital experience. hospitalisation. Indigenous. narrative. qualitative research

1 | INTRODUCTION

The disparity in health between Indigenous Australians and other Australians has been recognised as highly significant (Australian Institute of Health and Welfare [AIHW], 2014) and is characterised by the high prevalence of preventable diseases, including cardiovascular disease (CVD), and reduced life expectancy (Brown, 2009; AIHW 2011). Indigenous people make up about 3% of the Australian population (Australian Bureau of Statistics [ABS], 2014), and yet they bear the highest burden of ill health (Vos, Barker, Begg, Stanley, & Lopez, 2009). Statistics show that Indigenous Australians' hospital admission rate is more than twice that of other Australians (AIHW, 2015) and yet their health has remained poorer. One of the main explanations is that Indigenous Australians face many barriers to their use of the healthcare system (Artuso, Cargo, Brown, & Daniel, 2013), especially hospital services. Through shared understanding of underlying issues, appropriate strategies may be implemented. Stories from both patients and families therefore may provide insight into the caring aspects they particularly value that could be embedded into nursing clinical practice, education, policy and research.

2 | BACKGROUND

Cardiovascular disease is largely preventable and is a major contributor to morbidity, mortality and health disparity, worldwide causing an estimated 17 million deaths annually (United Nations, 2009; World Health Organization, 2011). Although a significant health problem for all Australians, CVD level and impact are much greater for the Indigenous population (ABS, 2015). Substantial evidence from Australian statistics indicates that it contributes to higher rates of mortality (AIHW, 2011) and is the main contributor to health inequality and premature death among Indigenous Australians (ABS, 2015; AIHW, 2016). In 2003–2007, it caused 37% of Indigenous deaths of those aged between 45–64 years, compared to only 9% of non-Indigenous Australians (ABS, 2013). Despite the known profound impact of CVD on Indigenous Australians, disparities persist, for example, in relation to access and appropriateness of care, and much remains to be achieved (Brown & Kritharides, 2017). Articulation of deficits in the delivery, receipt and monitoring of outcomes may contribute to reversal of the ingrained inequalities within this population (Brown & Kritharides, 2017). This should lead to implementation of appropriate strategies that would facilitate improved health outcomes for Indigenous Australians.

One of the factors contributing to Indigenous health disparity lies in how Indigenous peoples experience hospitalisation in terms of their perception, expectation and interpretation of their healthcare encounters (Chapman, Smith, & Martin, 2014; Shahid, Finn, Bes-sarab, & Thompson, 2011; Worrall-Carter et al., 2016). These studies demonstrate that they are faced with common challenges when encountering health care, such as language barriers, the need to relocate to access services and cultural isolation. Although they present to hospital, a significant percentage (5%) of hospitalised Indigenous

What does this study contribute to the wider global clinical community?

- Current hospitalisation experiences from Indigenous people's perspectives that provide a unique insight into their perceived cultural marginalisation and resultant lack of trust of health professionals.
- Events from the past and present, and future expectations are interconnected and can impact negatively upon Indigenous people's hospital experiences.
- Incorporation of cultural and spiritual aspects into care with positive interaction with nurses and other health-care professionals may improve cardiac care experiences of Indigenous people during hospitalisation.

patients self-discharge against medical advice, around eight times greater than other Australians (Australian Health Ministers' Advisory Council, 2015; Einsiedel et al., 2013). Furthermore, many of those that access health services do not attend follow-up appointments and may not attend rehabilitation services (AIHW, 2013; Katzenellenbogen et al., 2013).

While there is an abundance of studies that describe the disparity in health outcomes between Indigenous and non-Indigenous Australians, the Indigenous perspective on this issue is lacking, which provided the impetus for this study. This study is aligned with the *Closing the Gap* campaign which is attempting to bridge the health and life expectancy gap between Indigenous and non-Indigenous Australians (Australian Human Rights Commission, 2008; Commonwealth of Australia, 2017). It is also relevant to the Australian Commission on Safety and Quality in Health Care (ACSQHC) standard 2 which advocates for partnering with consumers (Australian Commission on Safety and Quality in Health Care, 2012). Although the importance of consumer involvement has been recognised as an important aspect of healthcare, evidence of that involvement is limited, especially with regard to Indigenous populations.

Of all healthcare professionals, nurses form the largest group of carers that has close daily personal contact with patients and their relatives. Due to the amount of time nurses spend with patients and relatives, they have a major impact on patient experiences and should be at the forefront of implementation, monitoring and evaluation of strategies that aim to improve the quality of patient care (Kieft, de Brouwer, Francke, & Delnoij, 2014).

3 | AIM

The aim of this study was to explore Indigenous cardiac patients' and their relatives' experiences of hospitalisation in order to advance understanding of the meaning of hospitalisation

from their perspectives. Healthcare improvements may be achieved by overcoming some of the barriers perceived by Indigenous people.

4 | METHODS

4.1 | Design

A descriptive approach using narrative methodology was employed using unstructured interviews to collect Indigenous people's stories about their hospital experiences. Qualitative research is concerned with the study of human experiences within natural contexts, focusing on description, gaining understanding and interpretation of issues as perceived by research participants (Holloway & Wheeler, 2010). The purpose of descriptive narrative research is to construct an accurate description of events in participants' lives that is meaningful; rather than constructing a *new* narrative, it reports already existing ones (Polkinghorne, 1988). Because this study was focused on Indigenous people, a nondirective approach to data collection was chosen in order to respect the values, feelings and experiences of participants. Narrative inquiry was used because of its use of stories which is a culturally affirming strategy that is appropriate when communicating with Indigenous people. Face-to-face collection of participants' stories enabled them to recount their experiences in their own words (Gorman & Toomb, 2009), allowing them to state issues that were important to them, rather than the interview having a predetermined focus.

According to Wiltshire (1995), "storytelling" and "narrative" are often used interchangeably, but stories are casual, and it is through further conceptual and structural development that they become narratives (Frank, 2000). While narrative inquiry has been criticised by some for its perceived subjectivity and lack of generalisability, Lincoln and Guba (1985) reject the idea of generalisation in favour of transferability, and others have emphasised the importance of not using language to critique narrative that was created for other forms of research (Connelly & Clandinin, 1990). It is considered a legitimate interpretive research method that can be understood as a form of reflection upon an event to make sense of the experience or deal with a problem (Koch, 1998). In the context of this narrative inquiry, the event was hospitalisation for acute cardiac care and the storytellers are the Indigenous patients and relatives that experienced it.

4.2 | Setting

The study was conducted at a tertiary hospital in Queensland and was devised in collaboration with its Indigenous Hospital Liaison Services team. Ethical approval was granted by the Hospital Research Ethics Committee (ref: HREC/13/QPCH/316), and the study was conducted following guidelines provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies [AIATSIS] (2012).

4.3 | Sample

Purposive sampling was used to recruit hospitalised adult cardiac patients and their family members that self-identified as Indigenous and were able to communicate verbally in English. The sample size was not predetermined and continued until a sense of completeness had been achieved within participants' stories. Of thirty-eight participants recruited initially, five were unable to be interviewed because they left hospital before their scheduled interview. Twenty-four participants were patients of whom the majority was male ($n = 16$). Their age ranged from 24 to 81 years. Most had been admitted to hospital for cardiac medical management ($n = 12$), with the remainder hospitalised for cardiac surgical intervention ($n = 9$) or cardiac mechanical device management ($n = 3$). Nine family members participated (four wives, two fathers, two nieces and one brother). Over half of all participants resided within the urban/metropolitan area around the hospital setting ($n = 18$) with the remainder ($n = 15$) coming from regional areas of Queensland. Of the latter group, six were family members.

4.4 | Data collection

Data were collected over 7 months from August 2014–February 2015. Initially, potential participants were approached by an Indigenous Hospital Liaison Officer who discussed the research study. Following indication of their interest to participate, the officer then introduced potential participants to a researcher who further explained the research study and participants' roles. A *Plain English Research Statement* that included information about the study and a consent form was provided based on AIATSIS (2012) guidelines. All participants were voluntary and provided written consent.

Participants were interviewed once. A single open-ended question was used to initiate the storytelling process: "Can you tell me about your experience this admission?" The interview was deliberately unstructured to enable participants to have full control over the content and direction of their stories without interruption. The length of each interview was variable, ranging from 10 to 45 min, and was concluded when the participant indicated they had nothing further to say. All interviews were digitally recorded and professionally transcribed verbatim. Names and other identifying features, such as area of origin, were omitted from the transcripts. To avoid distraction, notes were not taken during the interviews but were recorded in private afterwards by the researcher.

4.5 | Data analysis

Data analysis focused on enabling participants' words to be heard without researcher-imposed fragmentation of their accounts. Emphasis was placed on identification of plots rather than thematic categorisation of data. This allowed the stories to remain intact in order to present the real voices of the participants, and enable the significance and role of the experiences to be understood from their

perspectives (Polkinghorne, 1988). The aim of narrative inquiry is to understand how people think through events and what they value (Riley & Hawe, 2005). This helps to establish the significance of past events as well as the consequences of future actions (Polkinghorne, 1988). In this context, it is essential to plot time to enable composition of events into a narrative; the central structure is past-present-future in which the past conveys significance, the present conveys value, and the future conveys intention (Connelly & Clandinin, 1990). The process involved marking the beginning, middle and end of the narrative, selection of events to be included, ordering events culminating in a conclusion and making explicit the contributors to the story as a unified whole (Polkinghorne, 1995). To achieve this repeated reading enabled increased familiarity with data and deepened understanding of participants' meanings inherent in the data. Second, elements that contributed to the significance of the story were identified for each story and arranged in chronological order and then finally common storylines from all the stories were combined to make a core narrative (Polkinghorne, 1995).

4.6 | Rigour

The research team consisted of three members, which provided investigator triangulation (Creswell, 2009; Houghton, Casey, Shaw, & Murphy, 2013). Data were collected by the first author, and issues and findings were discussed at research team meetings. For data analysis, the first author developed initial plots which were then reviewed by other team members. All team members contributed to the development and refinement of the final plot in the narrative. The original transcripts were kept as point of reference, and frequently referred to, to ensure that the resulting narrative was fully grounded in participants' descriptions of their experiences. Participants' quotes are used in the narrative to evidence their perspectives (Houghton et al., 2013; Maxwell, 2009). Preliminary findings have been presented for peer scrutiny (Houghton et al., 2013; Shenton, 2004) in different environments including professional conference settings and consultations with Indigenous Hospital Liaison Officers at the research site.

5 | FINDINGS

Analysis of participants' stories revealed a sequential narrative, in which the plot unfolded in three themes: *The impact of the past*; *The reality of the present*; and *Anticipating the future* (Table 1). Although described sequentially, the themes and subthemes are interwoven, revealing a narrative plot in which the past, present and future are fused and, to a great extent, are inseparable. *The impact of the past* provides the back story of participants' personal experiences and history as a people; most of which were negative, and illustrates how relevant their predisposition was with regard to their hospitalisation. To a large extent, although participants appeared satisfied with their medical care, their experiences in *The reality of the present*, emphasised and reinforced their sense of cultural marginalisation. As their

attention was turned towards discharge home, their focus shifted to a brighter future in which there was a determination to do better and not repeat the mistakes of the past.

5.1 | The impact of the past

Issues relating to past experiences of healthcare, difficult family circumstances, and colonisation-related Indigenous experiences all impacted on the current episode of hospitalisation for participants. In this way, the past experiences and histories of Indigenous people, both in general and in relation to specific health-related experiences of themselves and their family members, revealed a somewhat negative predisposition for hospitalisation.

5.1.1 | We were getting younger and younger and we were dying

Participants described a common memory of poor health in their family histories associated with early deaths of relatives. Because ill health was commonplace, coming to hospital was morbidly associated and, based on previous associations with health professionals, was interwoven with feelings of persecution and mistrust. A particular issue concerned the death of a family member in hospital. In such cases, participants struggled with the idea of coming back to the same hospital. These histories affected the way participants felt about their current hospitalisation as memories of the past came flooding back. The following excerpts, often expressed with great

TABLE 1 Themes

Themes	Subthemes
The impact of the past	<ul style="list-style-type: none"> We're getting younger and younger and we're dying Everybody had negative thoughts. They kept thinking, "This is really bad" I could never forget about my bringing up I went back to my room and practised all my breathing and called on my spirits
The reality of the present	<ul style="list-style-type: none"> I was pretty sick when I came in The boss doctor was speaking big words As far as I am concerned we are still not welcome She is wondering why she is being disrespected like that It's like they think we do not know anything - that we are stupid or something I was scared... I know now why people leave hospital against medical advice We are all one people... but I believe that we should have that bit of a culture there for our own Just being there for my unde at the moment was the most important thing
Anticipating the future	<ul style="list-style-type: none"> What I'm worried about I learnt my lesson They don't communicate too good, do they?

emotional depth, illustrate the entwined relationship between their past and present:

My mother died from the heart and my father died from heart conditions so it's pretty much in the family. (Dorak).

*I have two kids, I did have... a girl and a boy, but the girl died. She was a spastic quadriplegic with cerebral palsy... and when she was born she came out with a dislocated shoulder... apparently the cord got wrapped around her head and cut off some circulation in her brain. Anyway, she wasn't breathing when she came out. So they thinged (sic) her and brought her back, then they rushed her off to intensive care unit... Anyway I went to the shops one day... and Allira [daughter] was in the car with two nurses – "she stopped breathing for four minutes" [they said] and all this shit, and I'm like "what?" and I'm thinking no, that can't be right, them c**s are trying to kill her, you know? ...they're big euthanasia c**s, like they believe in euthanasia... She made it through the night, she proved them wrong, and three nights later they said the same thing and we all had to go back again... I started putting two and two together and I realised why she wouldn't let go, because I wouldn't let go. I knelt down beside her and I gave her a hug and a kiss, and I whispered in her ear and said, "It's alright Allira, it's good to go now, you can go," and she just died like that... She was beautiful. Then nine months after she died my dad died... and then I lost my uncle Jarrah... and then my sister died, and my aunty died. There's a lot of deaths in my family, it's horrible... like when is it going to end? It's sad, and we're getting younger and younger and we're dying; heart attacks, cancer, overdosing, hanging... (Melinga).*

5.1.2 | Everybody had negative thoughts. They kept thinking, "This is really bad"

Coming to a "big" hospital was a source of concern as it was equated with being seriously sick and possibly dying. Thus, extra reassurance was needed from family members:

But yeah, coming down to [city] was fear. Our family as well, you know. Everybody had negative thoughts. They kept thinking, "This is really bad. It's [city named]." Where I come from once you have been told, you're going off to [local town named]... you're sick. Oh yeah. That's alright, [local town named]. But then when they said you are going to [city named], I thought the worst. (Tinga).

...My sons' faces were like – they thought they were never going to see me again. That was the last time because I was very sick in ICU... and then I pulled through and went back home. Now this time around

they just sort of encouraged me and they said, "Don't worry mum, you've been there before. You have done that. You'll be back. Just think of us. Keep us close to your heart and just think of us..." (Tinga).

5.1.3 | I could never forget about my bringing up

Past experiences of being mistreated were also a source of distress for participants. The history of past abuses of Indigenous people was strongly tangible in the present, portrayed vividly by Bakana:

There's too much racism around... we had to work on the station from when we were 14. Took all our money and our wages, took us away from our parents. Our parents were raped and all that. It's sad and now we have got to grow up and look up to try and forget about all that but I could never forget about my bringing up. I grew up never knowing my father. My mother was raped as a young woman. She went to her grave not knowing.

Participants conveyed a sense of being judged simply because they were Indigenous. Some felt they were viewed as being careless and were blamed personally for not taking care of their health and well-being. This stereotyping was a cause of the distress that was encountered at many levels, with Indigenous people being portrayed as careless and drunks. Participants lamented that it was not their fault that they had become ill, as Orad explained: "I have done everything right. I do not smoke or drink and yet I got the disease." Alinga described how her husband "has been a very fit, healthy person up till this problem when he started to fall over and collapse." On the other hand, participants reflected on the hard lives they had had, including problems with alcohol, as reflected here by Euroa:

My uncles were drunk and I used to grow up in the drinking life... I've had two wives, divorced both wives and they took all my money and they went, and that's when I hit the grog [alcohol] real bad... I've had a hard life, I ran away from home at 14, never been back, because of dad. He used to flog us and bash us and both mum and me have scars on my face. But I got him back when I was 17 and I got him, cleaned him up... But no, it's been a hard road, that's why I think a lot of people hit the grog, because of the life they have at home sometimes, and the streets are like their family, they're happier out there. And being a black fellow, me, I love the bush, I love the travel, I hate staying in the one spot too long, unless I enjoy it, unless it's good. But now I've got old, if I see anything that's going to disturb me, I'll go – you know, instead of doing that all the time, I just walk away from it now... I never want to come back to hospitals again, even though they've been good to me. It's just a waste of life... I've put all that behind me.

5.1.4 | I went back to my room and practised all my breathing and called on my spirits

The importance of the past in relation to the present as well as Indigenous cultural heritage was powerfully illustrated in Yama's story:

The surgery was supposed to be the week after the 3rd of November, I wasn't ready for it, my head was just going round and round, by myself, I'd just been through domestic violence, having to flee, I have high cholesterol because of all the fleeing and not eating proper diets and I only have the one child, she's 21 and she had to be my next of kin and my power of attorney. It was very hard for me because I did not want to put any pressures on her but I know with what we've been through, we could do it together and then I'm very spiritual and so I asked my ancestors to help me and to guide me and if I was doing the right thing using my daughter as next of kin and power of attorney but there was just nobody else out there that understood me and my wishes and I knew Talia being my daughter, understanding my wishes and being a very strong Indigenous woman, she would do that for me. Then there's another lady, I cannot remember her name... at the [hospital name stated] and my mum was Indigenous and my dad was not Indigenous and we never spoke much about the Dreamtime and that but as I got older, there was always bits and pieces; it's like a big jigsaw puzzle and they all came together when I spoke to this lady over at the [hospital named] and she said, she explained... my personal totem and when I wake up from the surgery, because I'm from the sea, just think of rolling with the sea. So I went back to my room and practised all my breathing and called on my spirits, my guardian angel and just dug deep for inner strength.

5.2 | The reality of the present

The main issues experienced while in hospital were related to relational aspects of the experience and included poor communication, cultural indifference and social isolation.

5.2.1 | I was pretty sick when I came in

Participants' stories relayed two contrasting experiences of coming into hospital. For those that were brought to hospital as an emergency, there was an overwhelming sense of gratitude that they were alive. However, they had little time to prepare:

...watching the football, rolled over and I got short-winded. So I tried to use – my puffer was no good, so then I rang 000 and then the two boys came and then they wired me up. (Apari).

I was pretty sick when I came in... yesterday morning at about 1 o'clock. I was under a code 1, lights and sirens, I was at risk of cardiac failure, my heart rate was only 40... they were quickly onto it. (Komanh).

Such participants were happy to have come to hospital and receive treatment, with resultant positive changes in the way they felt. They felt the treatment was effective, and they were feeling better. While some participants considered that the hospital had saved their lives and were grateful for this, for others whose admissions were planned, especially those living a long way from the hospital, a lack of preparation time was an issue. This was confounded by perceived deficiencies in the healthcare system, such as late arrival of appointment letters:

We only had four days the first time to organise ourselves to get down here... when the hospital sent him letters, they sent them late... the hospital needs to improve their communication. (Aleria).

This was more difficult if they were to travel with an escort. Issues to prepare for included taking leave from work, arranging funds for travel and upkeep while away from home:

...the fella that was coming up with me had to pull out because of his grandchildren. So at the last minute I had to make this arrangement... you can't rely on people, because they're broke, because they haven't got a car, their car break down. (Inkata).

Those that were unprepared for admission found it stressful. This impacted on how they experienced the hospital stay in terms of their readiness to take on information and concentrate on their health. Others were grateful for the way arrangements were made for their appointments because they had been scheduled all together and were able to see several specialists in the 1 day. Another positive aspect was the way their accommodation and transport was arranged by the hospital's Indigenous liaison service. They also appreciated being visited by the Indigenous Hospital Liaison Officers. These visits were mainly to offer information and at times just to converse and provided someone to talk to that was from the same culture. This was special to some participants especially when they had to stay in hospital for a long time with no family or friends nearby.

5.2.2 | The boss doctor was speaking big words

Healthcare professionals' use of difficult language was problematic, especially for those that did not understand or speak English very well. This was more evident in those that had never left their communities until they were admitted to hospital. Information about what was going to happen while they were in hospital was important to the participants, but in most cases, it was presented in

written form that some could not understand, and they did not know what they were being asked to do. This lack of understanding caused distress as they were uncertain about what was expected of them. In some cases, this led participants to believe that they were going to have the same procedure they had had previously, whereas in fact, the planned procedure was more advanced and invasive, involving a longer hospital stay than they had anticipated. Some participants recalled the booklets they were given in preparation for their cardiac surgery, reflecting on the low education level of Indigenous people and voicing concern that:

I was just given the booklet. No one asked me whether I can read or write. (Inkata).

Participants reflected that staff did not realise when they were using "big" words or medical terms which were hard for participants or their family to understand. This was confusing and a source of stress:

The boss doctor was speaking big words. It was good the junior doctors explained it in simple words... he explained to me that I needed to have a tube down into my heart to have a look... and explained to me how serious the situation actually really was. It's like a show-off of their university education. (Gelar).

Even taken-for-granted things like ordering a meal in hospital were sometimes difficult:

Omelette... Why can't they just call it egg? I told aunty... do you want an egg or...? (Ekala).

5.2.3 | As far as I am concerned, we are still not welcome

Participants reflected on the fact that although people knew that there are cultural differences between Indigenous people and popular hospital culture, there was little that was being done about it:

It was nice to have Indigenous flags at the entry of the hospital and some paintings in some of the corridors of the hospital but that's where it ended. No one spoke your language and there is hardly any Indigenous staff... apart from the Indigenous Liaison Officer. It would be nice to have some nurses and doctors who are Indigenous. (Bakana).

In many ways, participants felt that consideration of their Indigenous culture was tokenistic. Gender division in Indigenous traditions is very important. Participants felt that they were expected to leave such traditions at home and to assume a different way of behaving while in hospital. It was reflected that when they were in a ward bed, it did not make a difference whether they were Indigenous or

not: they were treated the same as non-Indigenous people. However, they encountered stereotypical attitudes that made them feel marginalised and disrespected:

There is no real change... as far as I am concerned we are still not welcome in hospitals. They still do things in the white way. The door is still closed for Indigenous people. When you are lying in bed and people are treating you, the flags, paintings and liaison officer are not there with you. (Bakana).

Participants hoped for change in the way hospital care was delivered to Indigenous people, especially the attitude of those providing direct care to patients at the bedside:

Change must be implemented in systems and people who you get in touch with within the hospital, especially at the bedside. (Bakana).

5.2.4 | She is wondering why she is being disrespected like that

Communication issues spilled over into how participants were treated on an interpersonal level. During interactions with hospital staff, perceived issues included not being listened to or respected. Some participants felt disrespected in the way they were addressed. People that were esteemed elders in their communities, demonstrated, for example, by being addressed as "aunty," felt confronted when called by their first name, as illustrated by Ekala, when referring to her aunty:

She has not been called by that name for many years. That is why she was not even responding when they called her name. She is wondering why she is being disrespected like that.

Elders are respected consultants within their community. In hospital, when they were being told what to do by staff that were younger than them, which was demeaning for some participants. This was confounded when, on some occasions, what were considered intimate or private issues were discussed insensitively by these younger staff within hearing range of others, causing distress:

I was being asked whether I had gone to the toilet or passing wind in the hearing of everyone... it was embarrassing. (Inkata).

5.2.5 | It's like they think we do not know anything—that we are stupid or something

Many participants felt that they were not being listened to. Having a chronic condition made them well aware of their needs and

condition, but at times, some staff did not want to know what they had to say:

I asked staff to take my temperature because I felt hot and they didn't do it. We're expected just to obey what they say and they do not listen to what we say. ...It's like they think we do not know anything - that we are stupid or something. (Binda).

The doctor there did not want to listen to what I had to say. I have had this condition a long time... I know what works for me. (Maka).

The relationship between staff and participants was essential and had an impact on how participants experienced hospitalisation. One participant was pleased to report how happy he was when a staff member had a joke with him. This was just before an unpleasant procedure and helped to allay his anxiety.

5.2.6 | I was scared... I know now why people leave hospital against medical advice

Participants reflected on the fact that traditional ceremonies were nonexistent in hospital. For example, Indigenous people practise smoking ceremonies as a healing ritual to rid themselves of bad spirits and a way of blessing people. In hospital, this was not possible. Some participants felt unsafe sleeping on beds that were not cleansed of the past spirits that had slept and died in them:

I was scared. I kept wondering how many people died in the bed I was occupying. It was hard... the pain I suffered inside was more than physical pain. I wanted to just leave and go home. I know now why people leave hospital against medical advice... If this is happening to me, and I'm an educated person, what does the poor fellow right up in the middle of Australia, what does he go through? Now I understand why Aboriginals walk out the hospital. (Inkata).

Some participants had concerns about the site on which the hospital was built. As they came from elsewhere, they were worried that the building may have been erected on sacred land. For their peace of mind and to feel safe, it was essential for them to find out by consulting the area elder. Indigenous country is divided into traditional areas, and several participants explained the imperative to be welcomed into the hospital's area either physically or spiritually, mentioning that it was vital to consult ancestors of the land and ask for their protection. Several expressed the need to consult the traditional owners of the land but noted that nurses did not know who they were:

I wanted to know the traditional owners of the land but the nurses didn't know. I was scared because I

couldn't call upon them for protection. I was having some weird dreams and thought people were doing corroboree outside the window ...I was wondering what it was like when I'm going to be dead for a bit, they're going to take the heart out of my chest or whatever they do. The machine's keeping me alive, but I'm still dead. So am I going to see a vision? I thought I did... I seen [sic] these people dancing in front of me... doing corroboree, and I was spending it [energy] on that. (Inkata).

Participants thought that there was a lot of reliance on Indigenous Hospital Liaison Officers for such information. That nurses appeared to be ignorant of Indigenous knowledge communicated to participants their lack of interest in Indigenous issues because they felt that it was easy to obtain such information.

5.2.7 | We are all one people... but I believe that we should have that bit of a culture there for our own

Hospital language isolated Indigenous people, especially those who did not understand English well and/or could not read. Some participants were not sure what was happening due to their limited understanding. Most of the participants felt that Indigenous belief systems were not acknowledged and that cultural issues were not on the agenda within the hospital:

...I don't know but I'm really not a racist person, really in my heart I'm not. We are all one people... but I believe that we should have that bit of a culture there for our own people. (Bakana).

Issues such as smoking the areas for cleansing purposes, acknowledging elders by their titles or practising female/male sensitivity considerations were lacking most of the time and often absent altogether. There was no Indigenous spiritual facilitation because there was nowhere for Indigenous people to go to pray in their own way:

More information about traditional owners... across every hospital ...I reckon. So you're able to check there's been an Aboriginal who has come in ...got an elder, Aboriginal elder, a traditional owner of this land to give you his blessing, the same as Jesus... That was the most important thing for me. (Inkata).

It was a lonely journey for some family escorts and the patients. Between visiting hours, they had nowhere to go. There was no central meeting place, and even though there were other Indigenous people in the hospital, it was difficult to meet them because they were dispersed throughout the hospital, in different wards. They wished there was an open area where they

could go and meditate and possibly meet with other people. Meeting other Indigenous people was a welcome event as Gelar described:

...And over the period of my stay, I've seen a few cousins and stuff here, so it's made it a little bit easier just to talk and on common ground, we know where each other comes from, yeah, instead of having to make new friends all the time.

Because of the cultural isolation of participants, while in hospital, when they met someone else from "home" it felt good and was comforting.

5.2.8 | Just being there for my uncle at the moment was the most important thing

Almost half of the participants came from the regional areas. They had left their home, family and community to come to the city for treatment. In this sense, they were geographically and socially isolated, separated from the normality of their everyday lives:

...the cardiac team came up to... my community, and they come and got me to go up and do an ultrasound on me heart ...and they said, "Oh, something's wrong with your heart... in a couple of days' time you'll be going to [city], and you'll go and have an angiogram." (Inkata).

...it was my first experience on a plane, like I was right scared of heights. (Kindilan).

Although some patient participants were accompanied to hospital by a family member, it was often difficult for them to stay due to the imposition of transportation and accommodation expenses:

...She was 23 years of age, she was stressing out to the max. Then she had to pay for this motel. I said, well look, you've got to get out now girl... because I can't afford with the motel. Luckily we've got a friend here, and the friend came and got her and let her out of town. (Inkata).

For participants, it was also difficult because family members were not always with them due to restricted visiting hours, which limited contact. As well, family members had to access accommodation outside of the hospital, leaving patients alone at night. As a consequence, some participants feared that they might die alone, with no family at their bedside, as illustrated by Kindilan: "Just being there for my uncle at the moment was the most important thing for me; yeah... yeah... I'm staying in a hostel at the moment."

Some participants had had to leave their young family at home and worried about how they were faring. In most cases, their

contact was limited to occasional phone calls. Adina reflected on his inability to make contact with his family simply because his phone was not charged: "Kind of miss my kids; I've got two little ones at home." Participants felt isolated and alone, especially those from regional areas. However, not all participants wanted involvement from family. Some felt guilty for being in hospital, often due the chronic condition they had, and had resolved to tell relatives only if they were facing death:

Family ...I don't tell them, I tell them, "Don't worry about coming up." I've been in and out of hospitals for years. Unless I'm dying it will be a different story. But I reckon at least every one of them is going to walk away with a lot of memories from me. (Melinga).

5.3 | Anticipating the future

All participants related how their present experience had an impact on the future on several levels: in the immediate period in their planning for their return home, and in the longer term in their resolve to change their way of life.

5.3.1 | What I'm worried about

In the immediacy, participants considered what would happen after discharge in terms of the level of support available at home, taking medications—especially remembering directions, whether they would recall all instructions given to them on how to look after themselves, and how to inform their families about their new way of life. Thus, most were seeking information that would help equip them for their return home:

... it's just a matter now of what help I get at home and with my medication, that's what I'm worried about. (Apari).

One family member was worried about how she was going to cope looking after her sick relative after discharge. This was because she felt inadequate due to her own state of health:

I've had a back operation and I'm not fit, I had a foot operation only four months ago so I haven't been walking very well and with my back operation, I'm not able to lift or anything. (Harah).

5.3.2 | I learnt my lesson

Due to their present illness being attributable to their past experiences, some participants were planning to change their way of life to a more health conscious one:

I learnt my lesson. It took me until I was 50 but I learnt, you know? ... I like this life better, no alcohol, no hang-overs, no waking up getting straight on the grog at 7 o'clock in the morning, having a charge – that's what I used to do. (Euroa).

The intended change was not focused on themselves only. Some planned to direct their family members towards a healthier lifestyle. They also sought to influence their community, especially young members, to embrace so-called Western views in terms of education and taking up healthcare professions such as nursing:

Our people should get on into this hospital and do courses... these kids – they don't put a lot of them through schools and that... to be nurses and doctors you know. When I go back to working in the preschool, I'm going to start in that preschool how important doctors and nurses and all that mean. (Bakana).

