

Original Research

Travelling to the city for hospital care: Access factors in country Aboriginal patient journeys

Janet Kelly, RN, RM, MN, PhD,¹ Judith Dwyer, BA, MBA, FCHSM, FAICD,¹
Eileen Willis, B.Ed, M.Ed, PhD,² and Brita Pekarsky, BEc Hons, Grad Dip HE, PhD³

¹Health Care Management, Flinders University, and ²Social Health Sciences, Flinders University, and ³South Australia, Baker IDI, Flinders University, Adelaide, South Australia, Australia

Abstract

Objective: This study described the challenges for rural and remote Aboriginal people requiring transport to city hospitals for tertiary care.

Design: Semi-structured qualitative interviews.

Setting: South Australian rural and remote health services and tertiary hospitals.

Participants: Twenty-eight urban health professionals from six hospitals and 32 health professionals from four rural and remote regions were interviewed. Twelve patients, three carers, four people responding as patient and carers, and one patient and carer couple were also interviewed, with eight elder women meeting as a focus group.

Main outcome measures: The study identified specific structural barriers in urban health services or policy that prevented rural and remote Indigenous patients from receiving optimum care.

Results: Problems accessing transport were identified as the most significant factor affecting access to care by the majority of patients and staff. They reported that travel to an urban hospital was costly, and coordination of travel with care was poor. A further problem was travelling while unwell.

Conclusions: Travelling to a city hospital is a significant barrier for rural and remote Indigenous patients. Arranging and supporting travel is a time-consuming work that is not recognised by the health care system.

KEY WORDS: Aboriginal health, health services access, Indigenous health, patient issues, remote health delivery.

Introduction

This paper aims to highlight specific transport challenges for Aboriginal people requiring city hospital care, including planned, emergency, inpatient, outpatient and diagnostic care. This paper is part of a larger study, the Managing Two Worlds Together Project, which sought to enhance knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote parts of South Australia.¹ Other access barriers such as communication difficulties and cultural concerns are reported elsewhere. Approximately 30 000 Aboriginal people live in South Australia, about half in rural and remote areas.² Many Aboriginal people experience high levels of chronic illness such as diabetes, cardiovascular and kidney disease, and do not always have access to essential primary health care services. This is reflected in the high numbers of potentially preventable hospitalisations^{3,4} and, paradoxically, in the observation of ‘missing patients’ by clinicians and statisticians (i.e. patients who present late in the course of their illness, or not at all).¹ While SA Health and Country Health SA have upgraded regional hospitals, the majority of specialist care is provided in Adelaide hospitals.

Travelling long distances from a rural or remote setting to a city hospital for medical treatment can be logistically challenging, tiring and at times frightening.^{5,6} Access to safe transport is often restricted due to road conditions and poor access to public transport in rural and remote areas.⁷ Each Australian state has in place some level of travel reimbursement and support, with differing eligibility criteria (see for example^{8–11}). The experiences of patients and carers and the insights of staff provide an important perspective on existing problems and gaps, and possible strategies for improvement.

Methods

Recruitment

Six city hospital wards (cardiothoracic, renal, respiratory, maternity/neonatal, injury, mental health) that

Correspondence: Dr Janet Kelly, Health Care Management, Flinders University, Level 2 Health Sciences Building, GPO Box 2100, Adelaide, South Australia, 5001, Australia. Email: janet.kelly@flinders.edu.au

Accepted for publication 7 January 2014.

What is already known on this subject:

- Transport is a major factor in determining access to health care, particularly for people in rural and remote areas.
- Financial assistance schemes have strict eligibility criteria that can disadvantage patients leading to significant financial costs to them.
- Travelling to a city hospital for health care is highly disruptive for patients and their families.

receive high numbers of rural and remote Aboriginal patients were identified. Ward leaders identified experienced nurses, doctors, managers, allied health and administration staff who were invited to participate in interviews individually or in small groups if preferred. Twenty-eight in total responded to flyers and email invitations. Four regional and remote areas were identified, and staff from hospitals, general practice, Aboriginal and mainstream community services, aged care and support services were invited to participate through staff meetings, flyers and email contact. The first thirty-two who responded were invited to participate in individual or group interviews. Sixteen staff overall identified as Aboriginal. One remote clinic and one city Aboriginal Liaison Unit declined the invitation.

