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Yarning to reduce take own leave events in First Nations patients presenting to the Emergency Department-presenting the qualitative themes and co-design of the Deadly RED project

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Abstract

Issue Addressed: The Deadly RED redesign and implementation research aimed to improve take own leave (TOL) rates within a Queensland emergency department by providing a culturally competent care pathway.

Methodology: A mixed methods pre/post evaluation of the feasibility, acceptability and usability of the Deadly RED pathway for First Nations patients presenting to ED was performed. This pathway combined early welcome and information sharing, introduction of screening and follow up for patients who TOL and enhanced access to alternative community healthcare. Yarning circles facilitated co-design of research protocols and tools while a purposefully designed research Yarn enhanced understanding of the 'story' of the people. Qualitative analysis of Yarns allowed deductive themes to be extracted. A Participatory Action Research (PAR) approach and Indigenous research methodology involving First Nations people in design, knowledge sharing and joint ownership of results was used.

Results: Common themes from the 85 yarns included the negative impact of long waiting times and positive impact from wholistic care. Unique themes identified included interpretation of waiting room placement and paracetamol prescription as a dismissal. Knowledge dissemination from yarning drove improvements in communications and processes to promote treatment completion resulting in elimination of these themes in post implementation yarns. Eighteen patients who had TOL were included in the post implementation yarns, however only eight of these believed that their treatment was incomplete.

Conclusion: The use of yarning for consumer engagement has allowed deeper understanding of the reasons for TOL in First Nations emergency patients. The reciprocal knowledge sharing has guided targeted improvements in wholistic emergency care

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Patients who identified as Aboriginal and Torres Strait Islander at the point of registration were given a Consent to Contact form. Verbal Consent was confirmed prior to the research yarn and only this portion of the yarn was transcribed for analysis.

and communication resulting in First Nations patients feeling their care is complete even when the 'number' reports otherwise.

So What? Indigenous Research methodology including yarning with First Nations patients suggests alternative engagement methods to guide enhanced quality of care monitoring for ED presentations.

KEYWORDS

aboriginal and Torres Strait islander, culturally safe, participatory action research, take own leave, yarning

1 | INTRODUCTION

'Take own leave' (TOL) is a term used to describe patients who either do not commence treatment or who leave prior to completion of their healthcare. Aboriginal and Torres Strait Islander (respectfully referred to as First Nations) people presenting for emergency care have TOL rates four times greater than the remaining population[1] and a burden of disease 2.3 times higher with significantly lower life expectancy.[2,3] The reasons for this are complex including ongoing institutional racism, poorer social determinants of health and barriers to accessing culturally appropriate health care.[2] A systematic review exploring TOL reported similar themes expanding to include distrust of the health system, unfriendly environments, communication issues, insufficient Indigenous health liaison officers (IHLO) and the impact of social and cultural responsibilities[1] on treatment completion. The Australian Commonwealth, States and Territory Governments and Coalition of the Peaks partnered to present the 'National Agreement to closing the Gap'[4] in 2019. In the Emergency Departments(EDs), performance on the 'number' of First nations patients who TOL has been used to indicate inadequacy of care[5] and despite previous interventions,[1] rates remain alarmingly high nationwide.

To positively influence health outcomes, ED environments must be welcoming, staff culturally competent and the identified staff must be available for connection.[1] Bold changes[6] will be needed to redesign services with support from community to improve procedures and engagement including regular analysis of the reasons for TOL.[1] Patient Reported Outcome and Experience Measures(PROMs and PREMs) have been introduced to inform the delivery of healthcare,[7,8] however, these tools have not been validated with First Nations methodology incorporated. Small studies are progressing to adapt these scores to the First Nations context,[8,9] yet rating scales and impersonal forms of engagement are unlikely to get the true perspective. The use of relational yarning to facilitate connection, and two-way reciprocal knowledge transfer to guide improvements respects the principals of self-determination[10] and community driven changes that underpin the health equity strategies and outcomes.[6] Yarning allows time for the establishment of relationality to the land, each other and storylines. Studies in cardiac wards,[11] and EDs[12] show that yarning and narrative accounts enable deeper listening and enhanced understanding of First Nations perspectives. Combining yarning with Participatory Action Research(PAR) has provided a powerful framework in falls programmes[13] and stroke information resources[14] but it is use in clinical redesign is not yet widespread.

