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“First time here, I didn’t know it was hospital”.

Travelling for treatment: the structural complexities identified via the stories of Aboriginal women who relocated for treatment in the State Adult Burns Unit at Fiona Stanley Hospital.

Mrs Tiffany Ryan

Being a research thesis submitted as a requirement for the degree of Master of Philosophy via the school of Physiotherapy, at the University of Notre Dame Australia.

Submitted October 2018

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ACKNOWLEDGEMENT OF COUNTRY

I acknowledge and pay my respects to the Whadjuk Ngoongar People past and present.

Kya Nidja Kwobba Ngoongar Whadjuk Boodja. (I acknowledge this beautiful Ngoongar Country on which we stand and share).

Translated for this document by Gidgup, R. (2018). Traditional language translation of Acknowledgement of Country, with thanks.

WITH THANKS

My sincere thanks to all who contributed to this research. This includes, but is not limited to, my supervisory team, consisting of Associate Professor Dale Edgar, Nyikina Traditional Custodian Dr Anne Poelina, Winthrop Professor Fiona Wood, Head of Department Social Work at Fiona Stanley Hospital Mrs Melissa Edwards, and long-time clinical supervisor, mentor and friend, Senior Social Worker Mr John Van Der Giezen.

This research would not have been possible without the considerable time and efforts of Aboriginal Health Liaison Officer Karen Waigana, who ensured that recruitment of the participants was ethically sound.

This research aims to draw attention to the strong links between the participants and their families. My family has provided me with unwavering support, and for this I am extremely grateful to them – my parents, Peter and Helen Broughton, my husband Paul, and our three ‘fur kids’; Windsor who was with me at the start but not at the end, and Morgan and Maitri who did their sincere best to distract me from my writing.

My genuine thanks to my colleagues within the State Adult Burns Unit, who give so much of themselves in the care and support of our burns patients, and who were supportive and accommodating of this research, with particular regard to Burns Senior Dietitian Michelle Cork, and Burns Clinical Nurse Consultant Sharon Rowe, and special heartfelt thanks to Burns nursing staff member Carol Brough, who encouraged me to keep going when the going got tough.

And lastly, but certainly not least, to the participants of this research, without whom this research would not have been possible. Thank you.

ABOUT THE AUTHOR

This research asks participants to tell their story, and in doing so, to tell the readers about their lives. Sharing their lives with us should not be taken lightly; it was apparent during the interviews that some participants were uncomfortable with parts of the interviews and questions, and especially with being voice recorded. Despite this, all participants continued with the interviews, detailing intimate aspects of their journeys. This display of bravery should be honoured, respected and reciprocated.

Given this, it seems only fair that the author is also placed in a position of vulnerability, sharing dearly held details of her life:

My journey began when I was born on the island of Mauritius. My birth mother was not able to care for me, so I was left in the local hospital. When my birth mother was not able to be located, I was placed into the care of an orphanage where I remained until I was flown to Australia. I had been adopted by an Indian-born Perth couple.

Unlike the participants in this research, my first experience with air travel occurred when I was merely months old, during a time when I was unaware and unable to remember how it made me feel, heralding the beginning of a life where travelling long distances by planes and trains, was considered normal.

This privilege of being familiar and confident with travelling nationally and internationally is similar to many of my peers, and so starkly different to the participants' stories. It makes the following stories so brave, so special and very much in need of being heard.

My career as a social worker has allowed me to hear many stories. I have worked with voluntary and involuntary mental health patients, their families and their carers. However it has always been the stories of Aboriginal women, which have resonated and have had the greatest impact on me. Truthfully, I am not sure why this is the case. Perhaps it is because I

am of a similar skin colour, or perhaps it is that as woman, that the struggles of other woman are easier to understand and relate to, if only in a very small way.

I was fortunate to work primarily, with Aboriginal families who had contact with mental health services, and over the ten years of my mental health career, built relationships with the families. I worked extensively with Aboriginal women, listening and learning from their experiences of navigating the public mental health care system. As I consider my time as a mental health worker, my most treasured relationship, and the one which taught me the most, was with one young Aboriginal women whom I worked with for approximately five years, and with her family. Much of my time with this patient and her family was spent talking about the role of both Western medicine and Traditional medicine. We talked and negotiated, developing a fluid and individual holistic ‘medicine’ plan, which she and her family were happy with. It was through hours of talking, that a bilateral genuine, trusting, relationship was developed. The value of talking was in the forefront of my mind as I developed this research and considered what I wanted it to achieve.

As well as being influenced by my previous relationships with Aboriginal women, this research was also influenced by who I am, as a social worker.

The Australia Association of Social Workers states that social workers “will promote justice and social fairness, by acting to reduce barriers and to expand choice and potential for all persons, with special regard for those who are disadvantaged, vulnerable, oppressed or have exceptional needs” (Australian Association of Social Workers 2010, page 13). For myself, social justice begins with listening to, and valuing people’s stories, with the acknowledgement that they are the expert of their lives. The aim is to work with patients to transform the systems which perpetuate inequality (Baines 2011, page 6). This principle of social justice is fundamental and guides my social work practice, as well as being the drive for me to complete this research. This drive is underpinned by my experience as the Senior Social Worker within the Burns Unit, where, prior to commencing this research I witnessed systemic challenges faced by Aboriginal burns patients. For example, within my role as the Burns Senior Social Worker, I advocated strongly and over the course of multiple days, to obtain permission from the Patient Assisted Travel Scheme (PATS) to allow multiple family

members to obtain funding to travel to the State Adult Burns Unit to be with an Aboriginal patient from a remote community with a life-limiting burn injury. The patient was dying, and as she was not dying on country, it was important that many family members were present with her when she passed away. It is in conjunction with experiences such as these, and the knowledge and desire that I, as a social worker, can work with Aboriginal women to assist in systems change. This will have a genuine positive outcome, and greater likelihood of translation into practice for future Aboriginal women who travel to the State Adult Burns Unit. Exploration of these changes will be discussed further in this paper.

ORIENTATION

In line with the National Health Medical Research Council guidelines, this thesis was written ensuring the six values of conducting research with Aboriginal and Torres Strait Islander communities, were upheld. In particular, this paper was written with the value of responsibility in the forefront of the author's mind. Responsibility in this context can be considered as ensuring that outcomes of this research are accessible to the participants (National Health and Medical Research Council, 2018). Given this, much of the participant stories and findings are written using the language of the participants, ensuring that connection with the participant stories is able to be honoured, and is in line with Aboriginal ways of knowing (Geia, Hayes, & Usher, 2013).

The terms Aboriginal Australians, Aboriginal, Australian Indigenous and Indigenous are used interchangeably in this thesis and refers to First Peoples of Australia, not including Torres Strait Islanders. Within this thesis, the definition of Aboriginal refers to, 'people of Aboriginal descent through immediate Aboriginal genealogy bloodline'...who have identified, lived and were known and accepted in their Aboriginal community. This definition is validated by Fejo-King (2013).

ABSTRACT

Background

International and national research confirms the disparity in life expectancy between Aboriginal and non-Aboriginal populations. Inequity of access to healthcare for remote and very remote Aboriginal people makes relocation for specialist medical services a necessity. The aim of this research is to investigate the effects of relocation on Aboriginal patients admitted to the State Adult Burn Unit at Fiona Stanley Hospital.

Aims

This qualitative study sought to define and describe this experience of relocation, with a strong focus on structural complexities. Aboriginal women were asked to describe their experiences of relocating from remote and very remote communities to the State Adult Burns Unit for treatment. In addition, information was also sought on the participants' experience of isolation from family, whilst in the State Adult Burns Unit.

Methods

A case series used qualitative data collected from three semi structured interviews by 'yarning'. These were conducted by the researcher and in the presence of an Aboriginal Hospital Liaison Officer. Thematic data analysis and cross-case analysis was used to identify themes in the participants' experiences.

Results

Four main themes emerged which had layered complexities. Firstly, communication difficulties with health staff, secondly, prolonged travel, including multiple modes of travel to reach Perth, and thirdly, concerns related to maintaining contact with family. Participants also discussed receiving good care within the Burns Unit both from staff, and complimented the quality of the hospital meals.

Recommendations

Six recommendations arose that aimed to address these three themes; to improve difficulties with communication with health staff, to ensure that ongoing contact with family was optimised, and to assist with transport difficulties. Practical solutions, such as upskilling for relevant health staff, consideration for referral to an Aboriginal Health Liaison Officer for all

remote Aboriginal patients, and providing remote patients and their families with the correct address and contact details of the State Adult Burns Unit, prior to travel to Perth improve ongoing family contact.

Despite the restricted sample size, rich data was extracted, which will be used to promote best practice for future remote and very remote Aboriginal burn patients via the implementation of the recommendations, commencing with education initiatives for staff, to address communication challenges.

DECLARATION

The author declares that this thesis contains the author's own work, and no material which has been accepted for the award of any other degree or diploma in any university or other institution.

To the best of the author's knowledge, this thesis contains no material previously published or written by another person, except where due reference is made.

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The author wishes to formally and gratefully acknowledge the contribution of the following people, who have been integral to this research.

Firstly, University of Notre Dame Australia Assoc. Prof Dale Edgar, who is the principle supervisor of this research.

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Finally, the researcher also gratefully acknowledges Assoc. Professor Caroline Bulsara from the University of Notre Dame Australia, who provided expert guidance and comments in relation to the sample size of this research.

INTRODUCTION

Burn injury presents a complex, long-term challenge to all survivors. Seldom understood by lay public, the journey to recovery commences with a painful *and systemic* inflammatory response, *regardless of the size of the burn*. In the Western Australian (WA) context, up to half of these injuries occur in isolated situations, with limited access to adequate first aid, a crucial action which minimises tissue damage (Duke et al, 2011). The sparsity of health facilities in remote and very remote WA mean that the stress, pain and anxiety of a burn injury are often compounded by a perceived or actual reduction in access to early high quality health care and support. In addition to the unique challenges of providing integrated health services across a land mass of 2.5M km², the majority of Aboriginal patients live outside major cities and are injured at a proportionally higher rate than their standardised population numbers indicate (Duke et al, 2011). Thus, many Aboriginal patients face complex structural barriers and are placed in a position of vulnerability when requiring transfer to Perth in order to *survive* their burn injury. Anecdotally, our multidisciplinary team within the State Adult Burns Unit all recount cases of sub-optimal care received by remote and very remote Aboriginal patients with a burn injury. This study was therefore designed to allow those stories to be described, elaborated on and shared from the patient's point of view to improve care for future Aboriginal burn survivors. Initially this research was to be grounded in interpretivist and constructivism paradigms. However, it quickly became apparent that given the degree of relation between these paradigms, and given the scope of this research, that an interpretivist approach was sufficient to ensure that that this research was theoretically sound. An interpretivist approach was embedded into all aspects of this research as discussed below.

Interpretivism can be defined as the belief that there are many intangible, socially constructed realities (Chilisa, 2012). Confirming this definition is Coffey, Holbrook & Atkinson (1996), who frame interpretivism as the belief that all people interact with the world through their own unique lens, which is shaped through interactions with social systems and is interpreted uniquely.