During country visits, flyers and contact details were distributed through community groups and rural and remote staff, inviting Aboriginal people who had travelled to Adelaide for hospital care (and their carers) to participate in individual or group interviews. On return visits, researchers met with any interested patients and carers. Each participant chose whether to be interviewed as a patient ($n = 12$), carer ($n = 3$), as both a patient and carer ($n = 4$) or a patient and carer couple ($n = 1$ couple). One group of eight elder women chose a group interview ($n = 8$).

Interviews

Interviews were conducted at a time and location that best suited each participant, for 30–60 min. Staff were asked open questions about barriers and enablers, gaps and possible strategies of care, with the researchers using a set of prompt questions based on literature review to probe aspects mentioned by staff. Patients and carers were asked to describe their patient care journeys, with additional open questions, based on the main theme areas in the staff interviews, being used to prompt further discussion. See Table 1 for interview guides.

What this study adds:

- Aboriginal patients and health professionals agree that transport is a major barrier to access for health care, but identify different aspects and problems.
- Aboriginal people from rural and remote areas report that travel to urban hospitals for care can result in increased pain and discomfort, challenges to personal safety and unexpected costs. They note there is a lack of flexibility and coordination between travel arrangements and appointments with medical specialists.
- The extent to which travel and travelling is coordinated and supported directly affects access to care, but the work involved is not recorded or recognised within the health system.

Interview data were transcribed and inductively analysed using NVivo 8 (QSR International NVivo 8).

Ethics and agreements

Ethical approval was given by the Flinders University, Aboriginal Health Council of South Australia, The Queen Elizabeth Hospital, Child Youth and Women's Health Services, Royal Adelaide Hospital and Department of Health. Formal partnership agreements were negotiated with the Aboriginal Health Council of South Australia and all four major public health services in South Australia. A Project Management Group guided the research.

Results

Transport was highlighted by the majority of patients and staff as one of the most significant barriers to accessing tertiary health care in Adelaide. Approximately half of all patients and carers travelled to and from Adelaide in their own cars; the other half relied on family, local health services or public transport. Four of the 21 patients/carers interviewed said there was no public transport serving their towns or communities, and limited access was reported by eight elders in the focus group. Five patients reported cancelling trips to Adelaide due to transport problems.

Travelling long distances while unwell

Most patients and two thirds of city and country staff identified concerns about patients travelling long dis-

TABLE 1: Interview guides for health staff and patient and carers

Outline for Interview: Staff

1. Role – *please explain what you do in your job*
2. General discussion of barriers – *Can you talk about your experiences of providing care to Aboriginal people from remote regions and what gets in your way in your efforts to provide effective care?*
3. Discussion of perceived causes and picking up on underlying issues – *Why do you think this happens?*
4. Discussion of enablers – *Thinking about your experience of these problems or barriers, what are the factors in your working environment that have helped to make things better?*
5. Discussion of strategies – *Thinking back on your experiences if you had the power what are the important changes, in hospital care, that need to be achieved to improve the care for Aboriginal people from remote areas?*

Prompt questions derived from literature review:

Outline for Interview: Aboriginal patients and carers

Clarification of scope of experience 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 an 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 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 (8 issues arising from staff interviews)

1. *Could you talk about your travel and accommodation during your last visit?*
2. *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?*
3. *Do you feel that you had particular needs as a country person, and as an Aboriginal person, and were these met?*
4. *Did you feel you could talk with the staff in the hospital and health services? Why or why not? Consider Aboriginal Liaison, interpreters, Ngangkari (healers).*
5. *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?*
6. *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?*
7. *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?*
8. *If a new nurse or doctor was starting in a hospital or health service, what do you think they need to know about working well with Aboriginal patients from rural and remote areas?*

tances in private cars or on buses while unwell, in pain, feeling nauseous or immediately post discharge. Patients and carers reported travelled from 3 to 16 hours to Adelaide for appointments and admissions, with many travelling home again the same day if accommodation was unavailable or too expensive. The distances involved are significant. One man drove 1500 kilometres every 3 weeks for cancer treatment over an 18-month period. He drove alone, while nauseous with an underlying cardiac condition as his wife could not afford time off work, and the twice-weekly bus service did not coincide with his treatment regime. Another man stopped travelling by public transport when he became too unwell to climb onto the bus. He relied on family to transport him until it became too difficult and he refused to travel to Adelaide any more. City staff spoke of patients arriving exhausted and stressed, with negative impacts on their health and the quality of

testing and consultation discussions. Rural and remote staff identified concerns when patients travelled long distances home immediately post treatment:

If someone comes out of hospital with a broken leg you are worried about DVT [deep vein thrombosis. You're going to bus them out and you've got a 13 or 14 hour [journey] – and you can't [tell] the bus driver . . . 'every two hours pull up, I want to stretch my legs'.