Most anticipated good community support and looked forward to changing their health for the better with that support. Several participants, however, were concerned about their immediate future and worried about how they would cope after discharge. One participant lived with his daughter's family and worried about how this would affect him after discharge and was planning for an alternative accommodation:

So I'm going to try and get a housing commission or a house to live in so I've got a bit more privacy and the kids aren't stressing me out – grandkids. (Euroa).

5.3.3 | They do not communicate too good, do they?

Some participants wondered how they would inform or educate family members about their new ways of living. They sought requisite information both for themselves and for the relatives that would provide support at home. They thought it would be easier if there was direct communication from healthcare professionals to other family members so that they understood and could offer better support. It was suggested that use of teleconference and pamphlets for those that could read would be more useful than leaving the information only in the hands of the patient and their escort to disseminate to the rest of the family.

My brother lives with her...his wife does...they understand the pamphlets. But I just think reinforcing, reinforce, reinforce, reinforce the message that these are the things that she can't do. (Ekala).

Some participants wanted the significant others involved in their care to access information and to negotiate on their behalf on how

they could assist them. Others were satisfied with the information they were given and referrals that were made while they were in hospital, both of which would enable them to have a help base outside the hospital, as illustrated in the following quotes:

There seems to be lack of liaison between each party in there. They don't communicate too good, do they? See, I don't know what's going on because I've got the hospital here helping me and I've got two lots of Aboriginal mob in there that come around at home there, so they've just got to get together and work it all out for me. (Apari).

That was good because they informed me about things like the medication... I've never been told that I can get free medication being - this is going to help us out being a big family of six children. (Matari).

Yeah, he gave me this... some numbers and just some stuff to do for next time, transport, medication and scripts and stuff like that that I can get some help with... told me about the doctors' surgeries... which are Aboriginal and Torres Strait Islander, and they're completely free... (Komanh).

For participants, contemplation of the future held a twofold intent: preparing for re-entry into their community and making meaning of the present by endowing their experience with purpose. Reflecting on their current experience enabled participants to re-engage the future, for them and for their families and community.

6 | DISCUSSION

The findings in this inquiry resonate with and expand upon many issues associated with hospitalisation experiences for Indigenous people. The stories told by participants illustrate the interconnectedness of health and everyday life for Indigenous people: issues experienced in their past affect their present and future decisions regarding their health. In relation to the study aim, although participants were hospitalised for major cardiac care, this was rarely the impetus for their stories, which were focused mostly on their experiences with regards to relationships and interactions, culture and spirituality, and their identity as a people. Nevertheless, the narrative provides insight into barriers and challenges faced by Indigenous people when needing hospital care for their cardiac conditions; it also points towards some enablers, which are discussed below.

There is an indisputable relationship between the enduring impact of colonisation and current health status of Indigenous Australians (Eckermann et al., 2010; Sherwood, 2013), enforced by the direct link between the history of the harmful past and present political and social policies (Mitchell, 2007; Sherwood, 2013). This colonised and colonising mindset continues today among Indigenous Australians and most public services such as the healthcare system (Eckermann

et al., 2010). Past and present policy decisions have created determinants that influence the health and lives of Indigenous Australians which some participants reflected upon in this study, such as education level, abuse of women and lack of acknowledgement of Indigenous cultures and traditions. These continue to impact Indigenous people's perception of healthcare systems (Eckermann et al., 2010).

Encountering the reality of the present was demonstrated by the many challenges participants faced while hospitalised. Although some expectations of Indigenous people are no different from any other patient admitted to hospital, what makes their experiences unique are mainly their historical encounters with healthcare, cultural and spiritual differences, and ways of communication and personal interactions. This enduring problem may be contributing to the often poor perception of hospitalisation held by Indigenous people. As found in other studies, participants were faced with many challenges including communication difficulties (Amaert & Schaack, 2006), poor interactions with staff, cultural, social and spiritual isolation (Tanner, Agius, & Darbyshire, 2004), and relocation from their communities for services (Shahid et al., 2011). There is a sense of vulnerability expressed in their descriptions of fear of the hospital, cultural discrepancies and the disempowering practices that made them feel dependent on, or at the mercy of, healthcare professionals (Tanner et al., 2004). Although displaying Indigenous flags and artwork has been promoted in other studies (Chapman et al., 2014) and was appreciated by participants, these were considered tokenistic, as their visibility in the hospital was in contrast with what happened at the bedside where a distinct lack of knowledge or acknowledgement of Indigenous culture was displayed by staff, and participants felt somewhat invisible. Unable to recognise any practices that were based on their beliefs or culture (Durey & Thompson, 2012), they felt unwelcome. These complex historical and social factors impact how Indigenous people experience hospitalisation and engage with the health system at large.

Participants desired to be in the company of others like them, a need identified in other studies (Tanner et al., 2004). The Indigenous Hospital Liaison Officer position was seen as vital because it provided some companionship and a link to their culture. Although participants felt that it was positive to have visiting Indigenous Hospital Liaison Officers, they also suggested there needed to be more Indigenous health professionals on the treatment team. A study by Taylor et al. (2009) demonstrated that introduction of an Indigenous Health Worker into a cardiac inpatient care team improved outcomes including reduced numbers of discharges against medical advice, improved patient follow-up and increased participation in cardiac rehabilitation by Indigenous patients. Indigenous staff exert a significant impact on hospitalised Indigenous people due to the increased cultural security felt by patients and their families.

Anticipating the future was identified as an essential aspect of hospital experience. To continue with management of their conditions participants identified the need to change their behaviours and to have effective support at home. Effective communication and information provision during hospitalisation can improve after hospital care for Indigenous people. If not equipped with adequate

information to change, manage or teach other people, their future plans may not be achieved (Corbett, Francis, & Chapman, 2006). For example, participants worried about medication, and how to relay information to the rest of the family. However, some were pleased with referrals they were given to help them manage at home and in their community. They desired information to be shared with other family members involved in their care so that they could understand and assist them adequately and appropriately. Discharge planning for this population should reflect such culturally appropriate communication, interventions and patient capabilities, with clinicians providing culturally appropriate care to their patients through recognising the needs of individual patients and developing ways to address them effectively. While partnering with consumers and patient-centred care have been promoted in many documents (Australian Commission on Safety and Quality in Health Care, 2014), these need to be translated into policy and practices in order to provide holistic care to Indigenous health consumers and improve their health outcomes.

6.1 | Limitations

This narrative inquiry was conducted at a single Australian tertiary hospital and therefore is reflective of this particular context and its inhabitants. Thus, there are inevitably differences to be found in other contexts or cultures. However, the relatively large sample enabled collection of a diversity of stories that provided rich and meaningful accounts of participants' experiences. While the findings of this inquiry are not generalisable in the positivist sense, the issues presented can enhance understanding about what Indigenous people experience when they come into hospital and what matters to them. Much of this knowledge is highly relevant and transferable across other clinical settings. While it was the intention of this inquiry to focus on the Indigenous voice, further inquiry is merited that considers healthcare professionals' perspectives of Indigenous care.

7 | CONCLUSIONS

The narrative revealed that there were many unmet needs during hospitalisation of Indigenous people. With participants' hospital journeys starting and finishing at their community, past experiences and future expectations were demonstrated to be inextricably linked in ways that impact on current hospitalisation perceptions and expectations. Consideration of issues in all the three lifeworlds can augment Indigenous people's hospital experiences and thus their cardiac health outcomes. It is important for healthcare providers, especially nurses, to be aware and focus on person-specific and contextualised aspects of Indigenous people's experience of hospitalisation.

7.1 | Relevance and implications for practice

This narrative inquiry has exposed the cultural disadvantage that Indigenous people suffer when hospitalised for cardiac care. This

especially impacts the quality of their communication and interpersonal relationships with healthcare professionals. Health services in general and in particular hospital services should consider implementing strategies that would improve the hospital experiences for Indigenous Australians including demonstrating awareness using communication through listening and inclusive language, and provision of information delivered in an apposite format; provision of time and space for inclusion of relatives and other Indigenous colleagues, and inclusion of the patient as a member of the team; and heeding traditional nuances such as being welcomed into a new territory and appropriately dealing with the spirits of those that have died in hospital.

There were few concerns expressed about the medical skills of staff or their technical abilities within the hospital. However, it is not enough to continue relying on the effectiveness of biomedical therapy and treatment, but to go beyond by recognising cultural, historical, and social impacts on Indigenous people's health to enhance their cardiac care. Indigenous people should be central to the partnership, agenda, and conduct of healthcare delivery processes that affect them. Exploration and implementation of further strategies to more competently care for Indigenous patients would improve their hospital experiences, with resultant enhanced health outcomes.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.


AUTHOR CONTRIBUTIONS

Study design: VM, PF, MJ; data collection: VM; data analysis: VM, PF, MJ; manuscript preparation: VM, PF, MJ.

ORCID

Vainess Mbuzi  <http://orcid.org/0000-0002-6111-6053>

Paul Fulbrook  <http://orcid.org/0000-0002-6547-1861>

Melanie Jessup  <http://orcid.org/0000-0002-5243-9117>

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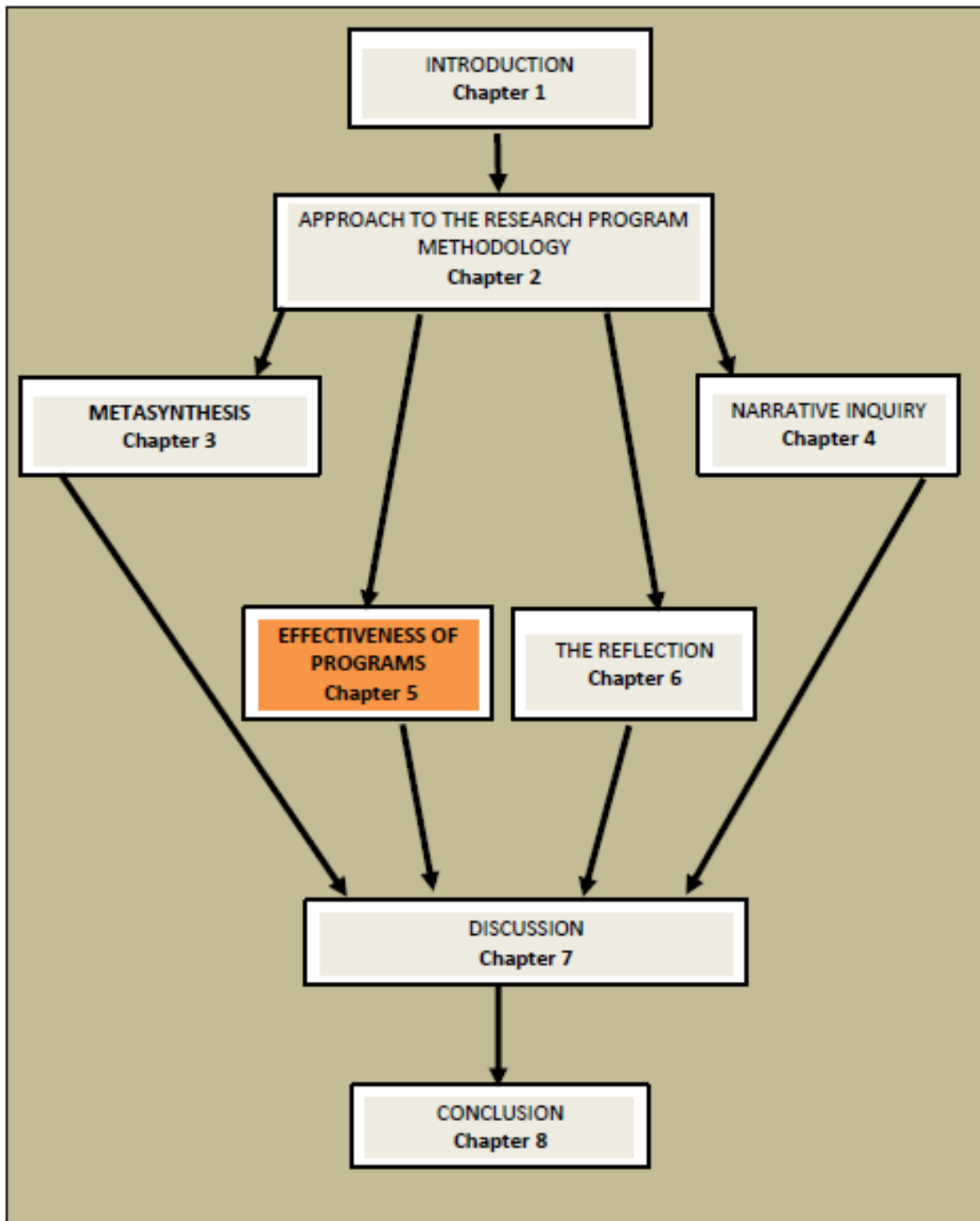
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Chapter summary

This chapter presented findings that reveal current issues faced by Indigenous Australians while hospitalised for acute cardiac care. The findings show that there are several persisting barriers and difficulties that they face when hospitalised. Indigenous people continue to suffer cultural disadvantage when hospitalised. This impact their experiences and due to mainly poor interrelations and communication with the healthcare service. The question comes as to whether there is enough consideration of Indigenous people's issues in clinical practice or research activities. This led to the study that follows in the next chapter, which was designed to investigate effectiveness of current cardiovascular programs targeted for Indigenous population within Australia.

Chapter five presents results of an investigation into effectiveness of programs for the improvement of cardiovascular health among Indigenous Australians.

Chapter five: Systematic review- Study three



Chapter overview

The following chapter presents a systematic review of the effectiveness of cardiovascular programs designed for Indigenous Australians. The aim was to investigate how effective the programs are, given that Indigenous health issues persist. Previous chapters have highlighted the disparity in healthcare outcome between Indigenous and non-Indigenous people. Results of a systematic appraisal of literature in the areas would highlight programs that have been successful and the strategies that have been effective and made the programs work. It is presented in its published form from the International Journal for Equity in Health with permission (Appendix 8).

The following section of this chapter presents the published article, which is presented verbatim in the style of the journal in which it was published.




Journal metrics: International Journal for Equity in Health [Scimago Q1, Impact Factor 2.473, SJR ranking: 31/242 Medicine, Health Policy]

SYSTEMATIC REVIEW

Open Access



Effectiveness of programs to promote cardiovascular health of Indigenous Australians: a systematic review

Vainess Mbuzi^{1,2,3*} , Paul Fulbrook^{1,2,4}  and Melanie Jessup^{1,5} 

Abstract

Background: Indigenous Australians carry a greater burden of cardiovascular disease than other Australians. A variety of programs has been implemented with the broad aim of improving Indigenous cardiovascular health, however, relatively few have been evaluated rigorously. In terms of effectiveness, understanding how to best manage cardiovascular disease among this population is an important priority. The review aimed to examine the evidence relating to the effectiveness of cardiovascular programs for Indigenous Australians.

Methods: PubMed, CINAHL, PsycINFO, Scopus and Web of Science databases were systematically searched for relevant studies, limited to those published in English between 2008 and 2017. All studies that used experimental designs and reported interventions or programs explicitly aimed at improving Indigenous cardiovascular health were considered for inclusion. Methodological quality of included studies was appraised using design-specific Joanna Briggs Institute critical appraisal checklists. Data were extracted using the Joanna Briggs Institute data extraction form and synthesised narratively.

Results: Eight studies met the inclusion criteria and were assessed to be of varying methodological quality. Common features of effectiveness of programs were integration of programs within existing services, provision of culturally appropriate delivery models with a central role for Indigenous health workers, and provision of support processes for communities such as transportation. It was noted however, that the programs modelled the interventions based on mainstream views and lacked strategies that integrated traditional knowledge and delivery of health care.

Conclusions: Very few cardiovascular healthcare programs designed specifically for Indigenous Australians, which had undergone rigorous study, were identified. Whilst the majority of included articles were assessed to be of satisfactory methodological quality, the nature of interventions was diverse, and they were implemented in a variety of healthcare settings. The limited evidence available demonstrated that interventions targeted at Indigenous cardiovascular health and related risk factors can be effective. The results indicate that there are opportunities to improve cardiovascular health of Indigenous people at all stages of the disease continuum. There is a need for further research into evidence-based interventions that are sensitive to Indigenous culture and needs.

Trial registration: Registered with PROSPERO International: CRD2016046688.

Keywords: Cardiovascular disease, Indigenous Australians, Interventions, Systematic review

* Correspondence: vainess.mbuzi@health.qld.gov.au

¹Nursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane, Australia

²School of Nursing, Midwifery and Paramedicine, Australian Catholic University, Brisbane, Australia

Full list of author information is available at the end of the article



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Background

Indigenous Australians experience significant health disparities compared to the non-Indigenous population [1]. Although Indigenous peoples throughout the world suffer health disadvantages resulting in reduced quality of life, when compared to non-Indigenous people, the health disparity among Indigenous Australians is significant. It is characterised by the high prevalence of preventable disease, including cardiovascular disease (CVD), which has contributed to lower life expectancy of this population [2]. In adopting its *Closing the Gap* policy, the Council of Australian Governments (COAG) committed to address this inequality. Targets were set for a range of health and wellbeing indicators with the aim of closing the Indigenous life expectancy gap within a generation [3]. Subsequently, many healthcare policies, strategies, and programs have been implemented with the explicit aim to improve Indigenous health.

In this context it is essential to monitor and evaluate the effectiveness of such programs, especially those focused on CVD, which has a higher incidence among Indigenous Australians compared to others [4] and is the leading cause of morbidity and mortality in this population [1]. Recent data show little improvement in equity of health outcomes and extensive disparity persists [1, 5].

Although CVD is largely preventable [6, 7] it is a major contributor to morbidity, mortality and health disparity worldwide [8, 9] and there is substantial Australian evidence of its contribution to higher rates of morbidity and mortality among Indigenous Australians [2]. In 2009, CVD was 4.6 times more prevalent in the Indigenous population than in other Australians [10]. And, in the most recent Australian burden of disease study, CVD accounted for 12% of the total burden of Indigenous disease, and was responsible for 19% of the gap in total health burden disparity between Indigenous and non-Indigenous Australians [1]. In 2012 it was reported that Indigenous people are more than 70% more likely to die from CVD than other Australians [11], and Australian national statistics from 2016 attributed 13% of all Indigenous Australian deaths to CVD [12]. In addition, the risk factors for CVD are disproportionately higher among Indigenous Australians compared to other Australians. The fourth national report (2012–2016) of Indigenous primary health care national key performance indicators revealed that although there has been a reduction in CVD, most primary healthcare organisations recorded the necessary risk factors to enable CVD assessment for fewer than 50% of their clients [13]. Although many risk factors are theoretically preventable, effective health promotion campaigns in the Indigenous context are met with challenges such as geographical isolation contributing to lack of access and poor resource distribution, cultural sensitivity issues [10, 14, 15], and the complexity of disease [16].

While it is crucial to understand the root causes of Indigenous CVD disparity in terms of the social and economic forces that contribute to, or influence the development of risk factors, it is equally important to formulate strategies that are effective for improving Indigenous health. Cardiovascular health promotion interventions encompass areas such as the definition of the cardiac condition in terms of aetiology, diagnosis of the problem, identification of treatment courses, how to deliver services effectively, expected outcomes in terms of improvements, and maintenance strategies to prevent deterioration of cardiovascular health [17, 18]. The goal of such programs should be to reduce cardiovascular risk, identify and manage complications, provide appropriate and timely health care, and provide support to Indigenous people in their efforts to modify their lifestyle and self-manage their cardiovascular health [19, 20].

The disparity between Indigenous and non-Indigenous Australian morbidity and mortality represents an important target for the design and implementation of effective cardiovascular health improvement programs. Opportunities to prevent and enhance treatment and management of CVD for Indigenous people are important if closure of the health gap is to be achieved. In this context it is imperative that effective programs are provided that are best suited to their unique contexts and needs. Programs should take into consideration Indigenous factors that impact health, such as political history and cultural views and beliefs that affect disease understandings. Whilst it is well-recognised that there is much that needs to be done to optimise Indigenous cardiovascular health, at present there is limited evidence of the effectiveness of cardiovascular programs that aim to improve it. Despite the fact that many healthcare programs have been implemented, the majority have been reported descriptively (e.g. [21–23]) and most lack a rigorous approach to evaluation of their effectiveness. Thus, it is unclear which programs have greatest benefit.

An evidence-based summary of the effectiveness of cardiovascular programs for Indigenous people would provide important information to assist with the development and evaluation of future programs. Thus, the aim of this study was to evaluate the effectiveness of interventions focused on the management of cardiovascular health among Indigenous Australians. The review results may guide health professionals and policy makers towards best practices that in turn may help to improve cardiovascular health outcomes for Indigenous Australians. The review question was: How effective are current programs that aim to improve cardiovascular health of Indigenous Australians?

Methods

Design

A systematic review was conducted based on Joanna Briggs Institute (JBI) guidelines [24]. Systematic review

methodology enables use of rigorous methods to synthesise previous research data in a scientifically sound manner through formulation of a research question; identification, selection, critical appraisal, data extraction and analysis; and presentation of aggregated outcomes of studies included in the review [25, 26]. The protocol for this review was registered with Prospero International [27].

Eligibility criteria

This review sought to identify studies within the published peer-reviewed literature that focused on implementation of programs designed specifically for Indigenous Australians, aimed at prevention, treatment or management, or rehabilitation of CVD that were published in English between 2008 and 2017. The date range was selected to identify interventions implemented following the launch of the *Close the Gap* campaign [3]. Experimental studies eligible for review included both randomised controlled trials and non-randomised studies that measured outcomes associated with the cardiovascular program implemented. The inclusion criteria were:

- **Population:** Indigenous participants, and mixed sample studies with a larger proportion of Indigenous participants.
- **Intervention:** interventions reporting an explicit aim of prevention, management/treatment, or rehabilitation of cardiovascular disease among Indigenous Australians
- **Comparator:** comparisons between intervention and control group or baseline results for single group pre-test and post-test studies.
- **Outcomes:** demonstration of changes in, but not limited to: behavioural risk factors (e.g. increased participation in exercise, rehabilitation, and dietary management), knowledge of cardiovascular disease, and health assessment measures (e.g. decrease in blood pressure, weight loss).
- **Study design:** all types of experimental (randomised and non-randomised) designs.
- **Limits:** peer-reviewed journals; publication date range 2008 to 2017; English language.

Search strategy

The search was conducted in two stages. In September 2016 an initial search of CINAHL from 2008 onwards was conducted to estimate the quantity and quality of published articles. This initial search retrieved very few potential articles for inclusion in the review and even fewer randomised controlled trials. Subsequently, librarian colleagues were consulted to assist with refinement of the search terms, to include all experimental (randomised and non-randomised) designs. A comprehensive

search strategy was developed, which was implemented from October 2016 to June 2017. It used a combination of MESH terms and text words that was purposely broad to capture the breadth of available studies. The following sources were electronically searched: CINAHL; Pubmed; PsycINFO; Scopus; and Web of Science. A search strategy using all identified keywords with filters was applied for each specific database (see Table 1). A hand search of the reference lists of the selected articles was also conducted.

Study selection process

The database search results were imported into Endnote™ where duplicates were removed; after which the titles and abstracts were screened by three reviewers to identify studies matching the inclusion criteria. Full texts of potentially relevant studies were retrieved for

Table 1 Search strategy in CINAHL

Search	Search terms
S1 Population of interest	((MH "Indigenous Health") OR (MH "Aborigines+") OR (MH "Indigenous Peoples+") OR (Aborigin* OR Indigenous OR "Torres Strait Islander*" OR "Australoid race" OR Koori* OR Murri* OR "Oceanic ancestry group*"))
S2 Disease	((MH "Heart Diseases+") OR (MH "Coronary Arteriosclerosis") OR (MH "Coronary Disease+") OR (MH "Cardiovascular Diseases+") OR (MH "Cardiovascular Risk Factors") OR (MH "Cardiovascular Abnormalities+") OR (MH "Cardiac Patients") OR (Cardiac OR Cardiolog* OR "Heart disease*" OR "Heart failure*" OR Coronar* OR Cardiovascular OR "Heart health" OR "Heart problem*" OR "Heart disorder*"))
S3 Intervention	((MH "Patient Education+") OR (MH "Diet+") OR (MH "Health Services+") OR (MH "Health Promotion+") OR (MH "Public Health+") OR (MH "Epidemiology+") OR (MH "Treatment Outcomes+") OR (MH "Rehabilitation+") OR (MH "Therapeutic Exercise+") OR (MH "Exercise+") OR (Prevent* OR Educat* OR Diet* OR Exercise* OR Rehabilitat* OR "Health Promotion" OR "Treatment outcome*" OR "Public health" OR Epidemiology))
S4 Setting	((MH "Australia+") OR (MH "Western Australia") OR (MH "South Australia") OR (MH "Queensland") OR (MH "New South Wales") OR (MH "Australian Capital Territory") OR (MH "Northern Territory") OR (MH "Tasmania") OR (Australia* OR Queensland OR "New South Wales" OR Victoria OR "Australian Capital Territory" OR "South Australia" OR "Western Australia" OR "Northern Territory" OR Tasmania) NOT (Canada OR Columbia))
S6 Design	("Randomized controlled trial*" OR "controlled clinical trial*" OR "random allocation" OR "double blind method" OR "single blind method" OR "clinical trial*" OR placebo* OR random* OR "research design" OR "comparative stud*" OR "evaluation stud*" OR "follow-up stud*" OR "prospective stud*" OR "cross-over stud*" OR (control* OR prospect* OR volunteer*) OR ((singl* OR doubl* OR treb* OR tripl*) W2 (blind* OR mask*)))
S6	S1 AND S2 AND S3 AND S4 AND S5

further assessment against criteria. All outcome data claimed by the original authors to measure the construct of interest were considered eligible for inclusion. Studies were included if they used quantitative measures to examine effectiveness. Mixed method studies were considered if significant quantitative outcomes were reported.

Data extraction and synthesis

Quantitative data were extracted from the included studies. One reviewer extracted data using the JBI data extraction form for experimental/observational studies [28]. Data extracted included: author details; year of publication; study design; sample and setting; methods; intervention description; outcomes; and comments/conclusions. These were cross-checked by two reviewers for completeness and accuracy.

The results are synthesised using a narrative approach supported with tables. Heterogeneity of the studies in terms of interventions, settings, outcome measurements, and study designs precluded conduction of a meta-analysis. Studies were categorised by type of intervention strategy (prevention, management or treatment, or rehabilitation). The focus was on changes that occurred as a result of implementing an intervention and measurement of its impact or effectiveness.

Results

Study selection

The selection process is presented in Fig. 1. A total of 724 studies were retrieved and 124 duplicates were excluded. 470 articles which were: non-specific to Indigenous Australians, qualitative studies, protocols, reviews, editorials or letters; and 122 articles that were purely descriptive or did not involve strategy implementation, were excluded. Eight studies were included in the full review (see Table 2).

Methodological quality of included studies

Studies selected for inclusion in the review were assessed for methodological quality. Three researchers reviewed and assessed each study for quality and relevance, using tools appropriate to its design. Joanna Briggs Institute [29] checklists for randomised control trials (13 criteria) and quasi-experimental non-randomised studies (9 criteria) were used. Overall quality was graded using categories cited by Reilly et al. [30] in relation to the proportion of criteria met (poor < 50%, moderate 50–80%, good > 80%), but was not used to exclude studies. Any disagreements that arose between reviewers were resolved through team discussion.

The overall weakness of the included studies was a lack of randomised trials; only two studies were found: a pragmatic randomised trial [31] and a parallel arm

cluster randomised controlled trial [32]. The other six studies were of various designs, of which three employed mixed methods [33–35]. The two randomised studies were judged to be of moderate quality (see Table 3), while four of the quasi-experimental studies were judged to be of good quality, with one assessed as moderate [36] and another as poor [37] (see Table 4).

With the exception of two studies [32, 36] samples sizes were small (≤ 100). Two studies compared different cohorts before and after the intervention [36, 37] whereas the remainder reported repeated measures. Two studies did not report any statistical significance of outcomes [36, 37] and one [33] reported several outcomes as being “statistically significant” but did not cite associated values. Only one study [33] reported effect sizes, but did not provide associated significance values, although it was stated in the text that the outcomes were not statistically significant.

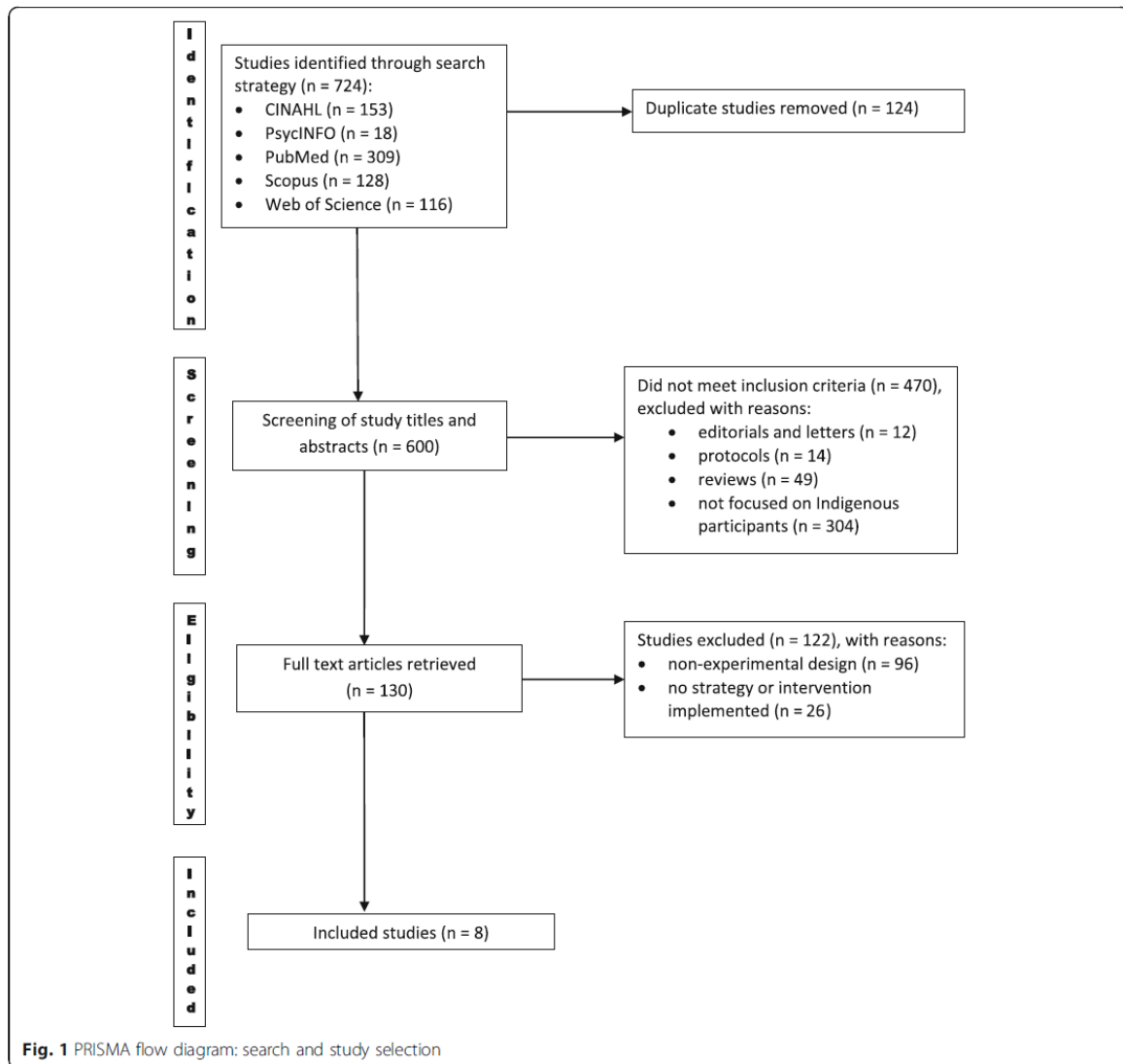
Study characteristics

Considerable heterogeneity of cardiovascular health programs and settings was represented in the eight included studies (see Table 2), which were conducted within the following Australian states and territories: New South Wales [34]; New South Wales and Queensland [32]; Northern Territory [36, 38]; South Australia [31]; Tasmania [33]; Victoria [37]; and Western Australia [35]. The studies were conducted in several settings: Aboriginal medical services [33, 35]; metropolitan [31, 34, 37] and primary care [31, 36, 38].