There is tension within the paradigm of interpretivism, as previous knowledge production from the interpretive paradigm has been social constructed using Euro-Western philosophies, which have excluded the world views of former colonised societies (Chilisa, 2012). The researcher therefore addressed interpretivism with a post-colonial Indigenous perspective. That is, with an application and understanding within this paradigm that culture and historical context will add further dimensions to these world views and should be considered by the qualitative researcher (Coffey et al., 1996). That is, that the view of reality as experienced by Aboriginal people is just as valid as the dominant discourses' understanding of reality (Chilisa, 2012). In addition, interpretivism gives legitimacy to the stories, belief systems and claim of spiritual and earth connections (Chilisa, 2012). This is particularly relevant to Aboriginal people, whose ties to land, to their country, are well documented (Burnette & Kickett, 2009; McGrath & Rawson, 2013; Stamp, Miller, Coleman, Milera, & Taylor, 2006).

Furthermore, this Indigenous research was developed to gain a clear understanding of the nature of relocation for Aboriginal women within a Western Australian burn injury context. It therefore fits that the primary paradigm is one of interpretivism, give that the primary intent of interpretivist research is to 'understand people's experiences' (Chilisa, 2012, p. 33). While interpretivist research is ideally and predominantly conducted in a familiar, natural setting for the participant (Chilisa 2012) this was not able to be facilitated within the scope of this research project. A mitigation strategy of the inclusion of an Aboriginal Health Liaison Officer during participant interviews was implemented into the design of this research, to ensure that as far as possible, participants were culturally safe within the setting of the State Adult Burns Unit. This is discussed further in the ethical considerations of this thesis.

Interpretivist research dictates that the researcher collects the data while acknowledging their own 'values, ideological biases and relationship to the participants' (Chilisa, 2012, p. 34). Data was entirely collected by the researcher within this research. The concept of the subjective nature of the data was again met by the inclusion of the Aboriginal Health Liaison officer, who ensured that the researcher's own views and assumptions were not influencing the data. This occurred by the Aboriginal Health Liaison Officer providing clarity on the data when the researcher was unsure of specific cultural details. Further consolidation of the

integrity of the data was provided by the inclusion of the West Australian Aboriginal Health Ethics Committee (WAAHEC) as well as by Research Supervisor, Dr. Anne Poelina.

Chilisa goes on to state the importance of the researcher establishing ‘trust, rapport and authentic communication’ (2012, p. 34). This interpretivist concept was addressed within this research with the development of the semi-structured interview guide. The first question in the interview guide begins with rapport building via the researcher discussing her own origins, family and life. This display of authenticity and self-disclosure is imperative to establishing trust and rapport with Aboriginal people, and was utilised within a yarning framework as discussed by (Bessarab & Ng’andu, 2010). Further information on yarning is discussed within the literature review.

Further consideration was given to ensuring that interpretivism was woven throughout this research, with the data analysis of this research utilised the participants own words and phrases, ensuring their experiences were not subjected to interpretation by the researcher.

It is anticipated that with the paradigm of interpretivism informing all aspects of this research, that the participants’ personal assertions will assist to demonstrate the need for, and assist systemic change, for future female Aboriginal burn patients.

It has long been recognised that there is a disparity between Aboriginal health outcomes and non-Aboriginal health outcomes, with tragically, the life expectancy approximately twenty years less for Aboriginal people (Gruen & Yee, 2005). In the 2011 census of Western Australia, 69, 664 people identified as Aboriginal or Torres Strait Islander (Australian Bureau of Statistics, 2013) with more than half of the Aboriginal population in Western Australia identifying as living in non-metropolitan areas (Australian Institute of Health and Welfare, 2015).

The topic of this research is remote and very remote Aboriginal women's experience of specialist tertiary inpatient healthcare and utilises the Australian Statistical Geography Standard (Australian Bureau of Statistics, 2011) to identify individuals who live in remote or very remote Western Australia. The inequity of access to healthcare in non-metropolitan areas compared to metropolitan areas is well documented (Burnette & Kickett, 2009; Humphreys & Wakerman, 2008) as is the necessity of Aboriginal people to travel to metropolitan areas for specialist tertiary healthcare (McGrath, 2007; McGrath & Rawson, 2013). International research confirms the psychosocial disruption experienced by women who are transported from their country, to urban areas for medical treatment (Burnette & Kickett, 2009; Chamberlain & Barclay, 2000). The psychosocial impacts include finances, related to the costs of paying for food, and systemic challenges related to accommodation and transport to remain near the medical facility as well as lack of family support due to the rest of the family remaining at home.

Burn injuries occur throughout the world, and therefore attract differing definitions. The World Health Organisation (2018) defines a burn injury as an injury or damage to the skin or tissue, with the mechanism being a variety of means, such as heat, chemical or friction. This definition, however, does not incorporate other factors related to the injury, such as the current impact of the tissue pathology or the treatments applied on the mental health, wellbeing and psychological adjustment of the patient throughout their journey to recovery.

The Burn Injury Model of Care was developed by the West Australian Department of Health (2009) to provide a comprehensive explanation of a burn injury in Western Australia, and encompasses factors related to the care necessitated by the severity of burn injury, and the current functioning of the patient. The definition then provides for three categories of burn injury; minor, moderate and severe (Department of Health, 2009). A severe burn requires surgical intervention, and it is these patients who are recommended for relocation to a tertiary service for specialist burn treatment (Department of Health, 2009). This assessment of a burn injury promotes referral to allied health disciplines within the multi-disciplinary burns unit team. Referral to the Burns Unit Senior Social Worker provides the opportunity for systemic barriers and psychosocial factors to be identified, relayed and advocated for, to the wider

multi-disciplinary team, and incorporated into the treatment and discharge planning process. As all research participants are from Western Australia, this is the definition which shall be applied, as all the research participants will be assessed against this definition and its corresponding criteria.

Fiona Stanley Hospital in Perth is home to the State Adult Burns Unit of Western Australia, providing specialist inpatient, outpatient and telehealth services. Remote and very remote Aboriginal people are often required to come to Fiona Stanley Hospital for inpatient treatment, as burn injuries often require specialist medical and allied health treatment in an inpatient setting. Research conducted by Duke et al (2011) found that Aboriginal people are admitted for inpatient burn treatment more frequently than the non-Aboriginal population in Western Australia with Ballestas et al (2011) confirming that Aboriginal people were hospitalised at a rate of more than four times the non-Aboriginal population. The State Adult Burns Unit consists of 10 single ensuite rooms; patients are discouraged from leaving their rooms with the exception of attendance at therapy sessions, in order to minimise the risk of infection. For cultures which are highly social and family orientated, this hospital enforced isolation can prove challenging. Shahid, Finn, Bessarab and Thompson (2011) report that family members experienced significant structural and systemic barriers to providing ongoing care to their loved ones, whilst they were receiving cancer treatment in urban hospitals. As described above, the burns unit's physical environment, in conjunction with burns specific infection control policies, could provide a further barrier for patients and their families.

The purpose of this research, therefore, was to examine and define the impact of this travel and relocation and any related systemic challenges, within a burn injury context.

Additionally, this research sought to ascertain if hospital induced isolation from family and country, as well as isolation related to the geography of the Burns Unit added a further dimension and impact to the experience of relocation.

The questions that this research sought to answer were:

- What is the experience of relocation, and what structural challenges are encountered by remote and very remote Aboriginal women, who travel to Fiona Stanley Hospital for inpatient treatment of a burn injury?
- To what extent, and in what ways, do Aboriginal women experience isolation as a result of their relocation to the State Adult Burns Unit?

WHAT IS THE CONTRIBUTION OF THIS RESEARCH?

Every burn injury is impacted by the first aid and initial medical treatment that it receives, and even further benefits are recognised if this initial care is provided by a burns specialist team (Department of Health, 2009). Patients from non-metropolitan areas tend to have burn injuries of greater severity, depth, and involving larger areas of their body area, than patients in metropolitan areas (Department of Health, 2009) with admissions for patients in very remote areas being three times as high as patients from metro areas (Burns Registry of Australia and New Zealand, 2018).

Therefore, any delay in these remote and very remote patients accessing specialist care at the State Adult Burns Unit, may have an adverse outcome on their burn injury, and consequently, their burn scar. The appearance of the burn injury and its associated scarring is well understood as having a psychosocial impact (Lawrence, Mason, Shawn, Schomer, & Klein, 2012), with a link between burn scarring and feelings of stigmatisation (Lawrence et al., 2012) with Wallace et al (2017) finding that women in particular, are at risk of a poorer scar outcome than men.

This research sought to understand the experiences of female Aboriginal patients travelling to the Burns Unit, and if they experienced system challenges which hindered their desire and ability to travel for treatment, and if so, how these concerns and issues can be ameliorated for future patients, thereby facilitating the best care possible for remote and very remote patients.

LITERATURE REVIEW

In order to place this research in context, it is necessary to understand what is already understood in other countries about the effects of relocation for health care for Indigenous populations. In addition, current knowledge of the effects of relocating for medical care as experienced by Australian Aboriginal people will be described. This literature review forms the basis of this research project.

Literature was sourced utilising the PubMed and PsychINFO (Ovid) search engines via the Department of Health library, with keywords including *Australia, Aboriginal, Indigenous, Healthcare, Relocation, Travel, Burn Injury* and *Remote Communities*. The search produced literature in the form of international and national journal articles. In addition, reports and resources from other sources such as the Cancer Council of Western Australia, was included.

RESEARCH INTO RELOCATION:

Since the establishment of cities by those who colonised lands owned by Indigenous people, the relocation of these Indigenous people for the provision of specialist medical attention has been a jarring consequence (Burnette & Kickett, 2009; McGrath & Rawson, 2013; Stamp, Miller, Coleman, Milera, & Taylor, 2006).

In order to truly understand the current literature on the effects of relocation for healthcare, we must first understand the key factors which are intertwined with Indigenous health. The 1999 World Health Declaration on the Health and Survival of Indigenous Peoples states that there are four key interlocking concepts which comprise the concept of the health and survival of this population, worldwide. These dimensions are “spiritual, intellectual, physical and emotional” (WHO 1999).

Intertwined in the Australian Aboriginal understanding of health lies kinship and cultural responsibilities. Kinship is a both a ‘network of social relationships and a form of

governance' (Fejo-King, 2013). The understanding of the concept of connection to kin is paramount when considering the nature of relocation by a single person, away from their kin, for health treatment. It is in this context that the research into relocation will be considered.

There is a paucity of literature describing the effects of relocation for the treatment of burn injury in the context of Aboriginal people from remote and very remote Western Australia. An extensive literature review was conducted via PubMed and PsychINFO (Ovid) and no previous studies or research with these parameters was located.

National research has been conducted into the effects of relocation for Australian Aboriginal people, with the research reporting concerning tales of emotional disruption, and systemic challenges, promoting feelings of fear and isolation from family and country (Burnette & Kickett, 2009; McGrath & Rawson, 2013; Stamp, Miller, Coleman, Milera, & Taylor, 2006). Cancer patients relocating for treatment in Western Australia experienced difficulties navigating systems and structures, producing reactions of fear, with patients describing fear of using the hospital lifts for the first time (Thompson et al., 2011). In similarity to burns patients, cancer patients have to manage some comparable challenges, such as maintaining optimal nutrition. The community report produced by Thompson et al. (2011) details the experiences of these cancer patients or their family members with travel issues related to PATS again discussed with the researchers with these patients experiencing systemic issues such as navigating practicalities related to managing their Patient Assisted Travel Scheme (PATS) accommodation bookings. Communication with health care professionals was also discussed as a barrier to patients' understanding of their treatment due to the use of complex medical jargon. Further barriers to communication and therefore effective treatment related to the apparent lack of knowledge by some medical professionals about the interlocking relationship between health, family and country. This dislocation from kin and the accompanying emotional disruption at the critical time of receiving medical treatment for cancer was reported as a consistent theme throughout the interviews.

