

# Fire and Smoke: Using Indigenous Research Methodologies to Explore the Psychosocial Impact of Pediatric Burns on Aboriginal and Torres Strait Islander Families

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#### **Abstract**

Aboriginal and Torres Strait Islander children and adolescents are disproportionately affected by burn injuries, yet often omitted from burns literature or inadequately portrayed under Western frameworks. We highlight and address the urgent need for knowledge about pediatric burns among Aboriginal and Torres Strait Islander people to be produced from within Indigenous research methodologies and in response to Aboriginal and Torres Strait Islander peoples' expressed needs. Through the use of decolonial ethnography, we applied a novel combination of participant observations, retrospective thinking aloud, and yarning methods to explore the psychosocial impact of pediatric burn injuries and care on Aboriginal and Torres Strait Islander families. To our knowledge, this is the first example of these three methods being interwoven to explore a multifaceted health issue and in a way that privileges Aboriginal and Torres Strait Islander peoples' knowledge systems, voices, and experiences. We suggest that these approaches have strong relevance and potential for other complex issues affecting Aboriginal and Torres Strait Islander people.

#### **Keywords**

Indigenous research, psychosocial impact, decolonial ethnography, qualitative research, ground theory

Pediatric burns are complicated and challenging injuries that place significant psychological and social burdens on patients and their caregivers (Bakker et al., 2013; De Young et al., 2012; Rivlin, 1988; Rivlin & Faragher, 2007). These injuries affect Aboriginal and Torres Strait Islander children and adolescents at more than twice the rate of non-Indigenous children and adolescents (Pointer, 2016; Tracy et al., 2019). Yet, there is limited literature on pediatric burn injuries and care for Aboriginal and Torres Strait Islander people, particularly from their perspectives or knowledge systems. This is demonstrated by a recent systematic review which revealed a lack of enquiry into psychosocial interventions for Aboriginal and Torres Strait Islander pediatric burn patients and their caregivers (Williams et al., 2020).

# Colonialism and Western Research

Burns literature in general is predominantly written from Western biomedical frameworks. Such frameworks maintain colonial practices by continuing to privilege the dominant culture and marginalize and oppress Aboriginal and Torres Strait Islander people (Dyll-Myklebust, 2014; Rix et al., 2019). This is maintained by the dominant culture holding authority over knowledge production including what constitutes valuable and

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meaningful knowledge, how this is assessed and (mis)interpreted, and for whom and what purpose knowledge is produced (Nakata, 2007). This authoritarian approach upholds Western ideologies as conventional standards and attempts to assess Aboriginal and Torres Strait Islander people against definitions, tests, and scales designed to serve the dominant culture (Angrosino, 2007).

The knowledge produced through these frameworks largely portrays Aboriginal and Torres Strait Islander people, their injuries and care needs from a deficit discourse (AIATSIS & The Lowitja Institute, 2013; Drawson et al., 2017; Fforde et al., 2013; West et al., 2012) and as problematic others (Alonso Bejarano et al., 2019; Denzin et al., 2008; West et al., 2012). Deficit discourses focus on "negativity, deficiency, and disempowerment" (Fforde et al., 2013) while describing Aboriginal and Torres Strait Islander people as the "problem" and holding them responsible for health "deficiencies", rather than acknowledging and addressing the impact of policies and inadequate health services (Fogarty et al., 2018). Within these frameworks, Indigenous knowledge systems are viewed as less than and either ignored or reworked to fit within Western biomedical frameworks (Durie, 2004; Geia et al., 2013). Consequently, these frameworks inaccurately portray Aboriginal and Torres Strait Islander people and provide little context from their knowledge systems, practices, and experiences.

The impact of Western dominant frameworks and literature is particularly evident in health settings where policies and practices informed by them continue to oppress and exclude Aboriginal and Torres Strait Islander people (Wingard & Lester, 2001). The institutionalized racism that remains prevalent within these settings (Paradies et al., 2008; Rix et al., 2019; Williams & Mohammed, 2013) is evidenced by Aboriginal and Torres Strait Islander people being less likely to receive appropriate medical care (Paradies et al., 2008), and having poorer communication with health professionals (Ben et al., 2017). Experiences of institutionalized racism contributes to Aboriginal and Torres Strait Islander people having lower healthcare satisfaction (Ben et al., 2017) and a mistrust in healthcare systems and professionals (Ben et al., 2017; Geia et al., 2013; Henry et al., 2004). Ultimately, institutionalized racism and oppression of Aboriginal and Torres Strait Islander people within health settings results in a "systemic failure" to meet their unique needs (Hunter New England Health Aboriginal and Torres Strait Islander Strategic Leadership Committe, 2012). Evidently, Aboriginal and Torres Strait Islander people cannot be empowered by such frameworks as they continue to be spoken for and about (Fredericks et al., 2011), with little opportunity for collaboration or acknowledgement of their knowledge systems.

# Indigenous Research Methodologies as Decolonizing Approaches

Indigenous health research can decolonize Western frameworks by using methods and epistemologies that, in an Australian context, fulfil Aboriginal and Torres Strait Islander peoples' aspirations, and privilege their knowledge systems and experiences (Rigney, 1999). Indigenous research methodologies are "decolonizing" as they prioritize the non-dominant culture and focus on fostering self-determination among Aboriginal and Torres Strait Islander people (Drawson et al., 2017; McIvor, 2010). These research methodologies are defined and controlled by Aboriginal and Torres Strait Islander people (AIATSIS, 2012; Jamieson et al., 2012; West et al., 2012) and, consequently, redirect the power from Western agendas to Indigenous Australian people and communities (Denzin et al., 2008).

