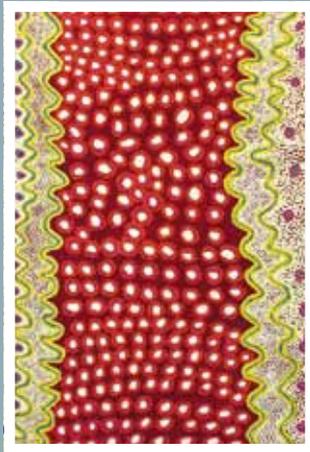


Janet Kelly
Judith Dwyer
Tamara Mackean
Eileen Willis
Kim O'Donnell
Malcolm Battersby
Brita Pekarsky



Managing Two Worlds Together:

Study 3—The Experiences of Patients and Their Carers



Cover Artwork:

*Kuntjanu – Mingkiri
Tjuta Tjukurpa
(Marsupial Mouse
Dreaming)*

by Rama Sampson
painting (no.74),
courtesy Better
World Art

Janet Kelly
Judith Dwyer
Tamara Mackean
Eileen Willis
Kim O'Donnell
Malcolm Battersby
Brita Pekarsky

Managing Two Worlds Together:

Study 3—The Experiences of Patients and Their Carers



© Flinders University, 2011

ISBN 978-1-921889-15-8

This work has been produced by Flinders University and is published as part of the activities of The Lowitja Institute – Australia’s National Institute for Aboriginal and Torres Strait Islander Health Research, which incorporates the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH). The CRCATSIH is a collaborative partnership funded by the Cooperative Research Centre Program of the Australian Government Department of Innovation, Industry, Science and Research.



This work has been funded by the South Australian Department of Health. The views expressed herein are solely those of the authors and do not reflect the views of the SA Department of Health or its Minister.

This work is the copyright of Flinders University. It may be reproduced in whole or in part for study or training purposes, or by Aboriginal and Torres Strait Islander Community organisations subject to an acknowledgment of the source and no commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holder(s).

Additional copies of the *Managing Two Worlds Together: Study 3—The Experiences of Patients and Their Carers*, along with downloadable pdfs of all six reports emanating from this project, can be obtained from:

Department of Health Care Management

Flinders University
Bedford Park, SA 5042 AUSTRALIA
T: +61 8 8201 7755
F: +61 8 8201 7766
E: tiffany.carlin@flinders.edu.au
W: www.flinders.edu.au

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA
T: +61 3 8341 5555
F: +61 3 8341 5599
E: admin@lowitja.org.au
W: www.lowitja.org.au

Authors: Janet Kelly, Judith Dwyer, Tamara Mackean, Eileen Willis, Kim O’Donnell, Malcolm Battersby and Brita Pekarsky

Managing Editor: Jane Yule

Copy Editor: Cathy Edmonds

Cover Artwork: *Kuntjanu – Mingkiri Tjuta Tjukurpa (Marsupial Mouse Dreaming)* by Rama Sampson painting (no.74), courtesy Better World Arts

Design and Print: Andrea Gill and InPrint Design

For citation: Kelly, J., Dwyer, J., Mackean, T., Willis, E., O’Donnell, K., Battersby, M. & Pekarsky, B. 2011, *Managing Two Worlds Together: Study 3—The Experiences of Patients and Their Carers*, The Lowitja Institute, Melbourne.

Table of Contents

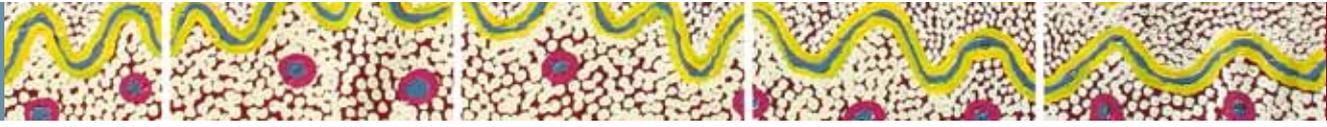
The Managing Two Worlds Together Project.....	v
Acknowledgments.....	vi
Abbreviations and Terms.....	vi
Summary.....	1
Methods.....	1
Results: health care from the recipient perspective.....	1
Five underlying factors.....	2
Five gaps or breakpoints in the system of care.....	3
The policy challenge.....	3
Introduction.....	5
What is already known about this topic?.....	5
Research questions.....	5
Methods.....	6
Participants.....	6
Results: Analytical Framework.....	7
The Direct Interpersonal Encounter.....	8
Positive care experiences.....	8
Problems.....	8
Causes.....	10
Strategies for effective care.....	11
Conclusion.....	13

System of Care: Access	14
Travelling for health care	14
Accommodation	19
Problems for remote Aboriginal patients	20
Roles of carers	22
Access to spiritual carers	22
Language and interpreters	23
Informed consent	23
Financial resources and implications	24
Conclusion	25
System of Care: Coordination and Quality	26
Communication across health services	26
Logistics and the hospital environment	27
Discharge and follow-up care	29
Conclusion	31
Social and Cultural Environment	32
The importance of family	32
Coping with diagnosis or illness	34
Death and dying	34
Systemic racism, post-colonial realities	35
Conclusion	36
Discussion and Conclusions	37
Analytical framework: the five underlying factors	37
Five gaps and breakpoints, and potential solutions	38
The city/country divide	39
Acute/non-acute divide	40
The language divide	40
The financial divide	40
Aboriginal/non-Aboriginal cultures	41
The policy challenge	41
References	42

Attachment: Methods	43
Ethical approval.....	43
Advisory structure.....	43
Data collection.....	43
Interview/focus group outline	44

Figures and Tables

Table 1: Five factors that affect access and quality of care.....	3 + 37
Table 2: Summary of opportunities to bridge the five divides in the system of care.....	4 + 38
Figure 1: Three domains of factors affecting health care experiences.....	7
Table 3: Summary of themes in the direct interpersonal encounter.....	9
Table 4: Summary of themes regarding access to care.....	15
Table 5: Summary of themes in coordination and quality of care.....	27
Table 6: Summary of themes in social and cultural environment.....	32



The Managing Two Worlds Together Project

The Managing Two Worlds Together project aims to add to existing knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia (and parts of the Northern Territory). It explores their complex patient journeys and what happens when they come to Adelaide for hospital care

The relationship between patients and health care providers is the foundation of care and requires communication across cultures, geography and life experiences. As a staff member in one rural Aboriginal Community Controlled Health Service put it: 'It's like managing two worlds together, it doesn't always work'.

Stage 1 of the project focuses on the problems. Four studies were conducted and are reported in six documents:

- *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People Project Report* (available on the website and as a printed document)
- *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People Community Summary* (available on the website and as a printed document)

- *Managing Two Worlds Together: Study 1— Report on Admissions and Costs* (available on the website)
- *Managing Two Worlds Together: Study 2— Staff Perspectives on Care for Country Aboriginal Patients* (available on the website)
- *Managing Two Worlds Together: Study 3— The Experiences of Patients and Their Carers* (**this report**—available on the website)
- *Managing Two Worlds Together: Study 4— Complex Country Aboriginal Patient Journeys* (available on the website).

Stage 2 will focus on solutions and will consist of a small set of action research projects. During 2012 the research team will work with partner organisations in this study to develop and/or document the implementation of strategies to improve the health care journeys for country Aboriginal patients, based on existing good practice and on the findings of Stage 1.

Full details about the project are available at the Managing Two Worlds Together website, which is hosted by Flinders University at: <www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/>.

Acknowledgments

We thank the participants in this project—the patients, carers and staff in hospitals, support services, primary health care and aged care settings throughout South Australia—who have generously contributed their insights and experiences.

The research team is also grateful to our industry partners, and to members of the Project Management Group, which has functioned as a true sounding board for our emerging ideas and as a dynamic source of advice about the ‘two worlds’ we have explored.

We acknowledge the support of the Department of Health in South Australia, which funded this study through the Strategic Health Research Program.

We thank Paul Basso, Phillip Battista, Tiffany Carlin, Alwin Chong, Charlotte de Crespigny, Karen Dixon, Zell Dodd, Cathy Edmonds, Grant Emmerson, Mitchell Fitzgerald, Ruth Harris, Kylie Hermann, Rosie King, Monica Lawrence, Laney Mackean, Pam Maslin, Nicole McLachlan, Sonia Mazzone, Azi Mian, Debra Miller, Dave Moodie, Kim O’Donnell, Sharon Perkins, Mark Ramage, Roland Ruff, Emily Tinning, Catherine Turnbull, Tez Williams, Gai Wilson, John Willis, Rae Winter, Chris Zeitz and Rob Zadow who contributed in various capacities.

Abbreviations and Terms

AHLO Aboriginal Hospital Liaison Officer

GP general practitioner

PATS Patient Assistance Transport Scheme

Country In describing where people live, we use the terms *country* and *rural* to include all non-metropolitan areas. We use the more specific terms *regional*, *remote* and *very remote* in accordance with Australian Bureau of Statistics Accessibility/Remoteness Index for Australia (ARIA) definitions to indicate remoteness in terms of access along the road network.

Country is used by Aboriginal people with a larger meaning of belonging and as a spiritual, as well as a geographic, home. The context of usage is a guide to interpretation of meaning.

Mainstream We use *mainstream* to refer to non-Aboriginal systems, institutions and practices.

Summary

This report presents the results of a qualitative study of the perspectives and experiences of country Aboriginal patients (and some of their immediate family and carers) who received health care in Adelaide public hospitals. This study is part of a larger project that aims to add to existing knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia. More information about the Managing Two Worlds Together project, and the other studies that are part of it, is available at www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/.

Methods

We interviewed 21 Aboriginal patients and their carers, and a further eight women in a single focus group. In-depth interviews were conducted in four regions of country South Australia. We invited each person to tell his or her story, and then asked clarifying questions about experiences and perceptions of health care and support. Data were then transcribed and analysed using a software program.

Results: health care from the recipient perspective

Aboriginal patients and their carers spoke of positive and negative experiences in three domains: the direct interpersonal encounter between staff and patients; the system of care; and the broader social and cultural environment. The accounts of patients and close family members give important insights into the entire country Aboriginal patient journey from home to hospital and back home, involving multiple agencies and services.

The direct interpersonal encounter

Most patients and carers spoke of being treated well by staff generally, but negative experiences with a minority of staff were also common. There were communication difficulties associated with clinical information and health literacy, with some patients not understanding medical explanations or care plans. When communication and rapport failed, patients felt shamed and disrespected, were concerned about their safety or expressed a desire to leave hospital earlier. Patients and carers attributed communication difficulties to discomfort in relationships between staff and patients, a lack of understanding of cultural differences and generalised assumptions made about Aboriginal people. Preferred approaches involved staff taking time to have friendly two-way conversations, giving clear explanations, welcoming patients and making them feel part of a wider 'family'. Patients and carers appreciated explanations about why delays to care were unavoidable. They highlighted the importance of receiving respectful and safe care, and of staff having adequate training in this area. Some patients and carers identified that their own education, ability to ask questions or seek answers (including on the internet) and knowledge of their rights improved their interactions with health staff.

System of care: access barriers

The most significant access barriers experienced by the participants in this study were affordable and appropriate transport and accommodation options. Some patients and carers travelled enormous distances, or even moved to another town or city, in order to access health care. Support services assisted to varying degrees, but strict rules and administrative requirements were confusing and restrictive. The majority of patients stayed with family or friends, with others seeking affordable options in Aboriginal hostels and accommodation close to hospitals.

Most participants were on pensions or earned low wages. Poverty, combined with chronic health problems, made financial difficulties almost inevitable, with many patients struggling to purchase medications and make trips to Adelaide for health care. Financial assistance from family or government services was vital.

Carers and escorts were supported by hospital staff to varying degrees. The need for interpreters was relatively low among those interviewed. However, many patients spoke of the importance of effective communication for informed consent and said that their ability to understand complex medical concepts was often overestimated by staff. Patients with a good command of English, access to written information and the ability to keep asking staff questions until they were answered were best informed.

System of care: coordination and quality

Coordination across health carers and services was effective in some areas, and patchy or non-existent in others. In some cases patients experienced unacceptably long delays, or missed out on needed care, due to poor communication and lost results. Patients and carers highlighted the difficulty of arranging transport and hospital appointments and the apparent lack of understanding of most city services and staff to accommodate this. Some patients found hospitals cold and lonely, with little personal or cultural support.

Patients and carers reported some well coordinated, collaborative and supportive discharge and follow-up care experiences. Others were disjointed and had little consideration for patients' home conditions or follow-up needs. Local primary health care services, particularly Aboriginal health services and/or general practitioners (GPs), played a major role in coordination and ensuring follow up through case managing patients' health care journeys.

Social and cultural environment

Patients and carers stressed the importance of having family nearby, or in contact via telephone. Family members provided patients and carers with much needed support (physical, economic, social, spiritual and emotional) and often travelled long distances to maintain contact. Some carers discussed extensive periods of time caring for family members but overwhelmingly valued this role and did not discuss it as a burden. They made difficult decisions and faced personal challenges when supporting family members during death and dying. Patients and carers also spoke of the struggle to come to terms with an injury, diagnosis or treatment, and the impact this had on their lives and wellbeing. Some patients felt that there is increased response to cultural needs in hospitals, although stereotyping still leads to discomfort for patients and carers alike.

Five underlying factors

Analysis of the results of both this study and the related study of staff experiences highlighted five underlying factors (Table 1) that impact on health care for this group of patients (and others).