Burnette and Kickett (2009) conducted research in remote Western Australia, with local Aboriginal end stage renal disease patients. Hospitalisation was described as a frightening experience, with isolation resulting from limited contact with family (Burnette & Kickett, 2009). This isolation from family discouraged engagement with western medical treatment for some patients (Burnette & Kickett, 2009) and has been reiterated by cancer patients from remote areas of Western Australia, who described choosing not to relocate to Perth for specialist treatment due to the lack of family support in the metropolitan area (Thompson et al., 2011).

These findings of the importance of family was articulated in the 40 in-depth interviews conducted by McGrath and Rawson (2013) in East Arnhem Land (Northern Territory), which is an area classified as very remote Australia. Interviews were conducted by a third party - an Indigenous woman with local knowledge of the complexities of kinship and cultural obligations within the community. This insider knowledge enabled the interviewer to develop significant rapport with the participants.

This qualitative study found that the women who were relocated for specialist cancer treatment experienced fear in a variety of ways, such as fear of the treatment, and fear associated with being on another country. As identified by the WHO (1999), the priority of personal health was also described in a hierarchy of other considerations, with physical connection to country and emotional connection to family being factors which the women considered prior to travelling. PATS was also discussed as a helpful route for assisting patients to travel to urban hospitals.

PATS was again discussed by Aboriginal people living in South Australia, however was not always seen as supportive, as many patients experienced out of pocket expenses (Stamp et al., 2006). 11 cases were studied in this case study designed research, with patients and primary health workers interviewed. Stamp et al (2006) also found that patients spoke of fear related to the actual physical process of travelling. Patients described being fearful of travel to such a

degree that some delayed their travel and relocating for specialist healthcare, thereby placing their health at risk.

The wish to remain on country, to remain at home with family and in familiar surroundings, has also been documented by McGrath (2007) in qualitative research undertaken with terminally ill Aboriginal people, family members, and health care professionals in the Northern Territory. Qualitative methods were utilised in this two year study, with participants from four geographical areas articulating systemic and communication concerns. Many participants echoed fears related to the logistics of travel, with participants also expressing fear for their cultural safety in the unfamiliar surrounds of major cities and hospitals without the support of kinship networks (McGrath, 2007). This was articulated as 'disempowerment', perhaps at a time when patients need to be the most empowered and sure of their choices, than at any other time in their lives (McGrath, 2007). Uniquely described in this research was the added cultural concern of dying outside country. This needs to be considered as an additional complexity for these participants.

Rix, Barclay, Stirling, Tong and Wilson (2014) documented the first qualitative research on the disruption of relocating for haemodialysis for 18 haemodialysis Aboriginal people from New South Wales, and the accompanying isolation and uncomfortable reliance on a healthcare system that does not fit with their way of being and their holistic view of healthcare. This reliance on an unfamiliar health system may also be experienced by relocated burn patients, who have greater nursing and allied health dependence during their admission, due to their burn injury.

The above research was conducted with a variety of research participants, both patients and health care providers and during and after relocation had occurred, providing a comprehensive understanding of the complexities of relocation for Aboriginal Australian people. Common themes of systemic and communication barriers flow throughout the research. In addition, these complexities include a differing view of the definition of one's health, and therefore differing priorities between Aboriginal people and western medicine.

This differing understanding appears to be poorly understood by not only many of the health professionals who cared for these participants, but as well as by policy makers, which in turn influences the experience which Aboriginal patients have with government systems such as PATS and tertiary hospital settings. These systemic complexities appear to be a commonality of experience of many of the relocated Aboriginal patients Australia wide, however given that all the research discussed in this review was contained to specific Aboriginal populations with specific health concerns, transferability of the complexities is uncertain but is a probability.

In terms of international research, Camberlain and Barclay (2000) undertook research with Inuit women accessing maternity services in Canada. Data was collected on the effects of relocation of pregnant women and their partners in the Canadian Arctic who relocated for birthing services, against pregnant women who were able to birth at a specialised community centre within their community. Face to face semi structured interviews were conducted with 23 expectant mothers and fathers from two remote communities. Participants were asked to describe their experiences, be it birthing at home or being transferred from home to a medical centre to give birth. Three major themes emerged from these interviews; emotional stress at being separated from family; lack of choice with regards to the need for relocation and lack of support due to isolation from family. The participants who were not relocated experienced far more favourable outcomes, describing a reduction in stress in the birthing process. Contributing factors related to having health care staff who were often of the same language group as the participants. In addition greater family involvement in the birthing process was highly desired by the participants.

A more thorough understanding of the journey of relocation is required to comprehensively understand this complex issue. Issues related to the ways in which relocated patients experience the distance, time and modes of travel associated with relocation are not explored in the current research. Given the above knowledge that these studies have generated over at least the last 15 years, it is disappointing that Australian Aboriginal people continue to experience far less than a seamless, integrated, holistic and comfortable health care experience with tertiary healthcare systems, no matter where their country lies.

As a statewide service, the State Adult Burns Unit (SABU) at Fiona Stanley Hospital has invested considerable resources and initiatives to bridge this gap between western and traditional understanding of health. The SABU have cultivated relationships with remote and very remote health care professionals via formal teaching programs and liaison. This relationship development takes the form of burns specific education and in particular, extensive clinical liaison prior to remote patients being relocated to Perth, by a dedicated Burns specialist Clinical Nurse Consultant. It was not evident from the afore mentioned research that such a liaison position within other medical specialities in tertiary hospitals in Australia, exists. Given this differing application of resources and communication, this research will seek to discover if the systemic complications experienced by these research participants is replicated within a Burns context, or if the enhanced communication efforts with remote health care practitioners assists with alleviating these systemic and cultural concerns.

In order to address the gap identified in the literature, it is important to understand the specific and accepted research methods supported by the literature to be an appropriate, culturally safe platform to ensure that accurate representation of Aboriginal patients is assured. As briefly discussed above, many of the above research studies have incorporated the use of semi-structured interviews with yarning as a specific method of data collection.

CULTURALLY APPROPRIATE RESEARCH:

This research endeavours to collect data on the experiences of relocation for female adult Aboriginal burn patients, via talking face to face with the participants. This ‘talk’, is referred to as yarning by local Aboriginal Nyoongah people, and is commonly known to mean a conversation, or talk (Bessarab & Ng’andu, 2010). It also dictates a reciprocal flow of information between research participant and researcher and aligns with Aboriginal oral traditions. Shahid et al (2011) utilised yarning across 30 in-depth interviews, recognising the importance of the voice of Aboriginal people within research. This approach was utilised by many of the afore-mentioned researchers with McGrath and Rawson (2013) adding a further dimension with the utilisation of a researcher who originates from a culture which uses

yarning as a frequent form of communication. Rix, Barclay, Stirling, Tong and Wilson (2014) also utilised this method of data collection when conducting research with a remote Aboriginal community in New South Wales, utilising yarning to construct rapport prior to the commencement of the formal research interview. Bessarab and Ng'andu describe the different roles of yarning, be it to develop rapport, identified as 'social yarning', or 'research topic yarning', known as the process of gathering information related to the research topic in a semi-structured interview (Bessarab & Ng'andu, 2010). These types of yarning are employed in this research and fits with the in-depth, qualitative nature of this study. In addition, the afore mentioned reciprocal flow of information is built into the semi-structured interviews with the interview developing rapport via providing information on herself.

The review of the above literature leaves no doubt as to the ongoing effects of colonisation. Despite this research and subsequent generated knowledge, international healthcare systems have yet to acknowledge, develop and implement a culturally appropriate healthcare system that takes into account the values and needs of their Indigenous population.

ETHICAL CONSIDERATIONS

As stated by Bainbridge et al (2015), the need for vigilant oversight when conducting research with Aboriginal people remains necessary as historically, research with Aboriginal communities has not led to many tangible positive outcomes in terms of improvements in health.

This research was developed in conjunction with a supervisory team to ensure credibility and robustness, and also followed the directions of the National Health and Medical Research Council (NHMRC) which describes the six core values for responsible and ethical research with the Aboriginal community.

Prior to this research proceeding it was presented to, checked and approved by the West Australian Aboriginal Health Ethics Committee, the University of Notre Dame Australia Ethics Committee and the South Metropolitan Health Service Human Research Ethics Committee. The process was comprehensive and obtaining these approvals took more than ten months to complete. Of note, the conditions of approval imposed by the third committee necessitated the establishment of a new relationship with an independent group of advisors who identified as Aboriginal. This group of advisors provided further governance of this research. Ethical approval was granted from September 2016 until September 2019 with this timeframe allowing for recruitment and data collection past the date of when this thesis was written. It is hoped that this additional time will allow for further participants to be recruited to this study.

Unique to this research was the researchers' considerable experience working with Aboriginal people. This understanding and experiencing working with Aboriginal people meant that consideration was given to the researcher being considered an insider within this research. An insider in research can be described as conducting research on topics which are related to the researcher (Saidin and Yaacob, 2016). This is opposed to having no previous knowledge of the topic being researched. Via this researcher's experience working within the State Adult Burns Unit prior to commencing this research, the researcher was exposed to

observations and knowledge of the issues which Aboriginal women encountered when relocating from country to the Burns Unit.

Saidin and Yaacob state that insider research should be used to the advantage of the researcher, in order to develop a thorough understanding of the topic (Saidin and Yaacob 2016, p. 1). In this research, the researchers' specialist knowledge of burns care, as well as the researchers' well developed interpersonal skills, was used to develop rapport with the participants. Given the researchers' insider knowledge, this research mitigated the risk of the data being viewed unobjectively by the researcher, via both the analysis framework, as well as by the inclusion of the Aboriginal Health Liaison Officer who was present during the participant interviews and ensured that the questioning, and therefore information provided by the participants' was not influenced by the researchers' knowledge of the topic.

A further ethical consideration of power within the social work relationship was discussed with the supervisory team in the development of this research. Reflection was required on the inherent power of the position of the Burns Senior Social Worker, given the researcher holds this role, in addition to being the researcher, and was therefore likely to interact with the research participants in these dual roles. The Burns Senior Social Work position is one which holds considerable authority within the Multidisciplinary team. Conducting professional assessments and intervening on issues of safety, both child protection and safety related to cognitive capacity as well as assisting with legal issues is a primary responsibility of the role. Therefore referrals to relevant statutory agencies, such as the Department for Child Protection are routine undertakings of the Burns Senior Social Worker. The power of referral to statutory agencies cannot be underestimated, especially when considered within an Australian historical context where the trauma of children being removed forcibly from their families is still a lived reality for Aboriginal people. With this understanding of Australian Aboriginal history, and with the consideration of the dual role of the researcher and the Burns Senior Social Worker, exclusion criteria were developed which determined that any participant who also had involvement with a statutory agency was classed as ineligible for this research. This meant that patients who were already an active client with a statutory agency, or any patient

who was likely to be referred to a statutory agency during her admission to the State Adult Burns Unit were automatically excluded from this research.

