School of Psychology
Stress and Pregnancy in Western Australian Aboriginal Women

Kelly Johanna Prandl

This thesis is presented for the Degree of

Doctor of Philosophy

of

Curtin University

STRESS AND PREGNANT ABORIGINAL WOMEN

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**Declaration** 

To the best of my knowledge and belief this thesis contains no material previously

published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other

degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with

the National Health and Medical Research Council National Statement on Ethical

Conduct in Human Research (2007) – updated March 2014. The proposed research

study received human research ethics approval from the Curtin University Human

Research Ethics Committee (EC00262), Approval Number # HR 113/2009

Signature:

Date:

22<sup>nd</sup> September 2017

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#### **Abstract**

While Indigenous peoples are some of the most researched people world-wide, there is still a lack of understanding of how mental health difficulties are conceptualised within these populations. The relationship between high levels of maternal stress and poor perinatal outcomes has been described in the literature, yet to date this has not been examined in an Australian Aboriginal population. To address this, the aim of the current study was to develop an understanding of the experience of stress in Aboriginal women during pregnancy. In addition to this, this information was important in determining whether it was feasible to develop a screening tool. The proposed screening tool was hoped to be useful in identifying women during pregnancy who would benefit from extra psychosocial support and therefore potentially reduce the rate of preterm birth and low birth-weight babies.

In the first stage of this research a process of engagement with members of the Nyoongar community was undertaken with the formation of a community women's Reference Group and the identification of a Nyoongar woman to take the role of Cultural Consultant for this research. This engagement took place over several years and was informed and developed through meaningful relationships and an acknowledgement of the importance of a position of respect for cultural diversity. My role and position as a non-Indigenous woman is an influential part of this research and highlights the importance of adopting a decolonising approach to Indigenous health research. As a part of adopting decolonising methodology, yarning was the chosen data collection strategy. Yarning has been described by Bessarab and Ng'andu, (2010) as a culturally appropriate approach to sharing information within the protocols and rules that are specific to Australian Indigenous culture. Yarning interviews were conducted with 19 Nyoongar women, (n= 6

Indigenous professionals, n=7 pregnant women, n=6 non-pregnant women), recorded and then transcribed for analysis.

Study One was an exploration of cultural considerations in conducting this type of research and an opportunity for Nyoongar health professionals to provide their views on the types of issues faced by young women in the community. The yarning discussions were transcribed and analysed utilising Thematic Analysis (Braun & Clarke, 2006). Study Two was an in depth exploration of stress as described by both pregnant and non-pregnant Nyoongar women. Causal Layered Analysis (CLA) as described by Inatullah, (1998), was the qualitative analytical technique that was adopted for Study Two. This approach provides a framework for exploring complex social issues by exploring the data within different layers: the litany, the social causative level, worldviews and myth/metaphor levels.

The findings of both studies provide evidence that the experience of stress is high in Nyoongar women and does not appear to vary between pregnant and non-pregnant women. This research confirms that while pregnancy presents some specific worries, the nature of the stress is chronic and related to the ongoing experiences of social exclusion and racism. These findings indicated that developing a simple screening tool is unlikely to be feasible or practical and that the issue of stress during pregnancy in Australian Aboriginal women is an important area for further exploration. These findings also provide an insight into the experiences of ongoing colonisation and oppression that is experienced by this group of Aboriginal women. The personal conflict experienced by these women is highlighted by the incompatibility of living within their own cultural values while living in the so-called "post-colonial" Australian culture. These conflicts have important implications for

how the health disparities between Indigenous women and infants and their non-Indigenous counterparts may be addressed in future health and social services policy.

# List of Publications Included as Part of the Thesis

Prandl, K. J., Rooney, R., & Bishop, B. J. (2012). Mental health of Australian Aboriginal women during pregnancy: Identifying the gaps. *Archives of Women's Mental Health*, *15*(3), 149-154. Doi:10.1009/s00737-012-0276-0

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### **Chapter One: Introduction**

The health outcomes for Indigenous Australians are noticeably poorer than for non-Indigenous Australians on a wide range of indicators ranging from life expectancy, rates of low birth weight babies and infant and maternal morbidity and mortality. The differences on many of these health measures are large, for example the life expectancy for Indigenous people is twelve years less than for their non-Indigenous counterparts (Australian Institute of Health and Welfare (AIHW), 2012). The infant mortality rate in the general population in Australia of 9.2 infant deaths per 1000 live births is lower than in other comparable countries, including the United States of America, New Zealand and Canada (Australian Institute of Health and Welfare (AIHW), 2012). This is in contrast to the pregnancy outcomes statistics of Australian Indigenous women where the rate of infant mortality is double that of their non-Indigenous counterparts (Li, McNally, Hilder, & Sullivan, 2011). Other key markers of health outcomes in pregnancy include gestation at birth of the infant and the birth weight of the infant at birth. A normally progressing pregnancy has a duration of approximately 40 weeks. A preterm labour or birth is said to occur before the completion of the 37<sup>th</sup> week of pregnancy (Hedegaard, Henriksen, Sabroe, & Secher, 1993). The birth weight of an infant at birth is identified as "low birth weight", when the infant weighs less than 2500gms at birth (AIHW, 2012). Australian Indigenous women experience twice the rate of preterm labour and birth and their babies are lighter in weight (by 190gms) than non-Indigenous babies (AIHW, 2012).

Health care providers have acknowledged these disparities in outcomes and have attempted to address the health needs of the Indigenous women by developing health programs that specifically target Indigenous women (Brown et al., 2016;

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Carter, Lumley, Wilson, & Bell, 2004; Gibson-Helm et al., 2016; Kildea, Kruske, Barclay, & Tracy, 2010; NSW Health, 2005). Many of these programs have been developed to address a particular health behaviour that has been shown to be detrimental to maternal and foetal outcomes. For example, the rates of Indigenous women smoking and consuming alcohol and other teratogenic substances during pregnancy are significantly higher than in the non-Indigenous population: 51.8% of Indigenous women smoke during pregnancy, compared to 14.8% of non-Indigenous women (Eades et al., 2012; Kelly, Graham, & Sullivan, 2010). Indigenous women are less likely to seek antenatal care in the early part of their pregnancy and have more difficulty accessing specialist services. Programs targeting Indigenous pregnant women include smoking cessation programs, alcohol in pregnancy campaigns, and outreach midwifery led antenatal services (NSW Health, 2005; Panaretto et al., 2005; Passey, Bryant, Hall, & Sanson-Fisher, 2013). These programs have shown modest improvements in some of the key measured outcomes, for example women in the NSW Aboriginal Maternal and Infant Health Strategy (2005) showed an improvement in the number of antenatal appointments and the gestation at first contact and a small increase in average birthweight has been noted. In spite of these improvements the rates of smoking and alcohol have remained stable and the preterm birth rate continues to be poorer in Indigenous births.

While the Australian Institute of Health and Wellbeing acknowledge the complex relationships between the social determinants of health and the health outcomes experienced by individuals, health services policy makers have mainly focused on the perceived needs of the population based on the health outcomes and health behaviours observed alone (AIHW, 2012). One of the health determinants strongly influenced by social determinants of health and which has been shown to

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have both a direct impact on birth outcomes and also an effect on maternal health behaviours is stress. Stress is a complex construct that is often defined in different ways. For the purpose of this research, stress includes the psychological and physiological responses experienced when there are insufficient resources available to cope with a stressor or situation (Cohen, Kamarck, & Mermelstein, 1983).

The relationship between stress and health has been researched and debated over at least the last 50 years. In particular it has been shown in the general population that chronic stress has a detrimental impact on health (DeLongis, Folkman, & Lazarus, 1988). Within the Australian literature, mental health research during the pregnancy and postnatal period has generally focussed on the diagnosis and experience of depressive symptoms, anxiety symptoms and pre-existing mental health diagnoses (Milgrom et al., 2008). Yet within the international literature researchers have reported that stress during pregnancy decreases the duration of the pregnancy, and has a role in increasing the risk of low birth weight of infants (Hobel, Goldstein, & Barrett, 2008; Littleton, Bye, Buck, & Amacker, 2010; Loomans et al., 2013). In addition to immediate pregnancy outcomes, stress in pregnancy has been linked with long-term negative outcomes for child development, learning, and behaviour (O'Donnell, O' Connor, & Glover, 2009). Whilst these outcomes are very important it is vital to also consider the sequelae of prematurity and low birth weight. Infants born prematurely and/or of low birth weight are at greater risk of ongoing physical and emotional health problems such as mental health difficulties and Attention Deficit Hyperactivity Disorder (O'Connor, Heron, Golding, Beveridge, & Glover, 2002; Rooney, Hay, & Levy, 2003). The relationship between stress and pregnancy outcomes has not been explored within either clinical or research settings with an Australian sample, despite researchers identifying that Australian Aboriginal

people are at particular risk of experiencing high levels of stress (Zubrick et al., 2004). In addition, while there has been a range of studies on risk factors, stress, depression and the lived experiences of Westernised women there have been no studies to date investigating how Aboriginal women perceive and conceptualise the experience of stress or how their experiences of motherhood and childbirth affect them and their babies.

#### 1.1 Research Aims

It is my first aim in this thesis to explore the lived experience of a group of Aboriginal women in the southern suburbs of Perth Western Australia, in order to gain an understanding of their conceptualisation of stress. Health service delivery in Australia is based predominantly on a Western medical model of health. This ethnocentric approach is also apparent in health research that relies on a Western view of stress. In order to develop or provide culturally safe and appropriate services to Aboriginal women, it is essential that a thorough exploration of how stress is viewed, experienced and described by Aboriginal women is conducted. This approach has been described by Kleinman (1978) as an 'explanatory model'. This model allows the researcher or clinician to try to understand not only the lived experience, but also the language and cultural nuances that capture the experience from the individual's perspective (Kleinman, 1978).

Building on this exploration of stress from Aboriginal women's perspectives, the second research aim was to determine whether it is possible to develop a measure to identify Aboriginal women who are at risk of high levels of stress during pregnancy. A screening measure would allow health practitioners to identify those women who were at risk, and to develop supportive interventions to reduce the negative impact stress can have on birth outcomes. Thus the research questions are:

- 1. How do Aboriginal women conceptualise stress and mental health?
- 2. How do Aboriginal women conceptualise and experience stress during pregnancy?
- 3. How could non-mental health professions (primary health care professionals) best identify Aboriginal women experiencing stress and mental health difficulties during pregnancy?

#### 1.2 My Background and this Study.

Australian Indigenous peoples include people from many different

Aboriginal clans or nations and people from the Torres Strait Islands. This research

has been undertaken within the Nyoongar community in the southern suburbs of

Perth, Western Australia primarily because the Nyoongar people are the traditional

landowners and the cultural group of the majority of Indigenous people within this

geographical region. To avoid confusion and over generalisation, when referring to

Aboriginal and Torres Strait Islander people I will use the term Indigenous, however

for specific information that pertains to the participants of this research and the

specific geographical region known as the Nyoongar Nation, I will use the term

Aboriginal.

Prior to pursuing a career in Psychology, I was a midwife and community child health nurse. I had worked in a variety of settings, including rural and remote areas, metropolitan hospitals and community health centres. It was during my final nine years of nursing that I was employed by the Armadale Health Service in the southern suburbs of Perth, Western Australia. During this time I worked as a midwife, a child health nurse, a Clinical Nurse manager and an outreach Midwife. Armadale Health Service has a catchment area with a population of over 200,000 residents, of which approximately 8.2% are Indigenous (Department of Health,

2012). Indigenous families have historically, been reluctant to access the health services due to a multitude of factors, including access issues, transport difficulties and perceived racism and negative experiences of the health service. Indigenous pregnant women largely presented to the labour ward at the end of their pregnancy once they were in labour or when there were significant complications, which reinforced the negative experience they had in the hospital.

In 2007 a Nyoongar Women's Community group approached the Armadale Health Service with a request to develop a culturally safe antenatal service for local Nyoongar women. The Boodjari Yorgas program was developed in partnership with the Nyoongar community and offered a home based antenatal service with a midwife and an Aboriginal Health worker. As the midwife in this program I was increasingly aware of the high levels of emotional distress experienced by the women we were visiting. At the time I was an undergraduate psychology student and I believed that many of the women I was visiting may have met some or all of the criteria in the DSM-IV TR for a diagnosis of major depression. I expressed these thoughts to the Aboriginal Health Workers I was working with and was told with a matter-of-fact confidence that these women were not depressed, they were stressed. This was where my PhD journey began. I continued to work in the Boodjari Yorgas program until commencing my PhD program in 2009. The Nyoongar women in the community and the Aboriginal Health Workers I worked with have been, and continue to be, the motivation for this research.

#### 1.3 Overview of the Thesis.

In this first chapter I have introduced the thesis and described the aims of this research. In chapter two I have provided a review of the literature in the area of psychological distress (stress) and pregnancy outcomes. The relationship between

Aboriginal women has been highlighted. There is limited literature in this area related specifically to an Australian Aboriginal population, so international literature in both Indigenous and non-Indigenous populations has also been described. The importance of culturally sensitive and focussed research is highlighted in view of the paucity of research in this area specific to Aboriginal women.

I have provided a brief overview of Aboriginal health and more specifically Aboriginal mental health within the historical context of colonisation by the British in chapter three. I have not included an in depth description of the history of colonisation in Australia, not because it is not vitally important to the context of Indigenous people today or the context of this research, but because there are several excellent publications that have already provided a comprehensive description of this history (Broome, 1994; Chesterman & Galligan, 1997; Collard, 2000; Wilkie, 1997). I also want to emphasise that while researchers and historians write about the history of colonisation in Australia, I feel that by relegating it to a past tense history, we are failing to acknowledge the ongoing experiences of colonisation that are experienced by the Indigenous peoples of Australia to this day. For many, this history is a day to day lived experience so I am focusing on the experiences of Aboriginal women today.

I have then described the rationale for this research (Chapter Four). I have included information about the choice of methodology and some important aspects of cross cultural research that I have employed in this research. Important methodological decisions included the adoption of de-colonising methodology which involved the formation of an Aboriginal reference group, and the use of yarning as a data collection and engagement strategy have been described. In addition to the

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rationale, I have included a Process chapter (Chapter Five), which has assisted to contextualise this research and my position within this context. I have described how my position or role within the community has developed over time and how this has affected my experiences of this research. I believe this is an important aspect of the research and includes my thoughts around the challenges of being a non-Indigenous researcher in what has been described as a highly contested arena (Garvey, 2015).

The first study, described in chapter six, explored the views of Aboriginal health professionals on the appropriateness of the proposed methodology, cultural concerns and their understanding of the issues faced by pregnant women in the Aboriginal community. This was effectively the scoping study to inform and guide the second study. The second study involving both pregnant and non-pregnant Aboriginal women has been described in chapter seven. This study aimed to address the main research aims by exploring pregnant and non-pregnant women's experiences of stress and the feasibility of developing a screening measure. This chapter includes the method, findings, and discussion.

To conclude this thesis, a review and evaluation of the findings of both studies, within the context of current research and service delivery in Western Australia, has been described in the final chapter (eight). I have described the implications of the findings of these studies to clinical midwifery or obstetric practice. I have then explored the limitations of this current research and identified recommendations for future research and practice that will assist to improve the health outcomes for Aboriginal women in this community.

# **Chapter Two: Pregnancy and Stress**

This chapter is a review of the literature in the area of psychological distress (stress) and pregnancy outcomes. The relationship between stress and pregnancy outcomes has been discussed and the relevance to Australian Aboriginal women has been highlighted. There is limited literature in this area related specifically to an Australian Aboriginal population, so international literature has also been described. The importance of culturally sensitive and focussed research has been highlighted in view of the paucity of research in this area specific to Aboriginal women.

# 2.1 Defining Stress

In order to explore the relationship between stress and pregnancy, it is first vital to define the construct of stress. Defining stress is problematic as the concept of stress has been linked to both physiological stress and psychological stress (Lazarus, 1993). Stress was seen as being an "external load or demand on a biological, social, or physiological system" (Lazarus, 1993, p.2). Post World War II, research into the effects of stress and the attempts to predict stress was conducted with varied results. It was recognised that there were individual differences that were important when considering the effects of a stressor and the subsequent reaction, and early researchers such as Hans Selye focussed mainly on the physiological aspects of stress. The General Adaptation Syndrome (GAS) (Selye, 1955) highlighted the physiological responses and adaptation of the human body to stress, and continues to guide our understanding of the relationship between stress and some illnesses, however it has been through research conducted by Lazarus and others that the importance of the role of psychological stressors has been recognised (Cohen et al., 1983; Lazarus, 1993; Lazarus & Folkman, 1984). While psychological stressors were found to also produce the GAS, these stressors are experienced differently due to the

personal meaning that is placed upon the stressor which also involves cognitive appraisal and coping styles (Cohen et al., 1983; DeLongis et al., 1988; Lazarus, 1993).

For the purposes of this research, stress will be defined using Lazarus and Folkman's (1984) definition as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p.19). The environment or 'stressors' have been described by Elliot and Eisdorfer (1982) within a taxonomy (as cited in Segerstrom & Miller, 2004). The five categories of stressors that Elliot and Eisdorfer describe are acute time-limited stressors, brief naturalistic stressors, stressful event sequences, chronic stressors and distant stressors. The key differences between these types of stressors are the duration of the stressor and the stability or predictability of the stressor. The variability in defining stress has provided difficulties in both research and clinical practice, with different definitions resulting in different measures and results. Despite these difficulties, stress continues to be identified as an important predictor in health outcomes, not only for the person experiencing stress, but also the developing foetus during a woman's pregnancy.

# 2.2 Conceptualisation of Stress in Pregnancy in Research

One of the major difficulties in determining the impact of stress on pregnancy outcomes is the great variation in how stress is defined and thus identified. The conceptualisations of stress and distress are unclear and have been measured in various ways including the life events scale developed by Miller and Rahe (Li et al., 2013), perceived stress, depression, anxiety, pregnancy-specific anxiety and daily hassles (Littleton et al., 2010). Lobel et al. (2008) believed that these variations have contributed to the inconsistent findings across studies. This has led to teams of

researchers operationally defining pregnancy stress or prenatal maternal stress as "the aggregate of negative emotional state and stressful life events or conditions during pregnancy, and in some cases [researchers] have also included pregnant women's perceptions or appraisals of their circumstances" (Lobel et al., 2008, p. 604).

Ayers (2001) argued that in order to examine stress in pregnancy, it is essential that only measures validated in a pregnant population be used, based on the premise that stress during pregnancy may be conceptualised quite differently to stress at other times in a woman's' life. Ayers (2001) also suggested that research on stress should involve consideration of three main components: measures of stressors, appraisal processes and coping resources. This has proven to be problematic, with most published measures addressing only one part of the stress construct. Many measures include items about both chronic and acute stress which makes interpretation unclear when some suggest that daily hassles are better predictors of psychological well-being rather than life events (Ayers, 2001). The hassles and uplifts scale, a scale used frequently in this area of research, has been criticised for incorporating both chronic stress with stressful events and for failing to separate stressors from stress responses (Ayers, 2001). A revised version of the hassles and uplifts scale has been used in obstetric samples (Da Costa, Larouche, Dritsa, & Brender, 1999; Ruiz & Fullerton, 1999), and DiPietro, Ghera, Costigan, and Hawkins (2004) modified the daily hassles and uplifts scale to develop the pregnancy experience scale. This scale identified pregnancy-specific hassles and uplifts in order to determine the effect of both the positive and negative aspects of pregnancy. They believed that it is important to consider both positive and negative aspects as it was the relationship between the two that provided valuable information about the

emotional state of the women and that only examining the negative experience of pregnancy fails to acknowledge how women are "psychologically elevated by their pregnancies" (DiPietro et al., 2004, p. 189).

# 2.3 Conceptualisation of Stress and Mental Health Difficulties in Clinical Practice

Other instruments used to identify stress or psychological distress in pregnant women includes measures developed for the purpose of predicting postnatal depression (Austin, Hadzi-Pavlovic, Saint, & Parker, 2005; Buist et al., 2008; Leigh & Milgrom, 2008; Priest, Austin, Barnett, & Buist, 2008; Saisto, Salmela-Aro, Nurmi, & HalmesmÄki, 2008). These studies used a combination of measures including measures of depression, self-esteem, pregnancy anxiety and general anxiety to assess a woman's mental health during pregnancy. Leigh and Milgrom (2008) reported that psychological difficulty during pregnancy, defined as depression and measured by the Beck Depression Inventory, was the strongest predictor of postnatal depression; however, the usefulness of these measures to identify risks to birth outcomes has not been assessed.

Currently in Western Australia, women are screened for depression and anxiety during pregnancy using the Pregnancy Anxiety Screening Scale (Somerville et al., 2014) and the Edinburgh Postnatal Depression Scale (EPDS) as recommended by the beyondblue National Postnatal Depression Program (Campbell, Hayes, & Buckby, 2008). The EPDS has been extensively researched and translated into different languages, and although it was developed to identify postnatal depression, it has been suggested that it is also useful in identifying depression and anxiety during pregnancy (Murray & Cox, 1990). One of the difficulties of this measure is that there is limited information about its validity and reliability in the Aboriginal population.

Campbell et al. (2008) reported that the language of the measure was easily misinterpreted by Aboriginal women, which reduced the tool's usefulness. Through extensive community involvement, two translated versions of the tool were developed for the Mount Isa population and the Community Controlled Townsville Aboriginal and Islander Health Service (Campbell et al., 2008). The authors were cautious about the widespread use of these translated measures as the Aboriginal population is heterogeneous, and its relevance to Western Australian Nyoongar women is unknown. Another limitation of this translated measure is that each of the ten items was individually translated into a terminology relevant to each community; however, each of the items was based on a European Western construct of anxiety and depression. Although each item may be meaningful to the target population, whether these items captured the Aboriginal experience and understanding of emotional distress remains unknown.

A group of researcher's in the Kimberley area (northern Western Australia) have developed and validated an assessment tool that includes a local version of the EPDS and a psychosocial tool that provides contextualisation of the EPDS scores, the Kimberley Mum's Mood Scale (KMMS) (Marley et al., 2017). The findings of this study examining the results of 97 Aboriginal women across 15 health sites in the Kimberley demonstrated high internal consistency and a moderate specificity for the detection of depression and anxiety symptoms in this population. While this assessment tool does not assess stress, the measure was well accepted by the pregnant women and the authors suggested that this provided opportunity for the women to express themselves more openly to their health care providers (Kotz, Munns, Marriott, & Marley, 2016; Marley et al., 2017). One of the limitations in this

assessment however, remains the difficulty of determining its validity to be used with other Indigenous cultural groups.

Despite the validity or versatility of any of the mentioned measures with the exception of the EPDS and the KMMS, none have been validated in an Aboriginal population. On examination of the measures, for example the hassles and uplifts scale, it becomes clear that while some items would have relevance, many items as currently written may not be culturally meaningful to Aboriginal people, for example questions asking to rate daily events or experiences as 'uplifts' or 'hassles' such as 'Conserving (gas, electricity, water, gasoline, etc.) . Psychological research and practice within the Aboriginal community has historically been based on Western psychological theory and assessments. This lack of psychological measures that are inclusive of Aboriginal culture can be seen as a contributing factor in the continued disadvantage experienced by Aboriginal people (Rickwood, Dudgeon, & Gridley, 2010).

#### 2.4 Stress and Pregnancy

There have been mixed findings in the literature about the effects of maternal stress on pregnancy outcomes. Some studies have focused on physiological changes that occur as a result of chronic stress. Diego et al. (2006) found that women who reported higher levels of psychological distress during pregnancy, as determined by measures of depression, anxiety and daily hassles, exhibited higher cortisol levels during pregnancy which was related to lower infant weight at birth. Other research examined the relationship between self-reported life events, stress, anxiety and the timing of stress with pregnancy duration (Glynn, Schetter, Hobel, & Sandman, 2008). Glynn et al. (2008) found that the pattern of change of stress during pregnancy is an important predictor of a premature delivery. They reported that most

women show a decline in the response to stress over the duration of the pregnancy; however, women who do not experience this decline are at greater risk of preterm delivery (Glynn et al., 2008). Dole et al. (2003) suggested that women who reported a higher negative impact from stressful life events were at greatest risk of adverse pregnancy outcomes.

These measures of stress or anxiety have also been combined with other factors, including homelessness, drug and alcohol use, smoking, ethnicity and age, to develop complex models in an attempt to better understand the relationship between mental health and pregnancy outcomes (Field et al., 2009; Huizink, Robles de Medina, Mulder, Visser, & Buitelaar, 2003; Orr, Reiter, Blazer, & James, 2007). Whether stress has a direct impact on pregnancy outcomes or an indirect impact through poor health behaviours and other socioeconomic factors is not clear; however, the experience of distress for women during pregnancy has been shown to be detrimental for maternal well-being, pregnancy outcomes and later child development (Lobel et al., 2008).

Martini, Knappe, Beesdo-Baum, Lieb, and Hans-Ulrich (2010) conducted a study of 992 mothers to examine the impact of maternal mental health and perceived distress during pregnancy on maternal, obstetric, infant and childhood outcomes. They concluded that women experiencing high levels of self-perceived distress were at greater risk of developing postpartum depressive disorders, obstetric interventions and mental health pathology in their children (Martini et al., 2010). They highlighted that a significant limitation of their research was that perceived distress during pregnancy was not identified by a psychometrically sound measure.

There are some conflicting findings reported in this area of research, often due to the varied methodological approaches and measures used. Bolten et al. (2011)

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conducted a comprehensive study examining the relationship between maternal cortisol levels (measured by saliva samples at two times during pregnancy), perceived stress, as measured by Cohen's Perceived Stress Scale, and birth weight and length of newborn infants. The authors reported that the maternal cortisol levels accounted for 19.8% of the variance in infant birth weight after controlling for maternal age, parity, number of cigarettes smoked per day, maternal BMI, infant's sex and gestational age. These findings supported the findings of other studies that indicated that increased levels of cortisol during pregnancy (i.e., increased maternal stress) was a risk factor for lower birth weight (Bolten et al., 2011; Diego et al., 2006) What was interesting in Bolton's study, however, was that the researchers found no association between maternal distress and elevated levels of cortisol, nor any association between perceived stress and cortisol levels. It was suggested by the authors that some of the issues may be related to differences in how perceived stress or maternal distress is operationalised. This study was conducted on a sample of 70 healthy women, with a small sample size and a lack of comparison to groups of women known to experience high levels of stress. Therefore, interpretation of these results need to made with some caution.

Loomans et al. (2013) examined psychosocial stress in a large multi-ethnic community based cohort and concluded that babies born to women experiencing high levels of depression, high levels of anxiety and moderate job strain had significantly lower birth weight, than women with low levels of depression and anxiety. They explored different types of stress, for example, pregnancy-related anxiety, work stress, parenting stress and anxiety and depression symptoms. Interestingly the authors found that high levels of pregnancy related anxiety in the absence of other psychosocial stress did not appear to increase the risk of adverse birth outcomes

(Loomans et al., 2013). This study examined stress on one occasion only, and could not determine patterns of distress or identify women experiencing high levels of chronic stress.

Hayes, Campbell, Buckby, Geia, and Egan (2010) conducted a study examining the impact that social stressors have on obstetric outcomes in a sample of 92 Aboriginal women from Queensland, Australia. Despite the lack of power with this study, their findings supported international findings that suggest that there is a link between higher levels of stress experienced during pregnancy and lower birth weight babies (Hayes et al., 2010).

# 2.4.1 Pregnancy-specific stress.

While a significant amount of research has focussed on the effects of general and chronic stress on pregnancy outcomes, there is also a body of literature that has explored the impact that pregnancy-specific stress has on maternal and foetal outcomes. Pregnancy-specific stress is differentiated from general stress in that it is specifically related to the process of pregnancy. These processes include the physical and psychological changes that women experience, such as the physical changes of pregnancy, interpersonal relationship changes, concerns and worries regarding the labour and birth and concerns regarding the health and wellbeing of the unborn baby (Lynn, Alderdice, Crealey, & McElnay, 2011). There have been a number of reported studies that have strongly suggested that the experience of pregnancy-specific stress is associated with poorer birth outcomes, such as preterm labour, than other measures such as general stress or anxiety, when age, income, education and parity have been controlled (Da Costa et al., 1999; Dole et al., 2003; Lynn et al., 2011). Dole et al. (2003) also included race and experiences of perceived racism which contributed to the increased risk of preterm birth. Lynn and colleagues (2011)

used the Prenatal Distress Questionnaire (PDQ; Yali & Lobel, 1999) with a sample of low risk women during their pregnancies. They found that the PDQ was a useful tool to identify women experiencing high levels of pregnancy-specific stress, with young primiparous women with poor obstetric histories being the most likely group to express high levels of distress.

Despite the varied findings in the literature, there appears to be some relationship between high levels of stress and birth outcomes including preterm birth and babies born with a low birthweight. More importantly, the long term impacts of preterm birth and babies born of low birth weight appears to lead to significant ongoing difficulties for both the children and the parents.

# 2.5 Stress in Pregnancy and Infant and Child Outcomes

Preterm birth and low birth weight are leading causes of health problems that may persist through childhood and into adolescence (Lobel et al., 2008; Mackerras, 2001). The impact of stress during pregnancy is not only evident in the birth outcomes but also in life-long mental health, physical health and development trajectories of children (Christian, 2015; Fowden, 2017; La Marca-Ghaemmaghami & Ehlert, 2015; Slykerman et al., 2015; Van den Bergh et al., 2017). The Raine study, a prospective cohort study of 2,868 Western Australian children, identified that the significant risk factors for preschool mental health difficulties at the age of 2 years included multiple stress events in pregnancy, smoking during pregnancy and non-Caucasian ethnicity (Robinson et al., 2008).

Dailey (2009) conducted research examining the potential predictors of low-birthweight deliveries by exploring the occurrence of social stressors, which included measures of discrimination and trauma exposure with a sample of 119 pregnant African-America women. Women who reported experiences of discrimination,

including discrimination because of race, age or physical disability were associated with an increased risk of delivering a low-birth weight baby. The results also supported previous findings where it was found that birth weight outcomes were associated with the number of prenatal visits and tobacco use in pregnancy (Dailey, 2009).

The Telethon Institute for Child Health Research conducted a comprehensive survey of Aboriginal children between 2000 and 2002. In that study Zubrick et al. (2004) found that the factor most strongly associated with emotional or behavioural difficulties in Aboriginal children was the number of major stressful life events a family had experienced. Over half of the children surveyed had experienced at least three major life stress events, including illness, family break-up, arrests or financial difficulty (Zubrick et al., 2004). This significant level of stress experienced by Aboriginal families has been attributed to many factors, primarily the ongoing sequelae of past government policies, namely post-colonial treatment which included separation from traditional lands, concentration camps and the forced removal of children from their families (Collard, 2000; Raphael & Swan, 1997). These past actions have been suggested to have contributed to the unemployment rate being three times greater for Indigenous people when compared to non- Indigenous people, that one in two Aboriginal households required some form of government housing support in 2006, and that the median equivalised gross household income for Indigenous people was only 56 % of the median equivalised gross household income for non-Indigenous people. This equates to an approximate median income of \$362 per week for an Indigenous person when compared to median income of \$642 for non-Indigenous person (Australian Bureau of Statistics (ABS), 2008).

Huizink et al. (2003) reported that lower mental and motor development of 8-month-old infants were predicted by high levels of maternal anxiety during pregnancy. They saw the need for follow-up to determine whether these differences were persistent; however, other researchers have found that the effects of maternal anxiety during pregnancy continued to predict behavioural problems at the age of 4 years (O'Connor et al., 2002). The causal pathways to these outcomes are complex and remain unclear with some authors attributing the results in children to exposure to cortisol in utero, while others suggested the absence of emotional availability and the subsequent difficult attachment patterns between infants and their mothers as leading factors (Lazinski, Shea, & Steiner, 2008; O'Connor et al., 2002; Robinson et al., 2008).

