

# Understanding an Aboriginal and Torres Strait Islander child's journey through paediatric care in Western Australia

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Since 2005, the Closing the Gap initiative to reduce health disparities between Aboriginal and Torres Strait Islander (hereafter Aboriginal) and non-Indigenous Australians has been instrumental in working towards improving the overall health of Aboriginal peoples.<sup>1</sup> This includes health programs designed to be culturally inclusive and appropriate within health service delivery.<sup>2,3</sup> Yet despite current policies for delivering culturally appropriate health services, racism and culturally inappropriate care within the health system persist.<sup>4-6</sup> Fear and mistrust compounded by past policies and practices in Aboriginal communities, including the forced removal by the government of many Aboriginal children from their families, are key reasons why Aboriginal people reluctantly engage in mainstream health services.<sup>7,8</sup> While there have been some improvements in addressing health inequality through state and national initiatives, problems remain.

The higher burden of disease in Australian Aboriginal children compared to non-Indigenous children has resulted in an increased use of tertiary hospital care.<sup>9,10</sup> As a result, there is an ongoing need for high-quality services that meet the requirements of Aboriginal parents and carers who engage with the mainstream hospital system. In addition, hospitals need to consider the cultural and support needs of not just the

## Abstract

**Objective:** To explore caregiver perspectives of their children's journey through the specialist paediatric service, the Aboriginal Ambulatory Care Coordination Program (AACC), and non-AACC services at the Perth Children's Hospital.

**Methods:** Eighteen semi-structured interviews with families of Aboriginal children were completed. Indigenous research methodology and a phenomenological approach guided data collection and analysis.

**Results:** Four key themes were identified from interviews: hospital admissions, discharge and follow-up outpatient appointments; communication; financial burden; and cultural issues. Our findings suggest Aboriginal children and their caregivers using the AACC program had more positive and culturally secure experiences than those using non-AACC services. However, barriers relating to health providers' understanding of Aboriginal cultural issues and lived experience were commonly discussed, regardless of which service families received.

**Conclusions:** Australian Aboriginal children have an increased use of tertiary hospital care compared to non-Indigenous children. Healthcare programs specifically designed for Aboriginal children and their families can improve their experience of care in hospital. However, improvements in cultural awareness for other hospital staff is still needed.

**Implications for public health:** Dedicated Aboriginal programs in mainstream services can successfully improve cultural care to their clients, which is fundamental to improving service delivery for families.

**Key words:** Aboriginal, children, tertiary hospital, cultural competence, experiences

local community, but in the case of Western Australia, regional, rural and remote patients. These latter patients have additional barriers to receiving healthcare including travelling great distances from their family and community support systems, having limited access to transport and being away from their homes for extended periods of time.

Enhanced models of care coordination are being recognised as an effective way of engaging Aboriginal families in the healthcare system, suggesting their potential for widespread adoption. Examples of such programs exist across Australia, including the Wadja family program at the Royal Children's Hospital in Melbourne, which

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offers a culturally safe environment for Aboriginal families to seek assistance and an Aboriginal health clinic held one day per week for inpatients and outpatients.<sup>11</sup> Other state tertiary paediatric hospitals are taking the initiative to provide a more direct service to Aboriginal children and their families and include the Women's and Children's Hospital in South Australia, Monash Children's Hospital in Melbourne, Sydney Children's Hospital, and in Queensland, the Lady Cilento Hospital. All these programs provide support services that are culturally safe for Aboriginal families and are aimed at decreasing presentations to emergency departments and reducing the length of stay as an inpatient.

The Aboriginal Ambulatory Care Coordination (AACC) Program, currently known as the Koornly Moort program, was developed in 2012 and operates from the Perth Children's Hospital. The AACC Program was established to improve health outcomes and attendance to outpatient appointments and reduce hospital utilisation for Aboriginal children. This is achieved through working with families who have failed to attend previous hospital appointments or have children with complex health, social and/or behavioural problems, or if a referrer has had difficulties engaging with a family. The AACC program has three key interventions: partnership with community-based primary care providers (especially Aboriginal Community Controlled Organisations), nurse-led care coordination, and outreach care closer to home. Examples of these interventions in practice include coordinating multiple appointments to reduce the need to travel to hospital, offering appointments closer to home and ensuring information is shared between other health services who are involved in patient care. Partnership between the Aboriginal community and the AACC program involves delivering community clinics at outreach sites including at ACCHS to support families and their children. We have recently shown that Aboriginal children referred to the AACC program had significantly reduced hospitalisation admissions, emergency department presentations, non-attending appointments and mean length of hospital stay compared to before the program was implemented.<sup>12</sup>