This paper outlines the use of Indigenous research methodologies in a doctoral study exploring psychosocial impacts of pediatric burns on Aboriginal and Torres Strait Islander families. The study's focus was directed by feedback from caregivers of Aboriginal and Torres Strait Islander pediatric burn patients participating in the Coolamon study; the governing project that this study forms part of (Ivers et al., 2015). Within Indigenous research frameworks, we applied a decolonial ethnographic approach that incorporates three qualitative methods: participant observations, retrospective thinking aloud, and yarning. The purpose of this study was to reverse colonial practices by making the dominant culture the subject of assessment (Denzin et al., 2008). In this way, we aimed to explore the support provided to affected families; the interactions between families and burn health professionals; and the knowledge, attitudes, and beliefs of burn health professionals towards treating Aboriginal and Torres Strait Islander patients. In Figure 1 we outline the interaction between the study's theoretical framework, research approach, methods, and analytical approach.

# Ethnography as a Decolonial Approach

Ethnography was selected for its ability to incorporate multiple methods to gain rich, holistic insights into the culture, perspectives, and behaviors of people in the naturalistic study setting (Charmaz, 2006; Hammersley, 1992; Reeves et al., 2008). The predominant aim of ethnographic research is to gain an insider's perspective of the settings culture and how people within it create meaning (Charmaz, 2006; Eriksson & Kovalainen, 2015; Hammersley, 1992; Hammersley & Atkinson, 2007). By gaining this insider's perspective, ethnographers are able to explore, identify, and connect social phenomena that may not appear connected on the surface (Reeves et al., 2008). This insider perspective was particularly appealing to our need for an in-depth exploration of pediatric burn injuries and care beyond the surface level.

However, it is important to acknowledge that ethnography has deep missionary and colonial roots that have been extensively explored in academic writing since the 1970s (Alonso Bejarano et al., 2019; Barron, 2013; Behar, 2003; Denzin et al., 2008). As with other Western research approaches, ethnography historically privileged the dominant culture and benefited from the disempowerment and oppression of First Nations people globally (Alonso Bejarano et al., 2019; Barron, 2013; Behar, 2003; Denzin et al., 2008). Behar (2003) and Alonso Bejarano

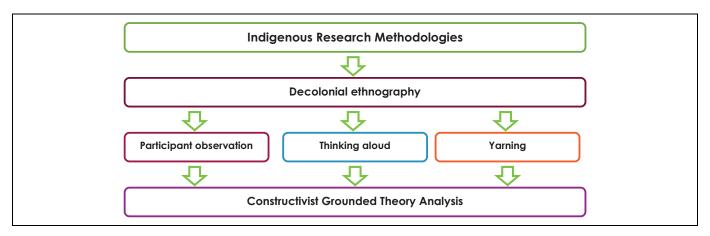


Figure 1. Overview of the theoretical framework, research approach and methods.

(2019) highlight the need to rectify the inequalities created by ethnographic research and its "shameful" past practices.

The rise in popularity of Feminist, post-colonial, and cultural theories since the 1970's has seen much progress in attempting to rectify these inequalities and injustices (Alonso Bejarano et al., 2019). Feminist theorists began responding to issues of gendered and racialized power (Alonso Bejarano et al., 2019); while cultural theorists explored concepts of "culture" and colonialism (Alonso Bejarano et al., 2019); and post-colonial theorists explored racialized power resulting from colonialism and the interconnectedness of "the West" and "non-Western" through colonial encounters (Alonso Bejarano et al., 2019; Said, 1978). Ethnography in general became more collaborative in nature and concerned with its benefit to the people being studied (Alonso Bejarano et al., 2019). However, ethnography largely remained heavily influenced by colonialism, and post-colonial theorists were particularly criticized for continuing to speak on behalf of oppressed people from a position of power and privilege (Spivak, 1988).

Decolonial ethnography was founded on insights from Feminist, cultural, and post-colonial theories (Alonso Bejarano et al., 2019). Similar to post-colonial theorists, decolonial ethnographers explore and challenge ways in which colonialism is a part of everyday life (Alonso Bejarano et al., 2019). However, decolonial ethnography extends beyond this to challenge the colonial underpinnings of academic pursuits of knowledge and how the knowledge of people being studied is presented (Alonso Bejarano et al., 2019). Like Indigenous research methodologies, decolonial ethnography privileges the voices and experiences of people participating in research (Durie, 2004; Rigney, 1999), and emphasizes their potential as valuable knowledge holders (Alonso Bejarano et al., 2019). Within an Indigenous research methodologies context, this approach shifts the focus away from fulfilling preconceived research agendas, to addressing the concerns of Aboriginal and Torres Strait Islander people by facilitating their production of knowledge and theories about their own experiences (Alonso Bejarano et al., 2019).

In our use of decolonial ethnography we incorporated the Indigenous research method of yarning with the Westernized

qualitative methods of retrospective thinking aloud and participant observations. This study centrally focused on Aboriginal and Torres Strait Islander families' experiences with pediatric burn injuries and care which were shared through yarning methods (Bessarab & Ng'andu, 2010). These experiences were further contextualized with participant observations of burns care appointments/procedures, and retrospective thinking aloud methods with burn health professionals following these appointments/procedures (Aitken & Mardegan, 2000; Chi, 1997; Ericsson & Simon, 1993).