Intervention categories were identified following completion of data extraction. There were three strategic intervention foci observed in the studies reviewed: prevention; management or treatment; and rehabilitation (see Table 2). All studies reported some statistically significant positive impacts, which were demonstrated by post-intervention improvements to varying degrees. The main outcomes measured were: increased participation [33, 37], reduction in physiological indicators, such as blood pressure and body weight [31, 35, 36], increased confidence of Indigenous staff [34] and overall improvements in identification and management of cardiac conditions [32, 36, 38].

Risk of bias within studies

Bias was distinguished from quality and reflected within the quality appraisal tools (see Tables 3 and 4). The included studies were assessed for six main domains; selection bias (randomisation), performance bias (blinding of participants/personnel), detection bias (blinding of outcome measures), attrition bias (incomplete outcome data), reporting bias (selective reporting) and other sources of bias [39] using the JBI tool quality appraisal tool [29] as used by Omura et al. [40].



The two randomised studies [31, 32] addressed the risk of bias through randomisation, and ensuring that treatment groups were similar at baseline (selection bias) and both specified the randomisation procedures used [computer Programs for Epidemiologists (PEPI) and permuted block procedure, respectively]. Both studies addressed performance bias by using appropriate statistical analyses for their studies, but neither blinded those providing treatment or participants. The six other studies had no randomisation allocation. Four were pre- and post-test single group designs, one was a before and after study [37], and one used a longitudinal design but made comparison to a pre-intervention population [36]. On the whole, the non-randomised studies used the

same measures before and after exposure to the program, on the same participants, and appropriate statistical analyses were used. However, in one study [36] virtually all outcome measures were post-intervention only, with no statistical analyses undertaken.

The two randomised studies were assessed at level 1.c evidence according to JBI levels of evidence for effectiveness of experimental designs, and the six non-randomised studies were assessed at level 2.d evidence [41].

Risk of bias across studies

Risk of bias across studies was conducted to address the following: risk of measurement, detection, attrition, and selection bias as reported earlier (see Tables 3 and 4).

Table 2 Characteristics of included studies

Authors, year	Study design	Strategy focus	Intervention	Sample and setting	Method	Outcomes	Comments
Burgess, et al., 2011 [38]	Interrupted time series study (6 years); pre- and post-measures; 6-monthly follow ups pre- (3 years) and post-intervention (3 years)	Early identification/preventative	Holistic CVD risk assessment as part of an adult health check	Indigenous participants (n = 64); remote primary health care service, Northern Territory	Questionnaires/charts review/investigations	Improved delivery of preventive care services; improved medicine prescription; reduction in estimated absolute CVD risk; better and earlier identification of elevated CVD risk	The program led to better and earlier identification of cardiac risk factors as well as generally improved delivery of preventive care services and cardiac treatment
Burgess, et al., 2015 [36]	Longitudinal clinical audits of cardiac prevention services; 3 monthly follow-ups for 2 years	Preventative	Chronic conditions management model	Indigenous participants (n = 12,428); remote primary health care services (n = 49), Northern Territory	Clinical audit of cardiac prevention services	Increased coverage of Indigenous population CVD risk assessment; assessment of modifiable cardiac risk factors; increased appropriate prescription of medication; achievement of clinical targets for risk reduction	The program demonstrated ability to reduce cardiac risk factors in rural Indigenous populations. It also enabled follow-up of patients
Canuto, et al., 2012 [31]	Pragmatic RCT Follow up 3 monthly (completed: n = 59, lost to follow up: n = 41)	Management/treatment	12-week exercise and nutrition program	Indigenous participants (intervention n = 51, control n = 49); metropolitan area, South Australia	Implementation of a structured exercise program	Reduction in weight and BMI	Low attendance but intervention had positive effects. Requires understanding the barriers to participation
Davey, et al., 2014 [33]	Mixed methods Pre- and post-program measures	Rehabilitation/secondary prevention	8-week supervised exercise and educational session - cardiopulmonary rehabilitation and secondary prevention program	Indigenous participants (n = 92); Aboriginal community-controlled health services, Tasmania	Implemented an exercise and educational program with Indigenous community	Increased participation in rehabilitation; positive changes in health behaviours, functional exercise capacity and health related quality of life. Decreased weight, BMI, and waist circumference Increased 6-min walk test results	Community based interventions have multiple positive impacts
Davidson, et al., 2008 [34]	Mixed methods Pre- and post-measures	Management/treatment	A partnership model among key education providers, policy makers, non-government organisations, the local area health service and Aboriginal community controlled organisations	Indigenous participants (n = 21); metropolitan Technical and Further Education (TAFE), New South Wales	Mixed method evaluation using questionnaires and semi structured interviews	Participants reported increased confidence in ability to provide CVD service to community and demonstrated enhanced CVD knowledge: post-course test mean score 70% vs pre-course score 42%	The model was useful in promoting cardiac knowledge in Aboriginal Health Workers while increasing Aboriginal health knowledge in the mainstream health setting. The model forged partnerships.
Daws, et al., 2014 [37]	Pre- and post-evaluation program	Rehabilitation/secondary	Working together model of care - (Aboriginal	Aboriginal and Torres Strait Islander	Retrospective audit	Increased referral rate (15 to 86%)	The partnership model approach to care

Table 2 Characteristics of included studies (*Continued*)

Authors, year	Study design	Strategy focus	Intervention	Sample and setting	Method	Outcomes	Comments
Dimer, et al., 2013 [35]	Mixed methods Pre- and post-program measures	prevention	hospital liaison officer and specialist cardiac nurse team)	participants (n = 13); metropolitan tertiary public hospital, Victoria		and attendance rate (0 to 62%)	coordination and system changes that were implemented led to improved attendance at cardiac rehabilitation in the participating group
		Rehabilitation	Cardiac rehabilitation program; weekly exercise and education sessions	Indigenous participants (n = 48); Aboriginal medical services, Western Australia	Evaluation of exercise and educational program	Decreased weight, BMI, BP, waist girth; improved 6-min walk test	Aboriginal Medical Service based cardiac rehabilitation proved to be effective in improving attendance, and cardiac risk factor and health management
Peiris et al., 2015 [32]	Parallel arm cluster- randomized controlled trial	Management/ treatment	Computer-guided quality improvement intervention	Aboriginal and Torres Strait Islander participants (n = 38,725); Australian primary healthcare centres (n = 60 services), New South Wales and Queensland	Implementation of computerised screening and management algorithm	The intervention was associated with improved overall risk factor measurements	There was minimal support required to implement the tool and had positive effects on improving cardiac risk measurement

BMI/body mass index, BP blood pressure, CVD cardiovascular disease

Table 3 Critical appraisal of randomised controlled trials

JBI checklist criteria (potential bias)	Studies	
	Canuto et al., 2012 [31]	Peiris et al., 2015 [32]
1. Was true randomization used for assignment of participants to treatment groups? (selection bias)	Yes	Yes
2. Was allocation to treatment groups concealed? (selection bias)	No	No
3. Were treatment groups similar at the baseline? (selection bias/design bias)	Yes	Yes
4. Were participants blind to treatment assignment? (performance bias)	No	No
5. Were those delivering treatment blind to treatment assignment? (performance/detection bias)	No	No
6. Were outcomes assessors blind to treatment assignment? (ascertainment bias)	No	Yes
7. Were treatments groups treated identically other than the intervention of interest? (systematic difference/containment bias)	Yes	Yes
8. Was follow-up complete, and if not, were strategies to address incomplete follow-up utilized? (attrition bias)	Yes	Yes
9. Were participants analysed in the groups to which they were randomized? (intention to analysis)	Yes	Yes
10. Were outcomes measured in the same way for treatment groups? (instrumentation/testing effects threats)	Yes	Yes
11. Were outcomes measured in a reliable way? (measurement bias)	Yes	Yes
12. Was appropriate statistical analysis used? (performance/detection bias)	Yes	Yes
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial? (design bias)	Yes	Yes
Total (%) and quality rating ^a	9/13 (69%) Moderate	10/13 (77%) Moderate

^aGood: at least 80%, moderate: 50–80%; poor: less than 50%

Table 4 Results of critical appraisal of quasi-experimental studies

JBI checklist criteria (potential bias and threat)	Studies					
	Burgess et al., 2011 [38]	Burgess et al., 2015 [36]	Davey et al., 2014 [33]	Davidson et al., 2008 [34]	Daws et al., 2014 [37]	Dimer et al., 2013 [35]
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)? (causation/reverse causation)	Yes	Yes	Yes	Yes	Yes	Yes
2. Were the participants included in any comparisons similar? (selection bias)	Yes	Yes	Yes	Yes	Yes	Yes
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest? (history threat/systematic difference/contamination bias)	Yes	Yes	Yes	Yes	Yes	Yes
4. Was there a control group? (measurement bias)	No	No	No	No	No	No
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure? (maturation threat, regression to the mean)	Yes	No	Yes	Yes	No	Yes
6. Was follow-up complete, and if not, was follow-up adequately reported and strategies to deal with loss to follow-up employed? (attrition bias)	Yes	Yes	Yes	Yes	Yes	Yes
7. Were the outcomes of participants included in any comparisons measured in the same way? (instrumentation/testing effects threats)	Yes	Yes	Yes	Yes	No	Yes
8. Were outcomes measured in a reliable way? (detection/instrument/measurement bias)	Yes	Yes	Yes	Yes	No	Yes
9. Was appropriate statistical analysis used? (performance/detection bias)	Yes	No	Yes	Yes	No	Yes
Total (%) and quality rating ^a	8/9 (88%) Good	6/9 (67%) Moderate	8/9 (88%) Good	8/9 (88%) Good	4/9 (44%) Poor	8/9 (88%) Good

^aGood: at least 80%, moderate: 50–80%; poor: less than 50%

Randomisation was used to assess selection bias for the two randomised trials; both described procedures for randomisation. Due to the nature of the programs, blinding of those who delivered the program and participants was not possible. One study used a single-blinded design in which outcome assessors were blinded [32].

Results of individual studies

Significant results of individual studies are presented in Table 5. Meta-analysis was not possible due to heterogeneity of the studies.

Description of studies

Two studies were specifically focused on preventative programs [36, 38], providing a combination of primary and secondary prevention interventions, including CVD risk assessment [36], and holistic risk assessment [38]. The main outcomes measured included coverage of CVD risk assessment for the Indigenous population, appropriate prescription of medication, achievement of clinical targets (such as reduction of blood pressure and weight), and exercise tolerance.

Implementation of CVD risk assessment opportunities in remote Indigenous communities was conducted in the Northern Territory using a holistic approach as part of an adult health check in a primary health care service [38]. The intervention provided a 'one-stop-shop' for participants that included provision of transport services to facilitate access. The aim of this six-year interrupted time series study was to identify whether risk assessment led to better identification of elevated CVD risk, improved delivery of preventative services, and improved the CVD risk profile of participants. The results demonstrated that adult health checks were effective in the early identification of CVD with 24.9% ($n = 75/301$) of patients identified as having elevated risk, of whom 64 participated in the study. Compared to baseline, significant improvements in CVD-related medication prescription rates ($p < 0.001$) were observed at 6-month follow-up. As well, significant improvements in CVD risk factors were demonstrated at health check review follow-up (on average, around a year following initial health check): waist circumference reduction ($p = 0.04$) and HDL cholesterol reduction ($p = 0.001$), with significant reduction in expected versus observed mean estimated 10-year CVD risk ($p = 0.004$). A high level of engagement of Indigenous participants was observed, with the majority undergoing care planning (98%) and pharmacotherapy (89%) by the study end.

In a longitudinal study, conducted over 2 years, a *Chronic Conditions Management Model* was implemented, based on early recognition of CVD [37]. The model focused on improving the prevention, early detection and management of chronic conditions by introducing strategies such as an

information system using an electronic health record offering easy access patients, cardiovascular risk assessments, structured care pathways, and standardised treatment manuals. Although CVD prevalence increased with age, 9% of those aged between 20 to 34 years were found to have a high level of cardiovascular risk. Subjects aged 75 years or more were excluded from the analyses as they were categorised as high risk by default. Due to the relatively young age of Indigenous people, the majority of participants were aged less than 45 years. Following implementation, the Indigenous population coverage of cardiovascular risk assessment doubled from 26 to 58.5%. Whilst post-intervention outcomes were reported (medication prescription, and CVD clinical targets, such as blood pressure), no comparisons were made with pre-intervention counterpart measures, thus it is difficult to judge the significance of the reported results.

Three studies addressed management or treatment interventions [31, 32, 34]. A pragmatic randomised study in a South Australian urban setting focused on the effects of a structured exercise and nutrition program [31]. Through education, participants were equipped with relevant knowledge to facilitate self-management of their condition and reduce complications. The program aimed to evaluate the effectiveness of a twelve-week structured exercise and nutrition program in a cohort of urban Indigenous Australian women on waist circumference, weight and biomedical markers of metabolic functioning. Participants were randomly assigned to an experimental 'active' group or a 'wait-listed' control group. Although the sample size was small ($n = 100$), statistically significant outcomes were demonstrated in weight reduction ($p = 0.046$; 0.013) and associated body mass index reduction ($p = 0.035$; 0.009), over time. Although small reductions in blood pressure were achieved (1.24 mmHg, 2.46 mmHg), though considered clinically significant, they were not statistically significant (although incorrectly reported in the abstract as such).

A parallel arm cluster randomised controlled trial was conducted in 60 Australian primary healthcare centres, which implemented a computer-guided tool for the management and treatment of CVD in the Indigenous population [32]. The tool was effective due to the provision of systematic, step-by-step guidance; practitioners were able to manage patients more effectively and efficiently. And, although the intervention achieved positive outcomes (improved CVD risk screening, $p = 0.02$; improved CVD-related medications escalation, $p < 0.001$ to 0.02), prescription rates per se did not improve, and effectiveness was limited by the availability of sites with computer access. CVD risk screening was significantly better in smaller healthcare centres (< 500 patients) than larger ones ($p = 0.02$).

Davidson et al. [35] sought to improve the confidence of Aboriginal Health Workers in their ability to provide CVD services to their communities. They implemented an educational program that involved multi-sectoral

Table 5 Significant results of individual studies

Author year Study design	Sample size <i>n</i>	Model or test used	Outcomes		Significance <i>p</i>	Effect size
			Measure	Result		
Canuto et al., 2012 RCT [31]	<i>n</i> = 100 Exp: <i>n</i> = 51 Con: <i>n</i> = 49	Regression analysis; adjusted for all potential confounders Repeated measures: baseline (T1); immediate post-program (T2); 3 months post-program (T3)	T1-T2 mean weight change (kg)	-1.65 (95% CI -3.27 - -0.03)	0.046	NR
			T1-T3 mean weight change (kg)	-2.50 (95% CI -4.46 - -0.54)	0.013	
			T1-T2 mean BMI change (kg/m ²)	-0.66 (95% CI -1.27 - -0.05)	0.035	
			T1-T3 mean BMI change (kg/m ²)	-1.03 (95% CI -1.79 - -0.27)	0.009	
Peiris et al., 2015 RCT [32]	<i>n</i> = 38,725 (60 clusters) Exp: <i>n</i> = 19,385 (30 clusters); HR cohort <i>n</i> = 5392 Con: <i>n</i> = 19,340 (30 clusters); HR cohort <i>n</i> = 4916	Repeated measures Generalized estimating equations	Appropriate screening for CVD (%)	Exp: 62.8 Con: 53.4	0.02	RR 1.25 (95% CI 1.04–1.50)
			CVD risk screening small service (< 500) (%)	Exp: 59.8 Con: 37.3	0.02	1.62 (95% CI 1.17–2.26)
			HR cohort: antiplatelet medication prescription escalation (%)	Exp: 17.9 Con: 2.7	< 0.001	RR 4.80 (95% CI 2.47–9.29)
			HR cohort: lipid-lowering medication prescription escalation (%)	Exp: 19.2 Con: 4.8	< 0.001	RR 3.22 (95% CI 1.77–5.88)
			HR cohort: BP-lowering medication prescription escalation (%)	Exp: 23.3 Con: 12.1	0.02	RR 1.89 (95% CI 1.08–3.28)
			HR cohort: proportion obtaining guideline BP targets (%)	Exp: 61.0 Con: 55.0	0.05	1.10 (95% CI 1.00–1.20)
Burgess et al., 2011 [38] Quasi	<i>n</i> = 64	Repeated measures t-test, McNemar's test, ANOVA	Delivery of CVD preventive services (%)	Baseline: 30 6-month post health check: 53	< 0.001	NR
			Proportion of evidence-based CVD services delivered (%)	Baseline: 29 6-month post health check: 57	< 0.001	NR
			Prescription of all CVD related medication (%)	Baseline: 28 6-month post health check: 89	< 0.001	NR
			Prescription of anti-platelet medication (%)	Baseline: 4.7 6-month post health check: 68.3	< 0.001	NR
			Prescription of lipid-lowering medication (%)	Baseline: 6.3 6-month post health check: 65.1	< 0.001	NR
			Prescription of ACEi/ARB medication (%)	Baseline: 25.0 6-month post health check: 63.5	< 0.001	NR
			Prescription of oral hypoglycaemic medication (%)	Baseline: 17.2 6-month post health check: 33.3	0.04	NR
			Number of cigarettes smoked per day (<i>n</i> = 41)	At health check: 3.5 At health check review: 2.6	< 0.001	NR
			Waist circumference (cm) (<i>n</i> = 56)	At health check: 98.3 At health check review: 96.4	0.04	NR
			HDL cholesterol (mmol/L) (<i>n</i> = 58)	At health check: 1.01 At health check review: 1.11	0.001	NR

Table 5 Significant results of individual studies (Continued)

Author year Study design	Sample size <i>n</i>	Model or test used	Outcomes		Significance <i>p</i>	Effect size	
			Measure	Result			
Burgess et al., 2015 [36] Quasi	Population: 49 primary health care services (<i>n</i> = 12,428) Sample: CVD risk assessment documented (<i>n</i> = 7266) HR cohort (<i>n</i> = 2586)	Post intervention descriptive measures No inferential statistical analyses	Ratio of total to HDL (<i>n</i> = 58)	At health check: 5.7 At health check review: 5.0	< 0.001	NR	
			Expected post health check 5-year CVD risk (%) (<i>n</i> = 58)	At health check: 3.5 At health check review: 2.6	< 0.001	NR	
			Expected post health check 10-year CVD risk (%) (<i>n</i> = 58)	At health check: 9.5 At health check review: 10.2	< 0.001	NR	
			Mean estimated absolute 10-year CVD risk (<i>n</i> = 58)	Expected at health check review: 10.2 Observed at health check review: 8.2	0.004	NR	
			CVD risk assessment: proportion of population (%)	Pre: 26.0 (<i>n</i> = NR) Post: 58.5 (<i>n</i> = 12,428)	NR	–	
			HR cohort (<i>n</i> = 2586): BP assessment (%)	Post: 93.3 (<i>n</i> = 2414)	NR	–	
			HR cohort (<i>n</i> = 2586): medication prescription (%)	Post: 66.8 (<i>n</i> = 1728)	NR	–	
			HR cohort (<i>n</i> = 2414): achieved BP treatment targets (%)	Post: 56.6 (<i>n</i> = 1366)	NR	–	
			HR cohort (<i>n</i> = 2586): lipids assessment (%)	Post: 96.5 (<i>n</i> = 2496)	NR	–	
			HR cohort (<i>n</i> = 2586): lipid lowering medication prescription (%)	Post: 54.8 (<i>n</i> = 1416)	NR	–	
Davey et al., 2014 [33] Quasi	<i>n</i> = 72	Repeated measures <i>t</i> -test	HR cohort (<i>n</i> = 2496): achieved lipids treatment targets (%)	Post: 39.6 (<i>n</i> = 989)	NR	–	
			HR cohort (<i>n</i> = 2340): non-smoking status (%)	Post: 50.0 (<i>n</i> = 1170)	NR	–	
			Weight change (kg)	−0.8 (95% CI −0.01 - -1.6)	NS – value NR	Cohen's <i>d</i> = 0.04	
			BMI change (kg m ⁻²)	−0.3 (95% CI −0.01 - -0.06)	NS – value NR	Cohen's <i>d</i> = 0.04	
			Waist circumference change (cm)	−3.6 (95% CI −2.5 - -4.7)	NS – value NR	Cohen's <i>d</i> = 0.22	
			Incremental Shuttle Walk Test change (m)	106.2 (95% CI 79.1–133.2)	NS – value NR	Cohen's <i>d</i> = 0.11	
			6 Minute Walk Test change (m)	55.7 (95% CI 37.8–73.7)	NS – value NR	Cohen's <i>d</i> = 0.11	
			Timed up and go test change (sec)	−0.8 (95% CI −0.5 - -1.1)	NS – value NR	Cohen's <i>d</i> = 0.11	
			Quality of life (SF 36) change	General health	9.7 (95% CI 4.4–14.9)	S – value NR	NR
				Bodily pain	7.4 (95% CI 0.5–14.4)	S – value NR	NR
Vitality	15.3 (95% CI 9.6–21.1)	S – value NR		NR			
Social functioning	8.5 (95% CI 0.8–16.3)	S – value NR	NR				

Table 5 Significant results of individual studies (*Continued*)

Author year Study design	Sample size <i>n</i>	Model or test used	Outcomes		Significance <i>p</i>	Effect size
			Measure	Result		
			Role emotional	13.5 (95% CI 1.0–26.1)	S – value NR	NR
			Mental health	14.2 (95% CI 8.6–19.9)	S – value NR	NR
Davidson et al., 2008 [34] Quasi	<i>n</i> = 17	Repeated measures <i>t</i> -tests MANOVA	Knowledge score (range 1–25)	Pre: 9.93 (SD 4.02) Post: 17.43 (SD 3.32)	< 0.001	NR
			Confidence in knowledge score	Pre: 4.46 (SD 1.84) Post: 8.08 (SD 1.60)	< 0.001	NR
			Confidence in skills score	Pre: 4.29 (SD 2.75) Post: 8.16 (SD 1.84)	< 0.001	NR
			Confidence in communication score	Pre: 5.52 (SD 2.39) Post: 8.34 (SD 1.69)	< 0.001	NR
Daws et al., 2014 [37] Quasi	Pre: <i>n</i> = 68 Post: <i>n</i> = 13	Retrospective audit Descriptive analysis. No inferential statistical analyses	Referral for cardiac rehabilitation (%)	Pre (<i>n</i> = 68): 14.7 (<i>n</i> = 10) Post (<i>n</i> = 15): 86.7 (<i>n</i> = 13)	NR	–
			Attendance for cardiac rehabilitation (%)	Pre (<i>n</i> = 10): 0 Post (<i>n</i> = 13): 61.5 (<i>n</i> = 8)	NR	–
Dimer et al., 2013 [35] Quasi	Population <i>n</i> = 98 Sample <i>n</i> = 48 Sample subset (program completion) <i>n</i> = 28	Repeated measures <i>t</i> -test	BMI (kg m ⁻²)	Pre: 34.0 (SD 5.1) Post: 33.3 (SD 5.2)	< 0.05	NR
			Waist girth (cm)	Pre: 112.9 (SD 13.6) Post: 108.6 (SD 13.2)	< 0.01	NR
			Systolic BP (mm Hg)	Pre: 135 (SD 20) Post: 120 (SD 16)	< 0.01	NR
			Diastolic BP (mm Hg)	Pre: 78 (SD 12) Post: 72 (SD 5)	< 0.05	NR
			6 Minute Walk Test distance (m)	Pre: 296 (SD 115) Post: 345 (SD 135)	< 0.01	NR

ACEi angiotensin converting enzyme, ARB angiotensin receptor blocker, BMI body mass index, BP blood pressure, Con control, CVD cardiovascular disease, Exp experiment, HDL high density lipoprotein, HR high risk, NR not reported, Quasi quasi-experimental study, RCT randomised controlled trial, RR relative risk, S significant, SD standard deviation

departments such as key education providers, policy makers, and local Aboriginal community-controlled organisations. The education program, facilitated via a Tertiary and Further Education (TAFE) institution, offered experiential learning with participants (*n* = 21) working together as a team, facilitated by a mentor. Outcomes were assessed using a 25-item knowledge test and a confidence survey with three subscales (knowledge, skills, communication), with statements assessed using a Likert-type scale (number of items not reported). Four course participants did not participate in the evaluation (reasons not given), resulting in a small sample size (*n* = 17). The authors reported that participants increased their CVD knowledge ($p < 0.001$) and confidence in their CVD knowledge, skills, and communication ($p < 0.001$). However, statistical differences in the latter scores were assessed using *t*-tests, which should be reserved for use with normally distributed scale data. The involvement of various partners had a positive impact by exposing participants to different clinical situations and learning opportunities. This collaborative approach to education facilitated increased cultural

competence and expertise in the delivery of cardiovascular services to Indigenous communities.

Three studies investigated rehabilitation programs [33, 35, 37]. One study was conducted over an eight-week period within a cardiopulmonary rehabilitation centre in Tasmania [33]. The program was managed by Aboriginal community controlled health services, and included peer support from an Indigenous health worker. Recommendations from family and friends enabled new participants to join. Indigenous participants were provided with easy access via provision of transport services. The program was comprised mainly of supervised exercise and education sessions, with the latter focused on cardiovascular and respiratory health and disease, self-management, benefits of exercise, nutrition, medication usage, stress management and psychological well-being, and smoking cessation. These aspects of intervention were directed towards both prevention and maintenance of health behaviours. The outcome measures included participation level, development of positive health behaviours, and improved general health with improved exercise

tolerance. Although there was 22% loss to follow up, resulting in a relatively small sample size ($n = 72$), implementation of this program resulted in “clinically significant” improvements in several measures of cardiovascular health. Reductions in weight loss, waist circumference, and BMI were demonstrated, but were reported as statistically non-significant, although some cited effect sizes were medium to large. As well, Six Minute Walk Test distance, Incremental Shuttle Walk Test distance, and Timed Up and Go Test time were all increased, but were not statistically significant. Quality of life was also improved in most domains of the SF-36; although improvements were reported as “statistically significant” no values were cited. Success was attributed to a well-designed, one-stop-shop. The program had a holistic approach that addressed several health issues such as nutrition, exercise, smoking cessation and medication management. The program also addressed issues of cultural safety by conducting the study in an Aboriginal community controlled health service.

The study by Daws et al. [37] implemented a “working together” model of care in which an Aboriginal Hospital Liaison Officer and a specialist cardiac nurse teamed up to address the problem of referring patients to rehabilitation services post-acute care. The Aboriginal Hospital Liaison Officer made the initial contact with all patients and facilitated their meeting with the cardiac nurse. This introduction was vital for establishing relationships. Together, the partnership arranged referrals and provided education about the benefits of cardiac rehabilitation, and helped improve access to cardiac rehabilitation health services for the Indigenous participants. Retrospective medical chart audits revealed that the model improved referrals from 15 to 86% and rehabilitation attendance rates from zero to 62%. However, it is important to note that pre-implementation data were collected over a 3-year period ($n = 68$), whereas post-implementation data ($n = 15$) were collected over a 7-month period, and no comparisons were made between the two cohorts. Thus, it is difficult to draw conclusions about the effectiveness of this project. In a similar project, within an Aboriginal medical service, Dimer et al. [35] aimed to provide a secure environment for an eight-week exercise and education program for Aboriginal people with or at risk of CVD. Both visual and experiential learning opportunities were employed. Education and exercise through yarning helped to identify and address a range of issues such as medication compliance, risk factor reviews, and chest pain management. The cardiac rehabilitation program was well attended ($n = 98$), but only half of the participants (49%, $n = 48$) was surveyed (reasons not given). Of these, outcome measures were reported on 28 participants that completed the 8-week program only, thus it is difficult to evaluate overall effectiveness of the program as the outcome data reported is representative of only 29% of all

program participants. In the program-completion subset, statistically significant reductions in body mass index ($p < 0.05$), waist girth ($p < 0.01$), systolic ($p < 0.01$) and diastolic ($p < 0.05$) blood pressure, and increased 6-Minute Walk Test distance ($p < 0.01$), were reported. Success of the program was attributed to the delivery of the program in a culturally safe environment. The researchers concluded that rehabilitation programs for Indigenous people were more effective when they were planned as part of an already established service. The program enabled local community members to be involved in the planning of activities.

Discussion

The aim of this review was to systematically examine the published literature for evidence of the effectiveness of cardiovascular health interventions designed for Indigenous Australians. Eight studies were identified that met the inclusion criteria, demonstrating the dearth of formal research in this area.

There was considerable heterogeneity within the studies that were reviewed with interventions implemented in a wide variety of clinical settings across Australia, and measuring different outcomes. Thus, a meta-analysis was not possible. In order to examine the effectiveness of the interventions, there is a need for further experimental research to demonstrate objectively the effects of cardiovascular programs in terms of health outcomes as well as Indigenous engagement and satisfaction.

Although there was only a relatively small number of intervention studies available for review, the overall results indicate that targeted cardiovascular programs are effective in improving clinical outcomes, such as weight reduction, blood pressure control, and increased activity levels. As well, several programs demonstrated behavioural impacts regarding healthy lifestyle changes, and provided valuable insights into successful strategies for Indigenous people that may help to inform future programs. Indigenous people display cardiovascular symptoms at a younger age compared to non-Indigenous people [1]. However, poor screening of young Indigenous people has been reported [23], suggesting a need for earlier targeted assessment and advice about CVD risk factors, commencing during school years.

Although much higher rates of cigarette smoking have been reported for Indigenous Australians [1], intervention programs addressing this risk factor in association with CVD were not found in this review. Similarly, findings by Arjunan and colleagues [42] revealed the scarcity of local evidence crucial for promoting cessation among Aboriginal tobacco smokers. The risk to health from smoking and alcohol is widely acknowledged. In particular, smoking impacts cancer, respiratory, and cardiovascular diseases [1] whereas

Indigenous alcohol use is primarily associated with impacts on mental health [1].