Due to the improved hospital-related outcomes of AACC, we wanted to explore the positive and negative experiences of carers whose children attend the AACC program compared to those who receive

standard hospital services (non-AACC). Our primary objective was to explore caregiver perspectives of their children's journey through the specialist paediatric service, the Aboriginal Ambulatory Care Coordination Program (AACC), and non-AACC services. This would enable us to identify gaps in current approaches and provide feedback to the hospital to improve the quality of care delivered to Aboriginal children and their families.

## Methods

An Indigenist research approach guided the project and was chosen because it prioritises Aboriginal voices and situates Aboriginal people who are central to the research process.<sup>13</sup> This approach was developed by Lester-Irabinna Rigney (1999) who critiqued non-Indigenous approaches to researching Aboriginal peoples for often disadvantaging and further oppressing them and silencing or ignoring Aboriginal voices and their lived experience of colonisation.<sup>14</sup> His approach was guided by three principles: resistance, political integrity and privileging Indigenous voices. This included resistance to ongoing discrimination of Aboriginal people as a legacy of colonisation; political integrity where Indigenist research is conducted by Aboriginal peoples, which takes research to the heart of the Aboriginal struggle; and privileging Aboriginal voices where the focus is on the "lived, historical experiences, ideas, traditions, dreams, interests, aspirations and struggles of Indigenous Australians".<sup>14</sup> He positioned Aboriginal and Torres Strait Islander peoples at the centre of the research process, subjects of their own research rather than objects of non-Indigenous research. Sherwood (2010) argued further that excluding Aboriginal voices from the research process was unethical and could compromise health outcomes, and instead encouraged the development of Aboriginal/non-Aboriginal partnerships where non-Indigenous researchers had the opportunity to listen to and work with, rather than on, Aboriginal people.<sup>15</sup>

In our project, Aboriginal participants applied their own focus, perceptions and understandings to the issue and Aboriginal researchers were integral to the design, data collection and analysis.<sup>16,17</sup> While Aboriginal and non-Aboriginal researchers worked together, the lead researcher for data collection and analysis is Aboriginal, and her

analysis of the interactions and observations reflect her cultural awareness of issues including knowledge and understandings of the importance of family, country and cultural obligations. Non-Aboriginal researchers involved in the research process worked with their Aboriginal colleagues, underwent cultural competence training and were experienced working with Aboriginal families in a health context. Indigenous research methodology was complemented by a phenomenological approach that describes the essence of a phenomenon by those who have experienced it. In other words, it seeks to understand a person's experience from their perspective in ways that can offer new meanings to how others interpret that experience.<sup>18</sup>

## Study setting

Meeting rooms located at the Perth Children's Hospital were chosen to conduct most interviews due to their close proximity to the wards; they provided a non-threatening environment that provided a welcoming area with a children's play area, seating, toys, television and a parent's lounge with a table and seating that overlooked the children's play area. Other interviews were conducted on the wards or, in one instance, at the interviewee's home. Interviews conducted in the wards were mostly isolated and private to ensure there was little disturbance during the interview process.

## Participants

Children aged 0–16 years old were identified by clinical nurses from the hospital's clinical database. Although there are older children and adolescents that attend AACC and non-AACC services, the mean age of AACC children was 67.5 months between 2012–2014.<sup>12</sup> As a result, we decided that it was more appropriate to interview families rather than children for this study. Families were approached in hospital and asked to participate in the study if their child was Aboriginal and/or Torres Strait Islander and had had at least one hospital admission and one outpatient follow-up appointment with the Perth Children's Hospital in the past two years. Families who agreed to participate in the study were then invited to be interviewed. Children were further categorised as using the AACC program or non-AACC services. Children were referred to the AACC program if they had failed to attend appointments or had complex and/or social and behavioural

problems, or when the referrer experienced difficulty in engaging with the family. The program also accepted referrals from families who wished for their children to be reviewed closer to home and country. Children who weren't referred to the AACC program were considered to have received non-AACC services. Children who were under the care of child protection (i.e. had been removed from their families) were excluded from participation due to the additional ethics requirements needed for them to participate and the time constraints of the study to complete this work.

