

Yarning up about out-of-pocket healthcare expenditure in burns with Aboriginal families

Courtney Ryder,^{1,2} Tamara Mackean,^{1,2} Kate Hunter,¹ Julieann Coombes,^{1,3} Andrew J.A. Holland,⁴ Rebecca Ivers^{1,5}

Internationally, 100 million people are forced below the poverty line from healthcare spending.^{1,2} The majority of these people reside in low- to middle-income countries, however, individuals from high-income countries are also impacted.¹⁻⁴ In Australia, healthcare spending from out-of-pocket healthcare expenditure (OOPHE) by patients has progressively increased.³ OOPHE are expenses related to health conditions that are not covered by universal taxpayer-funded healthcare or private health insurance. These expenses include direct costs, such as gap payments, transportation, pharmaceutical costs, or equipment purchases for the home, as well as indirect costs such as carers taking time away from the labour force for care, resulting in a loss of household income.

When households need to increase expenditure on healthcare, disposable income is reduced. Households without savings use a variety of mechanisms to cope, including borrowing money, selling assets and forgoing general necessities.^{2,5} This can cause catastrophic health expenditure, creating severe economic hardship on families, even bankruptcy.¹⁻⁴ In these cases, households make significant choices between family wellbeing or financial survival,^{3,6} which can result in households avoiding or delaying medical treatment as a financial survival strategy.^{3,5,6} Households in rural and remote settings face additional OOPHE burden through travel for healthcare; additionally, these households are more likely to be in low-income brackets.^{5,7} In Australia, recent

Abstract

Objective: This study sought to understand the impact of out-of-pocket healthcare expenditure (OOPHE) on Aboriginal families of children with acute burns injury.

Methods: Families participating in a larger Australia-wide study on burns injuries in Aboriginal and Torres Strait Islander children were approached to participate. Decolonising methodology and yarning were employed with participants to scope OOPHE for burns care. Thematic analyses were used with transcripts and data organised using qualitative analysis software (NVivo, Version 12).

Results: Six families agreed to participate. Four yarning sessions were undertaken across South Australia, New South Wales and Queensland. The range of OOPHE identified included: costs (transport, pain medication, bandages), loss (employment capacity, social and community) and support (family, service support). The need to cover OOPHE significantly impacted on participants, from restricting social interactions to paying household bills. Close family connections and networks were protective in alleviating financial burden.

Conclusion: OOPHE for burns care financially impacted Aboriginal families. Economic hardship was reported in families residing rurally or with reduced employment capacity. Family and network connections were mitigating factors for financial burden.

Implications for public health: Targeted support strategies are required to address OOPHE in burns-related injuries for Aboriginal communities.

Key words: Aboriginal, burns, children, out-of-pocket healthcare expenditure

research has demonstrated families in low-income brackets are the most vulnerable for catastrophic health expenditure.⁵

Aboriginal people make up 3% of the Australian population and continue to experience the impact of colonisation, which manifests as ongoing dispossession and marginalisation.^{8,9} This is evident across multiple social and health inequities (employment, education, life expectancy and infant mortality).⁸⁻¹⁰ Burns incidence and severity is another example of health inequity for Aboriginal children, with hospitalisation

rates 2–3 times greater than for other Australian children.¹¹⁻¹³ This is being explored in the Coolamon study.¹² This paper aimed to explore OOPHE for acute burns injuries with a cohort of Coolamon study families.

Methods

In Australia, a tool exploring OOPHE has been developed, however, its focus is on general populations, particularly older people with a chronic condition.^{2,4} There has not been OOPHE exploration of Aboriginal and Torres

1. The George Institute for Global Health Australia, UNSW, New South Wales

2. Aboriginal and Torres Strait Islander Public Health, Discipline of Public Health, College of Medicine Public Health, Flinders University, South Australia

3. Jumbunna, The University of Technology Sydney, New South Wales

4. The University of Sydney School of Medicine, The Children's Hospital at Westmead Clinical School, Faculty of Medicine and Health, New South Wales

5. School of Public Health and Community Medicine, UNSW, New South Wales

Correspondence to: Mrs Courtney Ryder, Aboriginal and Torres Strait Islander Public Health, College of Medicine and Public Health, Flinders University, Sturt Rd, Bedford Park, South Australia; e-mail: courtney.ryder@flinders.edu.au