In addition, and as per Australia Association of Social Workers (AASW) Code of Ethics guidelines with regards to research, consideration was also given to ensuring that participants did not experience undue pressure or influence to participate in this research. The AASW states that “social workers will ensure that consent is given voluntarily, without coercion or inferred disadvantage for refusal to cooperate” (Australian Association of Social Workers, 2010, p. 37). This risk of pressure to participate in this research was mitigated by the inclusion into this project by Fiona Stanley Hospital Aboriginal Health Liaison Officer, Karen Waigana. Upon the researcher identifying a possible participant for this research, Karen Waigana met with the patient, and provided detailed information on this research project. Information was provided face to face within the patient’s room, orally and in written format. Following this discussion, if the patient was agreeable to participating in this research, Karen Waigana then formally recruited the woman to the project by completing the Participant Consent form. This method of recruitment was explicitly described in the above mentioned HREC applications, and was considered appropriate by all HREC’s. The researcher believes that this method of recruitment was successful with this project, as there were patients who met the inclusion criteria and were provided with information by Karen Waigana, and then declined to participate. However, it is worth noting that the rate of recruitment was affected negatively when Karen was not available to assist in the manner stated. This occurred on at least one occasion where an engaged patient was not able to be recruited prior to leaving the hospital.

Assumptions of homogeneity within the Aboriginal population were given consideration, as evidenced in the semi-structured interview questions. Participants were initially asked to describe where their country was, where they live now, and how they came to be there. The researcher believes that initiating the interviews with this conversation of country acknowledges that diversity within Aboriginal culture. The semi-structured interview questions were approved by the researcher’s supervisory team, as well as Karen Waigana prior to the commencement of participant interviews, with Karen Waigana also confirming

that the semi-structured interview questions demonstrated an acknowledgment and understanding of diversity within the Aboriginal population.

In line with this awareness of Aboriginal diversity, the utilisation of interpreters when conducting this research was considered. The option for interpreters was planned for, but not utilised as no participants demonstrated a need for interpreter assistance. This assessment was made by Karen Waigana during her conversations with possible participants, prior to formal recruitment, and the validity of these expert assessments was honoured without question by the researcher.

METHODS:

STRATEGY

A sample, drawn from a larger population of remote and very remote Aboriginal women with a burn injury, was selected. The participants were interviewed using a carefully designed schedule (Appendix 1). This data was analysed utilising the Miles, Huberman & Saldaña (2014) approach, with results and feedback being conveyed to the participants within 2 years.

DESIGN

This qualitative research utilised a case study approach, specifically multiple case studies. Case study lends itself to qualitative research, in that it allows for in-depth exploration of an issue, contextually (Baxter & Jack, 2008). Case studies fit with the constructivist underpinning of this research; the belief that every participant experienced relocation and isolation uniquely within their construct.

For the purposes of this research, a case was considered to be the experience of relocation from country, family and home to the State Adult Burns Unit, and isolation both physical within the State Adult Burns Unit, as well as experiences of isolation from home, country and family, as defined and described by each individual participant.

The use of multiple case studies assisted with the identification of commonalities and contrast between the cases (Yin, 2003). In order for comparisons and contrasts to be established, the case has specific, static parameters, such as a concrete definition of a burn injury, and specific geographical constraints.

Other qualitative methods were not able to be considered within this setting. A focus group of female Aboriginal burns inpatients would not have been feasible given Fiona Stanley Hospital Infection Control policies. In addition, it was not possible to predict when there would be enough patients who fit the research parameters at any one time.

Document review did also not afford the depth of knowledge required for this research, as the burns unit medical notes are highly medically orientated, with minimal psychological and psychosocial information, as questions pertaining to the effects of relocation on patients were not routinely asked by nursing and medical staff.

Participant interviews were conducted within the single, positively pressured burns specific patient rooms. As each participant was recruited only when medically suitable, participants were at differing lengths of time into their admissions to State Adult Burns Unit, which allowed for a settling in period into the ward.

Fiona Stanley Hospital Aboriginal Health Liaison Officer Karen Waigana was present during each interview, in line with West Australian Aboriginal Health Ethics Committee recommendations, ensuring that participant interactions were translated with appropriate cultural knowledge and consideration.

SAMPLE

In order for the research questions to be answered, sampling was purposive, selective and serial.

The participants were:

- adult Aboriginal women over the age of 18 years who had sustained a burn injury, and,
- whose usual place of residence was a remote or very remote location in Western Australia, and,
- with whom there is no statutory involvement (ie Department for Child Protection and Family Support or State Administrative Tribunal processes), and,
- who were able to provide written, informed consent.

The sample did not include children, nor individuals with a diagnosed mental illness.

The sample did include individuals with whom there was a dependent relationship, with the risk mitigation strategy including recruitment via an Aboriginal Health Liaison Officer, not related to this research.

The sample size was dependent on the number of patients admitted to the Burns Unit who fitted the above described case parameters within the recruitment timeframe of this study program. Malterud, Siersma and Guassora (2015) argue that ‘information power’, that is, the denser the information discovered, the less number of participants required. Three participants were recruited for this research in the timeframe available. The study will continue to respect the patients who have contributed to date and uphold the Ethics Committees parameters for approval, namely that this research was approved on the premise that the investigators aim for a sample size which reflects information saturation.

Dworkin (2012) writes that saturation is dependent on a multitude of factors, including the research timeline and differences in the research population. Saturation in relation to this research depended largely on the number of participants who were able to be recruited; and in attempting to recruit non-metropolitan, acutely injured patients; this number was influenced by a great many factors outside the control of the researcher.

DATA COLLECTION:

INSTRUMENTS:

Data was collected via a face-to face, semi-structured interview process, audio recorded, and transcribed verbatim.

Reber, Allen, & Reber (2009) define semi-structured interviewing as an interview which, although having topics for discussion, also allows some flexibility for changing and adapting the interview in terms of wording or flow, in order to provide further context and clarity for the interviewee. The semi-structured interviews included the use of open ended questions, with additional prompting questions to provide context, clarity, and generate robust responses. As described above, the researcher had the flexibility to ask additional questions, move off the course of the question schedule, clarify and learn.

Semi-structured interviewing compliments Aboriginal ways of knowing, as it allowed participants the time and space to provide in depth answers, while myself as the researcher, listened, observed and learnt. Martin (2003) recognises that the exchange of talk is frequently used between researchers and participants, as an effective means of data collection.

The differing views on relocation for inpatient burn treatment, and its impact, was explored via a semi-structured interview format. National Health and Medical Research Council Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (Commonwealth of Australia, 2003) are clear that the concept of difference blindness, i.e. that the Australian Aboriginal population is incorrectly identified as a homogenous group, has been perpetrated through systems, policies and practices, and that research should not be another avenue for this.

Differing experiences of relocation were likely multi-factorial, including the remoteness of usual home location and therefore the degree of previous contact with large scale tertiary

health systems. Other factors included both the participants' and their families previous experience with the health system, including intergenerational trauma suffered within health systems, as described in Henry, Houston and Mooney (2004). The process of conducting semi structured interviews allowed for this storytelling, or yarning, which is inherent in Aboriginal traditions (Geia et al., 2013; Ross, 1986). Yarning has been described as an effective style of engagement, when communicating and conducting research with remote Aboriginal people (Bessarab & Ng'andu, 2010; Lin, O'Sullivan, Coffin, Mak, Toussaint, & Straker, 2014).

The researcher developed the semi-structured interview questions with the research title in the forefront of her mind, shaping the questions to be open-ended and to encourage descriptive responses (Kingsley, Phillips, Townsend & Henderson-Wilson, 2010). In addition, the prompts which were developed ensured that data collection was maximised, by providing the participants with further context to the questions. The use of probing questions in conducting research with Aboriginal people was demonstrated by Kingsley et al., (2010) to generate discussion and therefore assist with the guidance of the interviews.

The interviews were structured to begin with questions which established rapport between the interviewer and the participant, prior to asking questions which may have evoked difficult emotions. Guillemin and Heggen (2009) speak to the balancing act between researcher disclosure to build trust and elicit valuable information from the participant, all the while maintaining an appropriate distance. During this research, this establishment of rapport was able to be accomplished by the researcher detailing aspects of her life, such as country of birth and family structure.

This 'tightrope' of rapport building is one the researcher walks daily within the clinical practice scope as a Social Worker, so the researcher felt well suited to being able to establish this rapport. As the technique of social yarning, as described by Bessarab and Ng'andu (2010) was incorporated to establish trust and comfort with the research process. Research yarning (Bessarab & Ng'andu, 2010) as an Indigenous process promoted the opportunity to

elicit the specific research information. It was important for the researcher to share part of her personal story to provide a sense of connection and meaning to the story as to why the researcher was undertaking this project, and also to build rapport and trust. As the researcher, I believe this was important due to the limitation of time and frequency to engage with these Aboriginal patients. The ability to make this connection was revealed through their willingness to engage with the research questions. Their responses to the concluding questions provided the participants with the opportunity to share their ideas on improvements to the system.

The specific interview questions (Appendix 1) were pre-tested with female Aboriginal Health Liaison Officers at Fiona Stanley Hospital. The Aboriginal Health Liaison Officers work closely with Aboriginal patients at Fiona Stanley Hospital to assist with the transition of coming to hospital, and therefore have a thorough understanding of the issue of relocation.

PROCEDURES:

Identification of prospective participants occurred during clinical handover meetings, for which the researcher was present. Burns Unit in-patients who were female, identified as Aboriginal, and had a usual place of residence in a remote or very remote location, were identified as appropriate research participants.

Once identified, a discussion occurred between myself and the Burns medical treating team, to ensure that it was clinically appropriate to discuss this research with the potential participant.

If clinically appropriate, the individuals who fitted these research parameters were provided with information on the research topic (Appendix 2). This information was delivered both orally and in writing, and was provided by a female Aboriginal Health Liaison Officer who was not a staff member of the Burns Unit, nor involved in this research, to ensure that participants experienced absolutely no pressure to participate in this research. This recruitment of research participants is in line with the Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities (National Health and Medical Research Council, 2018).

Data collection occurred within the patient rooms in the Burns Unit, with time spent developing rapport prior to the interview, ensuring the participant was comfortable within the process. Written consent was obtained, and the signed consent forms were stored in a locked drawer within the Burns Unit with the only key held by the researcher. The interviews were audio recorded, transcribed immediately by the researcher, and then deleted from the audio recording device. Transcribing the interviews myself allowed the researcher to fully experience all aspects of the interview process, allowing for complete transcripts, as the researcher had familiarity with the content of the interview.

In addition, consultation was sought with the Aboriginal Health Liaison Officer who was present during the participant interviews, to confirm the veracity of the transcripts. This was of particular assistance when transcribing the names of remote Aboriginal communities, which were unfamiliar to the researcher, but known to the Aboriginal Health Liaison Officer.

Electronic information, such as the spreadsheet with the participants' actual name and their allocated pseudonym, was stored on the researcher's laptop in excel format and was protected by 1) password access to log onto the device, 2) password access to protect the excel spreadsheet, 3) the information was further protected via encryption.

DATA ANALYSIS

As per the Miles, Huberman and Saldaña et al. (2014) approach, data analysis and data collection was planned to occur concurrently, where possible. However, as this research was dependent on participants who fitted the case parameters being admitted to the Burns Unit, there was significant time between cases, where no data collection was able to occur.