The ED and Aboriginal Health care workers including IHLOs came together as the Deadly RED (Redcliffe ED) redesign and research team to tackle the problem of First Nations patients TOL within a Queensland urban ED where TOL rates in 2019 were well above the national average. The Deadly RED pathway was a clinical redesign consisting of three(3) parts.

1. Early, culturally safe engagement and information sharing.
2. Clinical screening of TOL patients (48–72 h Follow-up call).
3. Enhancing connections and supports through increased referrals to IHLO and community services.

The overarching aim of the Deadly RED implementation study was to evaluate the Deadly RED redesign pathway's effectiveness in increasing treatment completion and improving culturally competent care. The research combined Indigenous and non-indigenous research methodologies and ethical guidelines, using yarning to allow respectful and reciprocal conduct of the study.[15] The First Nations researchers were integral to the study as they guided the construct of the research, performed the 'research yarning' with First Nations patients who had attended the ED, provided perspective and analysis of transcripts and subsequent theming. This allowed sharing of cultural knowing and understanding with all members of the team. The qualitative analysis of the pre/post implementation research Yarns and narrative on the journey of the PAR and knowledge exchange between the research team are the focus of this paper.

2 | METHODS

The Deadly RED Research study was a mixed methods evaluation of the Deadly RED redesign pathway to assess the acceptability, feasibility, usability and effectiveness of the intervention. The research was co-designed through Deadly RED yarning circles led by the Cultural Capability Officer who utilised a Guthalungra approach (Head Mouth in Birri Gubba dialect) or 'We think and all speak'.[16] This resulted in a redesign of the qualitative measures to include pre and post yarns facilitated by a First Nation's research assistant to evaluate the Deadly RED intervention. Patient engagement elements were modified including local Indigenous artwork for the ED journey card. Knowledge dissemination and analysis within the research team was planned utilising yarning circles and regular community knowledge sharing to facilitate culturally safe research practice. The result was a research protocol 'for and with' the First Nations community focusing on a qualitative narrative to interpret quantitative measures.

A sample size of 50 patient yarns was proposed with the planned yarns to occur before and after the Deadly RED pathway implementation. Pre-implementation, patients who identified as First Nations at the time of registration in ED were given written information and consent to contact forms as well as verbal consent prior to the research component of the yarn. A convenience sample of patients who presented during the study period was contacted by the First Nations research assistant. The conversation script was developed by the Deadly RED research team and extrapolated from the 'clinical yarning structure' as described by Lin et al.[17]' comprising a 'social yarn' to build trust and engagement, a 'research yarn' to enquire about their ED experience and a 'therapeutic yarn' to address clinical issues that were uncovered during the conversation. Only the 'research yarn' component of the conversation was recorded and then transcribed verbatim for qualitative analysis. Over 40% of the yarns included patients who had TOL to ensure their voices were heard.

Research Yarn transcripts were uploaded into NVIVO software and coded by a single coder. Data familiarisation occurred with multiple passes through the transcripts spaced in time. Transcripts were coded and cross checked to ensure completeness. The codes were themed using deductive analysis to reveal latent meaning. These were merged into distinct themes around the research questions of acceptable, feasible and accessible care. Additional themes in the post implementation transcripts were generated around care completion and follow up.

Themes were presented to the Deadly RED group for further cultural context and analysis facilitated by yarning circles. A PAR approach allowed for continuous learnings to be shared with the clinical team and community for continuous improvements to be facilitated. Finally, research team reflections were transcribed and coded for themes around the research process.

3 | RESULTS

A total of 35 yarns pre and 50 post were completed and transcribed for analysis. Two incomplete interview transcripts were excluded from the post file set. Themes were collated from the distinct pre and post datasets and were combined for the analysis.

Themes around good accessibility, feasibility and acceptable or usable care included 'good wait times', 'acknowledging family linkages', 'professional care from staff' and 'wholistic care' demonstrated by providing blankets, food and drink. As one elder stated, 'just them coming to sit down for a yarn, that would be really good'. 'Care during a traumatic event' appeared to also increase accessibility of care (Table 1). Deadly RED yarning sessions revealed that this was partly due to the reduced wait times with increased acuity but also due to the increased tolerance when patients were concerned about their condition.