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Strait Islander families. We sought to examine preliminary perspectives and experiences of OOPHE for acute burns injuries with a sample of Coolamon study families. Decolonising methodology was engaged to focus this study away from colonising constructs and existing dominant knowledge on OOPHE.¹⁴ This was focused over three main areas: i) Yarning; ii) Trust and relationships; and iii) No assumptions. Yarning, a conversational research method for data collection, was employed by an Aboriginal researcher (CR) with Aboriginal families to centralise their OOPHE knowledge and maintain the integrity of their OOPHE lived experience.¹⁵ All data analyses were conducted by Aboriginal researchers to ensure focus on Indigenous knowledges (knowing, being and doing).^{16,17}

Participants (parents or carers) were drawn from the Coolamon study if their child had sustained a burn to the face, hands, perineum or burns with a total body surface area $\geq 10\%$ that required a ≥ 1 -night hospital stay and follow-up care.¹² In this scoping study, the sample size was purposely small to facilitate building strong, supportive relationships and a safe environment that would generate rich data collection during Yarning.^{14,15}

Prospective participants were contacted by Coolamon study research assistants for interest and followed up by CR, who spent time building relationships over the phone in a process controlled by the participant, which was imperative to enacting decolonisation of processes. Yarning sessions were conducted over the telephone or in-person, with or without family members or Coolamon study research assistants. All sessions were recorded, transcribed and de-identified with NVivo 12 qualitative analysis software (QSR International) used for thematic coding. Participants were provided with feedback on the outcomes of this study through the Coolamon project.

Ethics for this scoping study was approved (Table 1).

Results

A total of 31 prospective participants were initially contacted; eight were happy to be contacted further. From this cohort, two declined and six were recruited to the scoping study with between three and 10 phone calls being made prior to Yarning scheduling. Four yarning sessions in total were conducted, three consisting of one participant and the first author, the other three with the participant, a research assistant and the first author. The data were arranged into themes summarised in Table 2.

Costs

Initial treatment

During hospitalisation, participants reported costs from travel, parking and food. The reporting of limited access to affordable foods was common and participants spent hundreds of dollars in hospital cafeterias each week, as they felt obligated to stay on the burns ward or in intensive care with their child.

When we went it cost us a fortune in meals ... And you want to eat close because you didn't want to go anywhere.

Feelings of being in crisis were common, where participants did whatever it took to get by. Having family bring in food or skipping meals were reported as alternatives to reduce costs while in hospital.

In hospital ... I would have like a brunch ... instead of having three meals I would only have two.

Follow-up

Accommodation, travel, and time were common expenses for follow-up treatment

(rehospitalisation or outpatients). Participants residing rurally reported major expenses for follow-up treatment, when it was not uncommon for these households to travel more than five hours for treatment. This created financial strain for these participants.

Every time we go, we would have to make sure you would have at least \$700 just like for the petrol, the food, everything.

At home

Ongoing treatment and care requirements caused a financial impact while at home through house utilities, pharmacy costs (prescription/non-prescription), the need for additional clothing and time (personal/family).

You would have to wash the silicone and you would have to wash your bandages, but you have to wash them separately and special ... I mean, it was just ... it was costing, because obviously you are running the water. Then it's time consuming.

Non-prescription treatment for burns, usually a necessity, was also a significant cost but this was not covered or subsidised for burns patients. This was difficult for participants on a single income or government benefits.

It's not subsidised at all. I needed sterilised water for their dressings because I did not get enough at the hospital to carry me, like, tide me over. So, I had to go get that from the chemist. And all the creams and stuff that you have to put on, they're not covered at all.

Finding it hard just, sometimes, for his bandages that I had to get, you know, because bandages cost \$30 and stuff I couldn't just, necessarily, go to the hospital and get new bandages... and just being on the Centrelink income, sort of, made it hard, as well.

In these cases, financial stress was evident with participants reaching credit card limits, not paying other bills or even selling assets to get by.

Because you have to have the money to be able to travel down there, so it was like you just paid the bare minimum of everything.

Loss

Money

Household income and employment capacity were affected for participants, especially those who were self-employed or ran family businesses.

I missed, what, six to eight – no ten – I – I had ten months off all up.

Yeah. I lost out on a lot of business through that but, you know, that happens.

Table 1: Human research ethics approval for scoping study by jurisdiction.

Human research Ethics Committee	State
Aboriginal Health and Medical Research Council	NSW
Sydney Children's Hospitals Network Human Research Ethics Committee	NSW
Townsville Hospital and Health Service Human Research Ethics Committee	QLD
Children's Health Queensland Hospital and Health Service Human Research Ethics Committee	QLD
Human Research Ethics Committee Office of Research Ethics the University of Queensland	QLD
Aboriginal Health Research Ethics Committee	SA
Women's and Children's Health Network Human Research Ethics Committee	SA
Flinders University Human Research Ethics Committee	SA
Central Australian Human Research Ethics Committee	NT
Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research	NT

Participants did report feeling supported by workplaces to meet the treatment and care needs of their child.