Data analysis was exploratory and inductive. Miles, Huberman and Saldaña (2014) define exploratory data analysis as the framing and then re-framing of the data, the goal of which is to develop a rich understanding of the research problem. The inductive nature of the analysis sought to bring together these understandings between the participant's accounts (Miles, Huberman & Saldaña, 2014). Inductive data analysis has previously been undertaken in research conducted with Aboriginal people who live in remote Western Australia to allow for identification of relationships between themes (Burnette & Kickett, 2009).

First cycle coding utilised the NVivo approach, thus utilising phrases and words from the participants themselves to generate patterns, by systematically examining each line of transcript. NVivo coding is of particular use when undertaking research with particular cultural groups, as it allows for these voices to be heard (Miles, Huberman & Saldaña 2014).

Second cycle coding identified themes, with the use of pattern coding, as per the Miles, Huberman and Saldaña (2014) approach with narrative description (Miles, Huberman and Saldaña, 2014) again identified via the systematic examination of each line of transcript.

As the codes for each case were common, case analysis occurred via the Miles, Huberman and Saldaña (2014) approach, utilising a meta-matrix to develop cross-case similarities (Miles, Huberman & Saldaña, 2014) to explore the data.

PARTICIPANT 1 (P1).

P1 lives in a very small, remote part of the North-East Kimberley; a ‘blink-and-you’ll-miss-it’ community of 6 houses and a big shed which contains the community’s generators. The community consists mainly of P1’s family; her big brother with his wife and children, and her aunty, with his sons and grandson and P1 keeps busy participating in a Centrelink required gardening program. The nearest town is a 30km drive along unsealed road, no buses or public transport out this way, so access to a car is important.

P1 sustained her burn injury three days prior to seeking medical treatment. She was assaulted in a case of Family Domestic Violence, where boiling water was thrown into her face, resulting in a scald injury of approximately 3% of her Total Body Surface Area. It was P1’s job provider, “*job pathway mob*”, who eventually brought her to Kununurra hospital in one of their vehicles. P1 was treated at Kununurra hospital, but thought she was going to Royal Perth Hospital, when she was told that she would have to come to Perth for further treatment “*no they didn’t make a dis...burns unit and I thought that was Royal Perth*”. The originating health service assumed that P1 knew the location of the State Adult Burns Unit.

P1 contacted her family before she left Kununurra, to let them know that she was going to Perth, but assumed that it was Royal Perth Hospital, because she wasn’t informed that it was at Fiona Stanley Hospital. “*Yeah, I ring my family my brother and his wife, yeah they got a bit shocked too*” and used the staff phone to contact her family once she came to FSH. “*I was talking to them yesterday and they were all right...payphone yeah*”.

P1 spoke of the phone situation in her community. With one payphone in the community, when a member of the community goes to hospital, they have to ring back to that one payphone to connect with family. Sometimes there might not be anyone to answer that phone, so getting through to a family member might take a couple of attempts. P1’s family did also have mobile phones, but these were not viewed as a reliable source of communication “*Yeah sometimes it’s hard there you got to get in the right spot to get a signal*”.

P1 was transported to Fiona Stanley Hospital via the Royal Flying Doctor Service. She described her long journey: *“it was midnight flight, we came with um flying doctor service...yeah Kununurra to Bayulu, Bayulu to Broome, Broome to Newman, Newman to here then...I was relaxing in the back in the long bed”*. P1 had some familiarity with air travel, which made this arduous journey, bearable *“yeah, I didn’t mind at all”*.

P1 shared her difficulties interacting with the hospital system and the treatments. *“When I’m having a good rest, trying to rest my body and things they come in and giving me all sorts of tablets... I’m not much on tablets, what sort of tablets I ask them... Yeah, and I ask them what this, what sort of tablet...oh that’s for your chest, and vitamins and Panadol for your headache...when I ask them I don’t want Panadol cause I don’t even headache”*.

There were positive aspects of P1’s stay in the State Adult Burns Unit too, including good, culturally appropriate food and staff. *“Mmm, great food down there and good company the doctors and um Aboriginal mob ladies”* with P1 stating that she would carry this good experience back to her community and tell others that *“in the hospital it’s all right for a feed and all that”*.

There are learnings for clinical practice which can be taken from this story of relocation.

Planning for care at home

As articulated in this story, P1 relied on transport from her job service provider, in order to gain access to medical treatment. This point of having access to a vehicle, is worth asking the patient prior to returning home so that this possible barrier to engaging in treatment can be factored into discharge planning arrangements. For example, it is worth considering if making outpatient appointments for the patient at the local health service prior to the patient returning home, is viable, given that the patient may not know if she can be transported to the outpatient appointment. Along with having access to a vehicle, is having an available family member/service provider who is able to drive the patient back to the local health service. A further consideration to this is also having the finances to assist with the cost of fuel to and from outpatient appointments. Given these complexities, it could be useful to liaise with the local health service prior to discharging a patient, to see if the care required can be practically offered, and whether the patient can access it. Without this consideration of post discharge care, remote patients could be at risk of being lost to follow up.

Awareness of the location of the State Adult Burns Unit

Ensuring that patients know where they are travelling to is imperative, so that family can be given correct State Adult Burns Unit contact details, minimising any chance of isolation from family during hospital admissions. Minimising isolation from family and country helps ensure that patients are comfortable enough during their stay, to participate in therapy as much as possible. Awareness of the location of the Burns Unit also relates to the surroundings of the Fiona Stanley Hospital campus. Unlike other tertiary hospitals in Perth, Fiona Stanley Hospital is situated within a residential area, south of the city, and can be difficult to access via public transport. In addition, there are limited accommodation providers nearby, with the Patient Assisted Travel Scheme approved Aboriginal Hostels, being at least 30mins drive away.

Contacting family by phone

If patients are asking to use the ward portable phone multiple times, the complexity of having minimal means of reliable communication within home communities might need to be considered, and staff should be generous with their allowance of remote patients accessing hospital phones. Patients may need to attempt to contact their families' multiple times, over multiple days, until a family member is reached. This delay in reaching family can be due to the person who answers the phone, being able to locate the right family member for the patient to speak to. Consideration also needs to be given to the fact that as described by P1, that there is only one source of reliable communication for the entire community to use. This one phone line might then be engaged during multiple attempts, as the whole community will be using it.

Fatigue from long travel

A working awareness of the intricacies of travel from remote areas is of use, when working within a State-Wide service. Knowledge of a patient's long journey can assist with staff empathy when patients arrive on the ward and express fatigue and appear unwilling to engage in talking/therapy shortly after arrival. This knowledge also needs to translate to the return journey for an appreciation for the journey ahead of the patient upon discharge, with this important return journey again spanning days of travel.

Importance of culturally appropriate services

P1 spoke warmly and with genuine appreciation for the support she received from not only the Aboriginal Health Liaison staff, but from medical staff who were able to spend time getting to know her, and from the dietitian who ensured that culturally appropriate food was made available. Feeling comfortable in a foreign environment is not just about being able to communicate with strangers, but also encompasses other senses, such as being able to taste foods which remind patients of home. This service of providing culturally appropriate food is facilitated by the State Adult Burns Unit Senior Dietitian, at times, with referral from the Social Worker.

PARTICIPANT 2 (P2).

Originally from the Western Desert, P2 now lives in a community in the Goldfields, with access to facilities such as a supermarket, secondary school, and a hospital.

P2's journey began at the local Home and Community Care clinic as it was known, which she went to after she got burnt "*that's just the clinic, but you know, when you need help, they get you down to the hospital*".

With the assistance of the Burns Digital Imaging Clinic which is operated by the Burns Clinical Nurse Consultant, the local hospital obtained specialist diagnosis and treatment advice of P2's burns, enabling P2 to remain in her home community for a period of time. During this time, Home and Community Care staff assisted P2 to get to the hospital for dressings changes "*they give me ride for the distance*", until it was recommended by Burns Digital Imaging Clinic that P2 comes to Perth for further assessment and treatment and was booked onto a commercial flight. She then made her way from Perth airport to Fiona Stanley Hospital via taxi "*taxi voucher from Leonora*", presenting to the Fiona Stanley Hospital Emergency department.

Upon admission to the State Adult Burns Unit, P2's scald injury was assessed as approximately 8% Total Body Surface Area, with this injury also sustained in Family Domestic Violence circumstances.

None of P2's family or friends had ever been admitted to FSH before "*Nah, not that come here*". After arriving at Fiona Stanley Hospital, P2's main concern was to alert family to her arrival in Perth, primarily her daughter, via contacting her cousin "*just wanted to let her know I was here, that's all...yeah but at the moment, she can't answer it...she goes to dialysis today*". The Aboriginal Health Liaison Officer offered P2 a key service – locating and contacting P2's family "*I think she'll be...what that place she say at, Guildford there...Yeah*

Autumn Centre. She rang yesterday to my cousin and she told them I was down here, so she can let my sisters know that I'm here...cause they see her and visit her, but they got no phones".

P2 was able to discuss her medical and allied health treatments, demonstrating a good understanding of her treatment pathway and how long she was likely to be in hospital *"just for, what they said, couple of days she said...just the dressing and the pain killers for pain. And they gave me some drips, but they took it out...yeah they came here before lunch and then they come back again, they say they're going to take me down somewhere, to the gym somewhere"*. P2 was happy to continue staying in the burns unit, stating *"Maybe I'll stay a little longer...I just want to get better mmm"*.

P2 again spoke of the desire to ensure that her family was contacted, confirming that the Aboriginal Health Liaison Officer would assist with this *"But if you get in contact with her, she will come back and get my sisters to come visit...yeah cause they've been here before seeing someone, yeah and my other sisters they come visit me here"*.

There are learnings for clinical practice which can be taken from this story of relocation.

Importance of relationships with regional health providers

The input from the Burns Digital Imaging Clinic assisted in ensuring that P2 received timely, best practice burns care. The importance of this weekday service provided by the State Adult Burns Unit in ensuring comprehensive care for remote and very remote patients, cannot be underestimated. This service also serves as a platform to build trusting relationships with key stakeholders in remote health clinics, including with Aboriginal Medical Service sites.

Crucial role of Aboriginal Health Liaison Officer in connecting family

Connection with family is a cornerstone of Aboriginal culture. The predominant thought content of P2 throughout her interview, was of contacting her family, with P2 discussing this at two points in the interview. The Aboriginal Health Liaison Officer's familiarity with local accommodation services meant that P2's family was easily contacted, assisting to alleviate isolation from family.

Empowerment via knowledge of treatment plan

P2's understanding of her treatment plan is important, in that it demonstrates that Burns Unit staff were communicating important medical and allied health information in language that was easily understood and remembered. This is of particular importance given many Aboriginal people from remote areas do not speak English as a first, second, or even third, language and when English is spoken, it may be a different form, such as Kriol.

PARTICIPANT 3 (P3).

P3 is also from the Kimberley, with dirt road access to the nearest towns, and with tourists requiring permission in the form of a permit, to enter the community.