A recent decline in availability of hostel or convalescent beds was reported to have made this situation worse.

Personal safety

Rural and remote staff and patients raised concerns about personal safety, particularly when buses dropped patients and carers off late at night or early morning,

or at remote roadside locations. (*If they are really sick it is terrible . . . often it's really hot and they might not be allowed to stay inside in the airconditioning to wait.*) In one community, an Aboriginal health worker began meeting the five o'clock morning bus at the highway in her own car after seeing a newly discharged elder get off the bus and lie under a bench to wait until morning light when she could walk into town and arrange a ride to her own home community. She felt unsafe to get off at the next highway stop due to previous racial abuse and being unsure whether anyone was planning to meet her.

Financial concerns

The costs of travel were repeatedly raised as a significant barrier by patients and carers. Nearly all interviewees were pensioners or on low incomes (19 of 21), and most spoke of struggling to pay travel costs up front.

. . . 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 very much, especially when you're on a pension and we've got the rent to pay, bills to pay, . . . kids to look after, putting petrol in the car, is \$75.

Four patients identified difficulty with appointments booked in the 'off pension week', and two had cancelled their appointments because they did not have enough money to travel. Several patients and carers discussed wanting to travel together, *but the families were unable to afford the time off work for the carer.*

The Patient Assistance Transport Scheme (PATS) provides limited financial reimbursement but does not cover all out of pocket expenses. Some patients on low incomes discussed the difficulty of paying travel expenses up front, while others said, without the PATS they would not have been able to travel to the city. Many patients, carers and staff were unsure what the PATS funded or what other options for assistance were available.

Emergency and urgent travel

One unexpected finding was the significant impact of differing levels of system support for emergency and urgent travel. Patients (11) described their emergency travel and admissions as being well supported and gave positive accounts of feeling secure and well cared for by road and air ambulance staff.

In contrast, patients reported having to rely on their own limited resources for urgent (but not emergency) trips to Adelaide. One patient received a call in the middle of the night that her donor organ was ready and she needed to travel to Adelaide immediately. Their car

was out of petrol and they had limited finances. In desperation, she went to the local hospital and her doctor gave her money to fill the car and drive to Adelaide with her husband. (New arrangements for fuel cards have since been organised.)

Similarly, a carer advised that when her husband was diagnosed in a regional centre with a suspected brain tumour, the general practitioner arranged admission that day, before the specialist left for the weekend. In a rush, they picked up their son from school and the husband drove to Adelaide as he was the only driver in the family. She explained:

On the way down his driving was a bit strange, he would sit in the right-hand lane doing 50 kilometres an 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).

These examples highlight a serious disconnect between clinical and support services and transport assistance. In both cases, the families and other road users were at risk of accidents, and the stress experienced by the patients and their families was severe.

Both country and city staff highlighted that people travelling in emergency and urgent situations often arrive without needed paperwork, cards, money, clothes or an escort. This impacts on care and additional supports are required. In addition, some older remote people refused to fly due to their own or others' past experiences, a belief that the trip to Adelaide was a one-way trip (that they would die), or having never flown before.

Coordinating travel, appointments and cancellations

A third of all patients and carers spoke of difficulty in timing appointments to match fixed transport schedules, or in explaining to city receptionists the distance involved or bus and plane arrival times. Often, they had no choice but to stay overnight. Notice for appointments could arrive in the post close to the appointment date, making booking transport more difficult and expensive. Many rural and remote staff discussed the long hours they spent trying to arrange transport and accommodation for planned admissions or outpatient appointments. Two inflexible systems – the hospital appointment system and the transport system – collide, and a clinic running late can have major consequences:

People in Adelaide don't realise if you miss the bus then you have to wait another 24 to 48 hours to catch the next one, find accommodation . . . some people don't have money or family down there (RC1).