In the main, it was observed that the reviewed programs were designed within a mainstream health model with somewhat limited consideration given to the perspectives of Indigenous patients, their families or communities, suggesting that there is a cultural sensitivity gap in the design of cardiovascular interventions. Culturally sensitive health care has been described as care that effectively responds to the attitudes, feelings, and circumstances of individuals that belong to a population group with common identifying characteristics such as race, religion, language, and socioeconomic status, and that which patients perceive as being concordant with their cultural values and beliefs [43]. Cultural sensitivity is, therefore, the extent to which ethnic or cultural characteristics, experiences, norms, values, behavioural patterns and beliefs of the target population as well as relevant historical, environmental, and social forces are incorporated into the design, delivery, and evaluation of targeted health programs [44]. In 2016, the World Federation of Critical Care Nurses made a declaration about culturally sensitive practice [45]. Its recommendations, whilst directed at critical care nurses, are applicable to many settings. Included are aspects such as self-assessment by clinicians, establishing trust with patients and their families, identification of patients' culture (language, food, gender considerations), and ensuring that dignity and privacy are protected.

Since the focus of the review was on the Indigenous population, each study was reviewed in this context by examining its aims and objectives, its focus on Indigenous participation, and particular Indigenous-sensitive aspects reflected in the design and implementation of its CVD program: access, empowerment, collaborative partnerships, and meaningful relationships. Following their 2012 study on effects of exercise and nutrition, Canuto et al. [46] went a step further by evaluating their program qualitatively. A main finding was that participants' perception of health benefits of the program influenced their attendance. They concluded that programs should be designed to meet participants' needs and expectations, and be conducted in a culturally safe environment. Healthcare providers should commit to the process of building and maintaining cultural relationships [47]. Neuwelt and colleagues, [48] in their study of the role of receptionists in general practice settings, revealed the importance of creating meaningful relationships with Indigenous patients. The receptionists helped patients to feel comfortable, demonstrating that trustworthiness and healthy relationships with patients are important factors that encourage sustained Indigenous engagement. Similarly, Hayman and colleagues [49] pointed to the fact that successful implementation of programs at a community controlled health centre was partly as a result of employment of Indigenous staff, good interpersonal

relationships, and effective collaboration and consultation processes with the Indigenous community.

In several studies, Indigenous access was enhanced by use of local community based services [31, 35, 36, 38] providing a one-stop-shop type of service [38]. Further, transportation was offered for those that needed it, enabling access for those living in more remote areas [33, 34]. A study by Tuttle, et al. [50] made comparison between Indigenous and non-Indigenous participants in an outreach program to measure completion of scheduled outreach visits of the intervention group. An interesting finding was that distance alone did not influence completion of visits. Although Indigenous participants resided further away from the hospital in comparison to non-Indigenous participants, the study revealed that there was no difference in the number of attempted and missed visits at baseline. A combination of distance and timing of the visits had a significant impact in that at six months visits there were more missed appointments. A similar pattern was also reflected in the study by Artuso et al. [51] who investigated the factors that influenced utilisation of health care among Indigenous cardiac participants. They found that the perceived need for the service influenced long term utilisation. Patients that felt they were 'fixed' or cured after a procedure, or in this case a program, they did not see the need to continue with treatment. The authors concluded that it was not sufficient to only provide a program but to understand the needs of individuals; emphasising to participants that health maintenance is a lifelong commitment.

Indigenous empowerment was enhanced both at individual and community levels, through use of individualised care plans [32, 36, 38], training of Indigenous workers [34, 37], and involvement of community advisory committees [31, 35, 37], and 'working together' approaches between multidisciplinary teams developed meaningful collaborative partnerships [31, 34–36, 38]. Multidisciplinary teams allowed for focused use of approaches that addressed Indigenous needs and team learning allowed for a better work environment [33, 38]. Continuity of care was possible with teamwork approaches [31, 35, 37, 38] and relationships that were appropriate and culturally safe were achieved through involvement of participants and their community [34, 35, 37]. Providing time to understand participants through yarning and other communication styles that are sensitive to Indigenous people contributed to a culturally safe environment [33–35, 37, 38]. Common components associated with intervention effectiveness were: integration and coordination of programs within the existing services, such as metropolitan areas [31], primary health services [32, 36, 38], Aboriginal medical services [33, 35], active involvement of Indigenous health workers in the form of education and clinical partnerships with other health care providers [34, 37], and provision of support to facilitate individual

participation through transport provision, peer/family support, and professional support [33, 38].

Our results indicate that an Indigenous perspective was crucial to not only deliver apposite strategies, but to ameliorate the subtle negative impact that colonisation exerts on Indigenous people, reminiscent of the initial forced changes in lifestyle, familial and cultural practices, and spiritual disconnectedness which affect Indigenous people in complex ways [14, 52]. Indigenous engagement was recommended in the studies, where findings illustrated that whilst the distance from health services influenced Indigenous access, there were other culturally rooted factors that contributed to success and required negotiation of meeting times and locations with the patients. Similar factors were reflected in a narrative report of an Indigenous cardiac outreach program in which success was attributed to integration of Indigenous values, which encouraged capacity building, and ownership of programs by either individuals or communities [21]. Our results suggest there is a clear need to employ healthcare strategies that incorporate traditional knowledge, and reflect Indigenous values. Without appropriate cultural and contextual knowledge, participants may hold mistaken beliefs about their health outcome, leading to a failure of some participants to engage.

The continued use of mainstream healthcare models displays subtle patronising implications, where traditional knowledge is not adequately acknowledged nor utilised when addressing health issues. Valuing and integrating Indigenous wisdom into the design of healthcare programs can enhance therapeutic relationships between Indigenous communities and health services by uniting and empowering both Indigenous and non-Indigenous peoples as contributors to health [53, 54]. The key to effectiveness of collaborative partnerships lies in genuine involvement of Indigenous people and validation of traditional practices and influences on policy [55]. For example, 'working together' programs in multidisciplinary teams have shown demonstrable benefits for participants [34, 37]. Such programs provide opportunities for learning and create a respectful and reciprocal relationship through genuine understanding by incorporating Indigenous worldviews and cultural preferences [56]. However, whilst cultural sensitivity is important in the prevention and treatments of behavioural ailments caution has been expressed [55, 57] that it should not be used as a buzz word or in a tokenistic way.

Although there was only a relatively small number of intervention studies available for review, the overall results indicate that targeted cardiovascular programs are effective in improving clinical outcomes, such as weight reduction, blood pressure control, and increased activity levels. As well, several programs demonstrated behavioural impacts regarding healthy lifestyle changes, and provided valuable

insights into successful strategies for Indigenous people that may help to inform future programs.

Implications for indigenous health care services

The results of this review provide a clear indication of the importance of Indigenous inclusivity and cultural sensitivity when implementing programs aimed at improving Indigenous CVD outcomes. To make a difference in improved health outcomes for this population group, sustainable interventions and continued development of new models of care that meet and manage Indigenous peoples' health needs is critical. This has implications for healthcare professional training and education, which should serve to enhance understanding of differences in individuals that seek health care, especially Indigenous people, emphasising the importance of constructing meaningful relationships and 'working together' approaches. This responsibility transcends departmental boundaries to the general public. For effective programs to be implemented and sustained, rigorous research methods and appropriate programs that are responsive to Indigenous issues and needs will enhance change and impact Indigenous health outcomes positively.

Limitations

There were two key limitations to this review. Of particular note was the lack of randomised trials, which would have provided stronger evidence of the effectiveness of interventions. As well, there was significant heterogeneity of settings, interventions and outcomes in the studies that were reviewed, making generalisation difficult. Despite these limitations, some clear themes were evident regarding Indigenous inclusivity and its association with successful outcomes, including both physical and behavioural components.

Conclusions

There are very few studies that have investigated the effectiveness of cardiovascular health interventions designed to address Indigenous health outcomes. Further rigorous evaluation would enable a better understanding of effectiveness and sustainability of cardiovascular programs among Indigenous Australians. Nonetheless, the reviewed interventions have demonstrated a range of tangible benefits and provided insight into factors that contribute to the success of such programs. Our results suggest that healthcare professionals should actively incorporate the values of Indigenous people into the design of cardiovascular healthcare programs, demonstrating respect and reciprocity through meaningful collaboration with Indigenous people. Clearly the synergy of multidisciplinary teams and collaborative partnerships benefits both patients and health staff alike in a way that can only advance cardiovascular health for Indigenous Australians.

Abbreviations

BMI: Body mass index; COAG: Council of Australian Governments; CVD: Cardiovascular disease; JBI: Joanna Briggs Institute; PEPI: Program for epidemiologists; TAFE: Technical and Further Education

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Author contributions

All authors had substantial contributions as follows: VM: Study conception, acquisition of data, analysis and interpretation of data, drafting of manuscript and revision of final draft. PF: Study conception, analysis and interpretation of data, critical revision of the manuscript for important intellectual content and supervision of the study, and revision of final draft. MJ: Acquisition of data, critical revision of the manuscript for important intellectual content and supervision of the study, and revision of final draft. All authors read and approved the final manuscript.

Availability of data and materials

All data analysed during this systematic review study are included and referenced in this manuscript.

Ethics approval and consent to participate

Not applicable. The review utilised only publicly available and published data.

Consent for publication

Not applicable.

Competing interests

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Author details

¹Nursing Research and Practice Development Centre, The Prince Charles Hospital, Brisbane, Australia. ²School of Nursing, Midwifery and Paramedicine, Australian Catholic University, Brisbane, Australia. ³Adult Intensive Care Services, The Prince Charles Hospital, Brisbane, Australia. ⁴Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa. ⁵School of Nursing, Midwifery and Social Work, Faculty of Health and Behavioural Sciences, University of Queensland, Brisbane, Australia.

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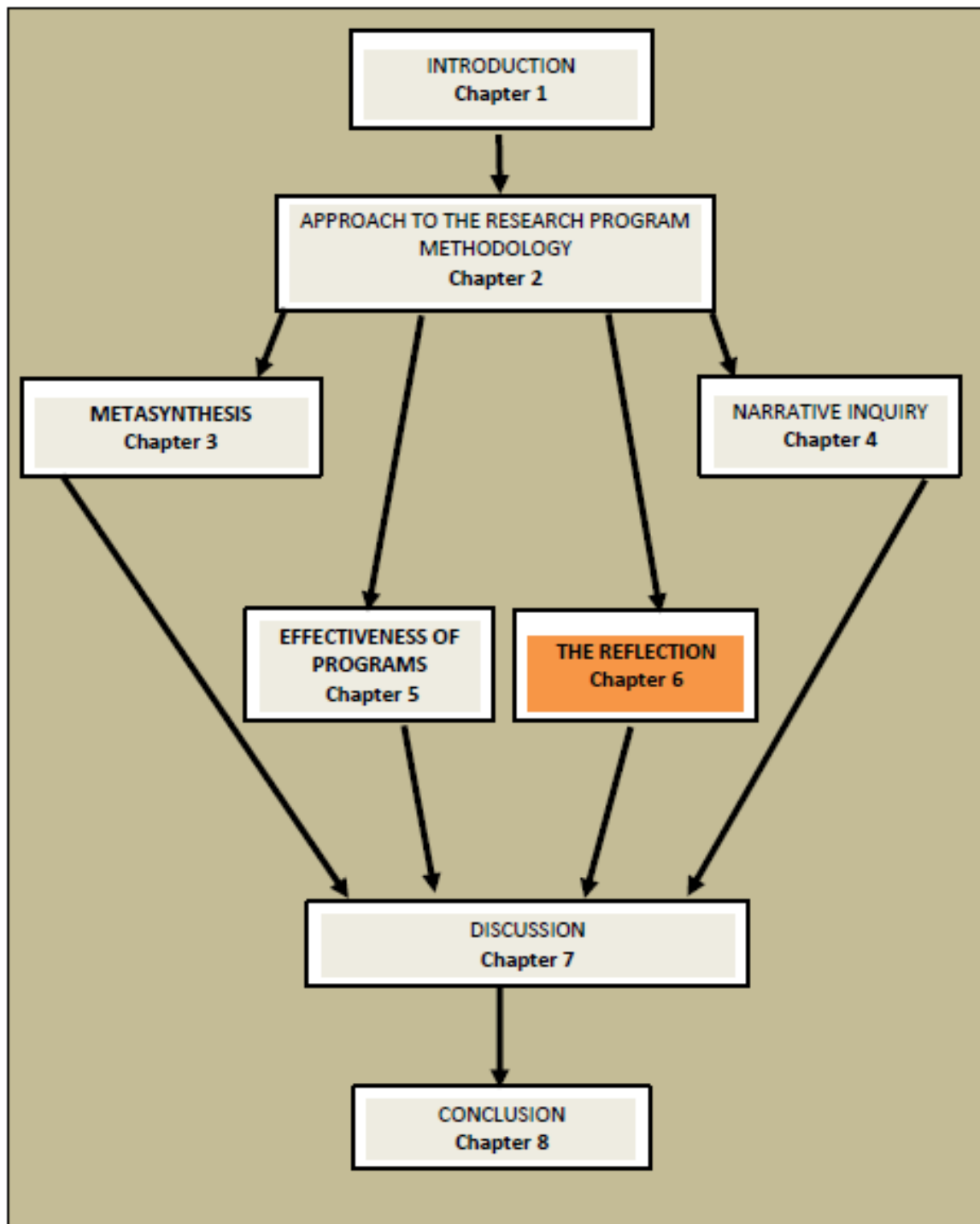
Chapter summary

This chapter presented a review of the effectiveness of programs that were designed to address cardiovascular health among Indigenous Australians. This was to evaluate how effective the programs were, and review what made the programs successful. Having investigated the experiences of Indigenous people from a worldwide perspective to local Australian contexts, it was vital to determine effectiveness of these programs. This study complemented the Indigenous experience story by revealing how programs specifically tailored for Indigenous people were conducted. The overall finding is that through a biomedical viewpoint, the programs were effective in addressing physiological parameters. However, the process of designing and implementing the programs still heavily lean on mainstream approaches.

One key observation was that limited cultural knowledge was incorporated in the studies. Although there is use of local health settings the biomedical model does not equip individuals with lifelong skills which they can practice at home with the resources that they have. There is, therefore, need to use strength-based approaches that can empower individuals and provide sustainability of the health activities in their individual lives and as a community. Strategic aspects that contributed to the success of the programs included ensuring access, empowerment of individuals, developing collaborative partnerships and meaningful relationships. Use of familiar methods such as yarning and family centred activities assisted in attaining good attendance.

The following chapter provides my personal reflective account regarding the experience of researching with Indigenous people. Having undertaken the program of research enriched me with a lot of insights and changed my point of view as far as Indigenous health is concerned. I therefore share these with readers for the purpose of enhancing the Indigenous experience of acute care story.

Chapter six: Autoethnography – Study four



Researching with Indigenous people: an autoethnography

Journal metrics: International Journal for Equity in Health [Scimago Q1, Impact Factor 2.473,

SJR ranking: 31/242 Medicine, Health Policy]

Chapter overview

This chapter presents a reflective account of the experience of researching with Indigenous people. In the context of completing a PhD, I conducted a program of research to gain an understanding of Australian Indigenous people's experiences of healthcare. It is my contention that a researcher not only influences the research process, but is also influenced by it, beyond just academic levels. The voice of the researcher is not always heard in most final reports, which generally focus on participants and research outputs. I am sharing my story of researching with Indigenous people through this article, utilising an Autoethnographical research approach. The purpose of this presentation is to provide insights into my experience and insights for others contemplating research with Indigenous peoples.

Research provides individual experiences to researchers, and we can learn from the experiences of others. There are unique issues that require to be thought through to be effective in the service provision to Indigenous peoples. They have specific and special needs that require an efficient and effective planning, and a critical evaluation by the health provider. Inclusion of a researcher reflective view in this program of research demonstrated the central concepts of narrative investigation which include co-construction.

Personal stories are central to narrative inquiry and they facilitate acknowledgement of who we are. Further, narratives assist people to reveal deepest meanings attached to stories of experiences, both as a participant of research or researcher. Through experiencing the research process together, a co-construction relation develops that informs final conclusions of a research study. We all learn from stories depending on the perspective or the lens used, and this section highlight researcher perspectives on the experience of the research process. While there is an extensive history of research about Indigenous peoples and their health status, conducting research studies with Indigenous people still presents unique challenges.

The following section of this chapter presents a manuscript that has been prepared and submitted for publication to International Journal for Equity in Health and is currently under review. It is presented verbatim in the style of the journal for which it is intended. Confirmation of manuscript submission and number is in appendix 10.

Abstract

Background: In the context of completing a Doctor of Philosophy, I conducted a program of research to gain an understanding of Indigenous people's experiences of acute healthcare. It is my contention that a researcher not only influences the research process, but is also influenced by it, beyond just academic levels. The voice of the researcher is not always heard in most final reports. In this article, I am sharing my story of researching with Indigenous people to provide insights into my experience and insights for others contemplating research with Indigenous peoples.

Method: This study used an autoethnographical research approach and a narrative approach was taken in presenting the findings. The study evolved from the parent program of research that investigated Indigenous people's experiences of acute health care. This autography focuses on the researcher experience and reflections of the overall experience of researching with Indigenous people. Individual notes and insights have been used as data to reflect on the research process, researcher transformation, and the personal insights regarding the challenges, lessons, and sociocultural aspects of conducting research with Indigenous people.

Findings: The Indigenous population has been described as one of the most researched groups in the world and yet, as researchers, we continue to get it wrong in most cases, rather than learning from our stories and improving research processes. It is possible that the lack of not only participant voices but also those of the researcher may be a contributing factor. Indigenous knowledge and approaches to research need to be incorporated.

Conclusion: Conducting research with Indigenous people can provide a challenge, but we can learn better approaches by involving Indigenous people themselves and sharing our experiences as researchers. Development of tangible, real-world effective strategies is required to transform research practice and maximise knowledge gain in researching with Indigenous people. The resultant valuable information to be gained through sharing the ups and downs, mistakes and successes, can inform practice, and contribute towards long-overdue best practice in Indigenous research.

Key words: autoethnography; narrative; qualitative; Indigenous health.

Background

Research with Indigenous peoples

There is an extensive history of enquiry about Indigenous peoples, particularly regarding their health status (Fredericks, 2008; Maar, Lightfoot, Sutherland, Strasser, Wilson, Lidstone-Jones, ..., Williamson, 2011). Indigenous peoples are recognised as one of the most researched groups globally (Smith, 2012). While research is conducted mostly to find solutions to Indigenous people's documented health disadvantages (Wilson & Neville, 2009), the results have not always positively impacted their lives, nor effectively informed policy or clinical practice. This is partly due to a lack of engagement of Indigenous people and their communities in the research process (Burnette, Sanders, Butcher, & Salois, 2011; Fredericks, 2008; Ninomiya, & Pollock, 2017). Furthermore, it has been suggested that some researchers have used these groups of people merely to achieve their own professional goals (Bond et al., 2016; Burnette, Sanders, Butcher, & Salois, 2011; Wilson & Neville, 2009). As a result, research is not an activity that Indigenous people look forward to due to their being over-investigated as a community, with minimal tangible benefits to them (Burnette, Sanders, Butcher, & Salois, 2011; Frederick, 2008; Smith, 2012).

Engagement and genuine participation with the Indigenous community can only be achieved through establishment of reciprocal relationships (Hunt, 2013; Jalla & Hayden, 2014). According to Fredericks (2008, p. 25), Indigenous people have tended to be objects of research in which they "have been weighed, given blood, urine, faeces and hair samples, given their stories, explained their existence, been interviewed, questioned, observed, followed, interpreted, analysed and written about for years". The use of research approaches that are not familiar to Indigenous people may have resulted in reports that only reflect interpretations from mainstream views and understanding (Burnette, Sanders, Butcher, & Salois, 2011; Doyle, Cleary, Blanchard, & Hungerford, 2017; Jalla & Hayden, 2014; National Health and Medical Research Council [NHMRC], 2018b). Such research outcomes may have contributed to widely held misrepresentation of Indigenous peoples.

Reliance on ill-informed perceptions and assumptions based on perspectives of western customs and norms have not advanced the cause for Indigenous people (Doyle et al., 2017; Fredericks, 2008; NHMRC, 2018; Smith 2012). On the overall, studies on and about Indigenous people have predominantly been conducted by non-Indigenous people with a tendency to investigate from the "outside" thus providing incomplete findings (Bond et al., 2016; Wilson & Neville, 2009). When

researching with Indigenous people it is, therefore, vital to be sensitive and responsive to their needs and sociocultural viewpoints to effectively impact their community (Castellano & Reading, 2010).

Ethical guidelines and recommendations on the appropriate conduct of research among Indigenous people are readily available (for example, (Australian Institute of Aboriginal and Torres Strait Islander Studies [AIATSIS], 2012; NHMRC, 2018). In the main, however, researchers continue to be trained in conventional frameworks and research approaches (Fredericks, 2008; Maar et al., 2011). Ethical guidelines alone cannot address all the issues that are critical in relation to research processes required in researching with Indigenous people (Castellano & Reading, 2010). Further, there is limited information available to guide how researchers should embed the stated Indigenous values into their research processes. This would provide scholars with opportunities to converse and find strategies to move towards better support for Indigenous research processes and integration of Indigenous knowledge (Frederick, 2008; Maar et al., 2011).

Most Indigenous health research has focused on illustrating disparities through use of the dominant positivist paradigm. Predominantly quantifiable indicators such as statistics on life expectancy, infant mortality, and prevalence of chronic medical conditions are the main studies researchers are occupied with (Auger, Howell, & Gomes, 2016). Such data and research results are important however emphasis on these epidemiological factors alone can lead to a disproportionate concentration on quantifiable health inequalities while inadvertently concealing the roots of disparities by paying little attention to the Indigenous voice. Against this background, there is a need for enlightened researchers to share their understanding to inform the processes and highlight issues for consideration when undertaking research with Indigenous people.

Situating my PhD studies within this context, I conducted a largely qualitative program of research, and focused on gaining an understanding of how Indigenous people's experience acute healthcare. It comprised four studies: a global synthesis of Indigenous people's experiences of healthcare (Mbuzi, Fulbrook, & Jessup, 2017a), a narrative inquiry (my main study) of Australian Indigenous cardiac patients' and their relatives' experiences of hospital care (Mbuzi, Fulbrook, & Jessup, 2017b), a systematic review of the effectiveness of cardiovascular healthcare programs designed for Indigenous Australians (Mbuzi, Fulbrook, & Jessup, 2018), and of course, the autoethnography presented in this article.

My research journey has provided an opportunity to analyse and interpret the sociocultural meanings of my experience (Chang, 2016). The aim of this autoethnography, therefore, is to present the lessons I have learned and to share insights that may be valuable to other researchers. Since storytelling is aligned with Indigenous culture, it is the predominant method I have chosen to present this autoethnography. To situate this article, I firstly provide my own story, briefly explain the research approach of autoethnography, and present the stages of my research journey and the changes I encountered, before drawing conclusions to emphasise key points.

My story

I was born and educated in Zambia; a country made up of several tribal groups. Each tribe has their own regions, traditional rulers, and unique culture wherein things are done a little differently - even the preparation of meals; some use corn as their staple food while others use cassava, or millet (Lambert, 2017). Zambian Nurses were expected to learn the local customs of the people, especially the language of the region in which they were working. This enabled nurses and other health professionals to provide culturally appropriate health care to the people they provided services for, acknowledging differences and showing respect for diversity.

My experience in Zambia, as a person and a health professional, was unlike that which I have witnessed since moving to Australia, where the dominance of one culture is unmistakable. For example, the English language is promoted, and for me, I see myself being viewed as the person with dark skin, with a non-English speaking background and heavy accent, who mispronounces words, has some unique mannerisms, is away from home, and is most probably an international student. Although most of this is true, these characteristics are often expressed with a negative tone, which makes me feel isolated, as if I am being asked to be someone else to fit in or to be regarded an equal human being.

I did not come to my research program value free: I had a vested interest in the issues experienced by Indigenous peoples. Further, I held many preconceived ideas about Australian Indigenous people. From my superficial knowledge of them, I formed some assumptions which were in many ways misplaced. Due to my background I thought I understood what Indigenous people felt and experienced. I have come to learn that my situation cannot equate to that of Indigenous Australians. The key difference being that I am here in Australia by choice. My similarity to their situation may just be related to a common sense of feeling different, isolated, misrepresented, and

having some similar beliefs and values, such as the importance of family ties, cultural ceremonies, and a general outlook on life that is different from western lifestyles. I “went in” to my research with feelings of researching my own “backyard”, but I was wrong. My knowledge about Australian Indigenous people’s experiences of health care was naïve.

Colonisation is one of the main contributing factors to health disparities in Australia (Eckermann et al., 2010; Sherwood, 2013), and although historically Zambia was a British colony, the differences are major. In Zambia, for example, the colonialists left, and Zambians took on positions of power (Lambert, 2017). Hospital staff, including doctors and nurses, are mainly Zambians, who have an understanding about their various cultures. In Australia, however, the colonialists stayed on and their descendants remain in dominant positions of power. Their culture is promoted within society and its institutions, including healthcare services. The same organisations that hurt Indigenous peoples in the past through discriminatory practices and policies remain in place, with remnants of these past ways of life and beliefs still subtly in play through mainstreaming (Sherwood, 2013). Taking part in my program of research gradually opened up more areas of concern than I had anticipated. However, I was fortunate to have an Indigenous member on my supervisory team from the beginning whose advice enriched my research journey. I was encouraged not only to review mainstream literature but to listen to what Indigenous voices had to say on the matters presented.

The story of my PhD journey began with my curiosity for knowledge. The main motivating factor behind my research is my role as a clinician within a cardiothoracic hospital setting where over the years, I have witnessed the expert use of technology and other medical procedures to improve management of patients and save lives or improve their health. I wondered how Indigenous people within the same country could miss out on benefitting from access to the first-class health services that others were receiving. I wanted to comprehend how knowledge gained from my research program could facilitate the development of understanding that would impact the way in which clinicians handle their cultural encounters as they work with Indigenous patients and their families. My goal was – and still is - to improve Indigenous people’s experiences of health care which would contribute to their improved health outcomes. I believe that there may be many researchers who have experienced such an awakening and insights or are yet to have similar encounters as they journey through research with Indigenous people, and who might find limited ways to express their perspectives due to conventional restrictions of research designs and reporting. Autoethnography has given me the opportunity to share my story.

Methodology

Designing the study

Autoethnography is a qualitative research approach that enables examination of an investigator's subjective and embodied experiences (Chang, 2016; Hokkanen, 2017). In terms of research rigour, Chang (2016) proposed five standards for judging the quality of autoethnography, which I refer to throughout this article.

In using autoethnography, I saw an opportunity to use my personal understanding and writing to critique practices, contribute to existing research, embrace vulnerability with purpose, and attempt to create a reciprocal relationship with readers for compelling their response to the issues presented (Jones, Adams, & Ellis, 2016). Although it is known to be ethically beneficial and important to reflect on and report aspects of researcher influence (Denzin, 2014), usually such discussions are not easily presented in research deliberations (Hokkanen, 2017).

As described by Chang (2016), autoethnography is a research approach that combines three aspects: self (auto), culture (ethno), and research process (graphy). It is therefore a research method that connects the self with the social (Chang, 2016). Further, there are two approaches to autoethnography: analytic and evocative. Each of these has an emphasis on the three aspects of the auto-ethno-graphy, to different degrees. The analytic approach focuses on cultural and research process aspects, whilst the evocative approach concentrates more on the "auto" element by focusing on storytelling than elements of culture and research process (Chang, 2016). However, these approaches need not be polarised. In this article, whilst my emphasis is on storytelling, it also aims to inform understanding of the culture and research processes that impact Indigenous experience.

Autoethnography acknowledges that everyone lives in a world that is connected to each other (Muncey, 2010). Thus, I chose this research design because both as a healthcare professional and a researcher, I believe that my experience, and that of others in my sociocultural group, are closely linked to the central issues surrounding health care of patients and their families, be it at clinical, education, policy making levels or through research. My learning as a professional and as a person has been through social interactions with others, and by sharing my experience I can make a contribution to my sociocultural groups (Banks, 2012; Chang, 2016; Fox et al., 2017). Thus, I have used a sociocultural lens to tell my story. I am positioned within this study as both the researched and

researcher, making me part of the text and not a separate entity with external realities (Chang, 2016; Creswell, 2012; Grant, 2010). In this study I recognise the importance of sociocultural aspects in knowledge building and implementation of real-world strategies to better Indigenous health experiences of health care and research. My own background had an impact on both the design, implementation of the study through to interpretation of findings.

Ethical considerations

The study evolved from the parent program of research that was conducted for Doctor of Philosophy program, entitled *“Understanding Indigenous people’s experiences of acute health care with focus on heart health”*. While conducting my PhD program of research, I ensured I had ethics approval from the relevant university and research sites (ref. 214 77N and HREC/13/QPCH/316 respectively). Further to that, one of Chang’s five standards is that of ethics toward others and self (Chang, 2016, p. 448). In doing so, it was both important and culturally significant that Indigenous research guidelines were followed (AIATSIS, 2012) and that Indigenous elders were consulted. As well, I have exercised my ethical responsibilities to those who are part of my story by not mentioning any names nor providing identifying details in this article. Care has been taken not to present this article for purposes other than advancing understanding of researching with Indigenous people and providing insights to readers.

The account that I present here offers a somewhat unique and personal perspective but develops perceptions that are relevant for others who intersect with the world of research. I was aware that in my efforts to share insights from undertaking my research, there is potential to not only publicly display my vulnerability but to also expose myself to those I relate to directly, including peers within the organisation in which I work (Chang, 2016; Luscombe, 2016). I realise, therefore, that my professional practice as a clinician and researcher does not exist without relationships with colleagues, students, friends and family; all of whom are implicated within my research (Ellis, Adams, & Bochner, 2011); especially in this article. As described by Tolich (2010, p. 1608), “the self is porous, leaking to the “other”. Stories are not made in a vacuum and mine will always have both visible and invisible “others” (Clandinin, 2013; Tolich, 2010).

My narrative as data

Autoethnography is a research approach that utilises personal perspectives as raw data and enables scrutiny of sociocultural interpretation of them (Chang, 2016; Lapadat, 2017). Thus, my data needed to be authentic and trustworthy (Chang, 2016, p. 448). To demonstrate and fulfil this requirement I acknowledge my data sources throughout this account. Authenticity of data is demonstrated further by my research is referred to in terms of provision of references to the studies that were undertaken (Mbuzi, Fulbrook, & Jessup, 2017a; 2017b; Mbuzi, Fulbrook, & Jessup, 2018) as evidence of my experiences.

A major source of data was the notes I wrote during and after conducting interviews with participants in my main study. As well, I have used comments and memory recall, documented as the research progressed, and reflections, insights and conclusions drawn as I processed data (Hughes, Pennington, & Makris, 2012). Another source of data was from my interactions with various people in gatekeeper roles to the Indigenous population, and workmates, both supportive and unsupportive, as well as those who guard knowledge development, such as journal reviewers, and academics and scholars who were my peer review teams and educators. Personal diary entries and the whole experience of my research journey generated data for this article.