When she sustained her burn injury of approximately 2% of her Total Body Surface Area, P3 was initially treated at the local hospital *“I got two operations in her, in the middle, in here, this part here. It was swollen, they cut my thing this way, and in the middle”* (showing on her hand where she had the surgery), and was discharged home for a few days, before infection set in *“Friday, Saturday, Sunday, yeah Friday, Saturday, Sunday I was there and Monday I went to clinic and the sister, look at the thing, my hand was black, and go for dressing, so sister rang hospital in Derby”*. She was then driven by ambulance to Derby, the nearest large town *“you drive from 7 or 8, you get there 9”*.

After spending two nights in Derby hospital, she was booked on a bus to Broome, and became sick on the journey *“I vomited too in the greyhound bus...yeah, Greyhound bus to Broome, from Derby to Broome...3 o'clock I left don't get there 5 o'clock I think. Someone there waiting for me to pick me up, hostel mob...I get to hostel in Broome and still vomiting. Hostel manager gave me hot tea and toast”*.

After an overnight stay in the Broome hostel, P3 came down to Perth on a commercial flight, still experiencing nausea *“Yeah...plane vomiting”*. Upon arriving in Perth, she made her way to a local hostel named ‘Allawah Grove’. *“Yeah and the lady say you gotta go tomorrow, to hospital appointment. Friday. Yeah. One night in there, Allawah Grove and in the morning I went this way round 8”*, arriving at the Burns Outpatient clinic around noon, with some assistance with way finding, from a Fiona Stanley Hospital volunteer. *“Talked to that man. You go there. I showed him the paper. Go there. And then old man upstairs helped me to go through that thing cause I don't know first time been, so all right I take you there. Was really kind old man, take me right through to clinic”*. P3 was admitted directly to the Burns Unit, and she underwent surgery that afternoon.

P3 navigating this long journey herself, whilst being unwell and travelling to a hospital that she didn't know existed. *“First time here, I didn't know it was hospital...I just hear about Royal Perth and Princess Margaret Hospital, and Fremantle Hospital, that's all. And King Edwards there. Didn't know this one”*.

P3 was able to contact her local relatives, via the use of her personal mobile phone. *“They came and talked to me, sitting down here, my daughter, my niece. I think they come in the afternoon”*. P3 was also able to contact her family at her home community *“yeah, what time you coming back (her family asks) I don't know, I don't know”*.

When asked about her experience in the State Adult Burns Unit, P3 replied *“Good food, and good thing, sister come up and down and check. No flies around like in Derby hospital”*.

There are learnings for clinical practice which can be taken from this story of relocation.

Five days to get to the Burns Unit

P3 is a resilient woman. She travelled for 5 days, with an infected burn injury, to reach the State Adult Burns Unit, where she was immediately assessed in the Burns outpatient clinic, with the recommendation for surgery that afternoon. This referral for immediate surgery is highly unusual and reserved for the most serious of injuries. In the case of this patient, it could be considered that had she arrived sooner, the risk of surgical intervention, may have been reduced. An articulation of this length of travel may be of benefit from the regional Patient Assisted Travel Scheme centre, to the originating health service, and in turn, discussed with the State Adult Burns Unit, so that an informed decision on the best care possible for the patient, can be made. This journey was long and gruelling, and when retelling her story, she didn't complain once.

Awareness of the location of the State Adult Burns Unit

As with P1, P3 was unaware that Fiona Stanley Hospital existed, let alone that the State Adult Burns Unit was located within it. P3 was fortunate to be able to contact her family with relative ease, however ensuring remote nursing and health provide travelling patients with accurate information of the location of the State Adult Burns Unit, would be of benefit. In addition, this information on the location of State Adult Burns Unit would then be taken with families back to their communities, ensuring that knowledge of the location of the State Adult Burns Unit, becomes widely known.

Importance of way-finding assistance from Fiona Stanley Hospital Volunteers

Shame can play a large role in the experiences of remote Aboriginal patients.

When P3 arrived at the doors of a hospital which she didn't previously know existed, she was provided with a warm and helpful service from the Fiona Stanley Hospital volunteer, with the volunteer going out of his way to take P3 to the Burns outpatient clinic entrance. This kindness clearly had an impact on P3, and assisted her not to feel any shame about needing to ask for directions and also assisted to reduce any anxiety she may have been feeling in an unfamiliar environment.

Good care from State Adult Burns Unit nursing staff

P3 welcomed the care checks provided by nursing staff, acknowledging that the State Adult Burns Unit nursing staff would walk up and down the corridors frequently, to ensure that she was ok. This best practice nursing care was welcomed by the patient, promoting a good relationship between herself and the nursing staff.

FINDINGS

The following four themes emerged from the participant interviews with two sub-themes for each of these main themes.

COMMUNICATION WITH HEALTH STAFF

Communication from local health service

Upon leaving their homes, two out of the three participants were unaware of where they were being sent to, for treatment. Although all participants had an understanding that they each required further specialised burns care at the ‘burns unit’, they did not have clarity on where the burns unit was located “*yeah I thought I was going to Royal Perth*” (P1).

Living in a remote community also meant that news of a new hospital in Perth, had also not reached participant 3’s family “*First time here, I didn’t know it was hospital... Didn’t know this one*” (P3). This vital information was not communicated effectively at the point of travel for this participant, leading to wonder if an assumption of knowledge of news of developments in metropolitan health services, was made by the originating health service.

Communication from Fiona Stanley Hospital/State Adult Burns Unit

Communication between State Adult Burns Unit health staff and participants was mixed, with two participants demonstrating good knowledge of their nursing and medical treatment plans. Consent for these plans was also articulated “*Tomorrow I think doctor will see it... Yeah I’m ok with that*” (P3). Participant 2 was also aware of the anticipated length of her hospital admission “*Just for, what they said, couple of days, she said*” (P2).

However, one participant described difficulties understanding the need for certain mainstream medications “*When I ask them I don’t want Panadol cause I don’t even headache*” (P1). It did not appear that an explanation of paracetamol being prescribed for analgesic purposes other than a headache, was understood by the participant.

Relying on others for transport

Consideration of transport within remote communities remains an issue for health staff to factor into discharge planning. Two participants spoke of relying on service providers for transport to their local health facility. Participant 1 was transported for medical assistance via her Centrelink employment provider “*I got a lift with my job provider, job pathway mob*” (P1).

In conjunction with this complexity of transport, distance from communities to the local health facility was also a complication for one participant. This participant was able to gain assistance from Home and Community Care, ensuring that she could access ongoing dressings “*they give me ride for the distance*” (P2).

Lengthy travel to Fiona Stanley Hospital

All participants spoke of different, but lengthy travel from home to hospital. For one participant, this meant five stops on her Royal Flying Doctors flight “*Yeah Kununurra to Bayulu, Bayulu to Broome, Broome to Newman, Newman to here then*” (P1). To put this in context of West Australia’s vast geography, the distance from Kununurra to Perth is approximate in distance to travelling from Perth to Melbourne.

Another participant spoke of flying to Perth on a commercial plane, and then needing to catch a taxi from the airport, to the hospital using a taxi voucher provided by her local health service.

In another example of extraordinarily lengthy travel, P3 endured five days of travel to reach a tertiary/quaternary health service “*Yeah travel Looma to Derby with ambulance...and then 3o’clock I get the bus to Broome*” (P3). On her journey, she was transported by ambulance,

greyhound bus and commercial airline. This participant also stayed overnight in a regional hospital and two hostels, on her journey to Fiona Stanley Hospital.

This commonality of lengthy journeys, comprising multiple stops and modes of transport, demands recognition and respect by health staff.

FAMILY

Dislocation from family

Remote area patients have difficulties ensuring that family can accompany them to Perth. This is due to a number of factors but is primarily reinforced by government policy related to the Patient Assisted Travel Scheme.

All of the participants in this study expressed a dislocation from family. This dislocation was articulated by participant 3 when she spoke of her family's concerns for her "*Yeah, what time you coming back (her family asks) I don't know I don't know*" (P3).

A second participant was concerned that her family would worry for her, as occurs when family members leave their country for health treatment "*just wanted to let her (daughter) know I was here, that's all*" (P2), expressing the need to remain connected to family.

Staff facilitating contact with family

Key to mitigating the effects of dislocation from family, was staff assistance with facilitating contact with home. Participant 2 was able to request this assistance from the Aboriginal Health Liaison Officer during the interview, "*But if you can get in contact with her, she will come back and get my sister to come visit*" (P2).

The interviewer, within her role as the Burns Senior Social Worker, also assisted Participant 1 to remain in contact with family *“Um, they got a thingy...Pay phone yeah, with your (interviewers’) phone here yesterday”* (P1).

Both of the above experiences reinforce the need for staff to check if assistance contacting family is required – both of these participants demonstrate that not all patients have access to their own mobile phone to contact family independently.

POSITIVE EXPERIENCES

Good food

Despite arduous travel and longing for family, the participants spoke warmly of their time within the State Adult Burns Unit, with two participants expressing their thanks for culturally appropriate food *“in the hospital it’s all right for a feed and all that”* (P1). The State Adult Burns Unit Senior Dietitian coordinates this important link between country and hospital *“Mmm, great food down there”* (P1), with this echoed by Participant 3, who also reported *“good food”* (P3).

Good care by Aboriginal Health Liaison Officers, Nursing and Medical staff

Specific staff disciplines were singled out by the participants, as positively impacting on their hospital experience. Participant 1 spoke of both the medical and Aboriginal Health Liaison Officer teams *“good company the doctors and um Aboriginal mob ladies”* (P1) as well as recalling the good care she received in from nursing staff *“the nurses, yeah”* (P1). Participant 3 also complemented the State Adult Burns Unit nursing staff, praising their attention to her care *““good thing, sister come up and down and check”* (P3). This good care resulted in Participant 2 feeling comfortable within the State Adult Burns Unit, stating *“Maybe I’ll stay a little longer...I just want to get better, mmm”* (P2).

DISCUSSION

The first aim of this research was to illuminate the journeys of remote and very remote Aboriginal women, who travel from country to the State Adult Burns Unit at Fiona Stanley Hospital, with particular regard to systemic challenges during these journeys. This aim was achieved supporting anecdotal feedback from previous patients, and staff, which led to the propagation of this study. Three women interviewed during their inpatient admissions revealed detailed and novel data regarding the process of relocation. The women spoke openly of their experiences of their journeys and of their time as patients in the State Adult Burns Unit, with both positive and negative factors identified.

Understanding of the experiences of remote Aboriginal women who travel to the State Adult Burns Unit is important in assisting to ensure that staff are culturally responsive, and to inform a service which is culturally secure (Aboriginal Health Strategy, 2017). Culturally responsive staff can be described as providing care that considers and allows for diversity in the domains of language, socio-economic status and spiritual beliefs (Aboriginal Health Strategy, 2017). A culturally secure service would seek to ensure that the expectations of Aboriginal patients are not impinged upon, thus privileging the right of Aboriginal patients to self-determination, and allowing for full participation in treatment (Aboriginal Health Strategy, 2017). A direct outcome of this research is the opportunity for culturally appropriate staff education, which will be developed by the researcher and offered to staff within Fiona Stanley Hospital.

As reported above, this research revealed new and original information into the process of relocation. The journey for treatment and therefore the experience of relocation for all the women began when they were injured and needed to access primary healthcare. Accessing this healthcare in a timely way depended on a variety of factors, including availability of transport to primary health care clinics, within their communities. The availability of this healthcare and initial first aid is crucial to the outcome of a burn injury.

