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Understanding burn injury among Aboriginal and Torres Strait Islander children – results of a two-year cohort study

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ABSTRACT

Background: Despite known inequalities, little is understood about the burden and healthcare experiences of Aboriginal and Torres Strait Islander children who sustain a burn injury and their families.

Methods: The Coolamon Study recruited parents and carers whose children (aged < 16 years) were Aboriginal and / or Torres Strait Islander children and had presented to burn units across four Australian states, New South Wales (Sydney), Northern Territory (Darwin), Queensland (Brisbane, Townsville) and South Australia (Adelaide), between 2015 and 2018. Consent was obtained and carers completed baseline and subsequent interviews at 3, 6, 12 and 24 months. Data were collected on the injury event, patient care and safety, sociodemographic factors, health related quality of life (PedsQual), and psychological distress (Kessler K-5).

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Results: Of the 208 participants, 64 % were male; 26 % were aged less than 2 years and 37 % aged 2–4 years. The most common burn mechanisms were scalds (37 %), contact (33 %) and flame burns (21 %), with more severe burns and flame burns occurring in rural and remote settings. Most carers rated their child's care as either excellent or very good (82 %). Family distress, measured by the K-5, lessened over the 24 months, however the changes were not statistically significant. While 77 % of carers reported that they received enough information, 18 % reported they would have liked more, and 3 % reported no information was provided before treatment. Parents described mixed access to information about the types of support available to them, such as accommodation, meals, travel or cultural support.

Conclusion: Data from this cohort provide rich new information about risk factors and care received from point of injury through to rehabilitation for Aboriginal and Torres Strait Islander children with burns, providing unique insights into what is needed for appropriate, culturally safe care.

1. Background

Burn injuries in children can be debilitating, potentially leading to lifelong disability and mental health conditions [1–3]. Globally, burn injury deaths occur in 2.5 per 100,000 children each year [4] however, deaths form only part of the burn injury burden: for each death many more children experience long hospitalisations for their burn injury. Inequities exist for burn injuries [5,6], with greater burden on children from low socio-economic areas, those in substandard living conditions or families experiencing job loss [7].

First Nations children globally are also over-represented for burns injuries [8–12]. In this paper we define First Nations people as the original inhabitants of a land; we do so recognising the sovereignty and diversity of all First Nations peoples. First Nations children are impacted further through ongoing impacts of colonisation, from child removal, loss of traditional lands, and institutional and overt racism, creating significant social and wellbeing hardship globally. In Australia and New Zealand, burn injuries in children account for nearly a third of all burn injuries, with First Nations children (Aboriginal and Torres Strait Islander children in Australia and Māori in New Zealand) being disproportionately impacted [8,13,14]. This overrepresentation reflects embedded health and social inequities experienced by colonised peoples [1,8].

Despite inequities in burn injuries, to date we have very little information detailing the burn care experiences and outcomes of First Nations children globally. Improved understanding of the injury event, healthcare experiences and outcomes for Aboriginal and Torres Strait Islander children could inform preventive and treatment strategies. This would ensure such strategies are appropriately tailored to better reflect the health needs of Aboriginal and Torres Strait Islander children and families. Previous Australian studies have largely described burn injury burden from routinely collected state or territory datasets with no exploration of patient or family experiences [9–11,15,16]. Understanding patient experience is key to providing quality, safe and responsive care, which redresses inequities in treatment and outcomes.

The Coolamon Study was established to describe burn injury burden, access to care, and outcomes among Aboriginal and Torres Strait Islander children in Australia and to inform appropriate models of care [17]. This paper describes the characteristics of participants enrolled in the Coolamon Study, including the burn injury, clinical care and impact of the burn injury on children and their families.

2. Methods

The study design and methods have been previously reported [17]. Wherever possible, the study has applied best practice approaches for research methodologies and methods in Aboriginal and Torres Strait Islander research [18–20]. We have reported the study and findings according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines, cohort studies extension [21].

