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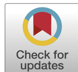

How deep does it really burn? Social and emotional implications of paediatric burn injuries and care on Aboriginal and Torres Strait Islander families

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ABSTRACT

Background: Paediatric burns are highly painful and traumatic injuries that affect Aboriginal and Torres Strait Islander children at disproportionate rates, yet their experiences are often omitted from burns research. This study aimed to better understand the social and emotional impacts and unmet support needs that paediatric burn injuries and care cause Aboriginal and Torres Strait Islander families.

Methods: This decolonial ethnographic study followed 20 Aboriginal and Torres Strait Islander families' experiences of paediatric burns care at a tertiary hospital in Queensland, Australia. Three methods were combined, including *participant observations* of burns care appointments/procedures (n = 54); *retrospective thinking aloud* sessions with burn specialists (n = 62); and *yarning sessions* with families (n = 14). Grounded theory analysis was conducted and triangulated for in-depth explorations of each family's experiences.

Results: Paediatric burn injuries and care cause profound and prolonged social and emotional impacts for all members of Aboriginal and Torres Strait Islander families. These include, but are not limited to, panic, shock, distress, guilt, and fear; along with social isolation, family disruptions, physical implications, and financial and food insecurities. These burdens were worsened when burns care was uncollaborative, culturally unsafe, and included minimal supports.

Discussion: Paediatric burn specialists play vital roles in supporting Aboriginal and Torres Strait Islander families throughout burns care and beyond. However, several barriers continue to hinder their ability to provide collaborative and culturally and trauma-responsive care. There is a strong need for burns care to incorporate routine mental health screening, and cultural and mental health supports for all members of Aboriginal and Torres Strait Islander families.

1. Introduction

Burn injuries are among the most physically and psychologically traumatising injuries a person can endure [1], especially children and adolescents. The distress and panic experienced during a burn event is profound and often continues into acute care as patients endure

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consistent pain that is worsened by regular dressing changes and procedures that are described as 'excruciating' [2]. This is further compounded by unique challenges to managing burn-related pain [3], which can lead to poorly managed pain [2,4] and further increased risk of social and emotional maladjustment for up to two years following hospital discharge [5].

Aboriginal and Torres Strait Islander people are hospitalised for burn injuries at more than three times higher rates than non-Indigenous people [6]. Aboriginal and Torres Strait Islander children and adolescents that are hospitalised for burn injuries also remain in hospital on average four days longer than their non-Indigenous peers [7]. This prolonged length of stay is associated with greater injury severity, increased number of flame burns, specialised treatment requirements, and the need to travel from rural or remote areas where appropriate health services are limited [7]. Prolonged hospitalisation can increase families' vulnerability to social and emotional burdens due to isolation from family and support networks; yet little is known of Aboriginal and Torres Strait Islander families' experiences when hospitalised for burns care.

The social and emotional impact of paediatric burn injuries has been well established in the general population and found to deeply affect both the injured child and caregivers [8,9]. This is highlighted by a recent systematic review by Woolard et al., summarising 42 studies that investigated the psychological impacts of paediatric burn injuries on children and adolescents [10]. The collective findings show that the most common implications are increased anxiety, acute stress disorder, and post-traumatic stress disorder (PTSD); followed by depression/mood disturbances, emotional issues, lowered self-esteem, impaired quality of life (QoL), and increased mental health diagnoses post-injury [10].

Bayuo and Wong's recent scoping review further summarised the impact of burn injuries on the broader family, including caregivers, siblings, and extended family members [11]. The collective findings highlight that siblings of paediatric burn patients often experience shock, sadness, and upset towards the burn wounds [12], flashbacks of the burn event or wounds [13], and jealousy towards the attention given to their injured sibling [13,14]; while grandparents, aunts, and family friends experience anxiety, confusion, and helplessness [12,15]. This review also highlighted that siblings of paediatric burn patients had a desire to be part of burns care [13,14], and were important in helping their sibling return to school and normal activities [14]. Further, studies by Ravindan et al. in India found that grandmothers, aunts, and female friends take on more helping roles during the child's recovery, including offering emotional and instrumental support [12,16].

Australia is the second leading producer of research related to psychological impacts of paediatric burn injuries (12 out of 45 studies worldwide) [10]. Yet only four of these studies included Aboriginal and/or Torres Strait Islander families [17–20] and only one focused on their perspectives and experiences [20]. Coombes et al.'s work, along with the current study, contributed to the Coolamon study, the first longitudinal exploration of the impact of paediatric burn injuries on Aboriginal and Torres Strait Islander families [21,22]. Coombes' work importantly highlights the various systemic barriers faced by Aboriginal and Torres Strait Islander families in accessing supportive burns aftercare. These included a lack of local support and services, poor communication from health professionals, a lack of trauma-specific support, and increased stress from transportation costs, schooling and work disruptions, and separation from their families and Country [20]. Further, Aboriginal and Torres Strait Islander peoples' access to equitable healthcare continues to be impaired by the ongoing impacts of the underlying social and cultural determinants of health, such as educational, employment and housing disadvantage, institutionalised racism, lack of cultural competency in health services, and lack of culturally appropriate resourcing and language [23–26].

The growing body of work in this area is shedding light on Aboriginal and Torres Strait Islander families' unique experiences with paediatric burns. However, little remains known of the trajectory and development of psychological symptoms amongst Aboriginal and Torres Strait Islander families undergoing paediatric burns care and the social and emotional impacts of the acute care phase. This is critical to understand as the social and emotional impacts caused by burn injuries can become chronic and debilitating if not addressed early with appropriate screening and support [8,19]. Many paediatric burn patients in general do not have access to adequate support and continue to experience unmet support needs [27]. It was anticipated that Aboriginal and Torres Strait Islander families' would likewise experience limited support; however, it is imperative to understand their unique support needs to improve burns care and adequately meet these needs. This paper provides an in-depth overview of the experiences of Aboriginal and Torres Strait Islander families during acute paediatric burns care (from time of injury to wound healing), including the level of care and support they received, the social and emotional implications, and their specific ongoing support needs.

2. Methods

This paper outlines results from the Fire and Smoke study, which explored the social and emotional experiences of 20 Aboriginal and/or Torres Strait Islander families undergoing paediatric burns care between 2017 and 2019 [28]. The hospital site is the sole specialist paediatric facility in its state and treats more than 75,900 emergency presentations, 46,500 inpatient admissions, and 304,000 outpatient appointments per year [29].