Unsurprisingly, patients who TOL reported more negative themes. Poor accessibility and unacceptable care had linked themes which included 'Staff not able to meet needs because of pressure', 'COVID making things harder', 'Poor waiting times' and 'Not listening to patient'. There were subthemes of understanding from the patients that whilst their care was substandard, that this was 'to be expected in ED' and that the staff efforts were hampered by limited resources resulting in poorer care. Of note, most patients felt respected in their ED encounter and felt 'enabled to make decisions about their healthcare' (Table 1).

In pre-implementation transcripts, there were prominent themes of 'unacceptable pain management', 'not being fixed' and 'misinterpreted clinical communication'. Some quotes from yarns with patients who TOL demonstrate this perspective; 'She ended up with me being able to get the treatment over the counter, so I waited over 5 hours for nothing' and 'I came in by ambulance and they took me out to the waiting room. I was a little bit confused why I was taken out there'. Analysis and discussion in Deadly RED yarning circles revealed a disconnect between the intention of the clinicians in providing care and the interpretation of their actions by the First Nations patients. When patients were offloaded from the ambulance trolley, the patients took this to mean that the clinical staff had assessed them as having a minor complaint and therefore they would be safe to TOL. However, those that were offloaded were often of higher acuity, but limited beds and an overcrowded ED meant that beds were seen as 'hot beds' and only those that could not sit were in beds for their complete treatment. The negative themes about over the counter (OTC) medication were explored and translated with the aid of yarning. For the clinicians, the OTC medications (paracetamol and ibuprofen) represented the first step along the analgesic ladder and the effects and progression to stronger pain relief aided clinical reasoning. In some First Nations communities, paracetamol is known colloquially as 'the shut-up pill'[18] with a perception that it is given to patients that the clinicians want to ignore. This was a revelation for the non-First Nations

TABLE 1 Qualitative Themes from research yarns.

Good accessibility, feasibility and acceptable or usable care	Poor accessibility, feasibility and unacceptable or unusable care
Good wait times	Staff not able to meet needs because of pressure
Acknowledging family linkages	COVID making things harder
Professional care from staff	Poor waiting times
Wholistic care	Not listening to patient
Care during a traumatic event	Unacceptable pain management
Enabled to make decisions about their healthcare	Not being fixed
	Misinterpretation of clinical communication

members of the research team and may explain some of the discontent and TOL that the staff had witnessed when prescribing these medications as standard care. These themes were presented to staff and community as part of the PAR approach and changes were made both in the narrative and time spent explaining to patients as to the reason for their placement in the waiting room and why pain management starts with simple measures. A co-designed leaflet on pain management utilising artwork and storytelling to convey this measure has also been developed in collaboration with community and the pharmacy team.

In post-implementation patient yarns, there were additional conversations around follow up, communication with staff and the degree of comfort that patients had with informing staff when they needed to leave. These were intended to explore the impact of the Deadly RED pathway which had included cultural capability training for staff about the diverse reasons for patients TOL. Apprehension and reluctance had been expressed in yarning circles with staff about the follow up process even if the presentation was concerning, as they feared their follow up calls would be unwelcome in patients who had TOL. However, when analysing the themes from this section of the transcripts, it was clear that the patients felt extremely comfortable letting staff know that they needed to leave and that they appreciated the follow up. Additionally, it became apparent from the yarning transcripts that the number of patients who felt that their treatment was incomplete was at odds with the 'number' that were documented as TOL (18 of the 48 post implementation yarns). The Deadly RED Team came to the realisation that the western construct of treatment completion, being defined by assessment and management completion by a doctor, was perceived very differently by the First Nations people who presented for wholistic and/or cultural reasons, not just medical. The early engagement with staff including IHLOs, reassurance and knowledge sharing throughout the ED journey including options for community care provision in some instances provided all the care they required. The patients chose to return home or seek care elsewhere because they considered their ED treatment to be complete. This narrative allowed the research team to reassess the 'number' of patients that TOL (8 of 48 not 18 of 48) and therefore showed that the Deadly RED pathway had achieved its aim of increasing culturally competent care completion despite it not being reflected in the 'numbers'.

