

# **“Nowhere to room...nobody told them”: Logistical and cultural impediments to Aboriginal peoples’ participation in cancer treatment**

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## **ABSTRACT**

**Background:** Cancer mortality among Indigenous Australians is higher compared to the non-Indigenous population and attributed to poor access to cancer detection, screening, treatment and support services. A large proportion of Indigenous Australians live in rural and remote areas which makes access to cancer treatment services more challenging. Factors, such as transport, accommodation, poor socio-economic status and cultural appropriateness of services also impact negatively on health service access and, in turn, lead to poor cancer outcomes.

**Design, setting and participants:** Qualitative research with 30 in-depth interviews conducted with Aboriginal people affected by cancer from across WA, using a variety of recruitment approaches.

**Results:** The infrastructure around the whole-of-treatment experience affected the decision-making and experiences of Aboriginal patients, particularly impacting on rural residents. Issues raised included transport and accommodation problems, travel and service expenses, displacement from family, concerns about the hospital environment and lack of appropriate support persons. These factors are compounded by a range of disadvantages already experienced by Aboriginal Australians and are vital factors impacting on treatment decision-making and access.

**Conclusion:** To improve cancer outcomes for Aboriginal people, logistical, infrastructure and cultural safety issues must be addressed. One way of ensuring this could be by dedicated support to better coordinate cancer diagnostic and treatment services with primary health care services.

## INTRODUCTION

Death rates for Indigenous<sup>a</sup> Australians are three times higher than for non-Indigenous Australians<sup>1, 2</sup>, with markedly higher cancer mortality rates<sup>3-6</sup>. Poorer Indigenous cancer outcomes are occurring despite advances in detection and treatment techniques and overall improvements in cancer outcomes in Australia<sup>7</sup>. Indigenous Australians are less likely to access cancer screening; diagnosed at a more advanced stage of cancer; have poor continuity of care; lower compliance with treatment; and lower five-year survival rates<sup>4, 8, 9</sup>. This situation clearly warrants consideration and appropriate action by both primary health care services and cancer treatment services.

Health service access is an important determinant of health outcomes for both preventive care and treatment<sup>10, 11</sup>. Access to health care is particularly difficult in geographically extensive territories like Australia<sup>1</sup> where many people need to travel large distances to health centres and services<sup>12, 13</sup>. Poorer access to cancer detection, screening, treatment and support services for rural and remote people as compared to urban dwellers, is a primary reason for a reduced likelihood of cancer survival<sup>2, 14</sup>. Thus, poorer cancer outcomes for Indigenous Australians are compounded by the rural and remote residency of over half of Australia's Indigenous people.<sup>2, 15</sup>

This paper utilises information from research undertaken to investigate the experiences and barriers of Aboriginal people in accessing cancer services and treatment in WA. An explicit aim of the research was to explore differences in experiences for Aboriginal people based upon their residence in urban, rural or remote settings. Basic infrastructure and logistical problems in accessing hospital-based treatment along with communication issues<sup>16</sup> and lack of culturally appropriate service delivery mechanisms were frequently mentioned by the participants. Inevitably, additional problems were reported by those who travelled from rural areas to receive cancer assessment and treatment. This paper focuses on what could be considered as infrastructure necessities for Aboriginal patients on their cancer journey including transport, accommodation, preparation for hospital-based cancer treatment, service affordability and support services. The study outcomes indicated that reconfiguration of cancer care, with a greater emphasis on support in local communities and better coordination with primary health care services is necessary to improve Aboriginal patient outcomes.

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<sup>a</sup> In this paper, the term Aboriginal has been used to refer to the Indigenous people of WA. We have used Indigenous when we are referring to features that are identified across different Indigenous peoples

## **METHODS**

### **Ethics Approval**

Ethics approval was obtained from the Human Research Ethics Committee of four organisations including the Western Australian Aboriginal Health Information and Ethics Committee. An Aboriginal Reference Group (ARG) consisting of Aboriginal health professionals was established, involved and consulted throughout the study period.

### **Data Collection and Analysis**

The research design ensured a culturally sensitive research approach by involving and supporting Indigenous people<sup>17</sup>. Descriptive qualitative research methods were utilised. Prior to commencement of the interview, steps were taken to ensure an introduction from someone trusted and known by the participant, build rapport and develop a relationship. Participants were encouraged to tell their story in describing their cancer journey. This mode of data gathering known as ‘yarning’ is an acceptable means of gathering data, aligning with Indigenous cultural oral traditions offering Indigenous people a voice by applying a non-threatening research paradigm<sup>18</sup>.