This study used Indigenous research methodologies and a decolonial ethnographic approach incorporating three methods: participant observations, thinking aloud sessions, and yarning sessions. Indigenous research methodologies encompass a diverse range of methods that incorporate vital reflection and "conversation with community members and collaborators to determine methods and frameworks that prioritise Indigenous ways of knowing throughout all stages of the project" [30]. Decolonial ethnography is a form of Indigenous research methodologies, which critically challenges the colonial roots of anthropology and ethnography and its deeply problematic framing of researchers as experts over the people and environments of which they study by honouring research participants as valuable knowledge holders and equal contributors to research and knowledge production [31].

Indigenous research methodologies and decolonial ethnography challenge colonial views on what constitutes knowledge and how it is produced, presented and used. In both approaches, the focus is shifted from preconceived research agendas of the dominant culture, to fulfilling Aboriginal and Torres Strait Islander peoples' and communities' aspirations, visions, and aims [31–33]. Indigenous research methodologies, including decolonial ethnography, must be led by First Nations people, prioritise our knowledge systems, and foster our self-determination and control over research through respectful and reciprocal involvement in all stages of the research process [30,34].

This study was led by an Australian Aboriginal researcher (HW) in collaboration with Aboriginal and Torres Strait Islander families undergoing paediatric burns care. The research aim was self-determined by the families during the collaborative conceptualisation phase, and was achieved through the families' ongoing and integral involvement as valued knowledge holders at each phase from conceptualisation, knowledge creation, translation, and dissemination. Our prioritisation of the Indigenous research method of yarning was combined and interwoven with the Westernised qualitative methods of thinking aloud and participant observations.

Participant observations were carried out by an Australian Aboriginal researcher (HW) on 54 burn appointments/procedures involving an Aboriginal and/or Torres Strait Islander child. These observations aimed to gain a deep understanding of the culture of paediatric burns care, Aboriginal and Torres Strait Islander families' SEWB whilst accessing care within this culture, and offers/provision of support by burn

specialists. These observations were immediately followed by 60 retrospective thinking aloud sessions with 26 paediatric burn specialists who provided care/support during the appointment. 'Burn specialists' included doctors, nurses, social workers, occupational therapists, and physiotherapists working within the paediatric burns unit. The retrospective thinking aloud sessions aimed to gain an understanding of burn specialists' perspectives of the care they provided and Aboriginal and Torres Strait Islander families experiences of this care. Yarning sessions were held between the Australian Aboriginal researcher (HW) and 14 families following their child's physical healing to gain a deeper understanding of their experiences of paediatric burn injuries and care. The family yarns involved any family member interested in taking part, including parents, grandparents, aunties/uncles, siblings, and cousins. The methods of this study are outlined in detail elsewhere [28].

2.1. Authors' positionality

The first author (HW) is an Australian Aboriginal woman, health psychologist and early-career researcher, specialising in Indigenous health and trauma research. KH is a non-Indigenous woman, nurse, and senior research fellow, specialising in Indigenous health and traumatic injury research. BG is a non-Indigenous woman and Professor of nursing, specialising in traumatic injury and emergency care research. RK is a non-Indigenous man, surgeon, and Professor specialising in urology, burns, and traumatic injury care and research. KC is an Australian Aboriginal woman and Professor of Indigenous health studies, specialising in traumatic injuries and ethnographic research.

2.2. Ethics approval

Ethical approval was received from the Health Service Human Research Ethics Committee (HREC/14/QRCH/328/AM04), and the Children's Health Queensland Hospital (SSA/18/QRCH/378). This study and the larger Coolamon study, under which this sub-study sits, were guided by ethical guidelines for research with Aboriginal and Torres Strait Islander people [35,36]. The Coolamon study was overseen by an Aboriginal and Torres Strait Islander Advisory Group, including Aboriginal and Torres Strait Islander health care providers, community members, and families affected by paediatric burn injuries. This sub-study was also conducted with consultation with Indigenous Hospital Liaison Officers at the study site.

2.3. Analysis

Sessions were audio recorded following participants' consent, professionally transcribed, and deidentified before undergoing Constructivist Grounded Theory (CGT) coding. In this approach, theories are constructed from the data rather than fitting data to preconceived frameworks or agendas [37,38]. Therefore, CGT aligned well with Indigenous research methodologies and further allowed this study to privilege the Aboriginal and Torres Strait Islander families' stories and experiences, and facilitate their autonomy in dictating the specific needs and priorities to be addressed. Our use of CGT analysis followed the standard core principles and cyclic process of initial and intermediate/focused coding, memo writing, continual comparative analysis, and concurrent data collection and analysis. [37–39]. Following CGT analysis, the three data points (participant observations, thinking aloud, and yarning) were triangulated at the family level for a deeper exploration of each family's experience. A detailed overview of this analytical process is outlined in the methods paper [28].

The yarning data was initially coded into emotional impacts (35 categories), social impacts (24 categories), and support needs (3 major- and 32 sub-categories). These were refined in collaboration with the research team and Aboriginal and Torres Strait Islander families into emotional impacts (16 categories), social impacts (5 major- and 15 sub-categories), and support needs (3 major- and 7 sub-categories). Burn specialists were asked for their perspectives on the Aboriginal and Torres Strait Islander families' coping, which was coded into emotional impacts (10 categories), social impacts (14 categories), and support provided (4 categories). The refined categories were compared through six matrix queries in Nvivo (Version 13/R1) [40]. The results from these queries were tabulated and relevant excerpts from the observational field notes were added to provide a three-pronged overview of the families' social and emotional impacts, offers of support, and unmet support needs.

3. Results

Burn injuries and care caused a multitude of severe social and emotional impacts for all members of Aboriginal and Torres Strait Islander families (Fig. 1), which were prolonged and widespread across the care trajectory (Fig. 2). Each stage presented a range of new challenges for families to navigate, causing a continuous cycle of social and emotional disruptions, followed by a sense of competence and understanding of burns care and emotional recovery, before repeating the cycle with the next stage and challenges of care.

The most commonly reported responses were anxiety, fear, shock, panic, guilt, blame, and worry. These were accompanied by social isolation, family disruptions, restricted mobility and bathing, financial strain, and food insecurity. For Aboriginal and Torres Strait Islander families, these common negative experiences of paediatric burns care are compounded by ongoing experiences of racism and culturally unsafe care, which contribute to debilitating fear of the Department of Child Safety (DoCS – also referred to as welfare), hospital settings, and health professionals. These burdens were exacerbated by challenges accessing burns care (travel expenses, long distance travel, difficulty finding accommodation), and uncollaborative burns care (insufficient healthcare information, exclusion from care decisions, limited opportunities for questions).