A 'participant' was the individual who was interviewed and identified as a parent or caregiver of an Aboriginal child meeting the criteria above.

### Data collection

Indigenous ways of seeing and knowing are important to data collection, analysis and interpretation.<sup>19</sup> An experienced Aboriginal researcher conducted the interviews with metropolitan, rural and remote Aboriginal parents and carers (participants) who used AACP and non-AACP services. All participants were provided with an information sheet and gave written consent prior to being interviewed.

Baseline demographic data were collected, and interviews were recorded, transcribed and entered into NVivo software to assist organisation and management of data. Data collected included the child's sex, age, number of hospital admissions and follow-up outpatient appointments (self-report), whether the child was an inpatient or outpatient, Aboriginal and/or Torres Strait Islander, residence of the child (metropolitan, rural or remote); AACP or non-AACP patient; number of children in the household; and type of medical conditions. Data collected on the participants included sex; relationship to the child and the participant's family group or community.

Face-to-face semi-structured interviews explored the child's journey through hospital services, including how the staff related to the child and participant during their visits to hospital. During interviews, participants were encouraged to be honest and were reassured that confidentiality was the utmost priority while validating their experiences. Questions related to hospital admissions and discharge, follow-up outpatient appointments and general concerns. The researcher ensured

each participant was asked all questions, which were reworded if there were any difficulties in comprehension, while being cautious not to alter the questions' intended meaning to retain consistency. Questions were designed to identify key issues and areas of concern.

### Data analysis

Interviews were transcribed and imported into NVivo. The iterative process of analysis was guided by a phenomenological approach and the principles of Indigenous research methodology.<sup>18,19</sup> Transcripts were read, reflected on, reviewed and coded independently by the Aboriginal researcher who completed the interviews, as her analysis of the interactions and observations demonstrate appropriate consideration of family and country in a way that is culturally aware. Findings were reviewed by co-researchers and discussed to identify and agree on categories and themes related to the project's aims. These were subsequently revised noting similarities and differences in participants' experiences. This iterative analysis identified key categories related to inpatient and outpatient care, and emerging key themes related to each category. Findings were then interpreted in light of research in the peer-reviewed literature for whether they supported, challenged or extended existing evidence. To protect participants' confidentiality, quotes were identified by their use of AACC or non-AACC services.

### Ethics

Ethics approval was obtained from the Western Australian Aboriginal Health Ethics Committee, the Child and Adolescent Health Service Ethics Committees and the University of Western Australia.

### Results

One hundred and thirty children were identified for potential inclusion in the study. Of these, 75 families were approached to take part in the study. Not all participants gave reasons for refusal; however, reasons that were provided included having no time, children or other family members being too sick for them to participate, not feeling comfortable with the interview, not being interested or being discharged before the interviewer could reconnect. Twenty-four were invited to take part in the study with just under half being from rural and remote areas.

Six were subsequently excluded as children were under the care of child protection. Eighteen participants remained; 12 used the AACC program and six used non-AACC services (Table 1). Interviews ranged from 11 to 32 minutes in length.

Participants' experiences of the barriers and enablers of their child's journey were organised into categories related to inpatient and outpatient care. Themes included hospital admissions, discharge and follow-up outpatient appointments; communication; financial burden; and cultural issues. Other common threads that were found from the interviews included overall satisfaction from most participants with their child's treatment including how doctors and nurses communicated information about their child's condition and subsequent discharge. However, other aspects of their child's hospital stay caused concern; these included stresses related to accommodation, transport for participants to and from the hospital, extra costs while in hospital, concern about other family and cultural obligations, and staff responses to Aboriginal cultural issues.

Negative responses were more evident in interviews where participants had additional responsibilities such as children with chronic and complex care, larger families, were carers of relatives, had extended community roles, were involved with child protection and were financially stretched. Little difference was noted between remote, rural and metropolitan participants on most issues except travel. Given the context, some issues such as coordinating several follow-up appointments, and family and cultural responsibilities weighed heavily on participants. Several participants commented that the AACC program was a bridge between them and general hospital staff, which alleviated some of their concerns.