# Participant Observations

Ethnographic approaches commonly include participant observations which involve researchers positioning themselves in the "field" to understand how people in the setting make sense of their experiences and surroundings (Emerson et al., 2001). Immersing oneself in the field as a subjective participant allows for the development of the "insider" perspective that is key to ethnographic research (Angrosino, 2007; Eriksson & Kovalainen, 2015; Spradley, 1980). This insider perspective provides rich insights into the social actions, behaviors, and practices of the setting (Eriksson & Kovalainen, 2015; Reeves et al., 2008) that are not ordinarily apparent to outsiders (Reeves et al., 2008). To gain these insights, the researcher objectively observes both themselves and others in the setting (Angrosino, 2007; Eriksson & Kovalainen, 2015; Spradley, 1980) to maintain their ability to describe the setting, people, and events to outsiders (Wolcott, 2005).

The process of participant observations has been appropriately and effectively applied to Indigenous health research involving health care equity within Primary Health Care (Browne et al., 2012, 2016); health promotion within an Indigenous Health Institute (McPhail-Bell, 2015); and alcohol and drug rehabilitation clinics (Chenhall, 2008). This approach has been commended in health research for its ability to "generate rich and detailed accounts" of patients' care experiences as well as clinicians' professional and inter-professional relationships, interactions with patients, and approaches to delivering care (Reeves et al., 2008). Further, research methods that are

responsive to naturalistic environments, such as participant observations, are able to gain insights into patient experiences and informal aspects of clinical care (Chenhall, 2008).

# Self-Reflection Through Thinking Aloud

Thinking aloud methods gather verbalized reports of a person's inner dialog relating to the completion of set tasks (Ericsson & Simon, 1980, 1993). Ericsson and Simon developed this method based on the Information Processing Theory (IPT) which distinguishes thought processes into short-term (working memory) and long-term memory (Ericsson & Simon, 1993, 1980; Newell & Simon, 1972). Thinking aloud has since grown into two distinct methods: concurrent to capture working memory (Ericsson & Simon, 1993), and retrospective to capture long-term memory (Aitken & Mardegan, 2000; Chi, 1997).

Concurrent thinking aloud elicits greater insights into decision making processes than retrospective methods (Kuusela & Paul, 2000). However, concurrent thinking aloud is not appropriate for clinical environments as participants (usually clinicians) are required to verbalize their thoughts in front of patients (Denig & Haaijer-Ruskamp, 1994); and the time taken to encode thoughts for verbalization can lengthen treatment time (Ericsson & Simon, 1980; Fox et al., 2011). Others have attempted to adapt concurrent approaches to clinical settings by using selective verbalization in patients' families' presence (Fonteyn & Fisher, 1995); and simulated written or audio-visual case scenarios (Denig & Haaijer-Ruskamp, 1994; Fonteyn et al., 1993; Fossum et al., 2011; Twycross & Powls, 2006). However, these adaptations are not representative of naturalistic settings or the complexities of clinical environments (Fonteyn et al., 1993); and therefore impractical for our needs.

In contrast, retrospective thinking aloud is more conducive to clinical environments as participants verbalize their thoughts immediately following the task (Aitken & Mardegan, 2000). Retrospective thinking aloud draws upon an individual's implicit theory (Nisbett & Wilson, 1977) and assesses knowledge structures stored in long-term memory including attitudes and beliefs (Leighton, 2009), and how these influence problem solving (Chi, 1997). The retrospective nature of this approach is less problematic for the two main issues common to thinking aloud methods: "reactivity," and "non-veridicality" (Eccles & Arsal, 2017; Leighton, 2009; Russo et al., 1989; Wilson, 1994). "Reactivity" occurs when the process of verbalizing thoughts during task performance changes an individual's thoughts surrounding the activity (Eccles & Arsal, 2017; Leighton, 2009; Russo et al., 1989; Wilson, 1994). "Non-veridicality" refers to the verbalization of thoughts that do not access the cognition of interest (usually working memory) (Leighton, 2009; Russo et al., 1989). These issues are less problematic for retrospective thinking aloud as verbalization is delayed, and the cognition of interest is more stable and less susceptible to interruptions or contamination (Leighton, 2009).

Thinking aloud methods have demonstrated promising results in health research, particularly in capturing health

professionals' clinical reasoning (Denig & Haaijer-Ruskamp, 1994; Fonteyn & Fisher, 1995; Fossum et al., 2011; Göransson et al., 2007; Lee et al., 2016; Lundgrén-Laine & Salanteraü, 2010; Twycross & Powls, 2006). To our knowledge, this is the first use of retrospective thinking aloud within an Indigenous health study and in combination with Indigenous research methodologies. This Western research method can be problematic in its privileging of dominant cultures and ideologies if not used in combination with Indigenous research methodologies. In the context of this study we found the self-reflective nature of thinking aloud to be reminiscent of the participant led characteristics of Indigenous research methodologies and yarning methods. We selected this method based on these similarities and its ability to provide insights into the knowledge, attitudes, and beliefs that shape burn health professionals' interactions and care of Aboriginal and Torres Strait Islander families. This self-reflective method was used to contextualize burn health professionals' role in Aboriginal and Torres Strait Islander families' psychosocial experiences of burn injuries and care.

# Story Telling Through Yarning

Yarning is an Aboriginal oral tradition and communication tool that has been used to share Indigenous knowledge systems for thousands of years (Barlo, 2017; Dean, 2010). Dawn Bessarab and Bridget Ng'andu formalized this communication style as a research method that is similar to in-depth interviewing but situated within Indigenous research methodologies and embodies practices developed by Indigenous Elders and Indigenous knowledge systems (Barlo, 2017; Bessarab & Ng'andu, 2010; Roe et al., 2012). Bessarab and Ng'andu describe this process as "an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study" (Bessarab & Ng'andu, 2010).