3.1. Burn event and injury

The burn events and injuries were described as 'horrific' and 'traumatic' by the families and caused several family members to experience symptoms of panic, distress, shock, and post-traumatic stress disorder (PTSD) for months following the event. Injured children and their siblings commonly experienced avoidant behaviours (particularly previously enjoyable activities that led to the injury, e.g., motorbike riding), flashbacks, fear, guilt, self-blame, and shame. Similarly, caregivers (parents, aunties, uncles who provide day-to-day care to the child) and other caring adults (grandparents, aunties, uncles who do not provide day-to-day care, but play significant roles in the child's life) commonly experienced emotional distress, panic, diminished self-confidence, guilt, and blame, which occasionally manifested as anger. See Supplementary Table 1 for full data of the burn event and injury impacts.

These initial responses were inconsistently acknowledged by burn specialists, who often misinterpreted families as being calm or mildly stressed. Some burn specialists self-reported being desensitised to burn injuries and experiencing frustration and confusion towards families' distress towards the wounds. Furthermore, some burn specialists tried to support distressed patients and caregivers by encouraging them to look at wounds; however, this caused some patients to be afraid or shocked by their injuries and caregivers to experience panic attacks, nausea, and trauma triggers.

All families displayed signs of guilt and blame, which were associated with one of two core beliefs: 1) the event was their fault (experienced by the injured child and siblings); or 2) they failed to protect the child by not preventing the injury (experienced by the caregivers, siblings, other caring adults) or trusting others to care for the child (experienced by caregivers). These core beliefs were shared among several family members; however, often were not discussed openly until months following the burn event. These unresolved feelings of guilt and

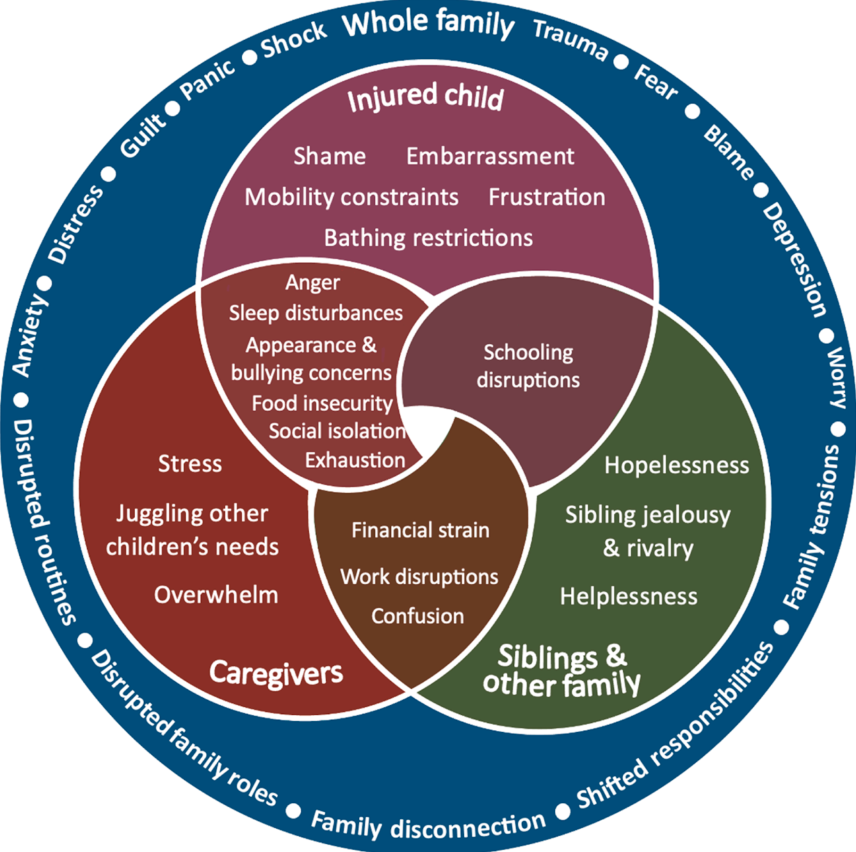

Fig. 1. Social and emotional impacts across the family unit.

blame caused tensions within families, diminished self-confidence among caregivers and other caring adults: 'It just makes me feel like a bad mum that it happened' (caregiver), and/or anger towards those considered responsible for the event: 'I was angry … because it could have been prevented. And it happened on a treadmill. Like kids shouldn't be playing with treadmills' (caregiver). Despite this, only two burn specialists referenced 'guilt' or 'blame' during a thinking-aloud session and this related to their perception that families did not experience these emotions due to the accidental nature of the burn events.

3.2. Fear of the Department of Child Safety and hospital setting

Many families were acutely aware of the historical involvement of hospital settings in the Stolen Generations and reported experiencing racial discrimination from health professionals and DoCS. As a result, caregivers were terrified that DoCS would remove their children from their care upon entering the hospital: 'They'll [DoCS will] take them off me when I got to [the hospital] … like I was going to vomit' (caregiver). This intense fear continued throughout the care trajectory and contributed to caregivers being hypervigilant with their child's care and making significant sacrifices to remain 'compliant' and avoid a DoCS report: 'It takes one phone call to Child Safety going – "Hey, you know, they haven't showed up for this appointment and they're putting her health in jeopardy" – and they're on your doorstep. So, it's making those drives and those sacrifices, going under that financial strain' (caregiver). Burn specialists were unaware of the families' fear of DoCS and interpreted their hypervigilance and over-compliance as coping well; while families' nervous behaviour was seen as suspicious and triggered DoCS reports or forensic investigations. Further, many burn specialists associated DoCS involvement with having provided families with high quality, holistic care. See Supplementary Table 2 for full data on fear of Department of Child Safety and hospital settings.

3.3. Initial and acute care

3.3.1. Mistrust of health professionals/services

Most of the Aboriginal and Torres Strait Islander families reported experiencing culturally unsafe and inadequate care in the initial stages of their child's injury. More than a quarter of the injured children (n = 6) experienced adverse events such as sepsis, other infections, and allergic reactions to medications and/or treatments. These experiences were traumatic for caregivers and siblings and contributed to intense fear regarding the injured child's survival as well as frustration, distress, helplessness, and overall mistrust towards health professionals and services. The impact of adverse events on families, particularly sepsis, was rarely acknowledged by burn specialists and no social and emotional wellbeing (SEWB) screening or support was offered to these families. See Supplementary Table 2 for full data mentioned in this section.

