

## ORIGINAL RESEARCH

# 'They get a bit funny about going' – transfer issues for rural and remote Australian Aboriginal people

G Stamp<sup>1</sup>, D Miller<sup>2</sup>, H Coleman<sup>2</sup>, A Milera<sup>2</sup>, J Taylor<sup>1</sup>

<sup>1</sup>Spencer Gulf Rural Health School, Whyalla Campus, University of South Australia, Whyalla Norrie, South Australia, Australia

<sup>2</sup>Ceduna Koonibba Aboriginal Health Service, Ceduna, South Australia, Australia

*Submitted: 5 January 2006; Resubmitted: 22 May 2006; Published: 12 July 2006*

Stamp G, Miller D, Coleman H, Milera A, Taylor J

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*Rural and Remote Health 6: 536. (Online), 2006*

Available from: <http://rrh.deakin.edu.au>

## ABSTRACT

**Background:** The integration of health care among providers to achieve good outcomes has been investigated in urban locations. However, more information is needed about what happens to people from rural areas, particularly when travelling away from their families and healthcare provider to receive hospital care. Therefore, a national project was conducted in 2004 that aimed: to document the experiences of people travelling to and from rural and remote areas to city hospitals; to identify factors that affect their optimal health outcomes; and to improve the exchange of information between primary healthcare providers and hospital staff. The Australian Rural Health Education Network (AHREN) coordinated the study, which consisted of several case studies. This article, part of the larger investigation, presents a segment on issues for Aboriginal people living in a rural and remote Australian area that were identified by local health workers, and suggestions that might assist in overcoming them.

**Method:** Research and ethics approval was obtained from our university, hospital and the Aboriginal Health Council. Three Aboriginal health workers, employed at the community controlled Aboriginal health centre, involved in transport, consented to be audiotaped in a group interview. They are named researchers. Questions were: What are the issues in transfer to and from the city hospital? What special problems exist for the Aboriginal people you are involved with? What improvements/systems changes would you suggest?

**Findings:** Funding and equity of the Patient Assisted Transport Scheme (PATS) created problems. Raising payments for PATS and extra costs to clients and families were big issues. Antisocial arrival times, separation from family, transport to hospital and



accommodation all caused distress and confusion. Potentially dangerous misunderstandings happened through language and cultural differences. Traditional people travelling unaccompanied were at risk. Often PATS notification requirements could not be met in emergencies and onsite accommodation was described as frightening and culturally inappropriate. At the time of interview, Stepdown transport did not cover people staying with families. Lack of privacy, different understandings of family and other issues important for Aboriginal people continue to add stress for families already suffering.

**Discussion:** PATS could be streamlined and more user-friendly. Aboriginal Liaison Officers in hospitals provide a link for Aboriginal clients, but unrealistic expectations may be placed on them and they are not available 24 hours a day. Strategies for improved communication are needed. A space and campfire in hospital grounds for traditional people and their families to gather would assist.

**Key words:** Aborigine, Australia, hospital treatment, patient transport.

## Background

From a client perspective, travelling long distances from a remote community to a city hospital for medical treatment can be a frightening experience. Usually there are unknowns about the city hospital environment and the types of treatments that will be encountered. The familiar GPs and health professionals are no longer the healthcare providers. Family and friends are often not with the individual to advocate for them and provide support. Clients often don't want to leave their community.

*A lot of patients...they get agitated especially if they are very unwell and you take the family member down because they don't want to go on their own. ...Sometimes they can't get on the plane, there's only a certain amount of people on that thing, but still they don't want to go you know. The family doesn't know what's going on and then they want to travel to get to the city by the time the patient arrives. We helped get one family member down with them because when you are going down querying cancer, querying something you know. (Aboriginal Health Worker)*

While there have been some valuable action research projects to improve the integration of general practice medical care and acute hospital care<sup>1</sup>, findings have not resulted in systemic changes nationally or at a state level. This is in spite of evidence that there are some deficiencies

that need addressing. Research shows that rural patients require more information about their impending hospital visit<sup>2-4</sup>. A study examining the experiences of Indigenous women travelling to hospital reported that none of the women preparing to travel to hospital to give birth was given information regarding what to expect when admitted to hospital<sup>5</sup>.

In order to provide further evidence about transitions of care, a national project was conducted in 2004 that aimed: to document the experiences of clients travelling to and from rural and remote areas to city hospitals; to identify factors that affect their optimal health outcomes; and to improve the exchange of information between primary healthcare providers and hospital staff. The Australian Rural Health Education Network (AHREN) coordinated the study, and it was funded by the Australian Department of Health and Aging.