Working with the data

Chang (2016, p. 448) refers to an “accountable research process”. My initial notes were written free-hand, recalling all the events I went through, with reference to my field notes and comments written at the time. These notes were written free of any constraint, allowing ideas to emerge, and these became my raw data. I elevated my personal reflections to become the primary source of data, blending subjectivity and objectivity together (Chang, 2016; Gergen, 2014). The blending came about because I had to view my subjective issues with an objective lens in order to reflect and learn from my experiences. I was both the researcher and the researched.

After compiling events that made up my story as a researcher, analysis involved revealing the hidden meanings of my various encounters (Hayes, 2016; Webster & Mertova, 2007). I read through the raw data and then arranged it into the meaningful themes that I present here. This process enabled me to identify exceptional occurrences and connect my present stance to my past experiences (Chang, 2016; Hayes, 2016; Hughes et al., 2012).

In the analysis stage, therefore, my interpretations were focused on explaining what my personal research journey meant in relation to others in my sociocultural groups, and to the participants, and the values that shape experience (Adams, Jones, & Ellis, 2016; Hokkanen, 2017). The reflections and story told had to hold meaning for a wider community (Hayes, 2016; Hokkanen, 2017) than that to which I belonged. This necessitates conversations in the broader research community regarding research with Indigenous people. I had to “move beyond being familiar” with my story to recognising the issues that were emerging from my research experience (Hayes, 2016). To enable me to focus I posed questions such as: “What have I learned from this journey? What can other researchers gain from it? Is this helpful to the way Indigenous research is done? Does this add value or insight, or extend understanding in researching with Indigenous people?” (Diary notes).

From my perspective I looked for transformative changes that have occurred in me as a result of engaging with the research process. Further, I have had to make value judgements based on what I saw as meaningful insights and make interconnections with my clinical and research practice (Hayes, 2016). In this article I analyse both my personal and professional life, and the culture that makes up my practice as a clinician with regards to Indigenous health and research activities.

Findings

This autoethnography is presented in three stages of a story: the beginning, middle and end of the lead author’s personal journey of researching with Indigenous people, as pertaining to five themes of the journey.

In the beginning

Opening gates

The beginning of my research journey was riddled with ups and downs due to the many choices that had to be made in conjunction and consultation with other people who would be part of my research experience and process. Following several false starts, gatekeepers closed the gate on my initial project as they had built a solid relationship with the target community for my project and believed that the introduction of a new research activity by a new face had the potential to risk that established relationship. Literally days before I was due to commence data collection, I was informed

that I could not go ahead. Gatekeepers reassured me that "...It has nothing to do with your qualifications". As I came to terms with this "closed gate" I noted:

This is true in many ways because people in the community will not be looking for my qualifications but will observe what I do and how I do it. Their perceptions, right or wrong, might have everlasting impact on the program. In any case I can't go by myself, I need the team. This is hard... (Diary entry).

Subsequently, I prepared a proposal to conduct my main study in a different environment. Reflecting on the previous closed door, this time I ensured that the Indigenous community and gatekeepers were consulted and involved from the early planning stages and throughout the whole research process. My previous experience highlighted this as the most important aspect of research preparation. I recall a reminder to myself as follows:

I need to know all I can before committing to this project, regarding processes of consultation with Indigenous community. They will show me all the hoops I need to jump through... consult the hospital Indigenous team (Diary entry).

Subsequently, introduction of the researchers by an Indigenous party known to the participants helped to establish a relationship with potential participants. The gates were opened, and the introduction process felt easier than had been anticipated. I noted and said to myself, "My consultation with the Indigenous team has paid off" (Diary note). After the introduction, none of the potential participants declined an invitation to take part in the study.

It was difficult to find support for my research in the clinical environment. Most of my workmates painted a negative picture of Indigenous people and told me that it was a waste of time pursuing studies in Indigenous health. I was told, "They never change" or "Why should they be treated any different?" but they never acknowledged that we have not made an effort to understand them (diary entry). I later realised that my workmates were as uninformed as me and I slowly started asking them questions to raise awareness, such as whether they knew any Indigenous language or local Indigenous custodians. These conversations helped to start discussions about Indigenous health, and slowly some of my workmates started showing interest and would bring to my attention events they had observed within our health service.

In the planning stages of my research, I considered whether to use a qualitative or quantitative research approach:

Most PhD studies are designed to prove something, discover something, or provide an answer to a certain question. I will have to think hard to offer something through a qualitative approach. It might be very hard to achieve results that are impactful. [Diary entry].

The overt intention of my program of research was to gain understanding and insight about Indigenous people's experiences of acute healthcare. In this vein, I settled for a predominantly qualitative approach because of its suitability to gather Indigenous perspectives; storytelling is culturally affirmative and characteristic of Indigenous cultures (Gorman & Toombs, 2009; Iseke, 2013; Kovach, 2009), and was key to my research program. For my main study, I selected narrative inquiry because it would enable participants to tell their story and facilitate their voices to be heard in a non-directive way. I positioned myself as the listener during data collection, and then as narrator of the collective story (Merriweather, 2015). Much of the data and insights presented in this autoethnography have been drawn from my experience of gathering stories from Indigenous people. As such, I identify with the words of Merriweather (2015, p. 64), who stated that the significance of the research process "was not in the tasks that were performed, although necessary, but in understanding who I was." In this case, this autoethnography is about my understanding of Indigenous people and where I stood within my culture, how the social environment of my practice influenced me, and how these in turn impact Indigenous people's experiences of acute healthcare.

Dissemination of research results was another issue to consider. To have an impact on the health care that Indigenous people receive, and to benefit both the participant population and the health provider community, I chose to complete my PhD program through publication. This allowed me to reach a larger and international audience. I also chose to pursue publication in mainstream journals to ensure dissemination of the findings beyond an Indigenous-specific audience.

My first interview was with a male participant

From the beginning I was sure I would meet some challenging situations because the study site was a hospital where participants would be enduring stressful situations. Some would have travelled long distances away from their community and family and therefore, stress would not be a

stranger during this time. Asking them to tell me the story of their journey might provide them with some relief. It would be an opportunity to tell someone what they were undergoing.

I was warned by others regarding some of the difficulties that I might face, such as rejection because of my gender and race. In particular, I was forewarned that it would be hard for Indigenous men to tell me their stories, and that, in general, “Indigenous Australians don’t trust Africans” [memory recall]. When the time came to interview my first participant, I learned he was male, so I was nervous because of the anecdotal advice that I had received. I was afraid as I approached the bedside, but I encouraged myself, “...You are of African origin... you are female... he is a male Indigenous participant...but you have got this!” [memory recall]. To my relief, my first interview went well. From then on, the rest of my data collection went smoothly as the gates were open and no one I approached as a potential participant declined to participate.

Multiple sources to learn from

The gate to Indigenous people’s stories of their experiences with healthcare was opened for me through listening to direct narratives, reading and reviewing literature, and taking an interest in Indigenous issues as presented in the media. I became a fan of National Indigenous Television and listened to various programs that were insightful for me. Songs I had heard before became alive and meaningful, with a new and different clarity from that which they held before. Indigenous song, such as the words by Yothu Yindi (1991), revealed the disillusionment Indigenous people feel due to broken promises and the taking away of their homeland, while at the same time wishing for a brighter future:

This land was never given up.

This land was never bought and sold.

The planting of the Union Jack.

Never changed our law at all.

Now two rivers run their course.

Separated for so long.

I’m dreaming of a brighter day.

When the waters will be one.

These words confirmed the sentiments which were portrayed by some participants in saying that they were not yet welcome into hospitals. The separate courses they lead as a people has had

the impact on them. As reflected in the song, the planting of a union jack did not change them as a people, and to-date the two cultures run their course and are separated for so long. To union of the two cultures as one can be achieved through acceptance and respect for each other's cultures and way of life. Integration of cultures in the way healthcare is designed and delivered through implementation of culturally appropriate care is critical. Although much has been written on ways to improve Indigenous people's access and experiences of health care, these are often at a tokenistic level, such as the display of Indigenous flags and paintings, and a sprinkle of Indigenous Hospital Liaison Officers here and there, and, indeed, promises that are like writing in the sand.

Centring in

Realising my responsibility: reciprocity

Participants had shared their stories with me and I had read widely on Indigenous people's healthcare experiences and synthesised qualitative understandings from the world literature. I had investigated the effectiveness of programs designed to address Indigenous health in the context of cardiovascular health in Australia. Each of my studies added a new dimension to my own emergent story and opened my eyes to issues that I had never considered before. I had been sensitised to issues of distinctiveness of Indigenous peoples, government approaches to Indigenous health issues, and practices that are generally masked regarding Indigenous people. My capacity to empathise with the participants deepened, and I started to recognise the innumerable ways their personal encounters influenced the way they experienced and viewed health services.

Before engaging in this research, my understanding was limited to the extent that sometimes I recall feeling annoyed with Indigenous people: "All they needed was to show up for appointments and take their tablets... right?". I had been so wrong and shallow in my views. Now, with real understanding, I feel that I have been given a responsibility to not only retell the information I had gained, but to do so with intent to change or influence others' practice for the better. I was given a different lens through which to view Indigenous health and the aspects that impact it. It was a privilege that I learned to take seriously, and to honour the participants by retelling their stories, to inform others, and by doing so, affect their outlook on Indigenous people's healthcare delivery, thus impacting their stories of healthcare experiences for the better. I was accountable to the university I was studying with, clinical practice, the scientific community, and to the participants and their communities, so I had to get the balance right in the dissemination of the research findings, and I needed to decide who would benefit from these.

Sharing stories

To begin the process of dissemination I ventured on a journey of oral and poster presentations at local and national conferences. Initially, my focus was on presenting at Indigenous conferences. Delegates at these conferences concurred with my presentation content. Further, they encouraged me to take the message to mainstream conferences as well. I was “preaching to the converted” by focusing only on Indigenous conferences (Diary entry). However, their feedback was critical because it confirmed that the messages from my research were acceptable to the Indigenous community. The findings seen as significant and valuable because they conveyed the voice of the Indigenous community.

At one congress I was given hugs from elders who were present, and we posed and took photos (Figure 6.1). This was a positive outcome for me because I felt that I had their blessing. I was thus encouraged and felt free to continue my research and make known the issues I had learned. I presented locally and nationally. The aim was to involve other health professionals and raise awareness of issues that affect Indigenous patients and families as they experience healthcare. My goal was that this would be a starting point for discussions with others to help garner a different view of Indigenous health issues.



Figure 6.1. The elder blessing.

Seeing a bigger picture

Over the course of my candidature, I have achieved professional growth that I never anticipated in relation to research processes as well as publication of results. I have come to appreciate that qualitative research methods place researchers very close to participants. This can have a personal and emotional impact on both parties. I started realising that, in research, more value is often placed on the scientific quality of the study than the social benefits. This second look revealed to me that it is important when conducting research, especially projects that focus on vulnerable populations, to consider social benefit to the community as well. I also came to realise that research can be such a political mine field due to many stakeholders who would all like to benefit or see results that favour them. Research endeavours should go beyond a research proposal that meets ethical requirements and a technically sound presentation that meets academic standards. The moral obligation is to always do right by the participants.

I experienced the interface of several cultures that were in play during my research. These included the cultures of my participants, my own, my professional training, and finally the academic culture and scholarly community. I thought: “Who is boss here; who is giving the orders? Whose needs are being met in the research process, and am I here just to show off how I can follow perfect research processes and to gain my qualifications? Who is at the centre of this process? What do I want from this?” (diary note). Such questions helped me refocus on the participants and my role to gain understanding of their experiences.

Engaging the community was critical to completing my research. The Indigenous Health Unit of the Health service I work with became the representation of Indigenous community and a team I could consult. Indigenous conferences enabled me to network with individuals external to my local service area. My experience has taught me that engagement must be genuine and not a tokenistic involvement. I came to know aspects of Indigenous people and their healthcare issues that I did not consider before. This led me to start questioning my everyday attitudes and practices as both a health professional and a researcher. Although I had a somewhat similar cultural background to Indigenous Australians, I was not immune to stereotypical assumptions and I have since re-examined what I thought I knew.

I had gathered evidence from different sources in the literature and everyday media, and participants’ stories. I kept asking myself whether I had enough power to project these voices “out

there” so that the issues would be heard by those who have the power to respond and act. I did not want the stories to be just academic information. I asked myself, “Will my research have any clinical impact that will result in changes to how Indigenous people are cared for and bring about a positive change to their health care experience stories?” (Daily note). My aim as a clinician and researcher is that this program of research will be translated into something tangible. This includes influencing change in practice, health professionals’ attitude or policy formulation processes, or simply by provoking discussion among clinicians.

The questions I asked myself gave me fuel to go beyond just achieving my academic pursuit, but to see some changes implemented by those who hear the stories through face to face presentations and published work. My clinical area and the hospital where I work were the best avenues to make the story come alive, through active participation in improving the stories of Indigenous peoples’ hospitalisation experiences. Improvements can be as easy as knowing an area’s traditional custodians or simply asking Indigenous patients what name they prefer to be called, with a smile and attitude that acknowledges the other (Mbuji, Fulbrook, & Jessup, 2017a).

Discussion

An end to a continuing story

Researching Indigenous people is unique and requires particular consideration to be a successful research experience for both participants and researcher. Professional development regarding Indigenous health and sociocultural perspectives has been patchy, ad hoc and lacking in cohesiveness (Ewen, Paul, & Bloom, 2012; Gwynne & Lincoln, 2017) and education provided to healthcare professionals, such as cultural competence training, has tended to lack direction on how to apply such learning in an environment that is dominated by biomedical and disease-based approaches to care (Gwynne & Lincoln, 2017). As a result, some learning programs can be a source of reinforced stereotypical perceptions and may achieve the opposite effect to that intended, leading to judgmental and derogatory views that result in negative outcomes (Farrelly & Lumby, 2009). In clinical situations, Indigenous people are expected to repress their cultural knowledge in preference for mainstream health views and such attitudes or expectations are not only experienced in health service settings but are widespread in society, affecting all aspects of Indigenous life.

There is value in using integrated research approaches which include a subjective lens when researching with Indigenous people. As Denzin (2014) states, it is not possible to give an objective account to issues relating to culture or social situations. Knowledge of the social and human world cannot exist independently of the knower nor can we know or tell anything without being involved and implicated in the knowing and the telling (Douglas & Carless, 2016). Using autoethnographic approaches, narrators can be both researchers and the researched (Richards, 2008). The sociocultural analysis and interpretation (Chang, 2016) of my personal research experiences provides evidence to help judge the quality of this article. Engaging in autoethnography enabled me to examine my historically held prejudices about my practice and Indigenous people and, as others before me have reported. This has helped me to acknowledge, discover, and change myself for the better in the way I view Indigenous health issues (Douglas & Carless, 2016; Merriweather, 2015).

My testimony as presented in this study bears witness to the fact that I became more aware of ambiguities in health practice. The main issues that impact healthcare service originate from biomedical, political, cultural and social spaces, including research (Sturmburg, 2012). One main observation is that research is extremely institutionalised through a variety of disciplines and fields of information. The institutionalisation is formed and influenced by communities such as scholarly communities, health organisations and their interest groups, or academic institutions and funding bodies (Huutoniemi, 2016). This influence is an essential part of structures that are built around communities such as funding bodies, healthcare organisations, tertiary education, and government and non-government organisational policies (Huutoniemi, 2016).

An example of institutionalisation is the fact that those who conduct research are skilled and socialised into viewing issues in certain ways. Specialised language and technical skills are learned as they participate in research (Coryn, 2006). The commonly used research approaches in healthcare are towards demonstrating effectiveness of treatments (Hoffmann, et al., 2017). Again, these efforts are in line with a biomedical approach to healthcare provision. It is important, however, to consider the use of alternative approaches that advantage consumers of research outcomes such as Indigenous participants and their communities (Homan, 2011).

Indigenist and decolonising research approaches continue to emerge, and these must be recognised and included in the mainstream epistemologies and ontologies (Rix, Wilson, Sheehan, & Tujague, 2019). A holistic approach and understanding of health that is based on Indigenous values and cultural health practices needs to be implemented otherwise the barriers as a result of reliance

on biomedical approach to health will continue to disadvantage Indigenous peoples. There are works by a variety of authors that are advancing Indigenist methodologies, including those by Smith (2012) and Kovach (2009), and a variety of authors are increasingly using research approaches such as yarning (Bessarab & Ng'andu, 2010). These research approaches are designed to empower participants or to work in partnership with participating communities.

In my program of research, I attempted to use methods that privileged Indigenous values, attitudes, and practices (Rix, et al., 2019). I believe that all the expertise and knowledge that can be accumulated can only make sense if used to change even one person or their community (Homan, 2011). Indigenous people require research that is sensitive to their needs because everyone in the world is shaped by their sociocultural environments (Chang, 2016). Researchers should learn from Indigenous peoples and respectfully work with them in order to facilitate integration of knowledge in research that are inclusive of Indigenous ways (Rix, et al., 2019).

I came to the realisation that mainstream approaches have conceptions of dominance and otherness that I might be replicating in my professional practice, personal life, and indeed, research practice. There are many approaches to research and healthcare that continue to reject understandings of health from Indigenous people's perspectives wherein their knowledge, culture, histories and languages are not valued in a genuine way, privileging western health views and practices (Doyle et al., 2017; Wilson, Kelly, Magarey, Jones, & Mackean, 2016). There is a need to challenge the obvious, even in health research and practice (Kinchin, McCalman, Bainbridge, Tsey, & Lui, 2017; Wilson & Neville, 2009). Indigenous health embodies a heritage that is deeply connected with local lands, seas, waterways, skies and kinship, and yet these are set aside in mainstream healthcare. There is a failure to challenge existing western views, resulting in limited culturally appropriate knowledge (Doyle et al., 2017; Kinchin, McCalman, Bainbridge, Tsey, & Lui, 2017; Wright, Lin, & O'Connell, 2016).

To be true participants in research and healthcare Indigenous people need to be genuinely involved, and integration of their ways of knowing is crucial. Healthcare clinicians, educators, and researchers are sometimes inadequately prepared to meet the needs of Indigenous people due to dominant mainstream methodologies and research processes (Simonds & Christopher, 2013). Guidelines for conducting research with Indigenous people do exist, however, as yet no definitive Indigenous research models have been established. It is fundamental that research protocols for use in Indigenous research reflect cultural sensitivity, partnership, specific ways to engage the community

members (gate opening), and most of all, how the community may benefit from the research (reciprocity).

I found that there is still a struggle to find a method that enables Indigenous voices to be heard. There is a need to design models that allow incorporation of both academic and Indigenous knowledge (Bearskin, 2011). Respect is a core value that overarches such a process of incorporation. It leads to openness and comprehension that lends itself to collaboration, trusting relationships, and reciprocal obligations (Bearskin, 2011). I have wondered many times whether the use of unfamiliar terms in research and healthcare settings contributes to misunderstanding more than it is credited to do. Even within mainstream views there can be barriers to research utilisation (Kim, Wilcher, Petruney, Krueger, Wynne, & Zan, 2018). I now understand that an insistence on conforming to western customs and norms continues to impact Indigenous people's ways of life, which has brought about their feelings of isolation, discrimination, being ignored, unwelcome, and misunderstood in society (Eckermann et al., 2010; Sherwood, 2013).

Further conversations

Despite current guidelines, without achieving a certain level of respect for participants who might be mainly non-academic or non-research oriented, there is still the possibility of being insensitive to Indigenous culture and traditions in both research and clinical practice (Jalla & Hayden, 2014; Kim et al., 2018). Diversity does exist, and the question remains as to how clinicians are engaging with it within research or healthcare service delivery. Non-Indigenous researchers and clinicians have a role in improving Indigenous health. This can be achieved through appropriate training that addresses health issues or research issues that are specific to Indigenous peoples.

Autoethnographic investigation of these issues is critical because it starts with self-exploration through to the synthesis of broader sociocultural concepts related to the subject area (Luscombe, 2016). Social and organisational practices require critique because in many cases these have been taken for granted, especially within hospital care (Luscombe, 2016). Although there has been an increase in Higher Degrees by Research enrolment and completion by Indigenous students, a question still remains whether socialisation into their new roles enable them to uplift their "cultural banners" and influence academic or clinical practice. Are they provided with an opportunity to lead and teach the cultural ways to practice and be effective in Indigenous health improvement? There are calls for a cultural shift within healthcare research and practice to maximise the real-world use of the evidence

or knowledge gained (Kim et al., 2018). This call is to all healthcare professionals to take responsibility and respond. To have a better understanding regarding Indigenous research issues, it is critical for researchers to view them within a broader historical context, cultural and social contexts and finding a balance across Indigenous and western scientific perspectives (Doyle et al., 2017; Riddell, Salamanca, Pepler, Cardinal, & McIvor, 2017).

Genuine engagement is required in the preparation of clinicians, educators, researchers, and policy makers. It is regretful that the omission of cultures and languages continues, contributing to the marginalisation of Indigenous views and experiences of health in Australia (Hunt, 2013). There are opportunities for healthcare workers to develop tangible skills to help them improve effectiveness in their care of Indigenous patients and their families that can contribute to better health outcomes. One way of achieving this is to share their stories and learn from the Indigenous communities themselves. Further, by sharing their perspectives, researchers can improve processes and thereby contribute to positive perceptions of research and healthcare practices in Indigenous communities.

Discussions, such as those regarding research approaches, can promote methods that suit Indigenous communities and use ethical frameworks that incorporate Indigenous worldviews (Castellano & Reading, 2010). For example, the 2013 update of the *Declaration of Helsinki* highlights that Indigenous people and other close-knit groups require extra protection through involvement of significant community leaders when consent for research is required (American Medical Association, 2013). For Indigenous Australians that means consulting and collaborating with community elders in all phases of the research process.

Personally, I was challenged by a delegate at one of my oral presentations who posed a question that I have carried throughout the research process and will continue to consider in my future research endeavours. I was asked what I had done to change practice at my hospital or to impact my colleagues' attitudes because of my research. I started involving colleagues through presentations. I also started asking questions when I encounter staff resistance towards taking special considerations when nursing Indigenous patients. I started challenging workmates to have knowledge about traditional owners of the land we are working on. I reminded colleagues that it was their responsibility to be open and learn more about Indigenous issues that impact their health. Most of the time staff found it easy to just pass such issues to Indigenous Health Liaison Officers to deal with. I have continued to challenge my workmates to the fact that such knowledge should be common place for

every health professional. I pass on this question as a challenge to my readers to review what they are doing to improve Indigenous people's healthcare experiences.

Another aspect that had an impact on me was that the research program at Doctoral level was not only concerned with the actual progression of developing information and learning of the enquiry process and the range of methodological approaches available. Equally importantly, socialisation into the impact the project may have on participants, professionals, organisations, academics and, at a personal level, on the researcher was critical. Until Indigenous research approaches have methodological space within academic research discourse, policy, and practice, the tension that produces otherness will continue to disadvantage Indigenous knowledge (Kovach, 2009). My aim is to motivate other researchers to start reflecting critically on their clinical and research practices, and their views of self and how they interact with others, especially their Indigenous participants. The purpose was to stimulate readers to think about the Indigenous issues raised, and if that is achieved, then I have contributed to the field. Drawing conclusions and making recommendations from my autobiographical experience represents my attempt to make a scholarly contribution (Chang, 2016, p. 448).

This autoethnography has allowed me to explore my own views, offering a true picture of conducting research from my perspective (Chang, 2016; Denshire, 2010). My experience has evidenced a need to develop skills beyond those that are currently offered, in order to be responsive to Indigenous people's healthcare needs while involving them in the production of knowledge and incorporating them into the research process (Ninomiya & Pollock, 2016) and practice.

Where to from here?

Conducting research with Indigenous people can provide a challenge, but we can learn better approaches by involving Indigenous people themselves and sharing our experiences as researchers. The Indigenous population has been described as one of the most researched groups in the world and yet, as researchers, we continue to get it wrong in most cases, rather than learning from our stories and improving research processes. It is possible that the lack of not only participant voices but also those of the researcher may be a contributing factor. Indigenous knowledge and approaches to research need to be incorporated. Development of tangible, real-world-effective strategies is required to transform research practice and maximise knowledge gain. The aim of sharing my story and reflections on conducting research with Indigenous people is that other researchers will take the

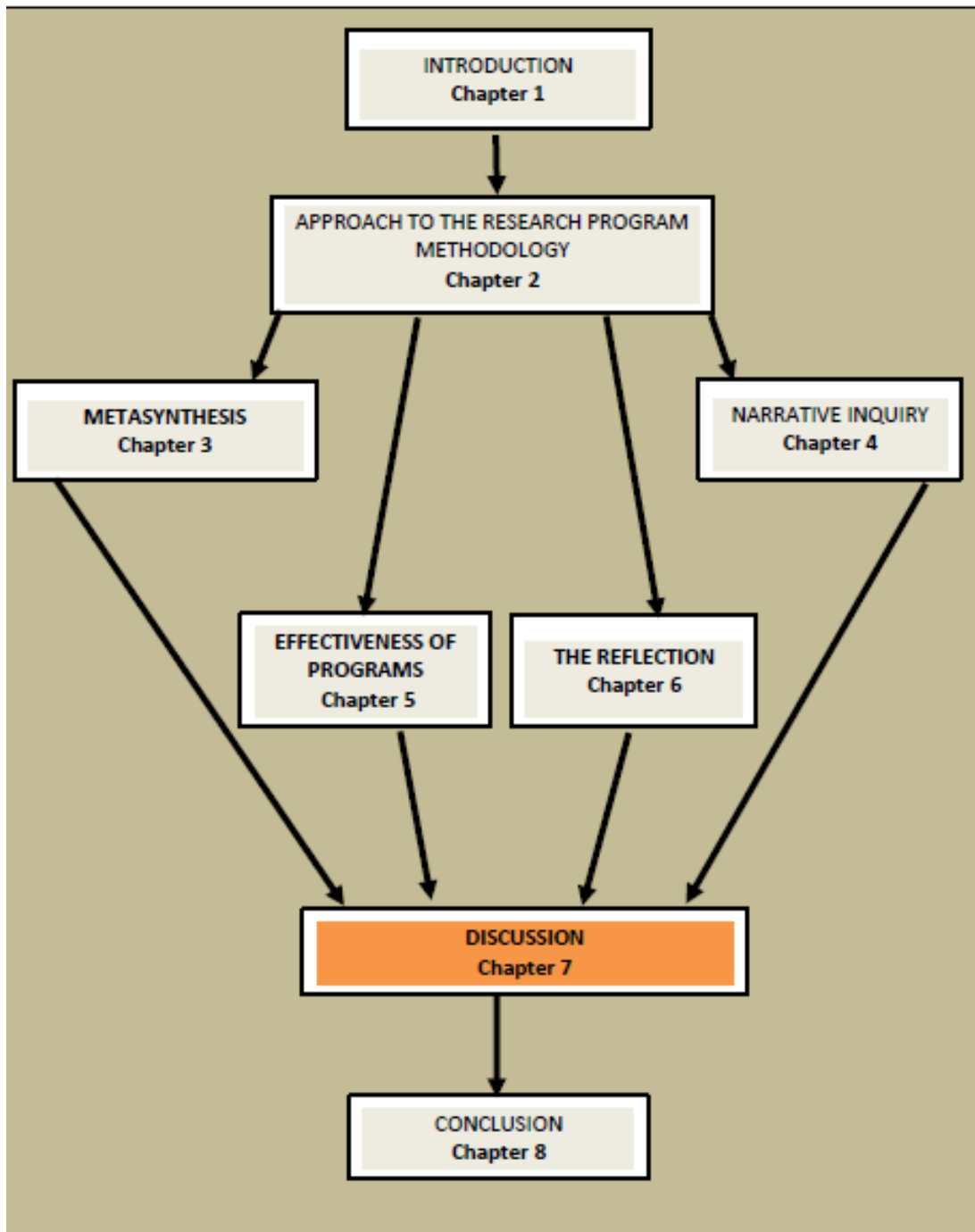
opportunity to be transparent about their experiences. The resultant valuable information to be gained through sharing the ups and downs, mistakes and successes, can inform practice, and contribute towards long-overdue best practice in Indigenous research.

Chapter summary

This chapter presented an account of my experience while conducting research with Indigenous peoples. It is important to share successes and challenges of experiencing events in order to inform others. Conducting research with Indigenous people has its unique challenges, which are as result of several factors such as the history of colonisation, and the experiences of being researched on. Further, use of unfamiliar methods and presentation of findings has alienated research and Indigenous communities and lack of tangible outcomes have been experienced in the past. Researching with Indigenous peoples can only be improved if practical stories of experience are shared.

The following chapter presents an integrated discussion of findings from this program of research. This puts together the Indigenous experience story and highlights the main points.

Chapter seven: Integrated discussion



Chapter overview

This chapter presents an integration of findings from the four studies in this program of research. Previous chapters presented a metasynthesis of qualitative studies which explored Indigenous peoples' experiences of hospitalisation from a worldwide perspective (Chapter three); a narrative inquiry exploring acute health care of Indigenous people, within a cardiac care setting (Chapter four); a systematic review of effectiveness of programs for Indigenous cardiovascular health (Chapter five); and an autoethnography of the experience of researching with Indigenous people (Chapter six). All four studies generated findings relating to the experiences of Indigenous people with health care, and multiple issues were identified that impact on that experience. This chapter synthesises the findings from each study and situates overall findings within the broader literature. The program of research tells a story of a long movement in time from a worldwide perspective of health care experiences by Indigenous peoples, through to national and local Australian contexts. The use of a storytelling approach has allowed the Indigenous health experience story to be appreciated from pre-colonisation through to present day and beyond.

Synthesis of findings

The urgency to gain understanding of and implement strategies that can improve the health of Indigenous peoples is acknowledged by governments and organisations, especially in the health sector, and also the public in Australia (Australian Health Ministers' Advisory Council, 2015; COAG, 2008; Commonwealth of Australia, 2019). The findings from this program of research are a contribution to this quest for a better understanding of acute health care experience issues that affect Indigenous peoples, and highlight the urgent need to examine current clinical, education, policy, and research practice approaches regarding Indigenous care.

Each study progressed and strengthened the Indigenous healthcare experience story. The stories were told to the researcher who in turn played the role of narrator in progressing the story. Figure 7.1. is a graphic representation of how the story progressed. It shows how stories from each study were narrated to the researcher, who analysed and integrated the individual stories into a collective story. Through synthesis of the collective story, the narrator makes the findings relevant to Indigenous people and the healthcare professionals who care for them. The narrator can emphasise important findings and how these can be integrated into healthcare practice and education.