3.3.2. Financial strain

Accessing specialised burns care caused financial strain for families due to the frequency of appointments interfering with caregivers' work and income, and the hospital being poorly accessible via public transport and having limited and expensive parking. Caregivers were afraid that the impact of burns care on their work would cause them to lose their job and lead to further financial hardship (see Bobby*'s field notes below). These unexpected costs and stresses forced families to reserve fuel solely for trips to hospital, sell personal items, go on payment plans, and/or seek support from charity organisations to cover expenses. This impacted both caregivers and older siblings, which led to further depleted self-esteem and shame for caregivers: 'My [eldest] son's sold his phone there [back at home] to buy more food for the house 'cause they ran out. I didn't know that until two, three days ago' (caregiver). See Supplementary Table 3 & 5 for full data of financial strain and work

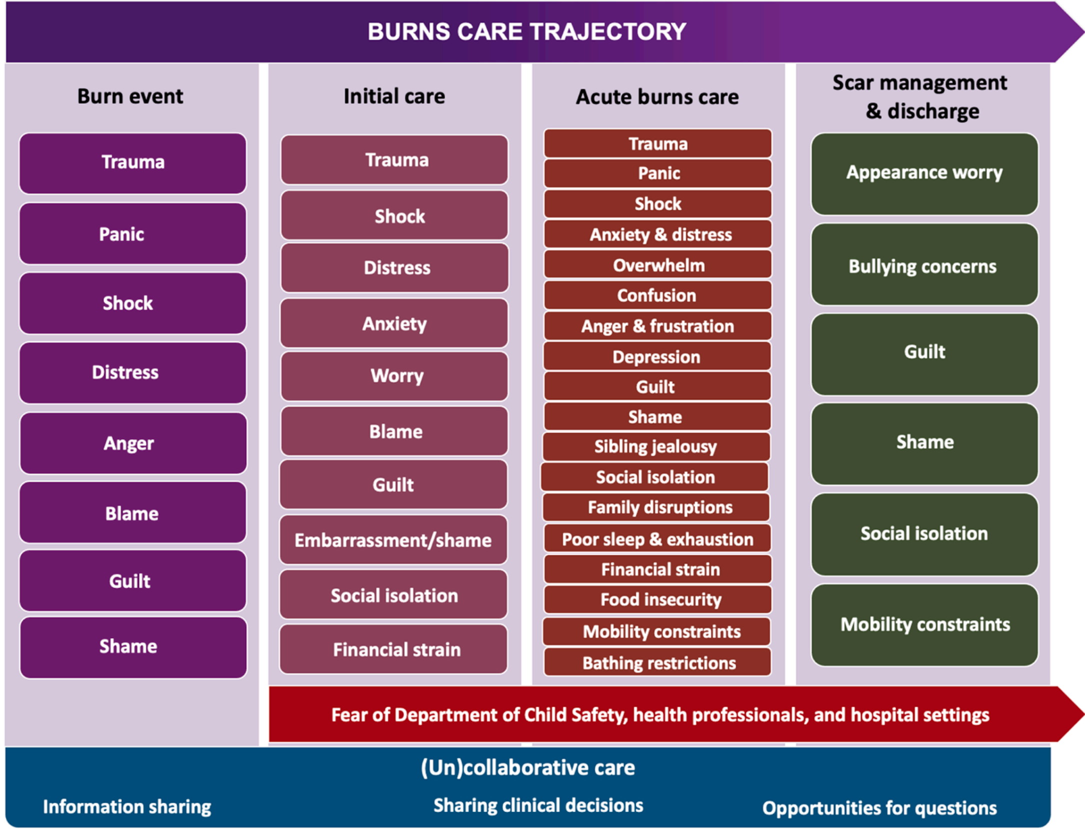

Fig. 2. Social and emotional impacts across the burns care trajectory.

disruptions.

Burn specialists were often unaware of the financial strain and stress that burns care caused families and described families as 'trying their best' with the resources they had available. However, a small group of burn specialists were conscious of these stressors and made accommodations for families to attend care in ways that worked for their families (see Bobby*'s field notes below).

Field notes – Bobby*'s first appointment

Doctor's review: Nell* (Bobby's mother) anxiously asked the doctor when they would need to return to hospital and explained they could only come on Monday's as it is her only day off work. The doctor nodded sympathetically and said they understood and would see if they could return on Monday; however, if Bobby required a skin graft, he would be booked for surgery later in the week. Nell tearfully explained that her work is very strict, and she would lose her job if she missed any more days of work. The doctor nodded and reassured Nell that they understood. The burns team later organised for Nell and Bobby to return outside of burns clinic hours to accommodate Nell's work.

* Pseudonyms used to protect participant's identities.

The Patient Assisted Travel Subsidy Scheme (PATSS) partially reimburses families' fuel costs related to travel to the hospital for care. Theses financial support services were not well explained or offered to families and burn specialists often expected families to voice concerns and seek hospital financial support themselves. However, families were generally reluctant to discuss financial hardships with burn specialists out of embarrassment and were therefore unaware of the financial supports available to them. As a result, none of the families used the PATSS service as it was either not offered, poorly explained, included too many barriers with complicated forms and processes, or was offered too late in the care trajectory to be useful: 'You've got to go into the hospital to get the [PATSS] forms and I don't, I'm illiterate, so I don't know how to fill half the stuff out anyway, so that, it's just not worth it' (caregiver). Instead, families accepted the exponential costs as part of burns care. This highlights a need for families to receive sufficient information early, and support to apply for PATSS and other assistance to reduce the financial strain of burns care. See Supplementary Table 12 for full data on the PATSS service.

3.3.3. Social isolation and family disconnection

The injured children and primary caregivers (the caregiver that attended hospital care with the child) experienced complete or partial disconnection from their family and support networks during hospitalisation and care. This was prolonged, often spanning several months, and caused extreme social isolation and disruptions to family roles and responsibilities within the home. This disconnection contributed to injured children experiencing increased symptoms of anxiety, depression, frustration, and 'fear of missing out' on social events. Primary caregivers also experienced increased symptoms of distress, anxiety, depression, loneliness, frustration, and helplessness as their vital support networks were not accessible to them: '[My sons'] went through stress there, 'cause I weren't there. And then I was going through stress here 'cause I felt lonely' (caregiver). Similarly, caregivers who remained home to care for their other children experienced increased stress, guilt, and helplessness as they were unable to lighten the burden for their partner who was caring for their injured child: '[My partner] felt horrible about it. Like, he hated what I had to deal with up here, while I was up here by myself' (caregiver). Siblings of the injured children also experienced distress towards their sibling's wellbeing and frustration towards changes within the home. See Supplementary Table 4 for full data on social isolation and family disconnection.