**Table 1: Characteristics of Aboriginal children by program.**

	AACC	Non-AACC	Total
	12 (67%)	6 (33%)	18 (100%)
<b>Age group</b>			
0-5 years old	8 (67%)	2 (33%)	10 (56%)
6-16 years old	4 (33%)	4 (67%)	8 (44%)
<b>Gender</b>			
Male	4 (33%)	3 (50%)	7 (39%)
Female	8 (67%)	3 (50%)	11 (61%)
<b>Location</b>			
Metropolitan	8 (67%)	1 (17%)	9 (50%)
Non-Metropolitan	4 (33%)	5 (83%)	9 (50%)

### Hospital admissions, discharge and follow-up outpatient appointments

All except two participants were satisfied with their child's experience of being admitted to hospital. While most participants were reasonably satisfied with the discharge process, concerns were raised about the lack of information conveyed on discharge, frustration with waiting times for the doctor's final review, and medication, regardless of the service model they received.

*... they say [we'd be] out of here 10am, we never leave at 10am, I think we got out of here about 5pm. (AACC)*

Some participants' frustration was also evident post-discharge. This included delays in follow-up appointments, being given the wrong day and time, difficulty scheduling times to suit participants, and length of time between appointments, with some being given appointments during peak-hour traffic and school pickup and drop-off times, which made it difficult to attend. Consecutive or multiple clinic appointments on the same day/week affected both metropolitan and rural patients as wait times, costs associated with travel and other hospital needs were financially burdensome.

*I've had the frequent attendance stickers and everything and they don't make the times when you want the times, it's like oh my god I've got, I mean I've got kids who have got to get to school and yet I've got an appointment at 8.30. (AACC)*

Compared to standard hospital services, assistance provided by the AACC program significantly improved participants' experiences of admissions, discharge and follow-up appointments. AACC program staff appeared more effective at engaging Aboriginal families through providing medical information/advice and a culturally safe environment, building rapport with parents/carers, and discussing support systems available to patients.

*Information at the end gets changed three or four times before you leave, for the next time we come back. It was, is, the hardest part because it won't be written down on paper to give to us, to follow up before we get here; it's just verbal. That's the only information I get, three or four people will give us verbal, different verbal information towards us, for us, but nothing written. That's the hardest part, where it stuffed up, we could have been out of here by now if we knew exactly what's really going on. (Non-AACC)*

*The Aboriginal ambulatory care were pretty helpful, they would give me a call before the appointment, like a few days before, and remind me, they would even come to the appointment to see how we're going and help us through, and if they needed another blood test they'd come down with us, so ambulatory care is pretty helpful when we come in for appointments for (name of child). (AACC)*

AACC program staff provided additional assistance to help keep families engaged in the healthcare process, and ensure a smoother transition from emergency to the wards, and wards to home and then outpatient clinics, and to advocate on families' behalf both within the hospital departments and externally to health providers state-wide. They also communicated with participants to ensure they presented for appointments, making it less likely that children and their families re-presented to the emergency department.

*Yeah, every other time I've been, like had to come for a hospital appointment, they (AACC nurses) check in on me and that. I haven't seen them this time round but normally I would have seen them, but you know they're always checking in on me and make sure everything's good. (AACC)*

### Communication

Overall, participants were very satisfied with how medical and nursing staff communicated with them. Barriers were identified in the non-AACC interviews suggesting general hospital staff, general practitioners and other health providers played key roles in whether the patients received appropriate care, particularly when it came to understanding concerns related to the participant's child. One participant felt hospital staff were too busy to communicate effectively or had rushed conversations:

*... it was just ... not being told anything, being left in the dark ... Yeah, and you know he really didn't come in and say anything to us at first in any sense he just came in looked at the child and walked away with the other doctors talking instead of informing me. (Non-AACC)*

Another participant from a remote area was unsure of travel arrangements from the airport to the hospital:

*Well, I didn't know who was going to pick me up but I had the school principal pick me up ... my nurse told me I had to meet someone from the hospital there and I waited for a*

*little bit there and then the man came to help me and gave me the taxi, gave me the direction where to go to. (Non-AACC)*

Poor communication led to confusion about treatment and use of medication or equipment on discharge. While some participants were confident asking questions, others were not or felt embarrassed or 'shame', as it is colloquially known as in Aboriginal culture, particularly if they were unsure of instructions following discharge. As a result, more issues arose upon returning home with a child with a complicated condition that required more medications and/or equipment combinations. This suggests that poor communication from hospital staff is a risk factor for participants and led to frustration and confusion about accessing and administering medications once home.