4 | DISCUSSION

As healthcare professionals working within a western dominant health system, the focus is on the patient presentation using an illness and injury construct. The goal of the emergency encounter is to diagnose, commence investigations, provide urgent treatments, and determine disposition. The wholistic concept of healing for First Nations patients considers physical, emotional, cultural, social, and spiritual causation of illness, factors which are rarely considered by Australian clinicians during the ED presentation. Numerous studies have outlined reasons for the high 'number' of First Nations patients that TOL which has been used as a surrogate measure of culturally safe quality care.[1,4,5,19,20] Within this study in an urban ED, the research team focussed on factors that would improve accessible, usable and acceptable care. This study found that although themes surrounding family linkages and responsibility, communication issues and wait times[4] were present, specific misunderstandings around clinical intent and ED processes were more prominent in this study compared to previous literature. The issue of waiting room patients being overrepresented in TOL rates is noted in previous literature,[19] along with the belief that if they are in the waiting room with a lower triage category then they must be 'ok'.[20] With increasing access block and demands for acute ED beds, patients with a higher acuity and potentially serious conditions are left in the waiting room, increasing clinical risk if these patients TOL. Knowledge sharing between community and clinicians about the reason behind ED processes such as ambulance offloading into the waiting room, simple analgesia and the ED journey has commenced the risk mitigation for these patients. However, more needs to be done to increase ED capacity and community understanding of ED process to encourage safe treatment completion for these higher acuity patients.

The prominent theme of dissatisfaction around pain relief resulting in TOL was unique to this study. Studies reveal the understanding of pain in diverse populations is enhanced by describing pain according to a person's ability to fulfil their role within their cultural group.[21] Visual scores are more valid than numerical pain scores in culturally diverse groups.[22,23] Limited literature on pain scores for First Nations patients revealed the difficulties with expression of the intensity and quality of their pain for adolescent patients[24] and the lack of understanding of pain expression for central Australian women by non-First Nations health care workers.[25] The Deadly RED team translated the pain experience between the clinical and cultural context through yarning. These thoughts were shared with the community and together a functional pain score and translation of the pain ladder into a journey pictorial was produced. The pain score pictures represent function within First Nations communities including pictorial representations of family, cultural and community responsibilities that may be impacted. The pain ladder concept was translated into a culturally appropriate 'journey' with increasing analgesic requirements representing each stop (see Appendix A: Snippet from the pain pamphlet). This was likened to the journey of the canoes in Moreton Bay with the analogy that you would travel only as far as your own destination up the pain journey.[16] This pamphlet will be implemented and reviewed with feedback from the First Nations community.

Using the PAR approach allowed reciprocal learning on both sides. The clinical staff learnt that their actions were being misinterpreted (offloading from the ambulance trolley, no sense of urgency, OTC medication) and learnt that basic needs (warmth, food and drink, taking a moment to make connection and have a yarn, acknowledging importance of family) went a long way to ensuring acceptable and effective care. This time spent 'walking in the other's shoes' allowed the staff to realise that regardless of the quality of the clinical care, if wholistic care was not provided, the patient would be dissatisfied, lose trust in the clinician and be unlikely to follow any advice given and therefore, would be unable to heal. The staff made changes to the way they engaged and communicated, and this allowed further improvements.

Finally, the beliefs of staff about the patients' perspectives were challenged. Staff learnt that the patients understood that staff would like to help more but that they were not resourced to do so, and that they genuinely appreciated the calls, engagement, and care provided as follow up even if they had TOL. They shared stories of 'epic saves' which further encouraged this shared understanding and follow up approach. And finally, they began to challenge the medical premise for an encounter when presented with evidence that patients regarded treatment completion without necessarily seeing a doctor. These learnings were invaluable for both the research team and clinical staff as they grew towards more culturally competent care and a shared understanding of patient's needs and expectations.

5 | LIMITATIONS

This was a small study at a single urban centre with a convenience sample of only 85 yarns representing the patients who answered the phone and were consented. Further studies in different EDs including regional and rural contexts will be needed. The arrival of the COVID pandemic to Australia introduced prominent themes that may have diminished other relevant themes and will likely not be an ongoing significant impact on TOL rates for First Nations patients in future analyses.