A segment from one of the case studies is presented here. In depth discussions with Aboriginal Health Workers involved in transfer processes highlight issues for Aboriginal people travelling or transiting from remote communities to a metropolitan hospital and returning home again. On another level it is about 'transitions of care' and specifically what might bring about better integration of healthcare among providers in remote locations and metropolitan hospitals to improve the health and wellbeing of clients.



## Methodology

A case study design, collecting survey data, was used in the national study with 11 cases. The methodology was consistent in each site and involved interviewing patients who had returned from a city or regional hospital to their home location during 2003. Up to four primary healthcare providers, including GPs, were also interviewed at each of the case study sites. Staff familiar with transport and transfer of care arrangements at the metropolitan hospitals were also interviewed. The focus of interviews was the transfer experience from the patient's perspective. Issues of importance to providers were also investigated, such as information transfer and follow-up arrangements. Common themes from all the case studies were analysed and key issues were identified that were reported to the funding body.

The case study location where this research originated<sup>6</sup> is a 10 hour drive by car to the state capital city. The research component reported on in this article explores the transfer issues for Aboriginal people living in the location who have to access medical care in the distant capital city. In this location, the Aboriginal people, traditional custodians of the land, are from different language groups. They comprise 22% of the district population estimated to be 3658 in 2002<sup>7</sup>. An Aboriginal community controlled health service (ACCHS) provides primary health care with a range of health professionals including a GP. Ethics approval to conduct the research was obtained from the associated university and the Aboriginal Health Council.

### Method

The research segment in this paper is qualitative and narrative. Three Aboriginal health workers, also authors of this paper working at the ACCHS and hospital, who are involved in transport for clients consented to be audio-taped in a group interview. As members of their community they are also family members and potential clients themselves. Some of the discussions involve real events in their and their

family members' lives. The discussion provides insights that were guided by the use of three questions:

1. What are the issues in transfer to and from the city hospital?
2. What special problems exist for the Aboriginal people you are involved with?
3. What improvements and/or systems changes would you suggest?

The tape was transcribed and transcripts sent back to participants for verification before being analysed for themes.

## Findings

Several recurring themes arose from the discussions.

### *Reluctance to travel*

Most Aboriginal people have experienced a family member going to the city and not coming back. These experiences may, in part, contribute to clients delaying medical visits with their health problems. However, having agreed to travel, on arrival clients' fears increase and the needs of any accompanying family may not be met, thus escalating the stress as highlighted in the two quotes below. This can be particularly devastating if the illness is life-threatening.

*You know they want to go home and they're signing to you their reactions that they want to go home. And because the family is split, you know, once the family is split they can die quicker in hospital than being home, or having family there as their main support. But to have them there, only not have them together... They split the family up, one family in one hostel, one family in another... they couldn't put them all together. So one lot was here, one lot was there, you know, so how can you lean on one another in time of grieving and in that time and if it comes the time to turn something off.*



*There are issues with accommodation as well, so these are really serious problems because people won't fly if they feel uncomfortable .... yes, it's just a problem getting clients to the city. And it is the same as on the bus, sometimes they have to make their own way from the bus to the hospital and because they get in at 6 o'clock in the morning, there is nowhere for some people to go. So they get a bit funny about going...*

## **Patient Assisted Transport Scheme, Stepdown and financial considerations**

The Patient Assisted Transport Scheme (PATS) provides financial assistance for people who need to travel more than 100 km to obtain specialist medical services.

Working alongside PATS, Stepdown provides a link-up transport service from airports and bus or train stations to accommodation and/or medical services for Indigenous clients and approved relatives coming in from rural and remote areas. However, they do not collect clients who are staying with relatives in the city.

PATS is subsidised at \$AU30, but this amount can be hard for clients to find and is only the beginning of the expenses incurred. Already disadvantaged families, most on low incomes, are placed under huge financial pressure, for despite the existence of PATS, the associated expenses for a trip to the city can amount to hundreds of dollars. For example the cost of hostel accommodation for the client and accompanying family members who travel to and from the hospital is high and not subsidised. Emergency financial assistance is critical because of basic essential costs.

*... a lot of them go from here and they have to go to Centrelink [social security service] to ask for an advance on their pensions or whatever, and they give them a \$50 advance or whatever, so they have a little bit of money to buy food when they get there. Some of them have to use that to pay for taxis. You know how*

*expensive taxis are getting now. So that needs to be looked at.*

For health workers, claiming back costs is time consuming and PATS processes are not user-friendly. In addition, the local hospital was seen to have advantages for PATS not shared by the ACCHS.