*I didn't know that you can actually get the medication that she was on for the neurology, ... like her epilepsy tablets. I didn't actually know you can get the sprinkles in [rural town], I was just assumed that you had to only get them from the hospital here ... So, she went without them for a couple of months, and like my doctors ... just kept asking me "Oh, when are you going to be getting back on them?" And it sort of like made me feel like I was bad because I didn't know where I could get them from. (Non-AACC)*

This experience highlighted the importance of service providers clarifying that patients have understood the information correctly, aware that they may feel uncomfortable asking questions of medical staff, particularly if doctors or nurses were rushed. Most participants would have liked a follow-up phone call from staff once home to check they were managing their child's health and medical needs appropriately.

Participants required to administer minimal amounts of medication to their child were quite confident and understood dosages. It was evident that non-AACC participants were the most affected by poor communication of information and lack of understanding, which increased their anxiety. Participants who regularly engaged with the AACC program appeared more at ease and confident in approaching staff for assistance. They indicated that services involved with the AACC program were also more proactive in ensuring patient care and channels of communication worked effectively. Interviews also revealed that most participants using AACC services



were generally well informed about relevant medical information concerning their child and were encouraged to call if they had any issues after leaving hospital.

*Yeah, I was told who to call for medication, I've got the ambulance ambulatory care here who've got scripts on file, if I can't make it into hospital to get those, they'll usually get them sent out to me, or if that's not the case we'll just go to the GP and get a script written up for her. (AACC)*

### Financial burden

The financial pressure placed on families attending the hospital was a common theme for most participants coming to the Perth Children's Hospital. Lack of money, costs associated with public transport, petrol, parking fees, food and drinks for themselves and their children led to more stress and frustration. It was also a factor in participants' non-attendance at planned appointments. Additionally, costs of travelling back and forth to hospital and purchasing food while staying put pressure on their already limited funds.

*I've only got \$60 left and I've spent so much money ... I've bought my food and I paid for parking, so it does go real quickly. (AACC)*

*Yeah, we had to come down find our own accommodation then forking out money for food and everything on our own accommodation, travel, everything on our own. (Non-AACC)*

A key issue that compounded the problem seemed to be health providers' lack of understanding of the lived experience many Aboriginal families face attending the hospital. This was illustrated by one participant who was expected to stay the night despite several family obligations.

*I said no. I said I'm the only one in the family who's got a licence, only one who's got a car, so I've got to take her home I've still got eight other kids I've got to pick up for school, and she said, oh well you can get someone else to do that can't you? (AACC)*

The lack of empathy added stress, as it discounted the challenges of meeting competing demands on this participant's time.

*Just like a bit more compassion about my circumstances and, you know, I'm not just looking after one high-needs kid, I've got a few with speech issues and I've got appointments with them, and I care for people with chronic liver disease at home, you know, I'm not ... I don't just have one kid. (AACC)*

Hospital policy at the time only granted amenities assistance to patients admitted for seven or more days. While most participants from remote areas were satisfied with the assistance they received for meals and accommodation provided by Ronald McDonald house, when accommodation there was full, families were housed elsewhere, which often caused distress.

*In the basement, elevators, it's not good for the kids, if the kids jumped on the elevators there'd be warning signs, it's \$700 to get them out, they won't get them out until you cough up your \$700, the bill you know. It don't make sense. Why put us in a place like that, that's very dangerous for kids? I didn't see one female in that place, it was all weird people. It's a backpackers' place, your doors lock, if the kid comes out the room to go to the toilet that door is locked. (Non-AACC)*

Many participants were unable to get change for the parking meters from the hospital shops. Furthermore, delayed appointments meant they could not refresh their parking meter, which led to parking fines. Petrol and car maintenance were costly, particularly for those from outer suburbs and rural areas. Others could not take the free patient transport due to too many children, or appointment times not aligning with school pickup and drop-offs. Some participants were unfamiliar with the city public transportation system and were not provided with taxi vouchers. However, most participants using patient transport organised by the AACC program staff were extremely satisfied.