2.1. *Governance*

An Aboriginal Governance Committee was established, comprising of representatives from Aboriginal Community-Controlled Organisations, government stakeholders, patients and/or Aboriginal people with lived experience of burn injury and Aboriginal members of the investigative team. The Aboriginal governance committee was central in informing the Coolamon study's design, conduct, interpretation, and policy translation to ensure a continued focus on meaningful community outcomes.

2.2. *Design*

2.2.1. *Recruitment and eligibility*

The study included five Australian tertiary burn units across four states: New South Wales (The Children's Hospital, Westmead, CHW); Northern Territory (Royal Darwin Hospital, RDH); Queensland (Townsville Hospital, TH and Queensland Children's Hospital, QCH, Brisbane); and South Australia (Women's and Children's Hospital, WCH, Adelaide).

Aboriginal and Torres Strait Islander children aged ≥ 16 years and their carers were eligible to participate if they presented to one of the participating services or were referred for burn injury treatment. At each participating site, nursing or allied health staff reviewed emergency or ward admission data to identify eligible participants and communicated this to the Coolamon study research assistants. The research assistants, the majority of whom were Aboriginal or Torres Strait Islander research staff, approached eligible families and, through an informed consent process, invited them to participate in the study.

Research assistants obtained consent from parents or guardians, and children who were 12–16 years of age or where their parent or guardian deemed them suitable to participate in the consent process. Carers were given the opportunity to discuss participation in the study with family members prior to signing the consent forms. Interpreters were available if required across locations. Recruitment took place between April 2015 - January 2018.

2.2.2. *Questionnaires*

The questionnaire was developed by the investigator team, including research assistants in consultation with the Aboriginal Governance Committee. Participant and family socio-demographic characteristics, and questions about family disruption and family structure were adapted from previous surveys including: the NSW Population Health Survey [22] and the Western Australian Aboriginal Child Health Survey [23]. Burn injury diagnoses, treatment and other relevant clinical indicators were extracted from patient medical records. At the time of project commencement, no validated quality of life tool had been developed specific for Aboriginal and Torres Strait Islander children. Post-burn Health Related Quality of Life (HRQoL) was therefore measured through a multidimensional modular approach using the PedsQL 4.0, which has been psychometrically assessed in other Australian children [24,25]. Parental trauma was assessed through the Kessler 5 (validated in Aboriginal and Torres Strait Islander peoples) [26]. Information was also collected in open-ended responses about first aid, travel related to treatment, family disruption, out of pocket health expenses and experiences related to care received.

2.2.3. *Data collection*

Data were collected and managed using REDCap electronic data capture tools hosted at The George Institute for Global Health [27,28].

2.2.4. *Baseline interview*

Information collected at the baseline interview included basic socio-demographic data (age, place of residence, measures of family structure, parental employment status and education), the burn injury and burns first aid treatment (type, time from injury and duration), the timing of treatment, and mode and timing of transportation to hospital.

2.2.5. *Follow-up interviews*

Follow-up interviews with the parents/carers were conducted at 3, 6, 12, and 24 months post-injury. Data were collected on care received (and out-of-pocket costs) since the last interview, PedsQl HRQoL [25], pain, itch, and return to school. Parents/carers were asked to complete measures as outlined above along with psychological distress for themselves (K-5), and questions on disruptions to family or employment due to treatment or caring needs.

2.3. *Clinical data*

Research assistants at each study site extracted information from the hospital medical record. Data included variables submitted to the Burn Registry of Australian and New Zealand (BRANZ) registry such as date of burn, external cause and context of injury, percentage of total body surface area affected (%TBSA), depth of burn, anatomical location of burn, referring agency, mode of patient transfer, operative procedures, admission/length of stay to intensive care units, discharged destination, outpatient visits, including specificity and frequency of services (e.g. occupational therapist, psychologist, Aboriginal Health Worker, access to interpreter services), and scar management.

2.4. *Analysis*

Descriptive statistics were used to report the cohort's individual and family demographics, burn injury event, treatment at baseline and impact of injury. Sub-group analyses were conducted on recorded burn injury outcomes (itch, scarring and quality of life) among children with a burn injury of at least 10 % TBSA.

For the PedsQl and K-5 analyses, the data distribution for the PedsQl and the Kessler 5 was skewed, making transformation to the normal distribution not possible. Data analyses were conducted using STATA/BE 17.0 and SAS.