6 | CONCLUSION

The Deadly RED team had a goal of improving the 'number' of treatment completions for First Nations patients presenting to ED as a surrogate measure for culturally appropriate care. Whilst the 'number' did not improve, the quality of care, the First Nations peoples' interpretation of their care completion and intangible benefits on relationships within the hospital and community were substantial. Yarning was successfully used as the primary engagement and research method and allowed the team to hear the patient story, guide improvements and apply a cultural lens to both the qualitative and quantitative results. The stories behind the interpretation of the number of TOL patients and findings of the Deadly RED research team have been primarily given back to the First Nations members of the research team and local community.

Understanding the reasons for TOL including the importance of social and cultural considerations in provision of emergency care allowed empathy and understanding from ED staff. They learnt alternative ways of navigating clinically and culturally safe health options and facilitated autonomy for their patients. This in turn meant that the First Nations person was more likely to represent if needed and engage meaningfully in future interactions with the ED providers. Spending time to understand the interpretation of their clinical processes and treatments within the cultural context, such as the use of paracetamol, allowed adjustments to explanations and improved understanding. The overall local community response to the findings was that the Guthalungra research approach and yarning used in this project has resulted in 'cultural capability in action'. Improvements are guided by, with and for the First Nations community and the team has been privileged to engage in deep listening and learn new ways of understanding healing. Whilst this study was small and resource intensive, it challenges both the key performance measures that are used as markers for effective care and the engagement methods used with First Nations patients when seeking feedback on care and proposed improvements. Future studies should expand on the use of yarning as a source of meaningful engagement in the acute care areas.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available.

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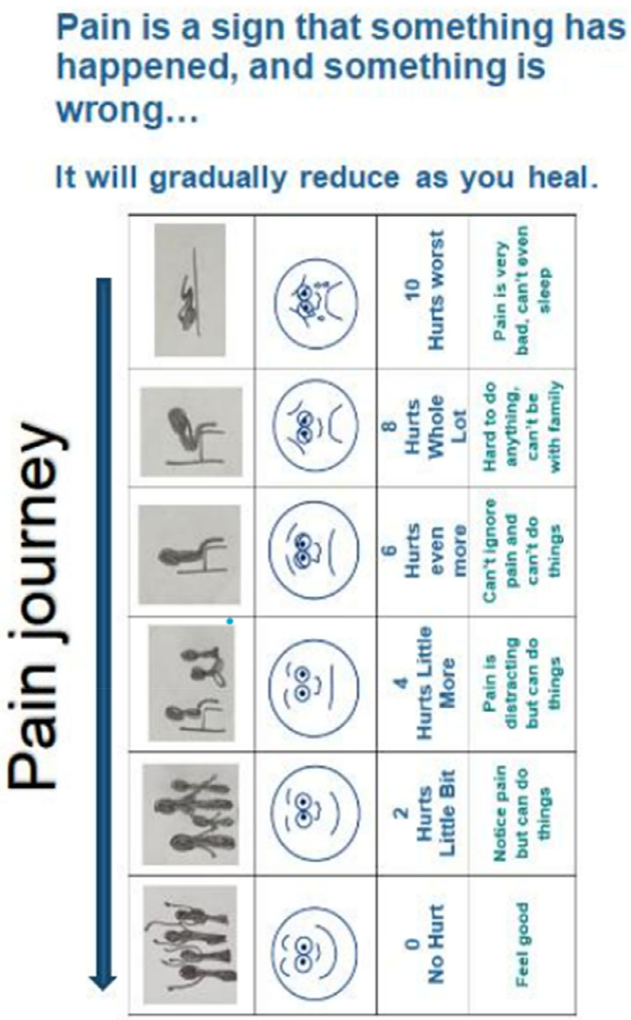
APPENDIX A

With permission extract from the Redcliffe Hospital Adult Pain Pamphlet designed in collaboration with the Redcliffe Hospital pharmacy team.



Pain is a sign that something has happened, and something is wrong…

It will gradually reduce as you heal.

Pain journey

0 No Hurt	2 Hurts Little Bit	4 Hurts Little More	6 Hurts even more	8 Hurts Whole Lot	10 Hurts worst
Feel good	Notice pain but can do things	Pain is distracting but can do things	Can't ignore pain and can't do things	Hard to do anything, can't be with family	Pain is very bad, can't even sleep