Well, we are quite, both quite lucky ... both works have been, really flexible.

Social and community

Social and family activities were impacted. Going without household items, not participating in community events and cancelling holidays were all actions taken to alleviate costs and meet the care requirements.

We didn't have our holiday that we had planned ... luckily, they refunded us the money.

Participants living away from family networks or their community reported feeling isolated and restricted in the types of support they could access. This created additional burden and cost through juggling family life and treatment.

So, for the first week and a half I had family up here, but after that ... I'd have to get up early and get the two bigger ones. One wasn't at school yet, so they went to day care and I'd sent my eldest to before-school care. So, I would get them there at about quarter to seven.

Family support (isolation)

Overwhelming feelings of stress, guilt and emotional isolation were reported by participants, where the burden was intensified through financial strain.

It was a split-second decision that changed all our lives.

... while she was in hospital I would be, like, have no idea how I'm getting through.

... always a bit worried that he will ... hurt himself again.

This burden was expressed by siblings as well.

They started getting, like, very clingy, ... it got to the stage where I couldn't even get them to sleep in their own bed. They were just in my bed every night. The minute I was home they had to still be just attached to me.

Support

Family

Family support was a major protective element in decreasing financial stress in families. Participants approached extended family for support to get by.

Ask family members for, you know, a hand with some money until the next payday, sort

Table 2: Themes and sub themes of out-of-pocket healthcare expenditure in Aboriginal families whose child has sustained a burn injury.

Costs	Loss
Initial (Parking, Consumables)	Money
Follow Up (Travel, Accommodation, Parking, Extra Treatment, Time)	Employment Capacity
Home (Pharmacy, Clothing, Food, House Utilities)	Social & Community
	Living Activities
	Family Support (Isolation)
Support	Strain
Family (Partner, Extended)	Exhaustion - Indigenous Cultural Dimensions (Physical, Psychological, Spiritual, Cultural)
Service Support (Hospital, Government)	Cultural Dislocation, Isolation
Siblings	Financial stress
Educational	Selling Assets
Psychological	Borrowing Money (Loans/Family)
Social	Increased Debt (Credit Cards, bills)

of, for your food and your electricity bills and whatever else that come in at the time.

For other participants, this was a regular occurrence, where family networks regularly purchased important items.

Mum and Dad and my husband's parents would take turns in buying formulas for me, so I didn't have to fork out that much money.

Often participants commented on the significant financial role family networks played in keeping them away from poverty.

It took probably about four or five months to get everything back on track but as I said, I had my family to help me out when I couldn't do things and most people, either their family aren't in a situation to do that or they wouldn't.

I had my family to help me out. If I didn't, I would have had to sell stuff.

Family networks also assisted in other ways, playing significant caring roles with siblings, in getting through initial and ongoing treatment.

They had to have him the night before, because I wasn't waking him up and dropping him off at their house before 7.00 am.

For others, this support was limited, where some reported not being able to ask their family networks for support.

I could really turn to, like, you know, other than Centrelink or, you know, not for - not for that amount of money, anyway.

Others reported support being one-sided, or not feeling comfortable talking or approaching some family networks for their financial needs.

I know that if I needed money, I could get money off any of my brothers or sisters and that. But yeah, it's like that they are all in the same boat as me They are working to get

by as well ... I would rather suffer and not everybody else...

Service support

Tangible support not related to family networks was identified. Some participants reported hospital social workers arranging fuel and cafeteria vouchers.

I once got a \$100 one (fuel voucher) and that one lasted about a week and a half.

On hospital discharge, participants reported being provided with supplies until their next visit. In one case, a participant was told by hospital staff to take supplies present in their child's room as it could not be reused.

She said anything that's in this room, like, all the Hypafix, everything, she goes, take it, because it's open in the room they have to ditch it. She goes, it'll save a lot of money, so just take it.

Others commented on a lack of support, they did not see a social worker or Aboriginal health worker at the hospital. Some reported not being made aware of government initiatives, such as the Patient Assisted Travel Scheme (PATs).

I didn't see a social worker or anything. Like, I didn't see anyone ... I didn't see anyone at the hospital. I sort of got no, sort of, support there. It was just, you have to be here.