Open-ended responses to questions regarding parents'/carers' perceptions of the child's care were analysed using a qualitative descriptive approach [29].

2.5. *Ethics*

We obtained approval from the following ethics committees (Table 1).

3. Results

3.1. *Participants*

A total of 208 children (64 % (n = 133) were male and 37 % (n = 77) were aged 2–4 years) and their families were enrolled in the study. Fig. 1 shows retention rates across the five timepoints.

Participants' characteristics and demographics are in Tables 2 and 3. Majority of the children had excellent health prior to injury, with two-thirds of carers reporting their children having no previous chronic health condition (66 %, n = 138), while 29 % (n = 60) reported one prior health condition and 5 % reported at least two conditions. Almost three in five carers (60 %, n = 125) reported low levels of psychological distress on the K-5 scale; however, 12 % (n = 25) reported high to very high levels of distress at baseline (Table 3).

At baseline, family functioning was reported as high to very high on the family functioning scale with the most positive responses ('very much' or 'quite a lot') being "People in our family are accepted for who they are" (87 %, n = 180). Four in five families (81 %) spoke English as their main language at home and 7 % (n = 15) spoke either Kriol or an Aboriginal or

Table 1 – List of Ethics approvals for the Coolamon Study.

State	Ethics Committee	Approval Number
NSW	Aboriginal Health & Medical Research Council Ethics Committee (EC00342)	971/13
NSW	Sydney Children's Hospitals Network Human Research Ethics Committee (EC00130)	HREC/13/SCHN/440
SA	Aboriginal Health Research Ethics Committee (EC00185)	04 –14 –572
SA	Women's & Children's Health Network Human Research Ethics Committee (EC00197)	HREC/14/WCHN/65
SA	Flinders University - Social and Behavioural Research Ethics Committee	OH–00065
NT	Central Australian Human Research Ethics Committee (EC00155)	HREC–14 –253
NT	Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health (EC00153)	HREC/2014 –2214
QLD	Children's Health Services Human Research Ethics Committee (EC00175)	HREC/14/QRCH/328
QLD	Human Research Ethics Committee, JCU Clinical School	HREC/14/QTHS/209
QLD	The University of Queensland Medical Research Ethics Committee (EC00179)	2014001541
National	Department of Health Human Research Ethics Committee (EC00106)	39/2014

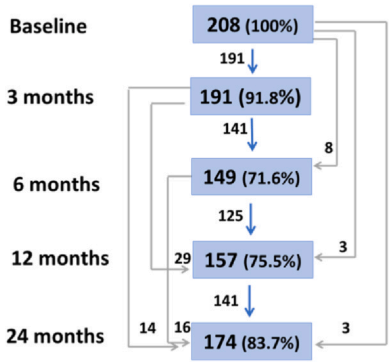

Fig. 1 – Flowchart of participant follow-up rates from baseline to 24 months.

Table 2 – Participants of the Coolamon study: child characteristics at baseline.

Variable	Category	Number (%)
Sex	Female	75 (36.1)
	Male	133 (63.9)
Age	< 1 year	12 (5.8)
	1 year	42 (20.2)
	2 –4 years	77 (37.0)
	5 –7 years	28 (13.5)
	8 –12years	37 (17.8)
	13 –18 years	12 (5.8)
Aboriginal status	Aboriginal	198 (95.2)
	Torres Strait Islander	5 (2.4)
	Aboriginal and Torres Strait Islander	5 (2.4)
Site	Adelaide	29 (13.9)
	Brisbane	70 (33.7)
	Darwin	10 (4.8)
	Townsville	27 (13.0)
	Westmead	72 (34.6)
Remoteness of residence	Major Cities	86 (41.3)
	Inner Regional	41 (19.7)
	Outer Regional	38 (18.3)
	Remote & Very Remote	43 (20.7)
Prior health conditions	0	138 (66.3)
	1	60 (28.8)
	2 or more	10 (4.8)
Total		208

Torres Strait Islander language. A little over half carers had three or more children aged ≤ 16 years living in the household (52 %, n = 108). Despite the hospitals being in major cities, three in five children (59 %, n = 122) were from regional or remote areas (Table 3).