3.3.4. Family disruptions

The burn dressings and appointments were a major disruption to family routines, including school attendance (for the injured child and siblings), other medical appointments (for siblings and caregivers), work (for caregivers), leisure activities (for all), and the injured child's

bathing and other daily activities. These disruptions were confusing for younger injured children and contributed to difficulties adapting to the care processes. The inflexibility of burns care also made it difficult for caregivers to juggle the needs of their uninjured children, causing increased stress, guilt, exhaustion, and frustration. The extra time and care provided to the injured child also caused jealousy and tension among siblings. This was especially difficult for primary caregivers to manage as they were unable to provide an estimated date for their return home.

Most burn specialists were sympathetic towards caregivers' struggles; however, some cast judgement without offering alternative care options that would better support families' needs: "she didn't really even want to come in … she said she had five kids, and she said that they were at [regional town] and she didn't want to come today, and she said [regional hospital] had cleaned it … so I said she needed to come today or Monday." (Nurse). This was especially frustrating and disappointing for caregivers who navigated multiple barriers and/or missed appointments for themselves or their other children to attend burns care.

The dressings also prohibited the injured child's bathing, which increased distress for families as bathing was often viewed as an important bonding activity between siblings. Burn specialists were unaware of the importance of bathing for the Aboriginal and Torres Strait Islander families and, therefore, did not consider alternative dressing options that could better facilitate this. However, many burn specialists recognised the families' excitement once bathing could recommence and fondly recalled sharing this news. See Supplementary Table 5 for full data on family and routine disruptions.

3.3.5. Sleep disturbances and exhaustion

Prolonged hospitalisation and care significantly impacted the injured child and caregivers' sleep, causing extreme exhaustion and fatigue. Sleep was disrupted by noisy hospital wards, heightened distress, and the injured child's pain and itch. Caregivers and other caring adults also experienced fatigue and exhaustion from long distance travel, lengthy burns care appointments, and stress related to maintaining dressings in between appointments:

> **Caregiver:** 'It's up to us to make sure that everything happens, and we have to be there on time, we have to do this, you have to make sure that this is kept clean, or whatever, for the burn. So, it is a lot of stress on … on you as a parent'.

This was especially difficult for caregivers who experienced PTSD symptoms and shock from the burn event, those with health conditions, and/or those with no access to their support networks. Out of all the burn specialists, only one nurse acknowledged the burden of at-home care on caregivers, while the remaining burn specialists generally perceived caregivers as coping well without need for additional support or alternative care options. See Supplementary Table 6 for full data on sleep disruptions.

3.3.6. Food insecurity

Families experienced high levels of distress due to food insecurity within the hospital and surrounding areas. The specialist hospital did not provide and was not in close proximity to many healthy food options, causing families to purchase grocery items from service stations, rely on fast food, or get lost finding the nearest grocery store. Additionally, one injured adolescent was not provided food during their 17-h hospitalisation and later experienced vomiting due to receiving Oxycodone on an empty stomach. Food insecurity was distressing for caregivers as they felt unable to maintain their children's normal eating habits and provide healthy options. This was exacerbated by burn specialists' judgement of families' 'unhealthy' food choices and physical appearance during burns care, as demonstrated by the following quote from an allied health professional towards a healthy, size 10 Australian Aboriginal mother: ""They [other health professionals] might say, 'Oh, that mum's really overweight', and even, um, the little sister – she's drinking chocolate milk out of a bottle not cow – not regular milk and I, I noticed that!" (Allied health professional). See Supplementary Table 7 for full data on food insecurity.

3.4. Scar management

Scarring, especially facial scarring, and bullying were major concerns for the families. Families with darker complexions were hyperaware of the increased risk of hypertrophic scarring and discolouration from sun exposure. The risk of discolouration was particularly concerning for caregivers, who explained that sun protection was not on their children's 'radar'. These concerns were understood by some burn specialists who strongly emphasised the need for sun protection. However, there was a large number of doctors involved in each child's burns care and the level and type of information that had already been shared with the family was not always conveyed between doctors. This led to miscommunications between the burn specialists, some key information not being shared with families, and added confusion for families.

Younger children were generally unaware or unbothered by changes in their physical appearance. However, their caregivers reported feeling helpless and anxious about potential bullying and were relieved if their child's face and/or scalp did not scar. There was a potential gender difference among adolescent patients; however, the disproportionate number of males ($n = 5$) and females ($n = 1$) in this age group should be considered. The only adolescent female in this study displayed extreme anxiety and reluctance to attend school out of fear of bullying due to her visible dressings. Nursing staff recognised this as a common concern among adolescent burn patients in the general population. In contrast, the adolescent males in this study were initially excited to 'show off' their burn dressings to school peers: 'I wanted to show everybody my dressings. But now I don't have it [the dressing]. [The burn's] exactly the same, [but] it doesn't look cool anymore. It's scarred a lot' (Cooper*, patient). However, they were also more likely to use dressings and pressure garments as 'covers' to cope with visible differences and avoid unwanted attention. This contributed to extreme anxiety and distress when these 'covers' were no longer required and removed, forcing them to confront their scarring and/or discolouration. The caregivers of adolescent males were often unaware of their appearance worries and, consequently, experienced heightened guilt when these issues were raised during appointments.

Adolescents' anxiety was lessened by support from siblings, cousins, and peers who helped them feel safe and confident to return to school and other activities. This transition was facilitated by social media, which allowed injured adolescents to share their burn injury progress in real time and avoid 'awkward' conversations upon returning home. The allied health professionals also routinely screened for SEWB issues related to appearance early in scar management and provided additional information and support where required. However, appearance and bullying concerns often began before scar management was introduced, and continued to escalate throughout acute care due to unclear information and resources. This delay in information was mainly due to burn specialists' struggling to identify an 'ideal' time to introduce scar management without overwhelming families during acute care. See Supplementary Tables 8 & 9 for full data related to scar management and information sharing on wound healing.