#### 2.6 Aboriginal Women and Pregnancy

On average, Aboriginal mothers are younger and more likely to smoke and consume alcohol during pregnancy than non- Indigenous women (Leeds et al., 2007). These behaviours, when combined with poor maternal nutrition and general health status, are generally considered to be causal of the complications experienced by Aboriginal women during pregnancy (Eades et al., 2012; Kelly et al., 2010). Another factor that contributes to the poor birth outcomes is how Aboriginal women access health services during pregnancy (Hunt, 2006). Aboriginal women present later in their pregnancy for midwifery/obstetric care, attend fewer antenatal appointments and are less likely to have received health screening during pregnancy (Brown et al., 2016; Hunt, 2006; Panaretto et al., 2005; Rumbold & Cunningham, 2008). It has also been suggested that Aboriginal women are less likely to perceive a need to engage with health services, as they are more likely to view pregnancy as a normal life event rather than a medical condition (D. Peate, personal communication, December 2007).

Researchers have also suggested that Aboriginal women choose not to access antenatal services due to the lack of culturally appropriate and safe services, experiences of racism, cost and transport issues (Carter et al., 2004; Panaretto et al., 2005; Rumbold & Cunningham, 2008).

Programmes have been developed to provide culturally sensitive services by engaging with the local community and employing local Aboriginal women. Evaluations of these types of programmes have suggested that a collaborative model of care utilising Cultural Consultants or health workers improves the access to the services by increasing the number of contacts and reducing the gestation at the first contact (NSW Health, 2005). The NSW programme, Aboriginal maternal and infant health strategy (AMIHS) was developed with an empowerment model in mind, and it was hoped, that with intensive support, Aboriginal women would feel empowered and confident to access the mainstream service with future pregnancies. This program was a targeted service that established a midwife and Aboriginal Heath worker or Aboriginal Liaison worker to provide community antenatal and postnatal services to Aboriginal women within six local government localities in conjunction with the current mainstream services being provided. In the evaluation of AMIHS it was suggested that the Aboriginal women preferred to continue with the highly supportive model with subsequent pregnancies. The authors believed that as the social circumstances and emotional well-being of the families had not necessarily improved, the need for intensive support remained important (NSW Health, 2005). These findings have also been found in a review of the Aboriginal Family Birthing Program in South Australia, where women who accessed the Aboriginal specific programs were more likely to report a positive experience, and access the services

earlier in their pregnancy (Brown et al., 2016; Brown et al., 2015; Middleton et al., 2017).

In addition to the issues around access of antenatal care, results of studies have suggested that Aboriginal women have limited knowledge of positive health behaviours during pregnancy, such as, the risks associated with smoking during pregnancy and the need for good nutrition and health (Eades et al., 2012; Thrift, Nancarrow, & Bauman, 2011; Wood, France, Hunt, Eades, & Slack-Smith, 2008). When discussing these behaviours with pregnant Aboriginal women in clinical practice, the women explain poor health behaviours and missed antenatal appointments in terms of lack of money, lack of transport and a range of psychosocial issues. It is becoming clear that while education and health promotion are vitally important, the social, emotional and environmental factors are often so overwhelming that these issues need to be addressed first in order for these women to have the capacity to make other changes.

### 2.7 Conclusion

It has been found that stress and emotional distress during pregnancy can influence the birth weight of infants and duration of a pregnancy (Lobel et al., 2008). While pregnancy is a time of joy for many families, it is a time when the extra demands of pregnancy place enormous stress on women. Despite the fact that Aboriginal women are faced with the additional burden of generational stress, poverty, loss of cultural identity and support, there is currently no culturally sensitive measure that assesses stress or psychological distress in pregnant Aboriginal women. While clinicians and researchers alike are quick to identify the health behaviours that Aboriginal women engage in that contribute to poor birth outcomes, it appears that they have not addressed the problems. Despite excellent targeted antenatal programs,

the rates of women smoking during pregnancy and other negative health behaviours continues to negatively impact birth outcomes. In order to develop strategies to support women and improve birth outcomes it is important to identify the broader issues. Until this occurs, it is unlikely that the mortality and morbidity rates for Aboriginal women and infants will improve.

# **Chapter Three: Historical and Social Context**

# 3.1 Overview of Chapter

In order to understand the current physical and mental health status of
Indigenous Australians, it is important to have an understanding of the historical
context of Indigenous Australia. I have only provided a brief summary of this history
as more extensive descriptions can be seen in several other works, including
Broome's (1994) book describing Aboriginal culture and history, and Dudgeon,
Wright, Paradies, Garvey, and Walker (2010) work exploring the social, cultural and
historical context of Aboriginal and Torres Strait Islander People, to name just two.
The impact of colonisation is explored with a particular focus on the physical and
mental health of Aboriginal women and the current statistics for Indigenous maternal
and infant morbidity and mortality.

### 3.2 A Brief History of Colonisation

Most Australian history has focussed on the years post colonisation, yet there is a rich oral history within Indigenous peoples, that goes back up to 70,000 years (Collard, 2000). A significant amount of this history has not been recorded, with certain cultural knowledge only being shared with particular members of the community. Over the last 20 years, some attempts have been made to record some of the earlier oral history. Prior to colonisation, Indigenous peoples lived a huntergatherer lifestyle within complex kinship relationships. There were up to 500 clan groups, each with their own language, cultural practices and geographical region (Bourke, 1993). While there are reported differences in the social organisation of different clans or groups, there are some human universals that provide some insight into the lives of pre-colonial Aboriginal people. Aboriginal people lived in families,

and competed for limited resources with other clans (Moore, Pybus, Rolls, & Molow, 2017). The health of Aboriginal people was varied depending on geographical location, however it has been suggested that the men often experienced better health than women and children, due to cultural taboos relating to particular foods and women's' menstrual cycles. In contrast to the myths that portray traditional Aboriginal societies as peaceful, mobile populations, mobility was often determined by the climatic conditions. The Law was relatively stable within a group, but land custodianship protocols varied between clan groups, with border disputes and defence of land occurring (Moore et al., 2017).

With the arrival of the British first fleet in 1788, settlements were established over the continent. As land was developed for agriculture and grazing, the traditional lands of the Indigenous people were reduced. This led to a significant loss of hunting grounds and negatively impacted on the spiritual life and social-cultural structure of Indigenous peoples (Sherwood & Edwards, 2006). The arrival of the British also introduced previously unknown diseases and the population of Indigenous people decreased dramatically (Aboriginal and Torres Strait Islander Commission (ATSIC), 1998; Gracey & King, 2009).

On arrival, the British declared that Australia was "Terra Nullius", land belonging to no one, which was the beginning of a series of policies and laws that resulted in the ongoing dispossession of lands and the destruction of Indigenous culture and language. Separate cultural groups were either shot or removed from their traditional lands and relocated, often great distances from their homes (Collard, 2000). It was decided by public servants and administrators that Indigenous people were incapable of managing their own lives and a series of policies were introduced

that allowed mission managers and police to take control over all aspects of an individual's life (Walker, 1993; Wilkie, 1997).

The Swan River Colony, what we know as Western Australia, was proclaimed in 1829 and the Aboriginal people were granted 'Protection of Law' (Hunter, 2001). As the colony expanded, Aboriginal people were treated increasingly poorly, and with the introduction of diseases such as measles and influenza, the population reduced significantly. This decline in population reinforced to the colonisers, what Darwin's theory of evolution had suggested, that Aboriginal people were at the inferior end of the evolution of human beings and that once they were in contact with more civilized people, they would soon die out (Hunter, 2001). This prompted the introduction of Protection Acts to protect the welfare of Aboriginal people in Western Australia. These policies provided basic medical care, blankets, and clothing for sick Aboriginal people and education for children but also resulted in segregation of Aboriginal people. The conditions and treatment of Aboriginal people did not improve so a Royal Commission was called in 1904 and headed up by Dr W. E. Roth (Hunter, 2001). Following this commission, the 1905 Aborigines Act was enacted, replacing the previous Protection Acts.

The 1905 Aborigines Act was in effect, a policy of segregation and isolation that controlled every aspect of an Aboriginal person's life (Wilkie, 1997). While this legislation was an official form of Aboriginal oppression, it must be acknowledged that prior to this legislation, wide spread massacres occurred throughout Australia. The Western Australian 1905 Aborigines Act provided the Chief Protector of Aborigines with legal guardianship over all Aboriginal people and the right to make decisions regarding the removal of children from their families to be placed in institutions, determine who could marry, where people could live and to prohibit the

speaking of any Aboriginal languages. These policies "attempted over time to displace, 'protect', disperse, convert and eventually assimilate..." Aboriginal people (Dudgeon, Wright, et al., 2010, p. 30).

The Act was amended in 1936 and was known as the Native Administration Act 1905-1936. This Act identified Aboriginal people as 'natives' and its primary function was for "further protection and care" (Hunter, 2001, p. 74). The 1936 Act continued to stipulate that all Aboriginal children were "wards of the state" and that the terms of guardianship were extended from 16 to 21 years, irrespective of whether the child had living parents or other living relatives (Hunter, 2001). The restrictions continued under this legislation and Aboriginal people did not have the right to vote and were disqualified from receiving any welfare benefits that were available to any other Australian. Despite the availability of exemption certificates for some Aboriginal people, claims for social security were denied "on the basis that the claimants were not sufficiently advanced to receive the pension" (Hunter, 2001, p.76).

Post World War II, the Western Australian Government enacted the Native (Citizenship Rights) Act 1944. Aboriginal people who were granted this citizenship were no longer subject to the Native Administration Act, on the condition that they sever all "tribal and native associations" (Hunter, 2001, p. 77); this included no longer speaking their traditional language, participating in cultural customs and traditions and 'adopting the manner and habits of civilised life" (p.77). Despite this citizenship offering the rights and privileges of any white Australian, these certificates were revoked or suspended at any time.

During the 1950s and early 1960s there were moves to slowly liberalise the laws and regulations pertaining to Aboriginal people. Changes were made to the

Social Services Act that allowed most Aboriginal people access to benefits or pensions. In 1967 the Commonwealth Referendum was a significant event in Aboriginal history as for the first time, Aboriginal and Torres Strait Islander people were granted full citizenship rights. However it wasn't until July 1971 when the Native (Citizenship Rights) Act was finally repealed that all Aboriginal people could enjoy, in theory, full citizenship rights and full equality (Hunter, 2001).

### 3.3 Stolen Generation

An important aspect of early Government policy that needs to be discussed separately are the policies that provided non-Indigenous Government officials the legal right to remove children from their Aboriginal families and place them into care. It is estimated that over 50,000 Indigenous children were removed from their families between the years of 1909 and 1970, while some considered this number to be excessive, Read (2014) believed that it could have been significantly higher.

Under different pieces of Western Australian legislation (each state was subject to different legislation) including; The Industrial Schools Act, 1874, and later the Aborigines Protection Act, 1905, the Chief Protector had extensive power as the legal guardian of all Aboriginal children under the age of 16 years, irrespective of whether the child was living with their parents or extended family. The implications of these policies were far-reaching, infants and young children were removed from their families to live in institutions or later, into white families. The type of placement was often determined by the colour of the child's skin, with families trying to darken their children's skin to avoid removal (Wilkie, 1997). The children with lighter skin were considered more likely to be assimilated into the European culture/community and were sent to live with white families, whereas darker skinned children were sent to group homes and institutions (Wilkie, 1997). Generally the

children were moved considerable distances from their country of origin, with the documented purpose to make reunification between families impossible (Wilkie, 1997).

The National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families (NISATSIC) was established to investigate these early practices and to also explore the ongoing issues relating to more contemporary practices of the separation of Indigenous children from their families (Cunneen & Libesman, 2000; Wilkie, 1997). The main findings of the Inquiry reported that the government early policies constituted genocide and that the main components of the forced removal involved a "...deprivation of liberty; deprivation of parental rights; abuses of power; breach of guardianship duties; and violation of human rights" (Cunneen & Libesman, 2000, p. 100). While these policies are no longer the guiding legislation for Indigenous health and welfare, the rates of Indigenous children removed from their families continues to be significantly higher than in the non-Indigenous population. In Australia in 2004-2005, it was reported that 39 per 10,000 of non-Indigenous children were in out-of-home care, compared to 265 per 10,000 Indigenous children (Tilbury & Thoburn, 2008). These disproportionate rates have been noted over many decades and are presented as evidence of the ongoing experiences of separation of Indigenous children from their families in modern Australia (Cunneen & Libesman, 2000; Tilbury & Thoburn, 2008; Wilkie, 1997). The NISATSIC noted the importance of not pathologising later generations of Indigenous parents, but acknowledge the transgenerational effects of having been removed as a child (Cunneen & Libesman, 2000; Dodson, 2009). Petchkovsky and San Roque (2002) conducted in depth mental health assessments of a sample of adults who were a part of the Stolen Generation as a part of the

NISATSIC and identified that in addition to significant increased prevalence of mental health disorders including Post Traumatic Stress Disorder, anxiety and depressive disorders, the adults interviewed described difficulty in establishing and maintain relationships and had difficult attachment relationships with their own children.

This early history has been compounded over the generations with ongoing trauma and grief being experienced by children and adults alike. Atkinson, Nelson, and Atkinson (2010) provide a summary developed by Blanco, of the generations of trauma experienced by Indigenous people of South America, which parallels the experiences of Australian Indigenous peoples. Fundamental to these experiences are the early policies that allowed Indigenous children to be removed from their families, the subsequent loss of cultural knowledge, language and family kinship systems (Atkinson et al., 2010).

# 3.4 Impact of Colonisation on Health

Australia was colonised by the British from 1788. When we consider how colonisation has impacted, and continues to impact, on the health of Aboriginal people, it is important to be clear on what was involved with the colonisation of this country. This has been explored briefly in the previous section, however the ongoing health and social implications can best be understood not only within the context of the events that have shaped this history, but the history of other Indigenous peoples who have also experienced colonisation.

There are similarities across nations that highlight the direct relationship between early colonisation and current poor health status. The Australian Aboriginal population was nearly wiped out through introduced infections in the 18<sup>th</sup> and early 19<sup>th</sup> centuries, as were the Maori people of New Zealand, native Hawaiians, native

Indians and the First Nations of Canada (Durie, 2003). Small pox, measles, typhoid fever and tuberculosis were some of the diseases that were previously unknown to these people (Durie, 2003). With the expansion of the British Empire in Australia, there was a loss of traditional lands, which impacted Aboriginal people through loss of traditional hunting grounds. These lands were gained through sustained warfare, which included strategies of stolen land, stolen women, stolen food sources and widespread massacres (Owen, 2016). This impacted on food sources leading to a reliance on 'rations' provided by white settlers, and also impacted on housing, family relationships, and economic trade links within different nations and peoples (Sherwood & Edwards, 2006). These impacts were also seen in Canada, where the loss of traditional lands has contributed to communities being relegated to reserve communities (Smye & Browne, 2002).

While treaties were signed between the Indigenous people and the colonisers in some countries, there was no treaty signed between the British and the Australian Aboriginal people (Smye & Browne, 2002). This lack of a treaty has highlighted the fundamental worldview clash between the British and the Aboriginal people. The inability for the colonisers to understand the implication of the loss of land and culture, and even today for the legal system to not fully appreciate Aboriginal land custodianship, has led to ongoing conflict, dispossession and oppression of Aboriginal people (Moreton-Robinson, 2005). Government policies saw the enforced erosion of language and cultural traditions that have further led to a loss of identity and community cohesion that has impacted on the mental, physical and spiritual health of Indigenous people (Durie, 2003; Moreton-Robinson, 2003; Sherwood & Edwards, 2006; Smye & Browne, 2002). Australian Aboriginal people are not the only Indigenous people who have experienced the devastating consequences of

colonisation, however, when compared to other Indigenous groups on certain health measures, such as life expectancy, they continue to experience poorer health (Ring & Brown, 2002; Shepherd, Li, & Zubrick, 2012).

### 3.5 Current Health Status of Australian Indigenous Peoples

The current social and health context of the lives of Aboriginal and Torres

Strait Islander people in Australia is a reflection of the history they have experienced.

Despite large Government investment into 'Closing the Gap', a government initiative that determined targets to be met in order to improve the health, education and employment opportunities and outcomes in the Indigenous communities (Council of Australian Governments (COAG), 2008), there are still significant disparities that are not meeting the targets (Commonwealth of Australia, 2016).

### 3.5.1 Infant mortality and morbidity.

It has been reported that infant mortality rates are on track for meeting the target set out by the Council of Australian Governments (COAG) (2008). In the 2016 report, it was stated that there was a decline in the Indigenous child mortality rate of 33%, and the infant mortality rates have decreased from 13.5% in 1998, to 6.4% in 2014, however, there remains an unsatisfactory level of disparity between Indigenous and non-Indigenous infant mortality rates. The mortality rate for Indigenous infants was 1.7 times the non-Indigenous rate (6.2 per 1,000 live births compared with 3.7 per 1,000 live births)(Australian Health Minister's Advisory Council (AHMAC), 2015). Interestingly, in the report to the Prime Minister, it was stated that the proportion of babies born of low birth weight remained stable at around 12%, twice the rate for non-Indigenous babies (see figure 1). These figures have again been attributed to maternal smoking during pregnancy (Commonwealth of Australia,

2016). The commitment to continue to work towards reducing this disparity has to date focussed on the delivery of antenatal services and postnatal interventions.

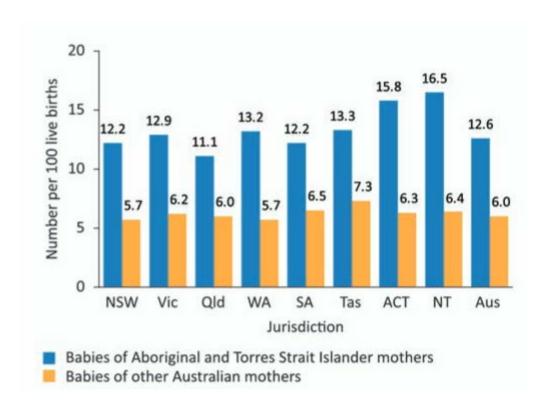


Figure 1 Low birthweight babies per 100 live births, by Indigenous status of mother and state/territory of residence, 2011. Adapted from "AIHW/NPESU analysis of 2011 National Perinatal Data Collection 2016 report" by AIHW, 2016. Australia's mothers and babies 2014-in brief. (Perinatal statistics series no. 32. Cat. No PER 87. Copyright 2016 by Australian Institute of Health and Welfare. Reproduced with permission.

### 3.5.2 Other health outcomes.

The Aboriginal and Torres Strait Islander Health Performance Framework, 2014 Report, which was published in 2015 (Australian Health Minister's Advisory Council (AHMAC), 2015), provides a comprehensive overview of the current health status of Aboriginal and Torres Strait Islander peoples. A detailed description of this report will not be provided here, however it is important to note that significant

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disparities in health outcomes are still evident. Indigenous people were admitted to hospital for a variety of health issues at greater rates in every state of Australia (other than Tasmania) than their non-Indigenous counterparts (AHMAC, 2015). In 2012-13 nearly half of all Indigenous Australian adults experienced a level of disability or had a long-term health condition that significantly impacted on their quality of life (AHMAC, 2015). There has been a slight improvement in the life expectancy of Indigenous people, yet it remains that Indigenous males are expected to reach the age of 69.1 years, compared to 79.7 years of age of non-Indigenous males. Likewise for females, 73.7 years for Indigenous women compared to 83.1 years for non-Indigenous women (AHMAC, 2015).

In the area of chronic disease and cancer, the picture appears to be deteriorating instead of improving. Cancer rates are increasing in the Indigenous community (11%) which is concerning when the cancer rates for non-Indigenous people has decreased over the same timeframe by 5%. Diabetes continues to be a major health issue, with 11% of Indigenous adults having diabetes, at 3 times the rate of non-Indigenous people. The impact of diabetes is also felt in the experience of chronic kidney disease, where it has been reported that end stage renal disease is identified within the Indigenous community 7 times the rate for non-Indigenous Australians (AHMAC, 2015).

These are just a few of the statistics that highlight the disparity of health outcomes between Indigenous and non-Indigenous Australians. While I have highlighted some of the factors in terms of the experience of colonisation, it is important to also consider the psychological health of Aboriginal women.

# 3.5.3 Mental health and Aboriginal women.

The research involving the examination of the mental health issues experienced by Aboriginal women has often been limited to women within the justice system and those dealing with drug and alcohol-related difficulties (Butler, Allnutt, Kariminia, & Cain, 2007). There has been a belief that Aboriginal men are struggling with drugs, alcohol and major mental illnesses related to loss of identity and culture; yet the women do not have time to become unwell as they are looking after the families (Vicary & Bishop, 2005). This belief has led to a socially invisible group of women who are raising families, maintaining the family home and enduring violence, poverty and distress without any support or even acknowledgement. While it is suggested that these types of environments are detrimental to the social and emotional well-being of children and families, there are also risks to the mental health of pregnant women, especially in terms of continued stressors.

Cunningham and Paradies (2012) analysed national survey data to identify the socio-demographic factors and psychological distress in both Indigenous and non-Indigenous adults in Australia. While the findings from this study were not reported by gender, it was found that very high psychological distress (VHPD) was more commonly reported by Indigenous than non-Indigenous Australians. The emotional distress was also associated with the traditional indicators of financial and social disadvantage, including education, employment, income and home ownership (Cunningham & Paradies, 2012). As with other areas of research with Indigenous peoples, the challenge of finding an appropriate measure to assess psychological distress was noted by the authors. In this particular research a modified version of the Kessler 10 Psychological Distress Scale (K10) was used.

### 3.5.4 Aboriginal views of mental health.

Although there is limited research specifically examining the mental health of Aboriginal women, there has been interest in mental health and mental health service provision within an appropriate Aboriginal cultural framework in recent years (Brown, 2001). Vicary and Westerman (2004) highlighted the importance of exploring how mental health is conceptualised by Aboriginal people. Aboriginal people view health and well-being within a holistic framework which involves the relationships between the land, family and culture, intertwined with spirituality (Garvey, Towney, McPhee, Little, & Kerridge, 2004). These beliefs influence the attributions of the causes and experiences of symptoms that a woman may experience, which may or may not fit into the Western understanding of depression or stress. This suggests that appropriate diagnosis and treatment may be dependent upon the cultural understanding and explanation given to the illness or experience by the Aboriginal people themselves (Kotz et al., 2016; Vicary & Westerman, 2004). This cultural understanding and explanation of an illness has been described by Kleinman (1978) as an explanatory model. The development of an explanatory model as a method of inquiry is dependent on meaningful engagement between the researchers and the Aboriginal community. By using this approach, researchers can attempt to address the imbalance of the dominant cultural view and give voice to the experiences of Aboriginal people. Ypinazar, Margolis, Haswell-Elkins, and Tsey (2007) conducted a meta-synthesis of peer-reviewed qualitative empirical research to identify what is currently known about Aboriginal Australian's understanding of mental health. While mental health during pregnancy was not specifically explored, dominant themes that emerged from the literature included culture and spirituality, family and kinships and historical, social and economic factors.

Other than a translated version of the EPDS (Campbell et al., 2008) and the KMMS (Marley et al., 2017), there has been no exploration of stress or emotional distress during pregnancy from an Aboriginal woman's perspective. This has significant implications when working with Aboriginal clients. When conducting a thorough assessment of a client, in either a clinical or research setting, it is important to select an instrument that is appropriate for the client and that it is administered and interpreted accurately (Australian Psychological Society (APS), 2007). There are very few psychological measures assessing mental health available in Australia that have been developed with an Aboriginal population. The results of assessments are meaningless unless the cultural meanings of language and the unique attributions or beliefs around symptoms are integrated and understood (Westermeyer & Janca, 1997).

### 3.6 Social Determinants of Health

Australia is a wealthy country where the majority of the population enjoy excellent health care, when compared to many other countries, and enjoy a life expectancy that is listed as the 6<sup>th</sup> highest in the Commonwealth (OECD, 2016). Despite this apparent wealth, Australian Indigenous people experience significantly poorer health outcomes. This disparity, between Indigenous and non-Indigenous people is seen across the world and has led to an important area of research into the understanding of the intricate balance between the social environment and health (World Health Organisation (WHO), 2003).

There has been a particularly strong focus on the relationship between a person's socio-economic status (SES) and their experienced health outcomes (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010; Thrift et al., 2011). When operationalising SES, it is often described as the economic factors including

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education, employment and income that constitute what is known as the social gradient (World Health Organisation (WHO), 2003). Those people within our community who are the most vulnerable to unemployment, poor educational outcomes, and economic hardship are not surprisingly those who also experience the poorest health outcomes (Marmot, 2011). Shepherd et al. (2012) pose another viewpoint regarding social gradient and suggest that based on their review of the literature in this area, there is a lack of research that examines the relationship between SES and health in Indigenous people. They found that there was less consistent patterning of SES and health and suggest that the "unique historical circumstances, social and cultural characteristics, and profound and persistent marginalisation of Indigenous populations in Australia" (Shepherd et al., 2012, p. 115) offered another interpretation for the inconsistent social gradient they identified in the research they reviewed.

WHO's (2003) social determinants of health publication accepts the importance of social gradient as one of social determinants of health, in addition to early life experiences, the experience of stress, social exclusion, opportunities for employment, the type of work we do, social support, addiction, food resources and availability and transport. While some of these facets of life are sensitive to levels of SES experienced by individuals and communities, they also incorporate other factors that have an important role in what leads to people experiencing poor health.

Shepherd et al. (2012) included recommendations for further research on identifying potential mediating factors that may assist researchers to understand the social gradient and health. One potential mediating factor identified was the high levels of stress experienced by Aboriginal people (Shepherd et al., 2012).

### 3.6.1 Stress as a determinant of health.

The impact of stress on pregnancy and infant outcomes has been described in chapter two. The experience of stress, while detrimental in pregnancy, has also been included as an important determinant of health (WHO, 2012). The physiological responses to stress include a cascade of changes in the nervous system, cardiovascular system, endocrine system and immune systems. In the short term, these responses are adaptive and allow energy to be utilised in order for the individual to respond to the particular stressor (Scheiderman, Ironson, & Siegel, 2005). This response can become maladaptive however, when stress is experienced on a chronic basis. Exposure to long term elevated stress hormones have been shown to increase the risk of cardiovascular disease, susceptibility to infections, diabetes, depression and other mental health difficulties (DeLongis et al., 1988; Scheiderman et al., 2005; World Health Organisation (WHO), 2003).

Another important consideration when exploring stress as a determinant of health, are the coping strategies people employ as a result of chronic high levels of stress. There are clear links that identify stress as a barrier to changing behaviour, for example engaging in health behaviours (McKenzie & Harris, 2013) and a relationship between behaviours such as smoking, alcohol and drug taking that are often utilised as a maladaptive coping strategy in response to high levels of stress.

### 3.7 Conclusion

The areas of Indigenous physical and mental health are both complicated and challenging. There are a multitude of facets that need to be considered in order to even attempt to understand firstly, how we have arrived at the current health status of Indigenous Australians and secondly, where we start to improve the health outcomes experienced by Indigenous Australians. We cannot ignore the role our troubled

history has had in creating the social and health problems of today. However, it is equally important that we do not ignore the unique cultural and social perspectives in order to better understand how to move forward in this highly contested arena (Garvey, 2015). Some of the background that has played a part in how this research has developed has been described in chapter two. As mentioned earlier, while it is discussed as a past historical perspective, this is not history to most Indigenous people, this is their day to day lived experience of life in Australia. This history must be held in mind while reading the following chapters of this thesis.

# **Chapter Four: Rationale**

### 4.1 Introduction

The previous two chapters have outlined some of the social and health issues faced by Aboriginal women today. As has been outlined there are gaps in our current understanding of these issues and a need for quality research to be conducted to begin to identify and develop solutions. This chapter will include the rationale and explanation for the choices made in the early stages of this project, including why this research is important, why this particular methodology was selected and some of the key processes involved in this type of research.

# 4.2 Rationale and Significance of the Study

Research in the area of Indigenous women's birth outcomes in Australia has, to this date, been focused on the health behaviours of these women without taking into account the impact of stress. This positivist approach to health research has failed to take into account the social context of Indigenous women and the complex relationship of Australia's history and current health status of Indigenous peoples. Given the known relationship between poor birth outcomes and stress, and the acknowledgement of the chronic high levels of stress experienced by Indigenous women, there would be advantages in health professionals being able to identify those women who are experiencing high levels of stress during pregnancy in order to offer support or psychological interventions in addition to the current targeted programs available.

Screening tools are ideally quick and easy to administer, low cost to the practitioner and sensitive enough to discriminate between those experiencing the phenomena measured and those who are not. In Australia, pregnant and postpartum women are currently screened using the EDPS (Austin, Highet, & The Guidelines

Expert Advisory Committee, 2011) a screening tool which identifies women at increased risk of antenatal/postnatal depression and anxiety. The use of this screening tool is considered best practice and is a part of routine antenatal and postnatal care offered to all women in Australia, however it is primarily designed to screen for anxiety and depressive symptoms and as not been validated in an Aboriginal population. This study aims to explore the experience of stress from an Aboriginal women's perspective in order to determine whether a screening tool could be developed. Ideally this screening tool would also be administered to Indigenous women during pregnancy to identify those women experiencing high levels of stress that may potentially negatively impact on the pregnancy/ birth outcomes.

### 4.3 Research Design and Methodology Overview

An important aspect of research within an Indigenous context is the utilisation of decolonising methodology. As described earlier, the Indigenous people of Australia have been subject to ongoing colonisation by the dominant western culture. Psychological research in the past has perpetuated this colonisation through the adoption of Western approaches and methodologies that have maintained the power imbalance and effectively discounted Indigenous knowledge and ways of knowing (Bainbridge et al., 2015; Zavala, 2013). The use of decolonising methodologies ensures that the research is conducted in a respectful way that incorporates Indigenous partnerships and values Indigenous culture.

My studies are based on an ecologically oriented approach to research labelled as "Substantive Theorizing" by Wicker (1989). It is based on social constructionism and uses qualitative methods to generate theories. It is an in-depth study of individual's perceptions of their lived experiences where participants have been selected through a variety of sampling strategies (purposive, opportunistic and

snowballing). A key component of this research is the process of engagement with the community and the need for culturally safe and respectful methodology. This process will be described in both the study design and the procedure sections.

### 4.3.1 Social constructionism.

Before I describe the nuances of substantive theorising, it is important to explicitly explain the philosophical underpinning from a social constructionism perspective. In contrast to the experimental approaches to psychological research that have been dominant in Western psychology, social constructionism, as described by Gergen and others, is primarily concerned with the idea that, the way in which we see and understand the world, is socially constructed (Burr, 2003; Gergen, 1985). Our 'knowledge' or 'reality' is based on historical and cultural experiences that influence the way we communicate and make sense of our world. From this perspective, there is not necessarily a universal truth, but an attempt to explore and understand the phenomenon by being open to alternative explanations through the consideration of the "social, moral, political, and economical institutions that sustain and are supported by current assumptions about human activity" (Gergen, 1985, p. 267-268).

### 4.3.2 Substantive theorizing.

Substantive theorizing (Wicker, 1989) is an approach based on the premise that throughout the process of conducting research, the researcher makes a number of choices that ultimately determines the final outcome. Wicker (1989) describes research as consisting of three facets, which are awarded different levels of importance or weighting depending on the phenomenon being examined. These facets include the conceptual domain, the substantive domain and the methodological domain (Wicker, 1989). Researchers have often developed research questions based

on a theoretical concept that then guides the methodology and design and finally the substantive area that is evaluated. The research path taken in this research has weighted the substantive domain as the first step, followed by the conceptual domain which then informs the methodology. The advantage of substantive theorizing is that it is well grounded in the context of the phenomenon that is being explored (Wicker, 1989). This is particularly relevant to this research as the research question emerged from the substantive domain, that is, the Nyoongar women in the community identified the area of mental health that they believed needed to be explored and better understood.