Metropolitan staff also raised concerns about cancellation of appointments and admissions after patients had already begun their journeys and were unable to be contacted.

Discussion

Transport to the city can become a major access, health and safety issue for rural and remote Aboriginal patients and their families. The seemingly inevitable disconnect between health care, transport and support systems further complicates already complex and challenging journeys. Many staff strive to meet individual patient needs by either ‘working the system’ for maximum benefit of patients, or by working outside of the system, filling the gaps that exist between health and transport systems. This work is often time consuming, unrecorded and unrecognised by both the health care system and the patients themselves. Ongoing changes to PATS arrangements and transport support in South Australia and interstate in response to patient needs and adverse events have led to both improvements and new challenges for patients and staff coordinating journeys. This study, like others,¹² has identified that transport reimbursement schemes address only one aspect of supporting patient journeys; improved coordination and communication between health and support providers and culturally, personally and financially responsive arrangements are also necessary.

If equitable access to specialist services for Aboriginal patients from rural and remote regions is to be achieved, improvement in access to transport and support services is needed. Greater awareness about the realities of distance and transport, and more coordination of appointments (and flexibility to accommodate late arrivals) in city hospitals are also essential.

Acknowledgements

This study was funded by SA Health, and supported by the Lowitja Institute.

Author contributions

Each author was involved in the original research and data analysis from the three studies this article is drawn from.

J.K. wrote the first draft of the article, with significant input and discussion by J.D., E.W. and B.P. Each author then contributed to developing specific themes within the article.

References

- 1 Dwyer J, Kelly J, Willis E *et al.* *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People – Project Report*. Melbourne: The Lowitja Institute, 2011.
- 2 Australian Bureau of Statistics. Population distribution, Aboriginal and Torres Strait Islander Australians – 2006. [Cited 4 November 2013]. Available from URL: <http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4705.0,2006>.
- 3 Department of Health and Ageing (DoHA). *The State of Our Hospitals June 2009 Report*. Canberra: Australian Government, 2009.
- 4 Australian Institute of Health and Welfare (AIHW). *The Health and Welfare of Australia’s Aboriginal and Torres Strait Islander People: An Overview*. Canberra: Australian Government, 2011.
- 5 Shahid S, Finn L, Bessarab D, Thompson SC. ‘Nowhere to room . . . nobody told them’: logistical and cultural impediments to Aboriginal peoples’ participation in cancer treatment. *Australian Health Review* 2011; 35: 235–241.
- 6 Stamp G, Miller D, Coleman H, Milera A, Taylor J. ‘They get a bit funny about going’ – transfer issues for rural and remote Australian Aboriginal people. *Rural and Remote Health* 2006; 6: 536–544.
- 7 Helps YLM, Moller J, Kowanko I, Harrison JE, O’Donnell K, de Crespigny C. *Aboriginal People Travelling Well: Issues of Safety, Transport and Health*. Australian Government Department of Infrastructure, Transport, Regional Development and Local Government, 2008.
- 8 Country Health SA, *Patient assistance transport scheme*, South Australian Government [Cited 4 November 2013]. Available from URL: <http://www.countryhealthsa.sa.gov.au/Services/PatientAssistanceTransportSchemePATS.aspx>, 2013.
- 9 Department of Health, *Patient assistance travel scheme, – new improved service*, Northern Territory Government, [Cited 4 November 2013]. Available from URL: http://www.health.nt.gov.au/Hospitals/Patient_Assistance_Travel_Scheme/, 2013.
- 10 WA Country Health Service, *Patient assisted travel scheme*, Government of Western Australia, [Cited 4 November 2013]. Available from URL: <http://www.wacountry.health.wa.gov.au/index.php?id=pats>, 2013.
- 11 Queensland Health, *Patient travel subsidy scheme*, Queensland Government, [Cited 4 November 2013]. Available from URL: http://access.health.qld.gov.au/hid/HealthConsumerInformation/TravelHealth/patientTravelSubsidySchemeEligibility_ap.asp, 2013.
- 12 Lawrence M. *Inquiry into operation and effectiveness of patient assisted travel scheme*, Lowitja Institute, [Cited 4 November 2013]. Available from URL: <http://www.lowitja.org.au/sites/default/files/docs/Inquiry-PATS.pdf>, 2007.