Bessarab and Ng'andu outline four distinct types of yarning that are crucial to the process: social, research, collaborative, and therapeutic yarning (Bessarab & Ng'andu, 2010). In all forms of yarning, the researcher and participant offer "equal contributions" to the research as listener and knowledge sharer (respectively) with mutual responsibility and accountability to producing meaningful research for Aboriginal and Torres Strait Islander people (Bessarab & Ng'andu, 2010; Dean, 2010). In this way, research is co-created between the researcher and participant as the power imbalance commonly occurring between the two is removed (Geia et al., 2013; Walker et al., 2014) and reciprocity is strongly emphasized (Bessarab & Ng'andu, 2010).

Yarning processes are guided by the participants (Walker et al., 2014) to ensure their experiences are shared in a way that reflects their perspectives and knowledge systems. The central focus for the researcher and point of rigor is in effectively listening and allowing the participant's stories to flow naturally whilst relating this to the research topic (Bessarab & Ng'andu, 2010; Dean, 2010). This study increased participant autonomy

and research rigor from Indigenous perspectives by incorporating deep listening, known as *Dadirri* to the Ngangikurungkurr people of the Daly River area of Australia's Northern Territory. *Dadirri* is an Indigenous Australian form of "inner, deep listening and quiet, still awareness" (Ungunmerr-Bauman, 2003). It is a "culturally respectful conversation" (Stronach & Adair, 2014) that deepens understanding and valuing of the participant (West et al., 2012) by not "just listening by the ear, but listening from the heart" (Atkinson, 2002). Ungunmerr-Bauman importantly teaches us that *Dadirri* is not hurrying the process as "there is nothing more important than what we are attending to" (Ungunmerr-Bauman, 2003).

Yarning methods are highly successful in Indigenous health research with examples in assessing a community based women's wellness program (Walker et al., 2014); policy change surrounding community based smoking projects (Fredericks et al., 2011); and collaborative yarns surrounding qualitative health research in Indigenous communities (D'Antoine et al., 2019). The use of this method has been described as a culturally safe approach (Dean, 2010; Fredericks et al., 2011) that aids in the decolonization of research (Geia et al., 2013) by prioritizing Indigenous knowledge systems (Rigney, 2001; Smith, 1999), and ways of communicating (Walker et al., 2014). These relaxed and open discussions (Fredericks et al., 2011) produce rich descriptions of the topic from the participant's perspective (Fontana & Frey, 2000; Geia et al., 2013).

# **Methods Application**

# Setting

Data collection was carried out in the burns unit of an Australian pediatric hospital. The burns unit operates via a large multidisciplinary team of burn health professionals including doctors, nurses, occupational therapists, physiotherapists, and social workers.

# **Participants**

Eligible participants included: 1) caregivers of all Aboriginal and Torres Strait Islander burn patients aged  $\leq$ 16 years who received care at the study site between June 2018 and June 2019; and 2) all burn health professionals who provided care to these patients. Attempts were made to invite all eligible participants; however, a very small number of families could not be approached as their child's appointments/procedures conflicted with those of already recruited families.

Aboriginal and/or Torres Strait Islander status was self-determined by patients at their first presentation/appointment at the burns unit. At this time, treating nurses provided expert guidance on ideal timing to approach families with utmost sensitivity. The study was introduced to burn health professionals through a series of information presentations delivered prior to the study commencing. Burn health professionals were approached immediately following these presentations or following a burns clinic.

All participants were encouraged to take three or more days to discuss the study with family/significant others (if desired) before providing written consent. This time was vital for the Indigenous research methodology to ensure Aboriginal and Torres Strait Islander families had an opportunity to discuss the project with important cultural connections and maintain autonomy over their participation.

## Data Collection

All data was collected by myself (the lead author), a young Aboriginal woman with a background in psychology and no medical knowledge of pediatric burns care. Prior to commencing this study, I worked at the study site as part of the Coolamon study and had a base level of familiarity with the setting and burn health professionals. However, I had not witnessed a pediatric burns appointment/procedure prior to this study and was unaware of the processes involved.

I was conscious of the privileges associated with my level of education as a doctoral student and the potential for families to view me in a position of power by virtue. It was imperative that the concepts of Indigenous research methodologies were not only embedded in the methods but also my conduct as the researcher by emphasizing rapport and connections with the families, and continuously privileging their voices as the experts on their own experiences. Being a young female was helpful in removing barriers and facilitation more equal relationships with the caregivers who were predominantly also female and older than me, and therefore holders of greater knowledge and life experience than myself. My own lived experiences were closely related to the Aboriginal and Torres Strait Islander families which also greatly aided rapport building and my understanding of their perspectives during the study conduct. However, my position as a student and lack of pediatric burns care knowledge initially proved challenging in building rapport and trust with burn health professionals, and potentially impacted the richness of retrospective thinking aloud data in the initial stages of the study.

The three qualitative methods (participant observations, retrospective thinking aloud, and yarning) were carried out and interwoven throughout the family's care experience. Firstly, I conducted participant observations at all consented appointments/procedures to observe the families' experiences with burns care. Immediately following these observations, I conducted one-on-one retrospective thinking aloud sessions with any burn health professional that provided treatment to the patient during the appointment/procedure. The participant observations and retrospective thinking aloud processes continued until the patient was discharged from the burns unit; either from the inpatient/outpatient wards, or scar management. At this point, I organized a suitable time and place with caregivers for the yarning session to occur. All sessions were audiorecorded to allow natural interactions, and later transcribed verbatim to undergo Constructivist Grounded Theory (CGT) coding.

Participant observation processes. Participant observations were conducted from a non-intrusive position in treatment rooms to avoid influencing treatment flow. During waiting times, I engaged in social yarns with families as we mutually shared information and stories about our Aboriginal and/or Torres Strait Islander heritage and developed vital rapport and trust. During the observations, I acted as a moderate participant and quiet observer (Spradley, 1980) while attempting to "suspend preconceptions" in search of meaningful discovery (Ball, 1990). Throughout these observations, I endeavored to make the "strange familiar, and familiar strange" (Gordon et al., 2001) to document elements of treatment that were considered both familiar and unusual to the setting and care process (Barron, 2013).