### 4.3.2.1 Substantive Domain.

My original idea for a research topic was to explore depression from the perspective of Nyoongar women after working as a Midwife and Community Nurse in the Armadale area for many years. I had observed the struggles and obstacles that Aboriginal women faced, which impacted on all areas of health; of the individual women, their families and the wider community. Wicker (1989) suggested that when identifying the appropriate research path, one of the primary considerations is the social significance of the area researched. After a series of informal conversations with Aboriginal staff and women, it became apparent that the experiences of these women were far more complex and far reaching than depression alone. The Aboriginal health workers who worked for a local health service were very clear those Aboriginal women's lives were extremely stressful and that this stress was having negative consequences on the health of the women, their children and how the Nyoongar families and community functioned.

# 4.3.2.2 Conceptual Domain.

The next step in this path was the conceptual domain. The gaps identified and described within the literature review, when combined with the substantive knowledge gained from the community, provided direction in what was to be researched and how this research needed to be conducted. It has been said that Indigenous people are the most researched in the world (Smith, 1999). The outcomes of this research have not always benefitted the community and have at times caused harm, so in order to protect cultural integrity and knowledge, the National Health and Medical research Council (NH&MRC), in collaboration with Indigenous representatives have developed the "Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research" (NH&MRC, 2003). These guidelines formed a part of the conceptual domain that has underpinned the methodological approach taken.

# 4.3.3 Aboriginal women's reference group and Cultural Consultant.

One important strategy that has been identified to ensure that the cultural needs and values of Aboriginal people are respected during all stages of the research process is to ensure that the research is a cooperative and collaborative process between the researcher and the Indigenous community. Fielder, Roberts, and Abdullah (2000) provide recommendations of including a Reference Group or Steering group to guide the direction of research projects. This strategy involves identifying key community stakeholders and involving them in the early stages of the research development. While it is impossible to ensure that every individual in the community is represented, the aim is that these reference group members will be the voice of the community and work closely with the researcher to ensure that the

by Vicary and Bishop (2005) who identify this as an important first step in conducting cross cultural research.

In addition to the Women's Reference Group, a Cultural Consultant plays a pivotal role in ensuring that cross-cultural research is conducted in a respectful, and culturally appropriate way (Vicary & Westerman, 2004). The Cultural Consultant (CC) for this research was a Nyoongar woman, local community member and health professional working with Aboriginal families.

# **4.4 Summary**

The historical and political context has led to many safe-guards that have been recommended or mandated to ensure that researchers conduct high quality, ethical research that does not cause harm to the Indigenous community. The important focus of this research is to understand the experience of stress from an Aboriginal women's perspective which can only be explored within a model of engagement with the Aboriginal community. While the processes of this research and the methodology selected are instrumental in ensuring that this research abides by these guidelines set out by the NH&MRC, there is an important aspect of the research that cannot be discounted. It is naïve for a researcher to discount the very real influence they hold over all aspects of the research process. In the following chapter I will explore my own experiences and position within this research area and the importance of the development of meaningful relationships with the local Nyoongar community.

Chapter Five: Reflection Process: The Risk of Perpetuating the Impact of

Colonisation in my Research

#### 5.1 Introduction

When I reflect on the years that I have been working on this PhD research I feel an uncomfortable uncertainty about every aspect of this journey. I am a non-Indigenous 'white' middle class woman conducting research in Indigenous women's mental health. These details have become increasingly important as this research has progressed. I began this research with a somewhat naïve view of my position within this research field and an overly optimistic outlook on the impact this research could possibly have on the health outcomes of Aboriginal women. I had worked as a health professional providing clinical care to Indigenous families for many years and had worked closely with Aboriginal Health Workers. I had participated in the required Cultural Awareness training mandated by my employer and always believed that I had a reasonable understanding of Indigenous culture and the needs of Aboriginal people accessing the health system. When I reflect back on my early experiences, I realise, that relative to many of my peers and colleagues, this belief may have been partly true, however, the reality is that I entered this arena with limited understanding and a naïve desire to "do good". The desire to "do good" is a noble position to begin, as I would be devastated if my work was to "do harm", however the desire to do the right thing is a concept bound by cultural values and judgements (Rix, Barclay, & Wilson, 2014). History shows that the desire to do good was often a term used to justify the paternalistic and oppressive policies of past governments (Gray & Oprescu, 2016; Henry, Houston, & Mooney, 2004). These government policies have caused harm in the past, and continue today to do harm to Indigenous people. The

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essential problem is that as white researchers we do not have any point of reference to ground our behaviour. Are we doing good, or naively continuing a cultural approach that is a reformed version of oppression, but still an oppressive dominance, where the clients are still the objects we 'work' on.

These are some of the motives that have guided and at times tormented me during this research process. These are important issues to consider and the tensions around non-Indigenous researchers working in the area of Indigenous health research continue to challenge new researchers, Indigenous health professionals and the Indigenous community alike (Rix et al., 2014). In this chapter I will describe and explore some of the ongoing dilemmas and challenges I have faced as a non-Indigenous researcher in this field through reviewing my own journal reflections and actions throughout this process. There is an inherent tension in the fact that I am not from within the Indigenous culture; I am from the dominant cultural group that has a long history of colonisation in this country. This results in the biggest challenge for me as a researcher, which was how to avoid perpetuating the impact of colonisation through my own research practice and actions. In this chapter I have adopted a reflexive approach to explore and examine the sorts of issues and concerns that arose throughout this research process. I will describe particular events that have highlighted the tensions that exist between the notions of protection (of a vulnerable population) and paternalism and re-colonisation. My strategies to overcome these tensions and potential conflict through the long engagement process will be explored in an attempt to describe how non-Indigenous and Indigenous people can work together in an attempt to improve health outcomes of Indigenous Australians.

# 5.2 Reflexivity: Keeping the Research Real

One of the many challenges of conducting qualitative research is recognising the impact the researcher's position has on the research. This impact can be felt in all aspects of the research from the development of the research question, the recruitment of participants, interpretation of data and the reporting of the findings (Berger, 2013). To ensure that the voices of the participants are fairly represented it is vital that the researcher engage in an ongoing critical self-evaluation of their position within the research process and content. The aim of this chapter is to illustrate the reflexive position adopted. Reflexivity has been described as a continuous process of self-reflection and recognition of the researcher's position (Aronowitz, Deener, Keene, Schnittker, & Tach, 2015; Cuncliffe, 2004; Rix et al., 2014). This position can be based on the researcher's gender, cultural background, religious beliefs, to name just a few.

On reflection, I am a non-Indigenous woman, who had a previous relationship with some of these women as a midwife, and is now a psychologist/researcher. All of these 'parts' of me impacted on how I recruited my participants, how I conducted interviews, how the women responded to me, how I interpreted the data and how I have represented the women in this thesis. It is impossible to be completely bias-free and neutral within this area. I had expectations and despite my training and understanding of cross cultural issues, I am a part of this research. With this in mind, through supervision, conversations with Indigenous peers and colleagues, and the support of my Cultural Consultant, family and friends, I have met these many challenges. One important thing I have learnt from this experience is how valuable supervision is and even more importantly, how vital cultural supervision and support are in this area of research.

### 5.3 The 'Before the Research" Work

While traditionally a PhD begins with a research idea and candidacy, this research started informally years before while I was employed as midwife in the Southern Suburbs of Perth, Western Australia. I was providing outreach antenatal midwifery care to a group of women that traditionally did not access the mainstream hospital services readily. This is really when the story began. The importance of the process of engagement with the Aboriginal women in this area cannot be stated strongly enough. While this process is called 'engagement', what is important to recognise, is that this process is about forming meaningful, mutually respectful relationships. These meaningful relationships are a key component of de-colonising research (NH&MRC, 2003; Smith, 1999). True engagement is more than a token gesture of consulting with some Indigenous people. Ideally the research needs to be addressing a particular area of interest or need, as identified by the Indigenous community and conducted in ways that both meet the needs of the community and support the cultural values of the community (NH&MRC, 2003). In order to achieve these aspects, the community needs to be involved with the research, to be collaborative partners from the very beginning. In reality, this process is as important as the analysis and findings in this research, as it has been the parallel process that has shaped every aspect of the outcomes. The desire for engaging in decolonising research methodology is constantly challenged by the institutions (and processes) that are charged with the responsibility of ensuring that researchers do not inflict harm on perceived "vulnerable" people. This is also heard in the stories described by the participants, where the systems and institutions are often seen to be the barriers to the positive social and health outcomes that people deserve.

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Working alongside Aboriginal Health Workers and being invited to share in the lives of Aboriginal women during their pregnancy provided me with a unique perspective on the interaction between mainstream health services and the lived day to day experience of Aboriginal women. As a representative of the Health Service I was often called upon to listen to women's experiences of our health service, often negative, and to explain how these experiences occurred. I was asked to provide some education to a group of Aboriginal women who had volunteered to be support women to young pregnant women in the community through a Church initiated Women's program. When I arrived at the Community centre, prepared to teach a group of community women the importance of early Antenatal care, I was welcomed into a large group room with a white board at one end of the long table. All of the women sat at the other end of the table. I was struck by how symbolic this was, the non-Indigenous 'expert' standing at the front of the room in front of the whiteboard, telling a group of Aboriginal women how their pregnancies (and those of other women) should be managed. I felt uncomfortable with this and asked if it was OK if I sat on the spare chair in the middle of the group of women instead. I was welcomed into the group with some surprise, as I was not behaving in a way that was representative of a "white health professional".

The session I had prepared was not presented on that day, my agenda was not the important aspect of that meeting. The morning became an opportunity for 'the health service' and the community to share experiences and ideas to better understand each other. I was asked to explain many aspects of what I would assume was 'routine' care that all women understood. I was asked to hear stories of each of these women's birth experiences at the hospital that I worked in, both good and bad. I learnt about women's expectations of pregnancy, which were different to mine,

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family structures and the role of the elder women in the community. Through these discussions we planned a tour of the hospital ward as the community women felt that if they were going to be encouraging young women to access the services, they needed to be familiar with them also. It was interesting to note that at the end of the meetings with these women, I was asked an important question, "we know you, but how do we know that others who work in the hospital are like you?". This highlighted both the importance of relationships, but also the mistrust that the community had of the hospital. I was unable to provide assurances that all of the staff were culturally sensitive and provided culturally safe care, however I felt that my role within the midwifery unit was changed from that point onwards, from midwife to advocate.

The relationship that developed with this group of women allowed me to participate in community activities and meet women away from the context of "midwife at the hospital". I believe that this made a considerable difference in how my role was accepted when I began my PhD research. As a midwife in the community I was provided with word of mouth referrals from Aunts and Grandmother's and was invited to visit women at their homes during their pregnancy. The working relationship that developed between myself and the Aboriginal Health Worker allowed us to work in the women's homes, often seeing several pregnant women in one visit. Boodjari Yorgas was the midwifery program that emerged from these activities. This program was an outreach service that was delivered by a midwife and Aboriginal health worker and was delivered in a more culturally appropriate way. By engaging with the older women and grandmothers in the community the number of Aboriginal women delivering at the local hospital

increased, the breast feeding rates increased and the relationship between the community and hospital greatly improved.

What this experience also allowed, was the experience of developing relationships with a group of women that I would not otherwise have known. I was granted access to women's lives and invited to share in the most personal of journeys with these families. This experience challenged all of my 'knowledge' of Aboriginal culture and my personal views of myself as an Australian woman and my place in this community that I share with Aboriginal people. This experience is as important as the findings of this research, as it has enabled me to 'hear' and 'see' these experiences of Aboriginal women more clearly, than had I just decided this was a good research project and pursued it. This awareness and foundational relationships before commencing my PhD made doing my PhD possible. It became possible and appropriate for me to pose my questions and engage the community, so while I did not 'collect data', the learning for me that took place prior to starting my PhD, allowed me to develop my research proposal and ethics applications with the input and guidance of the Aboriginal women. This was the beginning of this research, and in many ways the essence of the research. Much of the research process has been developed to protect Aboriginal people, but is still based in a non-Indigenous framework and viewpoint. The Aboriginal community have been instrumental in the development of this research idea and it has only been possible to conduct this research within the context of my relationship with the community. In this respect, I am as much a part of the research as the women I have interviewed and this must be considered when reading this thesis.

### 5.4 Wadjullah Researcher and Nyoongar Women

# 5.4.1 Ethical guidelines.

It has long been recognised that research being conducted in the area of Indigenous health is uniquely different than research being conducted in the general public. As a part of this recognition, the first ethical guidelines for conducting Indigenous health research were developed in 1991 (Humphrey, 2001; Stewart et al., 2006).

The current National Health and Medical Research Council (NH&MRC) guidelines for the ethical conduct of research with Indigenous people describes six values that should guide all aspects of the research process; from early exploration and relationship building to dissemination of research findings (NH&MRC, 2003). These values; Spirit and Integrity, Reciprocity, Equality, Respect, Survival and Protection, and responsibility have been developed with the history of Aboriginal and Torres Strait islanders in mind, and as an attempt to ensure that no research is conducted in this area without genuine Indigenous involvement and collaboration in order to prevent further disadvantage or harm. These guidelines are referred to explicitly by human research ethics committees in Australia and when submitting a research proposal for ethical consideration, if these Guidelines are not mentioned or acknowledged, approval is unlikely. In addition to seeking approval from the institution where the research is being developed, there is a requirement in health research to obtain approval from the ethics committee in the relevant state of Australia. In Western Australia, this is the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) (Wand & Eades, 2008). Again, an extra layer of approval is an attempt to maintain the quality and integrity of research conducted with Aboriginal and Torres Strait Islander peoples. This research entails

more that getting the necessary ethical approvals, it is also about a process of critical reflection about what 'Western' research means in this context. While there is acknowledgment in these guidelines about the cultural nuances that must be considered, the structures and processes are deeply embedded in Western ways of conducting business.

To add to the great deal of the confusion around conducting research in Indigenous health, is the ongoing commentary around the role of non-Indigenous researchers conducting research in this arena. Humphrey (2001) described Indigenous health and 'Western' research in terms of "Dirty Questions". Humphrey explores the history of western research and adds weight to the importance of culturally safe research guidelines. However, there is significant confusion and contradiction on who should be doing this research, and how it should be done. I recall a meeting with an Indigenous researcher in the very early stages of my PhD. I went to discuss my ideas with him and in some way, was hoping to gain a sense of permission from a research colleague. I asked him if it was acceptable for me (as a white woman) to conduct this research, and would it be better if an Indigenous woman were to do it. His response to me was that of course it would be ideal if an Indigenous woman were to do this research, however, he also reminded me that there was no Indigenous woman doing this research. He believed the importance of the research outweighed these issues, and reassured me that I "had a good story, sister" and "it is great that someone is wanting to do this research". This affirmation was powerful and I have recalled these conversations on many occasions when I felt I needed to 'defend' my position.

Part of the confusion in my mind, has come about from the debate around Indigenous methodologies and the history of 'Western research' continuing to

colonise and marginalise Indigenous people. I have been challenged from the very beginning about appropriate methodology and a particular construct called "Indigenous Terms of Reference" (Oxenham, 1999). The debate on who should be involved in this type of research was clearly addressed in some of these publications (Martin, 2008; Oxenham, 1999), where there was suggestion that there was not a role for the non-Indigenous researcher in this field. While I can respect the beliefs of these authors, I strongly believe that as much as non-Indigenous Australians have had a role to play in the creation of the challenges and issues faced by Indigenous people, I feel that we all have a role in the search for and implementation of solutions. As a health professional, I have a duty of care to provide the most appropriate and effective care to all of my clients/patients, irrespective of cultural background. As a researcher (or scientist-practitioner), I believe my position as a non-Indigenous researcher is also important.

### **5.4.2** Ticking the boxes.

### 5.4.2.1 Community consultation.

Throughout the stages of this research I was mindful of the ethical considerations and the specific challenges cross-cultural research can present to both the researcher and the research participants alike. During the early proposal stages of the research, it was evident that the process of obtaining ethical approval within a "University PhD" environment, did not necessarily fit the time line required to really engage with the community I was hoping to work with, or the process required for that engagement. The ongoing dilemma was; how much collaboration and communication can I engage in within the community prior to having any ethics approval? Versus how can I submit an ethics application for a research project that I have not been able to develop with full consultation from the community? The ethics

process can be an arduous and at times a very time consuming process and in order to gain candidacy within the prescribed time frame there was an expectation that the research questions, hypotheses and methodology were developed to a level that the ethics committee could make a judgement about the research proposed. The ethics process is inherently based on Western knowledge and by the very nature of this knowledge, is colonising (Glass & Kaufert, 2007). In the recognition of the impact of colonisation on research practices and ultimately negative outcomes experienced by Indigenous people, the processes have become more prohibitive of the improved outcomes they were designed to try and promote.

To illustrate how ethics committees are not immune to perpetuating colonisation and racism, I am reminded of the request from the University Ethics committee to revise my participant information sheet, as they felt that it was not appropriate for the target audience. I was unsure what the difficulty was, so I presented the Information Sheet to the Aboriginal community and asked a number of women to read it and advise me how it should be worded. All of the women unanimously said it was fine and understandable, they suggested minor changes such as headings to break up the text and sign post important information. I resubmitted the information sheet to the ethics committee with no rewording, and stated that the Aboriginal community had been consulted and it was deemed as appropriate and it was subsequently approved. At the time, I interpreted the ethics committee's actions as being racist, in that, they believed the information sheet needed to be expressed in more simple terms or "dumbed down" in order for Aboriginal women to understand the content. I found this offensive and discussed this with my Cultural Consultant who expressed her frustration when government departments or organisations feel that all that was needed to make documents culturally appropriate was to include

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random pictures of kangaroos and Aboriginal art and write in very simple language. This highlighted to me, that while the guidelines and ethics processes were designed to minimize harm and to prevent on going colonisation, these systems are far from perfect. This realization has led me to consider my own position and to really appreciate that there should not be a 'one size fits all' approach to ethics (Glass & Kaufert, 2007).

I was in a unique position, in that I had worked within this community in another role as a health professional and in the early stages of thinking about further post-graduate studies, was able to think 'out loud' with my Aboriginal colleagues and be guided in my thinking around this future research. The NH&MRC guidelines suggest that the Aboriginal and Torres Strait Islander communities need to be partners in the research, and be actively involved in the research process. Developing these types of relationships takes time, to start from the very beginning is often more time than the 6-9 months recommended for a prospective PhD student to obtain candidacy allows. These constraints have been addressed by being advised to obtain ethics approval in stages. As the relationships develop and the project takes more shape, an amended proposal is submitted for subsequent approval. This approach may allay the fears of the researcher by providing some approval from the institution during those early stages of negotiation and relationship building, but can also prove to be time consuming and delay the progress of the research. These delays and obstacles can lead to more important considerations however, and that is the risk that researchers will feel the need to 'tick the boxes' to meet the ethics approval requirements, but in turn, spend less time in developing those vital relationships within the Aboriginal and Torre Strait Islander communities, or decide against conducting potentially valuable research in this arena entirely. The ethics committees want a degree of certainty with the ethics application, yet it is impossible to provide that level of certainty until adequate consultation has occurred within the community (Glass & Kaufert, 2007).

I spent many hours, days and weeks discussing my research ideas with my Aboriginal colleagues and previous clients prior to even applying to undertake a PhD. I was able to prepare my initial candidacy document and ethics application without formally having engaged the community, but with a substantial amount of time already invested in the community. As a part of the ethics process, as a health researcher in Indigenous health I was required to also obtain ethical approval from the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC). This additional requirement poses an interesting ethical situation. What does it mean when one HREC deems the research proposal to be safe and ethically sound, yet the second HREC imposes additional requirements that can mean that approval is delayed for a substantial amount of time (years in some cases) (McCloy, 2016). Once again, while I understand the importance and risk associated with health research, I am unsure that these processes, that are designed to protect the Indigenous community, really assist in ensuring the research is culturally appropriate and safe.

A part of the WAAHEC application process required me to obtain community support from an Indigenous health provider. This is often the stumbling block for many prospective researchers, particularly if they are new to working in this area. The Director of a government Aboriginal health program had been instrumental in developing the ideas and plans of this research and provided her unwavering support to this project and became my key Cultural Consultant and mentor. I had worked with this woman from many years in a variety of roles, at one

stage I was her line manager, in other roles we worked side by side visiting

Aboriginal women. As her career developed and she took a greater leadership role

we remained in close contact and a friendship had developed.

I had previously approached another Indigenous organisation to gain support for my application to WAAHEC. It was a difficult experience and despite numerous meetings and discussions about the proposed research, I was unable to present it to the Board of Directors of the organisation for approval. The CEO, or 'gatekeeper' of this organisation, while we shared some goals in respect to improving the outcomes for Aboriginal women in pregnancy, had an agenda that did not support the expressed needs of the community I had been consulting with. This highlighted another dilemma, that while the CEO was a Nyoongar woman, she was not necessarily representative of the Nyoongar community. While I was representing the concerns and goals of a particular group of women in the Southern suburbs of Perth, these concerns were not necessarily shared by the entire community

It was interesting to explore the barriers we encountered with the other Health Organisation and it became more apparent that there were politics and internal issues within the Nyoongar community that while seemingly unrelated to my research, were in reality representative of the complex contextual issues experienced within the Nyoongar community. These barriers were not unique to my research, and it had been explained to me, by my Cultural Consultant (CC) that conflict between Indigenous organisations was not uncommon. This conflict has become a theme throughout this project. It is not unexpected in many ways- when I consider the historical context of Aboriginal people. In order to gain acceptance in the Colonised state of Western Australia and to obtain 'Citizenship', Aboriginal people had to renounce family and friendships within the Nyoongar community, cease speaking in

language and refrain from engaging in traditional cultural practices (Chesterman & Galligan, 1997). This created such deep felt divisions and while this is no longer policy, the scars that remain have created great suspicion and mistrust both within the Nyoongar community and with the wider non-Indigenous community (Dudgeon, Garvey, & Pickett, 2000).

A particularly painful incident that can demonstrate this further occurred at a University conference, where I was presenting a paper on the "Meaningful application of the National Research Guidelines in developing culturally safe engagement of Aboriginal women in health research". An Aboriginal woman in the audience questioned my presentation on the basis that she did not know who my Cultural Consultant was and was not consulted about this research. I attempted to address her concerns at the time, however nothing I could say at that time was going to allay her concerns or diminish her anger. Unfortunately this was done in a very public forum and while this individual's anger was not really directed at me, I became the 'white' representative of Australian policy and history. The conference proceedings were halted, while the Indigenous members of the research group I was involved with, allowed this woman to express her concerns publically. What ensued was a debate and acknowledgement of the impact that colonisation has had on Aboriginal people, but as the recipient of the initial anger, it felt like I was seen as 'the enemy' and that I did not have any legitimate place in this research domain, as viewed by both this individual woman and the Indigenous researchers I had worked alongside for several years. This was the day I decided that I was not able to complete this research, and the only option I felt I had left was to quit!

On reflection, one of the main reasons this event was so distressing for me, was because I have felt confident that I have consulted with the key people within the

community I have been working with, and have always had the support and confidence of my Cultural Consultant and reference group, yet this does not stop others in the wider community feeling aggrieved at not also being included or feeling that they too should have been included. The NH&MRC recommend that health researchers 'consult with community' and stakeholders, however, this becomes problematic when the community is extremely diverse and it is impossible to consult with the entire community. My self-doubt has come from a real fear and awareness of the risk of a 'well-meaning' researcher inadvertently perpetuating harm through a lack of awareness or sensitivity of the power differential and ongoing impact of colonisation. When I felt like this was too difficult, or felt inadequate for the challenges it presented, my Cultural Consultant would remind me why we started the project, and for whom the project was for. She would remind me of the many pregnant women we had worked with and the potential this research had to make a difference to those specific women. She would also tell me to 'toughen up'! She has always challenged me not to let the doubts knock me down, because, as she constantly reminds me, she and the community she lives and works in, believe we are on the right track.

#### 5.4.3 White privilege.

This experience (and many others like it) are what Kowal describes as the stigma of white privilege (2011). Throughout this research I have been at times wracked with self-doubt, critical of my actions and intentions and seemingly stuck in the middle of two opposing factions- Indigenous Australians and non-Indigenous Australians. By virtue of my birth, I am born into a world of white privilege, yet I am a member of a group of individuals who hold an ideal that there is hope for a future where Indigenous peoples are "lifted out of disadvantage to participate fully in

Australian society, statistically equal to but culturally distinct from other Australians" (Kowal, 2011, p. 315), an ideal that Kowal describes as 'post-colonial justice'. I cannot escape my whiteness, nor ignore the fact that I benefit from the privilege that my whiteness brings, however, working in Indigenous health and research has exposed me to experiencing a form of stigma as a result of being 'white'.

White stigma has been described as a controversial concept, particularly when some authors suggest that stigma can only occur towards a group with less power than the dominant group (Link & Phelan, 2001). Kowal (2011) however likens white stigma to the concept of 'negative occidentalism' which refers to the way in which non-Western cultures portray negative stereotypes of western people and culture. In this example, my whiteness is seen as negative, it represents colonisation, oppression, and racism, characteristics that should be avoided. These views, or representations of White people are supported widely in the literature, where the suggestion is that the ongoing oppression experienced by Indigenous people is attributed to whiteness (Moreton-Robinson, 2005). As there is further discussion around perpetuating colonisation and 'doing harm' to Indigenous Australians by white people, the greater the fear and trepidation faced by the few that choose to embark on careers in this field. A colleague read some of my work and urged me to "stop being so apologetic" and to "own your claim" (P. Dzidic, personal communication, October 21, 2016). The fear of causing more harm is at the core of every action, and it is with some relief that I read the words of Atkinson regarding the 'White anti-racists' and realise that I am not alone with these fears (Kowal, 2011, 2012).

An example provided by Kowal in her 2012 paper was particularly close to my own experiences and reduced me to tears while reading it. I have realised now, several years since the incident, that the experience I described earlier where I was publicly shamed by an Aboriginal audience member was made all the more painful as I was left undefended by any of my Indigenous colleagues. At the time, although devastated and very emotional, I rationalised the actions of the Aboriginal woman (and my colleagues) in terms of historical events, the result of being oppressed and colonised, and that my experience was just a part of working in this very challenging area. Kowal proposes that white anti-racists desire approval and love from the Indigenous people we work with, because if we are loved, there is a belief that we are not doing any harm (Kowal, 2012). This belief comes from a sense of insecurity as a result of white stigma, which allows the white anti-racist to endure, rationalise and accept acts of humiliation and betrayal (Kowal, 2012). In hindsight, I do feel a strong need to be accepted and liked by the Aboriginal people I work with, both clients and colleagues alike. The complexities of being a non-Indigenous researcher/health professional in this area of health research continue to shape my experiences and understanding of my own position within this unique 'space' I have chosen to work in. I cannot denounce my whiteness, but can only acknowledge that I view the world through the filter of my own cultural lens.

## 5.5 My Own Cultural Lens

Another key purpose of the NH & MRC guidelines is to ensure that the research process is "not blind to difference" (NH&MRC, 2003, p. 11). The harm that has occurred in previous research, has often occurred when the researchers make judgements and decisions based on their own view of the world and their perception of how the participants conform to those world views (Garvey, Dudgeon, & Kearins,

2000; Porteus, 1973). This ethnocentrism is an insidious phenomenon, and is an innate part of all of us. By definition, ethnocentrism is the experience of viewing the world through our own cultural filter (Matsumoto, 2006).

As mentioned earlier, one of the biggest challenges as a non-Indigenous researcher in this area, was the fear that I would inadvertently perpetuate the harm that early researchers have caused by not recognising the impact ethnocentric views can have. Despite my years of working in Indigenous health, I came to an important realisation working with my Cultural Consultant about how powerful our own cultural filter can be. I had worked in Indigenous health for many years and had participated in training programs on cultural awareness, worked alongside Aboriginal Health workers extensively, yet it was only during this research process that I really understood what ethnocentrism was. I always believed that if I was respectful, listened to my clients and followed their lead, I would behave in a culturally appropriate way and not offend my clients. What I have realised, however, is that while I could acknowledge people's different experiences, histories and how those experiences impacted people's behaviour- I still maintained a fundamental view that as human beings, we all thought the same way. It was only when I spent more time with my Cultural Consultant and the other Aboriginal health workers during the first study, that I realised that in fact, my viewpoint of the world was directly a result of my western, white middle class upbringing, education and life experiences, which were completely different to the worldviews of the women I was working with.

An important area of difference that I have discovered is the understanding of what family means. I come from a European/Australian family background, where my parents and siblings are very important to me, but more so in certain aspects of my life. My extended family, grandparents, aunts, uncles and cousins, while I care

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about them, and we gather on important occasions to share in family experiences, are not overly involved in my adult life, or decisions I make regarding my own childrearing. Spending time with my Cultural Consultant offers me a glimpse into a different world. The relationships within her family, and the importance of these relationships are visible in every situation. With this, comes expectations of how family members behave and respond in situations. Where as in my family the responsibility may fall to my parents to act, in my Cultural Consultant's family, as an aunty or sister, the responsibility is no different to that of a parent, but often shared. The role of an aunty, is seen as equal to the role of the mother or grandmother and provides this vast network of caring adults who nurture children within the family. When I was asked if I would be an Aunty to my Cultural Consultant's children, it was an incredible honour to be treated with such respect and to be included into that special family system. My own daughter (even as an 18year old young woman), still refers to my Cultural Consultant as 'Aunty' and has been made to feel a part of that family group, and knows that should the need ever arise, 'Aunty' will be there.

Another aspect that struck me, was how different our roles are within our own community. As a midwife, or psychologist/researcher, I finish my day and head home to my family and friends. My job or career, as important as it is, is generally quite separate from my personal life and I can generally choose when I engage with work outside of my paid work hours. This is a very different experience when compared to all of the Aboriginal health workers and Aboriginal academics I have worked with. The expectations from the wider Aboriginal community are not restricted to the health worker's paid work hours and their cultural obligations and responsibilities continue well beyond their 'job'. I have witnessed the ongoing demands placed on my Cultural Consultant when visiting her family home. The

expectation from the wider community is that she is available to mediate conflict, provide support and advice to families and act as a resource person for any cultural issues within the community. This is not seen as an imposition, this is an accepted part of being an Aboriginal woman, and particularly when employed to provide health/support services to the Aboriginal community.

This realisation of how different our worldviews are struck me as really quite momentous. It has led to a re-evaluation of my relationships within the Aboriginal community, how I view this research, my interpretations of the data, and how I view myself. It has enabled me to take a more curious standpoint, rather than interpreting differences through my understanding of the world, it is an entirely new world that I am learning about. Yet, at the same time, I have felt a sense of shame, that despite my long career in this field, that I am really only truly understanding how blind I had been to the cultural differences at this late point. This has effectively shaken my world, and has irreversibly changed how I view it and the world that I share with people and other cultures.

# 5.6 Going 'Native': The Insider/Outsider Observer

Within the world of psychological research, as a non-Indigenous women researching within the Indigenous community I am considered an outsider observer (Merriam et al., 2001; Merton, 1972; Puch-Bouwman, 2014). This term is most commonly used in ethnographic anthropology, and while this research is not ethnographic nor anthropology, there are aspects of exploring the lived experiences that share similar underlying philosophies. I am not from the same cultural group, I do not hold the same belief systems and history and my worldviews are not necessarily the same as those of the women I am working with in this research. In some contexts this is seen as disadvantageous. There is the belief that insider

observers will be more readily accepted by the participants and better positioned to create an environment of trust due to issues of power, relationships and cultural conventions (Shah, 2004). This concept of insider and outsider observers is an interesting one to consider within the context of research conducted with Australian Indigenous people. Research guidelines highlight the importance of "insider observers" described by the NH & MRC (2003) as Cultural Consultants or local Indigenous researchers, leading and being actively involved with the research process. What I have found throughout this process is that there are many different ways to explore the lived experience of others and how the researcher positions themselves within the research has wide reaching implications in all aspects of the process.