3.5. Collaborative care

Being collaboratively involved in care was paramount to the families' autonomy, preparedness for care, confidence with at-home-care, and overall resilience and coping. This included receiving sufficient information, being involved in clinical decisions, and having opportunities to seek clarification. Receiving this type of care reduced families' stress and anxiety, and facilitated partnerships between clinicians and families that promoted the injured child's coping, self-determination,

and sense of mastery over care.

However, most of the families did not receive this level of care and felt like passive recipients rather than partners in the care process. This was due to burn specialists' heavy workloads and limited time with each family, miscommunications within the team, heavy use of medical jargon, and exclusion of families from key conversations. Some burn specialists also misconceived Aboriginal and Torres Strait Islander families as less knowledgeable than non-Indigenous families and disinterested or embarrassed to seek information. Consequently, there was often a disjoint between burn specialists' perceptions of sufficient information and families' feeling excluded from clinical decisions and experiencing inadequate information, poor procedural preparation, and limited opportunities to seek clarification. See Supplementary Tables 3 & 9–12 for full data.

3.5.1. Information sharing

Limited information and clarity around injury severity, treatment processes, and care options contributed to families experiencing heightened distress, worry, shock, fear, and frustration towards the care and burn specialists: 'It's frustrating because instead of going, "Oh, I'm going to go talk to the nurses", how about you actually stand there and inform the parent of the child what the hell is going on!' (caregiver). Burn severity can take days to fully present; however, this was not always conveyed to families and contributed to increased distress, worry, and fear towards the child's survival and/or wound healing. Injured adolescents were especially anxious about their injury severity and often pulled or played with dressings to see their wounds. This was followed by shock, panic, and distress once the severity was revealed, particularly if surgical interventions were required. Some burn specialists acknowledged the families' distress and shock; however, this was rarely followed up with SEWB support. See Supplementary Tables 2 & 9 for full data on fear of survival and information sharing challenges.

3.5.2. Procedural preparation and sharing clinical decisions

Burns care processes were foreign to the Aboriginal and Torres Strait Islander families and a lack of procedural preparation contributed to high levels of distress, disorientation, panic, fear, and trauma symptoms. Injured children and their caregivers were afraid and intimidated by the number of burn specialists involved in care and the fast-paced nature of treatment. This was exacerbated by inconsistency in burn specialists, which led to injured children often being treated by 'strangers' at each appointment. These unfamiliar and inconsistent care processes caused some caregivers to re-experience past medical traumas and worry for their child's wellbeing.

The lack of procedural preparation and informed consent also led to injured children creating their own expectations of care and being afraid, panicked, and/or feeling violated during dressing changes and surgical procedures: 'When all them people [health professionals] were in there, [I thought] that they were going to cut my skin off with scissors' (Shae*, patient). This caused increased guilt and distress among caregivers and a break down in trust and communication with burn specialists. Two burn specialists acknowledged that the number of specialists involved and the care processes can be stressful for families. However, burn specialists' desensitisation towards burns care contributed to them assuming families were comfortable, understood the treatment processes, and expected multiple specialists in the room. See Supplementary Table 10 for full data on procedural preparation and shared decision making.

3.5.3. Opportunities for questions and clarification

The burn specialists' heavy workloads creates a 'patient in, patient out' modality that left limited time for families to formulate and ask care-related questions. This caused doctors to feel guilty when additional time was given to families' questions, and left allied health professionals and nurses primarily responsible for fulfilling families' information needs. These time pressures also placed large expectations on families to know the 'right' questions to ask, which required a base level of burns care knowledge. Consequently, the families often described burn specialists, particularly doctors, as 'unwelcoming' towards their questions and not providing sufficient details to meet their information needs: 'I don't think he [the surgeon] appreciated me asking questions, whereas from my point of view, this is my kid, mate!' (caregiver). This was stressful and frustrating for caregivers as they felt unable to gain the knowledge needed to feel confident in providing at-home care for their child. See Supplementary Table 11 for full data on opportunities for questions and clarification.

3.6. Support needs

3.6.1. Family and social support

The families received limited hospital support and primarily relied on family members (grandparents, aunties/uncles), friends, and their community. It was common for multiple family members to accompany the injured child during care to provide emotional and instrumental support. The number of family support people ranged from two to seven, with an average of three family members attending each appointment. Instrumental support was provided in the form of sharing long-distance drives, providing/booking accommodation, supplying healthy meals, and minding siblings during care appointments and/or the caregivers' work times. This received mixed responses from burn specialists with some praising families' supportiveness and associating this with improved coping, while others expressed frustration towards the 'crowd' and requested family members to leave appointments or excluded them from care. The latter was detrimental to the families' wellbeing as it further isolated them from their already diminished support networks. See Supplementary Table 12 for full data on support provided by family and social networks.

3.6.2. Hospital instrumental and SEWB support

Hospital-based support was delivered by a social worker and the occupational therapists. This included general check-ins, assisting family-clinician communication, car park vouchers, and public transport passes. The occupational therapists also offered an annual paediatric burns camp to a select group of patients with the intention of building connections and self-confidence. This program was offered to two of the injured adolescents of this study, one of which attended and found the camp beneficial. See Supplementary Table 12 for full data on SEWB support provided by the hospital.

However, SEWB screening and support was not part of routine burns care and therefore not provided to most of the families: 'Technically [there was] nothing. No, sort of, check on mum, dad, or even Chelsea* (sibling), you know? Psychologically, if there's, um, ah, is anyone okay' (caregiver). This was due to poor referral pathways, limited capacity within the clinical team, limited availability of formal SEWB assessment tools, and a lack of culturally appropriate tools and resources for Aboriginal and Torres Strait Islander peoples: 'If you did ask for someone, they took their time about it … sometimes it's, you need a little bit more support' (caregiver). This led to burn specialists assessing SEWB from overt behaviours and missing important cues that the Aboriginal and Torres Strait Islander families required additional support. This was troublesome as the families, particularly caregivers and adolescent males, often displayed stoic fronts to burn specialists that masked deeper emotional burdens. This can be seen in the contrasting views of Mia*'s treating doctor and nurse, neither of which offered Mia*'s mother support following her account of the traumatic events surrounding Mia*'s burn.

> **Nurse:** 'Hearing with the mum's stories of how the burn actually happened, that felt a bit sad. I mean, she lost her brother-in-law and stuff like that and then … ended up the child having a burn. So I, I would understand if she was finding it a bit hard to cope. I don't know if, um, the whole, like, she put on a good face, but I don't know

if deep inside she might be a bit sad about all the things that happened all at once'.