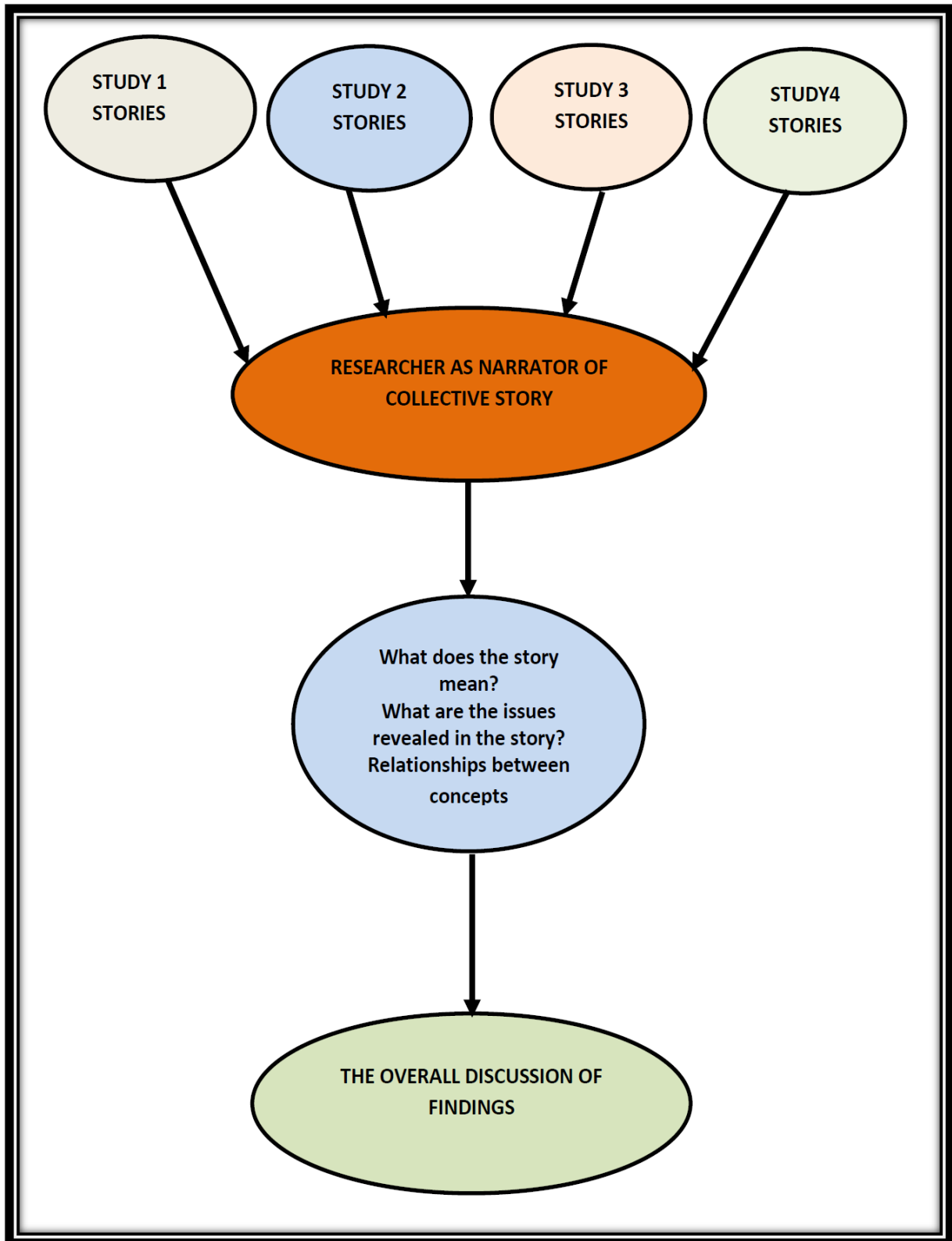


Figure 7.1. The collective story progression

Through an appraisal of evidence, the first study (Mbuli, Fulbrook, & Jessup, 2017a) presented a worldwide Indigenous story of the experience of health care, showing Indigenous people have feelings of isolation. The three themes from that study, Strangers in a strange land, Encountered dysfunctional interactions, and Suffered stereotyping and assumptions, during an encounter with health service, highlight the difficulties that Indigenous people encountered with communicating and trying to negotiate the hospital environment and processes. Further, they felt challenged by the interpersonal relationships which were temporary, making them feel isolated. This was compounded by the stereotyping that occurred because of their Indigenous identity. Most patients relocated to find the health care they required, and as a result were faced with financial burden, which was often not recognised by the treating team. The study confirmed how healthcare services fell short of accommodating the needs of Indigenous patients and their relatives. The healthcare settings culturally marginalised Indigenous people, while the relationships developed in these settings were not perceived to be meaningful. Healthcare professionals and health services at large are encouraged to be aware of and actively implement approaches that enable all-encompassing and patient-centred care.

The second study (Mbuli, Fulbrook, & Jessup, 2017b) was designed to directly elicit participant stories of their experiences. The themes from this study are: The impact of the past, The reality of the present, and Anticipation of the future. The findings highlight that cultural marginalisation persists within acute care settings and that past experiences and the present are interlinked. Having a past that segregated and marginalised Indigenous people has impacted on their present experiences of health care and these also inform their future expectations. Indigenous people felt their cultural and spiritual aspects could only be practiced within their private rooms, and they had nowhere to go even though they are known to be outdoor people. They could not identify their culture in the healthcare practices in hospital, even in language and the names of food. These findings link to issues suffered under colonial rule and confirmed the subtle ways in which the remnants of colonisation are actioned, even today. Their culture continues to be oppressed and their ways of life and traditions disregarded. In all this, however, participants remained hopeful that one day a better story will emerge.

The third study (Mbuli, Fulbrook, & Jessup, 2018) investigated the effectiveness of programs designed specifically for Indigenous people's cardiac health. The study revealed that there were few programs reported, and most were designed within a biomedical model with emphasis on measuring physiological parameters to determine effectiveness. Indigenous-sensitive factors that contributed to the success of the programs included local community involvement and engagement. This was demonstrated through use of local facilities, training of local health staff, better communication

strategies such as yarning, and Indigenous staff involvement. These findings exposed the fact that healthcare programs continue being designed based on mainstream views with a lack cultural or traditional and local knowledge integration.

The fourth and last study (Chapter six), provided a personal analysis of the research experience and lessons that were revealed through it. This study adds to the story of Indigenous experience with acute health care by presenting the perspective of the researcher within of the collective story. Having a wider view of issues that impact Indigenous experience of acute care provided impetus for the researcher's story. The study highlighted the fact that diversity does exist. The variances can be along the dimensions of race, culture, gender, socio-economic standing, age, physical capabilities, spiritual principles, political opinions, or philosophies (Churchill, Ocloo, & Siawor-Robertson, 2017; Dreachslin, Gilbert, & Malone, 2013). Recognising and respecting difference can assist in creating reciprocity which can build a more harmonious experience of life. It is about gaining understanding that moves beyond superficial knowledge to that which embraces and celebrates the richness contained within everyone as an individual, community or population group.

Regarding researching Indigenous people, several aspects need to be considered. Indigenous people are marginalised at many levels, and current research approaches and the way research findings are presented may be difficult to understand or enact in practice. For research activities to be effective and have tangible results, there is a need for researchers to understand by learning and appreciating Indigenous worldviews. Actions also need to be taken through implementation of strategies that are acceptable to Indigenous people. Advancing Indigenous health is a responsibility for all, whether an educator, bedside clinician, researcher or policy maker. There is a need to recognise that Indigenous people live holistically, with every aspect of life connected. From that understanding, emphasis is also placed on relationships that are respectful and reciprocal in nature. New approaches that integrate Indigenous viewpoints are vital, starting by hearing Indigenous people's voices, involving them in planning, and making them genuine participants in health care.

The findings from this program of research fit with several previous studies in the area of Indigenous people's experiences of health care, which have shown challenges that are faced by Indigenous people when they access health care (Anderson et al., 2012; Artuso, Cargo, Brown, & Daniel, 2013; McGrath, 2006; McGrath & Rawson, 2013; Worrell-Carter et al., 2016), especially in the areas of cultural differences that are usually absent in practice, such as a lack of interpreters leading to a language barrier (Arnaert & Schaack, 2006; Wilson & Barton, 2011). Communication is generally in a foreign language for Indigenous people with no regard for their different language backgrounds (Arnaert & Schaack, 2006; Watson, 2002). It is simply assumed that they understand English and can

read as well. This highlights the need to provide Indigenous language assistance and interpreter services in acute health care settings. It is not English language alone that can cause communication problems. Use of medical jargon is an added impediment to effective communication with Indigenous peoples. This was reflected by participants in the second study (Mbuzi et al., 2017b). In such cases, even interpreters are not adequate or sufficient to effectively deliver information to patients (Mbuzi et al., 2017a).

The culture of Indigenous peoples has been oppressed on many levels, with study findings revealing how Indigenous people feel isolated from their cultures when they come to hospital. Other studies have revealed the impact of colonisation effects, such as the way patients are accommodated in mixed wards, how most health professionals are non-Indigenous, and how there is limited culture integrated in the procedures and hospital care routines (McGrath, 2006; Kell et al., 2009; Worrall-Carter et al., 2016). Lack of their own culture, including language, food, and spiritual care disempowers Indigenous people when accessing health care. Some feel it is like being in prison and being in a vulnerable position. Their lack of language or ability to read and comprehend information disempowers them further (Mulemi, 2008; Rix et al., 2014). Stereotyping and negative assumptions were also reflected upon in other studies, such as those regarding financial matters (Tanner et al., 2004; Treloar et al., 2014; Watson et al., 2002) or lack of respect (Brown et al., 2016; Burnette & Kickett, 2009). This highlights a need for Indigenous staff recruitment, and more effective use of Indigenous Hospital Liaison Officers, as well as provision of a culturally safe meeting area within the acute care environment.

To synthesise the findings from this program of research, a thematic analysis was conducted of the findings from all four studies. Categories were formed of similar themes by analysing what they stand for and referring to discussions presented in respective chapters in which they are deliberated in detail. For the purpose of integration, the themes from each study were then further analysed to develop general themes explaining global meanings, significance, and relevance of the overall findings. Common themes were grouped together (Petty, Jarvis, & Thomas, 2018), resulting in identification of three final themes, including the impact of colonisation history on Indigenous health care experiences, cultural difference and its impact on Indigenous health and impact of the power differentials and the healthcare systems on Indigenous health.

A summary of findings from the four studies is presented in Table 7.1, while Table 7.2 shows how findings were combined to form three final themes for integration. These three themes will now be discussed.

Table 7. 1: Summary of key findings

CHAPTER	STUDY METHOD	RESEARCH OBJECTIVES	MAIN FINDINGS
3	Qualitative: metasynthesis of qualitative studies	Appraise current evidence on Indigenous peoples' experiences of health care	Participants: 1. Felt like strangers in a strange land <ul style="list-style-type: none"> • Communication challenges • Environmental restrictions 2. Encountered dysfunctional interactions <ul style="list-style-type: none"> • Poor interpersonal relationships • Isolation of individuals 3. Suffered stereotypes and assumptions <ul style="list-style-type: none"> • Indigenous status • Socioeconomic disadvantage
4	Qualitative: exploration of Indigenous hospitalisation experiences	Explore current experiences of acute health care	Participants were: 4. Affected by the impact of their past encounters <ol style="list-style-type: none"> 1. Family dying young 2. How they were brought up within the colonial policies/rule 3. Associating hospital with death 5. Confronted the reality of the present <ol style="list-style-type: none"> 4. Pretty sick when coming in 5. Use of big words by health professionals (doctors) 6. Disrespect and assumed lack in knowledge 7. No cultural spiritual aspects in care- scared participants 8. Isolation from culture, family, and other Indigenous people 6. Anticipated a better future <ol style="list-style-type: none"> 9. More cultural education for staff 10. Young Indigenous people to take up health careers 11. Better preparation for discharge especially home support-medication/referrals 12. Participants desired to go back home and influence better health attitudes in their communities from what they had learnt through their experiences

5	Quantitative: systemic review of CVD programs	Explore the effectiveness of current cardiovascular programs designed for Indigenous people	7. Limited integration of Indigenous culture in programs 8. Dominant biomedical approach to program design and evaluation of programs 9. Limited reflection in acknowledgement of diversity
6	Qualitative: autoethnography of researcher experience	Reflect on the research experience of researching with Indigenous people practice	10. Dominant mainstream approaches to research 11. Lack of examples on how to integrate Indigenous values in research processes 12. Training, designing & evaluation of research is predominantly through mainstream lens

Table 7. 2. Final themes for integrated discussion

INTEGRATED THEMES FROM THE FOUR STUDIES	FINAL THEMES	RECOMMENDATIONS
<p>13. Affected by the impact of their past encounters</p> <ul style="list-style-type: none"> • Family dying young • How they were brought up within the colonial policies/rule • Associating hospital with death <p>14. Confronted the reality of the present</p> <ul style="list-style-type: none"> • Pretty sick when coming in • Use of big words by health professionals (doctors) • Disrespect and assumed lack in knowledge • No cultural spiritual aspects in care- scared participants • Isolation from culture, family, and other Indigenous people <p>15. Limited reflection in acknowledgement of diversity</p> <ul style="list-style-type: none"> • Indigenous sensitive aspects -Access, empowerment, collaborative partnerships, meaningful relationships • Provision of support to individuals- transport, family support, professional support 	<p>1. Impact of colonisation on Indigenous health care experiences</p>	<ol style="list-style-type: none"> 1. Staff training regarding impact of colonisation on the health of Indigenous people. 2. Bi-directional teaching and learning between staff and patients/Indigenous staff through working together approach. 3. Integrate Indigenous culture and knowledge by increasing Indigenous health-care workers in clinical teams and numbers of non-Indigenous health staff being educated in cultural safety and development of an inclusive environment and providing patient centred care.
<p>16. Felt like strangers in a strange land</p> <ul style="list-style-type: none"> • Communication challenges • Environmental restrictions <p>17. Encountered dysfunctional interactions</p> <ul style="list-style-type: none"> • Poor interpersonal relationships • Isolation of individuals 	<p>2. Cultural difference and its impact on Indigenous health</p>	<ol style="list-style-type: none"> 4. Treat patients with dignity and respect in manner of communication and how to address them by preferred name or tittle. 5. Practice holistic health care through recognition of individual needs, such as spiritual aspects by providing space for traditional worship and knowing the traditional custodians upon whom some Indigenous people pray to. 6. Indigenous cultural training and education for health-care providers as early as possible in their career training and hospital orientation programs

<p>18. Suffered stereotypes and assumptions</p> <ul style="list-style-type: none"> • Indigenous status • Socioeconomic disadvantage 		<p>7. Create opportunities and space for expressing cultural connections such as outdoor spaces as a meeting place or meditation areas</p>
<p>19. Limited integration of Indigenous culture in programs</p> <ul style="list-style-type: none"> • Employment of Indigenous staff • Understanding local conditions • Patronising tendencies <p>20. Dominant biomedical approach to program design and evaluation of programs</p> <ul style="list-style-type: none"> • Focus on physiological parameters • Focus on behavioural risks- smoking, alcohol, diet • Quantitative measures of effectiveness <p>21. Limited reflection in acknowledgement of diversity</p> <ul style="list-style-type: none"> • Indigenous sensitive aspects -Access, empowerment, collaborative partnerships, meaningful relationships • Provision of support to individuals- transport, family support, professional support <p>22. Dominant mainstream approaches to research</p> <ul style="list-style-type: none"> • Focus on conventional methodologies in literature <p>23. Training, designing & evaluation of research is predominantly through mainstream lens</p> <ul style="list-style-type: none"> • Lack of Indigenous methodologies • Neglect of participant perspectives 	<p>3. Impact of the power differentials and the healthcare systems on Indigenous health</p>	<p>8. Self-reflection for healthcare services to ensure a culturally safe environment, that is welcoming to Indigenous people by providing Indigenous specific information and recruitment of Indigenous people in clinical areas.</p> <p>9. Operate within a strengths-based perspective and use strengths-based approaches that empower Indigenous communities and individuals by involving them in healthcare plans, and considering what they know and then build on that instead of assuming lack of knowledge</p> <p>10. Respect patients/clients' choices and beliefs while empowering them via informed decision making and incorporation family support that reflects their kinship system and invite families participate in the care decisions as appropriate</p> <p>11. Critique power imbalances on the wards during interaction with Indigenous patients by practicing active listening and involving them in the decisions for their care.</p> <p>12. Collect feedback from patients and significant individuals to patients to assess effectiveness of current practices within healthcare that can be part of the continuous quality evaluation processes and research to ensure sustainability and improvement of practice</p>

Integrated findings

Impact of colonisation on Indigenous health care experiences

The first theme concerns a long-standing issue of colonisation in Australia and other countries that experienced colonial administration. A colonial past has formed the disproportion in health between Indigenous and non-Indigenous peoples in Australia as well as in other first nations such as Canada, with Indigenous people experiencing a disproportionate burden of ill health (AIHW, 2018a; Brook-Cleator, Phillips, & Giles, 2018; Eckermann et al., 2010; Vos et al, 2009). Colonisation has been described as having been maintained in healthcare systems (Brook-Cleator, Phillips, & Giles, 2018; Hole et al., 2015; Reading, 2015) due to a lack of change in the way healthcare is managed and operated with no integration of Indigenous knowledge.

From my findings it is evident that colonisation is the ever-present elephant in any room where Indigenous people gather (D'Eon, 2016), worldwide and locally in Australia (Mbuzi et al., 2017a, 2017b). Participants in the narrative inquiry study expressed concern that nothing had really changed in Australia because the same structures and processes remain with the same type of people holding power. The same institutions that hurt them during colonial times remain and continue to dominate both their individual and public lives. Because of this, hospitals are associated with governments and oppression of Indigenous people. As well, they associate hospitals with death because of the disproportionately high death rate they experience among family members (Mbuzi, Fulbrook, & Jessup, 2017b), as reflected by participants in their narratives. This highlights a need for strengthening the use of Indigenous hospital liaison officers and Indigenous care pathways, to show Indigenous people that they are expected to be discharged back to their community, not to die in hospital.

The subtle remnants of colonial policies, such as racism and stereotyping are experienced in the contemporary through paternalistic views in which Indigenous voices are not heard and use of a deficit-based approach to Indigenous health, which focuses on fixing what is wrong with Indigenous people to cause their health problems (Eckermann et al., 2010; Paradies et al, 2015; Sherwood, 2013). Further, racially negative assumptions, such as looking down on them as drunks, and lack of respect for Indigenous people's views by not genuinely including them in care planning, have continued to disadvantage Indigenous people and produced inequitable healthcare outcomes (Eckermann et al., 2010; Paradies et al, 2015; Sherwood, 2013). If healthcare professionals were to at least learn a greeting ritual or welcome and ask about and listen to Indigenous patients' stories and concerns, this could go a long way in addressing these issues. Healthcare facilities and professionals could be

encouraged to make use of government information resources, such as the Australian Indigenous HealthInfoNet (2018b), which provides Indigenous specific information and support.

Aspects of the impact of colonisation were expressed across all four studies as being the main root of most current Indigenous health problems and this is consistently mentioned in literature addressing a variety of healthcare settings (Browne, Smye, & Varcoe, 2005; Rix 2019; Sherwood, 2013). Participants revealed how they are affected by past experiences of colonial policies, such as lack of familiar language at the bedside to communicate health issues. They reflected that they felt they were actively experiencing the remnants of these concepts through a disrespect they experience to their culture due to lack of its expression at a local clinical level. They stated that walking into the hospital setting made them feel like a foreigner due to a lack of anything that resembles their culture. This included language and food; hence the statement, *we are not yet welcome into hospitals* was expressed by participants (Mbuzi, Fulbrook & Jessup, 2017b). This draws attention to a need for use of an Indigenous specific information brochure to provide to hospitalised Indigenous patients. This could contain a welcome from the traditional local custodians of the land, and information about the hospital meeting place for yarning, as well as some key words and phrases useful for hospital treatment.

The causes of health disparities are complex, owing to the impact of the history of colonisation, and these affect a variety of socioeconomic, psychosocial and other lifestyle factors (Wilson & Barton, 2012). There are still, therefore, many unresolved issues, particularly power inequalities and attitudes. Some assumptions that are held by the public keep diminishing the impact that colonisation had, by perceiving that it occurred in the past and should not be an issue for current Indigenous health and social positioning. Colonisation promoted racism and segregation, to the disadvantage of Indigenous people; and further, their way of life and identity were stripped, their beliefs and traditions devalued, and culture and language taken away (Mitchell, 2007; Sherwood, 2013). The concept of difference was not accepted, and cultural homogeneity was promoted, in which western ways were the order of the day (Sherwood, 2013). The hurt from this experience is still present and needs to be acknowledged in order to start the healing process for Indigenous peoples. Using a local greeting and referring to the local traditional landowners would show Indigenous patients that hospital staff do recognise cultural differences.

The findings from this program of research revealed how the impact of colonial activities and policies still affect Indigenous peoples' experiences of health care. Across the studies, colonisation was

a common explanation for Indigenous peoples' poor experiences with health care in a multitude of healthcare settings (Mбузи et al., 2019a; 2017b; 2018). This is because, while colonisation discriminated against Indigenous people, it also created dependency among them through paternalistic systems and control. They were forced into a socioeconomic crisis due to lack of opportunities for education and employment. Similar explanations have been presented in studies elsewhere in which colonisation has been described as a determinant of Indigenous health (Artuso et al., 2013; Worrall-Carter et al., 2016). The socioeconomic hardships experienced by Indigenous patients and families highlight the need for governments to fund and provide assistance with travel and accommodation for those travelling from regional areas to tertiary hospital settings. The system that is currently in place is not user-friendly. Participants in study one reflected on the fact that the process used to access funds is demeaning because it made them feel like they were beggars. At the same time, the process is complex for an everyday person, such that participants said it was easier just to abandon the idea of asking for assistance. Ideally social workers would assist with this process, but hospitals could also seek local volunteers for Indigenous support and assistance to access funds. It also would help to have Indigenous staff that are part of the clinical team and are co-located within the hospital. It is important in this case to implement strategies that will help address colonisation remnants, such as recruitment for more Indigenous staff. Currently there are only a few positions for Indigenous staff in acute care facilities, and in most cases, they operate as a separate entity and not as part of the treating team. The research site for this program of research has demountable offices for the Indigenous team on the periphery of the hospital. Indigenous Hospital Liaison Officers are not readily available on each ward. They come in like visitors. This separation keeps the two cultures apart and bi-learning is not possible. Working together may help the identification of issues as well as solutions and strategies to implement as a team (Mбузи, Fulbrook, & Jessup, 2018).

Cultural differences and its impact on Indigenous health

Study findings revealed that the power of the dominant culture is underestimated by health services providers and healthcare professionals in mainstream health. A focus on biophysical treatment approaches to healthcare ignores Indigenous viewpoints and culture (Mбузи, Fulbrook & Jessup, 2018). Lack of actual Indigenous culture within wards communicates to participants a lack of respect and acknowledgement of them as a people and sends messages of an unwelcome environment by the health service. Adopting strategies such as an Indigenous specific information leaflet, with local greeting signs and involvement of local Indigenous elders, when required, for a welcome tradition at the bedside would be a useful resource for staff to help assist with looking after

Indigenous people. Study participants saw the hospital as an environment that was closed to them because of a lack of their own culture, such as no provision of a cultural space for their spiritual needs. For example, being an outdoor people, it was hard to be continuously indoors without seeing nature while in hospital (Mbuzi et al., 2017b). The participants longed to be outside for meditation and an opportunity to meet with other Indigenous people around the hospital (Mbuzi et al., 2017b), but this was lacking. Participants expressed this concern about the way care is given that exclude their culture. Provision of outdoor spaces and signs pointing the way are important inclusions for hospitals.

The culture of a people intersects with many aspects of life, such as identity and the values that are held dear to them (Brook-Cleator, Phillips, & Giles, 2018; Darroch & Giles, 2016). Indigenous people have been forced to conform to an outsider's view of standards to live by, including an approach to health (Dreachslin, Gilbert, & Malone, 2013; Sherwood 2013). A difference in culture brings with it a different worldview to health. For example, Indigenous people have a different belief system regarding health which is holistic in nature (Eckermann et al., 2010). It includes environment, family and spiritual concepts. It becomes difficult, for example, to be separated from family when seeking health care. Admitted patients have to spend night and day away from family. This made participants in study one and study two feel alone and insecure/unsafe (Mbuzi, Fulbrook, & Jessup, 2017a; Mbuzi, Fulbrook, & Jessup, 2017b). Even after realising that culture is important and that it impacts on people's health, integration of Indigenous culture has been limited, particularly in hospital settings (Mbuzi, Fulbrook, & Jessup, 2017a; Mbuzi, Fulbrook, & Jessup, 2017b; Mbuzi, Fulbrook, & Jessup, 2018). Across the four studies it was clear that there is much work to be done to make hospital care and indeed health services culturally safe for Indigenous people. Care models remain based on biomedical approaches, even with programs that are designed to specifically target Indigenous population (Mbuzi, Fulbrook, & Jessup, 2018). This highlights the need for development of skills and a resource base for staff on Indigenous issues that impact on health care.

It has been reported that acknowledging cultural difference can bring harmony and provide an improved health care experience for Indigenous people (Bowne et al., 2016; Brook-Cleator, Phillips, & Giles, 2018). Mutual respect for this difference in culture and worldviews is required in healthcare practice (Brook-Cleator, Phillips, & Giles, 2018). It appears that issues of lack of integration of alternative views to health, in mainstream health, is a factor that has persisted (Dodgson & Struthers, 2005). There is very little flexibility because of standardised procedures and task focused care. Lack of genuine consultation and lack of integration of Indigenous knowledge in health care has disempowered Indigenous communities. Indigenous systems of kinship and family setups of elders

and the power and respect they have in their communities is stripped away when they enter healthcare arenas (Wright et al., 2016).

The kinship system, for example, may mean that the next of kin, for some patients, may be their niece instead of their husband, therefore, staff need to respect that. This issue was reflected in study two where the Indigenous kin system was not recognised and a participant, away for the first time, felt disrespected by staff using first names (Mbuzi, Fulbrook, & Jessup, 2017b). Staff need to learn to ask about preferred name or mode of address for all their patients, as part of establishing a therapeutic relationship (Mbuzi, Fulbrook & Jessup, 2017b). Emphasis on western constructs of health continue to impact and hinder inclusion of Indigenous health beliefs in current practice (Durey & Thompson, 2012; Li, 2017). Managing critically ill patients may require quick judgements and the faster rate of operation may negatively impact the treatment of Indigenous people, especially when stereotyping comes into play (Wylie & McConkey, 2017). It is possible to integrate better bedside manners that acknowledge Indigenous people's culture and identity and enable them to contribute to their own healthcare decisions (Wilson et al., 2016).

Deliberate planning, and implementation of ways of improving this cross-culture relationship is required within the practice of health care at all levels. Increased practice knowledge and promotion of a more effective and sustainable relationship between Indigenous Australians and healthcare, especially within hospitals, is crucial. This research has revealed that the relationship between Indigenous Australians and the healthcare system has remained socially, economically, culturally, psychologically, and geographically isolating. There is a need for more exploration of how healthcare professionals engage with Indigenous peoples. Most of the information we have about Indigenous people was created and disseminated by the same people who colonised and subjugated them (Fredericks, 2008; Sherwood, 2013; Smith, 2012). Therefore, information to use for health care should be provided from the perspectives of Indigenous people, their community and families.

Participants in this program of research reflected personal aspects which the health system ignored, such as late arrival of appointment letters due to long mailing distances. The system was then inflexible with appointments and timing of consultations without considering individual circumstances, and participants were labelled as non-compliant if they were unable to attend (Mbuzi et al., 2017a; 2017b). On the other hand, all that might be required is to negotiate. For example, flexibility in timing of program meeting or attendance proved effective to ensure participation (Mbuzi

et al., 2018; Tuttle et al., 2016). Given the distances travelled, re-consideration of appointment making is important to accommodate those coming from far away from the health setting.

Impact of power differentials and healthcare systems on Indigenous health

Following colonisation and isolation of Indigenous people from their communities and culture, they were left with no power base to support themselves and meet their healthcare needs. They were forced to be dependents for everything, leading to disempowerment (Baum, 2007; Eckermann et al., 2010; Sherwood, 2013). The damage was done politically, socially, culturally, spiritually, and economically, through oppression and lack of recognition or misrecognition, misrepresentations and disrespect of their way of life as a people, by the dominant western cultures (Baum, 2007). Their healthcare systems and kinships were dismantled and disabled (Eckermann et al., 2010; Hampton & Toombs, 2013; Sherwood, 2013; Wright et al., 2016). Family and social structures are essential as study participants, in studies one, two and three, placed great emphasis on family and kinship (Wright et al., 2016). There is great value placed on each person's role in contributing to family and community at large. For example, they all placed great value on the elders for their practical knowledge and wisdom that is used to teach and advise the community (Wright et al., 2016).

Health systems have failed at many levels to acknowledge Indigenous beliefs regarding health by dominating the everyday procedures, traditions, communication styles and a general outlook within western ways and beliefs. Family inclusion and the practicing of family centred care suits Indigenous patients and should be used more in the hospital setting. This is part of culturally congruent care (Wiebe & Young, 2011), where a trusting relationship is established through respectful communication, a welcoming and flexible environment, and culturally responsive and accessible social and spiritual supports.

Although from a spirituality perspective there was a mix of both Christianity and other religions among the participants (Mbuzi, Fulbrook, & Jessup, 2017b), it was important to acknowledge the native spiritual aspects which are practiced in many ways among Indigenous peoples, because they use these aspects to guide their approach to life in a sacred and holistic manner (Eckermann et al., 2010; Sherwood, 2013). Participants expressed concerns over a lack of spiritual aspects within the acute care setting. For example, this research revealed that staff did not find it needful or important to at least know the traditional owners of the land, and the organisation had not considered provision of space for Indigenous spiritual activities such as outdoor meditation spaces, yet they have provided a chapel for other worshippers (Mbuzi, Fulbrook, & Jessup, 2017b). This demonstrates the power that non-Indigenous people have and the advantageous position they hold because their culture is

dominant, and standards are set within their belief systems. This again highlights the need for Indigenous specific resources, such as a meeting space and information about other spiritual requirements within hospital settings.

Study two (Mbuzi et al., 2017b) reflected the fact that, not long ago, education for Indigenous people was viewed unnecessary. They were forced to leave school early to work as house servants or cattlemen when they reached year four or 14 years of age (Eckermann et al., 2010), a situation that left them with no choice to progress in education that would lead to better job opportunities. Participants in this program highlighted the fact that there is an assumption that everyone can read, but not all of them could do so. Without the resources they had before colonisation and lacking educational resources they became dependent for jobs and even for health care needs (Baum, 2007; Eckermann et al., 2010). This research confirms that Indigenous people feel blamed for issues which were and are out of their control. It was not uncommon for participants to relate to how they are stereotyped as being ignorant just because of their Indigenous status and lack of western education. For example, participants reflected the fact that during ward rounds, the treating team would just talk among themselves at the bedside without involving them. In most of these instances, the team used unfamiliar language that the patient or relative did not understand. Participants reflected that they sometimes had to ask the team to explain to them in simpler terms or language. No interpreters are readily available for the Indigenous population. In another scenario, a participant with a chronic condition was ignored when he tried to tell the treating team what works in his situation (Mbuzi et al., 2017a; 2017b), sending a message of devaluing his input or simply assuming ignorance. Culturally congruent care (Wiebe & Young, 2011) that involves the family and provision of interpreters when needed and support from Indigenous Hospital Liaison Officers on ward rounds, should be available.