Upon the need to relocate to Perth for specialist inpatient burns care, the participants spoke of the assumptions made by practitioners from within their local health care systems. These assumptions of knowledge lead to the participants being unaware of their relocation destination, as hospital staff believed that the participants knew that there was a hospital named 'Fiona Stanley Hospital' in Perth, and that the State Adult Burns Unit was located within it, and, by extension, how the patients families would contact their loved ones when they were at the State Adult Burns Unit. These assumptions underline the need for clear, transparent communication between health services and patients travelling for treatment, and reinforces the view that communication continues to play an integral part in the comfort of remote patients relocating for treatment, as discussed by Durey, Thompson and Wood (2012). It makes sense for patients and their families to be as informed as possible as to their travel. This communication also needs to be considered in the context of English not being the first language for many remote area patients. Durey et al describe that this consideration of language can lead to a lessening of anxiety and increased rapport with the patient (2012). As a direct result of this study, enhanced communication strategies will be implemented between the State Adult Burns Unit and remote health sites.

The process of relocation was unique to each participant, but a commonality was the length of travel, and the multiple forms of transport. It is important for originating health services to be aware of these travel complexities when arranging travel via PATS. This knowledge could be integrated into clinical decision making, ensuring that burns patients do not suffer a deterioration of their burn injury and their physical health during their lengthy journey, as was the case for P3. These findings will therefore be made available to remote medical and nursing staff. In addition, shedding light on this complex journey is important to ensure that Burns Unit staff are mindful of these lengthy and often tiring journeys, when initially meeting and reviewing patients.

The length of travel that these participants experienced, to access specialist healthcare, was substantial. These participants then also faced extended journeys to return home. P1 required further hospitalisation; therefore, she was transferred to her local secondary hospital, with an

escort to the airport provided by a Fiona Stanley Hospital Aboriginal Health Liaison staff member, assisting to ensure a safe transition through busy transport facilities.

P2 experienced less expedient forms of transport, for example train and bus transport, as opposed to flying on her return journey, including an overnight stay at a regional hostel, before she could catch her connecting transport.

An escort to Perth airport was also provided by Fiona Stanley Hospital for P3, again ensuring that she was comfortable with the process of navigating her return journey via the main Perth airport.

This lengthy but necessary travel to and from Fiona Stanley Hospital was a common experience of the participants, despite their homes, their country, being in vastly different corners of the state.

Travel related difficulties within home communities, was also a commonality. Knowledge of the complexities in accessing ongoing healthcare as a consequence of this travel issues, was also revealed. This information emphasises the need for thorough, early discharge planning, completely involving the patient and where possible, Aboriginal Health Liaison Officers and the originating health services/Aboriginal Health Service sites, to gain a systematic understanding of any barriers to continued treatment at home. Knowledge of these barriers to ongoing care at home can then be used to inform discussions on the patient's optimal length of admission with this coordinated approach to discharge planning is echoed by Thompson et al. (2011) in their recommendations for care of remote cancer patients.

Participants also utilised at least two different forms of transport in their journey to and from Fiona Stanley Hospital. For all participants, their journey included at least one flight. Flying was a preferred method of transport, due to the severity of their burn injuries and therefore

the need to expedite specialist medical care. When participants were journeying home, flying was often chosen due to the vast distances required to travel. A certain level of comfort with flying and navigating busy travel hubs, was assumed by both the originating health service and Fiona Stanley Hospital.

Family and Domestic Violence (FDV) was briefly mentioned by P1 as the context of her injury. She did not mention if she was provided with FDV assessment, information and referral at her originating health service. This safety assessment and intervention was provided by the researcher within her role as the Burns Unit Senior Social Worker and incorporated the expertise and guidance of the Aboriginal Health Liaison Officer to ensure that all of P1's health needs were met during her hospital admission.

The second aim of this research was to understand the extent and in what ways, Aboriginal women experiences isolation as a result of their relocation to the burns unit. Isolation can relate to both the physical environment of the State Adult Burns Unit, as well as isolation from country and family.

Physical environment

Participants did not report isolation resulting from the single positively pressured burns rooms, instead, remarking that the caring staff and good food, made them feel at home.

The importance of this good, culturally appropriate food, cannot be underestimated in assisting patients from remote areas to feel at home in a hospital environment. This has been documented by Thompson et al (2011) with remote West Australian Aboriginal patients who travel to Perth for cancer treatment. The need to provide culturally appropriate food is enshrined in Department of Health WA Nutrition Standards for Hospital Food Service (2012). The interconnectedness between country and health is well documented with this connection being described as part of self (Kwaymullina, 2005).

Isolation from family

Isolation was instead experienced as the longing for family, with this expressly identified by P2 and P3. The extents of this isolation lead to both the participants and their families attempting to maintain their connections with one another. This data confirmed already known experiences of Aboriginal women in Australia who relocate for tertiary healthcare as per Rix et al. (2014), Burnette and Kickett (2009). This isolation from family was specifically discussed by Thompson et al. (2011) as being of particular detriment to Aboriginal patients, who often identify their own health needs as interconnected with their family, wider community and country.

Given this importance which Aboriginal patients place on the need to remain connected to family and country, the Fiona Stanley Hospital Aboriginal Health Liaison Officers hold a pivotal role due to their knowledge of family systems, and their ability to contact family members. The Aboriginal Health Liaison Officers hold a key role in reducing hospital induced isolation. This contact with family also works in reverse – if local family are able to be contacted, information on the patient can be passed back to family on country; the local family become a conduit for getting news on the patient, to home.

The presence of the Aboriginal Health Liaison Officer during the research interviews ensured that cultural subtleties were correctly interpreted, reducing the chance of any assumptions or misinterpretations on the part of the researcher and is in line with interpretivist research. These misinterpretations of non-verbal communications have led to remote cancer patients becoming isolated from their treatment in metropolitan hospitals, as found by Thompson et al. (2011) and this communication misinterpretation was identified by P1 when discussing her confusion over the use of Panadol. Given this, the researcher wonders if it should be considered routine practice to request an Aboriginal Health Liaison Officer's assistance for discussions between the patient, and the medical team, especially if complex, sensitive discussions are required.

FUTURE RESEARCH:

There is the potential for future research which builds on the learnings detailed in this document. Key future areas of research could include the views of remote Aboriginal patients relocating for other specialist tertiary health care, such as for renal treatment, to contrast these experiences of remote and very remote burn patients.

In addition, research into the generation and testing the efficacy and acceptance of application of a tool or resources to familiarise remote and very remote patients with the journey to the State Adult Burns Unit could be considered, with the aim of preventing some of the distress documented in this research.

LIMITATIONS AND STRENGTHS

LIMITATIONS:

Missed connections

Four possible participants, who fitted the parameters of this research, were unable to be recruited.

Two of these possible participants were inpatients within the State Adult Burns Unit. Unfortunately, the recruiter was unavailable, due to ill health, during these admissions. The limitation of having only one named Aboriginal Health Liaison Officer recruiting participants was a limitation that was not identified in the design of this research project. The two possible participants were discharged prior to the Aboriginal Health Liaison Officer returning and were unable to be contacted via telehealth post-discharge, however, interviewing participants via tele-health services may not have afforded rich data due to the difficulties in discerning non-verbal cues, and may have also impacted on participants comfort with the research process.

Another possible participant was identified via the Burns Digital Imaging Clinic program. With a substantial burn injury, the Burns Clinical Nurse Consultant recommended to the primary health service that the patient be flown to the State Adult Burns Unit for inpatient treatment. Unfortunately, the participant declined to travel to Perth. Contact was made with the originating health service to ascertain the reasoning behind the patient's refusal to travel. It transpired that the patient had children at home whom she couldn't leave. This is an example of Aboriginal women considering their health in the context of family, community and country needs, as discussed in Thompson et al. (2011).

The last possible participant was an inpatient at the State Adult Burns unit from a very remote area. She had also been advised to travel to Perth and had had to use several means of transport in her journey. The author is aware that she experienced difficulties with

communication from the health services involved with her care; however, unfortunately, she declined to participate in this study. It is unknown whether this reluctance to participate in this study was due to the historical ramifications of research with Aboriginal communities, such as discussed by Geia et al. (2013).

Restricted sample size

Fortunately, not as many Aboriginal women from remote areas, required inpatient admission during the timeframe of this Master's program, as originally predicted from historical census data.

The trustworthiness of a qualitative study should not be judged solely on sample size. The quality and credibility of the data collected should also be taken into account (National Health and Medical Research Council, 2017). Qualitative studies take into account the objectives of the study, as well as the theoretical basis (Liamputtong, 2013) to inform the number of participants deemed suitable for a recruitment strategy. Themes obtained from the three interviews demonstrated synergies and three interviews were deemed sufficient by the researcher to identify some key themes which were consistent between both interviews. Although, this cannot be said to be representative of the entire population, nevertheless they give a good insight into the experiences of Aboriginal women relocating for Burns treatment in Western Australia.

Language

It is important to note that this study was conducted with Aboriginal women in English, and not in traditional languages. Although the Aboriginal Health Liaison Officer was present during the participant interviews, ensuring that cultural subtleties were correctly interpreted, it could be considered that further information and cultural knowledge could have been ascertained if the participants were speaking comfortably in their first languages or in a form of English more comfortable and familiar to them.

Time Constraints

Conditions of ethics approval imposed by the third HREC committee necessitated the establishment of a new relationship with an independent group of advisors who identified as Aboriginal. This took further time away and pushed back the commencement of recruitment by approximately 4 months as careful negotiation and timely engagement was required to ensure that this group was a credible addition to the study methods.

STRENGTHS ARISING FROM THIS RESEARCH:

Cultural skill development

The cultural learning that the researcher was afforded during the process of conducting this research is immeasurable. This informal learning has encompassed the development of practical skills, such as rapport and trust building skills, as well as being provided with reflection and comment on the author's non-verbal skills, such as the intensity of author's eye contact and the appropriateness of this.

The above learning and reflection on author's skills has dramatically improved the author's confidence when working with Aboriginal conversation and interview skills with Aboriginal women, and with the Aboriginal Health Liaison Officer's guidance, learnt to really listen to what the Aboriginal women were saying. The author anticipates passing on this learning and skill development to other State Adult Burns Unit clinicians and Fiona Stanley Hospital Social Workers, to ensure that this knowledge is spread as widely as possible, via staff training opportunities. These skill development opportunities could include both formal Professional Development sessions, as well as staff working closely with the author and learning via shadowing and observing. The author's learning will then not only benefit future Aboriginal women admitted to the State Adult Burns Unit, but other Aboriginal patients admitted to Fiona Stanley Hospital.

Strengthening of the relationships between staff

A more familiar, warm and comfortable relationship between the recruiter and wider Aboriginal Health Liaison Officer Team, and the author as the Burns Senior Social Worker, has developed. The ongoing development of this mutual trust and respect will continue to benefit future Aboriginal patients.

Positive feedback for State Adult Burns Unit staff

The positive feedback to State Adult Burns Unit staff and support service staff is particularly important, particularly in regard to the feedback provided about participants experiences of the culturally appropriate food. These participants' will take their experiences back to country, relaying their interactions with the State Adult Burns Unit staff, to their families, and assisting to promote familiarity with both the State Adult Burns Unit and Fiona Stanley Hospital in general.