The notion of positionality is described as a number of characteristics about the researcher, for example, the researcher's (or interviewer) "social location, personal experiences, and theoretical stance; the interpersonal and institutional contexts of the research; and the effect of these on the interview [research] process" (Sands, Bourjolly, & Roer-Strier, 2007, p. 355). When working in a cross-cultural space, characteristics such as gender, race, class and other factors that are relevant in the interaction between researcher and participant are also part of a myriad of factors that contribute to the sense of position. What is also important to consider is that a researcher's position is not static, it can and does shift as the context changes (Merriam et al., 2001).

While there are advantages to being an 'insider observer', as discussed earlier, there are also perceived disadvantages. Malinkowski introduced the phenomenon of what he described as the "imponderabilia of actual life" (Malinkowski, 1932, as cited in Vangkilde & Sausdal, 2016, p. 2). This

imponderabilia was described as the subtle peculiarities of an experience no longer being noticed, due to the familiarity of the surroundings, cultural practices or life. This has been described as a particular risk when researchers are insider observers, and involved in research in a setting that is close to the researcher. This concept of 'imponderabilia of actual life' illustrates some of my difficulties in conducting research in an environment that was in some ways familiar to me.

My position within the interviews (yarning) with the participants changed according to the level of familiarity between us and the context of the introduction to the participant. What I initially failed to consider was that I had worked in this community for many years. While the individual participants in Study 2 were not previously known to me, many of the health professionals in Study 1 were previously colleagues and associates from my previous career. The women that participated in study 2 were in effect, representative of the many women I have visited as a midwife and child health nurse over the years. The experiences of trauma, poverty, grief and joy were uniquely each woman's experiences, but they were also familiar and shared experiences of the women I had met and cared for previously.

I had not considered this to be an issue, in fact, this was seen as an enormous advantage in the process of gaining trust and engaging with the women. It was not until I was struggling with the analysis and sat with my supervisors in frustration and expressed my concerns that there wasn't really anything to say or talk about in the data. I was so disappointed and believed that everything that had emerged was just as I thought it would be, the experiences and stories reflected what I thought I knew and understood about the lives of the Aboriginal women in this area. I was caught by the 'imponderabilia of actual life', the data was so familiar, I was failing to see it as important. My supervisors read some of my transcripts and coded with me and were

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overwhelmed by the experiences of the women and commented on the richness and power of the women's words. One of my supervisors, an experienced social psychologist, remarked that I was finding it difficult to 'see' the data as I was so familiar with both the data and the lived experiences of these women. While I was not an Aboriginal woman researching Aboriginal women, there was a sense of familiarity and comfort in the community that had almost led to the 'imponderabilia' of the experiences of these women. The familiar was no longer seen as different to my own experiences, it was not seen as novel or interesting, I had become caught up in the day to day struggles of these women. Having assistance in coding enabled me to be challenged in my interpretations of the data, to stand back a little and reposition myself in this research. I believe this has strengthened this research, and has forever changed my perceptions of my role as a researcher and a woman in this context. I am now more aware of the privileged position I have been afforded by the women in this community which reinforces my sense of responsibility to do this research 'right', and to do justice to the experiences of these women.

This particular phenomenon has also been referred to as 'going native' (B. Bishop, personal communication, 2010). The experience of recognising that our own worldview is in fact a 'phenomenal world' as described by Kuhn's work (as cited in Tesch, 2001) is made apparent when there has been an encounter with a new way of seeing the world. Going native is where the researcher/observer starts actively taking part in the 'phenomenal world' or system of knowledge that are being studied. Tesch suggests that this should be an aim of this type of research, as this acculturation enables the researcher to "be as convinced of its [the knowledge system/phenomenal world being studied] validity as those who initiated him or her" (p. 314.) This position is criticised however, when there are suggestions that it is impossible to hold

two worldviews at once, however while recognising my own worldviews, there is an ability to recognise, acknowledge and in some sense, hold another world view also.

As described earlier with the idea of insider observers, it is impossible to believe that I became a part of the Aboriginal community that I was working with. I do believe that the familiarity and the relationships formed within the community have allowed me a position of privilege that has allowed certain insights into the worldviews of what was described by Tesch (2001), as an "alien system" (p.314), however I do not believe the Aboriginal women in any way saw me as a part of their community. I would like to think that my familiarity enabled me to engage in a genuine, sincere manner that provided the cultural safety for women to engage with me in a meaningful way and that these relationships formed the foundations for the research to develop.

## **5.7 Code Switching**

One final area that is extremely important in the process of this research is the concept of code-switching. In simple terms, code-switching is when a speaker alternates between two or more languages (McConvell & Meakins, 2005). This concept is where individuals may switch from speaking their first language, for example Indian, in some contexts, to then speaking English in others. It is also accepted that there are many dialects of English, for example Standard Australian English, Standard British English and Standard American English to name just a few. Eades (2013) describes another dialect known as Aboriginal English. While this dialect of English has been referred to as 'pigin english' linguists recognise this as a dialect in terms of 1. it is understood by speakers of other varieties of the same language and 2. it differs from Standard English in systemic ways (Eades, 2013).

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During my time working in health within the Indigenous health context, I have become more familiar with particular expressions and words that are commonly used by the Aboriginal community in describing family, health and general phrases. I had an experience during this research when I reflected on a conversation I had with a group of participants. I was driving home and was thinking about the conversation and realised (for the first time!) that my language changed when I was sitting with these women, from how I would normally speak. My first thoughts were around paternalism, and that I was being condescending by changing my language in these circumstances, however, I now understand that this was a form of code-switching.

When I reflected on my own code-switching I was concerned that I was using different language with the assumption that the women would not understand my 'normal' language. It was not until I attended a presentation by an Indigenous researcher who was exploring code switching in terms of health literacy that I realised what I had been doing for many years. I had picked up expressions and some Nyoongar words that had become part of my vocabulary and I was generally unaware that I was doing anything differently. Interestingly, I have recently had occasions when communicating with an Indigenous academic colleague, that I have been very cognisant of my use of Standard English and noted that she too used similar language. An example of the way in which this Aboriginal woman could code switch, was observed when she was communicating within the University context, and then reverted to Aboriginal English when describing a family interaction in general social conversation. I have no doubts that this ability has been fundamental in my ability to engage so positively with participants and community members throughout this process.

#### **5.8 Summary**

In this chapter I have attempted to explain and make sense of the personal processes involved in engaging with this research within the Aboriginal community. I realise that the more I learn, the less I am really sure of, and the greater my need for further learning. I feel particularly privileged that despite our cultural differences the women I have been working with continue to accept my involvement and are so willing and open to sharing their knowledge, experiences and lives with me.

As I reflect on this chapter, I realise that I am talking about the ability to form meaningful relationships within a framework of cultural competence, and the continual striving towards cultural proficiency (Ranzijn, McConnochie, & Nolan, 2009; Thackrah & Thompson, 2013). While guidelines can be developed in order to reduce the risk of harm and to encourage researchers to engage with the Indigenous communities, there is a great deal more to understand than what the NH&MRC can explain. I can't help but believe that there are some innate qualities and characteristics of a person that allows them to develop these types of relationships and work in this cross-cultural setting. I'm certain that many of these things can be learnt, but there needs to be a real desire and passion within someone to want to work in an area that has been so fraught with tensions and challenges. I believe that Non-Indigenous researchers can conduct good quality, culturally safe and appropriate research in Indigenous health research. What my experience has taught me, is that the importance of time and relationships cannot be understated. Without these solid relationships, the risk of perpetuating colonisation through ignorance and western worldviews is great and the potential harm that can be done is real and potentially devastating.

This process of reflexivity and positioning is the context in which the following two chapters need to be placed. These thoughts, reflections and realizations have directly influenced each aspect of the following studies and particularly the analysis and understanding of the participant's stories.

**Chapter Six: Study One** 

# **6.1 Chapter Overview**

Study One involved firstly establishing an Aboriginal Women's reference group and secondly meeting with Aboriginal health professionals who worked with pregnant and non-pregnant Aboriginal women in Perth. There were several aims of this study; firstly, to determine whether the research design and methodology, a) was appropriate to address the perceived needs of the community, b) was proposed to be undertaken in a culturally safe and respectful way, and c) whether the interviewees could anticipate any barriers or difficulties in engaging the community that hadn't been previously considered. The second main purpose was to establish my credibility as a researcher in order to gain support from the health professionals to 'vouch' for me in order to recruit potential participants from within the community.

## 6.2 Research Design

The research design of study one has been informed by both grounded theory and phenomenology. While there are some aspects of literature that guided this early study it was exploratory in nature. As described earlier in chapter four, the approach taken was described by Wicker (1989) as substantive theorizing, where the research methodology is guided and influenced by the substantive domain, conceptual domain and the methodological domain.

#### 6.3 Methodology

Study one was conducted in a two stage process, guided by the NH&MRC guidelines for Ethical Research in Aboriginal Communities as described earlier (NH&MRC, 2003). The first stage entailed the recruitment and formation of an Aboriginal Women's Reference Group and the second stage was a series of yarning interviews with Aboriginal women who worked in roles supporting pregnant

Aboriginal women in the community. As I was known to the community in a different role (previously as a midwife and community nurse) it was important to reestablish old relationships within the context of my new role as a researcher. This was important for many reasons, I firstly needed to prevent the risk of any dual-role conflicts developing when expectations from the community may have been different or beyond the scope of my current role. Secondly, I needed to establish my credibility as a researcher in order to earn support from the community to enable me to engage with women within the community to participate in this research.

# 6.3.1 Aboriginal women's reference group (WRG).

Based on my experience of over a decade of working in the Armadale community and my relationship with the local Aboriginal women, key Aboriginal professional women were identified and invited to participate in a reference group to guide this research. This process of engaging community women in the reference group was guided by the recommendations described by Fielder et al. (2000). The authors proposed that as a first step, key stakeholders for the research topic should be included in the research process. The women selected for the Women's Reference Group represented a number of organisations that provided services to the Nyoongar community, including the local government, a local representative from the Department for Child Protection, and local health service providers. In addition to organisational representatives, community women, who were identified by the Aboriginal professionals, were also invited to participate. An initial community meeting was held at a local community centre where participants were provided with information about the research team (including supervisors), some background information regarding health outcomes for Aboriginal women, a plan for the research and a preliminary plan for community dissemination of results (Appendix A). The

potential members of the Women's Reference Group were also provided with a copy of the NH&MRC guidelines for Ethical Research in Aboriginal Communities. The first meeting involved the negotiation of the role of both the Women's Reference Group and the researcher, and the responsibilities of both the Women's Reference Group and the researcher. The primary role and functions negotiated and agreed on by the women's reference group included, 1) to provide cultural guidance in the research processes, 2) assist in the advertising of the research and the recruitment of participants, and 3) ensure that the research was conducted according to the principles outlined in the NH&MRC guidelines for the ethical conduct of research in Indigenous communities. As the researcher, I agreed to conduct the research within the guidelines set out by these guidelines, and the requirements of Curtin University. As ethical clearance had been obtained prior to meeting with the Reference group, the proposal was presented and the group were invited to provide general feedback and specific feedback about how participants could be recruited and the most appropriate way to record the women's stories.

The women in the reference group all identified as Nyoongar women. The levels of education and training varied, with most participants having completed between 10 and 12 years of secondary education, and 2 members having completed post secondary education to diploma level. All women were between the age of 35 and 50 years of age. One key reference group member, agreed to take the role of Cultural Consultant for this research project. A Cultural Consultant is generally a respected member of the community who is selected (by the community) to represent and protect the cultural values and beliefs of the community by working collaboratively with the researcher (Vicary & Westerman, 2004). The busy schedules of the members of the Aboriginal Women's Reference group made it difficult to

meet on a regular basis as initially proposed. A confidential group was established via social media with some early success; however the most effective method of communication with the members was on an individual basis by phone and email. The reference group met on several occasions during the early phases of the research development and recruitment of participants, the frequency of meetings decreased over time which was understandable given the extended time frame of my PhD. Decisions regarding the research were made when a minimum of three members were available, an example of these decisions was on an occasion the recruitment strategy of placing flyers in community locations was not successful, individual members of the reference group provided instruction on appropriate ways to inform the wider Aboriginal community of the proposed research, through community activities and functions held at community locations.

## **6.3.2** Participants overview.

Participants were recruited from a range of areas within the Metropolitan Health Service area. Aboriginal and Torres Strait Islander people make up approximately 2.4% of the Australian population (Australian Institute of Health and Welfare (AIHW), 2012). Due to the small numbers of Aboriginal people within this area, minimal demographic information has been provided to ensure that the participant's identity remains confidential.

An important aspect of the sampling and recruitment of participants when working in an Indigenous research paradigm is the concept of 'vouching' (Vicary & Bishop, 2005). The 'vouching' process is the way in which a Non-Aboriginal worker (for example, health professional or researcher) is given a positive recommendation from someone who is respected and from within the community to the broader community. This informal system has arisen from a long history of

distrust between Aboriginal people and non-Aboriginal workers. Aboriginal people employ a variety of methods to gain information about a non-Aboriginal worker, including telephone calls, and discussions with family and friends in other regions (Vicary & Bishop, 2005). This "Nyoongar Grapevine" (D. Peate, personal communication) is a highly effective process and without a positive recommendation, Aboriginal clients and families can be reluctant to engage with NA workers.

## 6.3.2.1 Aboriginal Health Professionals.

A purposive sampling strategy was employed to recruit health professionals who provided direct services to pregnant Aboriginal women and who identified as being Aboriginal. Purposive sampling is a strategy that is often used when identifying members of the population of interest may be difficult (Langdridge & Hagger-Johnson, 2013). This has also been called snowball sampling, when one or more individuals are identified from the target population to participate in research and are then used as informants to identify further participants and so on (Langdridge & Hagger-Johnson, 2013). Initially one health professional (known to the researcher) was invited to participate, this participant then suggested other potential participants.

The health professionals (N=6) were employed by the public community child and adolescent community health service and were based in a variety of locations in the Perth Metropolitan area. In order to protect the anonymity of these women, limited demographic information will be reported here, as the population from which this sample was obtained is extremely small. The number of participants was determined by the availability of Aboriginal Health workers to meet with me. I was particularly interested in the views of the health workers working in the area of pregnancy and early childhood within the geographical area of the proposed

participants of study two. All participants identified as Nyoongar women, from a variety of different family groups. Most women were employed as Aboriginal Health Workers, other than one participant who was employed in a senior management position and one participant who was employed as the Heath Promotions Officer. Aboriginal Health workers have completed some form of recognised training, either through Marr Mooditj or other nationally approved training organisations. Marr Mooditj Training is a registered training organisation that provides training to maximise the employability of Aboriginal and Torres Strait Islander people. The ages of the participants ranged from 33 to 65 years of age, and all had been working within the Aboriginal Health programs for a minimum of 5 years, with some participants having worked for over 40 years with Aboriginal families and children. An introduction to these women was provided by the Cultural Consultant who 'vouched' that I was a credible researcher and that the research was important and valuable to the Aboriginal community.

## 6.3.3 Data collection.

Qualitative research approaches provide a unique opportunity to gain a 'holistic understanding' of the participant's experience (Berry, 1999). This often involves the use of either a semi-structured interview or an unstructured interview, which allows the researcher to probe and explore areas that are identified as interesting or pertinent to the research question. For this research project a method of data collection, known as Yarning was adopted from the literature as culturally safe Indigenous research methods (Bessarab & Ng'andu, 2010; Vicary & Bishop, 2005). Yarning is not entirely unlike the western qualitative approach to obtain information by the use of semi-structured or un-structured interviews. Yarning differs from the Western approaches by recognising that there are rules and protocols that are specific

to the cultural group and that it is a shared exchange of information (Bessarab & Ng'andu, 2010). Bessarab and Ng'andu (2010) proposed that there is a process of yarning, which acknowledges that there are multiple forms of conversations that occur within interactions.



Figure 2. The Yarning Research Process. Adapted from "Yarning about yarning as a legitimate method in Indigenous research", by D. Bessarab and B. Ng'andu, 2010, International Journal of Critical Indigenous Studies, 3, p. 40. Copyright 2010 International Journal of Critical Indigenous Studies. Adapted and used with permission.

Social yarning is the vital communication that occurs between the researcher, the participant and quite often a third party. The third party may be the Indigenous person who is vouching for the researcher or Cultural Consultant in the project. This social yarning was not included in the data in this project, but allowed the

participants to decide whether they were comfortable in sharing their stories with me, and to what depth they were comfortable sharing.

Research yarning was slightly more formal as there was a specific question asked of the participant. One of the main differences between a Western research approach of an unstructured interview and research yarning, is that in the Western research approach there are clear boundaries and a one sided approach to the gathering of information, whereas in yarning, the interviewer is a part of the conversation. The research yarning is a conversation with purpose, but is a shared, two-way experience for both interviewer and interviewee. While the research yarning process was a more mutual sharing process, there was a purpose and an interview protocol was developed (Appendix B).

Collaborative yarning was an important aspect of the interviews with the health professionals, where information about the research project was shared, and ideas around methodology, and cultural appropriateness were explored together.

Therapeutic yarning occurred when I became the listener as the participant revealed important personal or traumatic aspects of their story. Bessarab and Ng'andu (2010) describe therapeutic yarning as when the participant is "assisted to make sense or have their story affirmed" (p. 41). This type of yarning is not counselling, but it is the process of giving voice to the important personal story that is being disclosed.

#### 6.3.4 Procedure.

The Cultural Consultant supported me to invite Aboriginal health workers from different areas in the Perth metropolitan area to participate in this research. The Health Workers were invited to participate in the research via email and telephone calls, and were provided with an information sheet that introduced the researcher and provided some information on the research process (Appendix C) and face to face

contact details. Participants were also provided with an opportunity to gain a verbal explanation about the proposed research and if they wanted to continue, they were then asked to sign a consent form (Appendix D). A convenient time and place to meet was negotiated and a yarning interview was conducted based loosely on a series of questions developed as a prompt for the purpose of gaining some understanding of the nature of stress in the community, checking the appropriateness of the proposed research, the research methodology and the participant information sheets (Appendix E).

The yarning interviews were approximately one hour long and were recorded with both verbal and written permission of the participants. All of the yarning interviews were conducted in the participant's workplace. Some demographic information was obtained to enable the participant to be contacted to verify the data collected, including contact numbers, current employer, and position (Appendix F). The yarning interviews were recorded on a Samsung digital voice recorder and downloaded onto the researcher's university computer. The audio file was saved using a unique code and delivered to the external transcriber via an external storage device. The transcriber was experienced in working with sensitive data and confidentiality was assured during all stages of the transcription. The interviews were transcribed verbatim using word processing software and all names disclosed in the interview were noted as a single alphabet letter. The interviews were identifiable by the unique code, only the researcher had the information to link the transcribed interviews and the demographic data and this information was stored separately to the transcribed data. On receipt of the transcript, the researcher checked the accuracy of the transcript by listening to the audio file while reading the transcript. Any illegible dialogue or errors were corrected and the final transcript was saved. The deidentified transcriptions were stored securely on a password protected computer and hardcopies were kept locked in an office within Curtin University.

#### 6.3.5 Validation of data.

There is much debate regarding how reliability and validity is established in qualitative research (Freshwater, Cahill, Walsh, & Muncey, 2010; Gergen, 2014; Meyrick, 2006; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Reliability and validity are terms that have been used to indicate rigour in quantitative research and many have suggested that these are not appropriate terms or measures in qualitative research. Morse et al. (2002), however, suggest that these concepts remain important when considering qualitative research, and that researchers need to implement strategies throughout the research process to ensure that qualitative research also demonstrates rigour. Lincoln and Guba (1986) described a set of criteria that could be adopted to determine the 'trustworthiness' of qualitative data. Their argument was that qualitative research was fundamentally different to quantitative research and that 'trustworthiness' was the appropriate equivalent to the concept of 'rigor' in quantitative research (Lincoln & Guba, 1986). The criteria that Lincoln and Guba described included; credibility, fittingness, auditability, and confirmability. These terms aim to ensure quality research have been conducted, however Morse et al. (2002) expressed concern that the terms don't necessarily reflect the actual process of ensuring rigor of the research, and that the commonly used post hoc evaluation strategies employed have little to do with actual attainment of reliability or validity.

To ensure rigor in this research project, I have been guided by the work of Morse et al. (2002). Morse and colleagues describe the importance of verification in research, being "the process of checking, confirming, making sure, and being certain" (p.17, 2002). This process occurs through a variety of mechanisms

throughout the research process, primarily through the responsiveness of the researcher. Morse and colleagues argue that if the researcher is responsive, meaning they "remain open, use sensitivity, creativity and insight, and be willing to relinquish any ideas that are poorly suggested..." (p. 18, 2002) they will be able to identify and correct errors at every step of the research. Chapter Five of this thesis has described my reflexive thoughts and corresponding decision making throughout this research. Through this reflexive approach, in which I maintained a reflexive journal, I was able to adjust, correct and most importantly challenge my own thinking and position within the research, which ultimately contributes to the quality of this work. At the completion of each interview I made notes in regards to my impressions of the process and understanding of the content. My own observations and feelings in relation to the interview or participant were also recorded and any issues or difficulties were then discussed with my supervisors during supervision or my Cultural Consultant.

Morse et al. (2002) also identified verification strategies to further ensure the research is of quality. These include methodological coherence, appropriate sampling, collecting and analysing data concurrently, thinking theoretically and theory development.

- a) Methodological coherence has been demonstrated in this research through the adoption of culturally appropriate engagement process and yarning data collection strategy. The involvement of a reference group and ongoing guidance from a Cultural Consultant also ensured methodological coherence.
- b) Appropriate sampling: participants were targeted and invited to participate based on information provided to the researcher that they had appropriate

experience and knowledge in the area the researcher sought to explore. This was also an important aspect of the formation of the women's reference group- these members were not part of a general convenience sample, they were individuals identified within a small population that had specific experience and skills that were valued and important for function of the reference group.

- c) As the data was collected and transcribed, the transcripts were examined closely and initial thematic coding was commenced. This guided subsequent yarning with participants as commonly described experiences were explored further based on early analysis. This concurrent data collection and analysis also allowed a greater familiarity of the data in order to identify when an adequate number of interviews had been conducted.
- d) Thinking theoretically: this is related to the previous point, where ideas that emerge from the data are reconfirmed in subsequent data, and as new ideas emerge, they are also verified within the previous data. The transcripts were examined and coded continuously; this process was also verified by two of the supervisors who also coded interview data.

Another strategy that has been described in the literature is member checking (Lincoln & Guba, 1986). For the purpose of this study, member checking was to allow the participant to edit or remove any information that they did not feel comfortable in being reported, and to clarify any areas of confusion or information that may have been misinterpreted. While this opportunity for validation was offered to all women interviewed, no women chose to meet for a second time. Discussion around the content of the interviews and the process observed was discussed over the telephone. One participant was contacted to obtain permission to include quoted

material, which despite being de-identified, was particularly identifying within the Perth metropolitan area. The participant provided written permission to include the quote. No information was deemed to be inappropriate by the participants and all interviews were analysed as complete interviews.

#### 6.3.6 Analysis.

The records of discussion were analysed utilising a thematic analysis approach. Thematic analysis is a method of identifying, analysing and reporting on patterns or themes within qualitative data (Braun & Clarke, 2006). This is a flexible approach that allows a researcher to make decisions about the type of analysis being conducted. For this study, I have taken a combination approach, meaning that I will report findings based on both a realist or essentialist method and also a more constructionist method. Braun and Clarke (2006) describe the realist method as being a report or description of the experiences or reality of the participants. The constructionist method provides an opportunity to examine more latent themes that are reflective of the ways in which these realities are influenced by the socially constructed world the participants live in (Braun & Clarke, 2006). In order to understand how the professionals who worked in this area viewed the relevance and methodology of the proposed research, and to provide some baseline data about the perceived 'stress' experiences of the women being researched, from a health professional's perspective a series of questions were asked during the yarning interview.

Once the data was transcribed, and the transcripts were checked for accuracy against the audiotape recording, the transcripts were read again to familiarize myself with the data. As the yarning interviews were re-read, comments and observations were written on the hardcopy transcript. The word file was uploaded in the NVivo

computer software to make the coding process easier to manage and to compare across transcripts. Once each of the transcripts were read, there were some consistencies observed between the interviews that were identified and labelled as codes. Some examples of these early codes included 'lack of knowledge', 'chronic stress', and 'depression vs stress'. As each interview was re-read and coded, comparisons were made across all of the interviews to collate the codes into themes. As these themes were developed, the codes pertaining to the themes were extracted and re-examined for consistency and then refined further into sub-themes. This inductive approach has highlighted a number of themes that can assist in understanding the perceptions and experiences of the health professionals.

#### **6.4 Findings**

#### 6.4.1 Introduction.

To ensure that the findings are presented as a coherent 'story' a decision was made not to present each question from the yarning interview in the findings section. The findings have been reported under the overarching themes and the identified sub-themes will be discussed and explained (see Table 1 for a summary of key themes). Some of the questions were asking for very specific information so the responses are described, for example "Is this research area important to the Aboriginal Community?" Other questions, however, elicited more complex responses, for example "What might some of the issues be with this methodology?" These questions were analysed and reported accordingly.

Table 1
Summary of themes within each of the major topic areas

Overershing Thomas	Key sub-themes
Overarching Themes	Key sub-themes
6.3.2 Research relevance to	Research proposed accepted as relevant and useful to the Aboriginal community
the Aboriginal community	<ul> <li>Recognition of the paucity of research exploring stress during pregnancy</li> </ul>
	<ul> <li>Acknowledge need for greater understanding</li> </ul>
6.3.3 Appropriateness of	<ul> <li>Proposed methodology deemed as culturally safe and appropriate</li> </ul>
proposed research	• Debate within Indigenous research/Non-Indigenous researcher paradigm- particularly regarding vouching
methodology	and confidentiality
6.3.4 Perceived needs of the	<ul> <li>Two major overarching themes identified</li> <li>Stress and mental health</li> </ul>
community	2. Women's engagement with mental health services
	<ul> <li>Key themes related to stress include housing issues, for example lack of housing availability and the resulting homelessness. Alcohol and drug use and the impact of chronic and transgenerational stress and trauma.</li> </ul>
	• Key themes related to engagement with mental health services include personal barriers to access for example experiencing a sense of shame, competing needs within families and the complexities of the health system making it difficult for women to access. Another theme identified was that cultural beliefs and understanding of pregnancy often clashed with the Western medicalised view of pregnancy.
6.3.5 Solutions	Paternalism versus self determination

# 6.4.2 Research relevance to the Aboriginal community.

The theme described was the relevance of the proposed research. Participants were asked if they believed that stress in pregnancy was an important area to research within the Aboriginal community and how they felt any knowledge gained from this research could be utilised to best support the community. All participants

acknowledged the importance of this research and the particular relevance to the Aboriginal population.

I think all research pertaining to Aboriginal communities is really important to enable broader knowledge about where the health service falls down with Aboriginal people.

Participants also recognised the paucity of research in this area and how as clinicians working with Aboriginal women, it is vital to have this information in order to provide relevant and effective care.

That way if we've got more information we can better help Mums in their situation.

I see it as useful. We have never done this sort of thing before and we have a lot of, we visit a lot of Aboriginal women that are pregnant.

While there had been consultation prior to the research proposal being submitted, it was essential that the clinicians working directly with the potential participants valued the research and felt that it was relevant to their community. All participants saw emotional wellbeing as a vital component of their client's ability to parent their children.

## 6.4.3 Appropriateness of proposed research methodology.

An important aspect of this study was to explore potential pitfalls and problems with the methodology of this research with pregnant Aboriginal women. The participants were asked a series of questions and were asked to provide guidance around whether they believed the methodology was culturally appropriate, any potential issues with recruitment and the interview process, including the use of a Cultural Consultant or Indigenous interviewer, and whether there were any topics that would be seen as culturally sensitive or inappropriate to discuss.

## 6.4.3.1 Methodology: non-Indigenous researcher.

The proposed methods and procedure of this research were seen as culturally safe and appropriate. Participants highlighted the importance of anonymity, particularly in reference to the recording of interviews and de-identification of participants.

*OK*, as long as they are not being identified.

As long as that's [confidentiality] put really strongly across that, you know, I would imagine they wouldn't. I mean if they did [feel uncomfortable] they would tell you anyway so.

The idea of recording interviews was seen as acceptable, providing there were very clear explanations around the handling of the interview data and transcripts. The physical handling of the data was important, and led to discussions around the appropriateness of particular topics and any culturally 'taboo' topics I should avoid. All participants recognised that if the interviewee was comfortable and felt respected, there were no topics I should necessarily avoid. The importance of the relationship between the interviewee and the interviewer was highlighted as the single most important factor in the collection of sensitive data.

No, I think that once you build up that relationship you will be able to ask any question.

You might just need to be sensitive around issues like domestic violence or anything dealing with the stolen generation or maybe DCP was involved or their kids were being removed or something, they might think they're bad parents.

# 6.4.3.2 Vouching and Confidentiality.

One important procedural consideration was whether the non-Indigenous researcher (myself) was the most appropriate interviewer, or whether I should utilise an Indigenous woman to conduct the interviews. There were two distinct themes that were dependent on whether I was known to the participants or not. The participants who did not know me personally were more likely to suggest that an Indigenous woman or health worker should be involved in introducing me to the prospective participants, those health professionals that I had a previous relationship were more emphatic in that I was the most suitable person to conduct the interviews and provided a number of explanations as to why this might be the case.

I think it would be better for you because if they have us there they might not come out with what they'd like to come out with.

Damned if you do and damned if you don't. It depends if the community members know that other Aboriginal person... But some might say, no, don't want to because the grapevine effect. Is that person then going to go back?

This participant identified the dilemma in trying to meet the needs of all women. Some women would find being interviewed by a non-Indigenous woman difficult, yet others would prefer that to an Aboriginal interviewer.

Maybe you could get some of the health workers to help with the interviews, because they've already got a relationship with them. I mean, some people, they're probably more happy to talk with someone they don't know because then they don't feel embarrassed to tell personal stuff. Either way, if they're comfortable to talk with you that would be alright.

The issue of confidentiality within the Nyoongar community was expressed by all participants. They voiced a sense of mistrust within the Nyoongar Community and acknowledged that cultural and family relationships could impede the data collection by a Nyoongar woman.

Sometimes we are related to someone and we work with them and may be frightened to bring things out that they'd like to.

I think all women are the same; you tell them something and they go out and tell somebody else. That's just what like Nyoongars are like.

One participant suggested that if I were to use an Indigenous person to conduct interviews, I should get them to sign a confidentiality agreement.

Interestingly, at no time was this same requirement suggested for me.

If you are going to have an Aboriginal person they'll need to sign a confidentiality and that needs to be sighted by the community member that you are interviewing, that this information is confidential, that it won't be shared with others.

There is an implied acknowledgement that as the non-Indigenous researcher, whether it be due to my professional background, or my position outside of the Nyoongar community, that it was assumed that I was aware of, and could be trusted to keep this information confidential. Another hypothesis, however, was that some of the participants (particularly those who did not know me) made assumptions that I was not involved in the Nyoongar community in any way other than through my work. This presented a sense of confidence that I would not share information within the community.

Despite the confidence that all participants expressed in the appropriateness of the interview procedure, this was all based on the premise that I was 'vouched' for

by someone within the community. All participants believed that there would be benefit in being introduced to women and the community by an Aboriginal health worker, and that this would provide a sense of safety for the potential participants.