It is not education alone which wedged a barrier. Language was a barrier as well because in Australia English is the official language. Those born here, especially, Indigenous Australians who were even forced to comply with English speaking in all circles, are assumed to know and understand English. The findings revealed that, even with interpretation, it is rare to have an Indigenous interpreter. In most cases, family members fluent in English are relied upon as interpreters. This can be stressful for the family member because of cultural norms in which, for example, a daughter or son is not able to explain in detail to a parent issues to do with private affairs, like urinary catheterisation for lack of words or fear of being disrespectful (Mbuzi et al., 2017a). Without understanding the language, participants can be seen as ignorant. Lack of understanding the used language imposes power differentials. Healthcare professionals should recognise that other forms of communication can

be used, such as cards with pictures or common words in Indigenous language for use in clinical areas (Queensland Government, 2016).

Moving into the future

The marginalisation of Indigenous people's views revealed in this program of research points to the need for developing future healthcare approaches that are culturally and physically safe for Indigenous populations. There is a need to go past a superficial understanding of Indigenous culture by actively involving and engaging patients and their families in identifying what they see as a service that is culturally safe, and a service that empowers Indigenous clients/families/communities to be active participants in the determination of care needs and solutions. The starting point is to be culturally competent by implementing aspects in practice that acknowledge Indigenous peoples; but this must go beyond knowledge, by practicing respectful communication, engagement, empowering Indigenous identity, and policies that encourage ownership and shared decision making. Training courses with meaningful content and outcomes are key to this. These courses must be planned and preferably delivered by Indigenous people.

Practices and strategies that contribute to transformation of views and attitudes of health professionals as well as health service organisations are required. This can create culturally safe healthcare which utilises strategies to enable decolonisation of care through awareness of the impact of the history of colonialism, racism, and discrimination. Healthcare service organisations can commit to building partnerships, sharing of power, and decision-making in the provision of care that considers Indigenous people's points of view. One example of building partnerships is for the role of the Indigenous Hospital Liaison officer to be based on specific wards. This can be beneficial by being readily available on the ward for both patients and staff instead of just being a visiting staff member. They must be fully incorporated into daily health care, ward rounds and team meetings and not separated to an outside building.

Health service providers and individual clinicians need to practice analysis of positional powers, including colonisation constructs that restrict cultural norms or values of Indigenous people, genuinely investigating issues from the larger context and perspective in which care is provided. Lack of reflective practice has left many Indigenous clients and families with unmet care needs, such as spiritual and emotional needs, despite it being an important part of care. Participants voiced hope for a better future through healthcare models that are inclusive. Instead of depending on a biomedical

approach to health service provision, which mainly focuses on physiological ailments, health organisations must offer strategies that have the potential for delivery of ethnically acceptable and culturally congruent care which considers the cultural, political and social constraints that impact on Indigenous health as well (Gorman, 2017). Participants in this research were concerned due to lack of traditional aspects of care, such as a smoking ceremony (Mbuzi et al., 2017b). An example to address this concern would be designing alternate ways to incorporate a smoking ceremony at the bedside. This can be in the form of periodic involvement of local elders to perform the ceremony and can be done outdoors but be representative of cleansing the whole hospital. The activity can be incorporated into the yearly National Aboriginal and Torres Strait Islanders Day Observance Committee (NAIDOC) activities, in which there is a week in July dedicated to celebrating Indigenous cultural heritage (AIATSIS, 2017). Use of a controlled smoking device can be used for ward areas. Implementing something acceptable to the Indigenous community can be helpful to acknowledge this important Indigenous cultural aspect.

Findings from study one (Mbuzi et al., 2017a; Mbuzi et al., 2018) revealed many recommendations to improve the experiences of Indigenous peoples of acute healthcare but these can only be useful if put into practice and appropriately evaluated for effectiveness. Without action the issues can influence perpetuating enduring inequalities of influence and privilege resulting in increased risk for adverse health and wellness outcomes among Indigenous peoples. It is not enough to be aware of the cultural aspects of caring for Indigenous people's health, action needs to be taken. There should be a deliberate intent, for example, within education, policy making and research practices to foster transformation and offer Indigenous population groups freedom from contextual constraints that disempower them as they experience acute health care. Changing views must be reflected by acknowledging cultural variance, demonstrating onus for accommodation of diversity, and recognition of the role of authority and privilege in healthcare service development, delivery, and appraisal (Churchill, Ocloo, & Siawor-Robertson, 2017; Dreachslin, Gilbert, & Malone, 2012). This impetus should be transmitted to all healthcare professionals. Having a specific healthcare team member as an Indigenous issues champion on every ward is one way of ensuring transmission of information on Indigenous issues to clinicians at ward level and promoting culturally congruent practices.

Education of concepts sensitive to Indigenous worldviews should start as early as possible in student education and be sustained through to qualified staff. Education and training of health professionals has been addressed elsewhere with similar recommendations to address this and

strengthen courses in colleges and universities (Power, Viridun, Gorman, Doab, Smith, Phillips & Gray, 2018; Gorman, 2017) through to inclusion of organisational cultural orientations that support Indigenous students as well (Gorman, 2017). Participants reflected the fact that education should be bidirectional in which both cultures learn from each other (Mbuzi et al., 2017b). For example, participants noted a lack of cultural knowledge on the part of staff where they were unable to acknowledge respectable positions elders hold by using their first names. Further, participants noted inadequate education among staff about Indigenous people which was demonstrated by their lack of knowledge about the traditional owners of the area in which they work (Mbuzi et al., 2017b). Healthcare providers need to encourage and challenge staff to recognise a need for their commitment to acquiring cultural knowledge and demonstrating it in their practices.

There is little scholarship on approaches to culturally safe health care for Indigenous peoples. Identification of such approaches that are culturally acceptable and appropriate has the potential to deepen understanding of the type of care required and contribute to improvement of Indigenous people's experiences of healthcare. Therefore, scholarship on healthcare needs to focus on operational conceptualisations of culture. Investigations on how to incorporate cultural aspects to care can lead to a culturally safe healthcare practice for Indigenous people. By designing and implementing strategies which can address the continued paternalistic approaches engaged during service provision, influenced by colonialism and dominant biomedical models (Mbuzi et al., 2018), Indigenous people may feel culturally and physically safe in hospital settings. Such a transformation will necessitate efforts at the personal, organisational, and policy level, and methods that encourage Indigenous autonomy.

A commitment by health organisations will need to be genuine and actionable. This contrasts with tokenistic sentiments, such as those noted by participants in study two about flags and paintings that decorate most hospital corridors with no change to bedside manners, which are abundant in current practices (Mbuzi et al., 2017b). While symbols and writings or objects representing Indigenous culture, such as flags and paintings, were seen to be a great idea because they provide the environment with familiar artefacts, most important is the respect that individuals receive as they interact with a health service. Culture is not only displayed physically, but also in the way interpersonal relationships are built and interactions that occur (Brook-Cleator, Phillips, & Giles, 2018; Darroch & Giles, 2016). Again, staff need to participate in this interaction.

Although there are cultural training programs for health professionals, they usually lack evaluation of implementation into practice. The training is at an academic level and no follow-up is done to ensure integration into daily practice. Monitoring is only done of completion rates not of incorporation of the learned values into practice. Because training of staff is inadequate, this leads to limited and superficial knowledge which can result in gross misunderstandings and breed stereotypes which can worsen the situation. Previous research on healthcare delivery in various settings reveals that healthcare professionals display stereotypical thinking about Indigenous people and continue to make racist remarks during their clinical practice, sometimes unknowingly (Paradies et al., 2015). Findings from both study one and study two revealed that participants perceived a lack of Indigenous values among staff, commenting that they need to learn (Mbuzi et al., 2017a; 2017b), particularly about kinship and the commitment family members have to each other and their communities. For example, some longed for other family members to be informed directly by health professionals what is expected of them to support the patient upon discharge. This was important because of the shared responsibility they practice in families (Mbuzi et al., 2017a; 2017b). Practicing culturally congruent care that involves families (Wiebe & Young, 2011) would resolve some of these issues, as would incorporating appropriate discharge planning practices.

Use of a biomedical approach, where medication, mechanical devices, and technology use has advanced health outcomes for patients, is a logical strategy to address and manage disease. But the persistent poor health outcomes of Indigenous people worldwide (Mbuzi et al, 2017a) demands a critical assessment and evaluation of current program approaches and healthcare models. None of the participants mentioned issues to do with the expertise of the professionals. All issues pointed to relational issues that have roots in past experiences, and elements of current experiences that reopen or remind them of past encounters. Communication workshops where participants practise actual skills would enhance the development of therapeutic relationships. Use of culturally appropriate resources for healthcare professional learning, such as those available online by the Australian Indigenous Health *InfoNet* (2018b), would help to address some relational issues.

Respect for Indigenous people's culture is important. Intergenerational traumatic events about healthcare practices and societal positions inform Indigenous people's perceptions. Cultural, economic, political, and social factors impact on Indigenous people's experiences of acute health care. For example, participants in study two reflected on how they were brought up and the hardships they encountered that have put them in the current state, especially regarding educational opportunities

that might have improved their social standing. This warrants examination in the quest for improved contemporary approaches to healthcare for Indigenous health. This might mean staff learn an Indigenous language so that they are able to communicate effectively. It can be as simple as asking a patient their preferred name.

Participants who directly experienced health care took part in this program of research to highlight their encounters from their perspectives (Mbuzi et al., 2017a; Mbuzi et al., 2017b). In many research studies the researchers and regulators are privileged, but in this study, the voices of participants were foremost. Although participants' voices could be lost in the process of translation of a study, an effort was made to include as many direct quotes as possible from the participants' own words. This program of research draws on the experiences of Indigenous participants to uncover essential knowledge that can enhance understanding for healthcare services and practice development. There is need to develop culturally suitable and effective interventions to address this important health issues that impact Indigenous people. Whilst strategies to address Indigenous issues are planned for, such as cultural orientation and presence of flags and Indigenous paintings, these seem to be at tokenistic levels, because patients still feel isolated and out of place while in hospital and at the bedside (Mbuzi et al., 2017a; Mbuzi et al., 2017b). Further planning is required to address these personal and relational issues.

The efficacy of the present strategies remain questionable and inadequate since participants could not identify much of their culture in the practices at the bedside (Mbuzi et al., 2017a; Mbuzi et al., 2017b). Aspects such as language, staff attitudes, communication styles, foodstuff, ward routines, accommodation style, relationships, time restrictions, and relocation had an impact the experiences they had (Mbuzi et al., 2017a; 2017b). Indigenous Hospital Liaison Officers were present to have a chat with patients, but this was not adequate because they were not available all the time especially after hours. They were also not part of the treating team and were absent for support during ward doctors' rounds (Mbuzi et al., 2017b). This was a time when interpretation and support was needed due to language and cultural barriers. The study site, being a referral centre that provides tertiary health services, may have had an advantage by having IHLO services as part of the hospital establishment, in comparison to some that might have no one. This is why it is essential for staff to be culturally competent so that they are able to support their patients appropriately and allay their anxieties. This highlights the principle that Indigenous issues are everyone's business.

Patients were riddled with fear of dying alone, especially overnight, because relatives did not stay by the bedside (Mbuzi et al., 2017a), a practice that is unfamiliar to their culture. Family members travelled with the sick to provide support and would stay around the hospital for as long as they could, but had to retire for the day, which frustrated both the patients and relative (Mbuzi et al., 2017a). Overall acute healthcare settings feel unsafe for Indigenous people. Lesson can be learned from paediatric healthcare model where a family member is accommodated at patient's bedside overnight or provision of relatives' rooms near to the ward.

Tokenistic gestures were acknowledged by participants and these activities were not enough to impact real change at the bedside, as well as service level. Business was run in western ways; an approach that devalued their ways of life. They hoped for a better experience where they would feel the acceptance, acknowledgement, respect, reciprocal treatment, and recognition that they are a unique group of individuals, with unique values that need to be integrated in their health care. Organisations are obligated and must take initiative to improve Indigenous peoples' stories of experiences of health care; showing genuine interest in Indigenous culture by, for example, taking part in championing projects and being actively involved in celebrating the difference.

Conclusion

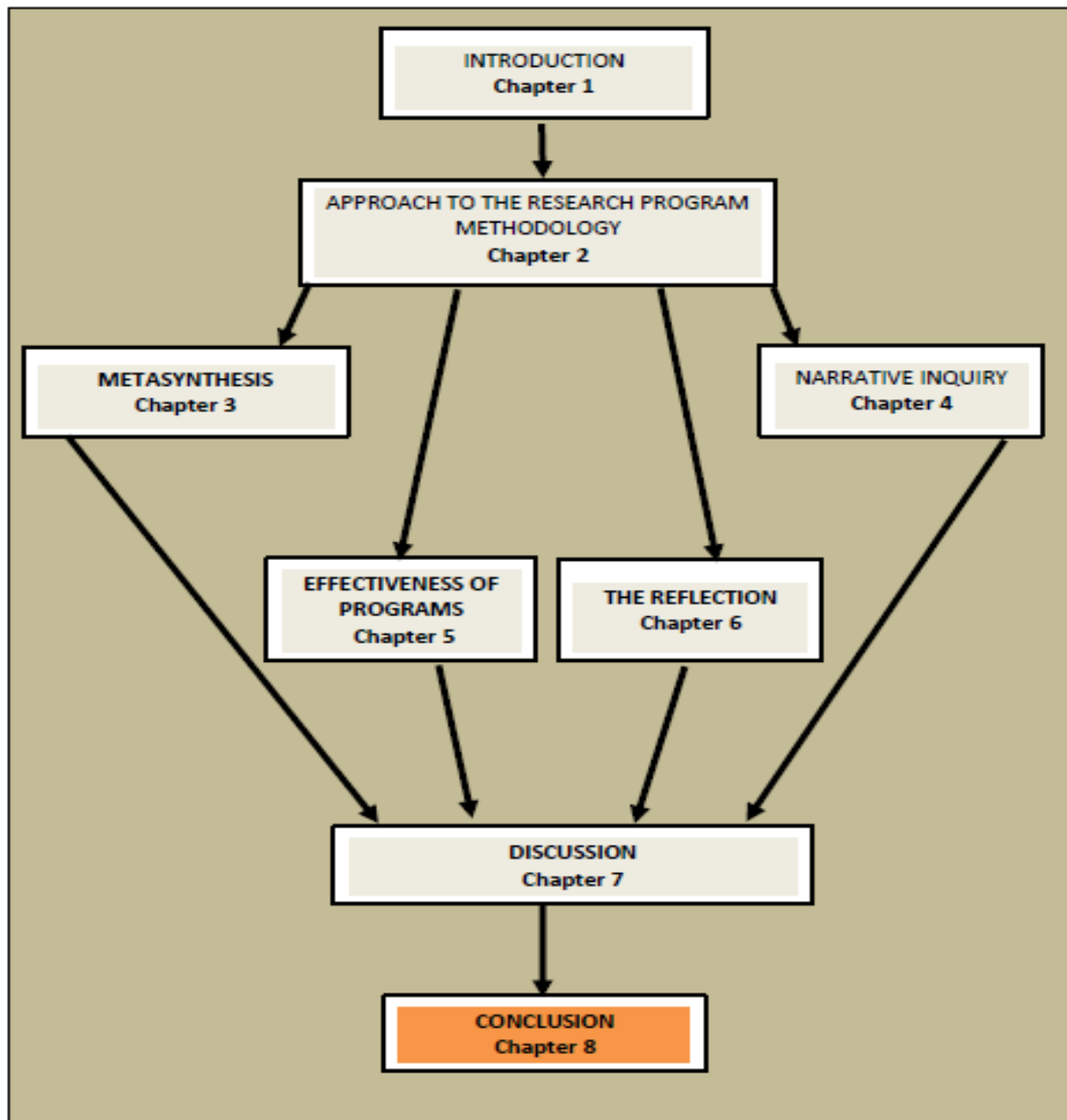
The synthesised findings indicate the complexity of health care and challenges encountered that go beyond technical methods of healthcare delivery alone. Across the studies it was clear that Indigenous people, in the main, did not experience acute healthcare in a positive way. They still meet challenges that make their experiences uncomfortable beyond the discomfort from their physical conditions for which they seek acute health care. Use of unsatisfactory health models continue to fail efforts by the health systems towards improved health outcomes for this population. Insistence on biomedical approaches and procedures that neglect interpersonal interactions, recognition of individual strengths, cultural beliefs and historical traumas have worked against efforts towards improved health outcomes for Indigenous Australians. The healthcare settings have been part of this process of domination, discrimination, stereotyping and pure racism have been exercised. Coming to hospital brings feelings of isolation. Hospital settings are riddled with western ways of approach to healthcare and all the processes and procedures are modelled around a western medicine train of thought. A biomedical approach is convenient and can reveal evidence-based practices, practices that seem effective and efficient, but they fail to integrate individuality of circumstances especially those concerning the cultural and social factors of an encounter as seen from individuals, especially the perspectives of Indigenous people.

At the time of completion of this program of research, the research site had become one of the sites for a project known as the Lighthouse Project. Through this initiative, visual representations of Indigenous culture have been implemented. A space for Indigenous people has been provided in the form of a garden with some edible Indigenous plants and mural paintings. Further, maps representing different Indigenous countries have also been placed strategically throughout the hospital, and a statement of commitment and acknowledgment of traditional owner of the land on which the hospital is built. This is a step forward because the items are educational and a source of conversation for staff and visitors, and a visual reminder to recognise and respect. A health professional champion program has been initiated to have individual on treating teams driving Indigenous issues in their workplaces.

Chapter summary

This chapter provides an integrated discussion of findings of this program of research. It also discusses main points from across the studies that consists this program of research. There are key issues that are discussed which impact on the experiences of Indigenous peoples with health care, particularly hospital care. The main issues include history of colonisation, difference in cultures and the power differences that impact on health care as experienced by Indigenous peoples. The chapter that follows presents the overall conclusions and the highlight in terms of contribution of the program of research to the body of knowledge. Strength and limitations are presented, and recommendation are suggested for clinical practice, future research and policy making. The following chapter presents concluding remarks.

Chapter eight: Recommendations and conclusion



Overview of the chapter

The previous chapter presented an integrated discussion of the overall findings of this program of research which explored Indigenous people's experiences of acute healthcare. The Indigenous story of health care experiences was discussed and situated within healthcare practices. The preceding chapters provided the background for this program of research, inclusive of my own impetus, and identified concerns regarding Indigenous people's experiences of acute health care within varied healthcare organisations.

This final chapter presents a conclusion to the program of research, which includes the contribution of the program as well as recommendations for policy, clinical practice and research. The chapter concludes with a review of strengths and limitations of the program. The value of the research is highlighted in the form of new insights and understanding that the program brings to the area of Indigenous healthcare encounters. Finally, recommendations are made for future research and healthcare practice, based on the information gathered through appraising literature and conducting studies of Indigenous healthcare experiences. I hope that the provision of recommendations will be the beginning of another chapter for the story of Indigenous people and healthcare.

The narrator's conclusion

My program of research was designed to increase understanding of the central issues related to Indigenous people's acute care experiences and was conducted around cardiovascular health. The cardiovascular health area was appropriate because reports indicate a higher incidence of cardiovascular disease among Indigenous Australians. It was also of clinical interest to me because the research site is a cardiac hospital where I work and see Indigenous patients and their relatives come for treatment of their cardiac condition. I anticipated that conducting this research would provide rich insights if participants were Indigenous people who were able to provide information on the unacknowledged contextual and subjective factors. Information that may explain the continued prevalence of higher burden of ill health among Indigenous people and the perception they might have about the care they receive.

I had previously assumed that that barriers to better health care among Indigenous people was a consequence of deficiencies in their own knowledge and self-negligence resulting from insufficient education and complacency. This program has allowed me to realise that there are deeper issues than seen which are rooted mainly in the colonial history of Australia and its peoples. Telling the story of Indigenous people and their encounters with health care took me on a journey that

revealed perspectives from a worldwide scene to the local Australian context. I had not appreciated the barriers to access of health care that Indigenous peoples encounter, and I believe there are a lot of non-Indigenous people with no knowledge of the full scope of issues that influence Indigenous health. The oppression and marginalisation of Indigenous people contribute immensely to the disproportionate poor health outcome of this population. I can see that it is important to view Indigenous health from a holistic point which includes historical, socioeconomic, psychosocial and cultural factors that impact Indigenous health.

Reviewing research question and aim

The main research question that was addressed in this program of research was:

What are Indigenous people's experiences of acute care?

Six objectives were to be achieved to assist in answering this question. These included: 1) designing a program of research through selection of a suitable methodology, 2) appraising literature for current evidence on Indigenous peoples' experiences of health care on a global level, 3) conducting a narrative to explore experiences of Indigenous peoples, 4) appraisal of literature through a systematic review to investigate effectiveness of programs for Indigenous peoples cardiac health, 5) reflection of the experience of researching with Indigenous people, 6) integrated discussion of overall findings, and then finally the provision of recommendations from the overall findings of the program of research for practice. The objectives were achieved through the Indigenous story which was viewed from different perspectives and recommendations can be drawn from the findings of the program, to inform an understanding for education, clinical, policy making, and research practice.

The studies provided triangulation of information by investigating the story of Indigenous people's experiences from different angles. The story started from a worldwide perspective through to national, and local Australian contexts. As a researcher I provided commentary and presented how I see issues from where I was positioned in the process of this investigation. This story is open for readers to situate themselves in and appreciate the Indigenous story of healthcare experiences.

Chapters one and two addressed the research background and choice of methodology that informed the research. Chapter three, four, and five provided rich and in-depth stories by the Indigenous participants in a variety of settings, as they presented what they find to be issues that bother them and how they wish things would be in their experiences of health care. Chapter seven and eight are about the main lessons learnt and how these can be put into practice. They achieve the

objective of integrating the findings to draw recommendations for practice. This final chapter therefore continues to tell the Indigenous story by focusing on the implications and the recommendation for future practice. Table 8.1 presents the chapters relating to the type of study methods used in each chapter to achieve objectives of the research program. Table 8.2 is a presentation of how each objective was achieved and significant findings that point to new knowledge acquisition towards understanding Indigenous people’s experiences of acute health care.

Table 8. 1. Chapters and corresponding objectives of the study.

OBJECTIVE		CHAPTER	STUDY METHOD
1	Design a program of research	Chapter 1 Chapter 2	<ul style="list-style-type: none"> • Introduction of the study area and approach of the study • Outlining of the processes followed in the program of research
2	Appraise the current evidence on Indigenous peoples’ experiences of health care	Chapter 3 Chapter 5	<ul style="list-style-type: none"> • Qualitative: metasynthesis of qualitative studies • Quantitative: systemic review of CVD programs
3	Explore current hospitalisation experiences of Indigenous peoples related to acute cardiac care	Chapter 4	<ul style="list-style-type: none"> • Qualitative: exploration of Indigenous hospitalisation experiences
4	Explore the effectiveness of current cardiovascular programs designed for Indigenous people	Chapter 5	<ul style="list-style-type: none"> • Quantitative: systemic review of CVD programs
5	Reflect on the research experience of researching with Indigenous people	Chapter 6	<ul style="list-style-type: none"> • Qualitative: autoethnography of researcher experience
6	Discussion of findings and provide recommendations for clinical and research practice in Indigenous health	Chapter 7 Chapter 8	<ul style="list-style-type: none"> • Integration of conclusions from the program of research to enable recommendation, highlight strengths and limitations.

Table 8.2: Summary of research objectives and main findings

Research objectives	Chapter	Main findings
Appraise current evidence on Indigenous peoples' experiences of health care	3	<ul style="list-style-type: none"> • Evidence indicates that there are challenges faced by Indigenous people worldwide when they encounter acute health setting • Indigenous people continue to encounter stereotyping and isolation during access to acute health care
Explore current experiences of acute health care	4	<ul style="list-style-type: none"> • New care models are needed that integrate Indigenous values and culture such as spirituality • More knowledge required by health professionals about Indigenous issues such as the impact of history on Indigenous perceptions of acute health care • Recognition of sociocultural aspects that impact Indigenous health
Explore the effectiveness of current cardiovascular programs designed for Indigenous people	5	<ul style="list-style-type: none"> • There is limited integration of Indigenous culture and health worldviews in the planning and implementation of programs designed for Indigenous people cardiovascular health • Program continue to be designed using biomedical approaches
Reflect on the research experience of researching with Indigenous people practice	6	<ul style="list-style-type: none"> • Place Indigenous issues central in the practice of healthcare • Be open to other ways of knowing and practices • Reflect on own practices and culture to improve healthcare delivery to Indigenous people that would have an impact and better outcomes

Contribution to new knowledge base

Level of evidence

This program of research largely utilised qualitative methods to investigate Indigenous people's experiences of healthcare, with an aim to gain understanding and insights for use in healthcare practices. Three of the studies utilised qualitative approaches. In the main, levels of evidence address effectiveness of intervention studies, and sit well with quantitative approaches and the designs used in this approach. Therefore, studies with purposes such as intervention, diagnosis, prognosis, aetiology or screening effectiveness readily fit in the current levels of evidence or hierarchy of evidence (Jones, 2007). Qualitative hierarchy of evidence is not well established or even existing

currently although suggestions have been made. Although the place of qualitative methodologies has expanded (Jones, 2007), the levels of evidence for qualitative has remained unestablished. As a result, qualitative research evidence has continued to be compared to quantitative research outcomes in terms of level of evidence and does not fare well.

The purposes for conducting research are different in each of the main research methodologies. Qualitative research approach focuses on gaining understanding while the quantitative one focuses on effectiveness of intervention for practice (Jones, 2007). I agree with Jones (2007) in saying that “Understanding why an intervention failed may be even more important than recognizing that it was a success, and the importance of qualitative studies of the attitudes, beliefs, expectations, and behaviours of patients, particularly in relation to changing their behaviour in response to educational or public health interventions cannot be overestimated” (Jones, 2007. p. 321). Further, use of qualitative research methodologies in “which the fine grain of interactions are analysed, using audio transcriptions alone or in conjunction with analysis of video material, are capable of providing acute and important insights into the core of medical activity- the consultation between doctors and their patients” (Jones, 2007 p. 321). In this program of research, I intended to understand what it is like for Indigenous people when they access health care. This understanding can then be utilised in improving their experiences through practice change.

The studies included in the first study, metasynthesis of qualitative studies, were appraised using Critical Appraisal Skills Programme tool for qualitative studies (CASP, 2013), and the overall outcome was that they were of high quality because they scored between 7 and 9 out of 9 criteria questions and details are in Chapter three. The second study utilised qualitative methods as well. According to the hierarchy of evidence specific to qualitative research outcomes, the highest level are studies that can be transferable (generalisable) to different settings. The findings of study two are readily transferrable. This is because the sample of participants came from a variety of regions, gender, age groups and involved both patients and relatives (Mbuzi et al., 2017b). The principles for evaluating the input of qualitative studies in health, developed by Daly, Willis, Small, Green, Welch, Kealy, and Hughes (2007), which leads to a grading of evidence for qualitative methods studies was applied for the qualitative studies in this program of research (Table 8.3). According to Daly and colleagues’ (2007) proposed hierarchy of evidence for qualitative research studies, the studies in this program have been placed at level I, which is the highest. The overall findings and triangulation of research study approaches enriches the evidence to provide for practice and policy insights.

According to the JBI (2013) levels of evidence, only the systematic review (Chapter five) was measured against the level of evidence provided because it appraised quantitative studies. Two sets of studies were used, and these were randomised controlled studies and quasi-experimental studies.

Table 8. 3. A hierarchy of evidence for practice in qualitative research study types and levels.

Source: Daly, Willis, Small, Green, Welch, Kealy, and Hughes, 2007

LEVEL	TYPE OF STUDY	FEATURES
I	Generalisable studies (transferable)	<p>Sampling focused by theory and the literature, extended because of analysis to capture diversity of experience.</p> <p>Analytic procedures comprehensive and clear.</p> <p>Located in the literature to assess relevance to other settings.</p>
II	Conceptual studies	<p>Theoretical concepts guide sample selection, based on analysis of literature.</p> <p>May be limited to one group about which little is known or several important subgroups.</p> <p>Conceptual analysis recognizes diversity in participants' views.</p>
III	Descriptive studies	<p>Sample selected to illustrate practical rather than theoretical issues.</p> <p>Record a range of illustrative quotes including themes from the accounts of "many," "most," or "some" study participants.</p>
IV	Single case studies	<p>Provides rich data on the views or experiences of one person.</p> <p>Can provide insights in unexplored contexts.</p>

Appraisal was done separately using JBI tools. The randomised studies were assessed to be moderate in quality and placed as having evidence at level 1.c, while the rest were at level 2.d (JBI, 2013). According to the schema of viewing levels of evidence, the three qualitative studies were at level 5. As discussed in chapters one and two, the value of directly asking Indigenous people about their experiences and giving them a voice far outweighs the scientific value of research in terms of influencing future practice. For the types of practice changes required, a more personal level of understanding and commitment is essential. Qualitative studies provide rich and meaningful data which can be more readily incorporated into values-based practice. For example, for health professionals to know what to do, they should learn some welcome processes or words in local language and check how to address their patients, and such learning is best brought about by hearing directly from their patients. Research that collect direct data from participants, such as that conducted using qualitative approaches, assist in that learning. Qualitative research provides impetus for change in attitudes, processes, and relationships, more than the statistics of ill health of Indigenous population which is the usual research results provided in most healthcare studies.

The key findings of individual studies contained in this thesis provide insights and highlight the significant contributions to the body of knowledge regarding Indigenous people's acute healthcare experiences, and build on the works of other researchers (Anderson, Cunningham, Devitt, Preece, & Cass, 2012; Artuso, Cargo, Brown, & Daniel, 2013; Green, Anderson, Griffiths, Garvey & Cunningham, 2018, McGrath, 2006; McGrath & Rawson, 2013; Worrell-Carter et al., 2016). This research project fills a gap in literature on the importance of incorporating Indigenous perspectives in healthcare to facilitate improved access to mainstream healthcare by Indigenous Australians. It is only the Indigenous people who can provide information about their cultural, economic, personal, physical, psychological, social, or spiritual perspectives that impact their health. Interviewing Indigenous participants achieved that. The information added to the understanding of health in a holistic sense by revealing the importance of viewing a patient being who needs all aspects of life to be incorporated holistically to achieve wellness and in this case, improve hospitalisation experiences.

The research objectives and the key findings of the studies have contributed to the extension of knowledge around Indigenous people and their hospital/acute care experiences. Building on the literature reviews in chapter two and five, it was identified that although research has been conducted in Indigenous health, most cases Indigenous methodologies have not been promoted. There is more emphasis on biomedical issues and less psychosocial focus within the hospital/acute settings which has made implementation of strategies to address Indigenous access and experience needs of health

care non-existent. Most cultural considerations are not adequate and provide little knowledge because they are provided in haste through cultural training programs which are put in place, in most cases to fulfil a standard/requirement, while in practice the insights are not integrated.