Doctor: 'She didn't come across needy or wanting to open up. It did in a way just sound like the justification, the explanation of why this had happened. So, although I didn't delve into detail, I can assume, assumed it felt that she was coping okay despite those tragedies'.

Field notes – Mia*'s fourth appointment

Doctors' review: Malinda* (Mia's mum) sat on the treatment bed holding Mia on her lap while the doctor closely examined Mia's wounds, and the nurse stood silently beside them. Malinda looked saddened as she explained how the burn happened – 'My brother committed suicide [sic] –' The doctor continued looking at Mia's wounds and casually responded – 'Mmm'. Malinda appeared taken aback, but continued – 'Um, three months ago. Three days after we buried him, my brother-in-law committed suicide [sic] the exact same way'. The nurse and I looked at Malinda shocked. The doctor continued looking down and again responded – 'Mmm'. Malinda hesitated before continuing – 'So, we created a memorial section in our house with a cabinet. Her older brother knocked the cabinet. It had a candle … on it'. The doctor stood up straight nodding and responding – 'Okay'. Malinda continued – 'That's come down off the cabinet onto her head'. The doctor nodded and continued with the consult as normal. The circumstances of the burn event were not discussed again and the family were not offered SEWB support.

* Pseudonyms used to protect participant's identities.

The families received inconsistent follow-up support in between appointments and post-discharge. Some families received personal phone calls following their child's first appointment, regular check-ins throughout care, and/or contact details of the burns unit. However, most families did not receive any follow-up support or contact details. This led to several families being disappointed by the lack of follow-up care and feeling they had ongoing support needs that were not addressed.

3.6.3. *Hospital cultural support*

Two Indigenous Hospital Liaison Officers (IHLO) service the hospital site and play vital roles in helping Aboriginal and Torres Strait Islander families feel safe and welcome. This service was accessed by three of the families who received information, food, general emotional support, and/or advocacy support during DoCS investigations. Despite the importance of this role, many burn specialists were not aware of this service and referral pathways were poorly utilised or delayed beyond the point of being helpful to families. This resulted in IHLOs being unaware of families' presence within the hospital and, vice versa, families being unaware of this service. Upon learning of the IHLO service, most caregivers emphasised the need for this information to be shared with all Aboriginal and Torres Strait Islander families within the hospital and for an IHLO to be present within the emergency department: 'It could be nice for people to know that there is a, um, if they need it, that there is an Aboriginal liaison officer or something there for them if they need' (caregiver). This highlights the vital need for timely referrals to ensure families are adequately supported from their first contact with the hospital and throughout their care experience. See Supplementary Table 12 for full data on cultural support provided by the hospital.

4. Discussion

This research highlights a critical need for all members of Aboriginal and Torres Strait Islander families to receive culturally- and trauma-responsive care and support throughout burns care and beyond. Families described paediatric burn injuries and care as having wide-spread and prolonged impacts on everyone in their family, including complex social, emotional, and cultural burdens. These commonly caused heightened symptoms of acute distress, anxiety, depression, and PTSD; beginning at the time of the burn event and continuing throughout care. Despite a known risk of these symptoms, these symptoms were not screened for or managed with necessary support services, and were often worsened by families' receiving uncollaborative and culturally unsafe burns care in isolation of their families and cultural support networks. This was exacerbated by stigmatisation and judgement from health professionals at each point of the child's acute care trajectory – from initial contact with health services (e.g., general practices and local hospitals) and throughout specialised burns care. Consequently, the families' care experiences often triggered past traumas and fear associated with hospital settings, health professionals, and DoCS. The distress caused by the burn event and care experiences were also compounded by sleep disturbances and exhaustion, financial strain related to burns care, poor access to healthy foods during hospitalisation, disrupted family roles and routines at home, and concerns towards the injured child's appearance and potential bullying.

Similar to previous findings, these burdens were severe, regardless of the burn size or depth [8,41,42], the child's age [8,42,43], or gender [8]. Previous findings also suggest that mothers of paediatric burn patients suffer higher emotional burdens [44,45]. However, this study found that all members of Aboriginal and Torres Strait Islander families are severely impacted by the burn event, injury, and care. This included male and female caregivers, siblings, and extended family such as grandparents, aunties/uncles, nieces/nephews, and cousins. These findings reflect Aboriginal and Torres Strait Islander peoples' collectivist culture and that a 'whole-of-family' approach to care is needed to fit within our cultural values of kinship, family connections, and collective support. These kinship networks were also a major source of strength and support for the Aboriginal and Torres Strait Islander children and primary caregivers throughout paediatric burns care.

These findings highlight an urgent need for Aboriginal and Torres Strait Islander families to receive holistic burns care that includes family-wide SEWB screening and support, and instrumental support that is culturally- and trauma-responsive. However, the biomedical model underpinning paediatric burns care creates a 'patient-in, patient-out' modality that limits burn specialists' capacity to provide holistic care that effectively incorporates cultural and SEWB support. This is compounded by a lack of appropriate SEWB measures and resources, inconsistent financial support (parking vouchers, public transport passes, and PATSS), and poor referral pathways to support services. Consequently, burn specialists equate physical wellbeing with SEWB and/or resort to measuring SEWB from overt behaviours, which is highly ineffective for Aboriginal and Torres Strait Islander families who tend to display stoic fronts. This includes Aboriginal and Torres Strait Islander children who have previously been described as outwardly portraying resilient behaviours that mask deeper social and emotional burdens that go unnoticed and under supported [46].

Further, only one mental health professional was available within the burns ward and two IHLOs across the entire hospital. This level of support was insufficient in meeting the families' needs and led to delayed or lack of support and ongoing unmet needs. This reflects nationwide issues of poor identification processes, exclusion of IHLOs from burns care, and limited resources to support Aboriginal and Torres Strait Islander families' cultural care [47]. This level of support is also insufficient according to clinical practice guidelines, which recommend that all burn patients are referred to a social worker within 24 h of hospital admission [48]. Further, Woolard et al.'s systematic review emphasised the need for the clinical care team to focus on supporting paediatric burn patients' psychological recovery and consult mental health professionals during burns care [10].