3.2. *Injury event*

Table 4 describes the burn mechanisms and initial care. Burn size was mainly less than 10 % TBSA (73 %, n = 151), with 7 children (3 %) reporting a major burn of at least 20 % TBSA.

Burn injury mechanism differed by geographical remoteness (Fig. 2), with children from remote and very remote areas mostly experienced flame and scald burns (33 %, n = 14 for each), while children from major cities mostly experienced scald and contact burns (45 %, n = 39; 38 %, n = 33 respectively) (Table 5).

While the majority (94 %, n = 194) of cases received some first aid, only 26 % (n = 54) received 'gold standard first aid' (defined as cool running water for 20 min within the first three hours of the burn injury [30,31]) prior to seeing a health professional,. Most children (n = 176) presented to a health service on the day of injury, a further 16 presented the next day and 9 presented within seven days. Generally, children presented to a non-specialist burn service first (77 %, n = 160) before being transferred, with 37 % (n = 77) travelling via private vehicle. In most cases children were accompanied to hospitals by a family member (89 %, n = 186).

3.3. *Care received*

Only a quarter of all children's medical notes (25 %) included evidence of an Aboriginal/Torres Strait Islander/Indigenous Liaison Officer/Aboriginal Health Worker/ (ALO/AHW/ILO) attending or being consulted (see Supplementary Table A). At the first interview, when carers were asked if the hospital had provided information about any in-house support available through the hospital, only 62 of the 187 respondents said they had. Of those, 44 said they had seen an ALO, AHW or ILO and one had said they had seen an Aboriginal social worker. Following discharge from hospital, a third (34 %) of children did not have any further burn related hospital presentations.

Table 3 – Participants of Coolamon Study: family characteristics at baseline (missing values not shown).

Variable	Category	Number (N = 208) (%)
Children under 16 years in household	< =2	79 (38.0)
	3 –4	79 (38.0)
	> 4	29 (13.9)
Main language spoken in the home	English	168 (80.8)
	Aboriginal language	12 (2.4)
	Kriol	3 (1.6)
Parental/carer's employment status	Employed (full- or part-time or casual)	52 (27.2)
	Not employed/on government support	139 (72.8)
Family functioning		
The way we get on together helps us to cope with the hard times	Very much / Quite a lot	169 (81.3)
	Other	17 (8.2)
We like to remember people's birthdays and celebrate other special events	Very much / Quite a lot	178 (85.6)
	Other	10 (4.8)
We find it easy to talk with each other about the things that really matter	Very much / Quite a lot	168 (80.8)
	Other	19 (9.1)
We are always there for each other and know that the family will survive no matter what	Very much / Quite a lot	175 (84.1)
	Other	13 (6.3)
When it comes to managing money we are careful and make good decisions	Very much / Quite a lot	150 (72.1)
	Other	37 (17.8)
Our family has a lot in common in the interests we share and the things we do	Very much / Quite a lot	157 (75.5)
	Other	30 (14.4)
People in our family are accepted for who they are	Very much / Quite a lot	180 (86.5)
	Other	8 (3.8)
We have good support from our in-laws relatives and friends	Very much / Quite a lot	164 (78.8)
	Other	23 (11.1)
We have family traditions and customs we would like to pass on to our children	Very much / Quite a lot	157 (75.5)
	Other	28 (13.5)
Kessler 5	Low distress	125 (60.1)
	Moderate distress	36 (17.3)
	High distress	14 (6.7)
	Very high distress	11 (5.3)
Total		208

Fifty children (24 %) had at least four additional burn related hospital presentations (including outpatient care).

3.4. *Families' experience of the care received and communication about the burn care*

Most carers (n = 61, 9 %) reported staying overnight with their child in hospital and an additional 20 (10 %) carers reported staying overnight at a friend's house, motel, or in accommodation organised by the hospital. More than half of carers (n = 105, 50 %) said that hospital staff had not given them information about any in-house support available through the hospital.