In line with Reeves' (2008) recommendations, my observations specifically focused on elements of care that related to the families' psychosocial experiences and implications of burns care. I observed any visible and audible cues surrounding the patient, family, and burn health professionals' psychosocial wellbeing. I paid particular attention to any offers/provisions of psychosocial support including information sharing, logistical support (i.e. financial, travel, parking), and support services (i.e. social workers, Indigenous Hospital Liaison Officers). Any verbal (i.e. tone, mannerisms) and non-verbal interactions (i.e. facial expressions, body language) were also observed between family members, among health professionals, and between health professionals and family members. I made brief hand written notes/jottings during appointments (Barron, 2013; Eriksson & Kovalainen, 2015), that I developed into "thick descriptions" following the appointments (Emerson et al., 2001; Eriksson & Kovalainen, 2015; Geertz, 1973), and later expanded to complete reports that included my personal reflections (Angrosino, 2007; Eriksson & Kovalainen, 2015).

The use of participant observations was effective in documenting the interactions and behaviors present during appointments/procedures; however, the overt nature of these observations potentially altered the behaviors of burn health professionals and families (Thompson, 2016). Many of the families noted that my presence in the room made them feel more comfortable and supported in the clinical environment. It is possible that this increase in comfort may have influenced the families' confidence in interacting with health professionals and engaging in care. It is also possible that the health professionals' awareness of my observations may have positively influenced the level of care they provided to families. However, inconsistencies in the health professionals' care began to show early in the study. This indicates that any influences of my overt observations on care were minimal or not maintained.

The participant observations were heavily reliant on my acceptance into the setting as a reputable researcher and participant in the families' and burn health professionals' experiences (Angrosino, 2007). It was particularly challenging to gain a level of acceptance among the burn health professionals to develop insights into their world, whilst also maintaining enough space and distinction from them to remain accessible

and trustworthy to the Aboriginal and Torres Strait Islander families. This "push-pull" is a common challenge for Indigenous researchers as we engage with the cultural interface between Indigenous and non-Indigenous spaces (Nakata, 2007). Despite these challenges, I was able to achieve a balanced position by consistently building rapport and trust between myself and the caregivers and health professionals.

The greatest challenge in using participant observations was the need to be accepted and "go with the flow" of the setting (Angrosino, 2007; Reeves et al., 2008). The "flow" or norm of the settings Western biomedical framework often contradicted the processes required for integrity within Indigenous research methodologies. The participant observation field notes were also predictably labor intensive, time consuming (Sangasubana, 2011), and difficult to capture the multifaceted nature of the clinical environment (Reeves et al., 2008). However, this also allowed me to immerse myself in the naturalistic setting for longer and provide more focused attention to each family.

Thinking aloud processes. Sessions occurred one-on-one between myself and consenting burn health professionals in private treatment rooms as immediately following the appointment/procedure as possible. I initially sought to represent the multi-disciplinary team involved in each appointment/procedure by including a doctor, nurse, occupational therapist, physiotherapist, and social worker (where involved). Due to the health professionals' time constraints, this was later adapted to ideally capture a minimum of one retrospective thinking aloud session from any burn health professional for each family's first four appointments/procedures. However, on several occasions there were no burn health professionals available and a clinical perspective was not captured for these appointments/procedures.

Retrospective thinking aloud sessions commenced with a standard direction for the burn health professional to recall themselves walking into the treatment room and carrying out the appointment. I then invited the health professional to verbally share their thoughts and feelings from the appointment/procedure without interruption and with minimal cues. The thinking aloud process was considered complete upon the health professionals' indication and followed-up by short, structured exit interviews. The six standard exit interview questions are included as supplementary information.

At the outset, I was aware that some burn health professionals may be better able to verbalize their thoughts and actively participate in the process than others (Charmaz, 2006; Lundgrén-Laine & Salanterä, 2010). Unfortunately, I was not able to hold practice sessions with health professionals due to the hectic nature of the study setting. However, it was anticipated that burn health professionals would warm up to the process over the course of multiple sessions. The intense nature of the setting impeded burn health professionals' ability to participate in sessions, leading to some burn health professionals only participating once. This potentially impacted the richness of data from some burn health professionals.

The hierarchy of the burns unit also meant my position as a doctoral researcher was subordinate to the burn health professionals which often impacted my ability to gain mutuality and legitimacy in this power dynamic, and (predictably) resulted in a domination of colonial ideologies within this aspect of the project. However, this was not problematic for this study as this method's purpose was to gain an understanding of burn health professional's knowledge, attitudes, and beliefs. Rather, this represented the effectiveness of this specific method in accessing burn health professionals' implicit theories, and reflecting their knowledge, attitudes, and beliefs toward treating Aboriginal and Torres Strait Islander pediatric burn patients.

Yarning processes. Yarning sessions occurred one-on-one between myself and any family members wishing to partake via phone or face-to-face in a place selected by the family. These yarns took place after many hours of rapport and connection building between myself and families over weeks to months. The development of rapport was integral to the yarning process to build the families' trust in me, and my accountability toward the families (Bessarab & Ng'andu, 2010) as I began to see the world from their perspectives (Fontana & Frey, 2000).