The Aboriginal and Torres Strait Islander families repeatedly expressed a strong desire and need for collaborative involvement in burns care, including sharing in clinical decisions, receiving adequate information, and having opportunities to seek clarification. This was essential for the families' autonomy and ability to gain necessary knowledge and skills to feel empowered throughout burns care. However, burn specialists' provision of collaborative care was heavily affected by poor communication and treatment flow, limited resources and written information, heavy workloads and time pressures, and

reluctance to overwhelm families. Uncollaborative care was also influenced by burn specialists' misconceptions of Aboriginal and Torres Strait Islander families being disinterested in detailed information or 'reluctant' and embarrassed to ask questions, and perceiving injured adolescents as 'non-compliant' when seeking autonomy in their care.

It is well known that biomedical models of care do not allow Aboriginal and Torres Strait Islander peoples to practise self-determination and health sovereignty [49]. There is also little opportunity for Aboriginal and Torres Strait Islander people to initiate and influence conversations with their health professionals, leading to a lack of shared knowledge and ineffective communication [50]. The judgement and stigmatisation that Aboriginal and Torres Strait Islander families received throughout their child's burns care led to further break downs in communication and collaborative care; contributing to culturally unsafe care, hypervigilance from families, and increased distress. This study's findings emphasise the need for Aboriginal and Torres Strait Islander families to receive culturally-responsive burns care that facilitates their autonomy, including detailed information and active involvement as collaborative partners in care, and compassionate care that is responsive to families' unique needs [51].

4.1. Strengths and limitations

This Aboriginal-led (HW) study was conceptualised and conducted in response to the expressed needs and desires of Aboriginal and Torres Strait Islander families that were undergoing paediatric burns care for one of their children. The use of Indigenous research methodologies was imperative in centring the voices of the Aboriginal and Torres Strait Islander families in this study and incorporating their important input in reviewing data transcripts, analysis, and interpretation. Following this study, a sub-group of the Aboriginal and Torres Strait Islander families have continued to be collaboratively involved in the dissemination and translation of findings into resources and practice to improve care for Aboriginal and Torres Strait Islander families.

This study followed the care experiences of 20 Aboriginal and Torres Strait Islander families throughout paediatric burns care at a single tertiary hospital in Australia. While this sample was representative of all Aboriginal and Torres Strait Islander families that received burns care at the site during the recruitment period; it is not representative of all Aboriginal and Torres Strait Islander families' burns care experiences throughout Australia. However, corroboration of this study's findings with those of Fraser et al. [47], Coombes et al. [20], and Ryder et al. [52] demonstrate consistent themes surrounding the demands of paediatric burns care on Aboriginal and Torres Strait Islander families and national gaps in culturally-responsive and trauma-informed burns care.

This study was the first to use a novel decolonial ethnographic approach incorporating participant observations, thinking aloud sessions, and yarning research methods. This novel approach was minimally intrusive to the burns care process and allowed for multiple accounts of paediatric burns care that provide detailed insights into disjuncts between the care experiences of Aboriginal and Torres Strait Islander families and perspectives of burn specialists. This approach also allowed important time and opportunities for the lead author to build rapport, trust, and genuine partnerships with the families. The methodological approach was also culturally-responsive, adaptive to the clinical environment, and provided vital insights into this previously scarce field of study. However, the busyness of the burns clinic restricted burn specialists' participation, and the nature of the participant observations hindered data collection as the researcher was unable to observe more than one family's appointments at a time. While the rigorous analytical process provided detailed accounts of the families' experiences, it was time consuming and resulted in delays in dissemination and translation of findings.

4.2. Conclusions

This study outlines the plethora of severe social and emotional implications that paediatric burn injuries and care cause Aboriginal and Torres Strait Islander families, much of which are endured with limited access to resources and support. These burdens are exacerbated by culturally unsafe and uncollaborative care caused by judgement and stigmatisation from health professionals, poor access to necessary supports (including mental health and cultural support, food security, and financial assistance), and a disconnect between biomedical frameworks of burns care and Aboriginal and Torres Strait Islander peoples' holistic views of health and wellbeing. This study highlights an urgent need for all members of Aboriginal and Torres Strait Islander families to have access to routine, formal SEWB screening and culturally and trauma-responsive care and support. Screening and support should be offered consistently throughout the care trajectory to build necessary trust and effectively capture changes in SEWB and symptomology as various challenges arise along the healing journey. This study ultimately demonstrates a pressing need for increased access to mental health professionals within the paediatric burns team and IHLOs within the hospital to adequately address cultural and SEWB needs. These findings also illustrate the need for all Aboriginal and Torres Strait Islander family members to be involved collaboratively in paediatric burns care to promote their autonomy and facilitate knowledge and skills development related to long-term care needs. To achieve this, it is imperative that families are provided with appropriate information and opportunities to seek clarification at each stage of the care trajectory to sufficiently inform them of the burn injury severity, care options, key contacts when in need, and what to expect along the healing journey. This includes providing adequate initial care, procedural preparation, access to culturally appropriate burns resources, adequate follow-up support, and discharge preparation that effectively reconnects Aboriginal and Torres Strait Islander families with their communities following the injured child's discharge from hospital.

CRediT authorship contribution statement

Hayley Williams: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing – original draft, Writing – review & editing. **Kate Hunter:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – review & editing. **Bronwyn Griffin:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – review & editing. **Roy Kimble:** Conceptualization, Project administration, Resources, Supervision, Writing – review & editing. **Kathleen Clapham:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – review & editing.

Ethics approval and consent to participate

Ethical approval was received from the Health Service Human Research Ethics Committee (HREC/14/QRCH/328/AM04), and the Children's Health Queensland Hospital (SSA/18/QRCH/378).

Authors' information and positionality statement

HW and KC are Australian Aboriginal women, KH and BG are non-Indigenous women, and RK is a non-Indigenous man. HW is a psychologist and early-career researcher, specialising in Indigenous health and trauma research. KH is a nurse and senior research fellow, specialising in Indigenous health and traumatic injury research. BG is a Professor of nursing, specialising in traumatic injury and emergency care research.

RK is a surgeon and Professor specialising in urology, burns, and traumatic injury care and research. KC is a Professor of Indigenous health studies, specialising in traumatic injuries and ethnographic research. Recruitment and data collection was carried out by HW, data analysis and interpretation was conducted by HW, KC, KH, and BG in collaboratively with the Aboriginal and Torres Strait Islander families.

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Declaration of Competing Interest

The author is an Editorial Board Member/Editor-in-Chief/Associate Editor/Guest Editor for this journal and was not involved in the editorial review or the decision to publish this article. Prof. Roy Kimble is an Editorial Board Member and will not be involved in the editorial review or decision to publish this article. All other authors have no conflicts of interest to declare.

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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.2025.107837.

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