At baseline, 124 (60 %) carers indicated they were given information about the burn treatment their child may need before coming to the burn clinic, while a quarter (n = 51, 25 %) did not, but would have liked this information. Similarly, most carers (n = 128, 62 %) said that staff explained the risks and benefits before treatment, but a further 47 (23 %) said this was only done "to some extent". Overall, three quarters of carers (n = 145, 760 %) said they had received enough information about their child's condition; however, 38 (18 %) said they had either received none or not enough information.

When asked if they were involved as much as they wanted to be in the decisions about their child's care, 154 (74 %) carers selected "yes, definitely" while the remainder 33 carers (16 %) said either "no" or "only to some extent". Almost three quarters of carers (139, 67 %) said they did get responses that they could clearly understand, to their care related questions, while 45 (22 %) said either they understood responses "to some extent", did not have an opportunity to ask or simply that they did not receive a response they could understand. Most 158 (76 %) carers said they were told who to contact if they were worried about anything to do with their child's care, 21 (10 %) participants said no they weren't told.

Of the 167 carers who rated their child's care from the burn service at baseline, 81 (39 %) selected excellent, 76 (37 %) said either good or very good, while nine (4 %) said very poor, poor or fair. Of the 173 carers who responded to the question of whether anything carers thought was really good about their child's care or treatment, 142 (68 %) yes with 149 providing examples. Comments ranged from describing that they felt their child was well cared for, to being grateful for "sharing their knowledge and making me feel involved in the care and treatment of my child," and explaining that while some staff cared well for their child, other staff were rude. More than half of carers (n = 131) indicated things could be done to improve care. Responses included parents saying they: needed help organising bandages in preparation for discharge from hospital; needed support with accessing food

Table 4 – Burn mechanism and initial care of children in the Coolamon Study (n = 208, missing values not shown)).

Variable	Category	Number (%)
Burn mechanism	Contact	68 (32.7)
	Scald	79 (38.0)
	Flame	42 (20.2)
	Friction	12 (5.8)
	Other	7 (3.4)
Activity	Sport, leisure & play	91 (43.8)
	Eating, cooking, food preparation	50 (24.0)
	Other vital activities	35 (16.8)
	Other	18 (8.7)
	Not Stated	13 (6.3)
Event place	Home	117 (56.3)
	Other	24 (11.5)
	Not stated	66 (31.7)
Travel to hospital	Ambulance	23 (11.1)
	Air Ambulance or Helicopter Rescue or Care Flight	61 (29.3)
	Commercial flight	15 (7.2)
	Private Vehicle	77 (37.0)
	Other	13 (6.3)
Did any one travel with the child to this hospital?	No	5 (2.4)
	Yes	187 (89.9)
Where was the child referred from?	Scene of injury via ambulance retrieval	13 (6.3)
	Other hospital	125 (60.1)
	GP	19 (9.1)
	Self-presentation	22 (10.6)
	Aboriginal Medical Service	8 (3.8)
	Other	8 (3.8)
Burn depth	Superficial dermal	47 (22.6)
	Mid dermal (or partial)	61 (29.3)
	Deep dermal (or deep partial)	48 (23.1)
	Full thickness	29 (13.9)
Total body surface area affected	0 –9 %	151 (72.6)
Median - also	10 –19 %	22 (10.6)
	> =20 %	7 (3.4)
	Total	**208**

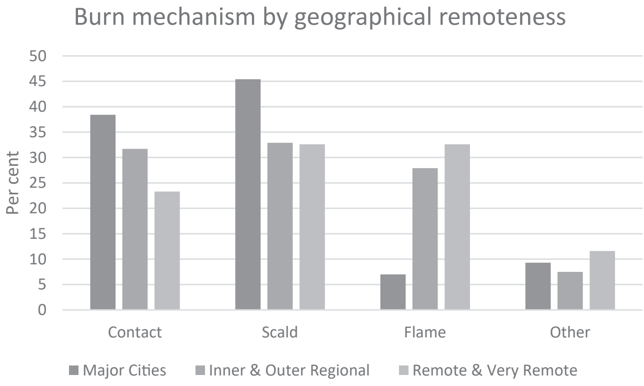

Fig. 2 – *Burn mechanism by geographic location.*

Table 5 – Burn mechanism by areas of remoteness.