It is the interaction of all these underlying factors—being a country person in a city setting, needing care across the hospital/non-hospital divide, perhaps not having English as a first language, perhaps being poor, and being Aboriginal in a mainstream system—that makes city hospital care for country Aboriginal patients a unique challenge for the patients themselves and their carers and staff. Each factor, and the interactions among them, has important implications for this group and, taken together, argue the need for explicit attention to the needs of country Aboriginal people. The commonality of some of these factors for country people, other patients with chronic or complex illness, and those of non-English speaking backgrounds also underlines their importance for the health system. As one of our advisers succinctly put it, 'if we could fix health care for Aboriginal people, we could fix it for everyone'.

Table 1: Five factors that affect access and quality of care

Issue	Explanation
City/country	Some of the problems facing country Aboriginal patients and their health care providers are common to all country patients.
High burden of illness	People with chronic or complex conditions are affected more by systemic health care problems, especially across hospital/non-hospital sectors, although any patient may experience care problems.
Language	Some communication challenges that patients and staff encounter are common to all population groups for whom English is not a first language.
Financial resources	It is harder for all people who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and time off work or away from home and family.
Aboriginal/non-Aboriginal	There are ways in which Aboriginal people experience unique disadvantage in their interactions with the mainstream health system (and other social systems); and mainstream worldviews and beliefs about health and health care are often different from those held by Aboriginal people.

Five gaps or breakpoints in the system of care

We conclude that patients experience five kinds of gaps or breakpoints in the current system of care that impede reliably good access and quality of care. The strategies (many of which are already in use but not systematically available) summarised in Table 2 were identified as opportunities for action.

The policy challenge

The ‘gap-filling’ approach outlined above will only work if it is undertaken in a supportive policy and program environment. To address the serious health and health care problems facing country Aboriginal people, it is essential that the high-level legislative and policy statements that

acknowledge the need for particular attention to Aboriginal health and health care are elaborated into operational policies, procedures and programs.

The SA Health *Aboriginal Health Care Plan 2010–2016* acknowledges the need for systemic implementation of relevant policies and mandates action and reporting by regional health services to this end (SA Health 2010:21, 34).

The patients and carers we interviewed identified gaps and problems, and the strategies they saw as most responsive to their needs. What is needed at policy level is a program for implementation of better access, quality and cultural safety in hospitals and health services in governance, management and care delivery.

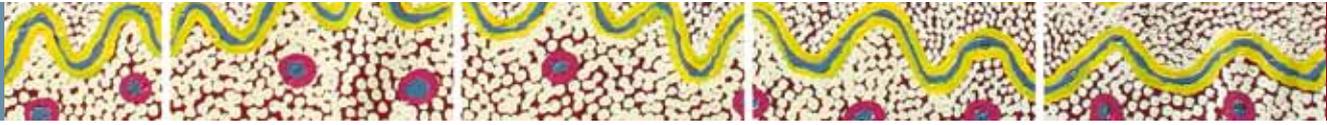


Table 2: Summary of opportunities to bridge the five divides in the system of care

System gap or breakpoint	Opportunities for action
City/country	<p>Regional transport arrangements.</p> <p>More low-cost accommodation near suburban hospitals.</p> <p>Transport support for patients staying with families.</p> <p>Streamlined Patient Assistance Transport Scheme (PATS) procedures.</p> <p>Specialist care in the country (outreach clinics).</p> <p>Improved use of information and communication technology.</p> <p>Support and case management for medical relocation.</p>
Acute/non-acute	<p>Role of primary care providers in care coordination.</p> <p>Apply S100 rules to discharge drugs; manage Medicare numbers.</p>
Language	<p>Ensure policy on access to interpreters is applied.</p> <p>Adapt informed consent procedures.</p>
Financial resources	<p>Funding changes are needed for complex patient journeys.</p>
Aboriginal/non-Aboriginal cultures	<p>Bring cultural safety and respect to the operational level.</p> <p>Formalise and support the roles of escorts and carers.</p> <p>Strengthen the roles of Aboriginal Hospital Liaison Officers and units in hospitals.</p>

Introduction

This report presents the results of a qualitative study of the perspectives and experiences of Aboriginal country patients (and some of their immediate family and carers) who received health care in Adelaide public hospitals.

What is already known about this topic?

Aboriginal people do not have equitable access to necessary primary health care services and this is reflected in high numbers of potentially preventable hospitalisations (DoHA 2009; AIHW 2011:95–8). Although emergency department visits and hospitalisation rates for Aboriginal people are relatively higher, procedure rates are lower. Waiting times for surgery are longer than for non-Aboriginal patients, and nearly double for some cardiac and cataract surgery (AIHW 2011:100). Aboriginal people are often sicker or clinically more complex at an earlier age and have some different care needs related to their life circumstances and positions in society. Experiences of shaming, misunderstanding and stereotyping make engagement with the health system less effective than it can and should be (National Heart Foundation of Australia & Australian Healthcare and Hospitals Association 2010; Purdie, Dudgeon & Walker 2010).

Travelling long distances from a rural or remote setting to a city hospital for medical treatment can be a logistically challenging and frightening experience for country Aboriginal people. Unfamiliar hospital environments, treatments and staff are encountered, often without family and friends nearby to offer support (Stamp et al. 2006). Cultural needs may not be accommodated, and access to Aboriginal liaison officers and interpreters may be limited (Kowanko et al. 2003; Stamp et al. 2006). Accommodation

and transport concerns within the city make the journey even more difficult for patients and their escorts. Sometimes the barriers are so great that patients refuse to begin the journey (Lawrence et al. 2009; Stamp et al. 2006).

Research has consistently shown that rural patients require more information about their impending hospital visits, and that improved communication and transition of care between health care providers in country and city services are needed. Transfer of care rather than discharge processes, and planning that involves both rural health carers and family members, provides better follow up for patients on their return home (Bolch et al. 2005; Davis et al. 1998; Knight & Baker 2001; Lawrence et al. 2009; Stamp et al. 2006; Taylor et al. 2009).

Research questions

This study is based on the proposition that an understanding of the experiences and insights of patients and carers as they travel through the health care system is a necessary basis for sustainable efforts to achieve improvement. Recipients of care provide a unique perspective on existing problems and gaps in care, and strategies and priorities for improvement.

This study therefore addresses two research questions:

- What are the main problems that affect country Aboriginal patients and carers when they need health care in city public hospitals, and what works well?
- What are their insights into the causes of the problems that have affected them, and the strategies or changes that would improve access and quality of care?

Methods

We set out to explore the experiences of Aboriginal country patients through in-depth interviews rather than surveys or other ways of ‘counting’. We did not seek to quantify the problems because such examination needs to be based on a better understanding of their nature and sources than we currently have.

The project team negotiated partnership agreements with the Aboriginal Health Council of South Australia and all the regional public health services in South Australia, and received ethical approval from six ethics committees. The project has been guided by the advice of a Project Management Group comprising industry partners and ‘end users’ of the research.

One Aboriginal and one non-Aboriginal researcher travelled to four country areas of South Australia (in the West, North, Riverland/Mallee and South East regions) to discuss the project with health service managers, staff and Aboriginal community representatives. Health staff approached patients (and their family/carers) who had recent experiences of city hospital care, and those who were interested in participating contacted the research team, usually via the health service. Interviews were conducted at a time and location that best suited patients and carers—in people’s homes, on front verandahs and in gardens, and in health services and dialysis units. One focus group was conducted with Elder Aboriginal women. Each person was given the choice of being interviewed by an Aboriginal and/or non-Aboriginal researcher, but most people did not express a preference, and many of the interviews and the focus group were conducted by both researchers. Interviews were 30 to 60 minutes in duration and were based on open-ended questions that invited participants to share their experiences of health care. Follow-up questions (developed through the staff interviews) were used to prompt further discussion of known areas of concern, if they had not already been addressed. The interview schedule is provided in the attachment.

The method of recruitment and interviewing means that people who were unable to communicate (or were uncomfortable communicating) in English are not included in the study group (even though interpreting was offered).

We recorded the interviews and focus group discussions in the form of notes (if preferred) or audio recording. We transcribed the recordings or notes, and analysed the interviews inductively—that is, we read the text and grouped like comments and ideas together to generate an overall picture of what the patients and carers were telling us, and the implications for the health system. A more detailed explanation of the methods is given in the attachment.

Participants

Twenty-one patients and carers were involved in 20 interviews, and one focus group was conducted. Twelve interviewees spoke of their experiences as patients (P1–10, P12, P14), two as carers (C2, C6), and five as both patient and carer (PC20–24). One couple spoke as a patient and carer journeying together (P&C30). Eighteen people met face to face and three preferred telephone interviews.

The patients and carers were aged from their thirties to their seventies and were living in cities, towns and remote communities in four regions of South Australia. They experienced a broad range of acute and chronic health concerns. Seventeen of the 21 people were receiving disability, old age or carer pensions, and four were employed.

Eight Aboriginal Elder women aged in their seventies and eighties chose to meet in a focus group rather than have individual interviews. They shared their experiences of being patients, carers, Elders and *Ngangkari*s. The researchers met this group three times, first visiting and explaining the research, then meeting as a focus group, and then returning to check the written record and discuss issues in more detail.

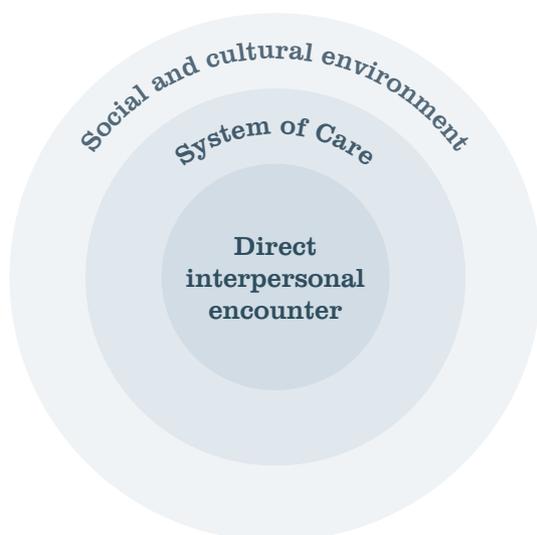
Results: Analytical Framework

Analysis of the interviews identified three domains of concern in common with the staff interviews (although with different emphases and content):

- the challenges of the direct interpersonal encounter with health staff
- aspects of the system of care and the necessary support services (problems with access, coordination and quality)
- factors in the broader social environment that impact on health care.

In presenting the results, we move from the core of direct clinical and care interactions to the care system and to the broader social and cultural environment (Figure 1).

Figure 1: Three domains of factors affecting health care experiences



There were several major themes in each domain. It is important to note that many of the problems encountered by country Aboriginal patients and their care providers also affect other people, such as the problems inherent in travelling long distances for care or not having English as a first language.

Representative quotes from interviews are included throughout the results below. Codes in brackets at the end of quotes signify characteristics of the participants:

- **P** (patient): experiences as a patient
- **C** (carer): experiences as a carer
- **PC** (patient carer): experiences as both patient and carer
- **P&C** (patient and carer): one interview with a couple (patient and carer)
- **FG** (focus group): one discussion with an Elder women's group.

The Direct Interpersonal Encounter

The relationship between patients (and their families) and health care providers is the foundation of care, and most patients and carers discussed both positive experiences and the particular challenges they face when that relationship requires communication across cultures, geography and life experiences.

The major themes in this domain are summarised in Table 3.

Positive care experiences

Being treated well by staff

Most patients and carers experienced mainly (or only) positive interactions with hospital staff:

I had no problems while I was in there. The staff were really good. We got looked after really good, perfectly (C2).

They know me now and I have no worries about going down. This is the first time I have felt good for a while. The doctors and nurses there, they changed my life this year. I like it down there. The staff there say, 'Mrs [X], don't say you are back again', joking and welcoming me in again. Hospital is a good place to be (P4).

Some midwives were caring, doing all the things you expect for that level of care, the gentle tone, supportive and nurturing (PC23).

Acceptance of Aboriginality

Several patients expressed a sense that their Aboriginality was not a barrier to their care. One woman reflected deeply on the aspects that made the health care experience positive for her and her daughter in a city hospital, and this included having their Aboriginality accepted

and welcomed. She identified the importance of the environment, as well as staff attitudes and approaches:

The actual service in the hospital is really good. I couldn't fault it. The staff were fantastic and did their job very well. There was the same level of care and respect shown for all families there. Our experience has been very positive. We didn't encounter anything negative based on being Aboriginal. You have your radar on when you go somewhere new, and there was nothing to detect... There are posters there, things around that are culturally inclusive. You can see yourself as a patient within the system. Aboriginality is acknowledged and it looks like it is respected. These signposts make a huge difference (PC23).

Problems

Negative experiences with a minority of staff were common

The majority of patients and carers spoke of difficult or negative interactions with one or two specific staff members. This variation was often described by patients and carers as differences in personality and approach:

It all depends on their personality, it is personality driven. Some go the extra step, some recognise culture as important, some take time with their attitudes (FG).

He'd ring the bell or something and they'd take hours and say, 'well, what do you want?'... Some of the nurses, they were lovely but it was just that one or two nurses, yeah (C6).

Table 3: Summary of themes in the direct interpersonal encounter

Issue/aspect	Major themes
Positive care experiences	Being treated well by staff. Acceptance of Aboriginality.
Problems	Negative experiences with a minority of staff were common. Communicating clinical information and health literacy. Consequences of communication failure.
Causes	Discomfort in intercultural relationships. Generalisations and assumptions about Aboriginal people.
Strategies	Building effective relationships. Cultural awareness, cultural respect, cultural safety. Patient's own personal knowledge and abilities.