Thirty in-depth interviews were conducted between March 2006 and September 2007 in Perth (urban) (n=11) and in one rural (9) and two remote areas (7) of WA. Several patients from other areas of WA who came to Perth for treatment around this time were also interviewed (n=3). Aboriginal interviewees were adult cancer patients, survivors (14) and family members (16) of people with cancer or people who had died from cancer. A detailed description of the recruitment strategy and data collection processes are described elsewhere<sup>17</sup>.

All participants could speak English and gave written informed consent. Participants were asked to share the story of their journey with cancer (either personal journey with cancer or journey with a family member who had cancer), including their experience with diagnosis and treatment, and to suggest strategies to better manage the problems they faced. The semi-structured interview guide explored difficulties in accessing treatment.

Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers before members of the team conferred. The interviewer maintained a reflective

journal throughout. Thematic analysis was chosen to analyze the data in that it allows a rich overall thematic description which is useful when an under-researched area is being investigated<sup>19</sup>. NVivo7 software was used to assist data management and analysis. Participants' narratives were divided into broad categories to allow identification of key themes and discussed by the research team. Feedback sessions with available participants assisted clarification of whether emerging themes were an accurate reflection of participants' experiences.

## RESULTS

A key theme identified in the analysis was the need for instrumental and emotional support in all aspects of the cancer journey. This was particularly the case in relation to the whole-of-treatment infrastructure and to practical logistical issues relating to all aspects of treatment. Difficulties encountered in these areas determined the experience of treatment - particularly for rural/remote Aboriginal patients. Issues included problems with transport and accommodation arrangements, particularly the hospital environment and Aboriginal support/liaison. The expense of treatment and medication costs was also raised. Not all experiences were negative with some positive experiences described when individual needs were met. Some participants recommended strategies towards better meeting Aboriginal needs.

### Transport

*“They don't know which end of Perth [city] is left, right or centre...like when people come to Perth they say ‘Just go to the hospital. How do people know where the hospital is... especially some people who have never left their home town.”* (Remote, Male patient)

Many interviewees spoke about rural and remote Aboriginal people who travelled to an urban centre for cancer treatment; people often arrived feeling disoriented and scared with many having travelled hundreds of kilometres over several days involving numerous changes of transport. These long journeys were viewed as deterring Aboriginal cancer patients, particularly older and more traditional people, from leaving their community to access the treatment they needed: *“People think ‘no I don't want to go down because I've got no way of getting there, going to the hospital, or I don't have any family down there’, so they choose not to.”* (Urban, Female family member)

Rural and remote Aboriginal cancer patients, some of whom had never left their home community, saw the journey and stay in an urban centre as akin to landing on the moon. Some participants reported that patients were sometimes just handed an air ticket and a taxi fare and told to head for the hospital. *“They just say ‘get to the airport and when you get to the airport [on arrival] you get a taxi and it will take you to where you are going to stay....”* (Remote, Male patient) One participant observed that some Aboriginal people were unfamiliar with different aspects of travel, such as using toilets on planes or pay telephones along the way. Some were terrified by speeding along a city freeway in a bus or a taxi. Remote residents often had no idea of the distance, costs of taxis and other expenditure in an urban area. These additional expenses rapidly diminished money which was needed for food or accommodation.

Although some participants received support from the Patient Assisted Travel Scheme (PATS) which covered part of their travel costs, significant numbers of Aboriginal people found the PATS system complicated and were unclear about what was covered by PATS and what was not; many rural participants reported difficulties dealing with the supported travel system. These findings concur with the conclusions of a review conducted by WA Country Health Service in 2006<sup>23</sup>.

Even patients who lived in Perth had problems accessing cancer treatment services. There were problems with the cost of transport and parking, the time required to travel from outer metropolitan areas and availability of public transport.

## **Accommodation**

*“We get down there and we have got nowhere to stay. My niece, she lives in Perth, and she is an hour away from Charlies, so we don’t even bother going there...too far”* (Rural, Female family member).

Accommodation while participating in cancer treatment is important. Schedules for chemo- and radiotherapy vary but appointments can spread over months and occur sequentially. Rural participants reported difficulty finding accommodation on arriving in a city. The picture emerged of a system where sometimes referral arrangements were poor, with the hospital unaware they were coming and accommodation bookings not made. Aboriginal patients sometimes got lost in the system, both for their initial and follow-up treatments. In a city that was strange and alien,

many non-urban Aboriginal patients were expected to buy food and cook for themselves while staying in hostel accommodation. Grocery shops were not close to some of the accommodation, and at a time when they were not well, patients might need to catch a bus or to walk some distance to buy food.