I think bringing an Aboriginal person along to introduce you at the beginning and if you are going to go back at more focus groups, then you would have built up that rapport with that group.

The underlying theme here, is the detrimental impact of past government policies and how the collection of research data from a non-Indigenous person can be seen with suspicion and also seen to perpetuate these past policies.

they'll be thinking what are you going to do with this information, how are you going to use it, where is it going to go, is this going to go to DCP, and then my children will be apprehended. I know that you are aware of past government policies so just be mindful of that, that some women may not want to discuss this with you and will accept how they are treated by hospitals as the norm when it is not. You and I both know that.

And I think we have to be mindful that people aren't going to be open and honest too with you, because they're going to be wondering what you're going to do with this.

## 6.4.3.3 Summary.

All health professionals interviewed reported that the proposed methodology was seen as culturally acceptable, within the proviso that the interviews be conducted within the context of a safe, confidential relationship between myself as the researcher and the women participating in the research. While there was some variation in the perceived need of an Aboriginal woman to be involved in the data collection, this appeared to be more related to the existence (or non-existence) of a

prior relationship with the researcher. Paradoxically, the dilemma of the preference for the interviewer to be known to the participant and from within the Aboriginal culture was also seen as a significant barrier for the participant to be comfortable discussing sensitive information. The perceived lack of confidentiality and mistrust within the Nyoongar community was seen as prohibitive and detrimental to the research.

Despite the risks of confidentiality breaches, the importance of the researcher being 'vouched' for was highlighted by all participants. This process of being introduced to the participants by a health worker was seen as an opportunity for a process of screening to have occurred. If I, as the interviewer, was being introduced to a potential participant, there was a sense that I had been accepted as a legitimate researcher, who was involved with research deemed to be valuable by the community. This 'vouching' also implied that the 'voucher', or the Aboriginal health worker introducing me to the community believed or felt that "I was OK" or could be trusted to behave in a way that was acceptable to the Aboriginal community.

The impact of past government policies and the Stolen Generations continues to be felt in the community and any intervention/research/collection of information, can be met with understandable suspicion and at times fear. This highlights the importance of the processes identified by the participants in terms of vouching and also transparency of the researcher in all aspects of the research.

## 6.4.4 Perceived needs of the community.

This theme related to the participants' understandings of the issues

Aboriginal women presented with when attending the health services and topics they
believed I would need to explore to gain a thorough understanding of the women's
experiences. The issues described were varied, however there were common

concerns identified by all of the participants that will be described in detail within two sub-themes; 1. *Stress and mental health, and* 2. *Women's engagement with Health Services*.

### 6.4.4.1 Sub-theme 1: Stress and Mental Health.

All participants were aware of the purpose of the research and were therefore primed to the topic of stress and mental health, so it was no surprise that this was a prominent theme throughout the interviews. What was apparent however, is that there appears to be some confusion around how mental health terms are defined and how these phenomenon are experienced by individual women.

What's the difference between depression and stress? You know, I don't know. Maybe that's what needs to be told to; that there is a difference between both of them.

Stress and depression are Western psychological terms, and the confusion expressed by an Aboriginal Health Worker is possibly a confusion shared by others within the community. This reinforced one of the primary aims of this research, which was to gain understanding of an explanatory model to understand the lived experience of these women from a culturally sensitive position. Although the definitions appear unclear, there were shared beliefs around the issues and situations that led to women experiencing high levels of emotional distress and the types of strategies women employed to manage this distress. Several main issues were described, they are presented here in order of frequency and salience. Housing was described consistently in great detail in all of the interviews. It is difficult to look at any of these issues in isolation of others, so at times there may appear to be overlap with other identified difficulties faced by the community.

6.4.4.1.1 Housing.

They're more or less worrying about where they're going to live, where the money's coming from, and where the feed's coming from.

They might live with their parents and a couple of the sisters and they've all got their own kids and some of them have come to try and get help for housing to get their own houses.

The issue of lack of stable or suitable housing was expressed by all participants and appeared to be seen as a major source of stress for the women who these health professionals supported. Many described their clients' difficulties securing stable housing, and also described their own family's struggles with overcrowding. There were many reasons offered for this difficulty including lack of financial resources, lack of availability of affordable public housing, the difficulties faced by young women, in particular pregnant teenage girls with limited choices of accommodation options.

It would be great if people could have somewhere to live. I mean, lack of housing is a big thing, you know, because they don't belong anywhere and they can't prevent having a baby, because they don't where to put it, in somebody's house or they're maybe in a bedroom or they're sharing a room.

When girls are pregnant too, they either go and live at the guy's place or their mother's place, you know, but if they haven't got them, where do they go? They overcrowd somebody else's place and it's a stress on both of them.

These participants were describing the impact across generations of the housing difficulties experienced by individual women. The expectations within the Aboriginal culture is that families support families, and there are cultural obligations

to provide shelter for family, even if there is not adequate space or resources to do so. This then places the burden of the lack of housing onto the shoulders of family members. Many generations of one family may be living in close proximity which can create tensions and conflict within the home. The participants, who were mostly older women with grandchildren, reported that they had experienced these intergenerational living situations and could identify the challenges these presented to all family members. As the elder family members, these participants felt a responsibility to ensure that the children were cared for despite the difficult circumstances. This often occurred with considerable costs to the emotional wellbeing of the individuals.

So the women are probably the people who would take on the extra kids, the extended family. If there were kids that needed looking after, then they'd be the one. Even if they're pregnant and they've got their own kids, it something that happens and they do.

This was supported by other participants, who described the significant waitlist for adequate government assisted housing as a significant contributor to the stress experienced by women and families. Often families were restricted in accommodation options, the private rental sector was often financially unattainable, particularly with young women with young families.

Just overcrowding and just the waitlist as far as having to wait so many years for a house and in the meantime that mother has had her first child and by her fourth child she's still waiting. So the stress increases, so not only that, it's being able to look after their kids too. You've got a family that there's the mother, father and they've got two young kids and they live in a house with the father's mother. There are eleven kids in the house all up and it's a three bedroom house. So

there are eleven children and four or five adults and they're there until... They're on priority, but priority is two years.

Lack of housing, instability of housing, the overcrowding of existing housing as a result of the former were represented very strongly throughout the interviews as a source of stress. All participants described examples of these difficulties and also hypothesised that these issues were related to other issues that increased the experience of stress.

6.4.4.1.2 Alcohol and Drug Use.

Alcohol and drug use were described as coping strategies to manage stress, and also stressors in their own right. Women in difficult circumstances use alcohol and or drugs (including cigarette smoking) as an escape from the realities of their lives.

It's a quick fix, so if someone is stressed, they will pick up a cigarette if they are a smoker. If they are a drinker, they will go for a drink. And that is there, it's reachable, it's something they can do and still then get back to their family.

I think sometimes when things do get tough, especially if they are younger, they want to turn to drink and that because you know all of their responsibilities and stress, and because they're young they wish that they could do those things, because everyone else is doing it around them, it puts pressure on them.

This was also described as one of the difficulties faced by young women who were experiencing housing difficulties and were unable to leave environments where alcohol and drugs were a significant problem. The participants suggested that women who may not use drugs or alcohol are often exposed to this in their living environments by their partners, and extended families. The desire to protect their

children or unborn baby is strong, but often circumstances make it impossible to make different choices.

## 6.4.4.1.3 Chronic and Intergenerational aspects of stress.

The participants described how some women may not recognise the levels of stress they experience due to the chronic nature of the stress. As children these women may have observed their own parents experience similar difficulties and there may be a perception that this is how the world is.

Being brought up in a household like that too, you know, nothing's changed. So that's just what happens in the life cycle. You go through it in childhood and then adulthood, then the kids do it too; unless you can break that cycle.

## 6.4.4.2 Sub-theme Two: Women's engagement with health services.

The experience of emotional distress is complex. The participants described a variety of circumstances and issues that they see as being important that are experienced by their clients daily. Another main contributor to this stress was described in how health and social services are provided, and the barriers that women in the community encounter when trying to navigate these services. An underlying theme that was seen across all participants was how the historical and political history was so closely interwoven in these barriers.

# 6.4.4.2.1 Shame.

The fear of being judged by health professionals was described by the majority of participants as a source of stress for young women. They believed that often young women experiencing difficulties would be reluctant to seek help, or refuse assistance when offered, in the fear that they would be seen as inadequate mothers and as a consequence be under scrutiny from the 'welfare' type services.

They'd quickly sort of clean up when they see, you know. And it's like, "Don't worry, you know, we're not here to look at your house. We're here to make sure bub's OK". So just reconfirming that because, you know, there's that shame factor, isn't it. And I mean, sometimes we have to rock up there opportunistically anyway because we can't get in contact with them

This sense of shame was also evident when participants described some of the barriers experienced by women accessing medical services during their pregnancy. A lack of culturally sensitive health services which included things like the gender of the health care provider, accessibility of the service, awareness of the cultural meaning of pregnancy and birth were consistently identified as causes of this sense of 'shame' that women, particularly young women, would experience.

Sometimes, being Aboriginal women, they get spoken down to and they don't like that. And even though with doctors too, they like to have a woman doctor. Shame's a lot of their problem too. Their ashamed to, maybe they haven't got the money to buy good clothes, you know. They're ashamed to go to a male doctor. These are some of the reasons I suppose.

This sense of shame makes it almost impossible for these women to be assertive, to make their needs or preferences known to health professionals. If these women are spoken down to or made to feel uncomfortable, they are less likely to have the confidence to request to be seen by a Doctor of a particular gender.

6.4.4.2.2 Competing needs and access of services.

Participants identified how complex the health system can be and stated that many of their clients needed assistance to try and navigate this system.

...the health system is quite sort of hard to try and understand as far as the community. It is trying to understand how the health system works, maybe how the justice system works and they're the things that I see people struggling with.

This system is even more complex during pregnancy where there are a number of appointments and different health care providers that women are required to attend. It was also highlighted that many of the barriers that prevented women from attending these appointments were related to the many demands placed on women. A lack of financial resources which impacted on their mode of transport affected their ability to access the services. Multiple family roles and other children often meant that women made choices to miss appointments in order to attend to other family member's needs.

One participant provided a detailed explanation of the types of barriers that can impact how women access health services;

You've got all your stresses if you've got a really stressful household and life in general and then you become pregnant. You've got to have those extra appointments; you've got to have the extra things that you need to do for yourself when you're pregnant. But then you also go do everything else that you need to do anyway. So, you know, it's that extra, it's all well and good being pregnant and at the end, baby and all, but it's all those things of, you know, "I can't go to the appointment today because my son's sick or my daughter's got to go to school or I just can't do it".

Another important factor in preventing young women from accessing health care was the experiences Aboriginal people have when interacting with health care services. The perception of the lack of culturally secure services by Aboriginal

women is identified as a major reason for the poor uptake of health services. These experiences of health services described by the professionals also touches on cultural factors such as the importance of female doctors providing care around "Women's Business" and the sense of "shame" of not having the right clothes, enough money and feeling like they are being judged by the health care providers.

I mean, for a young person to go along for their first antenatal checkup, they don't know what's going to happen. They're frightened too. People don't explain it either. I mean, if you go to the doctors, they don't tell you what's actually going to happen when you go. So, maybe when they first go, they might just go there and the experience wasn't too good, so they just don't go back until they really have to go back.

# 6.4.4.2.3 Aboriginal culture and pregnancy.

The participants interviewed identified that one of the factors that leads to young women not accessing antenatal care as frequently or as early as health care providers suggest is the cultural acceptance of pregnancy as a normal physiological process.

I mean before when you look back at history, we didn't have doctors and nurses around, so we would have our children under the tree. So I think as generation goes along, we will probably see mums that you know wouldn't feel it's important because they don't see that generational thing as distancing itself. So, I don't know, that's how I sort of look at it. Maybe people out in the community, Mums think that maybe "Well, my Grandma didn't need a doctor or checks and things like that; Mum was born under a tree". Maybe that's some of the thought that's in and around the place, I don't know.

This belief that pregnancy was a normal part of a woman's life was important and demonstrated the Indigenous woman's view that pregnancy was not an illness, and therefore attending a Doctor was not deemed necessary.

"Oh, I'm just pregnant, you know, and yes I'll go and have my ultrasound and I'll go and have my ultrasound to say yes, everything is OK". But as far as the check ups in between, unless you need to, unless you think something is wrong, they don't think that it's a huge... For those ones that have had kids before, like a few kids before, it's kind of "Oh well, I'll do my ones that need to be done, but as far as the check ups with your doctor and whatever in between..."

The family structure of Aboriginal families was also seen as a factor in how women viewed pregnancy and as a result accessed services. For those women living within large families there was a sense that they had the required knowledge and experience of pregnancy and childrearing to not necessarily need to access the services provided by the hospital.

But pregnancy is not a really scary thing for young girls who are from large families because you find that, you see the teenagers in families who have got big families, they actually care for their younger brothers and sisters too. So it's kind of just a "I'm pregnant. I know how to change nappies and to get up in the middle of the night and feed the baby and all that." The difference is that they're actually carrying it so they don't see that as being a very scary thing when it comes to having the baby. The stresses and everything is still the same going through it but not being afraid of it.

...our help is within our household like our Aunties who are older than us, so we go to them for help. So they're our counsellor, they're our, they're everything. So that's why we don't ask for help because we've got help from our Aunties, we've got help from our Grandma, you know? So yes, sometimes they're our rock kind of thing, our extended family.

Any questions or concerns women had about their pregnancy or labour were often answered by the older women in the family and extended family. These examples provided by the health professionals interviewed suggests that it is not necessarily the pregnancy itself that causes stress for young women. Rather, it is the social factors of their lives that pose the greatest challenges. As previously identified, housing issues, transport issues, a lack of financial resources are pertinent to a woman whether she is pregnant or not. While pregnancy may be seen to add a unique dimension to the experience of stress, the participants suggest that the main issues are a lack of those basic needs that were identified.

## 6.4.4.2.3 Summary.

The health professionals interviewed highlighted the complex and multifaceted nature of the experience of Aboriginal women. The impacts of unmet basic needs, such as housing (shelter) and safety were strongly described as important issues faced by Aboriginal women and families. Lack of safe, suitable housing for families appears to predispose families to high levels of distress which in turn affects how these families access services, the types of coping strategies people employ and ultimately the health outcomes experienced.

While housing presented significant issues, the participants also highlighted how a lack of cultural sensitivity in service delivery can also lead to poor uptake of clinical services by Aboriginal women. This, combined with the perception of pregnancy as a normal event in a woman's life contributes to the poor attendance reported by health professionals to Western mainstream pregnancy care. These findings present a challenging picture of a group of vulnerable women, with a

number of unmet needs managing complex family needs in isolation from support services.

#### 6.4.5 Solutions.

The theme did not come from an explicit set of questions, however all participants offered their thoughts on ideas of how to address some of these difficulties faced by Aboriginal women. This also related to the question posed to the participants of how can I, as a psychologist/researcher "give back to the community?" in terms of reciprocity. An important theme emerged around the dilemma of self-determinism versus paternalism, where the need for directed services needs to be balanced with the need for individuals to make decisions and take responsibility for their health. One solution offered by the participants was aimed at addressing educational needs of the young women. For example;

...they really need, I believe, these homemakers that they used to have years ago, when the wealthy used to pay Aboriginal women to go out and support these young people that can't manage themselves, and not only young people, but the older ones too. Show them how to spend their money, finance, bills and food that need to be paid for. It was good when it was going though. I don't know what they call it, Homemakers?

The older health professionals identified a program where older women from the community provided guidance to young women on the practical aspects of managing their homes and families. This was seen as a valuable program and particularly useful when considering some of their clients who experienced drug addiction and their children and family suffered as a result of this. In some ways a program like this (from the 1960s) hints of paternalistic 'do gooders', which is in

contrast to other views that highlighted the need for women to take responsibility for themselves and their families.

We can develop all these really great programs but it is up to the individual how to change their life. So we can talk about pregnancy and drinking in pregnancy or smoking in pregnancy, but it is up to the individual. You can fill someone up with so much information and they may see that as you are taking away their rights to be able to do things. So I think a lot of stuff goes back to the impact of past government policies upon the Aboriginal community and with Aboriginal rights being taken away from people. If we start to say "It's best that you do this", then you'll see a brick wall coming up. It's up to the individual to take control of their life. So it might have been seen as a norm for people to smoke or to drink during pregnancy.

These contrasting views may represent the views held within different generations in the community. The cultural role of the elder women as advisors and support to young women and families is still seen as important with younger women, yet the formal roles seen in the 1960s are no longer available. The difficulty of this approach however, as highlighted by another participant, is the perception of "being told what to do" in the sense of someone in a position of power taking away an individual's rights, which is reminiscent of previous policies and practices in Australia.

## 6.4.6 Final Summary.

The yarning interviews enabled important questions to be asked and answered prior to engaging with pregnant and non-pregnant women in study two.

The questions relating to specific methodological issues provided confirmation that the proposed approach was culturally appropriate, yet also highlighted the diversity

within the health workforce. This diversity of experiences and beliefs is reflective of the Nyoongar community and the literature that describes conducting health research in an Indigenous context. These findings will be explored in more detail in the following discussion.

#### 6.5 Discussion

An important step in this research exploring the experiences of pregnant Aboriginal women was to first determine whether the research proposed was deemed as important by the Aboriginal community and whether the methodology was culturally appropriate. It was also important to identify the types of issues faced by young Aboriginal women as perceived by the health professionals that support them. The findings presented earlier provided confirmation that the proposed research was both perceived as important to the community and planned in a way that was seen as culturally appropriate. These findings will be explored further in the following section along with recent literature that has contributed to the understanding of conducting health research within Indigenous communities. This will be followed by a discussion of the perceived stressors experienced by Aboriginal women.

## 6.5.1 Research topic relevance to Aboriginal community.

The participants interviewed believed in the importance of conducting research into understanding stress during pregnancy and expressed support for the project. While this may seem like a fairly simple concept it is extremely important when considering the history of health research in Aboriginal communities.

Community involvement and awareness has been identified as a key component to health research conducted with Indigenous communities (NH&MRC, 2003).

Historically, despite the experience of being 'researched to death', health research has not always been conducted with the support and input of the people who the

research outcomes are designed to help (Smith, 1999). Cochran et al. (2008) shared a quote from an Alaskan native "researchers are like mosquitoes; they suck your blood and leave" (p. 22) to illustrate some views held by Indigenous people about the research conducted in their communities. This was expressed in the context of the large body of research conducted within Aboriginal populations with minimal perceived benefit to the community. Research conducted in Aboriginal communities has, at times, been led by non-Indigenous researchers whose agendas have not been considerate of the needs of the community (Smith, 1999).

The lack of consultation with Aboriginal organisations and individuals has often led to research and services being developed and implemented that have either not met the needs of the community or failed to improve health outcomes (Anderson & Loff, 2004). Interestingly this research project could have been counted amongst the number of research projects conducted on issues not perceived as a priority by the Indigenous community. During the early 'pre-conception' days of this thesis, I was convinced the issue that needed to be explored was depression, however, the community were adamant that the issues were more specifically about stress. The assumption that a non-Indigenous health researcher or health professional can identify the issues and make decisions about services for Indigenous people without the Indigenous community being involved at every stage of the project is yet another example of the ongoing colonisation of Indigenous people. The paternalistic views that the 'experts' know more about the needs of Indigenous people is reminiscent of past policies and must be considered when the health data suggest that the disparity between Indigenous and non-Indigenous Australians' health outcomes continues to be a greater problem here than in other countries (Commonwealth of Australia, 2016; Gray & Oprescu, 2016).

The development of an appropriate research question or area of research is so important in improving the health outcomes of Aboriginal people. However, of equal importance is that the research is conducted utilising appropriate methodology and culturally sensitive approaches (Dudgeon, Kelly, & Walker, 2010).

## 6.5.2 Use of appropriate methodology.

There were some mixed views around some aspects of the methodology which was consistent with the literature in this area. Once the research topic was deemed as relevant and important to the community, the issues around data collection, data storage and dissemination were explored. There is a legacy of mistrust as a result of researchers making false assumptions or failing to understand the values and practices of Aboriginal people. Researchers have continued to collect data and interpret findings through the cultural lens of the mainstream dominant white culture which has led research and researchers to be viewed with some suspicion by the Aboriginal and Torres Strait Islander communities, and led to the necessity of the adoption of guidelines to ensure research is conducted 'with' Indigenous people, not 'to' them (NH&MRC, 2003; Oxenham, 1999; Wand & Eades, 2008).

The exploratory approach taken with this research and the utilisation of yarning as a data collection strategy was seen as culturally safe and appropriate by the participants interviewed. Yarning is the Australian Indigenous word for storytelling, which has been described as an ancient practice that is fundamental to Indigenous learning, and has been adopted and legitimized as both a research method and a strategy for data collection (Bessarab & Ng'andu, 2010; Geia, Hayes, & Usher, 2013; Walker, Fredericks, Mills, & Anderson, 2014). Storytelling or yarning is a fundamental part of Indigenous people's lives. The value of adopting this as a

methodological approach or data collection strategy is immeasurable when we consider how Indigenous people make sense of their lives and experiences through the process of shared stories. To engage in yarning as a non-Indigenous researcher is both a privilege and a daunting experience. Unlike other approaches, varning requires the researcher to share some of their own personal and professional stories with the participant, and in turn, becomes a part of the research (Bessarab & Ng'andu, 2010; Walker et al., 2014). The value of this shared experience is the reduction of the power differential between the 'researched and the researcher'. Yarning is a fluid process that captures aspects of the past, present and future, while continuing to maintain cultural integrity (Geia et al., 2013). By engaging in this shared process, the researcher gains an insight into the shared experiences of not only each individual, but the shared lived experiences of families and communities. The complexity of this shared process has been suggested to establish relationality and determines accountability between the researcher and the participants (Martin, 2008), both of which are vital in ensuring that the research process itself is not perpetuating the ongoing harm of colonisation.

The literature in the area of Indigenous health research has focussed on the importance of Indigenous knowledge and methodologies in recent years and has been critical of the research undertaken on Indigenous communities and cultures (Foley, 2003; Kowal, 2011; Menzies, 2001; Smith, 1999). Researchers have been complicit in the ongoing colonisation of Indigenous people both historically and more recently through the misuse of Western psychological practices, both in the areas of clinical practice and research (Cochran et al., 2008; Czyzewski, 2011; Davidson, Sanson, & Gridley, 2000; Ranzijn et al., 2009). Some early research, for example, exploring measures of intelligence of Indigenous children, was carried out using Western

psychological assessments and methodology (Porteus, 1973). The findings of these early studies have been used against Aboriginal and Torres Strait Islander peoples and have increased the levels of disadvantage by perpetuating and reinforcing negative stereotypes (Davidson et al., 2000; NH&MRC, 2003; Porsanger, 2004; Smith, 1999). Early research sought to label or categorise Aboriginal people and by engaging in culturally inappropriate methodologies and assessments, the findings served to contribute to the high levels of disadvantage experienced by Aboriginal people. As a result of these experiences, Indigenous researchers and academics have been vocal about the need for due recognition of Indigenous ways of knowing and that Indigenous methodologies should be adopted in this area of research. Geia et al. (2013) go as far as to suggest that "the days of white academics preening their feathers and building nests while basking in accolades from the gains of research conducted on Indigenous peoples are over" (p.14). This leads us to the important issue of role of the non-Indigenous researcher within Indigenous health research.

## 6.5.3 Role of Non-Indigenous researcher in Indigenous health research.

The role of non-Indigenous researchers in the domain of Indigenous health research has been debated and there are some authors who believe that Indigenous questions need to be answered by Indigenous people- and the most appropriate person to find these answers should be an Indigenous researcher (Oxenham, 1999). There are others, however, who acknowledge the contributions of non-Indigenous researchers, with the following caveat, "such research [conducted by non-Indigenous researchers] will only make a meaningful contribution if researchers change their approach so that it becomes part of a process of decolonization" (Menzies, 2001, p. 21).

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The question of whether it was appropriate for a non-Indigenous woman to conduct this research was not seen to be important by the participants in this study. The issues identified were more related to issues of confidentiality, trust and quality of the information shared by participants. Initially, it appeared that the differing views expressed by the participants were based on their prior relationship with the researcher. Those participants who were familiar with me in my previous roles were less likely to stress the need for an Aboriginal woman to collect the data, whereas the participants who were less familiar with me professionally were more hesitant and expressed the possibility of needing more formal introductions to women in the community. It was hypothesised that this highlighted the importance of relationships within the community, and this was testimony of my own position within the community. This could reflect the true nature of the quality of the professional relationships that had been developed over the previous decade, however, there could also be an alternate explanation.

One participant expressed the need for a confidentiality agreement to be signed by any Indigenous person involved with the research, yet this was never suggested of the non-Indigenous researcher. Once again, this could be reflective of the level of trust between the researcher and the participants, however it would be unwise to fail to consider the impact of colonisation and the inherent power differential between the researcher and the 'researched'. The Nyoongar community in Perth is diverse and within that diversity there are different priorities and perceived needs within the community. These conflicting needs, whether they are health needs or financial needs, can create conflicts within the community and often conflict within family groups. This level of conflict is well known and acknowledged by the community and has led to tensions and opposing views when it comes to

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engaging with health professionals. Some participants expressed concerns that there would be perceived breaches of confidentiality if the interviewer was from within the Aboriginal community, the idea that participants would feel 'shame' or embarrassment if disclosing information about emotional distress to someone from within the cultural group was commonly described. This may be reflective of the stigma of mental health issues within Aboriginal culture (Vicary & Westerman, 2004) and the fear of how that information would be received in the community. This was not seen as such a risk if the interviewer was non-Indigenous. I question whether the non-Indigenous person is seen as less likely to disclose personal information, or if they are seen as less likely to have personal links and relationships within the Nyoongar community, so not a risk of 'telling others about our business'. In Australia, and particularly in middle class white Australia, it has been found in research that less than 30% of non-Indigenous people associate or have friendships with Aboriginal people (Nelson, 2014). This perception of personal distance from the Nyoongar community (however inaccurate) may have been seen as a positive factor in ensuring the safety of the information shared by the women.

The other possible explanation that must be considered is that of the impact of colonisation. Despite the ongoing relationships with the Aboriginal health workers, was there an acceptance of my role as the researcher, purely on the basis of my 'whiteness'? Did the position of being the researcher impact on how participants responded to questions of methodology appropriateness or the appropriateness of the cultural background of the researcher? The answer to these questions, I believe, lies in the literature in this area that highlights the importance and immense value of the process of engagement with the community (NH&MRC, 2003; Vicary & Bishop, 2005; Wand & Eades, 2008).

Community engagement and community consultation are concepts that are consistently described as vital components of Indigenous health research (NH&MRC, 2003; Walker et al., 2014; Wand & Eades, 2008). The long process of engagement with the Aboriginal community for this thesis commenced well before the research was designed and continued throughout the research. Without this consultation and collaboration, the non-Indigenous researcher has the potential to become part of the problem, rather than an active collaborator with the Aboriginal community seeking solutions to difficult questions.

#### 6.5.4 Perceived Stressors.

The participants identified a range of stressors that they believed were the most salient in the lives of young women during pregnancy and parenthood. They included housing issues, drug and alcohol use, and difficulties accessing health services. These stressors have been identified as being particularly prevalent within the Aboriginal community in a comprehensive study conducted by Weetra et al. (2016), where out of a sample of 344, over half of the women were identified to experience high levels of stress related to social health issues including housing difficulties, drugs and alcohol, and bereavements. While these types of stressors are often experienced at varying levels by all women, Indigenous or non-Indigenous, one area of stress identified by the women interviewed that was more specific to Indigenous women was the experience of transgenerational stress.

The experience of transgenerational stress has been linked to the historical trauma experienced and remembered by women within the Indigenous community as described by Muid (as cited in Atkinson et al., 2010). The effects of this trauma continues to be passed on through the difficult attachment relationships, the ongoing impact on parenting and family functioning and the experience of disconnection with

family and culture (Atkinson et al., 2010). The difficulty with this type of trauma, is that the people experiencing it are often unaware of the high levels of stress, as it has become normalised within the culture (Duran & Duran, as cited in Atkinson et al., 2010).

#### 6.5.5 Conclusion.

The views of the health professionals provided a reference point in which to inform and guide the following study. The description of the stressors provided by the participants will be explored in greater depth in the following chapter. As previously stated, the primary aim of this study was to determine whether the research design and methodology were culturally appropriate and meeting the needs of the Aboriginal community. The second aim was to establish my role as a researcher within this community. Despite the potential challenges of being a non-Indigenous researcher within this cross-cultural research paradigm, this study provided the reassurances and guidance to ensure that the cultural values and experiences of the participants and health professionals were carefully considered at each stage of the research. This reassurance allowed the next study to proceed, with assistance from the participants in study one to recruit women from the community to participate in study two.

**Chapter Seven: Study Two** 

7.1 Chapter Overview

This chapter involves the design, methodology, analysis, and findings of study two. The aim of this study was to gain a culturally specific understanding of the phenomenon of stress from the perspective of the Nyoongar women interviewed in order to address the following research questions:

- 1. How do Aboriginal women conceptualize stress and mental health?
- 2. How do Aboriginal women conceptualize and experience stress during pregnancy?
- 3. How could non-mental health professions best identify Aboriginal women experiencing stress and mental health difficulties during pregnancy?

These questions are designed to determine whether it was feasible to develop a screening tool to identify women experiencing high levels of stress during pregnancy.

## 7.2 Methodology

## 7.2.1 Research design.

This study was based on a qualitative exploratory design. This research was attempting to understand the 'lived' or insider experience of the participants so it was decided that an interpretive phenomenological approach would be taken, both from a theoretical and an analysis view point. As a research design, phenomenological approaches aim to capture the nuances of a particular experience/s within the context that it occurs (Giorgi & Giorgi, 2008). This particular approach, unlike more positivist designs also acknowledges that the research process is a dynamic process that involves both the researcher and the participants. Based on this research

approach, it was initially planned that the data would be analysed using Interpretive Phenomenological Analysis (IPA). It became apparent, after familiarising myself with the early interviews, that the complexities of the lived experiences were closely interwoven with the social structures and broader political contexts. The interpretive aspect of IPA felt uncomfortable, particularly when considering my position as a non-Indigenous researcher within Indigenous research. It was decided that the Causal Layered Analysis (CLA) approach as described by Inayatullah (1998) would be used. CLA has been described as a form of research methodology, it has also been described as an analysis that is particularly valuable in exploring and describing complex social psychological issues (Bishop & Dzidic, 2014; Garvey, 2015; Inayatullah, 1998). For the purposes of this research, CLA will be used as an analytical technique only and the process used will be described in greater detail in the analysis section of this chapter.

## 7.2.2 Participants.

A snowballing strategy was used to recruit Aboriginal women who were currently pregnant (N=7) and those who were not currently pregnant (N=6).

Demographic information relating to the age of participants is presented in Table 2 for both currently pregnant participants and for non-pregnant participants.

Table 2

Mean Age Pregnant and Non-Pregnant Women

	Mean Age (years)	Range
Pregnant women n = 7	26 years	20-32
Non-pregnant women n = 6	32 years	22-43

As described in chapter six vouching is an important aspect of recruitment, and all participants were introduced to me via either an Aboriginal health worker or community member. Women were identified through a variety of different services, for example women attending local antenatal services and playgroups. These women lived in the southern suburbs of Perth and all identified as belonging to the Nyoongar culture. While only the women in the 'pregnant' group were pregnant at the time of the interviews, all participants were parents.

There is considerable debate amongst researchers around the number of participants required to capture the important information for qualitative research (Brocki & Wearden, 2006; Lincoln & Guba, 1986; Sandelowski, 1995).