One woman from a remote area highlighted that, for her, communication problems could occur regardless of the cultural background of the staff members involved:

Some was all right, some was not good. You get like that in hospitals... some might be racist or some might be good... It's not only white [staff], it could be Aboriginal people too (P5).

Several patients and carers spoke of the avoidance tactics they used when they had difficulties with particular staff, such as hiding in the bathroom, making sure they were absent at prearranged appointment times or waiting for the next shift. Two patients who were bed bound discussed the tension of not knowing which staff member would respond when they pushed the bell and how long it would take:

The not so good nurses, they are not thinking about you when you pushed the button. Just look and go past and not coming. And I tried to wave and sing out, but they just go past. It makes me really wild (P8).

I didn't bother pressing any buttons, I just stayed there until I got out... I know their attitudes, you know (P5)?

Communication of clinical information and health literacy

Some patients and carers indicated that they were well informed about their care. Others expressed concern about the way that health information and decisions about care were communicated, including why normal medications were withheld during admission (highlighting the need for explanations about drug and surgical interactions and complications):

They make these grandiose decisions about what you can and can't have because you go in with your medication, they look at your medication and then they decide what you have and I can't see that me having my HRT [hormone replacement therapy] had anything to do with any of them (PC20).

Others raised concerns about confusing medical processes and terminology:

The specialists I see, they don't explain things, they just tell you how it is, we will do this treatment, One, two, three, four. The specialist are flat out, pick up x-rays, do

this, do that. It is very intimidating. I didn't understand what the surgeon was talking about in his language (P7).

They bring out these big words and say, 'oh, you're going to have this', and I always say I don't understand that, I need it to be—you know, 'cut out the big words'... they don't explain it properly—it's medical terms which a lot of our people don't understand (C6).

Consequences of communication failure

Patients discussed the impact for them personally when communication broke down, or good rapport was not achieved between themselves and staff members, including feelings of shame and disrespect, concern about safety and desire to leave hospital:

The big doctor came around with his group and told me to close my mouth as I didn't need to breathe through it. Easy for him to say. He said that to me in front of all the other students (PC24).

The physio... had a really poor bedside manner. She would haul me up and get me to walk, and I had been so sick and so breathless, I just needed to take it a bit easy (P&C30).

There's absolutely no partnership whatsoever. It is 'you will do what I tell you to do. I am the specialist, you are the patient. You don't know what's going on, I do.' Now, this is my body. I know what's going on in my body, they don't (P1).

Some midwives were just nasty, particularly the night shift midwives. They would get [the baby's] head and physically force it onto my breast. If I was not so sore I would have gotten up and walked out of there (PC23).

Some patients felt that clinical care without positive interpersonal interaction was not healing. The Elder women in the focus group discussed 'feeling no good' when staff came into the room, did a procedure or dropped off food and didn't say hello. They said this made them feel like a non-person. They described a greeting as a sign

of basic respect, and said that, for them, human connection was as important as the physical care they received.

A patient from a rural city discussed how lonely and unsupported she felt, particularly while recovering in an Adelaide private hospital with little interaction with staff and no family to visit her.

Not being able to talk to staff... when you are getting better they just leave you to your own devices. It gets really lonely. If they could just pop in to say hi, how are you going... I understand that they are busy but... it would be good if they check you in the morning and afternoon again (P7).

Communication gaps can also add to the stress for carers. One carer spoke of her distress in finding her husband's bed empty when she visited:

They didn't let us know when they were going to take him into theatre and operate on him, see? Well, 72 and having a heart attack, we didn't know if he was in the morgue or where he was (PC22).

Causes

Most patients spoke about what they saw as one or both of two underlying causes of the problems they encountered.

Discomfort in intercultural relationships

The most common explanation recognised the challenge for staff who were seen to have different life experiences and frames of reference:

They've been brought up different than what we've been brought up and it's a communication breakdown (PC22).

Several also spoke of staff attitudes being linked to underlying racism:

I felt that I was treated—because I was an Indigenous person that they could treat me anyway they want... it's not across the board, there's just certain people—their attitudes... you can feel the feeling of another person's attitude towards you just by the way they look at you (P1).

Generalisations and assumptions about Aboriginal patients

The other main explanation identified the tendency for staff to make generalisations or assume all Aboriginal people are alike:

A lot of them still think that we all—Aboriginals are the same... that's the worst part, that's the annoying part, they treat you all the same and, oh, come on, we're our own now, we've got our own minds (C6).

One person believed that generalisations about her needs as an Aboriginal person prevented her from getting care in a timely manner:

I said if this means a delay, please, I don't need the Aboriginal health worker, I just need the nurse. No joy... I just wanted some help. The protocols for Aboriginal people meant that I didn't get it. These things need to be on an individual basis. It is a form of racial discrimination to assume we all need help, to be all lumped in together. It is offensive... It is not just overt racism, it is the underlying, underhanded racism. The reverse discrimination, we should not be categorised [as] 'Aboriginal people are all like this'... it is negative and derogatory (PC23).

Strategies for effective care

Building effective relationships

Patients and carers spoke of the importance of interpersonal connections and effective two-way communication. One patient discussed a range of interactions between herself and health staff in primary and tertiary care settings, highlighting the importance of having opportunities to talk with staff, of taking time and having friendly two-way conversations, with clear explanations:

The [Aboriginal health service GP] is really mindful of our needs. She is really busy and everything, but she makes time to talk about things and follow through. She explains things really well. With the medication she tells me why, what it does, not just taking it and not knowing. If you get the right help, you can get through... What we need is friendly people, with friendly processes. The specialists in Adelaide are not friendly, but the [rural and remote] mental health people... were better... There was a teleconference with the doctors in Adelaide, I chatted with her for a half an hour and discussed all sorts of things... We are pretty shy people, not right out there, it is a huge thing for us. Speaking to us makes a huge difference. Talking in terms that we can understand is much better (P7).

Remote patients who came to Adelaide repeatedly discussed their appreciation of being welcomed and reassured and being made to feel part of a wider 'family':

When I went to Adelaide the first time, I was a bit homesick. The nurses would comfort me, they said this is a very serious thing, this operation. They would talk to me about it. Now I see so many nurses and doctors and they all know me. When I go to Adelaide they say, 'you are one of the family now' (P4).

One patient and carer described her appreciation of open, honest interaction with a specialist who was treating his first private Aboriginal patient:

When I first met the specialist he said my daughter is the first Aboriginal person he had ever seen. He made quite a point of saying that. It was quite an epiphany for him I think. A moment of reflection. We spoke about it at length, was it because the issues were less in Aboriginal communities, or because of lack of access? I think the cost, distance and wait times have a lot to do with it. I know lots of Aboriginal kids with problems that should be seeing a specialist like him (PC23).

Patients and carers also expressed understanding about the workloads staff experience, and emphasised that acknowledgment and/or explanation of the delay was appreciated:

Some nurses came in as replacements and had to find their way around, but you made allowances for that... they would be looking

for things, and checking for things and apologising for taking a while, but you could understand that (P&C30).

But the good ones... if they are busy they sing out, 'I will be there in a minute', and they come (P8).

Cultural awareness, cultural respect, cultural safety

Patient and carer accounts highlighted the importance of respectful and safe care. The Elder women discussed the importance of being addressed as respectfully in hospitals as they are in their own communities. They spoke of being affronted when staff called them by their first names, or referred to them as 'girl'. They suggested that their correct names, 'Mrs [X]', be written and displayed so that everyone knows how to address them (FG).

Some patients suggested that city hospital staff could improve their interactions with Aboriginal patients through more training. Two felt more education of staff was needed:

They need to be educated in a kind way, not a nasty way, because you've got to remember their life is very different (PC22).

It's really just understanding the culture a bit more and understanding with Indigenous people that everybody is different and from their upbringing to where they've lived within their culture. I mean, my Aboriginal culture would be different from somebody that's lived on the Lands so it's just sort of getting an understanding of the variety of culture too (P12).

They need to sit down and study Aboriginal ways before going in and doing this and saying this and that. They need to learn off other people, how to work with more traditional people. They might sit in the bush and talk to them. Traditional people find it hard going to Adelaide hospitals; they need to help them more (P10).

One person discussed the importance of staff and hospitals supporting family and cultural needs, such as when family members visit very ill patients:

Well, when my sister was in hospital they didn't want a lot of people there—because there was a lot of blackfellas coming in and out—I said, well, this is the only way that's going to bring her back to us... if she hears her people, her mob, she'll come home. Well, [one nurse] she didn't want the people there. She said, 'only you'. I said, not only me. That's all her cousins, they're like her sisters and brothers, you've got to let them in, if you don't she'll only get worse. Let them in, she'll be home next week... and sure enough, she was too (PC21).

Patient's own personal knowledge and abilities

Some patients and carers discussed how their own education and ability to ask questions or seek answers (including on the internet) and knowledge of their rights improved their interactions with health staff.

I thought I was treated better than somebody else, only because I asked questions and... when they asked me anything I was able to answer them back (P9).

I am not a shy person, I am articulate, I speak my mind and know how to ask (PC23).

I am not frightened to speak up, I have done studies at uni about politics and have sat on boards. I speak up if I need to. I can be quite assertive (C2).

I used to work in a lot of places with people. I was okay (P10).

A number of patients reflected on their own experiences and expressed concerns about interactions being more difficult for Aboriginal people from remote areas who may be less comfortable speaking up:

Sometimes you gotta make yourself known a bit, speak up for yourself... It might be different for more traditional people (P10).

And several patients appreciated companionship with other patients:

When we were all at St Margaret's, we'd all get together, doing exercises and work out, then we sit and talk and have a cuppa together. We share our experiences about the phantom pain and things... Everyone is one big happy family (P10).

Conclusion

Most patients and carers spoke of being treated well by staff generally, but negative experiences with a minority of staff were common. There were some communication difficulties associated with the communication of clinical information and health literacy, with some patients not understanding medical explanations or care plans. When communication and rapport failed,

patients felt shamed and disrespected, were concerned about their safety and expressed a desire to leave hospital earlier. The causes of communication breakdown were attributed to discomfort in relationships between staff and patients, a lack of understanding of cultural differences, and generalisation and assumptions being made about Aboriginal people. Good strategies used by staff included taking time and having friendly two-way conversations (with clear explanations) and welcoming patients and making them feel part of a wider family. Patients and carers also appreciated explanations about why delays to care were unavoidable. They highlighted the importance of respectful and safe care, and of staff having adequate training in this area. Some patients and carers identified how their own education, ability to ask questions or seek answers (including on the internet), and knowledge of their rights improved their interactions with health staff, and they expressed concern for Aboriginal people from remote areas who may not have these skills.

System of Care: Access

Patients described serious difficulties with access to care. The major themes are summarised and analysed in Table 4.

Travelling for health care

Difficulties with limited transport options

The majority of patients and carers began their accounts by describing a lack of personal or public transport options, and serious financial concerns related to travel. In four of the 20 interviews, patients said they had no public transport in or near their towns or communities. Approximately half of those interviewed travelled to and from Adelaide in their own cars; the other half relied on family, local health services or public transport. Those who did not express concerns about transport tended to have access to more resources: they had their own vehicles, were not too ill to drive, had a higher income or fewer dependents, lived closer to a major town or city and had regular public transport routes close to where they lived, or transport support was provided by local Aboriginal health services.

Long trips to Adelaide for outpatient care

Travelling long distances to and from Adelaide for outpatient appointments and follow-up treatments was difficult for the majority of patients and carers. Each-way travel times varied from three hours to up to two days for very remote people. Many patients could not afford to pay for accommodation, or had no family to stay with in Adelaide, and some travelled many hours to the city and back home on the same day.

Consequences of travelling long distances while unwell

Many patients experienced chronic conditions such as diabetes with fluid retention, chronic or acute pain or disability, or were seeking cancer or cardiac treatments with associated tiredness and nausea. Carers expressed concern that their partners travelled such long distances while being quite unwell. One carer reported that her husband had driven 40,000 kilometres over the past 18 months for cancer treatment. He usually drove alone, even though he had a cardiac condition and felt tired and nauseous following cancer treatments. She could not afford the time off work and so he stayed overnight with friends at a halfway point and each city visit involved at least three days away from home.

Another carer discussed how difficulty with transport got so bad that her husband refused to travel for treatment anymore:

As the time passed he got more weaker and he wasn't able to get on the buses and so we had to make arrangements to get down there privately and... that's when all the heartaches and headaches started again... I wouldn't like to see anybody else go through what I've been through with this sort of transport and worry of getting him there. At times he said, 'oh, don't worry about it, I'm not going to appointments. I can't get down, not going' (C6).