One participant reported she had refused to stay in an Aboriginal hostel as she didn't know the hostel residents; they were strangers. Reports indicated that when accommodation failed, Aboriginal patients often aborted their treatment. They did not access available support to solve the accommodation problem because they didn't know and hadn't been told how to do so: *"Because a lot of people when they get here and have got nowhere to room, they like to wait until the next morning and go back. They don't even know about people like in the social worker side because nobody told them"* (Remote, Male patient).

Relocating for treatment could be particularly difficult for women with children. For example one woman whose child had to attend hospital in Perth for cancer treatment had four other children who had to accompany her. She couldn't leave them behind in the community because her husband was in jail and there was no-one else in the community to look after them. She had to withdraw her children from school and because she couldn't drive, trips to the hospital to visit her child were not easy. There are no childcare facilities associated with the adult teaching hospitals in Perth.

## **Hospital environment**

*"Unless you can read...I am lucky I have learned, but some of the elders and some young people who are stressed out and walking around trying to find B block [in the hospital] or whatever, the radiation centre...yeah, it's hard... you can't find the place"* (Rural, Female family member).

Many participants described the hospital environment as alienating. When Aboriginal patients arrived for their treatment, some participants reported they were just given a map of a big hospital which for them was akin to being in a strange city. It was difficult for them to navigate their way around and even more difficult if they were unable to read the signs. One participant spoke about accompanying her father to a city hospital, *"one big grey building"*, and how they had both felt like crying. Another participant was terrified of lifts and wouldn't get into them on her own; she had to climb flights of stairs and felt unwell going from one floor to another.

It was uncomfortable for a number of Aboriginal patients to step into Noongar country without any formal welcome or invitation. Patients come to the hospitals in Perth referred by a medical professional, often in a way that occurs quickly and unexpectedly. Travelling across country in a responsible way is significant in Aboriginal culture as it ensures that visitors are respecting the host and the country they visit (Department of the Environment and Heritage, 2004).

Hospital food was also an issue raised by a number of participants: *“There was the food – a lot of them don’t eat vegetables and what you get on the plate. A lot of them would ask for kangaroo, ‘Is kangaroo going to be served?’”* (Urban, Female family member).

Older Aboriginal men seemed to find the hospital regime and dependency particularly disempowering. One participant said her 84-year old grandfather *“hated being heavily dependent on strangers”* in hospital as he was a proud independent man who disliked having to ask for things when he needed them; he hated being restricted to bed and detested the food.

Perhaps one of the greatest difficulties experienced was the lack of hospital flexibility for extended family who wanted to give ongoing support to a patient. Hospital staff restricted the number of people allowed in a ward room. This was particularly difficult for extended family when a relative was dying or had died: *“...that’s our culture. Like when someone is close to passing away the whole extended family will come. That’s been like that for years. You can’t change that...they want the whole family to come in...”* (Urban, Female family member).

Embarrassment about invasion of privacy in hospital caused shame and discomfort for Aboriginal patients. Teaching sessions with medical students and ward rounds contributed to this discomfort *“...just having those ten people all staring down at you like this, that is intimidating enough in itself. So, I don’t know that people would feel that comfortable with asking personal questions about their private life, their personal body parts”* (Urban, Female family member).

### **Expense of medication and treatment**

*“In the real world we can’t order MRIs and things like that, and most of these things do attract an excess. A CT scan and most X-ray people, there is quite an extra amount of money you have to pay which our patients can’t afford.”* (Urban, Female family member)



Many cancer treatments are expensive and either unavailable or have long waiting lists in the public system. Indigenous Australians have less accessibility to specialist care, private hospitals and the services available to private patients because they have much lower rates of private health insurance. The 2001 National Health Survey shows that 17% of Indigenous Australians in non-remote areas had private health insurance compared with 51% of other Australians<sup>20</sup>. One participant described how her sister had continued working so she could afford cancer medication up until the time she couldn't work anymore. Once on a pension she was entitled to subsidized medication, but even then it was very expensive. Ultimately, the participant started paying for her sister's medication on a credit card because she could not afford to get it any other way.