The yarns commenced with social yarns before I introduced the research yarn and families were asked for their permission to audio-record the session. The research yarn commenced with a standard invitation for the caregiver(s) to "share what it has been like for [them] and [their] family going through the burns care experience". I remained present during the yarns by incorporating *Dadirri* deep listening and providing minimal interruptions during the caregiver(s) sharing. The caregivers were given small prompts/cues for further information where they touched on points of particular interest or already emerging categories. An hour was allocated for the yarning sessions; however, sessions were considered complete upon the caregiver(s) indication.

It is ideal to offer both male and female researchers when using yarning and Indigenous research methodologies to manage and respond to potential gender issues (Bessarab & Ng'andu, 2010). Unfortunately, I was unable to offer a male researcher to families as I collected the data as a sole doctoral researcher. While the number of male caregivers involved was relatively high, their participation was predominately accompanied by a female caregiver aside from two sole male caregivers. I was conscious of the cultural differences surrounding gender issues between Aboriginal nations and actively looked for cues from family members surrounding these issues. As such, I directed most of my interactions toward the female caregiver and waited for the family's indication of when it was appropriate to engage with male family members. Fortunately, the sole male caregivers did not express any discomfort or aversion to interacting directly or sharing their experiences with a female researcher; and there were no apparent gender influences present in the yarning data.

# Data Analysis

Grounded theory analysis. We used the analytical process of CGT developed by Kathy Charmaz (Charmaz, 2006; Rieger, 2018).

Grounded theory in general has been used within various Indigenous health research projects (Bainbridge, 2011; Bainbridge et al., 2013; Evans, 2017; Kandasamy et al., 2017a, 2017b; McCalman et al., 2015), with CGT approaches being particularly successful in this space (Bainbridge et al., 2013; Kandasamy et al., 2017a, 2017b; McCalman et al., 2015). The CGT approach works well with Indigenous research methodologies as it similarly acknowledges the researcher's power as nonobjective observers (Glaser & Strauss, 1967; Hall & Callery, 2001; Rieger, 2018) and seeks to remove power differences and build mutuality between the researcher and participants (Charmaz, 2006; Geia et al., 2013; Walker et al., 2014). The use of CGT analysis constructs ideas and theories from data rather than fitting data to preconceived frameworks or agendas (Charmaz, 2006; Rieger, 2018). This process further aligns with Indigenous research methodologies as the focus is shifted from the researcher's preconceived agendas, to addressing the needs of Aboriginal and Torres Strait Islander people and promoting their autonomy (AIATSIS, 2012; Alonso Bejarano et al., 2019; Jamieson et al., 2012; West et al., 2012). This approach is ideal for ethnographic research and has shown great success in other ethnographic projects (Bamkin et al., 2016; Charmaz, 2006). Further, the iterative process of CGT analysis is similar to verbal analysis commonly used with retrospective thinking aloud data (Leighton, 2009).

Our analytical process followed CGTs core principles and cyclic process of initial and intermediate/focused coding, memo writing, continual comparative analysis, and concurrent data collection and analysis (Birks & Mills, 2011; Charmaz, 2006; Rieger, 2018). Initial coding began once the first family's data collection was complete (including participant observations, retrospective thinking aloud, and yarn), and continued simultaneous to data collection until data collection was complete. Data collection, transcribing, and initial coding was conducted by myself, and intermediate/focused and advanced coding were conducted in collaboration with three co-authors. A unit of measurement was classified as a singular appointment/procedure, a retrospective thinking aloud session, or a yarning session. The intermediate/focused coding initially focused on the yarning data and continued until categories had complete descriptions and properties before proceeding to the retrospective thinking aloud data. Participant observation reports were examined for events and/or interactions pertaining to the families' psychosocial experiences, particularly aspects considered unusual to the setting or that provided context to the yarning and retrospective thinking aloud data.

Theoretical sampling. The grounded theory process of purposefully selecting participants through theoretical sampling was not possible for this study as the characteristics of eligible families was unpredictable and flow of patients inconsistent. The concept of selective sampling also does not fit well within Indigenous research paradigms as all individuals are considered to have important and valuable stories to share (Bubenzer et al., 1995; Wingard & Lester, 2001). Therefore, I attempted to approach all eligible families that attended the setting during

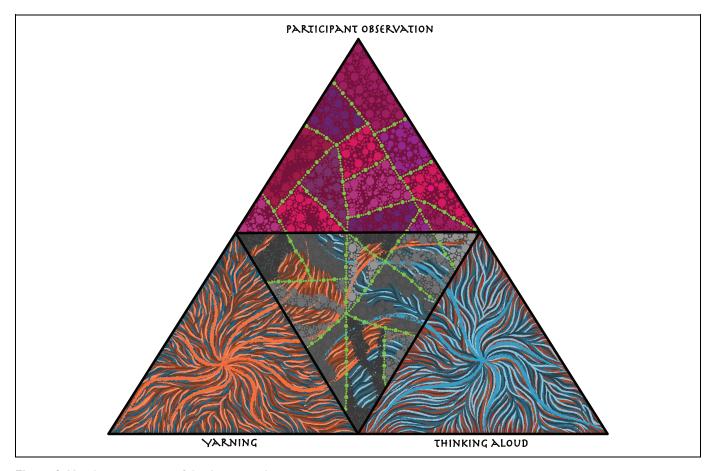


Figure 2. Visual representation of the data triangulation processes.

the study period. A trend emerged during data collection wherein Aboriginal teenage males became the dominant subgroup of the cohort. This is reflective of the overall population of Aboriginal and Torres Strait Islander pediatric burns patients; however, in the interest of gaining varied perspectives from families of different demographics (i.e. patient's age, gender, and injury mechanism/severity) I adjusted the sampling where, if given a choice, I prioritized families of children that were not Aboriginal teenage males.