Financial concerns

The costs of travel were repeatedly raised by patients and carers. Nearly all interviewees were on pensions or earning a low income (19 of 21) and most spoke of struggling to pay for travel costs up front. Four patients identified difficulty with appointments booked in the 'off pension

Table 4: Summary of themes regarding access to care

Issue/aspect	Major themes
Travelling for health care	<p>Difficulties with limited transport options.</p> <p>Long trips to Adelaide for outpatient care.</p> <p>Consequences of travelling long distances while unwell.</p> <p>Financial concerns.</p> <p>Urgent travel not well supported (unlike emergency travel).</p> <p>Difficulty coordinating transport and appointment arrangements.</p> <p>A regional solution: the clinic bus or car.</p> <p>Travel within Adelaide: getting lost and getting assistance.</p> <p>The challenges of getting home.</p> <p>PATS: help and limitations.</p>
Accommodation	<p>Staying with family and friends—the first, best or only option.</p> <p>Aboriginal hostels: supportive, secure and low cost.</p> <p>Step Down Units a safe halfway point.</p> <p>Cancer Council accommodation a good mainstream option.</p> <p>Hospital accommodation is valued but scarce and less secure.</p>
Problems for remote Aboriginal patients	<p>Remoteness and access difficulties: a multiplier effect.</p> <p>Medical relocation is a major disruption.</p> <p>Heavy reliance on family for accommodation and support.</p> <p>Only quick trips home for dialysis patients.</p>
Roles of carers and escorts	<p>Advocacy and assistance with care.</p> <p>Hospital staff support for carers was appreciated.</p> <p>Value of caring for family members.</p>
Access to spiritual carers	<p><i>Ngangkari</i>.</p> <p>Support of the church community.</p>
Language and interpreters	<p>Problems with access to appropriate interpreters.</p>
Informed consent	<p>Problems in communication, information or clarity.</p> <p>Patient actions to ensure informed consent.</p>
Financial resources	<p>Financial impact of chronic illness.</p> <p>Sources of financial assistance.</p>

week', and two had cancelled their appointments because there was not enough money in the family budget to enable them to travel.

Urgent travel not well supported (unlike emergency travel)

Problems with urgent (rather than emergency) travel also arose. Emergency travel and admissions were described as well supported. Eight patients discussed flying by the Royal Flying Doctor Service and three travelled by road ambulance, and all gave positive accounts of feeling secure and cared for by staff, regardless of their injury, state of health or state of consciousness. Four other patients and carers, however, had problems with urgent transfer to Adelaide for immediate care. Difficulties included the stress of travelling without an escort while dealing with acute illness, pain medication, and unfamiliarity with both air travel and the city, and the rigours of a three-day journey by car and public bus. One patient explained a problem with financial resources:

There's no... way of getting down there, like when they call you up in the middle of the night. We had no way of getting down so... we went to the hospital and our doctor had to give us money for petrol... We ended up getting down there, yeah, just went straight to the hospital... it's hard to get down there, especially when you've got no money... (P6).

A carer explained the risks when the ill person is the only driver in the family (in the following case, suffering a brain-related problem and having been told to get to the city by 5 p.m.):

I can't drive, and neither could my son and so my husband drove. They didn't tell him he couldn't drive. On the way down his driving was a bit strange, he would sit in the right-hand lane doing 50 kilometres a hour. My son said, 'Dad, get in the other lane'. So he changed, but further down the road, it happened again. We made it to the hospital by 4.30 p.m. (PC24).

We note that arrangements involving the new Aboriginal Patient Pathway Officers now provide assistance with logistical and cost aspects of these situations.

Difficulty coordinating transport and appointment arrangements

A third of all patients and carers spoke of difficulty in timing appointments to match fixed transport schedules, and of explaining to city receptionists about travel distances and bus and plane arrival times. Often they had no choice but to stay overnight, or make other arrangements:

[My son] drove me down. The only other way to get there for appointments is to get the bus. There's two buses, one in the morning and one at night. A lot of times you've got to go down the night before because the appointment could be 10.30 and the bus don't get in until about 11.30 or 12 o'clock (PC22).

In addition, notice for appointments may arrive in the post close to the appointment dates, which makes booking transport more difficult.

A regional solution: the clinic bus or car

Some regional areas have addressed these transport concerns by providing a small health bus or clinic car that travels to and from Adelaide on the same day for health appointments. Patients spoke positively about these forms of supported transport and about the improvements in comfort, ease and cost and the reduction in the effect of the travel on their disease symptoms:

Sometimes they send people with the big bus but the big bus is no good when you're on a kidney machine because your legs swell, but if you go with a car or little bus you can get out and stretch your legs... When I used to go down with [the big public] bus my leg was all swollen but with a car never (P3).

Travel within Adelaide—getting lost and getting assistance

For many country patients and carers, travelling within Adelaide is overwhelming, particularly for the first time, and learning how to use public transport is one more challenge:

I remember my first time in Adelaide and I wanted to get out of there. I got car sick going from the suburbs into town and I never [get] car sick (C6).

For more traditional people they just get into a city and they just get lost, they just don't cope at all. It's a very difficult thing for some of those fellas (PC20).

We wouldn't know what the bus timetables are. I understand that you have to go to little shops to get your tickets and we don't know any of that stuff, we just don't because we don't do it out here... yeah, it's very difficult (PC20).

I didn't want to leave it too late to catch the bus because Adelaide's got a bad name... It is very scary. I had to get off that bus in King William Street, Victoria Square, then I had to wait for another one... But then my sister helped me a lot, she showed me the bus, give me the number of the bus. She used to come with me every day (PC22).

I used to catch a taxi everywhere I wanted to go... and then [my cousin] told me about this free bus that pulls up in front of the hospital so I started jumping on that to go around the city. I made sure I knew where it pulled up to come home again, come back to the hospital again, yeah, so that was good (PC21).

Patients and carers without family support found it more difficult; several spoke of the problem of starting the familiarisation over again if, for example, they stayed in accommodation in a different location within the city.

Patients and carers used buses, taxis and family members for transport within Adelaide, with the city-based Aboriginal health transport service (provided by Corporate Shuttle, but generally known as 'Step Down') being most often used. The bus service provided by the Cancer Council was used by patients who stayed in Cancer Council accommodation. There was much discussion about Step Down services. Most people were very positive that the service was offered, but some had concerns about waiting a long time to be picked up:

The bus comes to pick me up. Sometimes if a group of us go, we have to wait until the last one is finished before we can leave, but that is okay, there is always someone to talk to. I just talk with people while I am waiting. I have a book full of taxi vouchers that they gave me, but I have never needed to use them. The bus works very well (P10).

The transport needs to be looked at. You go up there and you do your blood tests... [it] might only take about 20 minutes then you're out and you're waiting for Step Down to pick you up... I know we froze there a couple of times, the three of us (P3).

The Corporate Shuttle service previously picked people up from private homes, but no longer does so for most areas of Adelaide. Patients and carers discussed the difficulty of having to choose between paying to stay in hostels and getting free transport, or staying with family and paying for transport. One patient described borrowing money from family to pay \$200 each way for taxis from the northern suburbs (where family was her only option for accommodation) to Flinders Medical Centre. Her situation highlights gaps for patients accessing outpatient clinics and day surgery. Staff at the day surgery did not ask about her travel arrangements, and Aboriginal Hospital Liaison Units do not have the resources to support outpatients as well as inpatients.

One renal patient spoke of his concern for very remote renal patients who come to the city and get lost because they don't have enough guidance and support. He has interpreted informally on their behalf, and shared some of their stories:

They walk around in circles and they get lost in the street and have to walk around all night and policemen pulling them up and booking them... Yeah, that happens and they keep them three or four days and they don't realise they're on dialysis, you know?... It happens. It's really sad (P3).

He stressed the need for increased support:

From the hostel to the hospital they need two persons, one driver and one to take somebody in there and show them in and ask them what time we finish, we'd be back to pick them up, that's all. That's where they need help (P3).

The challenges of getting home

Travel back to home also raised difficulties, particularly for those who were brought to the city by emergency services. Rural and remote patients flown to Adelaide by the Royal Flying Doctor Service were generally driven home by family or caught the bus or commercial flights. Only one remote patient returned via the Royal Flying Doctor Service. She had injuries to her arm and leg and argued that she could not travel on a commercial flight or undertake a twelve-hour bus trip back to her local hospital. She explained:

I couldn't get up and sit on the bus, I would be in pain. They said you need to catch bus and I said, nah, I can't get on the bus, don't be silly. I can't use one of them frames or crutches... I was thinking I can't pull this foot and leg up and get up those stairs. And the plane too (P8).

At times city hospital staff—both ward staff and Aboriginal Hospital Liaison Officers (AHLOs)—provided clothes and shoes for patients so that they could travel by public transport.

They bought her clothes, PJs [pyjamas], slippers and helped with a bus ticket and cab charge to get to the bus. They helped her to get clothes to wear home (C2).

I was talking to the liaison officer and she was good. She helped me with clothes and things. She got me those shoes, they are not even my size (P8).

Passengers travelling on public transport are required to wear shoes, but patients often come without any in an emergency. AHLOs often supply slip-on (one size fits all) shoes to enable travel.

Some patients had a carer accompany them home:

When I had my back operation my mother came and we flew home together. PATS paid most of the plane trip back for us both. That was a pretty good thing (P7).

Others did not have a carer to accompany them home. One man who had 'quadruple heart bypass surgery' was transferred via a commercial flight back to his local hospital for a further two weeks of admission. He related his experience of travelling alone in a taxi to the

Adelaide airport, then from the regional airport via taxi to the local hospital with no one to advocate or assist:

Down in Adelaide they put me on the plane, you know... the taxi took me on a wheelchair to the desk and they put me on a... golf cart. Took me out to the plane. But here at this airport, I had to walk from the plane to the taxi. I had bandaids and bandages and that where they took the veins out... I had to walk a long way, that was the worst thing (P14).

PATS: help and limitations

The Patient Assistance Transport Scheme (PATS) provides limited financial support for travel and accommodation costs for the patient and, if needed, a single carer or escort, and has strict documentation requirements and limitations. Some Aboriginal health services provide up-front payment to patients and carers, but are 'out of pocket' if the trip does not take place, or the paperwork is not completed correctly and returned. Other services require patients to pay up front, but if they lose track of receipts and paperwork they may not be reimbursed. PATS was reviewing arrangements at the time of writing, and was trialling clearer guidelines, electronic 'paperwork', and prepaid petrol vouchers and bus tickets in some areas.

Some patients and carers spoke about how PATS provided crucial support to get to Adelaide:

Well there were times—like we got down there with—we only had the money from PATS. We only came down with our bus fares from PATS and the social worker helped me get through the weekend (C6).

Two people spoke of the problems of paying for trips themselves and then getting reimbursed, particularly as it takes time to bring back the receipts and get them processed:

But the thing is you've got to come up with the money for the travel first and then apply for the funding afterwards and that doesn't help much, especially when you're only on a pension and we've got rent to pay, we've got bills to pay, we've got kids to look after. Putting petrol in the car—which is \$75—is a lot of money out of the family [budget] (P1).

Three people reported not knowing about PATS assistance when they first began travelling to Adelaide. There was confusion for some patients about how PATS processes work and how payments are generated:

The Aboriginal health service from [regional town] and [regional town] used to argue about whose areas we were in. One of them must have gotten funding for us (P10).

Two patients who stayed at Cancer Council accommodation commented positively on the assistance given to country people regarding PATS. For example:

The lady at the front desk had rang me and asked if I wanted to meet with the PATS lady about accommodation and all that so it was quite good for them, they had a procedure where people were staying and they contact them so pretty much did all the paperwork and you didn't really have to worry about that side of things (P12).

Accommodation

Patients and carers discussed the cost, availability, location and suitability of accommodation options when their health care requires them to stay in Adelaide for days, weeks or months. Staying with family was the most commonly used option, followed by Aboriginal hostels, hospital accommodation and Cancer Council motels.

Staying with family and friends as the first, best or only option

Those staying with family and friends as outpatients and for subsequent visits, and longer term as carers, emphasised the importance of the option of staying with family and friends for financial and support reasons:

We stayed with my sister for five days... Just as well we had somewhere to stay, we couldn't afford \$80 a night. We still have to pay all the expenses for home as well (P&C30).

I've still got nieces in Adelaide and I just go and stay with them. If they weren't there, well, I wouldn't know (PC22).

Aboriginal hostels: supportive, secure and low cost

Seven of the 21 people we interviewed had stayed at Aboriginal hostels either alone or with their partners. They spoke of the importance of support, security and lower costs. Patients with renal disease, preparing for transplant or requiring dialysis stayed in hostels for one to two months and appreciated the facilities and support available in more medically focused hostels:

... you get fed well, you get your cup of tea at night time. You can go and help yourself with a cup of tea and sandwich and that; sandwiches are always in the fridge... You can go outside for a smoke and that but no one can't come in there when they're drunk (P3).

Patients with mobility issues discussed the importance of having carers staying in the hostel with them when they were in Adelaide for outpatient care:

They know what to do to help me (P10).

Sometimes, however, carers have young children themselves and there may be no capacity for children in the hostels. For one patient, this led to cancelling treatment:

The nurses are alright in the hospital, but in the hostel I would rather have my daughter. My daughter got really angry, she can't take [her son]. So we had to stay home. I really needed her to be with me. They need to make a big hostel for mothers and their kids. They can't leave their kids behind at home (P4).

Some patients and carers spoke of not staying at Aboriginal hostels because they preferred to stay with family, or because the hostels were a long way from the hospital or there was a shortage of beds.

Step Down Units as a safe halfway point

Two patients stayed in regional Step Down Units in Ceduna and Port Augusta and highlighted the importance of having a safe, supportive place to recover and seek ongoing medical care until they were able to continue their journeys home:

That's really good, yeah, instead of coming in and staying anywhere, it's risky, you know, staying like town camp or anywhere in the bush, baby might get sick, you know, it's good shelter here... comfort here, showers here, get three times meal here (P5).

Cancer Council accommodation as a good mainstream option

Two patients from country towns arranged to stay at Greenhill Lodge, the Cancer Council accommodation, with a family member as carer, and reported very positive experiences:

That's a really good set up at the Greenhill Lodge because they've got a bus to take people to their radiation and then my husband was sort of having radiation in the morning and then chemo in the afternoon (PC20).