*I think one of the ladies like your guys' support, she come in and she said we are an Aboriginal thing, like transport and stuff, she said if you don't have a car or whatever we can give you a lift in here and back and I was like, "Oh yes, that is pretty good". Like cause we are, where we stay that is, you know we live in the bush and this is all the way in the city with the lights and that, so I thought, "Oh well, fair enough they gave us a lift here and back, yeah! I will take that". (AACC)*

### Cultural issues

A few participants felt general hospital staff often lacked respect and understanding about Aboriginal cultural issues and obligations that was cause for great concern. This was exacerbated if behaviour was experienced as discriminatory, for example, by nurses not from the AACC program who "look down on you, like they've got no time for you". (AACC)

However, another participant who had missed appointments due to challenging life circumstances reported that they "never got any judgement so that was good". (AACC)

One non-AACC participant felt they were being singled out during their hospital stay and this was confirmed upon arriving home when confronted by allegations and child protection officers.

*But after getting home and Family Services comes and says oh, this has come to our attention, we're worried for his wellbeing and safety ... It was just false allegations, they pretty much told us ... Yeah, but they did say it sounds like it's false allegations because they did talk to other nurses, and they said that wouldn't have happened, so ... But that was just, that's pretty, umm, it came from here definitely because this is where she's always been the whole time, so that, that was, but she didn't know anyone but the nurses here, so she only got to know the nurses. (Non-AACC)*

The lack of support experienced by this participant was contrasted with another non-AACC participant who used the rural Aboriginal Medical Service to advocate on her child's behalf directly to the hospital Aboriginal liaison staff and hospital departments:

*The staff here were great actually when we first came, the staff were really good here at the moment. I mean I can't really complain about anything here with these guys professionally in their jobs and what they do. They organise anything that you need, I suppose. (Non-AACC)*

At least half of the non-AACC participants engaging directly with hospital staff had minimal issues and felt confident staff were culturally aware. An AACC participant, although happy with the program's nursing staff, was dissuaded from interacting with nurses outside the program, suggesting they needed cultural training:

*Cultural training should be compulsory, I know that you get given an opportunity and asked if you would like to do it. I think it should be compulsory. I mean they can sit there and talk and roll their eyes or whatnot at it. I mean you can't force them to learn culture, you can't force anybody to learn anything, but I reckon it should be compulsory. (AACC)*

This participant also stated that some staff outside of the AACC program were racially profiling the family, and false reporting of a child protection incident created a trust

barrier and a reluctance to engage with the hospital in general.

*I think the problem in here is the paint brush, if one Aboriginal family's done something wrong, well that nurse is going to paint the brush with the next one. (AACC)*

Some participants thought that non-AACC hospital staff, in general, lacked understanding of cultural issues such as awareness that different languages were spoken in different regions, where English might not be the first language spoken at home, which affected their visit to hospital.

*Well, sometimes they use hard English – hard words you know we can't understand what they talking about. (AACC)*

An Elder from a remote community also believed her community and family responsibilities were not considered by general hospital staff, including obligations around funeral attendance. She was worried she and her son would not return home in time for a cousin's funeral and would be unable to support her family members. Being away from home for long periods of time, missing family members, and cultural obligations caused her anxiety and concern.

Most participants using the program were satisfied it provided the services and resources their child needed to alleviate their cultural concerns. Participants also expressed that AACC staff had done all they could, were culturally appropriate and sensitive, liaised with their Aboriginal health teams, ensured participants were kept informed and provided the best possible care by being responsive and caring.

*And she is like, yeah, we are here for people and Aboriginal people like just to help and try and explain stuff. Yes, so that's good. (AACC)*

*Only because of the history I've got with the doctor and the girls; they know my girl off by heart so and they are so, cause the Aboriginal health team are so, they know how to work with Aboriginal kids and my child knows them and they go all out, they don't just do your crappy little appointment. They go all out so that's what I like. (AACC)*

## Discussion

Overall, findings suggested AACC services provided families with a supportive and culturally safe environment where they could engage with staff and express their concerns, so their hospital stay was a more relaxed

experience. Despite this, AACC did not always improve a family's journey through the hospital, with some aspects of care such as waiting times still impacting on families regardless of the service they received. Direct engagement with Aboriginal families about the care provided to their children offers insights that can improve service delivery and their experience in hospital. It also positions the Aboriginal experience of healthcare as one that is informed by broader socioeconomic, historical and cultural issues that cannot be ignored in mainstream health service delivery.