	Geographical Remoteness			
Burn mechanism	Major Cities	Inner & Outer Regional	Remote & Very Remote	Total
Contact	33 (38.4)	25 (31.7)	10 (23.3)	68 (32.7)
Scald	39 (45.4)	26 (32.9)	14 (32.6)	79 (38.0)
Flame	6 (7.0)	22 (27.9)	14 (32.6)	42 (20.2)
Other	8 (9.3)	6 (7.5)	5 (11.6)	19 (9.1)
Total	86	79	43	208

while in hospital; needed counselling due to the emotional impact of their child's burn injury; needed more information; needed more support for families who come from 'out of town'; felt disrespected and experienced racism in hospital, and felt the care in the first referring hospital (usually the hospital local to the family) was sub-standard with need for local services to be trained in tending to burn dressings after discharge from the hospital.

3.5. *Impact on family*

The level of family distress as measured by the K-5 appeared to lessen over the 24 months, however statistically these changes were not significant (Table 6). More than half of carers described having to stay away from home during their child's hospitalisation and treatment (57 %, n = 118), with the mean number of days being 12. Of those who stayed away from home, the majority (67 %, n = 79) of carers said they did not have to pay for accommodation. For families who had to pay for accommodation, costs ranged from $20 per night to a total of $750 out-of-pocket for accommodation expenses. We found 32 instances where carers in our interviews mentioned staying overnight in hospital for their child's treatment, although this parental attendance was not recorded in their child's medical records. Among those with no mention of overnight stays in the medical records, participants at interview had described having to pay between $20 to $400 to cover their accommodation costs. Carers described sharing time spent in hospital between parents and grandparents while other family members helped take care of their younger children at home. Carers voiced concern about needing to care for their other children, loneliness, being away from Country, community and missing cultural obligations. Of the 29 children with a burn of at least 10 % TBSA, almost half came from remote or very remote areas (45 %,

Table 6 – Measure of family distress across the timepoints.

Kessler 5 across the timepoints	Valid measurements	Mean (SD)
Baseline	186	7.5 (3.61)
3 months	125	6.2 (2.54)
6 months	104	5.4 (1.00)
12 months	112	6.0 (3.04)
24 months	106	5.2 (0.84)

n = 13) and all but 2 of the 29 children's carers spent at least one night away from home with their child in hospital.

Other parents also described the impact of the costs associated with travel to and from the hospital, such as unaffordability of fuel, parking fees of up to $600 for hospital stays, food and travel costs even when accommodation costs were nil. At baseline, almost half of carers said that they were concerned they would have trouble managing financially (42 %, n = 78).

3.6. *Burn outcomes*

Among the 173 children with medical records on any complications experienced, almost three quarters of the children (61 %, n = 126) were listed as having "no problems". Of those who did experience complications, the most common was infection, followed by psycho-social issues. Among the 96 children admitted for an overnight stay immediately following the burn injury, 62 were discharged partially healed, undergoing ongoing burn care.

Of those children with a TBSA burn of at least 10 %, 73 % experienced some itch at three months compared with only 40 % of children with a TBSA burn of less than 10 %. Within 24 months this had largely resolved: 90 % of all participants for whom we had 24-month itch data (37/41 participants) reported experiencing no itch. Similarly, experiencing burn-related pain was essentially resolved by the 24-month interview, with 94 % of those who responded to questions about pain (34/36 participants) reporting their child no longer experienced burn-related pain. Scarring, measured by the Patient Observer Scar Assessment Scale (POSAS), had improved from three months (mean score of 18 down to 10 at the 24-month follow-up interview (Supplementary Table B).

From Table 7, across each of the four follow-up time points, paediatric quality of life scores improved from a total mean score of 86.3 ± 18.4 at baseline to 93.4 ± 11.8 at the 24-month follow-up interview (n = 106), however these differences were not statistically significant. Higher scoring was noted in the physical domains compared with psychosocial domains across each of the interview timepoints, with greatest improvements noted across the physical domains, however these were not significant.