Phenomenological studies typically have relatively small samples sizes, particularly when compared to quantitative research. Sandelowski (1995) provided guidance on appropriate sample sizes for particular qualitative research designs, suggesting that as few as 6 participants can be useful for phenomenologies that are concerned with exploring the essence of particular experiences. However it was also suggested that if the aim was to explore the particular experience for purposes such as to develop a measure, at least 25 descriptions of the particular experience would be more appropriate. The a priori decision regarding sample size, was to aim for 25 participants, with an even mix of pregnant and non-pregnant women, however as the

interviews were transcribed and analysis began, it became clear that developing a measure was not a feasible outcome of the research. It was then decided that a minimum of six participants in each group (pregnant and non-pregnant) would provide an adequate insight into the experiences of this particular group of women as described by Morse (as cited in Sandelowski, 1995).

### 7.2.3 Data collection.

The aim of this qualitative study was to gain an in-depth understanding of the lived experience of the women interviewed. As described in the previous chapter, a culturally appropriate data collection strategy known as 'yarning' was employed. Time was spent social yarning, both individually and with a group of participants and service providers in order to establish the vouching process and develop rapport with the women.

As previously described, the yarning interviews were recorded on a Samsung digital voice recorder and downloaded onto the researcher's university computer. The yarning interviews were transcribed verbatim using word processing software and all names disclosed in the interview were noted as a single alphabet letter. On receipt of the transcript, the researcher checked the accuracy of the transcript with the audio file. Any illegible dialogue or errors were corrected and the final transcript was saved. The de-identified transcriptions were stored securely on a password protected computer and hardcopies were kept locked in an office within Curtin University.

### 7.2.4 Procedure.

Information about this research was distributed around the community in specific locations that provided a range of social and health services to pregnant women and women with children (Appendix G). This did not attract any response

from any participants, so I visited these locations to meet with the staff and personally invite women to participate. This was the most successful approach and provided an opportunity for further vouching to occur. The women were identified as potential participants by the workers and were given an information sheet (Appendix E) and verbal information about myself (vouching). I was introduced to the women by the professional (an Aboriginal worker) and negotiated an appropriate time and place with the woman to have a 'Yarn'. Most of the yarning interviews were conducted in the community location, for example, the local Aboriginal Community Centre or primary school. Some yarning interviews were done in the participant's home.

Prior to recording the yarning discussion, some time was spent social yarning. This usually occurred in a group setting with several potential participants and the Aboriginal worker/s present. The information shared in this informal yarn was important information about myself as a researcher, community member and woman. My background as a health professional and the rationale behind this research were topics discussed, as well as information about the women and their families. In one community group I participated in the planned group activities over several weeks, before engaging any women in interviews. The activities included a women's drumming workshop, art activities and a lunch, where I was given time to introduce my research and answer any questions or concerns the women had. During this time, women approached me and volunteered to be a part of the research. We would then find a quiet location and have a yarn.

The participants provided their consent to participate in the research (Appendix H) and for their stories to be recorded. It was at this point that the women were reassured that all the interviews would be transcribed, de-identified and that no

identifying information would be released. The research question was posed to the women for example,

What I'm really interested in is understanding, I call it stress but lots of people call it different things, is sort of what's it like? Can you think back when you are pregnant? What was life like for you then?

The women were asked an open question and then prompted to clarify meaning or explore an area in more depth. The yarning was unstructured, however themes that had been identified in previous discussions that had not been mentioned were prompted respectfully and explored.

#### 7.2.5 Validation of data.

The steps taken throughout this research to ensure rigour and quality have been described in some detail in the previous chapter. As in the previous study, participants were offered the opportunity to edit or remove any information from the transcript of their interview if they felt uncomfortable in the material being used in the analysis or the final thesis. Despite this offer, all interviews were included in their entirety. I was concerned about one particularly identifying quote, as even after the de-identification process, I was able to recognise this participant due to her public profile. I contacted this participant and confirmed again that she was comfortable with it being included in the thesis.

## 7.2.6 Analysis.

The transcribed accounts of the yarning interviews were analysed using the Causal Layered Analysis approach (Inayatullah, 1998). Causal Layered Analysis (CLA) consists of 4 levels of analysis; the litany, social causative level, world view and the myth/metaphor level. Each of these layers offers a unique perspective of the data that increases in depth and complexity. The value of this analysis is that it

allows the issues to be deconstructed within these four levels at the seemingly superficial level of the narrative or litany down to the deeper, often subconscious mythical stories and social archetypes (Bishop & Dzidic, 2014).

The transcribed word files were uploaded into NVivo, which is a research software package that assists in the organisation and analysis of qualitative data. The initial stage of the analysis was the familiarisation of the data. The transcriptions were read and re-read and checked for accuracy against the audio recordings. During subsequent readings, information that was identified to reflect the day to day experiences of the participant were coded as litany. Each of the four layers were coded separately and in order, starting with litany, social causative, worldview, and Myth/metaphor. This made the most intuitive sense to me, as the litany was the most obvious and was clearly identified and told the story of the participants' experience. Some areas of coding were entire paragraphs, other coded material was a segment of a sentence or even a few words.

Once I felt confident that I had captured the litany, I starting looking at the social causative level. This layer was not as clear, with some overlap noted with the litany. Discourse related to the social structures or systems was coded as social causative. The third layer, worldview discourse layer was coded next. This layer was more complex and required a series of co-coding meetings with my supervisors to deconstruct the interviews in order to identify the worldviews. The final layer of the analysis to be identified was the myth/metaphor layer which was not identified in this particular data set.

This process was followed for each of the transcribed yarning interviews.

Once I had completed the initial coding of two interviews I then compared the codes across interviews, for example, all data coded as litany was extracted from each

interview and collated in a separate document. I could then identify shared experiences, accounts and group information under themes. This almost circular process was continued for each interview conducted, 4 layers of coding within each interview, then individual layers across interviews to identify themes and subthemes. As new information or themes were identified, a reflective process was taken to review previously coded interviews to ensure that the subtle nuances of the participants' experiences were not being missed.

On completion of this process, the extracted layers, major themes, and subthemes were reconstructed into what is presented as the findings of this study. This involved white boarding each layer to make sense of the overall picture, at this point it became clear how each of the layers fed into the next layer, revealing more depth and complexity in the understanding of the experiences of the participants.

## 7.3 Findings

The data was initially examined as two groups; pregnant women and non-pregnant women. It was hypothesised that there could be distinct differences in their experiences that were important to explore. During the analysis, it became clear that any differences between pregnant and non-pregnant women were not related to pregnancy status and as a result, the findings are presented on the full sample of 13 Aboriginal women.

The findings have been described under three of the four layers described earlier. The litany has been presented first as the initial 'story' that was presented by the participants. Each layer examines the data in more depth and from a different perspective. As the analysis progresses into the deeper levels, it becomes clear that this can be likened to the iceberg metaphor; where the litany is what the world or community can see (refer to figure 3). These day to day stories are the visible,

tangible realities of these participants, unlike the deeper levels, that are below the surface of the sea. With some knowledge and understanding, the social causative layer can be explored, however the deeper truths or stories are stored deeply in the psyche of the participants and not overtly apparent to others. The shared beliefs and understandings of the world, in other words, worldviews, are usually not explicitly stated, but through insights gained from the data. During the analysis it became apparent that the extraction of the fourth layer; myth/metaphor was difficult. Typically, the myth/metaphor level includes the deep stories or what has been described as the "collective archetypes" (Bishop & Dzidic, 2014). My inability to differentiate these stories and deeper truths from the shared world views could be attributed to my outsider status of not belonging to the cultural group that the participants were from. Another possible explanation could be that the yarning discussions conducted did not allow this level of deeper reflection from the participants interviewed. CLA is a relatively new analysis technique and while it is certainly useful in identifying and exploring complex social issues, there may be some limitations in the cross cultural context that had not previously been considered.

# LITANY

The lived day to day experiences; Realities of pregnancy Realitities of Parenting Multiple roles

### SOCIAL CAUSATIVE

The social, economic, and political factors;

Poverty, homelessness

Financial Stress

Employment and Transport

#### WORLDVIEW

Deeper social structures and beliefs;
Aboriginal Culture: family roles and obligations
Women and Motherhood, Explanatory model of stress
Transgenerational Stress

Figure 3. Pictorial representation of major themes by layer, within the Causal Layered Analysis.

#### 7.3.1 Litany.

As described earlier, the litany is the lived day to day experiences of the participants. The lived experiences of these women predominantly revolved around their busy, demanding roles as mothers, yet the complexity of this role and the social circumstances that these women lived in, has meant that a great deal of the information was coded into the deeper levels of analysis. What is also important about the litany layer, is that it is often what is 'seen' or can be observed by the wider community. This is where behaviours are judged and assumptions made by others,

without any context or understanding of the deeper layers or experiences of the individuals' life.

## 7.3.1.1 Realities of pregnancy.

A theme that has been seen in a majority of the participants interviewed, both currently pregnant and non-pregnant women was the reality of pregnancy. Women described the early decision making process around conception, the stress or surprise of an unplanned pregnancy and then the questioning around the options of termination or continuing the pregnancy. This was particularly salient for young women, the following participant described her experiences when she discovered she was pregnant as a teenager.

I didn't know what to do really. I didn't know whether I should keep the baby or not and by the time I found out how far I was it was too late to have an abortion. The Aboriginal worker at school and all the students and all that were very nice.

The health of both mother and baby was also described by many of the participants. Women who had previous children were less likely to be concerned regarding the upcoming labour and birth, yet some described anxiety regarding their health and health behaviours during their pregnancy and the risk to their unborn infant. One participant stated

I was really stressed ... when I was pregnant with my son.

I think I was pretty stressed mainly because I just worried about everything like, I had a friend that I work with, she lost a baby at 26 weeks so I was really paranoid about it. Like the whole pregnancy I was just paranoid about everything. I think I had about 12 ultrasounds I was that worried because I just thought something bad is going to go wrong.

The experience of having a friend experience a poor birth/pregnancy outcomes was an important factor in this young woman's experiences. Other women described previous pregnancy or birth complications as the trigger for their anxiety. When discussing stress during pregnancy, several women described experiencing anxiety, panic attacks and depression. These experiences were often diagnosed during pregnancy and the risk of experiencing these symptoms in subsequent pregnancies also increased women's stress. While some women had received professional support during their pregnancy for mental health concerns, others did not. One participant said;

Because I suffered anxiety after the first one, I got diagnosed when this baby was a year old. So that would make me stress even more for ages, like there's a six year gap between the first and the second, so when I was pregnant with the second I was freaking out thinking it was get worse

Yet, another participant sought help but did not want to take medication.

I think I have some form of it [depression]. I think everyone does. I'm meant to be on depression tablets for anxiety because I've got anxiety.

Older women, particularly those with young children also faced challenging decisions when faced with another pregnancy. While participants didn't generally describe the pregnancy itself as being stressful, it was the added responsibilities and impact on other children that were identified as stressors. This participant was surprised at the timing of her pregnancy, and when asked about how she felt about this current pregnancy, she was six weeks gestation at the time of the interview, she

acknowledged the challenges of a young family where the children are very close in age.

No, it was a surprise. I was sort of, I knew it was coming because I had my implant taken out and it just really hit me because it wasn't expected so soon. I've dealt with it, baby is coming...

Stressful. My baby is only nine months. And the rest have all got two year gaps and I've already got five kids.

The challenge of a pregnancy within the context of busy family lives was highlighted by a number of participants. The demands of parenting, homemaking, and employment increased the experience of stress during pregnancy.

Yeah, every time when my daughter wanted me to pick her up or something and I was having to while pregnant and that just put stress on my back and made me angry always having to do stuff.

Washing in the laundry, I look at it and I think "Oh, great", washing. I think just chores; just the thing of having to constantly be up and doing something is just stress. And having baby and finding out I'm pregnant and that's just another thing on my plate.

Pregnancy is a unique time in a woman's life. The experiences described by these participants may very well be universal experiences of pregnancy shared by a large number of women in any community. There is, however a 'but' in this narrative. These experiences need to be considered within the context of the lived experience of being an Aboriginal woman in Australia. There appeared to be an added layer to their stories that will described in greater detail in the following layers of analysis.

## 7.3.1.2 Realities of parenting.

Parenting was described by all participants in terms of being busy, and the necessity of juggling many demands and roles. This was consistent in all interviews, irrespective of the number of children, or whether the participant was pregnant at the time or not. The types of demands varied, however there was a theme of 'business' that appeared to impact significantly on participants' stress levels and mental health.

Cause the kids do heaps of extra curricular activities like Monday we do craft group for me, but that just gets me out of the house. Then Tuesday I don't do anything besides night time, L has two hours dance. Then Wednesday I do playgroup. Then Thursday but the kids have dance until 7pm and then Friday is C's soccer. Saturday is dance all day and Sunday is C's soccer.

at night time, when everyone's gone to sleep, I'll give myself a little list of things to do and I don't do any of them. And that worries me because I should do these things and it's like why can't you do these things, can't you just get up and do them? It's not that hard, you know?... I've got to get her needles up to date and getting antenatal classes and all that going. And the big girl with school.

These demands that parenting places on these women are not necessarily seen as negative by the participants and the reality of their lives are seen as unremarkable by the women themselves. This 'matter of fact' acceptance of this busy-ness appeared to be part of the expectations of being a parent, and once again, shared experiences of women in the wider community. This acceptance of the demands may be as a result of the expressed joys the participant's experience in their roles of mothers.

I know when they are happy and they makes me...and my kids are really loving children, so I know that I'm doing a good job.

When I hear them laughing, you know, I'm really angry and everything, but when I start hearing them laughing and giggling, I feel, yes, like I'm happier and I feel like a want to cry.

One of the important factors that appeared to mediate the experiences of both pregnancy and motherhood was whether or not women felt that they had support. Support was described in terms of support from the father of the baby, parental and family support and the support from health professionals. The reality for many women is they manage these parenting roles and pregnancy with very little support from their partners, and rely on their mothers and other women within their family and friendship circles, for example a participant stated,

I was seeing my kids every day, my Mum only lives three streets away, so it's not like I didn't get to see them, but it was good. My Mum helps me a lot, my Mum has T every Monday and Thursday so that's good, or if I have appointments.

This participant lived within close proximity to her mother, however those that do not have family close by, rely on friends with young children or other older women within the community. Only one of the women interviewed used childcare services and for those women without family support, their experience of day to day parenting was stressful. The impact of the Fly in Fly out workforce, which is so commonly seen in the mining industry in Western Australia, also has implications for the parenting roles and stress experienced by these women.

...At the moment I'm just starting to get uncomfortable and having a toddler, it is hard to get around. My partner's away, week on and week off. So the week he's home, it's fine, he helps me out a lot.

For some women parenting alone was at times perceived as easier than managing difficult relationships, this was more commonly seen where there was a history of domestic violence.

And that was like really easy; I coped a lot better. I was freaking out thinking I wasn't going to be able to cope without him there. But I did really, really good without him there. And then we he got out it's all like,[harder]

And he'd always make excuses and I used to get really pissed at him and we used to fight and argue and I used to kick him out all the time because he wasn't doing his job.

### 7.3.1.2.1 Multiple roles.

The women interviewed, like many other women in the community, are multifaceted women who take on a variety of roles within the family and the community. The role of mother, wife/partner, provider, student, business person are just a sample of the multiple roles women adopt simultaneously. One participant described her 'busy-ness';

I guess I get busy. We have a café here and I have a band; I front a band and we play fairly high profile gigs and stuff. I also have a consultancy with doing arts and I specialise in Indigenous arts and events management...I've got three kids. I've got a 15 year old, a 13 year old and almost 2 year old and I'm involved with their lives.

Another participant describes her desire to pursue further education to enable her to broaden her employment opportunities once her children are a little older.

Well I did a Diploma so I've finished that one. But then I was going to go back and do the youth subjects of it cause I can chop a lot out already and I only have to do one or two days a week. So wouldn't mind doing that but I'm going to wait to next year, see how I go.

All of the women interviewed described busy lives as women, mother's, partner's and workers. The experiences of these women appear not to be dissimilar to women generally during this time of their lives with young families. The day to day experiences involve multiple demands on their time and energy resources with an increased need for support from their partners, extended families and social supports. What is very clear, is that the lives of these women is stressful, this stress is seen in both the positive aspects and the challenging aspects of parenthood, pregnancy and life in general. This is the litany, the lived experience of the day to day lives of these women, this is not, however, the entire story. In order to better understand the experiences of those women interviewed, it is important to consider the social- and political context that these women live in. The information gained from this level of analysis, informed the next, deeper level of social causative factors.

#### 7.3.2 Social causative.

The Social causative level of analysis identifies those social, economic and political factors that influence and impact on the experiences of these women. This layer really highlights the importance and influence of the social determinants of health. Once again, while some of these factors might be visible to the wider community- the understanding of the deeper impacts of policies and social structures are often not seen nor understood. The main theme that emerged from the interviews was overwhelming poverty. Poverty is a complex issue and has been broken down into subthemes included issues around housing, financial stress and transport. These themes are closely related to each other and are a reflection of Government policies and social commentary that then leads into the worldview level of analysis.

# 7.3.2.1 Poverty.

Poverty is the overarching term used to describe extreme disadvantage. While poverty can be seen in terms of financial disadvantage, it extends further into areas such as a lack of power in the social and political arenas. A lack of financial resources leads to disadvantage in terms of education and access to health services which in turn lead to further disadvantage. The main subthemes will be discussed individually here, however in reality, they are almost impossible to separate.

#### 7.3.2.1.1 Homelessness.

During the initial stages of analysis, it was apparent that housing was a significant stressor in the lives of these Aboriginal women. The availability of Government housing is limited and there are substantial waiting times. The women described their experiences of being homeless, with small children and the lengths they were required to go to in order to secure a safe shelter for themselves and their families. One woman described the necessity of moving between family members and friend's homes until housing became available, or in her particular case, a bed was available in a women's refuge.

I went into the refuge in October 2010 but before that I'd been homeless since... it was going on for two years, living at my partner's Nan's house, at my Uncle's house, few friends.

One woman described her life living in her car with her 10 children. Her partner was incarcerated and she felt she had no other options. She would park the car in the drive ways of family members, who were unable to provide a home for her family, until she felt that she had outstayed her welcome and then they would move to another location. Despite the difficulties and the distances she had to drive, this

mother was proud that she managed to keep her children in the same school throughout this time.

...ten kids and me and my kids were homeless for three years before we moved down to XXX. And we haven't looked back since... In our bus. All his relative's houses. And I had no license and I just used to drive everywhere. Yea, it was hard. Hard on the kids too. They were still going to school. They were enrolled at XXX Primary so I used to just drive them from wherever we were staying. Like if we were in XXX or XXX, I used to drive all the way from there to XXX and back. Used to be hard.

When there is a lack of easily accessible housing options, desperate people are forced to behave in desperate ways. One participant described her family's overwhelming distress when they could not find any housing. She was pregnant with her second child and was homeless; it became the only option apparent to them-her partner was able to stay with family, however it was difficult to find somewhere for a family of three, soon to be family of four to stay.

I even had to go to the point where I had to tell a little lie to get into a refuge because they wouldn't take someone who is just homeless. The amount of crap I went through just trying to get into a refuge because I was homeless was ridiculous and you think, you're pregnant, you got one kid, one on the way and then when she was a newborn that's when I was like I've got to do something to get into a refuge so I told them I was domestic violence all between me and their Dad.

#### 7.3.2.1.2 Overcrowding.

One of the difficulties when government housing is limited, is that those family members who have managed to secure housing are often expected to provide shelter to others. Unfortunately this leads to overcrowding and the potential for

conflict which in some cases results in physical damage to the houses or eviction due to 'antisocial' behaviour. One participant described the difficulties if a neighbour makes a complaint about a family.

It's that whole idea because it happens often in our community. All it takes is for a neighbour to complain once, you know, and it's on. And it is so hard for Indigenous people to get rentals in this day and age, it's hard.

Once a family have been evicted under these circumstances, it becomes increasingly difficult for them to secure housing in the future.

Because we got evicted from a [state housing] house when I had L, so to get a [state housing] house we had to do like supportive assistance and all that sort of stuff because we were evicted for antisocial behaviour and so to get back in there, yes, it was hard. But at X Emergency they helped us heaps and heaps and heaps.

Many women reported high levels of stress when their current housing was inadequate for the size of their families. This was particularly important for women who were pregnant and trying to prepare for the arrival of another baby.

So it was stressful because it was a small house and I had four or five kids for nine months and the kids couldn't have nothing in their rooms

One participant described how she had secured government assisted housing in a two bedroom flat on the first floor of an apartment building. She described the physical challenges of living upstairs with a baby and a toddler (and being currently pregnant),

The big girl's asleep and I've got shopping so I've got to take one of the kids up or shopping then come back down for the other stuff. It's like I do that many trips up them stairs daily it's wrong.

This participant also described how fearful she was of her children falling from the balcony. To avoid this, she locked the doors and windows to keep her family safe, but then suffered with the extreme heat and lack of space for her young family. She described the dilemma of the choice of leaving her young children upstairs alone, while she went up and down the stairs with the shopping, or the alternate choice, of leaving her children unattended in the car, neither option was viewed as satisfactory by this participant. Despite being told by the housing organisation that they would need to move her (when she initially moved in) she stated;

I'm in a two bedroom flat with two little girls and I've got a bubba on the way, I want a three bedroom house and that's another thing that's on me because I'm having to contact Homeswest every day and get on their back about my transfer.

Unfortunately, having housing does not appear to necessarily reduce the experience of stress. Living in Government housing is seen as relatively unstable and somewhat unpredictable. Some of these women describe their own childhood in terms of the stress and instability of frequently moving home and changing schools. These experiences are symptomatic of the transgenerational nature of the cycle of poverty and homelessness. These early experiences make it an even bigger priority and therefore perceived stressor to secure adequate housing for their own families.

And I mean, even though I've got a house, I'd still like to buy a house, a rental or Homeswest house. But it's not stability, it's not something

that you know you can be there forever. And with kids I think that, I don't know, for me I want them to stay at one place for a long time. I moved around a lot and I just want them to stay at one place, one school. I've been 22 schools. So I just want them to stay at one school and just the house I guess is still a little bit stressful like I wish we could not be renting and the renting prices are just horrific, that's ridiculous how they charge you all this rent for something that is falling down around you.

A big area of concern was also the condition and maintenance of Government housing and the potential negative impact on health. One woman described the physical condition of her home and the potential negative impacts this could have on the health of her family.

My bathroom's leaking. I've had my ceiling replaced. I've had the tiles replaced. I've had this and that and I'm still getting water leakage all throughout my bathroom. All in my roof, my roof is starting to mould, the ceiling, the girl's ceilings, I don't like them sleeping in the rooms now. So there's a health issue in the house with us.

### 7.3.2.1.3 Summary.

There are many factors that impact housing availability. There are underlying issues that limit the choices of many Aboriginal people. Private rentals are almost impossible for Aboriginal people to access, this may be due to the higher cost of rent in the private sector or due to private landlords being reluctant to rent to Aboriginal people. This lack of choice puts further pressure on the government supported housing services. It can be suggested that many of the housing issues are related to poor quality housing that is often inappropriately allocated for the needs of the families.

When poorly maintained housing is provided for a family that has extended family without housing, this leads to overcrowding and tensions of large numbers of people living in close proximity. This creates a cycle, where the individuals are punished, and their housing options are even further diminished, which then puts added pressure on those with some level of housing. Having adequate shelter is a basic human need, and not having somewhere safe to stay at a time when women are preparing to have a baby creates enormous stress and distress at both an individual and community level.

#### 7.3.2.2 Financial stress.

Another important area that was identified as causing stress in the lives of these women were financial concerns. Many of the women interviewed were reliant on Government support, however there were similar concerns expressed in those families where at least one adult was employed.

Not having enough. Because it seems to go from payday and then we get just before payday and sort of run out sort of thing, yeah, arguments over that.

Just, you know, crap, I've got to get a new cot, I've got to save up for a pram, car seats aren't cheap these days

Again, early experiences of women living in poverty as children made the stress about being unable to afford school lunches particularly salient. While some schools provided breakfast clubs for those 'at risk' children, the stigma of accessing these programs would impact children's attendance at school.

...if you don't have a dollar to get them a loaf of bread to make sandwiches, that worries me. I don't want her to have to deal with that because we had to deal with that, you know? They won't have to be like "You're not going to school because we got no lunch, we don't get paid 'til tonight". I don't want to do that sort of stuff. That worries me.

One participant highlighted how the financial and housing issues can compound difficult situations and lead again to desperate measures. One woman described the fear of breaching welfare services 'rules' when her estranged partner (and father to her children) stayed in her home. Lack of housing availability resulted in him sharing her home, scrutiny from neighbours led to investigation from the government services.

Because we were always worried because we got investigated by [Government department] because people kept dobbing us in all the time so that was one big extra stress...I didn't want to get in trouble by [government department]

### 7.3.2.3 Employment.

The majority of women interviewed were either pregnant or had young children. Those women whose partners were unemployed expressed how difficult it was for them, both financially and emotionally.

...like we did argue a lot because of our situation at that point in time because it was stressful because he's trying to work, I'm trying to get us a house and we're just not getting anywhere.

Because my partner doesn't have a job recently so it's pretty stressful having him home all the time and I don't really want him to be home.

### 7.3.2.4 Transport.

The women interviewed lived in the southern suburbs of metropolitan Perth,
Western Australia. The public transport infrastructure is very limited and almost nonexistent in some areas. Access to transport, whether it is public transport or an

individual having a valid driver's license and private vehicle contributed to the stress these women experienced.

like I didn't want to go anywhere because it was just too tiring because I had no car and had to get the buses, so it was just like, but the time I thought about doing anything it was like, no, just can't be bothered.

The reality for many women who have small children is that it is extremely difficult just physically getting on and off a bus when there are no other adults available to assist.

You know when you're catching [the bus] it's really stressful, you know, like some of the bus drivers they don't help you when you've got kids, you've got your kid, baby there, and you've got shopping and they're telling you you've got to fold up your pram before you get on. It's like they expect you to get your kid and your shopping and put it on the seat or give them to a stranger to hold while you're getting the pram and folding it up and putting it on. So how are we going to do all of that? Just stresses me out.

These situations, where the safety of young toddlers and children can become problematic, will often force women to drive (when not necessarily licensed to do so) or to use taxi services which are significantly more expensive and not without problems.

These issues are often not considered in the health care context. Women are often seen as 'non-compliant' when they fail to keep appointments or to attend the hospital or clinic for important ultrasounds or blood tests. The difficulties in actually physically getting to these appointments is often overlooked; there is an assumption

that as these women live in the metropolitan area they have appropriate access to transport.

### 7.3.3 Worldview and myth and metaphor.

These deeper levels of analysis with the Causal Layered Analysis approach include the world view or discourse layer and the myth/metaphor layer. The worldview level describes the deeper social structures and beliefs that are held by the participants. These deeper beliefs are not explicitly stated by the participants, but are the shared underlying world views that emerged from the stories and experiences described. The myth/metaphor are the deep stories that surround the beliefs held by the 'collective'. These are the stories that are shared by participants that describe the deeper archetypes. These layers will be reported and described together as described earlier. While the worldviews are often not articulated directly by participants, they are so closely interwoven with the stories or 'myths'. These could be described as the hidden truths, the stories and understandings of people that are not clearly understood by the wider community or by those that are not a part of this particular cultural group.

### 7.3.3.1 Aboriginal family-role and obligations/conflicts.

Family was a dominant theme throughout the majority of interviews conducted. The complexities of family structure and the conflicts that arise when there are competing demands of time and limited resources are described by a number of the participants. Housing issues related to family were most frequently described and while issues such as overcrowding were described as difficult, there was an acceptance that these difficulties were an important part of being family.

...if family turn up on an Indigenous person's doorstep, you've got to let them in. There's no "I'm sorry, this is not a convenient time, can you come back later". No, no, they won't come back later. They'll stay here and they'll sit down and they'll drink your coffee and they'll eat your food and you know, if you pull out the mattresses they'll sleep on your mattresses. And "Oh, yea, such and such's Aunty's here but her daughter's coming down as well". That's alright, we'll just make more room.

What appears to contribute or compound these conflicts are the strongly held beliefs around the concept of family. Many participants describe the sense of obligation to provide support for family members. This sense of obligation is expressed within the cultural expectations of sharing resources within the extended family system. The extended family and kinship relationships within Aboriginal culture are complicated and very different to the traditional nuclear family structure of modern western culture families (Bourke, 1993). This experience of acculturation with some Aboriginal women appears to lead to a sense of guilt when these two different worldviews are presented together. One participant described the expectations of sharing resources within the family as a form of pressure and having a negative impact on her own family.

All I've got is my kids. And I want to keep them a home, a safe home, you know? I don't want to have a lot of people there around my home. Like in our house everything is ours; it doesn't belong to anybody else. The things I buy for my kids last longer and they have it because it's theirs. If you are staying at other people's in their house you won't have the things. You have to share things, whatever you got; they'll go in your room and take whatever they want. And it's just, like being, I don't like it when it's overcrowded. I don't know, like some people they're not used to living on their own, you want to take that step out of their family thing and me; I can't stand my family at times. I just like to have my quiet times.

Another participant described the responsibilities of supporting family in terms of being stressful and adding to the overall stress experienced.

But I have, I get stressed sometimes when families come over and they want to eat and leave a mess and they don't clean up and they want to live for free and they come in there to my home and steal things from us.

However, while describing some of the stressful aspects of family obligations, participants also described the importance of family as a source of support. There is a sense of needing approval from the family, despite the challenges they present.

I'd try and ring up to families. Or go and look for them. Sometimes they're sitting down in the park. I'll go and sit down with them for a while, have a good little talk and a laugh while the kids are playing around and families admiring how big they've grown.

The challenges of raising children within the context of different cultural values and practices is also highlighted within the participant's responses. The worldview of family within Aboriginal culture is suggested to be very different to the worldview of family within traditional Anglo or white culture. These differences appear to manifest in an increase of emotional distress and pressure experienced by the women in this study.

But my family, I love being with my family, I love family atmosphere, I love my kids experiencing my side of the family because it's a lot of his most of the time. And their family life is completely different to how I was raised.

# 7.3.3.1.2 Summary.

The experiences these women describe is evidence of different cultural worldviews of family. The importance of this world view of family is lost within the day to day stressful experiences of securing adequate housing or providing support to family members without housing. What becomes apparent is the incompatibility of these competing views of family. The participants experienced distress when the obligations and responsibility of family are at odds with the Western view of family in terms of the living arrangements within the traditional Anglo or white 'nuclear' family.

# 7.3.3.2 Role of Women and Motherhood.

Within the context of family, there were strong stories about motherhood. All of the participants described highly stressful lives, yet the single factor that was reported as an aspect of life that was rewarding and offered some protective function, was the experience of being a mother. There was a sense of validation from this role, in that, if their children were happy and in good health, they had succeeded in life.

I know when they are happy and they makes me happy... and my kids are really loving children, so I know that I'm doing a good job. Like G mob they used to tell me I'm doing a good job, my kids are really good and that. I'll tell them that I won't know. you know, they tell me I should give myself a pat on the back, but I tell them that I won't know if I did a good job until they become parents themselves. If I know that they become parents and look after their kids and do the things, take their kids to different places and things you know, and have time with them and their kids grow up to be wonderful kids then I'll know that I did a great job.

For some participants, being a mother provided a lifeline or reason for going on, which helped them deal with major trauma and ongoing stressors.

Just look at the kids. That's the main thing that's holding me back from doing something to myself. Sometimes I just get that worked up that I just want to do it, go, leave this world because I've had it.

Yes, they're my world. They're the reason I get up in the morning. They keep me going.