Elements of theoretical sampling were maintained by carrying over emerging categories from initial yarns to subsequent sessions. For example, caregiver stress associated with insufficient information was raised in the initial two yarning sessions and carried over/prompted in subsequent yarns if not already raised by caregivers. Theoretical saturation was considered to have been achieved when no new codes or categories appeared in subsequent sessions, and categories were well developed with clearly defined properties and dimensions (Birks & Mills, 2011).

Member checking. Member checking is arguably not required for grounded theory methods due to the iterative process of concurrent data collection and analysis (Birks & Mills, 2011). However, this process is important in Indigenous research methodologies to ensure participants maintain

autonomy over their participation and data (Barlo, 2017). Therefore, participants were given the opportunity to provide feedback on their transcripts and data via email and/or phone. Any aspects of the transcripts that caregivers did not want included were removed, and any further data interpretations or clarifications were used to determine the direction of the final data analysis and theory development.

Data triangulation. Ethnographic approaches commonly use methodological triangulation to compare multiple data sources from different points of view and time (Reeves et al., 2008). This process aims to gain data completeness with holistic context, breadth and depth (Fielding & Fielding, 1986; Jick, 1979). It is with this purpose and goal that we incorporated methodological triangulation at an individual and interactional level (Knafl & Breitmayer, 1991) for each of the participating families. Data analysis was combined to develop holistic insights and theories surrounding the families' psychosocial experience of pediatric burn injuries from their perspectives (yarning); and the circumstances contributing to these including the burn health professionals input (retrospective thinking aloud), and interactions that occurred during their child's care (participant observations).

Figure 2 pictorially outlines the coming together of each data source in the triangulation process. The participant

observations depicted in the top triangle represents the segregated and multifaceted nature of the multidisciplinary team and pediatric burns care. The fluid design of the bottom two triangles portray the sharing of complex experiences and knowledge by caregivers (yarning) and burn health professionals (retrospective thinking aloud) in contrasting colors representing their different perspectives. The central triangle portrays the coming together of these methods in the triangulation process, interweaving as they describe the psychosocial impacts of burn injuries and care on Aboriginal and Torres Strait Islander families.

# **Ethical Considerations**

The study was guided by ethical guidelines for research with Aboriginal and Torres Strait Islander people (NHMRC, 2018a, 2018b). The Coolamon study that governs this 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 pediatric burn injuries.

We were conscious of the historical over researching of Aboriginal and Torres Strait Islander people (Bessarab & Ng'andu, 2010; Durie, 2004; Rigney, 1999; Rix et al., 2019; Smith, 1999) that has included them as "subjects of research endeavors, rather than consenting participants" (Drawson et al., 2017). The research misconduct toward Aboriginal and Torres Strait Islander people, their land, human remains, and knowledge has produced a high level of mistrust for some Aboriginal and Torres Strait Islander people towards research (AIATSIS & The Lowitja Institute, 2013; Durie, 2004; Geia et al., 2013; Rigney, 1999; Rix et al., 2019). As this study was carried out in a tertiary hospital, we were also conscious of the inequities created and maintained by mainstream health policies and practices; and the consequential reluctance of some Aboriginal and Torres Strait Islander people to engage with these services (Wingard & Lester, 2001).

It is imperative that studies such as ours uphold Aboriginal and Torres Strait Islander peoples' autonomy and control throughout the research process (Barlo, 2017). All participants were provided with written and verbal information about their involvement and specific data use. During the recruitment phase, I emphasized the confidentiality and anonymity of data, and voluntary basis of participation before obtaining consent. Following initial consent, I adopted an ongoing consent process to allow participants to negotiate their participation or withdrawal prior to each data collection point.

We were also conscious that eligible families were a highly vulnerable population enduring particularly distressing events. The study methods involved both caregivers and burn health professionals sharing their personal and professional experiences of pediatric burn injuries and care. These conversations had potential to cause distress and re-experiencing of traumatic incidences for participants. To reduce these risks, the yarning sessions were guided by the caregivers to ensure their experiences were shared in a way they felt comfortable. On the few

occasions a caregiver or family member became upset during a yarn, I ceased the research yarn and changed to therapeutic yarning in which I listened and affirmed the participant's story (Bessarab & Ng'andu, 2010). In these situations, I asked the family if they would like a referral to a hospital social worker, Indigenous Hospital Liaison Officer (IHLO), or support service external to the hospital. These offers were declined by all families except one who was re-connected with a IHLO who previously assisted them during their child's care.

The retrospective thinking aloud sessions also had potential to raise personal work challenges for burn health professionals and consequently invoke feelings of distress/concern surrounding theirs or colleague's employment. Throughout the conduct of this study only one burn health professional showed signs of concern toward information they had shared outside of the audio-recorded session. I reassured this participant of the confidential nature of their information and that it would not be included in the study or shared elsewhere. I also asked this participant if they would like a referral to a support service external to the hospital, which was declined.

# Strengths of the Novel Research Approach

This study's focus was directed by Aboriginal and Torres Strait Islander families affected by pediatric burn injuries, allowing us to genuinely respond to their expressed desires and needs. Building upon this foundation, the use of Indigenous research methodologies prioritized the non-dominant culture and privileged the voices, experiences, and perspectives of Aboriginal and Torres Strait Islander families. The combination of these research methodologies with decolonial ethnographic approaches facilitated the development of strong rapport and trust between myself and the families. This rapport and trust further deepened my understanding of the families' experiences with their child's injury and care. The central focus on yarning methods and interweaving these with participant observations and retrospective thinking aloud methods allowed me to explore the intricacies of pediatric burns care in a way that was culturally appropriate and safe for families, whilst remaining minimally intrusive to the care process.