*Our health service isn't funded for PATS, we use our grant money or generated income to assist Aboriginal people to go to the city. Now, the hospital over here actually gets funded by the government, through the PATS system, but they won't help Aboriginal people. They send them all to us, and our organisation is responsible to treat them and foot the bill. Now my question is, why can they get assistance to help non-Aboriginal people and we can't and yet most of the people that get sent out of this area are Aboriginal clients?*

Often health workers are trying to organise PATS for clients transiting from one of the more remote communities and considerable advocacy is required in order to access to this financial support.

*...we do deal with [Community A] to get some assistance from them especially if they are transiting from there or from [Community B]. We do as best we can, we only got a limited amount of money here that we can use but because they are transiting and coming down from A to us rather than straight out to the city, then you have got to use what's around you and A sometimes can be a bit miffy about it, but if you know who to talk to, and say, 'come-on this is ... they need somewhere to stay and need assistance to get down'. Like, say your father is dying, or something like that.*

Discussions demonstrated that Stepdown is under duress and does not operate an out of hours service. Formal Stepdown notification timeframes could not be met in emergencies,



which could result in very sick patients arriving with nobody to meet them, with potentially serious consequences.

*Well, see with Stepdown you've got to give them 24 hours notice, and a lot of time we don't have 24 hours notice here, because it's an emergency. And the only way our patients can get out is either, we fly them out on the night plane or the next morning plane or stick them on the bus that night. That's a 12-hour trip and then no-one will meet them at the other end.*

Travelling with an escort, although ideal, did not always happen:

*Some people we send down, next thing we get a phone call saying that we need someone down here, he's only got 24 hours to live and whatever. A family member needs to be down there so they can go through all this stuff.*

The following situation could lead to serious consequences. With minor variations clients and GPs described similar scenarios in the main study.

*... for the patients...you can talk up for them. I mean, I had to check on a PATS claim for a traditional man and find out if he went to his appointment so I could claim it back and they said well he walked into outpatients, now he had gone on the bus, I don't know how he got from the bus to the appointment, but I said to them, "well did he see the doctor"? And they said, "oh no, he turned around and walked out again." He probably didn't know what it was there. No-one was there to meet them.*

At the very least Cabcharge (taxi vouchers) may help, but this is not easily obtained.

People who stayed with relatives in the city became ineligible to use Stepdown when a policy changed. This was

an issue much repeated by clients and health workers alike and caused great disruption.

*...it's been useless to us because they won't support us if our clients don't use their hostel. Now some clients go over there and they want to stay with family, so why should they be forced to use a hostel, which is going to cost them money when they have family there.*

### **Hospital accommodation**

Finding somewhere suitable to stay nearby could also be fraught with problems. Accommodation in the hospital grounds in the old nurses' home, although conveniently located, was culturally inappropriate with 'unisex' shared bathrooms and toilets, and very basic facilities. A health worker who escorted a family member described it:

*And with the traditional people, when they go, they feel uncomfortable in the little rooms that they have at the hospital. They like to sit outside or that, out by a fire or that. And there are some things that they haven't got there... And maybe a nice little place down there, I mean I know they have lawns out the back [of the city hospital], maybe they could make a nice little place for the traditional people because I know there's a lot go down from [other communities] as well. And they can sit outside and have a little campfire, where they can all sit down and talk or whatever, you know. [That place] is dark and gloomy and an old corridor, and you go out of that room across the hall to make the cups of coffee and see the TV room area. Especially very late because you will sit with the client for as long as possible...It's an awful feeling going up there because it feels like there's someone behind you, especially if you are on your own...*



## **Shaming and the need for privacy**

For relatives, dealing with the shock of learning of a family member's illness and the lack of privacy and respect for personal space within the hospital setting caused needless suffering and the experience of shaming<sup>8</sup>. Visitor limitations also caused distress.

*And when we all travelled down in the car after, yes it was really hard to sit down and talk, like we already had the news that she had terminal cancer before we left here, but as soon as you go in there, they are in a room with about five or six other people, and then you just have to pull the blind around and natter away, you sort of sit there, it was really uncomfortable. The situation was really uncomfortable for her husband to sit down next to her because as soon as he saw her he burst into tears and because he is a traditional man, initiated man, he said, he got up shamed like, and walked out. I chased him up and said "look it's.. don't be embarrassed to cry you know, it's good to let your emotions out", because she was in a room with other white people and that as well, and he just didn't know how to....It is, they are all close together, very close and ...you haven't got the privacy. You say something and that was when we showed emotions, you know. And they would show it, and it might offend the person next to you or whatever, they might not understand. And this does happen you know. I mean when they are in the intensive care part, there are little rooms that can only have about 4 people in at the max around the bed because the machines are everywhere hooked up to the ceiling. And you have some in there, some outside the door you know, and then we have nurses say "We can't have that many in here"...that's family, that's a son, that's a daughter, that's the other son, you can't chuck them out.*

## **Improving communications**

The local hospital had consulted with the local Aboriginal community and addressed the lack of places for families to

be together when a family member was admitted. This met with widespread approval.