The experience of motherhood highlighted some of the difficult experiences that the women had with their own mothers, and provided the motivation to provide a different experience for their own children.

I just want to be a family, I want a home for my babies. I want to be a happy family, that's what I really want. Because I was fostered you see, I never had that, I never had a mum, never had a dad, and that's all I really want for my kids is to give them everything I never had. Yes, that's the ideal, yes.

I'm living my kid's life so I'm trying to give them the life that I never had without having that stress and thing that my parents went through.

The role of a mother is described in terms of being safe and of having a home, for several participants this was the most important priority and the focus of the discussion.

All I've got is my kids. And I want to keep them a home, a safe home, you know?

I don't know, this motherly instinct starts as soon as you're pregnant and you don't even have the kid but I knew that I wanted a house. I knew that I didn't want to take it to my dad's house.

Within the worldview level the mother or woman is a figure of strength and provides the safety for the family, but is also seen as the central figure that the family

comes towards. While the men are acknowledged by the participants in terms of being providers and partners, it is the women who appear to take overall responsibility of managing the family and ensuring cohesiveness of the family structure. This deeper held belief about women is clearly presented when the participants describe their own lives. When describing stress, the discussion returns to the expectations of themselves as women and as mothers. The ongoing juggle of multiple roles within complex intimate relationships is described frequently.

I feel like I just want to be by myself and just want to do this pregnancy by myself. I think him not being around would be so much easier and stress free. I think a lot of my worries and stress come from him.

The view of women being strong and busy is played out in the actions of these women, who are taking on significant additional roles in order to feel that they meet the expectations of the community, both Indigenous and Non-Indigenous.

Interestingly within the stories the women shared, this busy-ness was also seen as a way of managing depression or anxiety symptoms, the concept of relaxing or "sitting down" as a trigger for difficult emotions to surface. One participant described her need to be involved in many projects and to be busy as a way of feeling validated and not a burden.

...if people go "What are you up to?", I like to be able to rattle off a few things because it makes me feel like I'm contributing and I'm doing something. I'm not just sitting back and letting things happen.

One participant was describing herself as being "lazy" when she decided to take a step back while she was pregnant with her second child. She later justified her current role by explaining the future plans.

Busy, but I think sometimes I think that I could still try to be...I mean I still try to be involved, I apply for different things. Like I've applied to be involved in Aboriginal community project over in Vanuatu...

### 7.3.3.2.1 Summary.

The role of mother and woman is a deeply held belief by the women interviewed. The role is seen as complex and multifaceted, challenging yet rewarding. This belief of mother is often held up as a goal to strive for, particularly by those women who did not experience this themselves as children. This becomes a source of stress for these women; the paradox of feeling that they are only judged to be worthy when they are busy to the point of exhaustion. The pressure on these women to 'succeed' at motherhood is even more important when the safety and security of the family is dependent on them. While being a mother was seen as positive and protective in some cases, there appears to be a relationship with stress that will be explored further.

### 7.3.3.3 Worldview of stress.

Women conceptualised and described stress in a variety of ways, some described physical experiences, whereas others described stress in terms of psychological symptoms. While some aspects of the conceptualisation of stress may fit within the litany layer, these different perspectives of stress provide a broader understanding of how stress is viewed collectively. There were some similarities in the descriptions, however as several participants articulated there was some confusion around the terminology and they found it difficult to differentiate between stress and other psychological disorders, such as anxiety and depression. While the women found it difficult to articulate the experience of stress, there were strong

views around what stress can cause when experienced during pregnancy (whether currently pregnant at the time of the interview or not).

If I'm really stressed I try to just cover it over and push it down, but it's always there and you just think about it and I think it just bites away at you and being pregnant you know that people are always telling you if you're stressed you're going to have a bad pregnancy, you could harm the baby and stuff.

The fear of how high levels of stress could impact their unborn baby was expressed by many of the participants with one woman attributing stress with the loss of her baby. This woman had lost her brother to suicide, had moved her family interstate, and her husband had significant health problems, and as a result experienced extremely high levels of stress over a long period of time.

I had a miscarriage in 2009 and I reckon that was because of stress.

Most women, when asked "what was their experience of stress?" would respond with attributions of the causes of the stress. These causes were primarily relational with conflict with family members or partner being identified most commonly. These interpersonal conflicts were most commonly described in response to day to day stressors including financial difficulties and housing issues.

That was why I was stressed with my first pregnancy because I was living with my partner and his family in XX. My family are from XX and we had to travel from XX to XX to the doctor's appointments and that really stressed me out.

In order to understand the cultural conceptualisation of stress, questions were asked as to how it felt, either in their bodies or their feelings when they experienced

stress. Many women identified physical sensations such as headaches and feeling sick or dizzy, "I start feeling bit dizzy, tired, moody, not wanting to do stuff" and "just headaches" and others described it as a feeling of overwhelming tiredness, a lethargy that made normal daily activities difficult to complete.

And a normal person you think, someone's laying around in their room all day long, she's got two kids. The kids are locked up in the house. Is this woman depressed? But no one come and checked on me. I wasn't, I just couldn't be bothered doing anything because it was just a task to do everything. As long as I had food and went to the shops and that, like I didn't want to go anywhere because it was just too tiring because I had no car and had to get the buses, so it was just like, but the time I thought about doing anything it was like, no, just can't be bothered.

The more emotional responses to stress included feelings of sadness, "Just don't want to do anything, just want to sit in the room and cry, you know, because you've got no one to talk to and you talk to your family on the phone but it's not the same" and was often described interchangeable with anxiety "don't know, just really anxious like you know, get really hot, flustered, angry, frustrated. Sometimes I actually feel sick depending on how anxious I get, yeah".

I feel like there is a huge pressure inside me and I just want to get angry but I usually try to keep calm and do other things so that I can try to not be angry. It's like something waiting to blow up or something.

I just want to close everyone off, just leave me, yes. Yes, I get that feeling, don't touch me, don't look at me kind of thing.

There were varied responses from the women when asked how they manage their stress, or what helps reduce their stress. The most commonly expressed strategy was to either talk to someone or to go outside and walk,

I'll just get my kids and we go along and go to the park" and "I just wanted to get off and then I'd just go for a walk, for long walks".

I find that if I exercise, and it's a bit selfish, but I take an hour out each day and I just go and push the pram for a few kilometres and I feel like I'm a much better human being to be around.

I like going to the gym and doing my exercise. I find that I feel much more relaxed after I do that. I like to be by myself and do things but I feel like I shouldn't really be by myself to do things. Strange as that sounds.

Often during times of stress the women reported a lack of support or a reluctance to discuss their feelings with others, which increased their negative feelings. Another participant described one of the ways she tried to cope with stress through the use of alcohol and drugs.

I was really stressed ...All I was doing was drinking a lot and smoking marijuana a lot and hanging with the wrong people and arguing with my family and family arguing with me.

7.3.3.3.1 Pregnant vs non-pregnant women's experiences of stress.

While an important aspect of the research was to determine the cultural view of stress, the difference experiences of stress between women who were currently pregnant and those who were not currently pregnant was an important dimension to be understood. Overall, the responses from those women who were pregnant at the time of the interviews were very similar to those women who were not pregnant, the main difference being the priority and urgency of the issues.

I reckon it was just the same [experience of stress before pregnancy].

Just the fact that baby's coming now that's even more reason to make me push to get a house.

The housing difficulties described earlier were strongly presented by the pregnant women and non-pregnant women alike, however the addition of another person living in the home was seen as the breaking point for the already limited housing resources.

My house is too small at the moment for us. And my property manager's like "Oh, it's going to take you two years to get a transfer so I've got to live in this house with three kids, two bedroom house, upstairs.

Experiences of financial strain were expressed within the challenges of being pregnant, however, similarly to the housing issues these were highlighted by a change in priorities because of the impending arrival of another family member.

I've got to get a new cot, I've got to save up for a pram, car seats aren't cheap these days and you know, all of that now has come and it's even more so much so I feel like in my relationship with the other half isn't too good, I feel like I just want to be by myself and just want to do this pregnancy by myself.

The experience of pregnancy appears to increase the perception of urgency of the existing stressors in women's lives. Relationship difficulties, financial strain, housing insecurities were expressed widely by both groups of women, suggesting that while the salience of these stressors may be different, the stressors are not specific to pregnancy alone.

7.3.3.3.2 Transgenerational stress and loss of control.

Another important dimension of the experience of stress is the concept of control. This featured strongly in the women's stories, and was either referred to in terms of needing control, the importance of control, but was often in the context of living within a system where they experienced very little control over their own lives or circumstances. The result of this loss or lack of control was increased experiences of stress. Women described a lack of control in housing matters- rent and bills being deducted from their payments prior to them receiving them, landlords and government housing failing to ensure even the most basic of maintenance was done, and the fear of eviction if they complained. Women knowingly break the 'rules' of government assisted housing so they can provide a safe shelter for their families, they then live in constant fear of being reported to the authorities.

The stories shared by the participants highlighted the chronic nature of stress which was experienced by not only the participants, but by their children, the extended family and the generations before them. Most of the women, while describing occasions of acute stress related to specific incidents, denied experiencing stress on an ongoing basis, yet described their daily existence in terms that to an outsider appeared overwhelming and stressful. The need for women to provide different experiences for their children, highlighted the difficult circumstances in which they themselves were raised, violence, poverty, homelessness, foster and court systems were shared experiences by almost all of the women interviewed.

My parents split when I was a bit younger and Dad had a heart attack, he had a heart condition. I went and lived with him because Mum was an alcoholic. He died when I was twelve. The Court decided that she needed to be given the opportunity to be an unfit

mother so lived with her and her convicted rapist boyfriend who beat her regularly.

This woman would hide with her mother until it was safe to ring the police after her mother had been beaten on a fortnightly basis, until she was made a Ward of the State (to her great relief) and placed into foster care. When the stressful situations were acknowledged by the women, it was often seen within the context of 'normal' life, a life they had always known and accepted. One participant described being able to cope with the "biggest stressors", however "It's the minor ones that I don't seem to do really well with". This suggested that women can be habituated to high levels of chronic stress, yet a seemingly minor event can unravel their coping ability and cause enormous distress. One participant described a major source of stress was her teenage daughter not wanting to go to school. This same woman also described how her partner was currently in jail for violent offences towards her.

Yes, he sliced my throat and went to hit me with a tomahawk but he hit this old man who stepped in the way. So I'm doing it on my own now with the kids. He goes for parole next year.

This was told in a matter of fact way, and while she acknowledged the trauma of these types of events, and the fact that her children witnessed this violence, there appeared to be limited recognition of the ongoing impact of this on herself or her children. It is like the cumulative effect of these types of traumatic events leads to a sense of numbness, which enables the women to continue each day, dealing with the day to day challenges they face.

...in some ways you're just born into it. You don't know this different way of not having that on your shoulders, you think that's just normal.

#### 7.3.3.3.3 Summary.

Stress is presented as a multifaceted, complex experience that impacts all women in unique way. There are shared beliefs around the effects of stress, particularly during pregnancy and some similar experiences of both the physical and emotional responses to stress. It is difficult to describe an explanatory model of stress, however there are a number of perceived causes that are described commonly by the women that are reflective of the wider social and political context that these women live in. All women presented with, what can only be interpreted as highly stressful lives. The worldview of stress however, is understood within the context of specific events and ongoing hardships experienced. The pervasive, chronic nature of stress, the ongoing trauma is a part of the stories that make up these women's lives, again reinforcing the role of women as protectors and ultimately as survivors.

# 7.3.3.4 Experiences of racism / denial of experiences of racism.

Experiences of racism were actively denied by most of the women interviewed. This appeared to be a shared view, that while specific incidents occurred, overall Australia was not a racist place. However the stories that emerged suggest a deeper more insidious account of ongoing racism experienced by these women. This participant is describing the care she received in hospital when she was having her third child. She spoke glowingly of the care she received and described one particular midwife.

No, no, not at all. In fact, they were brilliant, they were wonderful. They were wonderful. The only time I...no, it just wasn't racism, no, nothing was racially based, I don't think. No, I can't even think of a moment where it might have been... There was one midwife who was an idiot but it wasn't that she was racist she was just really difficult with everyone. No, she was of these missionary types that was going to be the great white hope and wanted to tell me how much she knew

about Aboriginal culture because she read a few books...

This example is suggestive of a subtle racism, delivered in the guise of a 'multicultural Australia', where cultural awareness training is provided and this small amount of knowledge legitimises assumptions made about another cultural group that might otherwise be identified as racism. Other examples were not as subtle. Participants described the difficulties accessing services when they were seen as 'dark skinned' or 'more Aboriginal' than a fairer skinned Aboriginal person.

Whereas, my partner who's dark, if we are walking in the shops, like I do notice it like if he's been walking through a shop, the security follows him and this and that.

The same participant described how they had applied for several houses to rent, only to have every application rejected. She believed that the prospective landlords watched them very carefully and made judgements about their suitability to rent before the application was lodged based on the colour of her partner's skin. In contrast, when she applied with the same details, but viewed the property alone, the application was successful.

Example, when me and my partner were really struggling to find a place to rent and going to all different home opens, I ended up saying to him "Look, maybe you shouldn't come with me" and the second I did, we got a house.

This type of experience was described by other participants, one woman, married to a non-Indigenous man described how when they were travelling, if she enquired about accommodation she was told that there were no vacancies, however when her non-Indigenous partner enquired, there were rooms available. Another

woman described how her partner (quite dark skinned Aboriginal man) would be offered a job over the phone, however when he presented for work, the offer was rescinded. Despite the majority of participants denying that they experience racism, the participants described daily examples of racism in different contexts. Again, it appears that the chronic nature of these experiences alters the perception for these women. When describing these ongoing incidents one woman describes how her husband (non-Indigenous) expresses his ideas of how the general public view racism,

...we were talking about racism, and he said "Nowadays some people think that it's not as much", you know? But we said "That's not true, it's just as much there but people do it differently".

The idea that racism is somehow 'different' than in previous generations is suggestive of the concept of 'political correctness'. Overt racism has been deemed as unacceptable by society, so it is expressed in more subtle ways that continue to discriminate and marginalise Aboriginal people.

Another thing, even like when you are ringing for a taxi and that and the taxi driver will see because we are Aboriginals they drive past us. That's another thing... Yes. That's why sometimes I have to ring the operator and tell them "Yes and tell him that we are Aboriginal".

#### 7.3.3.4.1 Summary.

The incongruence between the worldview of racism and the actual stories and experiences of racism are telling of a deeper issue. It is suggestive that the rhetoric that is espoused publicly about the negative impacts of racism, the view that being racist is not acceptable has led to a view held in our community that racism doesn't exist. This belief is widely held, even by those people that experience racism on a daily basis. This conflict between beliefs and actual experiences can only lead to

greater cognitive dissonance which results in long term greater experiences of stress and emotional distress.

#### 7.4 Discussion

#### 7.4.1 Introduction.

The aims of this research included a) an exploration of how Aboriginal women conceptualise stress in order to inform b) whether the development of a culturally sensitive measure was feasible. While stress during pregnancy can have detrimental effects on the developing foetus and on birth outcomes, it was unknown whether the high levels of stress experienced by Aboriginal women was specifically related to the experience of pregnancy, or whether it was a more chronic experience related to other life factors. This was of particular importance to explore, as it could potentially guide the development of health interventions to reduce stress experienced by women during pregnancy. A further aim of this research was also to examine both pregnant and non-pregnant women's experiences in order to identify the aetiology of the experienced stress.

An exploration of the lived experiences of these Nyoongar women in metropolitan Perth has highlighted there are high levels of stress experienced by Aboriginal women that does not appear specific to pregnancy. The experiences described by these women, both pregnant and non-pregnant alike, however, describe an experience of ongoing colonisation that exists within our community today. While there have been very public attempts to address the inequity and injustices of our past (Council of Australian Governments (COAG), 2008), these women's stories in study two highlight how long-term colonisation and oppression continue to affect the lives of these women. This experience of ongoing colonisation and the almost inevitable sequelae of racial discrimination will be discussed with a particular focus on current

health service delivery and the relationship between these factors and the health outcomes of Aboriginal women.

#### 7.4.2 Explanatory model of stress.

Kleinman (1978) described a process by which a particular cultural group's explanation of the causes, symptoms and the most appropriate way of managing health conditions are elicited in order to provide health professionals, who are not from that particular cultural group, insight into the experience to assist them to provide culturally appropriate and sensitive care. A formal structured interview, as described by Kleinman (1978) was not used in this research, as the intent was to gain a broader understanding of the lived experiences of the women interviewed from a more collective cultural viewpoint. Rather than exploring a specific diagnosis, yarning (the most culturally appropriate method to gather this information) allowed us to explore a range of experiences within the social context of these women's lives.

It was found that stress, as experienced by Aboriginal women, is a complex, multifaceted phenomenon that manifests both physically and psychologically. It is often not identified as stress by the person experiencing it, due to the pervasive, chronic nature of this experience, which therefore suggests that women habituate to stress over time. These experiences are not unique to the women interviewed in this study as the health professionals interviewed in study one also reported similar experiences, however their stories suggest that these experiences are transgenerational and that this is likely to continue for future generations.

The findings in the current study of significant, high levels of stress experienced by Aboriginal women is not unexpected. Research that explores stress within Aboriginal communities has suggested that high levels of stress and exposure to stressful life events are seen across all areas of the Indigenous community, both in

Australia and internationally (Askew, Schluter, Spurling, Bond, & Brown, 2013; Bartlett, 2003; Burbank, 2011; Weetra et al., 2016; Zubrick et al., 2004). The types of stressors reported in this study are also consistent with other research, where issues including housing, financial resources, interpersonal conflict, violence and bereavement are often reported as being the most frequently reported stressful life events (Zubrick et al., 2004). What was apparent from exploring other literature is that there was no consistent approach to identifying high levels of stress or measuring the impact of that stress. Reporting an individual's experiences of a particular stressful life event does not provide an insight into how that stressor is perceived by the individual, nor does it provide any information on the cumulative effects of multiple stressors. This has been previously found in other research where it been has suggested that the appraisal of the stressor is an important factor in the response to stress (Cohen et al., 1983).

There is conflicting research findings about how stress influences health outcomes, and this is in part due to the difficulty in the identification or quantification of the experience of stress. High levels of cortisol have been thought to be the link between stress and health outcomes, yet these findings are inconclusive (Bolten et al., 2011; O'Donnell et al., 2009). Other researchers suggest the relationship between stress and health is through the immune system, where there are findings that suggest that there are increased risk of developing cardiovascular disease and other physical diseases (Scheiderman et al., 2005; Segerstrom & Miller, 2004). While the exact pathways appear to be unclear, there is strong evidence that there is a relationship between stress and poor health, which is of even more concern during pregnancy (Bartlett, 2003; Coussons-Read et al., 2012; DiPietro, 2012; Weetra et al., 2016).

# 7.4.3 Development of a culturally sensitive measure.

As discussed earlier, it is difficult to identify stress in Nyoongar Aboriginal women, and even more difficult to quantify the experience in order to develop clinical interventions to improve health outcomes. One of the aims of this study was to determine if it was feasible to develop a culturally appropriate screening tool to identify Nyoongar Aboriginal women at risk of high levels of stress in pregnancy. The purpose of identifying those highly stressed women was to then provide an opportunity for health care providers to offer additional support in an attempt to reduce the risk that chronic stress may have on birth outcomes.

Once the data had been analysed it became apparent that it would not be possible to develop a screening tool. The experience of stress, while widespread and experienced by all participants was extremely complex. There were common experiences and themes, yet to capture and attempt to quantify these experiences in order to identify women more at risk than others was not possible. This appeared to be due to the chronic nature of the stress and the fact that women at times denied experiencing stress, despite the difficult and often traumatic experiences disclosed. This was not entirely unexpected, as the literature around stress also struggles with the relationship between the stressful event or situation and measuring the impact on an individual, and the differences between pregnancy-specific stress and other causes of stress (Alderdice, Lynne, & Lobel, 2012; Ayers, 2001; DiPietro et al., 2004). Factors such as how an individual perceives the stressful event, personality factors and coping strategies all have a part to play in the overall effect the stress may have on health.

The women interviewed confirmed that as suggested by Institute for Child Health research (ICHR) researchers, Aboriginal families experience high levels of stress (Shepherd et al., 2012). What became apparent is that the experience of stress was such a chronic, intergenerational experience that when asked if they felt stressed, some women stated that they did not perceive themselves as stressed. Much of the stress research exploring the measurement of stress has examined 'perceived stress' yet if the individual does not perceive these experiences to be 'stressful' does this negate their experiences? A simple screening tool is unlikely to really capture those women who are at most need of support. The risk would be to either see a 'ceiling effect' as all the women interviewed would potentially score highly or minimising the experiences of the women screened by only recognising the overt symptoms. Either approach would be failing to acknowledge or respect the complexity of the deeper issues that are present within the community.

### 7.4.4 Pregnant versus non-pregnant.

The experiences described by both groups reflected the ongoing social and cultural issues within Australia today. While the pregnant women reported additional worry around financial issues and additional responsibility of the new baby in the family, the worry or stress wasn't specific to the experience of pregnancy. It highlighted how an addition to the family exacerbated their current stress around inadequate housing and limited financial resources. These findings make it clear that while the effect of stress is of particular importance during pregnancy, the real concern is the high level of chronic stress that these women live with on an ongoing basis. Research in this area has primarily focused on a specific stressful event (Rostad, Schei, & Jacobsen, 1995) or the pregnancy specific worry and anxiety that affects many pregnant women, including fears of the labour, concern over the wellbeing of their baby or worries of not coping (Da Costa et al., 1999; DiPietro et al., 2004). The findings in this study are in contrast to findings in the literature. Only

one pregnant woman out of the entire sample expressed concerns or worries regarding the health of her unborn baby and how she would cope with a new baby. It could be speculated that the competing needs expressed by the participants could explain this difference, however this was not specifically explored in this study.

Overall, the women in this study present a complex picture of stress that needs to be considered within a different paradigm.

#### 7.5.5 Ongoing Colonisation and Oppression.

The lived experiences of the women interviewed provides evidence that Aboriginal women live with extreme levels of stress that can be attributed to a plethora of causes. When examining the overall picture, it is clear that a root cause lies in the historical context that Australian Indigenous people live within. The poor health outcomes seen in the Indigenous community (Australian Institute of Health and Welfare (AIHW), 2012) and in particular, the poor birth outcomes that are reported, can be better understood within a model of social determinants of health. Social determinants of health, include socio-economic status, access to housing, healthy food, transport and employment. They also include experiences of stress, marginalisation and racism (World Health Organisation (WHO), 2003).

# 7.5.5.1 Social determinants of health.

When trying to make sense of the poor health outcomes that Aboriginal women continue to experience, the findings of this study provide support for the suggestion that poor health can be seen as a social issue. The focus of this research has been on the experience of stress, however this cannot be explored in isolation of other social issues including housing, transport, socioeconomic status and social isolation.

The temporal order of disadvantage is difficult to determine as it becomes a cyclical process that only seems to spiral into more disadvantage. In an attempt to deconstruct the social circumstances of these women's lives in order to understand the impact on health outcomes, I am going to start with an important theme that was identified in this study: family.

# 7.5.5.2 Family, culture and colonisation.

There is a mismatch between Western Anglo/white notions of family and Aboriginal notions of family. The women expressed stress when the two worldviews were deemed as incompatible. The western Anglo/white notions of family typically describe the nuclear family model, 2 parents and 1-2 children, and typically this nuclear family live together in a home and extended family live in other locations (Australian Bureau of Statistics (ABS), 2013). Some Aboriginal notions of family are different, the complex kinship relationships identify several key adults in a child's life that are of equal importance to the biological parents, and there is a collective approach to family life (Lohoar, Butera, & Kennedy, 2014). While a number of women described frustration and stress with the demands and obligations of the more traditional Aboriginal family life, these difficulties can be viewed within the restrictions imposed upon Aboriginal families by the dominant cultural views of family. The social systems and structures are such that, in order to 'be successful' you must conform to the cultural values that the system was built upon. One explanation for the stress and conflict is that our social systems are built on the premise of a 'nuclear family'. Our government housing policies and housing expectations are also built upon that premise. So, for an Aboriginal family to secure housing and to maintain secure housing, there is a need for them to conform to the western notion of family or in other words, assimilate. This creates the cognitive

dissonance and psychological distress that comes from being unable to live within the cultural values and beliefs of your own culture, and by being forced to adopt different values in order to survive (Alfred, 2009). While on the surface this can be described as a housing issue, the deeper underlying issue is that of ongoing colonisation.

Colonisation describes the process where there is control exerted over a dependent country, territory or people. To be colonised, is to be under the control of others, to have laws and beliefs imposed and in the process experience dispossession of traditional lands, culture and language (Czyzewski, 2011). While some might suggest we should be discussing current issues within the context of postcolonialism, the example described above suggests that our history is still guiding and influencing todays policies and social structures in Australia. The health implications of colonisation have been described in the literature extensively (Bartlett, 2003; Browne & Smye, 2002; Czyzewski, 2011; Durie, 2003; Moreton-Robinson, 2003; Sherwood & Edwards, 2006). The ongoing disparity between the health outcomes on numerous measures between Australian Indigenous people and non-Indigenous people has been described earlier in chapter three. While these differences are widely reported, and there is acknowledgement of the impact of colonisation, the links between these important factors are rarely considered, other than in the world of academia. We continue to see policies and services developed and administered in ways that continue to oppress, alienate and marginalise Indigenous people.

# 7.5.5.3 Oppression.

The concept of control was described by most participants in respect to a number of aspects of their lives. A lack of perceived control in matters of housing, in

accessing health care, in how their bills are paid each month, in who they choose to live with, how they access transport, are all examples that are reminiscent of early Australian policies when Aboriginal people were under the 'care' of the Protector of Aborigines (Hunter, 2001). While these are often areas of one's life that we can expect to have some control over, and some would say that these women also have control over these things, there are barriers in place that are only apparent if you are from within that particular group, barriers that are a part of the structure or organisation of society that can only be described as oppressive.

The result of ongoing colonisation, or dominance over another group of people is oppression. Oppression can be seen as a process where it "entails a state of asymmetric power relations characterized by domination, subordination, and resistance, where the dominating persons or groups exercise their power by restricting access to material resources and by implanting in the subordinated persons or groups fear or self-deprecating views about themselves "(Prilleltensky & Gonick, 1996, p. 129). Prilleltensky and Gonick (1996) further define oppression in terms of both political oppression and psychological oppression. Political oppression is seen in the legal, economic, material and other social barriers that prevent Aboriginal people from achieving self-determination, distributive justice and democratic participation. This is evidenced by the ongoing legal and political disputes over land rights in Australia, poor or limited access to housing, education, and employment.

The result of this oppression is then seen in the experience of psychological oppression. This is described by Prilleltensky and Gonick (1996) as "the internalized view of self as negative and as not deserving more resources or increased participation in societal affairs, resulting from the use of affective, behavioural, cognitive, linguistic, and cultural mechanisms designed to solidify political

domination" (p. 130). Political and psychological oppression usually complement each other, for example, psychological oppression is grounded in actual experiences of political oppression. When a participant described ongoing difficulties acquiring secure housing in terms of "we were evicted for antisocial behaviour" and "overcrowding". These terms are representative of the language used by the oppressors, terms used to indicate wrongdoings according to a certain cultural viewpoint and intended to remind these women that they are inferior. While the women valued the role of women, these same women felt the need to overburden themselves with 'busyness' and multiple roles in order to feel worthy, this ultimately comes from a place of feeling inferior. For these women, to remain still or have time to look inwardly and reflect resulted in negative feelings and significant distress, again, examples of psychological oppression, what Prilleltensky and Gonick (1996) describe as the intrapersonal level. This level leads to experiences of learned helplessness, obedience to authority and what is described above, the internalization of images of inferiority. This phenomenon has been described by Dollard (1937) where he believed that people who are oppressed, over time internalize the experiences and ultimately become oppressors of themselves.

## 7.5.5.4 Racism.

Racism has been defined in a number of ways. For the purpose of this discussion, I propose that a definition described by Berman and Paradies (2010) be adopted, that is, "racism [is] that which maintains or exacerbates inequality of opportunity among ethno racial groups. Racism can be expressed through stereotypes (racist beliefs), prejudice (racist emotions/affect) or discrimination (racist behaviours and practices)" (p. 217). In Australia the current political rhetoric describes

Australia as a multicultural country, where the existence of racism is largely denied.

The participants interviewed appear to support this worldview in their denial of experiencing racism. This can be seen as an example of oppression and ongoing colonisation, where the dominant cultural belief is imposed on others, and where the minority group's lived experiences are discounted and denied by those who perpetrate the racism. This phenomenon is a form of racism known as internalised racism (Berman & Paradies, 2010). While the participants denied experiencing racism, they later described multiple incidents of racism within the context of their daily lives which is more consistent with the literature examining racism within Australian Society (Dunn, Forrest, Burnley, & McDonald, 2004; Mellor, 2003). Other levels of racism include interpersonal racism, as described by the participants, this is racist comments and actions between people that serve to maintain disadvantage and finally systemic (or institutionalised) racism. Systemic racism is related to the systems and structures in society that also serve to maintain oppression and disadvantage (Berman & Paradies, 2010). The participants described examples of interpersonal racism with incidents involving other people, whether they be taxi drivers, hotel staff, shopping centre security, or health professionals. What is not stated but understood from the deeper levels of analysis are the ongoing experiences of systemic racism. This systemic racism has been linked to poor health outcomes in national and international literature and yet fails to be acknowledged in the area of health care service delivery (Feagin & Bennefield, 2014).

# 7.5.5.4.1 Racism and health outcomes.

Paradies and international collaborators conducted the first systematic review and meta-analysis of literature exploring the role racism has as a determinant of health across a range of populations, health contexts and reported health outcomes (2015). A total of 293 studies were closely examined and their findings suggest that

racism is significantly related to poorer health, with the strongest relationship found between racism and mental health outcomes. Although it was beyond the scope of this review, the authors recommended that further examination of a finer breakdown on mental health outcomes is needed, particularly in view of the evidence that the associations between racism and specific mental health outcomes, that is, psychological stress and depression may be different (Paradies et al., 2015). The relationship between racism and physical health outcomes, while not as strong as the relationship with mental health outcomes, was still significant in this systematic review. The types of physical health outcomes included were; blood pressure and hypertension, overweight, heart conditions and illnesses, diabetes and cholesterol (Paradies et al., 2015). What was not explored was the impact of racism on pregnancy, birth and infant health outcomes.

# 7.5.5.4.2 Racism and pregnancy outcomes.

While the research describing the relationship between stress and pregnancy and birth outcomes has been explored in earlier chapters, the relationship between racism and pregnancy and birth outcomes has not yet been explored. The focus in Australian literature on the causes of the poor pregnancy and birth outcomes of Indigenous women has focused mainly on the health behaviours of women, however American research has provided insight into the role of race and racism when trying to understand the disparity in birth outcomes between African American women and Caucasian women. This is an important relationship to explore when the findings of the current study describe significant experiences of racism in these women's day to day lives. Giscombe and Lobel (2005) concluded after an extensive review of the literature exploring birth outcome differences between European Americans and African American women, that there were disparities, even when controlling for

health behaviours, at all different levels of education and SES. They hypothesised that African American women may be more susceptible to the effects of stress during pregnancy due to the ongoing experiences of racism which may exacerbate the impact of stress. Similar findings have been reported by Braveman et al. (2010) where they found that low SES and education did not account for the disparity reported in infant mortality and adult life expectancy between different racial groups. The differences in outcomes between Black Americans and White Americans were consistent at each level of income and education, suggesting that there are other factors that may need to be considered, including racial bias. More specifically looking at birth outcomes, measured by birth weight and gestational age, Dominguez, Dubkel-Schetter, Glynn, Hobel, and Sandman (2008) also concluded that racism may play an important part in understanding the birth outcome disparities experienced between African American women and European American women. There is no data available to compare the findings described above from American research, when looking at birth outcome disparities between Indigenous and non-Indigenous women in Australia. This highlights a significant gap in our current understanding and offers important insight into further research that needs to be done within this population.