Combining ethnographic approaches with CGT analysis was a major strength of this study as the two were mutually beneficial in counteracting pitfalls within each other (Charmaz, 2006). The use of CGT analysis increased rigor in the decolonial ethnographic approach by providing focus to the fieldwork, data collection, and analysis (Charmaz, 2006; Coffey & Atkinon, 1996). This focus helped me avoid the common issue of participant observations producing lengthy, superficial and unfocused fieldwork and data collection (Charmaz, 2006; Coffey & Atkinon, 1996). Similarly, the data triangulation counteracted potential weaknesses of CGT, particularly when focused on singular data sources, by accounting for situations where peoples' actions differed or contradicted their statements during interviews (Charmaz, 2006). The inclusion of the Indigenous research method of yarning in the triangulation

strengthened the studies rigor and legitimacy within both Indigenous and Western research (Walker et al., 2014).

To our knowledge, this study is the first example of retrospective thinking aloud methods within Indigenous research paradigms or in collaboration with decolonial ethnography. The choice of retrospective thinking aloud strengthened the study's ability to adapt to the clinical setting and avoided the common issues of "reactivity," and "non-veridicality" (Eccles & Arsal, 2017; Leighton, 2009; Russo et al., 1989; Wilson, 1994). Similarly, the participant observations were designed and implemented in a way that was minimally intrusive to the care process and, as such, were adaptable to the rapidly changing nature of the appointments/procedures. Likewise, yarning methods have been praised for their ability to adapt to specific study needs while maintaining their core elements (Dean, 2010).

#### **Limitations and Recommendations**

Despite these methods being highly adaptive, the busyness of the clinic environment still hindered burn health professionals' ability to participate in the retrospective thinking aloud sessions. Further, some burn health professionals declined participating due to their aversions to "thinking that way" in reference to the self-reflective nature of the thinking aloud process. This resulted in some appointments/procedures missing a clinical perspective, and a smaller number of appointments/procedures included in the data triangulation. These elements could not be controlled and are accepted as a limitation of conducting research within naturalistic settings, particularly when clinical care of vulnerable populations is involved.

The participant observation processes restricted my ability to leave treatment rooms once a family's appointment/procedure started. Consequently, a very small number of eligible families were missed as their appointments/procedures conflicted with times I was present with other families. The study's sampling was limited by the relatively small number of Aboriginal and Torres Strait Islander families attending the setting during the study period, and inconsistent flow of their attendance. These sampling limitations are potential problems for the study's representativeness; however, the characteristics (i.e. injury mechanism/severity, child and caregivers age and gender) of the missed families were reflective of those included in the study. Further, qualitative research does not aim for generalizability and the goal of this study was to privilege the voices and experiences of included Aboriginal and Torres Strait Islander families.

To counteract these sampling issues, we recommend including a minimum of two researchers to conduct recruitment and data collection. An increase in researchers would have allowed for more families to be approached and improved representativeness of Aboriginal and Torres Strait Islander families accessing pediatric burns care at the study site. Ideally this should include male, female, and gender diverse Aboriginal and Torres Strait Islander researchers to provide culturally appropriate and gender responsive options.

Overall my experience was similar to that of Professor Dawn Bessarab's doctoral research experience (Bessarab & Ng'andu, 2010) in that the use of Indigenous research methodologies was met with suspicions from burn health professionals and academics. The rigor and validity of these processes were consistently challenged by academics within the burns team which potentially impacted burn health professionals' attitudes toward participating. Prior to this study, I presented a series of information sessions on the study purpose to the burns team including health professionals and academics. These sessions are a vital process in using these methods; however, it is recommended to also outline the legitimacy of Indigenous research methodologies to better prepare study settings for this type of research and aid in a smoother implementation.

## **Conclusion**

In this paper, we highlight the pressing need to expand current burns literature to include Aboriginal and Torres Strait Islander peoples' knowledge systems and experiences. We emphasize the importance of expanding this knowledge from within Indigenous research methodologies and outline our own use of these methodologies to explore the psychosocial impact of pediatric burn injuries on Aboriginal and Torres Strait Islander families. We describe a novel use of decolonial ethnography under this theoretical framework, and the innovative combination of three qualitative methods that, to our knowledge, had not been interwoven as such before. In combining these methods, we were able to explore the psychosocial implications of complex injuries and care in a way that privileged Aboriginal and Torres Strait Islander families' voices and prioritized their autonomy.

Further, we found the analytic possibilities of CGT to be widely useful and applicable to the study methods and theoretical framework. We outline the analytic possibilities of CGT for these various qualitative data sets and its ability to facilitate data triangulation for the production of rich meaning founded within data. The approach used in this study has strong potential to be adapted for the needs of other similarly complex issues affecting Aboriginal and Torres Strait Islander people. We recommended that future work incorporating such approaches are founded on the needs of Aboriginal and Torres Strait Islander people, and adopt realistic and adaptable processes that are responsive to the naturalistic clinic environment.

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#### **Author Contributions**

HW carried out consultation with Aboriginal and Torres Strait Islander families and burn health professionals to conceptualize the project aims and adapt these around expressed needs and desires. HW, KH,

BG, and KC further developed the project aims for depth and clarity, and conceptualized this paper. HW selected the theoretical framework and methods; designed the featured artwork; conducted the recruitment, data collection, and initial grounded theory coding; and led the writing of the manuscript. RK facilitated HW's engagement with the Burns Unit. HW lead the intermediate and advanced grounded theory coding in collaboration with KC, KH, and BG. All authors contributed to drafting and revisions of the manuscript, approved the final version, and agreed to be accountable for all aspects of the work.

# **Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# **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).

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# Supplemental Material

Supplemental material for this article is available online.

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