### **Aboriginal support and Liaison Workers**

*“Especially a lot of people when they come from the community, they don't know what they are gonna face. Yeah, like...where are they gonna stay, how they are gonna support themselves for six weeks, and if their family is gonna come. ...A lot of support should come from within the hospital as well, especially social workers.”* (Remote, Male patient)

The need in the mainstream hospital system for patients and families to get direct practical and emotional support from an Aboriginal person was emphasized. There was a lack of Aboriginal interpreters or Aboriginal Liaison Officers (ALO) to accompany Aboriginal patients, provide information and make them feel more comfortable about the whole process of cancer treatment. Many participants reported how hard it was for Aboriginal patients to leave their communities for the first time and travel to a city without family and a place where they knew no-one. The need for emotional and psychological support at this time was a consistent theme. However, rules pertaining to access to health services, costs and family responsibilities often precluded a family member being able to accompany them. One participant referred to the need for regional ALOs to explain the treatment program and what it entailed to Aboriginal people before they travelled. There was a need to *“...come down to their level about these issues like cancer and tell them...talk at their level that they can understand. This is what you are going to face...when you go to the big city. Don't be frightened”* (Remote, Male patient).

For rural cancer patients returning to their communities after cancer treatment, respondents reported that follow-up supports such as physiotherapy, practical information on post cancer treatment and counseling were lacking. Aboriginal liaison workers in the community could play

a supportive role by liaising patients with appropriate services and by providing culturally appropriate information. There were often communication breakdowns between the primary care service and the tertiary hospital with appointments made by the tertiary hospital for treatment and follow-up with little understanding of where the person lived, and the time and expense of travel. Appointments were arranged without involving the primary care service which, in many cases could have helped to organise logistical support for the patient to attend follow-up appointments.

### **Positive support experiences**

Not all participants encountered negative experiences with some people reporting positive experiences with support for issues such as transport and care. This included payment by the PATS for an airfare or fuel costs and contribution towards accommodation costs. Other participants, especially those from rural and remote areas, praised palliative care and home-nursing services. Participants appreciated this support because of the providers' warmth, friendliness and caring behaviour. They remarked on their willingness to spend time with the patient and family when visiting and their attention to detail when discussing issues that could arise.

*“The Silver Chain external nursing agency... they were very good and helpful...more supportive and friendly...the medication and stuff that they ensured over the first couple of weeks so that we knew exactly when to do it and all that ...they were brilliant” (Urban, Female family member)*

Other supports included that provided by local Aboriginal Medical Services, access to wigs from the Cancer Council and installation of amenities by Disability Services to assist patients affected by treatment or illness. A few participants talked about the extensive support they received from the Social Work department within the hospitals: arranging accommodation, maintaining links with family during treatment, access to discounted food supplies and assistance with returning home. However, it became evident that families who had connections with the health system due to their work and had sufficient familiarity with health and related support services to be able to negotiate the system were most likely to benefit from such services. This reflected that many Aboriginal participants did not ask for support services because they did not know about them, or because they were intimidated or overwhelmed. Unfortunately this often meant they did not receive them, suggesting there were inadequate proactive mechanisms around access to support services.

## DISCUSSION AND RECOMMENDATIONS

Many Indigenous people are reluctant to seek medical attention until their condition is serious<sup>21</sup>, and this is true for a life-threatening disease like cancer. Modern cancer treatments utilise high technology medicine for diagnosis and treatment and are carried out in tertiary hospitals which in WA are all based in Perth. While logistical issues are inevitable for all Australians who need to travel long distances to access health services, the difficulties encountered by participants in this study were compounded by the profound disadvantages experienced by Indigenous people across a broad range of indicators. Both financial disadvantage and socio-cultural barriers contribute to making the journeys of Indigenous Australians particularly difficult<sup>3, 11, 22, 23</sup>. The literature recognizes logistical, practical and economic difficulties impacting negatively on Indigenous Australian access to cancer treatment services<sup>22-24</sup>.

For people from remote areas, Indigenous Australians non-Indigenous have significantly higher rates of cancellation and non-attendance at hospital appointments and frequent premature hospital discharge against medical advice compared to non-Indigenous people<sup>22, 23</sup>. These attendance disparities indicate that it is not distance *per se* that impedes access to care, but the lack of mainstream treatment infrastructure to fulfill the specific needs of Indigenous Australian patients.<sup>13</sup> Our study found that Aboriginal patients from rural locations who travel for cancer treatment can feel distressed and demoralized. Service affordability including medication, care costs and dislocation from family compound the problem. While the PATS offers some financial assistance for rural and remote travel there are still many Aboriginal people who slip through the gap. It is worthy of note that the majority of the Aboriginal population in Perth who live predominantly in outer urban areas also need to travel for treatment; they do not receive any reimbursement for their travel costs. It is highly likely that if people think they cannot afford the treatment and cost of travel, they may avoid the embarrassment and shame of admitting their financial difficulties by choosing not to take up treatment.