Indigenous Australians are different from other Australians in that they have their own distinct beliefs about life in general and worldviews on health. Healthcare systems need to recognise the benefits of Indigenous knowledge and integrate these in clinical practice. It is easy to dismiss the differences in favour of globalisation or standardised care approaches, but recognition of the differences may contribute to improved health outcomes of Indigenous peoples. Lack of reflection of cultural aspects of Indigenous people denies them their human right and identity, making them feel like strangers in hospital settings. Individual perception of an illness as well as their cultural, social and economic dispositions predispose people to how they use health services. Health service providers may focus on availability of material resources, process structures, procedures and regulations through which the health services are delivered, but there is need to modify both resources and population characteristics to ensure continuing of effective provision of services. The degree of adjustment can determine the functional relationship that can develop between the consumer population and the health facilities that service them.

Strengths and limitations of this research program

Strengths

The triangulation of sources of evidence in this program of research have strengthened the level of evidence of this program. The use of storytelling as the thread linking the studies strengthened the process of gathering evidence that can inform our understanding of Indigenous people's experiences of acute healthcare. Use of stories from a worldwide perspective and then Australian context strengthened the research program findings on which to base recommendations.

A qualitative research approach strengthened this study because of the provision of comprehensive participants profiles on how they experienced acute health care. The approach allowed multiple perspectives on the experiences of Indigenous people to be elicited. Although this program of research focused on experiences around acute health care, and particularly heart health settings, themes that were identified are readily transferrable to most healthcare settings. They deal with respect for people, and acknowledgement of difference in healthcare provision. The subjugated position of Indigenous people in the health care hierarchy demands that their experiences and perspectives be given consideration through use of their individual stories.

Further, the strength of this program of research was enhanced through rigorous appraisal of literature on the topic by using multiple approaches, including, metasynthesis and systematic review. Investigation of the status of Indigenous hospitalisation experiences brought the issues to the current. Researcher experience reflections was included as part of the study to reflect co-construction partnership that occurs in qualitative research studies and to promote rigour. All these aspects strengthened and enriched the understanding of Indigenous people's healthcare experiences and factors that influence their perspectives.

Participants came from various regional areas and varied in age and gender. This strengthened the recruitment of participants by providing a combination of different experiences to strengthen the data of the study. Different backgrounds of participants came together to provide an aggregated story of hospitalisation experiences for Indigenous Australians. It is hoped that the findings would alert a reader to the complexity of Indigenous health care experiences. The importance of considering the influences that impact healthcare experiences for Indigenous people is vital. For this purpose, qualitative approach strengthened the study outcome due to its focus on human experience.

Limitations

This program of research was conducted at one site. This site may not be representative or typical of experiences from other hospitals. The hospital is an interstate referral centre which may have advantages in terms of resources available for use, such as having Indigenous Hospital Liaison Officers who are available daily. This is a limitation because one centre cannot adequately reflect all issues experienced by Indigenous peoples elsewhere within acute care institutions. Also, this was mainly a qualitative research program that focused on acute care experiences of participants. The program, therefore, did not cover experiences encountered prior to admission, discharge plans and post discharge care. These are essential for information that might impact Indigenous peoples' health and hospital experiences. Further investigation of these issues is recommended. The program provides current contextual experiences of a single hospital which can limit its reflection of issues. Despite this limitation, a comprehensive metasynthesis and systematic review offered a wide range of patients' and relatives' perspectives from a variety of health care settings.

Interpretation of data can lead to a loss of participants' voice. This can be a limitation that comes with use of interpretive research approaches as used in this program of research. To limit loss of participants' voices, quotations were used to illustrate points as much as possible.

This program of research did not investigate healthcare professionals' perspectives and may be a missing link. Investigating staff perspectives may reveal the challenges they face in implementing cultural aspects in their practice. Further research is therefore required to investigate perspectives of clinicians of Indigenous people's experiences of acute healthcare.

The studies that were included in the appraisal of literature did not include grey literature. There could have been further issues that would have added to what is contained in the published peer reviewed articles. There were limited published studies identified for both the metasynthesis and systematic review. This demonstrated lack of Indigenous voices regarding their experiences. The limited RCT studies found for the systematic review indicates the difficult in implementing such studies when it comes to health care.

Another limitation is that this program of research did not investigate the type of patients who do not make it to hospital or the fate of those who discharge themselves against medical advice. Further, this program of research did not address what type of preparation patients received before discharge and how patient fared post-acute. Further research is required to investigate these issues and follow up participants and investigate their situations post discharge. Indigenous peoples are health care consumers just as those who are non-Indigenous. Most issues are common to both groups of people and therefore, some recommendations may appear generic but are urgent for Indigenous people. As a result, this program of research has implications for various groups that have an impact on Indigenous healthcare, as well as the general population and these include: Healthcare clinicians, educators, researchers, and policy makers.

Implications of the findings

The research findings provide an understanding that stimulates the potential for change towards an inclusive health service that considers and integrates Indigenous people's cultural aspects to health care. Health services need to evaluate the services that they deliver in view of Indigenous people's expressed needs and cultural considerations. There is need to acknowledge the impact of their past experiences as a community of people and how this has disempowered them leading to a sense of disconnect with mainstream health services and other government organisations. Indigenous people, however, remain hopeful that one day the two cultures can live side by side and come to appreciate the difference and respect each other for it.

Unacknowledged cultural factors might explain, at least in part, the continued high prevalence of ill health among Indigenous people. Mainstream health through its dominant biomedical view to health and its management contains a belief that ill health can be avoidable if patients diligently comply with recommended practices as prescribed. The dominant approach intended to prevent or treat ill health concentrates on biomedical modelling of programs and their evaluation, with its training heavily weighted in favour of how to use technology, medications and other technical activities. This program of research revealed that while all that might be good, Indigenous people require extra consideration because of the impact of colonisation that diminished, disempowered, and placed them at a disadvantaged position through deliberate dislocation and suppression of their cultural lives. The findings from this program of research are that disparities in health between Indigenous and non-Indigenous people are not a consequence of deficiencies or insufficient skills in technical practices by staff, but poor relationships and interaction at the clinical interface which is influenced by the rest of society. The oppression of Indigenous people in general and their marginalisation in society contribute to the disproportionate high disadvantage experienced.

This program of research, therefore, provides insights into Indigenous people's experiences of healthcare. The following section provides recommendations for future health service and practice. From this program of research, several recommendations can be made for healthcare service practice and future research. The following section provides recommendation for clinical practice, education for health professionals, research practice and policymaking.

Recommendations for clinical practice

Healthcare continues to grow in complexity due to development in knowledge of care and increased accessibility of health information for health professionals and patients (Sibbald, Wathen, Kothari, & Day, 2013). Wellbeing is generally recognised to be influenced by multiple factors, therefore, healthcare professionals can facilitate improved outcomes by accepting and understanding these aspects holistically. Unless patient priorities are recognised and integrated into designing of the care, it is impossible to be responsive to their care needs and improve health outcomes. Clinicians should aim to understand barriers faced by their patients to provide better health care. An understanding of the influence of sociocultural processes on health has been principally ignored in clinical practice. It is vital for clinicians to deliberate the impact of cultural systems of values on health consequences because this is massive among Indigenous peoples. Although this impact is known, in clinical settings, the tendency is to standardise care. Such approaches are determined by both an absence of mindfulness of the diversity with which health is contextualised. Unless clinicians address

models of care that differ from what is assumed to be universal, the stereotypes and assumptions will continue to inform practice.

Clinical encounters have lasting effects on patients and families, and clinicians must learn to understand and observe respect for the diversity. This would provide Indigenous population with a better experience and a positive story to tell. Cultural competence has been promoted in healthcare. Clinicians need to understand how to implement insights learnt into their daily care activities by practicing patient centred care. From this study it was clear that there are still gaps on how to implement patient-centred innovations that reflect recognition of Indigenous patient values (Green, et al, 2018). As hospitals are the main providers of healthcare there is a crucial need to progress cultural safety in order to facilitate approachability for Indigenous people (Hunter et al., 2013).

Clinicians need to be adequately prepared to recognise and respond appropriately to diversity in their patient's cohorts. Indigenous culture has been challenged and influenced by many factors since colonisation. It is important to acknowledge this and set strategies to address cultural aspects of well-being for Indigenous patients to improve their health as individuals as well as for their community (Queensland Health 2014). It is important to have continuous feedback mechanisms within the hospital organisations to enable improvements and move forward towards better health outcomes for Indigenous people. The following are recommended for clinical practice:

1. Recognise, acknowledge and respect cultural differences

- Respect the needs of Indigenous patients and their family by including them in the care decisions through integration of cultural factors; such as recognising kin systems used by Indigenous families. Kinship structures, roles and responsibilities are relevant within Indigenous communities and families.
- Show interest and learn a language or greeting ritual and how to address Indigenous patients in communication, such as use of aunty /uncle terms.
- Ask for their preferences during daily care planning because issues such as men's and women's business segregation practices are fundamental part of cultural practices, and implementation of cultural gender specific protocols and practices should be considered.
- Provide language assistance when required and interpreter if appropriate and avoid assuming knowledge or lack of knowledge such as confirming whether they can read or write. Some older Indigenous people did not complete school education beyond year 4.

2. Integration of cultural practices within acute care settings through patient centred approach

- Design outcome-based evaluations that enable health care professionals and the health care organisation at large to be answerable and responsible for their performance. Programs such as competence training must have an evaluation tool to assess its effectiveness or impact on Indigenous peoples' health care.
- Development of care pathways for Indigenous patients for use in clinical areas that can prompt clinicians of factors to remember when caring for Indigenous patients- (not for standardisation of care or stereotyping). Know the cultural views of death and dying that are relevant for Indigenous people.
- Provision of outdoor or indoor space for use with family where they can feel comfortable and have opportunities for social interaction with other Indigenous peoples within the hospital setting.
- Indigenous staff recruitment must be on the agenda to increase staffing numbers and appropriate cultural care that is acceptable to Indigenous patients.
- Develop and understand the role of Indigenous Hospital Liaison Officers and provide a career path for them that recognise and enhance their career progression and retention.

3. Reflective practice to ensure critical review of practice in Indigenous health care delivery

- Ensure ongoing training for all staff in which they can reflect on own practice for improvement with regards to Indigenous peoples' health care
- Involve local Indigenous community into program development and delivery even through a variety of media such as video resources, online training resources and print materials.
- Staff to learn actionable strategies such as knowledge of traditional custodians to assist their patients when they require such information.
- Staff can actively get involved through participating in roles such as staff Indigenous champion programs.

4. Realisation and development of interest in Indigenous health as a business for all healthcare providers

- Avoid too much reliance on Indigenous Hospital Liaison Officers by adopting the principle of Indigenous issues is everyone's business and every member of staff must commit to learn and acquire skills that will enable them provide appropriate care. Every staff member has the duty of care to competently care for their patients and they must recognise this responsibility

Recommendations for educators of healthcare professionals

Institutions involved in preparation of healthcare professionals must take note that Indigenous health issues are a given privilege and not treated as a side show if improvements are to be realised. If staff are oriented from the beginning of their training, through to when they qualify and join a team, better attitude may be developed. It is currently difficult if such training is at a tokenistic level and provided only during orientation week for new staff or as a tool to meet accreditation requirements. Just as health professionals like nurses learn how important it is, for example, to give the right medicine, to the right patient, at the right time, and right dose and route, cultural safety must be elevated to such a level to make a difference. This can involve the following:

1. Better cultural training that provides or equip clinicians with skills to care for an Indigenous patient with teaching guidelines and processes for assessment are required.
2. Stronger educational emphasis on Indigenous cultural aspects of health and its impact.
3. Emphasis when teaching staff and students on respect for Indigenous worldviews of health concepts that can lead to development of inclusive practices and informed work force.
4. Prioritise Indigenous knowledge by making it one of the central issues in health professional and general education.

Recommendations for policy

Evidence-based policies are crucial in decision making and should have long term objectives and mechanisms on how to sustain the set objectives. In order to be effective, healthcare policy and planning should be informed by partnership between Indigenous people and healthcare services. This can enable Indigenous knowledge to guide implementation of frameworks that are responsive to priorities as seen from Indigenous peoples' perspectives as well as healthcare services. One of the areas is on how to build trust in healthcare policy by Indigenous people by developing policies and procedures that support clinicians to translate such policies into action in their interactions with patients and their families. Diversity in health views among society members should move health policy makers towards contextualising care.

While the care giver has obligations which are universally understood, healthcare policies should facilitate these obligations to be centred around patients' needs and reflection of their values. Policy makers and healthcare professionals must continue to pursue initiatives intended to involve Indigenous people in their well-being. There is need for evidence-based policy to promote rigorous analysis of service programs and policy options. Political, scientific and practical implementation of

knowledge is required in order to achieve appropriate policies that are sensitive to Indigenous healthcare services delivery. Without appropriate policies to guide practice, models for quality of care will remain incomplete for Indigenous Australians. Use of all evidence is important and not only depending on biomedical information but also that which is provided by those who experience the care.

The following section presents some recommendation for policy makers. To formulate policies that are effective and directed at improving Indigenous people's experiences of acute healthcare, and many options may be considered.

1. Appraise evidence through conduction of systematic review to assess effectiveness of interventions or strategies in use and use both national and international evidence about what works in Indigenous health. Gather evidence for use in policy formulation from those involved in the care of Indigenous peoples. This should be evidence from both qualitative and quantitative inquiry. Collaborate and partner with Indigenous advisory members in the formulation of policies. Develop policies that support frontline health professional in the implementation of culturally safe practice for Indigenous peoples through identification of resources to support the formulated policy.
2. Increasing the proportion of Indigenous people working in the health care service through deliberate recruitment of Indigenous health professionals.
3. National policies should promote positive health care through addressing specific determinants and risk factors that impact Indigenous population such as recognition of Indigenous history and provision of sustainable support systems for those affected. Focus mainly on building social and emotional wellbeing of Indigenous peoples through supportive practices and appropriate funding.

Recommendations for further research

The recommendations for future research point to the fact that local collaborative efforts are required to be responsive to issues faced by Indigenous peoples, especially within hospital settings. Health is inseparable from people's culturally affected perceptions of health and as a result there are pressing issues and needs that need to be addressed in every individual patient. It is vital to understand the relationship between culture and wellbeing, particularly the cultural aspects that influence health-improving activities and how to integrate these cultural constructions of health in practice. Indigenous people should be involved in research because without Indigenous input

researchers will continue to put, as priority, the agendas from their perspectives which reflect their values and worldviews.

Biomedical research is important, but it should not be at the expense of research into sociocultural determinants of health. Research into cultures of care should be promoted to gain insight and understanding that can facilitate provision of appropriate health care for Indigenous peoples and align care models and approaches with Indigenous culture and knowledge. In research, therefore, there are several areas that need further investigations, and these include:

1. Experiences of clinicians in caring for Indigenous people to provide their perspective
2. The role of Indigenous Hospital Liaison Officers and how much knowledge is required to equip them in representing Indigenous people and supporting them during hospitalisation
3. Use of research designs that are compatible or appropriate to Indigenous people's worldviews, needs and culture.
4. Investigation into post-acute care and collaborative structures between acute settings and community care centre.

Conclusion

This program of research has investigated the issues encountered by Indigenous peoples' in their experiences of acute health care in general. Through literature appraisal it was found that most of the studies have concentrated on highlighting and describing how bad the status of health is for Indigenous people and there is limited information on Indigenous perspectives on the issue. To be able to find effective ways of delivering appropriate healthcare, that can impact Indigenous health outcomes, Indigenous voices need to be considered and incorporated at every level of health system. Strategies that are appropriate and culturally acceptable are needed to improve Indigenous peoples' health experiences.

Future research is encouraged to investigate Indigenous health care experiences from health professionals' perspective. This would enable continuation of the story and gain insights into challenges that professionals face while providing care for this population group. Knowing both sides would enhance development of improved models of care.

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-

Appendices

Appendix 1: Key events in Australia's reconciliation history

Source: Reconciliation Australia, 2016.

1932

William Cooper establishes the Australian Aborigines' League. During the 1930s, Mr Cooper and other leaders of the Aborigines Progressive Association gathered 1,814 signatures on a petition calling on Prime Minister Joseph Lyons and King George VI to intervene "**for the preservation of our race from extinction and to grant representation to our race in the Federal Parliament**".

1938

The Aborigines Progressive Association and the Australian Aborigines' League declare 26 January a day of mourning for Aboriginal people.

1963

Yolngu leaders present the Yirrkala bark petitions to the Australian Parliament, protesting against the seizure of more than 300 square kilometres of Aboriginal land in Arnhem Land for mining.

1965

University of Sydney students, including Charlie Perkins, launch the Freedom Rides, travelling around NSW by bus to draw attention to discrimination against Aboriginal people.

1966

Aboriginal stockmen and their families stage the Wave Hill station 'walk-off' to protest against poor working conditions. The Gurindji peoples' struggle later develops into Australia's first successful Aboriginal land claim.

1967

In a national referendum, 90.77 per cent of Australians vote 'yes' to give the Commonwealth Government the power to legislate for Aboriginal people and **to include Aboriginal people in the Census**.

1971

The Gove land rights case, while denying recognition of native title, sets the intellectual framework for recognising land rights. **Neville Thomas Bonner becomes the first Aboriginal parliamentarian** following his election as Senator for Queensland.

1972

The Aboriginal Tent Embassy is established. The Department of Aboriginal Affairs is established.

1973

The Woodward Royal Commission into Aboriginal Land Rights is established, paving the way for **the Aboriginal Land Rights Act** in the Northern Territory.

1975

Australian Parliament passes the Racial Discrimination Act 1975 (RDA).

1976

Australian Parliament passes the *Aboriginal Land Rights (Northern Territory) Act 1976*, leading to the establishment of **land rights legislation in most Australian states** in the 1970s and 1980s.

1988

The Barunga Statement calling for self-management and land rights is presented to **Prime Minister Bob Hawke, who indicates his support for a treaty**.

1990

The Australian Government establishes the Aboriginal and Torres Strait Islander Commission (ATSIC). Dr Lowitja O'Donoghue AC, CBE, DSG is the first chairperson.

1991

The report of the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) is tabled. **The Council for Aboriginal Reconciliation (CAR) is established**. Professor Patrick Dodson is appointed inaugural chairperson.

1992

The High Court recognises native title in the landmark case *Mabo v Queensland (No. 2)* (1992). **Prime Minister Paul Keating delivers the 'Redfern Speech' recognising the history of dispossession, violence and forced removal of Aboriginal children.**

The Aboriginal and Torres Strait Islander Social Justice Commissioner position is created. Professor Mick Dodson AM is appointed to the position.

1993

Australian Parliament passes the *Native Title Act 1993*. **The first Week of Prayer for Reconciliation is held, which later becomes National Reconciliation Week.**

1995

The Australian Government officially **recognises the Aboriginal and Torres Strait Islander flags.**

1996

The first National Reconciliation Week is celebrated. The full High Court hands down its decision in *Wik Peoples v Queensland* (the 'Wik decision'), in which it determines that pastoral leases do not extinguish native title.

1997

The National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families releases **the *Bringing them home* report**. The Australian Reconciliation Convention is held in Melbourne.

1998

The *Native Title Act 1993* is amended based on Prime Minister John Howard's 10-point plan.

2000

The CAR delivers its final report to Prime Minister John Howard and the Australian Parliament at Corroboree 2000. Bridge walks are held across Australia.
Reconciliation Australia is established.

2006

The *Close the Gap* campaign for Indigenous health equality is developed following the release of the *Social Justice Report 2005*. **Reconciliation Australia's Reconciliation Action Plan (RAP) program begins**

2007

The Northern Territory Emergency Response begins. The Council of Australian **Governments (COAG) commits to 'closing the gap'** in life expectancy between Indigenous and non-Indigenous Australians.

2008

Prime Minister Kevin Rudd delivers the Apology to the Stolen Generations. COAG commits \$4.6 billion towards *Closing the Gap on Indigenous Disadvantage* for projects in health, housing, early childhood development, economic participation and remote service delivery.

2009

Australia indicates its support for the United Nations Declaration on the Rights of Indigenous Peoples. 2010
The National Congress of Australia's First Peoples is established.

2011

The Expert Panel on Constitutional Recognition of Aboriginal and Torres Strait Islander peoples lead wide-ranging public consultations and delivers its findings in January 2012.

2012

The campaign to recognise Aboriginal and Torres Strait Islander peoples in the Constitution begins.

2013

The Australian Parliament passes the *Aboriginal and Torres Strait Islander Peoples Recognition Act 2013* to maintain momentum towards a referendum.

Appendix 2: Critical Appraisal Skills Programme 2013.

Qualitative Research checklist 31.05.13

	Questions	Yes	Can't tell	No
1	Was there a clear statement of the aims of the research?			
2	Is a qualitative methodology appropriate?			
3	Was the research design appropriate to address the aims of the research?			
4	Was the recruitment strategy appropriate to the aims of the research?			
5	Was data collected in a way that addressed the research issue?			
6	Has the relationship between researcher and participants been adequately considered?			
7	Has ethical issues been taken into consideration?			
8	Was the data analysis sufficiently rigorous?			
9	Is there a clear statement of findings?			
10	How valuable is the research?			

Appendix 3: Ethics Approval letter

Enquiries to: R&ETPCH@health.qld.gov.au
Office Ph: (07) 3139 4198
(07) 3139 4500
Our Ref: HREC Final Approval



18 December 2013

Human Research Ethics Committee
Metro North Hospital and Health Service
The Prince Charles Hospital
Administration Building, Lower Ground
Rode Road, Chermiside QLD 4032

Mrs Vainess Mbuzi
Adult Intensive Care Services

Dear Mrs Mbuzi

HREC/13/QPCH/316: Indigenous cardiac patients' and their relatives' experiences of hospitalisation and acute care: a qualitative study.

Thank you for submitting the requested documents for the above project for further review which was received on 18 December 2013. This project was considered by Metro North Hospital and Health Service - The Prince Charles Hospital Human Research Ethics Committee (HREC).

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Human Research Ethics Committee has granted final approval of this research project. The documents reviewed and approved for the above mentioned project include:

Document	Version	Date
Application (AU/1/A785118)		
Protocol	Version 1.0	14 November 2013
Patient Information Sheet/Consent Form	1.1	16 December 2013

This information will be tabled at the next meeting on 23 January 2014 for noting.

Please note the following conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - a. Unforeseen events that might affect continued ethical acceptability of the project.
 - b. Serious Adverse Events that materially impact on the continued ethical acceptability of the project. In addition the Investigator must provide, at least six monthly, a summary of serious adverse events, in the specified format, including a comment as to suspected causality.

Office	Postal	Phone
Research, Ethics & Governance Office The Prince Charles Hospital	Administration Building, Lower Ground Rode Road, Chermiside Q 4032	(07) 3139 4500 (07) 3139 4198

2. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a cover letter from the principal investigator, providing a description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study. Hard copies of the revised amendments, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC coordinator as per standard HREC SOP. Further advice on submitting amendments is available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp
3. Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office/r (by-passing the HREC).
4. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly the HREC for review and, once HREC approval has been granted, submitted to the RGO.
5. Amendments which do not affect either the ethical acceptability or site acceptability of the project (e.g. typographical errors) should be submitted in hard copy to the HREC coordinator. These should include a cover letter from the principal investigator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.
6. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
7. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.
8. The Hospital & Health Service Administration and the Human Research Ethics Committee may inquire into the conduct of any research or purported research, whether approved or not and regardless of the source of funding, being conducted on hospital premises or claiming any association with the Hospital; or which the Committee has approved if conducted outside The Prince Charles Hospital & Health Services.

HREC approval is valid for **3 years** from the date of this letter.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer on the above phone numbers or email addresses. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Hospital & Health Services CEO or Delegate of that site has been obtained.

A copy of this approval must be submitted to the relevant Hospital & Health Services Research Governance Officer/s or Delegated Personnel with a completed Site Specific Assessment (SSA) Form for authorisation from the CEO or Delegate to conduct this research at the site/s.

Once authorisation to conduct the research has been granted, please complete the Commencement Form http://www.health.qld.gov.au/tpch/documents/form_notification.dot and return to the office of the Human Research Ethics Committee.

The HREC wishes you every success in your research.

Yours faithfully



Dr Russell Denman
Chair

**HUMAN RESEARCH ETHICS COMMITTEE
METRO NORTH HOSPITAL AND HEALTH SERVICE**

List of approved Sites:

No.	Site
1	The Prince Charles Hospital

Appendix 4: Site Specific Approval letter

Enquiries to: RGOTPCH@health.qld.gov.au
Office Ph: (07) 3139 4198
(07) 3139 4407
Our Ref: Governance Approval



13 February 2014

Research Governance Office
Metro North Hospital and Health Service
The Prince Charles Hospital
Administration Building, Lower Ground
Rode Road, Cherside QLD 4032

Mrs Vainess Mbuzi
The Prince Charles Hospital
Adult Intensive Care Services

Dear Mrs Mbuzi

HREC/13/QPCH/316
SSA/14/QPCH/25

Indigenous cardiac patients' and their relatives' experiences of hospitalisation and acute care: a qualitative study.

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site:

The Prince Charles Hospital

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC approval/rejection letter must be submitted to the RGO;
2. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the research governance officer;
3. Proposed amendments to the research protocol or conduct of the research which may affect both the going ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the research governance officer after a HREC decision is made.

I am pleased to advise Governance approval of this research project. The documents reviewed and approved include:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Site Specific Application AU/3/285619		

Please complete the Notification of Commencement Form once commencement of this protocol has occurred at this site (http://www.health.qld.gov.au/tpch/documents/form_notification.dot) and return to the office of the Human Research Ethics Committee.

Office Research, Ethics & Governance Office The Prince Charles Hospital	Postal Administration Building, Lower Ground Rode Road, Cherside Q 4032	Phone (07) 3139 4407
--	--	--------------------------------

On behalf of the Research, Ethics and Governance Unit, we wish you every success in your research project.

Yours sincerely



Anne Carle
CEO Delegate
Metro North Hospital and Health Service

Appendix 5: Registration of External Ethics Approval

2014 77N Registration of External Ethics Approval

From: Kylie Pashley <Kylie.Pashley@acu.edu.au> on behalf of Res Ethics <Res.Ethics@acu.edu.au>
Sent: Thursday, 3 April 2014 11:21 PM
To: Paul Fulbrook; Vainess Mbuzi
Cc: Res Ethics
Subject: 2014 77N Registration of External Ethics Approval

Dear Paul,

Principal Investigator: Prof Paul Fulbrook
Student Researcher: Ms Vainess Mbuzi
Ethics Register Number: 2014 77N
Project Title: Indigenous cardiac patients' and their relatives experience of hospitalisation and acute care
Risk Level: Multi Site
Date Approved: 04/04/2014
Ethics Clearance End Date: 30/11/2014

The Australian Catholic University Human Research Ethics Committee has considered your application for registration of an externally approved ethics protocol and notes that this application has received ethics approval from The Prince Charles Hospital Metro North Hospital and Health Service [HREC/13/QPCH/316].

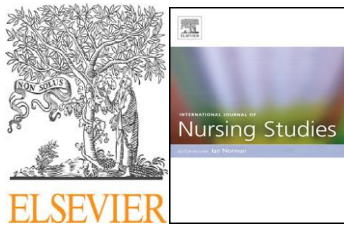
The ACU HREC accepts the ethics approval with no additional requirements, save that ACU HREC is informed of any modifications of the research proposal and that copies of all progress reports and any other documents be forwarded to it. Any complaints involving ACU staff must also be notified to ACU HREC (National Statement 5.3.3)

We wish you well in this research project.

Regards,

Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden
Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research)
res.ethics@acu.edu.au

Appendix 6: Authors' Right to Reproduce study one



International journal of Nursing studies

Title:

Indigenous peoples' experiences and perceptions of hospitalisation for acute care: A metasynthesis of qualitative studies. <http://dx.doi.org/10.1016/j.ijnurstu.2017.03.003>

Authors:

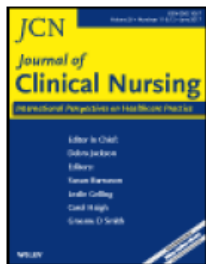
Vainess Mbuji, Paul Fulbrook, and Melanie Jessup

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Appendix 8: Permission to Reproduce study three

International Journal for Equity in Health

Title:

Effectiveness of programs to promote cardiovascular health of Indigenous Australians: a systematic review. <https://doi.org/10.1186/s12939-018-0867-0>

Authors:

Vainess Mbuji, Paul Fulbrook, and Melanie Jessup

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Appendix 9: Communication from Metro North Hospital and Health Service Indigenous Unit Team

From: Angela Scotney
Sent: Wednesday, 23 July 2014 4:42 PM
To: Vainess Mbuzi; Paul Fulbrook
Cc: Horace Nona; Henry Nona; Elwyn Henaway; Natasha White; Paul Drahm
Subject: Research with Indigenous people in TPCH

Hi Paul and Vainess,

Thank you for meeting with me earlier and I thoroughly enjoyed listening about what your research is about. I have copied in the following staff:

- Paul Drahm, Deputy Director (Holds the Cultural Capability Portfolio)
- Horace Nona (Rural and Remote, Cultural Capability Officer) – Horace will be based at TPCH from the 4th August
- Natasha White (Safety & Quality, Womens and Newborn, Cultural Capability Officer), and
- Elwyn Henaway and Henry Nona (TPCH & RBWH, Cultural Capability Officers)

I have discussed the research that you are conducting with all of the above named staff and all are happy to be of assistance when required.

All the best,
Angela



Angela Scotney
Director
Aboriginal & Torres Strait Islander Health Unit
Office of the Chief Executive, Metro North Hospital and Health Service
Level 14, Block 7
Royal Brisbane Women's Hospital
Herston Qld 4029
P: (07) 3647 9529
angela.scotney@health.qld.gov.au
www.metronorth.health.qld.gov.au



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Appendix 10: Confirmation of manuscript submission - IJEH-D-19-00265

Confirmation of your submission to International Journal for Equity in Health - IJEH-D-19-00265

International Journal for Equity in Health Editorial Office <em@editorialmanager.com>

Wed 26/06/2019 5:43 PM

To:

Vainess Banda Mbuzi vainess@hotmail.com.au

IJEH-D-19-00265

Researching with Indigenous people: an autoethnography

Vainess Banda Mbuzi, Master of Nursing; Melanie Jessup, PhD, RN; Paul Fulbrook, hD, RN;

Sandra Miles, PhD, RN

International Journal for Equity in Health

Dear Mrs Mbuzi,

Thank you for submitting your manuscript 'Researching with Indigenous people: an autoethnography' to International Journal for Equity in Health.

The submission id is: IJEH-D-19-00265

Please refer to this number in any future correspondence.

During the review process, you can keep track of the status of your manuscript by accessing the following website:

Your username is: vainess.mbuzi@health.qld.gov.au

If you forgot your password, you can click the 'Send Login Details' link on the EM Login page at <https://www.editorialmanager.com/ijeh/>.

Best wishes,

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