*The [local] hospital has started doing really good things now. They have got an area out the back of the hospital because after my [family member] was diagnosed and they couldn't help her, they flew her back to the hospital and they put her in a room down the back that has a kitchen facility, a lounge facility, the patient is in one room and there is a toilet facility, and family can sit in there and they talk, they discuss, they have cups of tea, they have a feed together and...they come back through the hospital through the back door. Yes, there's separate bedrooms. Three days before [family member] passed away when she came back...they probably should have put her there a bit earlier because by the time they did put her in there, she was dying and for 3 days family could come and go and sit with her and bring a minister in, we played music and all that sort of stuff and maybe that's what they need at the city hospital. And if you keep them together, like that the more they lean on each other's strength they get from one another...I mean, you don't even [need to] have that setup for people that are dying. You can have it set up for treatment, as for cancer treatment, for renal you know, you can use it for everything. It can be a shock thing. I think patients recover quicker when they've got family present.*

A need for ways to improve communications with the hospital liaison people was also highlighted and ways to access help at the airport or bus station. A place to relax and get some food prior to the appointment or admission is much needed.

*So, I know they probably got a busy workload too for all the Nungas that go there and they just don't have enough Aboriginal Liaison Officers. Maybe that we have a proper linkup with that Aboriginal section in the hospital to say, look this patient is coming over, can you arrange for someone to meet them at the bus stop, the airport you know because they get in at 7-8*



*o'clock at night or they get in at 6-7 o'clock in the morning and they don't know where to go from there and so maybe if they can say OK, we'll pick them up, we'll make the arrangements ... And if we have a direct link to the hospital and see like, 9 to 5 they work, no-one is there after 5, very rarely, no-one's there. I mean we don't deal with it on the week-ends either here, but if we have, like we had to fly a lady out just like that one night and it was after 5 o'clock, had to get on the blower to see if we can get her on the plane, we couldn't contact anyone in the city to pick her up or anything, we had to run around to try and find a cab charge to get her straight over there.*

*See, that's why we need somewhere they could take them till their appointment which may be that room and maybe some breakfast, tea facilities or whatever.*

## Discussion

One of the strengths of this type of qualitative research is that it enables the issues and experiences of participants, in this case the Aboriginal health workers and their clients, to be portrayed through narrative. While these accounts may vary in different settings, the issues highlighted are common across rural and remote Aboriginal communities<sup>9</sup>.

This study has highlighted a number of issues that could be addressed with good planning and cooperation between the different agencies involved. Some could be immediately applied. While these solutions are specific to this case study, it is clear that they could be implemented in other locations.

A common theme was reluctance to travel to the tertiary hospital from the remote community. Clients feared finding themselves in an alien environment often without an accompanying family member and the support of their kinship structure.

The city hospital is a tertiary referral centre that admits high numbers of Aboriginal people statewide and from interstate.

Clearly, a staff of three (one Aboriginal liaison nurse and two liaison officers) is insufficient to adequately meet needs. It is very common for Aboriginal liaison staff to be asked to perform a range of support tasks for their clients, including making family connections, housing arrangements, obtaining emergency relief, and organising transport. When these tasks fall to a small team of liaison officers it places added stress on them.

Provision of gender-shared bathroom and toilet facilities in the hospital accommodation is culturally insensitive, invades privacy, causes shame and would be relatively simple to rectify.

Health workers described the amount of time spent chasing up PATS forms, getting signatures and organising transfers. Occasional instances of misuse should not be used as an excuse to make these essential services increasingly bureaucratic and, therefore, harder to access and manage. PATS and Stepdown are vital services for people in need of medical attention unavailable in their locality. These systems need overhauling, strengthening and streamlining.

Stepdown in the past collected clients from private homes if they chose to stay with families rather than in the hostels. There were strong calls for this service to be re-established.

The willingness of the local remote hospital to introduce changes, in consultation with the community, suggests an approach that city hospitals could emulate. For example, the provision of an outdoor area where Aboriginal people can sit around a fire, which has important cultural significance, could be introduced without delay. This is a simple means of reducing stress on clients and family members, some of whom will be visiting a big city for the first time in their lives.

Finally, what is urgently needed is a greater commitment to consultation processes with the important consumers of emergency services themselves, the rural and remote Aboriginal people. These processes are best determined and controlled by Aboriginal people using family networks. It is



essential that when issues are identified through consultation that action is taken in a timely manner. The example of the local hospital provides a respectful and effective approach.

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