ACCOMPLISHMENTS AND RECOMMENDATIONS

ACCOMPLISHMENTS:

This research has ensured that an invaluable link with remote Aboriginal Medical Service clinics has been established. This has occurred with the assistance of the West Australian Aboriginal Health Ethics Committee, who ensured that written and visual information written by the author was disseminated to the Aboriginal Medical Service sites, assisting to ensure familiarity with State Adult Burns Unit prior to the transfer of patients. This connection has also assisted with best practice discussions and advice between the Burns Clinical Nurse Consultant and remote Aboriginal Medical Service sites.

RECOMMENDATIONS:

1. Development and immediate dissemination of a small business card, detailing the location of the State Adult Burns Unit, with relevant contact phone numbers, such as that of the Social Worker and the Burns Clinical Nurse Consultant. This would ensure that remote patients and their families know exactly where the State Adult Burns Unit is and have a reliable point of contact. This would also assist with ensuring remote staff have an awareness of the location of the State Adult Burns Unit, given that health staffing in remote areas can be fluid. This idea of a business card of contact details may also be of use in other specialty areas where remote Aboriginal patients relocate for treatment, such as Dialysis patients.
2. Adjustment to the Burns Digital Imaging Clinic automated message, to also include the contact details of the State Adult Burns Unit Social Worker, with the recommendation that these contact details are provided to the families of remote Aboriginal patients who are relocating to the State Adult Burns Unit. This verbal handover of contact details will ensure that families who cannot read the above-mentioned business cards, are also provided with the same level of service.

3. Development of a short, animated video, to be shown to remote patients prior to transfer to Fiona Stanley Hospital, which provides information on key burns topics, such as initial first aid, the different forms of transport which may be utilised to bring patients to Perth, and the different therapist and treatments which they may experience in the burns unit. When considered against a traditional video featuring human actors, an animated video is far superior in terms of sustainability, due to cultural rules with regards to death and viewing images of deceased persons. The utilisation of the Burns Digital Imaging Clinic platform for dissemination of such a resource would be valuable and would build on existing relationships with remote health facilities.
4. Consideration of an escort for patients exiting Fiona Stanley Hospital to travel facilities, such as the airport or bus stations, for patients unfamiliar with navigating large transport facilities, or for patients who are unlikely to request assistance from airport/bus station staff due to shyness or shame.
5. Consideration of the request of Fiona Stanley Hospital Aboriginal Health Liaison Staff to be present when initial and/or complex medical and nursing information and discussions occur with remote Aboriginal patients.
6. This research presents the unique opportunity for upskilling of staff when working with remote Aboriginal patients. The researcher, within her role as the Burns Senior Social Worker will develop and implement this skill development for State Adult Burns Unit staff, and the wider Social Work department at Fiona Stanley Hospital. In addition, feedback will be provided to remote health sites, with the aim of drawing attention to the systemic complexities these burn patients have experienced during their travel to Perth with a burn injury.

CONCLUSION

This research highlights the need for improvements in the care of our remote and very remote patients, as they transition to tertiary, metropolitan hospitals. It also encourages the identification of clinician assumptions in our communications with these patients, with the goal to ensure that Aboriginal patients are wholly and actively involved in their treatment.

The researcher firmly believes that the education of staff at both Fiona Stanley Hospital as well as at remote health sites, is integral to the improvement of the care of these patients. The Social Worker within the State Adult Burns Unit is uniquely placed to both disseminate this research, and provide formal training opportunities, as well as opportunities for reflexive practice and clinical supervision of staff, in this area of remote Aboriginal patients.

Participants detailed common experiences, resulting in synergies and common themes being extracted from their interviews, however a clear limitation is the limited sample size. Despite this restricted sample, rich data was able to be extracted from these participants.

APPENDIX A

SEMI-STRUCTURED INTERVIEW SPECIFIC QUESTIONS:

- I was born in Mauritius and now live in Perth. Where is your family from?
(Prompt – where are your people from, where is your country, where do you live now, how did you come to live there?)

- Can you please tell me about yourself?
(Prompt – do you have children, how old are they? do you have grannies, how old are they, do you have a partner, how do you spend your time?)

- What did you understand when you were told that you needed to come to the burns unit for treatment in Perth?
(Prompt – who told you, what did you understand this to mean, how long did you think you would have to stay? What did you think the burns unit would look like, does it look like how you imagined it would look?)

- How did you feel when you were told you needed to come to the burns unit?
(Prompt – were you happy, sad, worried, anxious, do you still feel the same way, have those feelings intensified or decreased?)

- Did you have worries about the care you would receive in hospital?
(Prompt – what did it mean to you when you were told you needed to go to hospital, were you worried that you may need an operation, did you have any worries about the staff?)

- What was it like travelling to the burns unit?
(Prompt - did you have any concerns about the distance to travel, or flying, or travelling alone to the city?)

- Can you tell me what your family thought about you coming to the burns unit?
(Prompt – what did they say, did they ask you not to go, were they worried about what sort of medical treatment you would get, were they worried about how you would get home?)
- Do you worry about family when you are away?
(Prompt – did you have to make arrangements for the care of your family, was your family / the community understanding of these arrangements?)
- Can you tell me if family know how to contact you?
(Prompt – do you have a mobile phone with credit for them to call you / you to call them?)
- Can you tell me if you have any family in Perth to visit you during your time in the burns unit?
(Prompt – do you have a mobile phone with credit for them to call you / you to call them, are there any reasons why they wouldn't visit?)
- Can you tell me about any things that made you happy about coming to the burns unit?
(Prompt – were there issues that you felt the hospital staff could help you with, to make things easier for you at home?)
- Can you tell me how you feel currently about being in the burn unit?
(Prompt – are you scared, lonely, happy, are you missing your family, your country?)
- Can you tell me how we could make your time in the burns unit more comfortable?
(Prompt – involvement from FSH Aboriginal Health Liaison Officers, food that you would usually eat, calling family?)

- Do you think there are any things we can tell other people who have come from country to the burns unit, which would be helpful for them to know?
(Prompt – should they be told what clothes to bring, what personal items to bring, what to expect?)

PARTICIPANT INFORMATION SHEET:

PARTICIPANT INFORMATION SHEET

Travelling for treatment for a burn injury: The experiences of Aboriginal women who relocate to the State Adult Burns Unit at Fiona Stanley Hospital.

Dear

You are invited to participate in the research project described below.

What is the project about?

The research project investigates the experiences of remote and very remote Aboriginal women, who have to travel from country to the burns unit. I wish to learn about your experience, and to find out what has been hard for you. This information will hopefully mean that we can make it better for women in the future.

Who is undertaking the project?

This project is being conducted by Tiffany Ryan and will form the basis for the degree of Masters of Philosophy at The University of Notre Dame Australia, under the supervision of Associate Professor Dale Edgar.

Dr. Anne Poelina from Madjulla Inc is also involved in supervising.

What will I be asked to do?

If you consent to take part in the study, you will be consenting to participate in an audio-recorded interview with the researcher. Please make sure that you ask any questions you may have, and that all your questions have been answered to your satisfaction before you agree to participate.

The study involves:

- An audio-recorded interview with the researcher. You will be asked about your experience after being burned. You will be asked how you felt about travelling to the burn unit, how you feel now that you're here, and if there are any parts of being at the burns unit which make you unhappy. You will also be asked what your family said about you travelling to the burns unit.
- The interview will take an hour, and will be conducted in your room in the burns unit.
- After the interview, there are no follow up requirements.

Are there any risks associated with participating in this project?

It is possible that you may have some distress during the interview due to some of the questions you will be asked. You will be monitored closely during the interview and you are free to withdraw at any time. If these feelings persist we will make arrangements will be made for you to access support from a Fiona Stanley Hospital health worker at no expense to you.

What are the benefits of the research project?

Benefits to you include having your story heard by a researcher, Tiffany, who is also a staff member of burns unit. Tiffany can advocate for the changes and ideas which you recommend.

Future patients of the burns unit may also benefit from your story and recommendations.

What if I change my mind?

Participation in this study is completely voluntary. Even if you agree to participate, you can withdraw from the study at any time without discrimination or prejudice. If you withdraw, all information you have provided will be erased from the audio recording device. **Non-participation or withdrawal will in no way whatsoever effect your ongoing treatment at the burns unit.**

Will anyone else know the results of the project?

Information gathered about you will be totally private. This privacy can only be broken if required by law.

Computer based information will be stored on the researcher's laptop in excel format and protected by 1) password access to log onto the device, 2) password access to protect the excel spreadsheet, 3) information will then be further protected via encryption. Once the study is completed, the data collected from you will be de-identified and stored securely in the School of Physiotherapy at The University of Notre Dame Australia for at least a period of five years. The data may be used in future research but you will not be able to be re-identified. The results of the study will be published as a thesis.

Will I be able to find out the results of the project?

Once we have analysed the information from this study we will mail you a summary of our findings. You can expect to receive this feedback within 2 years.

Who do I contact if I have questions about the project?

If you have any questions about this project please feel free to contact either the researcher on ph: 6167 2893 or the researcher's supervisor, Associate Professor, Dale Edgar, on Ph: 0413 070 384. We are happy to discuss with you any concerns you may have about this study.

What if I have a concern or complaint?

This study has been reviewed and approved by the South Metropolitan Health Service Human Research Ethics Committee. If you have a concern or complaint regarding the ethical conduct of this research project, please contact the Research Ethics and Governance Unit at (08) 6151 1180 or SMHS.REG@health.wa.gov.au quoting reference number: 16-164.

How do I sign up to participate?

If you are happy to participate, please sign both copies of the consent form, keep one for yourself and give the other one to the person talking to you about this research.

Thank you for your time. This sheet is for you to keep.

Yours sincerely, **Tiffany Ryan**

CONSENT FORM

Travelling for treatment for a burn injury: The experiences of Aboriginal women who relocate to the State Adult Burns Unit at Fiona Stanley Hospital.

- I agree to take part in this research project.
- I have read the Information Sheet provided and been given a full explanation of the purpose of this research project and what is involved in the interview(s).
- I understand that I will be interviewed and that the interview will be audio-recorded.
- The researcher has answered all my questions and has explained possible risks that may arise as a result of the interview and how these risks will be managed.
- I understand that I do not have to answer specific questions if do not want to and may withdraw from participating in the project at any time without prejudice.
- I understand that all information provided by me is treated as confidential and will not be released by the researcher to a third party unless required to do so by law.
- I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed.
- I understand that research data gathered may be used for future research but my name and other identifying information will be removed.
- I understand that once signed, this consent form will be retained by the researcher, and stored confidentially.

This study has been reviewed and approved by the South Metropolitan Health Service Human Research Ethics Committee. If you have a concern or complaint regarding the ethical conduct of this research project, please contact the Research Ethics and Governance Unit at (08) 6151 1180 or SMHS.REG@health.wa.gov.au quoting reference number: 16-164.

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Name of participant			
Signature of participant		Date	

- I confirm that I have provided the Information Sheet concerning this research project to the above participant, explained what participating involves and have answered all questions asked of me.

Signature of Researcher		Date	
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APENDIX D

SUMMARY OF RECRUITMENT:

- 3 participants successfully recruited to this research between September 2016 and December 2018.
- 4 possible participants, who fitted the parameters of this research, were unable to be recruited between September 2016 and December 2018. Further explanation as to these unsuccessful recruitments is provided on under “Limitations”.

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