Participants also reported struggling with accessing specific government initiatives. One participant reported ineligibility for a carer's pension, as despite the additional care requirements of their child they were deemed as requiring 24-hour care for their age.

Centrelink have decided because they are under three, they are an infant and already in 24 hours care; how is what they need any different.

Discussion

We found that Aboriginal families have a range of OOPHE costs related to their injured child. While in the hospital, most parents felt pressured to always stay with their child, which restricted their access to meals. Previous research reports that Australian families can spend more than \$400 a week for hospital meals and parking.^{18,19} Our participants were impacted financially, reporting exorbitant costs for meals in hospital. To cope, participants would either skip meals or have family bring them in. Actions to this extent have not been reported previously. The link between a child's health and wellbeing and that of their parent is well documented and parents are more likely to be physically and mentally at their best when not suffering food insecurity.²⁰ Social worker intervention was felt by families in our study to be a protective element in this area. Social workers are adept in understanding the effects of hospitalisation on families and are essential for acute paediatric burns admissions in Australia.²¹

Engagement in the labour force was negatively affected for our participants, with all requiring substantial time away from work for initial treatment and ongoing care for their child. Impacts of this nature for ongoing health requirements have been reported previously in Aboriginal households¹⁰ and also in other Australian households.^{2,4,19} A significant positive aspect was that most participants felt supported by their workplace and not insecure in their employment from initial and ongoing treatment for their child. However, self-employed participants did not report this same level of support and these households were financially affected. Comparable impacts have been reported by other Australian patients or carers who are self-employed.⁴ Additional financial support is likely required for households that are in these situations to ensure protection from catastrophic healthcare expenditure.

Costs associated with travel, accommodation and hospital parking were significant for participants and consistent with other Australian OOPHE studies.^{19,22} Participants who lived rurally were further affected financially, due to greater travel and scheduling requirements to attend follow-up treatment. These outcomes correspond to previous reporting of financial burden and stress in rurally located Aboriginal and Torres Strait Islander families attending specialised

medical care.^{10,23} Our data indicated that eligible Aboriginal families were not informed of, and subsequently did not access, government travel support initiatives. Concerns regarding eligibility, application processes and the restrictive nature of these schemes on Aboriginal patients has been reported for cancer treatment^{24,25} and more generally in the Northern Territory.²⁶ Reasons for not informing patients include health professionals and administration staff not comprehending the extent of OOPHE or being unaware of government-funded travel support schemes.²⁶ Aboriginal Liaison Officers (ALO) or Workers (AHW), play a pivotal role in advocating for patients and are in a primary position to provide links to transport and social support programs. Mandatory referral to an AHW/ALO and involvement for Aboriginal patients and their families would assist in navigating and accessing support initiatives.²¹

Our study identified injury-specific OOPHE described by participants. At home OOPHE spending, on over-the-counter medications and treatment consumables that were not subsidised for burns patients but were important for treatment were reported.⁴ Housing utility bills were also increased, due to ongoing cleaning of pressure garments for scar management. Comparable to previous OOPHE research, participants experienced significant stress and anxiety over whether they would be able to keep up with household bills and meet their injured child's care needs.²² In all cases, the child's health was a priority, but this often came at an expense to families who were paying bills late, selling personal items, accessing savings, reaching credit card limits or asking family for help. While these actions were a first response to prevent further financial burden, they also indicated financial stress.^{4,27} If OOPHE are prolonged or intensified to the point where all protections have been exhausted, catastrophic healthcare expenditure can be induced, which can push families into poverty.⁴ Additionally, for Aboriginal parents, increased financial stress negatively impacts parenting efficacy, while decreased parenting efficacy and economic hardship consequently impacts on a child's recovery from injury.^{10,23,28}

Strengths and limitations

Led by Aboriginal researchers and using decolonising methodology, this work has produced rich contextual data. Findings from this study have been used to modify

and psychometrically assess an OOPHE for Aboriginal families. Limitations in this study include the small sample size and the focus on acute burns only.

Conclusion

Aboriginal families whose child has sustained a severe burns injury are impacted financially through OOPHE for their child's initial and ongoing treatment, especially those residing rurally or with reduced employment capacity. Aboriginal family connections and networks were mitigating factors for OOPHE and critical in decreasing financial stress. Our results highlight the need to contextualise assessment of OOPHE such as injury area or disease as there are condition-specific costs borne by families. Future studies in this area need to consider OOPHE across a range of conditions, as well as the specific cultural and social nuances for Aboriginal families when developing OOPHE tools appropriate for Aboriginal communities.

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