Findings identified overall satisfaction with the care that participants' children received in hospital and especially by the AACC program. However, concerns were raised about poor communication from some staff and insensitivity to the lived experience, competing financial and sociocultural demands faced by many Aboriginal families whose child was in hospital. Poor communication led to participants misunderstanding advice about medication, equipment and treatment once discharged, suggesting this as a risk factor to patient compliance. Our results contribute to what is continuously cited as a barrier to high-quality care for Aboriginal Australians when in hospital.<sup>20-22</sup> Poor communication from staff, financial stressors and disrespect for Aboriginal cultural norms are barriers to Aboriginal families accessing necessary health services, thereby impacting on their overall health outcomes. Our findings suggest that while healthcare providers deliver evidence-based care, they also need to communicate respectfully with Aboriginal Australians to strengthen relationships and create a more inclusive environment that contributes to Aboriginal patients feeling culturally safe.<sup>22</sup>

Poor communication and lack of cultural awareness are ongoing and intertwined issues experienced by Aboriginal people and their families when in the tertiary healthcare systems. In this study, cultural issues influenced both AACC and non-AACC participants in various ways, particularly regarding community relationships and obligations. Participants wanted cultural issues to be respected within the health services. These included: their obligations to community and Elders; understanding cultural ways; and being given time to consider what was being said and whether that had bearings on their cultural beliefs. For AACC participants, Aboriginal health workers

were a critical support mechanism and they bridged the gap by providing first-hand knowledge and understanding of cultural obligations, and a welcoming and culturally safe place for Aboriginal families to engage within the hospital system. In addition, non-Indigenous paediatricians and clinical nurses in AACC who were culturally trained and experienced were also essential to Aboriginal families feeling more confident to discuss their child's medical needs. This included showing respect, understanding and support for the challenges faced by Aboriginal families.

Cultural awareness training has changed the way many health professionals view Aboriginal families and our findings support the notion that this is helping make hospital visits more beneficial.<sup>23,24</sup> Training contributes substantially to health service providers understanding Aboriginal culture and can break down barriers not only in the health system but within the wider community.<sup>25</sup> Continuous quality improvement, using tools such as the Organisational Cultural Competence Assessment Tool and implementing cultural training into health professional university training have all been shown to elicit awareness and positive organisational change.<sup>26-28</sup> Despite some success, there is still more that needs to be done. Across Australia, many tertiary hospitals have recognised that mainstream hospitals are not responsive to Aboriginal people's cultural needs.<sup>25,29</sup> In Department of Health Western Australia all health employees are mandated to complete online Aboriginal cultural training; however, it appears that more could be done to help support health service providers to provide appropriate cultural care to Aboriginal families. While racism in health services remains an issue,<sup>30,31</sup> dedicated programs to improve relations between health service staff and Aboriginal families should be highlighted in policy and practice,<sup>32</sup> particularly if they have been evaluated for their effectiveness.<sup>12,33</sup> These services offer examples of good practice that can improve the healthcare of Aboriginal Australians, help to build trust and understanding throughout the community and ultimately, work towards closing the gap on health outcomes between Aboriginal and non-Indigenous Australians.

There are several limitations. Although we attempted to recruit an equal number of families from both the AACC program and non-AACC services, we were unable to do

this. We recognise that the views of families attending non-AACC services may not be fully represented. As a result, we were also unable to definitively compare AACC to existing non-AACC services to determine which option provides a better service to Aboriginal children and their families. However, the information from this study is important for understanding how families experience care in a major paediatric hospital.

## Conclusion

Our findings indicate that healthcare delivered to Australian Aboriginal children in mainstream health services can be improved when dedicated specialist programs, such as AACC, deliver culturally appropriate care. However, there are still improvements needed in the wider hospital system for Aboriginal families to feel culturally safe when attending standard services. Similar programs throughout Australia are a step in the right direction to offset ongoing structural, socioeconomic and cultural barriers that negatively impact on health and social outcomes for Aboriginal people. Findings from this study have the potential to go beyond the mainstream health sector to guide services across sectors in delivering high-quality care for Aboriginal families. What is needed is a strong commitment at the level of organisational policy and practice to embed culturally appropriate care in their service. This requires relationships between mainstream services and Aboriginal families to be established and maintained so trust can develop, and improvements can be sustained. This also includes engagement and building strong relationships with Aboriginal Community Controlled Organisations who are the frontline service for many Aboriginal families and work in the community for their community. Lastly, a dedicated commitment is needed by policy makers, mainstream services and Aboriginal stakeholders to work together to ensure such programs are ongoing, well-resourced and remain effective.

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