Hospital accommodation is valued but scarce and less secure

Both patients and carers appreciated the benefits of being close to hospitals and their resources, including the AHLO units, especially when patients were critically ill:

My grandson is four years old and they brought out a bed so I could be with him (C2).

I spent most of the time with my husband and then I would go home, have a meal, shower, do laundry and get a good night's sleep (P&C30).

However, several people were unable to use hospital accommodation because of high demand. One patient attending for a series of outpatient appointments and tests appreciated being close to, but separated from, the hospital,

particularly when in pain and feeling that some health care interactions with staff were being coloured by racism:

It was just a pleasure to go back home and lay back and relax on the bed after you've had a hard day of rubbish being put on you (P1).

He was able to access this accommodation through the assistance of his local Aboriginal health service, but was concerned about how he would pay for it:

If it wasn't for [the Aboriginal health service] we would never have had a place to stay. We still owe [the Aboriginal health service] money because of that and I don't like owing people money (P1).

Some patients and carers declined onsite or nearby hospital accommodation due to its environment and size or personal safety concerns (including mixed-gender bathrooms):

It took me a while to go into there, they kept saying about it, and it was small but I'd heard... that many stories about it, how creepy, how scary, so my first night I just... locked the door, went to sleep... and I thought, 'oh, God how am I going to have a shower, a man went in there'. I got used to it after but I was really nervous with that (C6).

Oh, I hated that. I'd wait until about nine or ten and everybody was gone I'd go in. Or late at night, about twelve o'clock, go in and have a shower and back out again and lock myself in my room... Even when I was washing my clothes, 'oh, my goodness, hurry up and dry so I can get back to my room' (PC21).

Problems for remote Aboriginal patients

Remoteness and access difficulties: a multiplier effect

Many aspects of access to care are particularly difficult for remote Aboriginal people. The focus group of eight Elder women spoke extensively of their own and their families' experiences of delayed assessment and surgery due to

lack of local services or visiting specialists, lost paperwork, repeated tests for misplaced results, appointment letters being sent to the wrong address or a community post box, and very long-distance travel required in order to see specialists and use hospital services (even a basic x-ray requires travel to a regional centre 500 kilometres away).

Medical relocation is a major disruption

The need to move to a regional town or the city in order to receive health care is perhaps the most significant disruption for remote patients. Five patients and carers discussed their experiences of relocating from a country area to the city or major regional centre for periods ranging from six months to permanent relocation (for ongoing renal dialysis, without the option of returning home unless they received a kidney transplant). The change in circumstances can be quite sudden:

I originally come from [a remote town]. I was getting sick... I went to Adelaide to have x-rays and they saw my kidney was sick. So they took out my kidney, and I started dialysis... I can't go back [home] now. I can't go anywhere like I used to (P4).

The increase of dialysis treatment in rural towns and cities has given renal patients the opportunity to move out of Adelaide and to be nearer to home and family:

Going from Adelaide to Port Augusta is good because I am near family and that is good. When you are with family it is healing, you feel better (P4).

Heavy reliance on family for accommodation and support

Finding long-term or permanent accommodation for medical relocation is difficult. Sometimes hostel accommodation is used in the short term until more permanent accommodation is available.

Patients and carers with no other options stay with extended family for long periods, which can be difficult for both guest and host families:

In Adelaide he was on dialysis—we spent a year or two there on dialysis because there wasn't a vacancy here. We stayed at my nephew's until they got a vacancy and we were able to come home... (C6).

My brother, he is here twelve months... He lives here with me, I thought just he was going to come and stay [but] he brought the whole tribe with him (P3).

Patients, carers and their families who had medically relocated spoke of a drastic change in diet from a mixture of bush tucker and Western food to Western food only. Having to buy all food, especially meat, was very expensive:

And with this lot, they like meat, meat, meat, meat, don't think about veggies and things. They're used to all the Perentie and goannas and witchetty grubs (P3).

As well as food, the costs of rent, utilities, transport and so on are higher. Three interviewees spoke of the importance of social work assistance for paying bills and obtaining correct pensions.

Only quick trips home for dialysis patients

Trips to homelands were very important for three patients living in the regional centre:

Really, I'd like to go home, but my body is sick and I need to be here. I have to listen to the doctors and nurses... Aboriginal people all about here [renal unit], keep going back to country, when you go back home, you don't want to come back to [town], but we all have to. I go up for meetings... It is good to go back and see the old ones... It is important to go back up there (P4).

Patients and their carers travel up to 800 kilometres when possible for cultural, family and spiritual events. However, the maximum time they can safely be away from the dialysis centre is three days, so they travel for one day each way to spend a single day with family and community. Some patients become stranded by wet weather and need to be retrieved by the Royal Flying Doctor Service.

Roles of carers

Carers addressed three main themes in relation to the caring role: advocating for and assisting with the care of the patient; support for the carer role from hospitals and from each other; and the value of caring.

Advocacy and assistance with care

Carers focused on their role as advocates for their family members, particularly when they were seriously ill and unable to speak for themselves, and when decisions about leaving hospital needed to be made:

There was this time when they thought he was just sleeping all the time and I said to the nurse, I said, 'he's still asleep... he's a diabetic and have you checked his blood sugar?' He was going into a coma. I said, 'it's not normal for him to sleep like that'. When they did his blood sugar it was one point something (PC24).

Hospital staff support for carers was appreciated

Carers appreciated the support they received from hospital staff:

The staff were very supportive... they brought out a bed so I could be with [my grandson]. The nursing staff arranged for me to have meals when the trolley came around, help yourself they said, order what you like. I could go and get a cuppa from the kitchen (C2).

I had help from palliative nurses... and when it got to the end he just couldn't get out of bed. But they were lovely because they gave me a bed in the hospital in the room with him—right to the end, yeah (C6).

Yeah, the social workers were a great help. I mean, I didn't even know what a social worker was and you soon find out all these things (C6).

They also spoke about giving and receiving support with other carers and patients:

I'd go and have a smoke while she's having her dialysis and talk to all the other mob that used to come out from the hospital. I made a lot of friends down there... I made friends with the blacks and the whites. I had somebody to talk to instead of sitting there just smoking by myself (PC21).

Value of caring for family members

Only one carer discussed caring as a burden:

It is still like the day he come out of hospital... he will just sit, he won't do nothing. The information I got, he should be doing a little bit, like more exercise. He's got a walker now and I try to tell him 'no exercise, that can block your arteries again'. So I've got three kids now instead of two. I've got palliative care coming in and they just sit there and talk to him (PC22).

Others discussed their active caring role for their partners or family members, and their sense of loss when they could no longer provide this care due to worsening illness.

When we took him home for those three months... I used to give him his insulin, his pain medication... his shower, bath, I did all that... the nurses taught me... It was like a routine for me, I miss it now (C6).

He fell over once and I had to go screaming... to all my kids... they live not far—they all come and lifted him up. The hardest one was me putting him away, really terrible it was, but I visit him nearly every day (PC21).

Access to spiritual carers

Ngangkaris (healers)

The patients we interviewed did not directly mention the role of *Ngangkaris* in their own care. However, some of the Elder women in the focus group were *Ngangkaris* themselves and spoke of the spiritual environment of hospitals. They explained that sometimes lost spirits in hospitals call out to them and ask them to help them get back home again. They discussed the need to get another *Ngangkari* to come and help get

the spirit back home, and the effect on them of disrupting their sleep and rest. The women advised that sometimes spiritual issues are interpreted as shyness or fear:

Sometimes when our people are in hospital they might hear the spirits calling and they pull up the sheets and try to block it out or hide from it. Hospital staff may misinterpret what is going on, thinking it is fear or shyness (FG).

Support of the church community

Some patients also spoke of the importance of maintaining spiritual connection with their faith and church:

I asked the nurse to pray for me and she asked if I wanted a pastor. I said, please, can you get me a pastor... he came and seen me every Wednesday. And he said, 'you are getting better and better'. He shared stories about Jesus and all that (P8).

Most of the Elder women in the focus group had strong Christian beliefs and spoke of the importance of saying prayers, singing hymns, and having church members and preachers visit them.

Language and interpreters

Problems with access to appropriate interpreters

The majority of patients and carers interviewed spoke English as a first language. Three patients were bilingual, including two who understood and spoke English well and did not feel they needed interpreters. However, the Elder women discussed their concerns about the then imminent retirement of two known and trusted interpreters in Adelaide, and about carers and escorts being asked to interpret when they do not have health interpreting experience and have difficulty explaining medical concepts. The women also explained that, culturally, not just anyone can interpret; some discussions need to be gender specific or, if the patient is an

initiated Elder, the interpreter may also need to be initiated in order for the conversation to even begin.

Informed consent

Problems in communication, information or clarity

Patients and carers reported very different experiences in relation to informed consent. Approximately a third indicated that they felt well informed and freely consented:

I was quite happy with all the information that I received (P12).

Another third felt uninformed and would have liked more information but their questions went unanswered:

There's a couple of times when [name] had to have things done to him, we weren't told what or why that was done (C6).

Now what an x-ray on my chest has got to do with my back... He didn't explain it to me, nothing was explained to me. My wife asked why did I have to get an x-ray on my chest, he didn't answer (P3).

One woman undergoing dental extractions felt that vital information was not relayed until it was too late for her to ask questions or change her mind:

Just when they gave me the anaesthetic and I was going under I heard two doctors saying, 'don't know if you're going to make it or not because of your weight'. So here I was too late—why didn't you tell me that before you gave me the bloomin' needle (P9)?

Some put communication failure in consent processes down to individual staff personalities:

With my daughter, definitely good informed consent every step of the way. For myself, not as good in labour ward prior to the caesarean, I think that was just her nature (PC23).

Two patients raised concerns about possibly consenting inadvertently because they could not understand the accent of overseas staff:

Some of the girls [nurses], I can't understand what they are saying to me. I ask the English girls to tell me after. I am worried that I might say yes to things that I don't want. It is hard to understand them (P4).

Patient actions to ensure informed consent

Some patients were very active in ensuring they were fully informed, and asked further questions and sought information. However, this process was not easy for everyone:

I like to be organised so if I don't understand anything or I want more information I'm not afraid to ask people. I mean, obviously some people are different because some people are a bit quiet and a bit reluctant to sort of ask information (P12).

At first it was hard, I didn't understand what the surgeon was talking about in his language. I learned and began to ask questions. I would write them down and ask what he meant. I would read them out and he would tell me, in laymen's terms he said, what is happening and will happen in the future. We have to be a bit stronger, push more to get answers we are looking for (P7).

Financial resources and implications

Of the 21 people interviewed, 17 were on an old age, disability or carer's pension and four had full-time employment, with two of those on the minimum wage. The Elder women were all pensioners. Patients and carers spoke of not having much money after day-to-day and family expenses are met:

A pension is not a lot of money. It seems like a lot but it's in one hand and out the other straightaway (C6).

Financial impact of chronic illness

The impact of chronic conditions on income and expenses was significant for most of those interviewed, and patients discussed struggling to pay for medications at times. Those employed on low incomes were just over the income threshold for health care card assistance and faced particular difficulties, recently alleviated by new chronic conditions payments:

The pressure of trying to pay for the medications has been huge. Sometimes I don't get it because I can't afford it... [The Aboriginal health service GP] has helped me to get onto a program to help with medications. I spend up to \$100 a fortnight on medications for all of my health problems (P7).

Trips to Adelaide were sometimes delayed due to lack of sufficient funds, particularly on the 'off pay week':

We kept saying '... do appointments on a pension week' but it never is sometimes and that was a big problem for us (C6).

Sources of financial assistance

Two carers spoke of assistance from social workers to arrange wills and get carers' pensions when their partners lost income or became more incapacitated:

Well, when he had meningitis—I think I was on his pension but they did all the paperwork—I went to Centrelink here and they said I didn't have enough—what do they call it? ID [identification]? So I told the doctor and he said 'right' and got the social worker... within a week I got—I was on carer's pension. That was a lot better (C6).

Not all patients choose to access government assistance. Some prefer to borrow money from family in emergencies:

Blackfellas will find money somewhere. There's always an uncle, cousin, friend, brother, sister (PC22).

Conclusion

The most significant access barriers experienced by the participants in this study were difficulties with affordable and appropriate transport and accommodation options. Some patients and carers travel enormous distances or even move to another town or city in order to access health care. Support services assist to varying degrees, but strict rules and paperwork requirements are confusing and restricting. The majority of patients stayed with family or friends, with others seeking affordable options in Aboriginal hostels and other accommodation close to hospitals. Most participants were on pensions or earned low wages. Poverty combined with experiencing chronic conditions makes financial difficulties

almost inevitable, and patients struggled to purchase medications and make trips to Adelaide for health care. Financial assistance from family or government services was vital.

Carers and escorts were supported by hospital staff to varying degrees, with some becoming part of the care team and/or taking on a patient advocacy role. The need for interpreters was relatively low among the participants, but patients' ability to understand complex medical concepts was often overestimated. Effective communication was a major factor in informed consent. Patients with a good command of English, access to written information and the ability to keep asking staff questions until they were answered were best informed.

System of Care: Coordination and Quality

Many patient and carer accounts illustrated problems in the coordination between city and country, primary and tertiary, and Aboriginal and mainstream health services. The major themes are summarised in Table 5.

Communication across health services

Effective communication and coordinated care

Half the interviewees said there was reasonable or good communication between local and city health services.

The doctors and nurses here and in Adelaide seemed to talk to each other (P10).

Yes, with my daughter, it is good. The doctor and specialist send all the information to the GP at the Aboriginal health service. The intern checked the GP's name and contact details before I left the other day. They also said I or she can ring them at any time to ask questions (PC23).