4. Discussion

To our knowledge, this is the first study to follow a cohort of Aboriginal and Torres Strait Islander children, or any First Nations children globally, who have experienced a burn injury and reported on family and child experiences. Our research team comprised of Aboriginal and non-Aboriginal clinicians and researchers and the study was guided by an Aboriginal Governance Committee comprising representation of people from Aboriginal Community Controlled Heath Services and those with lived experience of burn injury.

Our cohort was similar to other cross-sectional and linked data studies reporting burn injury among Aboriginal and Torres Strait Islander children [8,16]. We report 57 % of children in our study were aged 1–4 years; both Möller [9], in a linked data study based on all hospital admissions across one state (New South Wales) and Ryder [8], who analysed data from BRANZ, reported a similarly large proportion of children being aged 1–4 years (63 % and 53 % respectively). A greater proportion of children in the Coolamon Study were from major cities (41 %) compared with children from remote and very remote areas (21 %). This cohort differs from both the Möller and Ryder studies where 44–65 % of children were from regional (inner and outer) areas and only 21–24 % were from major cities. This difference is possibly due to either identification of Aboriginal and Torres Strait Islander status in hospital data being lower in metropolitan areas [32] or due to Möller's study including all burn hospital admissions across one state, while the Coolamon study focused solely on children presenting to specialty burn services across four states – a factor likely to result in our cohort experiencing more serious burns than Möller's study and likely similar burn severity to Ryder's (BRANZ) study.

The most common mechanism of injury experienced by children in our cohort were scald burns followed by contact and flame burns (38 %, 33 % 20 % respectively), which is similar to Ryder (39 %, 32 % and 20 %) [8] and differs slightly from that reported by Möller, which reported a greater proportion of scald burns (47 %), fewer contact burns (23 %), similar flame burns (18 %) and included data from all hospitals across NSW, not just burn units [11]. Given most participants resided in urban or inner regional areas this result is not surprising with known association with rurality and type of burn [9]. Parents and carers in our study reported positive family functioning, measured by the Western Australian Aboriginal Child Health Survey (WAACHS) family functioning questions. Our findings were similar to those reported in WAACHS, where acceptance of people in the family was the most common response [33].

Most families in our study reported having to be away from home to care for their child in hospital. As the majority of families had more than one child, this meant having to leave children at home and being reliant on family and community for support and impacted on a carers' work commitments. This impact is also described in more detail in Ryder's paper on yarning about out-of-pocket healthcare expenditure which identified impacts on costs (such as transport and medication), employment capacity, social connection and need for family and service support [34].

Families' experience of care received was mixed. While the majority of families reported being happy with their child's care, being involved in decision making, the fact that some families reported not receiving adequate information, not knowing who to turn to if they were concerned about their child's burn, not being informed of the presence of

Table 7 – Paediatric Quality of Life Total Scores across the five interview timepoints.

	Psychosocial Health Summary Score			Physical Health Summary Scores		
Interview timepoint	Mean	Std. dev.	Valid measurements	Mean	Std. dev.	Valid measurements.
Baseline	86.29	18.37	188	90.97	18.26	186
3 months	90.06	14.97	124	93.09	17.02	124
6 months	89.09	14.53	107	96.26	10.13	107
12 months	89.79	15.82	112	97.50	8.21	113
24 months	93.43	11.82	106	99.06	4.27	106

AHW/ALO/ILO in the hospital and the supports available and reporting feeling disrespected and exposed to racism in healthcare warrants action. These experiences are not specific to burn injury. Aboriginal and Torres Strait Islander people's experience of the hospital system has long identified similar issues in cardiac care [35], cancer care [36], renal care [37] and the hospital system generally [38,39]. This highlights the need for institutional/managerial commitment to delivering care that ensures people experience cultural safety [40]. Based on what families told us, practical actions can be adopted immediately. This includes: identification of supports available to family (both in the hospital and community); clear, respectful and appropriate communication; linking with community services for discharge planning from hospital; ensuring parents know who to contact if concerned about their child's healing and how to obtain supplies such as bandages once at home.