Many of the issues raised by participants related to these infrastructure issues and the quality of care in the hospital setting. Issues of communication, trust and the cultural safety of mainstream health services have been discussed elsewhere<sup>16</sup> and require urgent expeditious consideration if Indigenous cancer outcomes are to be improved. There have been calls for the current structural

and financial arrangements that operate for cancer care provision to be reformed<sup>25, 26</sup>. This could include making primary care providers the coordinators of care within a multidisciplinary team environment or having regionally based cancer care coordinators who link patients between different interfaces of the health system. In this role they would be more able to service the holistic needs of patients and link them to local services, an arrangement which is particularly important for those who are most vulnerable. It also needs to be recognised that properly resourced, well managed Aboriginal Health Services would be ideally placed to provide the sort of support the patients need, and many no doubt already do. Case conferencing (either by video or telephone) between cancer specialist and primary care providers would be useful for coordination and developing a better understanding amongst all parties of issues related to an individual's treatment and care.

There are other ways that primary care providers can assist Aboriginal cancer patients and their families. It was evident in this study that patients often arrived at the hospital door, completely unprepared for the experience. Yet being aware in advance of what will happen and likely lengths of stay in hospital could help Aboriginal patients to be both physically and psychologically prepared for their stay. Where possible it is important to ensure the support of a trusted, caring family member who can assist a patient with finding their way to and within the hospital with understanding and adjustment. This has been clearly mentioned by Lawrence and colleagues who have demonstrated the importance of the principles of patient-centred care, cultural respect and systemic continuous quality improvement. They have emphasized the need to recognise that different patients have different needs and to make respectful systemic adaptations in order for best outcomes to be achieved for Aboriginal people with heart disease<sup>27</sup>. Similarly, there is evidence that efforts in improving discharge planning are effective and improve the interface between hospital and community care<sup>28</sup>.

The barriers faced by many Indigenous people in accessing specialist and hospital care are substantial. A cancer diagnosis is distressing enough, yet many Indigenous people will face extra stress before and during treatment. The psychological and physical health impacts of an inadequate and inappropriate structure of care are profound. Enough is known about the needs of Aboriginal people to require that oncology service providers broaden their focus beyond biomedical care to ensuring that the psychosocial and practical needs of Aboriginal patients are

adequately met. The infrastructure needs described in this paper will be addressed if care is truly patient-centered and respectful of an individual's culture and circumstances. These reforms are more likely to be expedited by an overall system reform which would take steps, firstly to include Aboriginal workers as part of the care team, proactively considering a patient's need for social and welfare support; and secondly, to increase awareness and understanding by health care providers about the historical and contemporary challenges facing Aboriginal people in accessing culturally-safe care.

## **Box 1: Suggestions and Recommendations**

### **Transport**

- Increase awareness of health service providers about the impact that distance and travel is likely to have on clients
- PATS program to be better promoted and entitlements made clearer to users
- The process of claiming PATS should be simplified and easier-to-understand
- Ensure workable arrangements that support travel of patients and accompanying persons for necessary travel while in the metropolitan area
- Establish cancer services in outer urban and large regional centres if feasible
- Reduce the need to travel when possible through alternative means of follow-up such as wound checks and minor follow up undertaken via video conferencing or telehealth or at a local health service
- Increase outreach delivery of specialist care in community-based services to overcome some of the barriers relating to distance, communication and cultural appropriateness of services
- Provide a welcome to country from a Noongar Aboriginal elder as part of arrival in the metropolitan area

### **Accommodation**

- Ensure provision of adequate and culturally safe accommodation facilities that are easily accessible to treatment services and offer adequate safety and support.
- Recognise the importance for Aboriginal people of family members being able to stay with them and provide support.
- Ensure patient support services have a welcoming atmosphere and are proactive in attending to the needs of Aboriginal patients
- Recognise the need for patients in self-catering facilities to have access to shops and transport and encourage the availability of healthy traditional foods.

### **Hospital Environment**

- Improve the hospital environment and make it welcoming for Aboriginal people by providing a culturally sensitive environment (through Aboriginal staff, Aboriginal artwork, opportunities for painting, yarning places, access to traditional foods, access to outdoor gardens)
- Facilitate return of Aboriginal patients to their homeland for continued care where possible
- Develop an effective and efficient coordination process that involves the hospital, the patient and their family, and primary care provider
- Ensure that there is access to Aboriginal interpreters for Aboriginal people who are not confident speakers of English, and that staff understand differences in Aboriginal

communication styles

### **Aboriginal Support and Liaison**

- Consider patient advocates or navigators to provide support and assistance to the patient and their family by negotiating system barriers
- Provide information and help in with accessing relevant support agencies

### **Transfer of Care**

- Develop systems that support improved linkages back with primary care services
- Ensure ongoing access to appropriate psychosocial support with an emphasis on enhancing well-being

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