The rural and remote mental health service was described as working particularly well with local mental health workers, the patient and GPs to enable coordinated responsive care.

Lost results, poor communication and delayed treatment

However, communication between different services was not always smooth. There were reports of lost paperwork, missing blood test and x-ray results, and appointment cards sent to the

wrong address, which caused treatment to be foregone or delayed and extended unnecessary travel. For example, a patient spoke about confusion regarding whether she had had a bone biopsy or not, and her sense of powerlessness, in a situation where there were two women with the same name in the community:

There is another Aboriginal woman here with the same name, exact same name. She did have a bone biopsy. They probably got mixed up. I knew what I had and I didn't have. I didn't worry about arguing with them, it was just—that's our life, whatever they tell you, you've got to accept it (PC22).

Another patient was considering another trip to Adelaide to get information for follow up after surgery:

The Adelaide doctor sent a letter to my GP saying that I had my operation done but nothing else. There is a huge gap, not much follow up. I have been left to my own devices a lot. I will have to go back and see the surgeon again and ask him what my options are (P7).

Effective case management by local Aboriginal health service or renal unit

About half the patients experienced delays and disjointed care until their health care was case managed by the local Aboriginal health service or a regional renal unit. Some patients discussed the importance of the local GP understanding their whole health and care needs, whereas hospitals and specialists focused on only one aspect. Another patient identified the benefit of a referral letter when she was sent to Adelaide for immediate (but not emergency) care:

Table 5: Summary of themes in coordination and quality of care

Issue/aspect	Major themes
Coordination across health services	Effective communication and coordinated care. Lost results, poor communication and delayed treatment. Effective case management by local Aboriginal health service or GP.
Logistics and the hospital environment	Inflexible appointment systems collide with stretched logistics. AHLO units provide needed support. Gender of care provider for intimate care. Genderless specialist care. Mixed-gender wards and bathrooms are embarrassing. Hospital environment is cold and lonely. Impact of hospital food.
Discharge and follow up	Well organised and planned arrangements are appreciated. Premature and uncoordinated discharge. Effective and coordinated follow-up care. Follow-up care not available.

When I arrived at emergency I had a letter that I had to give to them straightaway... this really nice nurse, he came up to me and took the letter off me and asked me questions and said, 'oh, we'll have to find you a bed'... and did straight away (P9).

Logistics and the hospital environment

Inflexible appointment systems collide with stretched logistics

Five patients discussed difficulty in making appointments and the limited understanding of many city staff regarding distance, travel times and the difficulty in coordinating public transport and health appointments:

I think sometimes the city people aren't aware of the travelling time... they'll ring up and say, 'yeah, we've got an appointment this afternoon', and it's like, 'well, we're four hours away'. I don't think they get the geographical sense (P12).

People in the city understand that you come from the country, but they don't understand exactly what that means, that you might need to catch a bus at a certain time to get back home or else have to stay another night. Sometimes you have to really push to get appointments on the same day. They say, 'oh, why?' (PC24).

Some people renegotiated appointment times:

Yeah, I used to tell them where I come from and tell them how many kids I got, you know, straight (P3).

No... They think that I can just go for an appointment. They really don't have any idea how far away I live. It is better now, they understand, but x-rays, MRIs [magnetic resonance imaging], they have no idea, they say we have very few afternoon appointments. They think that [my home town] is a hop, skip and a jump away. It makes it a bit hard (P7).

AHLO units provide needed support

Some patients spoke of appreciating practical, cultural and general support from Aboriginal liaison officers for food and accommodation assistance:

Aboriginal staff works in there, they come and spend most time with us, talking to us or if we need anything give them a buzz... asking us if we're right, we need anything, need a cup of tea or anything, if the baby's right... [Having] Aboriginal workers working there, that's alright; makes us a bit comfortable, someone there talking to us instead of waiting for the nurses all the time (P5).

Aboriginal hospital liaison staff and volunteers provided vital support services, particularly for patients who had no family nearby:

I was talking to the liaison officer and she was good. She helped me with clothes and things. She got me those shoes... The purple clothes lady [volunteer], she took me down to buy a track suit, in a wheelchair, she was pushing me, taking me down there. The liaison officer she took me down in the lift to get money. I had to send money to my cousin and sister, for my grandson and the nephews. My pension went in there the day before my accident. I left some money in there for the next day, but I never seen that next day (P8).

One carer appreciated support, particularly while her husband was in intensive care:

The [Aboriginal Liaison Officers] were really friendly and asked if we were okay financially (P&C30).

However, sometimes the expected help was not available:

I went down and spoke to the Aboriginal liaison and asked them to come up to the ward, but they never came (C2).

Sometimes we see the [Aboriginal Liaison Officer], sometimes we don't. It is hard to contact them because they are so busy... we need more [Aboriginal Liaison Officers] (FG).

Elder women in the focus group also spoke about difficulties for Aboriginal staff caught between hospital and cultural ways. Cultural and family ties may indicate Aboriginal staff should spend more time with Elders and family members, but this can clash with hospital expectations and ethics.

Gender of care provider for intimate care

Although some patients were less concerned, some had strong preferences for same-gender carers for intimate care (showering, dressing, skin treatments). One woman from a remote area was greatly relieved that nursing staff heard, respected and supported her preference for gender-specific care, which enabled her to feel safe:

Nuh, I don't trust mens, I said no, I don't want mens, I want lady, female. I always have female, they were really good to me. Once there was a male nurse, I heard them talking from my bed, the office was across the corridor. I heard the man say, 'I am just going to go over there...' they were saying, 'no, don't, she doesn't like having males, remember, she only like female...' They listened to me (P8).

One young woman had a severe disability after being beaten by a man, which left her with a tracheotomy and unable to talk for some time. She explained that sometimes she had a male nurse and that she found this shameful and frightening. Being unable to talk, she was unable to express her wish for female staff for some months. She now relies on disability staff to advocate for same-gender care.

Genderless specialist care

Most patients were pragmatic about seeking specialist care, regardless of gender. One younger woman said:

I've got that way where I think, 'well, if it's got to be done, it's got to be done' — so you've just got to talk yourself into it (P12).

Elder women from remote areas spoke of agreeing to see a male specialist, but stipulated the need to have another woman in the room as a companion for personal and cultural safety reasons.

Mixed-gender wards and bathrooms are embarrassing

Most patients stayed in single-gender wards or outpatient areas, or in single rooms, and many spoke of their strong preference for same-gender wards and rooms. They accepted the need for mixed-gender space (for example, in an intensive care unit). Some Aboriginal women discussed embarrassment and dismay when using mixed-gender bathrooms:

We had to use the one toilet and bath between us. I didn't like the idea of going... to the toilet and there's a man in there, it would be better if it was all women, have a women's ward or whatever. I walked in once and a man was on the toilet seat (P9).

Hospital environment is cold and lonely

Several patients and carers spoke about how cold city hospitals were, and how they asked family members to bring in blankets or warmer clothes (they were reluctant to ask staff for another blanket):

Yeah, wanting another blanket and they're too frightened to ask for it (P3).

Others spoke about how lonely it is in Adelaide hospitals, especially if they have no family nearby, and about the need for contact with the outside environment:

When I was up and walking I went to find a window to see out. I hadn't seen outside for a long time. And I really wanted to see trees (P&C30).

Impact of hospital food

There was a lot of discussion about the quality and range of hospital food, and the link between food and healing:

Food makes a big difference. I didn't like the food in the hospital. Food is like healing, when you can't have what you want, it isn't good (P4).

People from remote areas were keen to eat traditional foods again:

It will be good to have bush tucker. No bush tucker since I have been here. No wombat or kangaroo, sleepy lizard. They are coming out this month now... (P8).

Another woman appreciated a friend bringing in different food, no matter what it was.

Discharge and follow-up care

Well organised and planned arrangements are appreciated

Some patients reported that their discharge was well organised:

With discharge, the information got back okay. We had information and medication (P&C30).

Some patients were given choices of where to go after discharge:

The doctor told me you go back home or go to [the rehabilitation hospital]. I said I think I rather go back home (P8).

Premature or uncoordinated discharge

However, some patients were concerned that they were discharged before they were well enough to travel back to their rural and remote areas:

They said, 'we want that bed', and I said, 'no, not until I'm walking good. As soon as I'm walking good then you fellas can kick me out and I want accommodation for me before I leave' (P3).

At that stage they were sending me home. I said that that wasn't good enough, [and I] asked to go into a private hospital (PC20).

A mother who lived in a very remote area felt she and her baby were discharged too early and without enough support, information and follow up:

Like, they knew my baby was premature and the birth weight wasn't up. Why they didn't keep me in then?... they said, 'oh, he's still not putting on weight', and they still end up sending me back here, you know, why they send me back... the midwife from here told me they don't usually send babies back that way (P5).

One woman moved to the country to be closer to family, where she found more responsive primary health care services after her postnatal experiences in the city:

I wasn't so impressed with the follow up when I had the baby... No nurses from the hospital came and there was no appointment with Child and Youth Health straight away... That was appalling. I was not impressed at all. If not for my family I would have been really stuck. Coming back here to the local GP and health service has made all the difference. I wasn't getting any of that in Adelaide (PC23).

Effective and coordinated follow-up care

Almost half of the patients and carers spoke positively of follow-up services (in renal, cardiac, rehabilitation and palliative care) provided by their

local Aboriginal health services, local hospitals and/or allied or community health services. For example:

I got a lot of help up here with palliative care and all of that, which I didn't know about (C6).

The physio came and seen me and gave me this here [frame] and some exercises (P8).

I have been going to the GP and to [the Aboriginal health service GP] and been talking to the mental health line. It is a lifeline. If we didn't have that, I don't know what we would do. There is nothing else here (P7).

Medical specialist visits to rural and remote areas were appreciated by patients and carers who no longer had to travel long distances to Adelaide:

The specialists come to [local towns], so that is good. [These visits] are really important (P&C30).

However, there were often long wait times because visits were infrequent and demand was high.

Some specialists maintained contact by telephone, either directly with the patient or through the local health service:

The [city hospital] doctors get a bit worried for me. They ring here [town] and check that I am alright. They keep a watch on me (P4).

Follow-up care not available

In some areas, particularly in more remote towns and communities, there was a lack of available allied health and follow-up care, or staff did not have the needed skills and approach:

When I got back here, there was no one to help me learn to walk... I went to the physio, but they seemed a bit racist or something. I went to see them and they said, 'what are you doing here?' Well, I thought it was a bit obvious. She said she was too busy. I didn't like her attitude so I didn't go back. Now I have my gopher to get around town, but I would still like to learn to walk again. There is someone else who is helping me, but they are leaving for six months soon. I don't know if they will be replaced or not. I have a frame

that I need to use, but I need someone to help me with it. You need someone to start you off (P10).

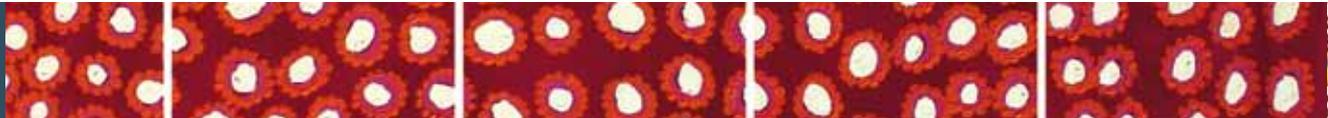
A significant number of people we interviewed did not have a full set of teeth or wore ill-fitting (or no) dentures. This was particularly distressing for one woman:

I felt like I was let down. I just felt that you took my life away when you took my teeth away but from there no one helped me, it just stopped. 'Oh, yeah, we've got rid of her teeth and now she should be right, she won't suffer with a toothache anymore'... I still won't leave the house because it's still up here in my head that I don't want people to see me with no teeth (P9).

Conclusion

Coordination across health carers and services was effective in some areas, and patchy or non-existent in others. In some cases patients experienced unacceptably long delays, or missed out on needed care, due to poor communication and lost results. Patients and carers highlighted the difficulty of arranging transport and hospital appointments and the apparent lack of understanding of most city services and staff to accommodate this. Some patients found hospitals cold and lonely, with little personal or cultural support.

Patients and carers also told quite different discharge and follow-up stories. Some services were well coordinated, collaborative and supportive; others were disjointed and had little consideration for patients' home conditions or follow-up needs. Local primary health care services, particularly Aboriginal health services and/or GPs, played a major role in coordination and ensuring follow up through case managing patients' whole health care journeys.



Social and Cultural Environment

Interviewees described the importance of maintaining social and cultural connections while receiving care in hospital. The environment and process of health services, and responsiveness of staff to personal and cultural needs, particularly during difficult times, impacted significantly on patients and carers and their perceptions of care. The major themes are summarised in Table 6.

The importance of family

Repeatedly, Aboriginal country patients and carers discussed the importance of family in their lives and at times of distress or ill health. Many patients preferred to have (and some relied on having) family members with them in hospital for company, advocacy, emotional support and physical care.

Family as companion, support and buffer

Patients valued the emotional and practical support and comfort provided by family:

It's important if anyone goes up for any treatment that they've got support people around them because it makes a lot of difference... otherwise you're sitting there by yourself... thinking a bit more about it too, whereas if you've got someone else, there's conversation (P12).

My daughter and husband was there so it didn't take me long to get better after that. A couple of weeks I was right, came home (P6).