Our study found little evidence in medical records of the hospital's AHW/ALO/ILO being included in the multidisciplinary burn team. In at least one hospital for some of our recruitment period, an AHW/ALO/ILO was not employed due to lack of resourcing. The role and value of AHW/ALO/ILOs in healthcare is recognised, providing benefits such as addressing communication divides, improving follow-up and referral processes, provision of cultural education [41–43]. We find potential for AHW/ALO/ILOs to be resourced to work alongside multidisciplinary teams in burn care and discharge planning.

The nuances of data collection across the sites must be considered in our findings. First, recruitment processes differed considerably across the services, with one service only recruiting potential participants who had been admitted as an inpatient while other hospitals recruited all Aboriginal and Torres Strait Islander patients (both inpatients and outpatients) who presented to the specialist burn services. Our recruitment processes were dependent on our Aboriginal, Torres Strait Islander and non-Indigenous research team building a close relationship with the burn team members. This also meant that we were reliant on hospital staff routinely asking the identifying question (Is your child of Aboriginal and/or Torres Strait Islander descent?) however, we know this did not always happen and research has shown that metropolitan hospitals are less likely to ask an identification question [32]. This highlights the need for ongoing effective cultural capability training for all hospital staff.

It is a strength of our study that all research assistants connecting with families were Aboriginal and/or Torres Strait Islander people or people who were experienced in working with Aboriginal families and communities. This likely correlates with successful initial recruitment to the study and particularly in being able to create and maintain connection with families over a two-year period, building a relationship of trust was pivotal in the study's success. Our study highlights the need for capacity and commitment to the provision of integrated, culturally safe burn care, providing pre-emptive support to Aboriginal and Torres Strait Islander families whose child presents with a burn injury. This implies that all staff are confident and capable in being able to deliver regardful care that creates families' experiences of cultural safety in healthcare and includes systematic approaches to respectfully identify all Aboriginal and Torres Strait Islander families to ensure appropriate care is received. This study supports broader recommendations regarding quality health care as per the Australian Commission on Safety and Quality in Health Care and as directed in the National Safety and Quality Health Service Standards [44].

The Coolamon study has resulted in a significant body of work from reviews (systematic, scoping) [2,3,45,46], analyses of registry data [8,14], collection of prospective data from Aboriginal and Torres Strait Islander children and their families hospitalised for a burn injury [43,47], along with interviews with burn services clinical staff [1]. We have also explored measures of out-of-pocket health expenditure following burn injury [34].

Our findings highlight an important need to develop programs and strategies to better support Aboriginal and Torres Strait Islander families whose child experiences a burn injury. Our study adds to this body of knowledge by both describing the experience of families as they and their children navigate the hospital system and by highlighting key factors along the burn injury pathway that can be better addressed. Specifically, we have identified the need for more targeted first aid support given the proportion of children who did not receive gold standard burn first aid in the first three hours following the injury; the need for effective and culturally respectful and regardful care and communication between services, and with families; the opportunity to more fully and systematically resource and incorporate the role of AHW/ALO/ILOs into the multidisciplinary burn team, and the need and opportunity to continue to build cultural safety capabilities among the healthcare workforce. If such initiatives were incorporated into health systems, significant improvements to both delivery of health care and patient outcomes would improve for burn care for Aboriginal and Torres Strait Islander children.

Significance: Aboriginal governance, rich contextual understanding of burns that has not been published before.

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CRediT authorship contribution statement

K Hunter: Project manager, supervision, methodology, data curation, writing – original draft, review and editing. C Ryder: Methodology, writing – original draft, review and editing. J Coombes: Methodology, data collection, writing – review and editing. K Clapham: Methodology, conceptualisation, supervision, writing – review and editing. T Mackean: Methodology, conceptualisation, supervision, writing – review and editing. AJA Holland: Methodology, conceptualisation, supervision, writing – review and editing. S Fraser: Data collection, writing – review and editing. H Williams: Methodology, data collection, writing – review and editing. B Griffin: Supervision, conceptulisation. H Möller: Data curation, formal analysis, writing – original draft. R Ivers: Funding acquisition, conceptualisation, supervision, lead investigator, methodology, writing – review and editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.burns.2024.07.018.

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