Table 6: Summary of themes in social and cultural environment

Issue/aspect	Major themes
The importance of family	Family as companion, support and buffer. Keeping connected with family at home. Family members in the city—a vital connection.
Coping with diagnosis or illness	Coming to terms with an injury, diagnosis or treatment. The frustration of waiting for treatment and dealing with symptoms.
Death and dying	Cultural and personal aspects of preparation for surgery and treatment. Importance of support when a patient dies.
Systemic racism, post-colonial realities	Racism and colonisation. Stereotyping reinforces discomfort.

For some older women it was important to have a female family member or carer with them when they were in single rooms because they never slept alone at home and there were always other women nearby.

For those in Adelaide for outpatient care, family provided vital after-hours physical care for applying treatments and mobility assistance:

It was good to have my mum there helping out as well... putting the cream on... washing all my clothes everyday (P12).

I would rather have my daughter shower me than someone at the hostel (P4).

For one man, having his wife present helped him cope (without retaliating) with interactions with staff whom he found negative and racist:

If my wife wasn't with me the day that Dr... called me a drug addict I probably would have punched him and I'm telling you now that's a fair dinkum fact... but she just put her hand on my lap because she knew the moment he said that, that I would have lost it (P1).

Keeping connected with family at home

Patients and carers stressed the importance of maintaining connection with family while they were in city hospitals. Five patients indicated that the most important thing staff did to support them socially and culturally was to ensure that they had access to a telephone to call family:

I think the most important thing is being able to keep in contact with family. To have a phone near the bed if you are on bed rest. If people are from the country and don't have family around, staff need to bring the phone in when family call. You do need contact with family; a lot of us have no family in town, so it is all by phone (C2).

Patients appreciated telephone contact with family even when they were extremely unwell:

At that stage [I was] very ill and I didn't really need a lot of people coming around, trust me... They had a phone beside my bed and I could speak to people, which was good (PC20).

Family members in the city—a vital connection

Most patients were visited by extended family members (nieces, nephews, in laws, siblings, grandchildren) living in Adelaide. Two patients spoke of city family members visiting them while they were still in accident and emergency units:

My brother and sister and her husband came in to see me in [accident and emergency]. My son must have rung them when I went in the ambulance. It was good to see them (PC24).

When city family members visited patients in the wards they provided vital ongoing company and support:

My nieces in Adelaide came to visit. Family makes a lot of difference. If I was on my own I would be thinking, thinking. But when family and friends come and visit it is alright (P4).

the kids are 'poppy, poppy' and you could see it in his eyes, you know, it sort of brightened him up too (C6).

Carers also identified the importance of extended family providing emotional and practical support for them while they were in Adelaide or regional hospitals:

My sister rang to see if I needed anything, I asked her to do shopping, I was in the hospital every day and just needed more things than the local deli could supply. I could get milk and bread there, but needed more (P&C30).

Many family members made extensive journeys to see patients in city hospitals. Some could only stay for a few hours, or visit when finances were available:

On pension day when they've got money they come down (P6).

Coping with diagnosis or illness

Coming to terms with an injury, diagnosis or treatment

Patients and carers spoke about the difficulty of coming to terms with an injury, illness or diagnosis. One patient recounted waking up in Adelaide following a car accident and Royal Flying Doctor Service retrieval:

I woke up and I was really frightened... The nurses were talking to one another and I can understand what they were saying to each other and I thought, I must have been hit by a car. And my family were ringing up from here and telling me too. Gave me a shock... I am lucky to be alive (P8).

Another woman discussed dealing with the complications of diabetes:

This year I have been going down to Adelaide a lot. I was really sick earlier, not wanting to bother with myself. I can't walk around and it was starting to get to me. I went down for test in Adelaide, and they operated on both of my legs [indicates amputated legs], and I feel better now... I asked myself, why did this happen to me? I don't smoke, I don't drink alcohol. Why? Maybe it is the diabetes (P4).

Another spoke of the long-term effects of having her teeth removed:

I'm a diabetic and I can't eat fruit and I can't have meat—so I just eat junk food because... it is soft and you don't have to chew. I think my weight's gone up again. My diabetes, my blood pressure—everything. And I'm on sleeping tablets because I can't sleep because of the stress (P9).

One carer discussed the difficulty of her husband's cancer diagnosis and treatment regime for both her and her husband:

Yeah, that's been a very difficult time, obviously the cancer stuff is a big deal when you first find out about it and then this whole process of ongoing treatment is quite difficult and time consuming (PC20).

Another woman spoke of wanting to prepare her children for a poor diagnosis she was given:

I try to tell them what the doctor says and get them to read the reports, what he wrote, but they don't want to listen... That's why I went and bought myself a funeral benefit (PC21).

The frustration of waiting for treatment and dealing with symptoms

Patients living in remote areas spoke of getting frustrated with blindness or incapacity due to delayed surgery and treatment. Others spoke of trying not to worry and to keep healthy and fit while waiting for a kidney transplant, of waiting to see if cancer treatments would be successful, and of dealing with chronic pain and disability:

All I want youse to do is give me a needle in the base of my back so that it kills the pain in the base of my back so then I can stand up properly and I don't need to be walking around cramped up... like a bloody old man (P1).

Death and dying

Cultural and personal aspects of preparation for surgery and treatment

The focus group members discussed an important cultural aspect of preparing for a major operation or treatment. They indicated that discussions with family are needed before undertaking treatment that might be dangerous—family can come together and 'make sure the person is spiritually strong and pray for them' (FG). This may mean that patients need to return to country after diagnosis and prior to consent to treatment. If the person cannot go home, family members need to visit them.

Importance of support when a patient dies

Two people spoke of their experiences of being carers for family members who died and the importance of staff support:

They told us in the city hospital that there was nothing more they could do. We wanted to bring him home and they transferred him to the local hospital... I took him home for about three months with help from palliative nurses... they gave me a bed in the hospital in the room with him so in the last—you know, we'd been together—43 years we were (C6).

Had to turn the machine off and that was hard, very hard. When I held her hand I just see this thing coming out of her body and it was white smoke, like a white light and it stopped up there for a minute and it just disappeared. Then everybody started to cry and I went and put my arms around them and calmed them down and wasn't even thinking about myself until I come home... She died in Adelaide and I had to bring her home then. I was looking after everybody else and calming them down and whatever else and the day they buried her I went crazy, I think it all just came out then (PC21).

Some years later this same person was called to the city to turn off her son's life support, and then her husband became ill. It was important for her that she and other family members were supported by hospital staff each time:

... the staff were good. They give me a room, they let all my mob stay in one big room and they were good to talk to (PC21).

Systemic racism, post-colonial realities

Racism and colonisation

Some patients and carers discussed how racism and colonisation impact on their lives generally and that even when they have good local relationships with the wider community, national issues may trigger racist or judgmental actions:

That's the worst part, that's the annoying part, they treat you all the same... we always mixed in. But then you do get... all this land thing [land rights] came out and I was walking down the street and there was a car load—they went past me saying, 'you're not bloody getting my land', and I said, 'what, I don't want your land'. They think, 'oh, yeah, she's after that' (C6).

One patient spoke of past colonising practices and negatives ways of being treated in institutions and how this has affected her family's attitudes to seeking health care:

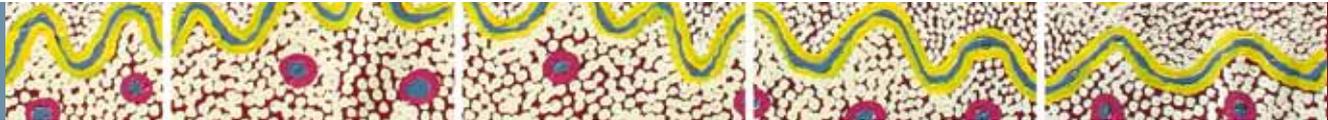
There were these boys... from the homes—they'd say, 'sir, I've got a headache, can you give me something?' and he said, 'I'll be right with you'. He got the pain killer and he put it on the kid's head and put sticky tape on there and said you're right now, your heads will stop hurting now... It's just some of the things that we experience... and the young kids, they've got a hate, a hate for non-Indigenous people... There's a lot of things that went on with Aboriginal people (PC22).

Stereotyping reinforces discomfort

Some patients experience discomfort due to the actions of non-Indigenous staff and patients:

Yes, some staff are still racist, it's not across the board, there's just certain people—their attitudes (P1).

You can see that, like with the white patients, you know... they stare at us too many times but I've been telling a couple of them white people 'stop staring, we all the same colour—we all got the skin, we're not animals' (P5).



But several patients were reluctant to label the behaviour of staff as racist. One person, when asked whether he/she thought bad treatment was race based, or if that particular staff member treated everyone the same way, replied:

I really don't know. I have mixed feelings about it. This is a question that as an Aboriginal person I find hard to define. It is often an immediate reaction, it is because of my Aboriginality. I try not to make a point of reading racism into it. At other times it is obvious, and you know it is. No, it was not really clear. I think maybe they were not nice to others too (PC23).

Some patients spoke of improvements in hospitals accommodating cultural needs and providing culturally safe environments:

Yeah, we're getting treated pretty good but it's just outside, you know (P3).

Conclusion

Patients and carers stressed the importance of having family nearby, or in contact via telephone. Family members provided patients and carers with much needed support—physical, economic, social, spiritual and emotional. Country family members travelled long distances to maintain contact. Some carers discussed extensive periods of time caring for family members, with past experiences influencing subsequent visits. They often made difficult decisions and encountered challenging times supporting family members during death and dying. Patients and carers also spoke of the struggle to come to terms with an injury, diagnosis or treatment, and the impact this had on their lives and wellbeing.

Some patients felt that there is increased attention to ensuring cultural safety in hospitals, although stereotyping still leads to discomfort for patients and carers.

Discussion and Conclusions

The accounts of patients and close family members give important insights into the entire country Aboriginal patient journey from home to hospital and back home. This section presents a framework for understanding the underlying causative factors of the problems identified. It then discusses the gaps and problems, and possible strategies towards improved access, continuity and quality of care for this group of patients.

Analytical framework: the five underlying factors

Analysis of the results of this study (along with the related study of health care staff experiences) suggests that the experiences of Aboriginal patients from the country who come to Adelaide for care are affected by five underlying factors. Table 1 (from the 'Summary' section of this report, and repeated here) summarises the major interacting factors that affect this group of patients (and others) and underlie many of the problems patients and staff encounter.

Table 1: Five factors that affect access and quality of care

Issue	Explanation
City/country	Some of the problems facing country Aboriginal patients and their health care providers are common to all country patients.
High burden of illness	People with chronic or complex conditions are affected more by systemic health care problems, especially across hospital/non-hospital sectors, although any patient may experience care problems.
Language	Some communication challenges that patients and staff encounter are common to all population groups for whom English is not a first language.
Financial resources	It is harder for all people who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and time off work or away from home and family.
Aboriginal/non-Aboriginal	There are ways in which Aboriginal people experience unique disadvantage in their interactions with the mainstream health system (and other social systems); and mainstream worldviews and beliefs about health and health care are often different from those held by Aboriginal people.

It is the interaction of all these underlying factors—being a country person in a city setting, having a high burden of illness and needing care across the acute/community divide, perhaps not having English as a first language, perhaps being poor, and being Aboriginal in a mainstream system—that makes city hospital care for country Aboriginal patients a unique challenge for the patients themselves and for their carers and staff. Each factor, and the interactions among them, has important implications for this group and, taken together, argue the need for explicit attention to the needs of country Aboriginal people. The commonality of some of these factors for country people, patients with chronic or complex illness, and those of non-English speaking backgrounds also underlines

their importance for the health system. As one of our advisers succinctly put it, ‘if we could fix health care for Aboriginal people, we could fix it for everyone’.

Five gaps and breakpoints, and potential solutions

Patients experience five kinds of gaps or breakpoints in the current system of care that impede reliably good access and quality of care. The strategies (many of which are already in use but not systematically available) summarised in Table 2 provide opportunities for action.

Table 2: Summary of opportunities to bridge the five divides in the system of care

System gap or breakpoint	Opportunities for action
City/country	<ul style="list-style-type: none"> Regional transport arrangements. More low-cost accommodation near suburban hospitals. Transport support for patients staying with families. Streamlined Patient Assistance Transport Scheme (PATS) procedures. Specialist care in the country (outreach clinics). Improved use of information and communication technology. Support and case management for medical relocation.
Acute/non-acute	<ul style="list-style-type: none"> Role of primary care providers in care coordination. Apply S100 rules to discharge drugs; manage Medicare numbers.
Language	<ul style="list-style-type: none"> Ensure policy on access to interpreters is applied. Adapt informed consent procedures.
Financial resources	<ul style="list-style-type: none"> Funding changes are needed for complex patient journeys.
Aboriginal/non-Aboriginal cultures	<ul style="list-style-type: none"> Bring cultural safety and respect to the operational level. Formalise and support the roles of escorts and carers. Strengthen the roles of Aboriginal Hospital Liaison Officers and units in hospitals.

The city/country divide

The most significant access barriers experienced by the participants in this study were difficulties with affordable and appropriate transport and accommodation options. Support services assist to varying degrees, but strict rules and paperwork requirements are confusing and restricting. Seven main opportunities for improvement are outlined below.

Transport: regional arrangements

Responses to transport problems were under development in 2011, through the work of eleven regional Community Passenger Networks convened by the South Australian Department for Families and Communities and involving the Red Cross and local government authorities. These networks aim to provide transport brokerage and information, and offer last-resort transport for medical, specialist and social appointments. Aboriginal health services and Patient Pathway Officers are also working to develop new solutions.

More low-cost accommodation near suburban hospitals

The main accommodation need identified by patients was for more low-cost accommodation near hospitals, particularly outside central Adelaide.

Transport support for those staying with families

A private transport company is contracted by Adelaide health services to provide patient transport between hospitals, hostels and transport terminals. Previously, patients could access this service while staying in private homes with family and friends, but a policy change has removed this option in most parts of Adelaide. Patients now have to choose between staying in hostels and having access to this free transport, or staying in a private home and making their

own transport arrangements. Removal of this trade-off would make the option of staying with family more feasible for some patients.

Streamlined PATS procedures

New PATS arrangements being trialled in 2011 (CHSA 2011) seek to address remote transport, advance payments and lost paperwork problems by utilising prepaid fuel cards, electronic PATS forms and electronic funds transfer.

Specialist care in the country (outreach clinics)

Patients described much simpler patient journeys when specialists visit rural and remote areas, and/or keep close contact with patients and local health carers by telephone. Increased specialist services in the country and improved referral and communication between health services and professionals could lead to cost and time savings for patients and the health system overall.

Improved use of information and communications technology

Improved information and communications technology systems to support transfer, referral and investigation requests, results and review would assist with continuity and coordination of care.

Support and case management for medical relocation

Medical relocation involves significant changes in lifestyle, accommodation, transport, connection with family and country, and financial arrangements. Patients and carers who relocated for care relied heavily on clinical coordinators and support staff to assist with day-to-day problems. Coordinators and Aboriginal Patient Pathway Officers assist through effective case management and referral. This support needs to be available, not only for renal patients, but for all Aboriginal patients.

Acute/non-acute divide

Coordination among health carers and organisations is a major challenge throughout the health system. For the patients in this study, it was effective in some areas, and patchy or non-existent in others. Two main opportunities for improvement are outlined below.

Role of primary care providers in care coordination

Although the local primary care provider does not act alone, where care was coordinated, the local primary care provider seemed to be critical to success. Care journeys for country Aboriginal patients require planning (where possible), with a focus on careful scheduling of appointments (and support services). Primary care providers may also be able to fill gaps in follow-up care. Where adequate follow-up services are not available, patients require choices about whether to return home or stay away for rehabilitation.

Apply S100 rules¹ to discharge drugs and manage Medicare numbers

Improved electronic means of managing Medicare numbers and applying S100 rules to discharge drugs would reduce inconsistencies and confusion between country and city health services for remote patients.

The language divide

The need for interpreters was relatively low among participants, but patients' ability to understand complex medical concepts was often overestimated. There were two major opportunities for improvement.

Ensure policy on access to interpreters is applied

Consistent, reliable implementation of existing policies on access to interpreters would help to address patients' concerns about understanding complex medical concepts and treatments.

Adapt informed consent procedures

Improved processes of informed consent are needed, and may involve both city and country health professionals. Pre-admission consent processes that begin in local health services may enable patients to be informed in a language and style more familiar to them (CHSA 2011). Attention to informed consent in city hospitals is also needed.

The financial divide

Funding changes are needed for complex patient journeys

The additional costs of care for this group of patients are a significant barrier to access, and there is no simple solution. Some of the measures outlined above in relation to transport and accommodation would help. Consideration

1 Section 100 allows patients of remote area Aboriginal health services (AHSs) to receive PBS (Pharmaceutical Benefits Scheme) medicines directly from the service at the point of consultation, without the need for a normal prescription form, and without charge. See RACGP website at: <<http://www.racgp.org.au/afp/200510/200510couzos2.pdf>>.

of a funding mechanism for particularly complex patient journeys (modelled on the funding for clinical complexity allocated to hospitals under case mix funding) may provide a solution.

Aboriginal/non-Aboriginal cultures

Bring cultural safety and respect to the operational level

One purpose of high-level cultural respect policies and principles is to guide health care providers in caring for Aboriginal patients. But operational policies and programs that give effect to this guidance need to be developed. This would enable health care organisations and staff to respond more systematically to the needs and priorities of Aboriginal patients.

Formalise and support the roles of escorts and carers

This study found that accompanying carers and escorts are often vital for patient wellbeing but that their role needs to be more systematically incorporated in care. A formal policy and supporting resources such as a written 'contract' template for negotiating the specific roles of individual carers in the clinical unit may help.

Strengthen the roles of AHLOs and units in hospitals

Many Aboriginal country patients rely heavily on AHLO units for support. AHLO units in hospitals are generally not resourced to support outpatients or day surgery patients. Aboriginal Patient Pathway Officers may assist further in this area.

The policy challenge

The 'gap-filling' approach outlined above will only work if it is undertaken in a supportive policy and program environment. To address the serious health and health care problems facing country Aboriginal people, it is essential that the high-level legislative and policy statements that acknowledge the need for particular attention to Aboriginal health and health care are elaborated into operational policies, procedures and programs. The *Aboriginal Health Care Plan 2010–2016* acknowledges the need for systemic implementation of relevant policies and mandates action and reporting by regional health services to this end (SA Health 2010:21, 34).

The patients and carers we interviewed identified gaps and problems, and the strategies they saw as most responsive to their needs. What is needed at policy level is a program for implementation of better access, quality and cultural safety in hospitals and health services, in governance, management and care delivery.

References

- Australian Institute of Health and Welfare (AIHW) 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview*, Australian Government, Canberra.
- Bolch, D., Johnston, J. B., Giles, L. C., Whitehead, C., Phillips, P. & Crotty, M. 2005, 'Hospital to Home: An integrated approach to discharge planning in a rural South Australian town', *Australian Journal of Rural Health*, vol. 13, pp. 91–6.
- Country Health SA (CHSA) 2011, *Patient Assistance Transport Scheme*. Accessed on 17 August 2011 at: <www.countryhealthsa.sa.gov.au/Services/PatientAssistanceTransportSchemePATS.aspx>.
- Davis, C., Girgis, A., Williams, P. & Beeney, L. 1998, 'Needs Assessment of Rural and Remote Women Travelling to the City for Breast Cancer Treatment', *Australian and New Zealand Journal of Public Health*, vol. 22, pp. 525–7.
- Department of Health and Ageing (DoHA) 2009, *The State of Our Hospitals June 2009 Report*, Australian Government, Canberra.
- Gerber, R. & Moyle, W. 2004, 'The Role of Theory in Health Research', in V. Minichiello, G. Sullivan, K. Greenwood & R. Axford (eds), *Handbook of Research Methods for Nursing and Health Science*, Pearson Education Australia, Frenchs Forest, NSW, pp. 32–55.
- Knight, J. & Baker, R. 2001, *Facilitating Admission Management and Discharge Strategies (FADS) and Rural and Remote Project*, Flinders Medical Centre, Adelaide.
- Kowanko, I., de Crespigny, C., Murray, H. & Groenkjaer, M. 2003, *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers—Report on Research Conducted in the Port Augusta Region*, (a collaborative project of) Flinders University School of Nursing and Midwifery & Aboriginal Drug and Alcohol Council (SA) Inc., Adelaide.
- Lawrence, M., Dodd, Z., Mohor, S., Dunn, S., de Crespigny, C., Power, C. & Mackean, L. 2009, *Improving the Patient Journey*, Cooperative Research Centre for Aboriginal Health, Darwin.
- National Heart Foundation of Australia (NHFA) & Australian Healthcare and Hospitals Association (AHHA) 2010, *Better Hospital Care for Aboriginal and Torres Strait Islander People Experiencing Heart Attack*, National Heart Foundation of Australia & Australian Healthcare and Hospitals Association.
- Purdie, N., Dudgeon, P. & Walker, R. 2010, *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice*, Department of Health and Ageing, Canberra.
- SA Health 2010, *Aboriginal Health Care Plan 2010–2016*, Government of South Australia, Adelaide.
- Stamp, G., Miller, D., Coleman, H. & Taylor, J. 2006, 'They Get a Bit Funny about Going—Transfer issues for rural and remote Aboriginal people', *Rural and Remote Health*, vol. 6, pp. 536–44.
- Taylor, J., Edwards, J., Kelly, F. & Fielke, K. 2009, 'Improving Transfer of Mental Health Care for Rural and Remote Consumers in South Australia', *Health & Social Care in the Community*, vol. 17, no. 2, pp. 216–24.

Attachment: Methods

Ethical approval

This study received ethical approval from Flinders University and the Southern Adelaide Health Service Social and Behavioural Research Ethics Committee, the Aboriginal Health Council of South Australia's Aboriginal Health Research Ethics Committee, The Queen Elizabeth Hospital Ethics of Human Research Committee, Child Youth and Women's Health Services Human Research Ethics Committee, Royal Adelaide Hospital Research Ethics Committee and Department of Health Human Research Ethics Committee. Formal partnership agreements were negotiated with the Aboriginal Health Council of South Australia and all four major public health services in South Australia at the time the project commenced: Central Northern Adelaide Health Service; Child, Youth and Women's Health Service; Country Health SA; and Southern Adelaide Health Service. These agencies incorporate the public hospitals and primary and secondary health and aged care services owned and operated by the state government.

Advisory structure

A Project Management Group made up of representatives of each of the partners and others with Aboriginal health and research expertise was convened prior to commencement of the project. The Project Management Group provided a vital source of information about issues of concern and the pattern of service delivery to Aboriginal people from the country, as well as advice to support the research team's thinking and the research design throughout this project.

Data collection

We set out to explore the experiences of Aboriginal country patients through in-depth interviews rather than surveys or other ways

of 'counting'. We did not seek to quantify the problems because such examination needs to be based on a better understanding of their nature and sources than we currently have. In consultation with the Aboriginal Health Council of South Australia and Country Health SA, four country regions were selected on the basis of geographic spread and different degrees of remoteness. One Aboriginal and one non-Aboriginal researcher travelled to four country areas of South Australia (in the West, North, Riverland/Mallee and South East regions) to discuss the project with health service managers, staff and Aboriginal community representatives. Staff in each region, most of whom were interviewed in the first round of staff interviews, were invited to promote the research to patients and carers with information sheets provided. Health staff approached patients (and their families/carers) who had recent experience of city hospital care, and those who were interested in participating contacted the research team, usually via the health service.

The researcher then made a time and place to meet that best suited each person. Some arranged to meet the researchers in a neutral place such as a health or community centre to discuss the research further before deciding to become involved. All were informed that their decisions about whether or not to participate in the research would have no impact on their health care, and that they could discontinue at any time during the interview process.

Interviews were conducted at a time and location that best suited patients and carers—in people's homes, on front verandahs and in gardens, and in health services and dialysis units. One focus group was conducted with eight Elder Aboriginal women. Each person was given the choice of being interviewed by an Aboriginal and/or non-Aboriginal researcher, but most people did not express a preference, and many of the interviews and the focus group were conducted by both researchers. Interviews were 30 to 60 minutes in duration and were based on open-ended questions that invited participants to share their experiences of health care. With this approach we sought to generate unguided commentary, as well as to assess the relevance

of existing explanations and understandings. Follow-up questions (developed through the staff interviews) were used to prompt further discussion of known areas of concern, if they had not already been addressed.

Patients and their family members were assured of confidentiality regarding their individual responses to the interview questions, and that the clinical units, country locations and agencies would not be identified. However, interviewers also alerted interviewees to the fact that effective protection of the anonymity of their communities or locations may not be possible, given the specialised nature of the care they received and the journey they travelled.

Although interpreting was offered, recruitment and interviewing did not include people who were not able or comfortable to communicate in English.

Interviews were audio recorded or notes taken depending on interviewee preference, and were transcribed and coded using NVivo8 software. Preliminary data were analysed after two interviews had been conducted to identify emerging explanations. Midpoint in the interview process the research team reviewed and interpreted the data to ensure questions and the participant sample remained relevant. When all data were collected, inductive thematic analysis (Gerber & Moyle 2004) was used to explore themes and care practices described by country Aboriginal people and to generate deeper understanding of current personal, cultural, organisational, political and structural factors that impact on health care delivery and health care recipients (and the implications for the health system and for health care delivery).

Interview/focus group outline

Clarification of focus on a single episode, or experiences with repeat visits for same condition.

Invite patient or carer to tell their story

Can you talk about your last experience, or a recent important experience of going to hospital in Adelaide (or another centre) and then coming home? We are interested in what worked well for you, and what you found difficult.

There are some things we would like to know more about regarding what happens for patients and their carers when they go to Adelaide.

You mentioned xx; could you talk some more about that?

Specific areas for discussion (seven issues arising from staff interviews)

Could you talk about your travel and accommodation during your last visit?

Did you feel that all of the people involved in your health care, from home to hospital and home again, were communicating with each other and working together?

Do you feel that you had particular needs as a country person, and as an Aboriginal person, and were these met?

Did you feel you could talk with the staff in the hospital and health services? Why or why not? Consider Aboriginal liaison, interpreters, *Ngangkari*.

Did you understand what was happening to you? Did you have to agree to treatment and did you feel you had enough information to make these decisions?

Did you have a support person travel with you? Was this important to you, and what role did they play in the hospital? Did your support person have needs that were or were not met by the hospital and other services?

We are interested in what happens for Aboriginal patients in hospital. Could you please share whether you thought you were treated differently because you were Aboriginal?

If a new nurse or doctor was starting in a hospital or health services, what do you think they need to know about working well with Aboriginal patients from rural and remote areas?



the
Lowitja
INSTITUTE

Australia's National Institute
for Aboriginal and Torres Strait
Islander Health Research

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA

T: +61 3 8341 5555

F: +61 3 8341 5599

E: admin@lowitja.org.au

W: www.lowitja.org.au