# 7.5.6 Conclusion.

In exploring the lived experiences of stress from the perspective of both pregnant and non-pregnant Aboriginal women, it is apparent that there is a great deal yet to be understood. In an attempt to develop an explanatory model of stress (Research question 1), it is clear that there are a number of key social factors that are associated with the stress that Aboriginal women experience. Women reported experiencing a varied range of physical and emotional responses to the daily

experiences of stress. These symptoms are often difficult to distinguish from the almost universal experiences of early parenting, however the women interviewed provided important information on shared experiences of particular social stressors. While it was not feasible to develop a screening tool, the insights into the types of stressors that Aboriginal women are managing in day to day life can be an important tool for health providers to use to identify women at risk. This information highlights the value and importance of primary care providers taking a holistic approach to maternity care. The information gained from these findings can provide clinicians with the knowledge that the social circumstances of their patient's lives is of vital importance when providing health care. There are questions that should be asked when meeting pregnant women for the first appointment that will allow appropriate referrals to be made to ensure basic needs can be met. Questions pertaining to the social circumstances experienced by the woman and her family may be useful, however the purpose of these types of enquiries would need to be very explicit and delivered with sensitivity and compassion. Further work needs to be done to explore the notion of racism within the construct of stress. While the negative health impacts of colonisation are well documented, the consequences of ongoing colonisation and oppression of Aboriginal women is not consistently considered when looking at health interventions or strategies to improve health outcomes.

# Chapter Eight: Implications, Limitations and Recommendations for future research

This final chapter will provide a summary of what we (researchers) now know and what can be done in the future to address some of the findings presented in this thesis. This will be followed by a discussion of the limitations of this research with some suggestions for future research.

## 8.1 What Can We Do Now?

In order to make sense of what we know and where we need to go next, I think it is useful to reflect on both studies in order to see what they add to our understanding of Aboriginal women and stress. We know that despite targeted health programs aimed at improving maternal and infant health outcomes, Aboriginal women and babies experience poorer health outcomes when compared to the non-Indigenous population (Australian Institute of Health and Welfare (AIHW), 2012; Campbell, Pyett, & McCarthy, 2007; Carter et al., 2004; Eades et al., 2012; Gibson-Helm et al., 2016; Kildea, 2008; Kildea, Tracy, Sherwood, Magick-Dennis, & Barclay, 2016; NSW Health, 2005; Rumbold & Cunningham, 2008; Thrift et al., 2011). When exploring the views and experiences of both Aboriginal health professionals and Aboriginal women (both pregnant and non-pregnant), the overall picture is not a positive one. The women have extremely challenging lives, fraught with poverty, social isolation and exclusion and ongoing violence, stress, and poor health. However, what is also evident is enormous strength of these women despite the challenges they face. The commitment of Aboriginal health workers to improve the lives of their community is seen not only their dedication to their paid jobs, but the sense of responsibility to their community and desire to make a positive difference. Women described horrific stories of domestic violence, yet also

expressed their sense of pride and accomplishment when they have raised their children, or left behind a life of drug abuse. As one participant said,

I just refused to accept that this is as good as it gets. And I refuse to believe, like, I just decided that if I can control what I can control and then I can...

What has become increasingly clear is that there is such a lack of understanding in Australian health service delivery about the impact of trauma, colonisation, and racism on the health of Aboriginal people. While there is a body of important research conducted in Australia by both Indigenous and non-Indigenous researchers that has highlighted the relationship between ongoing colonisation, racism, poverty and poor health, these messages don't appear to be reaching those with the power to make decisions regarding health budgets and service delivery models. Yin Paradies and colleagues have highlighted the impact of poor housing, racism, colonisation and mental health issues (Larson, Gillies, Howard, & Coffin, 2007; Paradies, 2016; Paradies & Cunningham, 2012; Priest, Paradies, Stevens, & Bailie, 2012) yet policies and government structures continue to isolate and discriminate against Aboriginal people.

Internationally, there is a body of research exploring the impact of stress and race on birth outcomes. While there is still much to learn about these relationships, there is enough evidence to suggest that racism has a significantly negative impact on birth outcomes in women from minority (and more commonly colonised) populations (Baskin, Strike, & McPherson, 2015; Braveman et al., 2010; Dominguez et al., 2008; Field et al., 2009; Riis, Sammel, & Elovitz, 2016; Rosenthal & Lobel, 2011). In Australia, the focus of research in the area of disparity in infant outcomes between Aboriginal and non-Aboriginal women has focused on health behaviours,

such as smoking during pregnancy and accessing antenatal care (Panaretto et al., 2005; Passey et al., 2013; Polen et al., 2014; Rumbold & Cunningham, 2008; Thrift et al., 2011; Wills & Coory, 2008; Wood et al., 2008). While it is not my intention to minimize the importance and value of this research, it appears that there is a gap in our understanding if we are failing to acknowledge the more fundamental factors that are known to impact these outcomes.

While a measure was not developed, the findings from this research can be presented in the form of education to health care professionals that provide midwifery/obstetric care to Aboriginal women. The conceptualisation of stress from the viewpoint of Nyoongar Aboriginal women is made up of complex social issues. Health professionals can make a difference by providing holistic care that sees the 'pregnant woman' as a member of a family, community and wider cultural group. Health providers need to ask questions about housing, transport, and financial stress in order to provide women with an opportunity to access services that are often unknown and/or difficult to navigate. These are key areas to investigate as indicators of stress for Nyoongar Aboriginal women in future research. These social stressors that have been identified by these women can be seen as 'proxy measures' of stress. While these experiences are difficult to quantify, early identification of these risks can alert health care providers so there is an opportunity to intervene with added support as required. This understanding of the cultural conceptualisation of stress is just one aspect however, and needs to be viewed and understood within the wider understanding of Aboriginal culture. Cultural competence skills should be an important aspect of any health professional's training and ongoing professional development (Ranzijn et al., 2009). Mental health professionals need to be mindful when assessing Aboriginal women who are experiencing mental health difficulties.

There appears to be overlap between the Western psychological views of depression and the symptoms described by the women in these studies. Experiences of rumination, loss of interest in usual activities, withdrawal from family and friends, tiredness/lethargy, feelings of sadness are all symptoms that may assist in the diagnosis of depression, but these same symptoms also are described in relation to experiencing high levels of chronic stress. While there may be underlying depression, traditional treatment of depression will not necessarily alleviate the experiences and circumstances of these women's' lives.

One explanation for the lack of research or acknowledgement of the relationship between colonisation, racism and health outcomes in Australia is ongoing racism. Henry, Houston, and Mooney published a viewpoint paper in 2004 highlighting funding inequalities, difference in treatment regimes, inequitable distribution of funding schemes and cultural barriers to Aboriginal people's use and access to health services (Henry et al., 2004). They described the Australian health care system as "institutionally racist" (p. 517). Institutionalised racism as described by the authors "refers to the ways in which racist beliefs or values have been built into the operations of social institutions in such a way as to discriminate against, control and oppress various minority groups" (McConnachie. Hollingsworth, & Pettman, as cited in Henry et al., 2004, p. 517). It could be said that the failure of research agendas to focus on key issues such as racism is an example of institutionalised racism, and the fact that research focussing on health behaviours becomes a form of victim blaming when the wider issues are not acknowledged.

The big challenge lies in how to address these issues and have a positive impact on the health outcomes for Aboriginal women and infants. There have been inroads made in the area of accessing antenatal services during pregnancy with the

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development of targeted programs that are culturally appropriate and safe for women to utilise. These programs are valuable and more likely to be utilised if they are delivered in a culturally appropriate way and recognise the unique needs of Aboriginal women and families. Programs such as the Boodjari Yorgas program at Armadale Health Service acknowledge the cultural values and practices of Aboriginal women by employing grandmothers and Aboriginal health workers to ensure the service is delivered safely in the community. The difficulty, however, lies in the sustainability of these targeted programs when health funding is restricted. The argument becomes one of equality and equity, the view that Aboriginal women have the opportunity to access the mainstream services is an argument of equality, yet in this scenario, equality does not equate to equitable access. Berman and Paradies (2010) discuss these concepts within the context of racism, where there are times when equality is deemed as unfair for example, when there are inherent differences between two groups. Both Aboriginal and non-Aboriginal women can access mainstream antenatal services, therefore support for an argument of equality, however this does not consider the specific factors that disadvantage Aboriginal women, that a mainstream service fails to acknowledge or accommodate, therefore resulting in inequity. While this is an extremely simplified example, it highlights how easily health services can continue to be complicit in ongoing disparity of health outcomes if we continue to do what we have traditionally done.

Berman and Paradies challenge the current views with the idea of antiracism praxis (Berman & Paradies, 2010). Within Australia's 'multicultural society' there is a lack of clear definition of racism and recently attempts to challenge some of the notions of free speech and racism based on the views of politicians is an example of the confusion (McGhee, 2017). Societal views are often reflected in the political

views of elected politicians, which then in turn influence the funding decisions around health service delivery. The Aboriginal community need advocates in the research arena, to continue to lobby and protest to ensure the findings of research are acted upon. This knowledge is valuable, but only if it is translated into real action that addresses the inequities researchers continue to identify.

## 8.1.1 Dissemination to date.

While the importance of engaging with those responsible for health funding decisions and policy development is of great importance, the knowledge gained from this research is also of value to the health professionals who provide primary care to Aboriginal women during pregnancy. To date, these research findings have been presented to midwives, Aboriginal health workers and mental health professionals in both formal and informal settings.

- Prandl, K.J. The process of engaging with the Nyoongar community from a Wadjallah perspective. 27<sup>th</sup> International Congress of Applied Psychology, Melbourne, Australia, July, 2010.
- Prandl, K.J. Stress during pregnancy: The views and experiences of Nyoongar women in Perth. Aboriginal Maternal and Child Health Conference. Perth, Australia. June 2012.
- 3. Prandl, K.J. Meaningful application of the National research guidelines in developing culturally safe engagement of Aboriginal women in health research. Building Mental Wealth: Improving Mental Health Outcomes for Indigenous Australians Public Seminar, Curtin University, November 2012

- 4. Prandl, K.J. Understanding stress from Australian Aboriginal women's experiences. 5<sup>th</sup> World Congress on Women's Mental Health. Lima, Peru. March, 2013.
- 5. Prandl, K.J. Exploration of Nyoongar women's explanatory model of stress during pregnancy and the development of a culturally sensitive assessment tool. 2013 Denis Glencross Memorial Student Conference. Perth, Australia. July 2013
- 6. Prandl, K.J. Stress and pregnancy in Australian Aboriginal women.
  Australasian Society of Behavioural Health & Medicine Annual
  Scientific Meeting, Perth, Australia. Feb 2015.

In addition to these formal presentations, I have been an invited speaker at professional development workshops and team meetings with the Aboriginal Child and Adolescent Community Health service, where I have had the opportunity to provide information about the experiences of Nyoongar women within the context of literature that explains the relationship between stress and pregnancy and birth outcomes. Health practitioners need to ask appropriate questions within a non-judgmental environment in order to provide the support women need.

## 8.2 Limitations

In this sections I will address the limitations of my studies, emphasizing the methodological, sampling and recruitment strategies employed. As an exploratory qualitative research project the aim was to gain understanding into the lived experiences of this particular cultural group of women. Initially an interpretive phenomenological approach was to be taken which was seen as appropriate for the research aim which was to explore the lived experience of the participants. Within interpretative phenomenological analysis (IPA) and research, the aim is not to

generalise to the wider population but to gain some understanding of how the women interviewed make sense of or perceive their own experiences (Brocki & Wearden, 2006). This has been an approach that has been described as particularly relevant to health psychology (Smith & Osborn, 2008). This was not however pursued after the initial yarning interviews had been conducted and the data was examined.

As I commenced the analysis process, I was very mindful of the influence my position and background potentially had on the interpretation of the participants' personal world. The more I immersed myself in the data, the clearer it became that beyond personal experiences and nuances of each individual women's story- there were deeper social and political issues present in each of the narratives. CLA provided a more transparent structure that I believe allowed the data to 'speak' more clearly with less 'influence' from the researcher. By firstly acknowledging the litany, or lived day to day experiences of the participants it became easier to see beyond the first order analysis and delve into the deeper areas of analysis that require more interpretation from the researcher.

Irrespective of the theoretical approach taken, the sample size within these two studies may be considered small. The first study (n=6) was done to identify particular information relevant to the proposed methodology and prospective participants in study Two. The sample, while small included health workers with a wide range of clinical experience and roles within Aboriginal health. There is no assumption that the findings described are generalizable to the wider Aboriginal community, however the findings were specific in answering the questions asked within the context of the second study.

The sample size of the second study was a total of 13 women, with pregnant women (n = 7) and non-pregnant women (n = 6). Again this is a relatively small

sample size when compared to some of the other qualitative methodological approaches. There is limited literature that provides guidance on the most appropriate sample size for a CLA. However, as with any qualitative study, the context and research questions need to be considered in addition to key issues such as the aim of the sampling (Sandelowski, 1995). In IPA, Smith and Osborn (2008) suggest that participants are purposively sampled and that small numbers are adequate to provide perspective within a particular context. The participants for study Two were purposively sampled according to their cultural identity, age and parity (ie., pregnant or non-pregnant). The potential pool of participants is particularly small when researching within a minority population (less than 3% of Australia's population) and then the additional criteria of female and pregnant further restricted this pool, so the intent was never to have a large sample size. The original aim to develop a screening tool would have required a considerably larger sample, however as analysis was commenced after the first interview, it was identified early in the sampling process that this was not a feasible option. Some authors of qualitative research describe either informational redundancy or theoretical saturation as a justification for sample size (Sandelowski, 1995), I am not suggesting that either of these were achieved within these studies. In depth yarning as a data gathering strategy enables such rich data to be collected that is so personal and individual, I am unsure that there would ever be a point where I could confidently make that claim. What I do suggest however, is that through the number of interviews conducted, there was sufficient data to provide insights into the lives of these particular Aboriginal women and the consistency of the experiences and underlying themes is useful in hypothesising about the wider social issues.

I do not claim that these women are representative of Aboriginal women in Perth. In part due to the difficult nature of engagement with the Aboriginal community and the importance of vouching, the recruitment was restricted to specific locations in the Southern suburbs of the metropolitan area and all of the participants accessed a health or education service. There are a significant number of women who do not engage or access any services, and their experience of stress may be very different to that of the women interviewed. The range of socio-economic status, determined by education levels attained and employment disclosed in the yarning discussion suggests that there was diversity within the sample. This demographic information was not collected, therefore not reported, however in both the pregnant and non-pregnant group there were women with secondary and post-secondary education in addition to women with minimal secondary education completed. Income and employment varied, with some women currently renting and unemployed (and partners unemployed) and others living in their own home and either studying or currently employed.

While these interviews have provided useful insights into the lives of these particular women, it is important to note that the Aboriginal community is not a homogenous group (NH&MRC, 2003). Even within the Nyoongar nation there are different beliefs and experiences and as the author of the findings of this study I do not and cannot presume that these experiences and interpretations are shared and valid across the wider Nyoongar community, or the Aboriginal community as a whole.

Understanding the experience of stress is difficult. While there are many measures, both self-report and physical markers, there has not been any real progress made into measuring this experience in terms of impact. Additional data including

cortisol levels, or other biological markers, may have provided another dimension to the argument of the stress experienced by the participants in these studies, but as the current understanding is still inconclusive I am unsure that this would have added anything overall. While the key aspect of this research was developed in response to poor birth outcomes, I have not examined birth outcomes in this research, but rather have extrapolated the likelihood of these outcomes based on the stress experienced by these women. The next step could be to replicate some of the US research that compares racial group's birth outcomes after controlling for a number of factors over different levels of education and SES status (Giscombe & Lobel, 2005; Williams, 2002). This will both potentially confirm these findings, but also provide evidence for addressing these inequities in a different way.

While I have described in some detail the issues and considerations taken into account as a Non-Indigenous researcher in this Indigenous health research area, it is important to also consider these cultural differences as a potential limitation of this research. I have explored this in some detail in both the findings and the discussion of study One, however the complicated relationships between Indigenous and non-Indigenous communities in Australia, both historically and today cannot be ignored and are an important part of this research. It is unknown whether the data would be different had the women been interviewed by an Indigenous researcher. Despite the reflexivity and cultural guidance I have engaged in and received, the interpretations of the data have been influenced by my own cultural background and life experiences.

## 8.3 Conclusion

Aboriginal women in Perth experience high levels of stress, which does not appear to be specific to the experience of pregnancy. While the experience of stress

is described in terms of physical and emotional/psychological symptoms, there are women, which despite disclosing high levels of stressful life events and difficult social circumstances deny feeling stressed. The chronic, transgenerational nature of these experiences suggest that it has been normalised and accepted as a part of life, yet may be contributing to the ongoing poor health outcomes, particularly poor birth outcomes currently seen in the Aboriginal population. In view of the fact that the women interviewed widely denied feeling stressed suggests that while this research has provided some understanding of the nature of the stressors, it is important to continue to investigate the idea of a cultural and uniquely Indigenous conceptualisation of what stress really is and how it is perceived. This is an under researched area of health and there would be value in further research that can build on these findings by allowing researchers to compare the stressors affecting Indigenous women and their non-indigenous counterparts to provide further support that additional resources are vital in order to improve pregnancy and birth health outcomes.

In 2017, despite 11 years of the Close the Gap government initiatives,

Aboriginal and Torres Strait Islander peoples of Australia continue to experience

poorer health outcomes than non-Indigenous people. Despite Indigenous people

being the most researched people in the world, they continue to experience

unacceptably high rates of disadvantage, stress and exclusion on a daily basis. There

are many health interventions that target these outcomes, but the pervasive nature of
oppression and disadvantage means that by the time a child is born, the trajectory of
health and social outcomes can already be predicted.

There is some excellent work being conducted in targeted antenatal programs that have identified the importance of providing culturally safe, person-centred care

by committed professionals. The difficulty is that many of these programs are underfunded, or are not formally evaluated to add to the wider understanding of these issues during pregnancy. While the relevance of maternal health behaviours on pregnancy and infant outcomes is well documented, the ongoing focus of these issues in the absence of any recognition of the wider social issues only serves to reinforce the victim blaming mentality within the community.

My findings provide direction for future research, by bringing disparate areas of research and clinical work together in order to recognise the relationship between the social and political environment and the emotional wellbeing of Aboriginal women. My research highlights the need for social change within a very conservative political and social climate currently experienced in Australia by contributing to the understanding of the ongoing impact of colonisation of Indigenous peoples. Future research that can clearly demonstrate the relationship between stress and pregnancy outcomes is vital to support the development of community strategies that can address some of the inequities currently impacting on the health of Aboriginal women and families.

As a white Australian researcher, psychologist, midwife, mother, and woman, I see the issues as complex and at times overwhelming. One of my participants explained the issues in a very clear way that highlighted how differently we all view the world. The holistic view of health and wellbeing from some Aboriginal cultural perspectives clearly recognises the interwoven relationships of our spiritual being, the earth, family, our body and mind. The answers are not impossible to find or understand, we just need to listen.

Non Indigenous people are very good at putting things in separate baskets without realising the relationships between things. So housing, it actually is almost like the centre point because if you've

got a secure stable home that you don't have to worry about, then you can send your kids to school because they can stay at the same school. Yes, education is taken care of. So you're not worrying about that. When your education stuff is taken care of, the kids are less likely to become offenders because they're not bored, they're not in trouble. So education is taken care of. When you've got your education and your health locked in, all the social justice stuff starts to take care of itself. So you find that there is less pressure...

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# **APPENDIX A Women's Reference Group Information**

Exploration of Nyoongar women's explanatory model of stress during pregnancy and the development of a culturally sensitive assessment tool.

Kelly Prandl
PhD Candidate
School of Psychology & Speech Pathology
Curtin University of Technology

Community Women's Meeting
Champion Centre
March 17<sup>th</sup> 2010
10.30am

A little bit about Kelly Prandl.....

Prior to a career in psychology...

- Grew up and went to school in Westfield
- Worked as a midwife and community nurse 15 years in Western Australia (13 years in Armadale/Kelmscott area)
- Managed Aboriginal Health Program in Community and Child Health (Armadale Health Service)
- Established the Boodjari Yorgas Antenatal Clinic at Armadale-Kelmscott Hospital
- Awarded Midwifery Fellowship 2007 to explore models of antenatal care for Indigenous women.

#### Currently...

- o Live in Bibra Lake with my husband and my 11year old daughter.
- Still have a connection to Westfield- my family and friends still live in Westfield
- Completed my Bachelor of Psychology (Honours) in 2008 at Curtin University
- Commenced my Clinical PhD in 2009 (Curtin University)

Supervisory Team;

Supervisor: Dr Rosie Rooney

Co-Supervisor: Dr Melissa Davis

Co-Supervisor: Assoc Prof Brian Bishop

My supervisors' role is to guide and assist me during my PhD. Dr Rosie Rooney has an extensive background working and conducting research with women during pregnancy and after the baby is born. Dr Melissa Davis is an experienced Clinical Psychologist and has an interest in psychological assessment tools. Associate Professor Brian Bishop has a long history of working with Aboriginal people and has valuable knowledge about conducting research in the community.

#### **Guiding values**

In order to ensure that this research is meaningful and respectful of the Aboriginal community all stages of research will be guided by the 6 values of

- Spirit and Integrity
- o Reciprocity
- o Respect
- Survival and Protection
- o Responsibility

#### Why is this research needed??

- Stress in pregnancy can be harmful for mother and baby
- Many Aboriginal families/women experience high levels of stress
- We want to be able to identify Aboriginal women who might be at risk due to their high levels of stress in pregnancy.

#### What is this research all about??

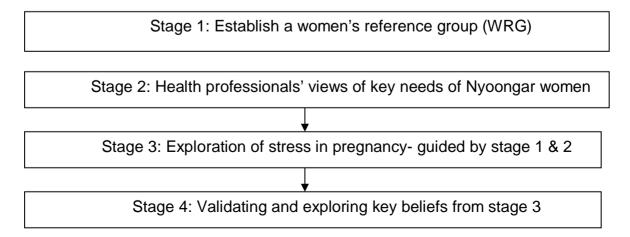
Study 1: Explore how Nyoongar women conceptualize stress (explanatory model)

Study 2: Develop a culturally sensitive measure of stress in pregnant Nyoongar women.

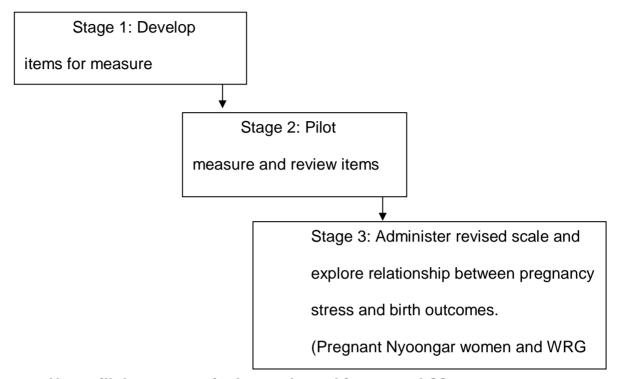
#### How is this going to be done??

This research will be done by conducting interviews and focus groups with Aboriginal women and professionals working with Aboriginal women.

# STUDY 1



#### STUDY 2



# How will the community know about this research??

- We will rely on word of mouth messages to share information with the community.
- Community meetings can be arranged to let the community know what is happening.

#### Where else will the information go??

- As this research is part of my PhD all the findings and results will be written up as a thesis which will be assessed by examiners.
- The studies will be written up and submitted to academic journals to be published internationally. This will only be done with due and appropriate recognition of the Aboriginal women's involvement and contributions.

 I am expected to present this research at conferences, both in Australia and internationally, again only with due recognition and input from the Aboriginal community.

Thank you for taking the time to come along to this meeting. If you have any questions or concerns about this research please feel free to contact myself or my supervisors.

Kelly Prandl: 9266 7619

Dr Rosie Rooney: 92663050 Dr Melissa Davis: 92662601

Assoc Prof Brian Bishop: 92667181



#### **APPENDIX B Yarning interview Protocol**

### Yarning interview 1

Exploration of relevance of research topic: Aboriginal support/health workers, Non-Aboriginal health providers.

Introduction: Brief explanation of proposed research from my perspective.

- 1 Is this research area important to the Aboriginal community? If yes, why...
- 2 If not, what are the issues you see with pregnant Aboriginal women?
- 3 What sort of areas do you think I need to explore with pregnant women to understand this topic?

Prompts: pregnancy, social/economic factors, family/friend relationships, housing issues, cultural issues, experiences of racism, employment etc

Brief description of methodology.

- 4 Is this methodology culturally OK? (interviews, recording of interviews, focus groups)
- 5 What might some of the issues be with this methodology?

Prompts: Non-Indigenous v's Indigenous interviewer
? need for Cultural Consultant present at interview
confidentiality

6 Are there any topic areas or questions that would not be appropriate if I asked (as a Non-Indigenous researcher). Is there another way?

Brief description of purpose- to develop screening tool.

- 7 How can this knowledge assist Aboriginal women?
- 8 How would you like to see the findings of this research used? *Reciprocity* 
  - 9 What can I give back to the community?
  - 10 What is the best way for me to recruit women for the research?
  - 11 Do you know any other women (working with Aboriginal women) who would be interested in talking to me?
  - 12 Would you be interested in being a member of the Women's Reference Group?

13 Is there anything else I haven't asked that you believe to be important?

Thank you for your time...

Check contact details.

# **APPENDIX C Information Sheet (Health Professionals)**

#### Information Sheet 1-Service providers

#### Understanding stress from an Aboriginal Woman's perspective.

#### The researcher:

My name is Kelly Prandl, I am a postgraduate student from the School of Psychology at Curtin University of Technology. The purpose of this study is to explore the experiences of stress in Aboriginal women during pregnancy.

#### What will this research do?

Ultimately the knowledge gained from this will assist in the development of a culturally appropriate way for health professionals to identify women experiencing high levels of stress in order to provide them with extra support during their pregnancy.

#### Why is this important?

This will benefit both women and their infants as there is a suggestion that high levels of stress can lead to greater risks of poor health for the infant.

#### What do I need to do?

This stage of the study will involve women who provide health and/or support services to pregnant Aboriginal women in the Perth metropolitan area. I am interested in your views on the needs of Aboriginal women and I am hoping for your assistance on the most appropriate way to conduct this research in the community.

#### How will information be collected?

Information will be collected through a tape-recorded yarning interview lasting approximately 60-90 minutes. This yarning will be conducted at a mutually convenient time and place. To ensure that I have understood and represented the information correctly, I would like to meet with you again to discuss the interview at a later date.

#### What if I feel uncomfortable with the questions?

During the interview you may wish to make comments 'off the record' in which case the tape recorder will be turned off. Also, if there are questions you feel uncomfortable about, let the interviewer know and these questions need not be answered. If you experience any feelings of distress during or after participation in this study a debriefing session with the researcher can be arranged on request. If further support is required please contact your health care provider or alternatively see the list of local support services available.

#### Is my information safe?

At all times the information provided by you will be kept confidential in a locked cupboard at Curtin University. After the second meeting with you, your interview information will be given a code and your name and personal details will be destroyed. While extracts from the interview may be used in the final report and in any publications, your name will not be reported and you will not be identifiable from the information used. Participation is voluntary and you may withdraw at any time.

#### How will I know how the research is going?

Information will be available about the research process and the final results through newsletters and community meetings. Community members will be notified of these events through local newspapers and community programs.

#### Who has approved this research?

This study has been approved by the Curtin University Human ethics Committee (Approval Number HR113/2009) and the Western Australian Aboriginal Health Information and ethics Committee (WAAHIEC) Ref 264/11/09. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/Office of Research and development, Curtin University of technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

#### Who can I contact for more information?

If you require any further information about this research please do not hesitate to contact me on 9266 7619. You may also contact my supervisors, Dr Rosie Rooney on 92663050 or Dr Melissa Davis on 92662601.

Thank you very much for taking the time to read this information sheet.

Regards

Kelly Prandl

Support Services Perth Metropolitan Area.

Ruah-Anawim Aboriginal Women's Services	9328 7562	Women's Domestic Violence Helpline	1800 007 339
Uniting Care West:	1300 663 298	Women's Health Service	9227 8122
Crisis Care Helpline	1800 199 008	Lifeline	131114
Gosnells Women's Health Service:	9490 2258	Derbarl Yerrigan Health Service	East Perth: 9421 3888 Maddington: 9452 5333
Anglicare WA	9325 7033		Mirrabooka:9344 0444 Mirrambeena:9439 1179

# **APPENDIX D Consent Form (Health Professionals)**

#### **Consent Form 1**

l,	(print full name), have read the information
sheet on the study exploring stress from a pregn	ant Aboriginal woman's perspective. I
understand the nature and purpose of the study	and what my participation involves.
I have been given a copy of the consent form. I u	understand that my participation is voluntary
and that I may withdraw at any time from the stud	dy without penalty. I am over the age 18
years.	
Signed:	
Participant	
·	
Signed:	
Researcher	
Date: / /	

#### **APPENDIX E Information Sheet 2**

# Information Sheet 2-Aboriginal women Understanding stress from an Aboriginal Woman's perspective

#### The researcher:

My name is Kelly Prandl, I am a postgraduate student from the School of Psychology at Curtin University of Technology. I am conducting a study exploring how Aboriginal women experience and describe stress during pregnancy.

#### Why is this important?

The reason I am interested in this is because high levels of stress can affect the health of both the pregnant woman and her baby.

#### What will this research do?

The information I collect will be used to develop a short questionnaire to assist midwives and doctors in identifying women who are experiencing high levels of stress so that extra support can be offered during pregnancy.

#### What do I need to do?

This study will involve Aboriginal women who are pregnant and women who are not pregnant. I am interested in how you feel/felt during your pregnancy, or how you experience stress. Information will be collected either by:

[		] A tape-recorded interview lasting approximately 60-90 minutes. This interview will
		be conducted at a mutually convenient time and place. To ensure that I have
		understood and represented the information correctly, I would like to meet with
		you to discuss the interview again at a later date.
[	]	A focus group discussion (tape-recorded) lasting approximately 90minutes.
		Focus group date/time://
		Location:

#### What if I feel uncomfortable with the guestions?

During the interview you may wish to make comments 'off the record' in which case the tape recorder will be turned off. Also, if there are questions you feel uncomfortable about, let the interviewer know and these questions need not be answered. If you experience any feelings of distress during or after participation in this study a debriefing session with the researcher can be arranged on request. If further support is required please contact your health care provider or alternatively see the list of local support services available.

#### Is my information safe?

At all times the information provided by you will be kept confidential in a locked cupboard at Curtin University. After the second meeting with you, your interview information will be given a code and your name and personal details will be destroyed. While extracts from the interview may be used in the final report and in any publications, your name will not be reported and you will not be identifiable from the information used. Participation is voluntary and you may withdraw at any time.

#### How will I know how the research is going?

Information will be available about the research process and the final results through newsletters and community meetings. Community members will be notified of these events through local newspapers and community programs.

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#### Who can I contact for more information?

If you require any further information about this research please do not hesitate to contact me on 9266 4149. You may also contact my supervisors, Dr Rosie Rooney on 92663050.

Thank you very much for taking the time to read this information sheet. Support Services Perth Metropolitan Area.

Ruah-Anawim Aboriginal Women's Services	9328 7562	Women's Domestic Violence Helpline	1800 007 339
Uniting Care West:	1300 663 298	Women's Health Service	9227 8122
Crisis Care Helpline	1800 199 008	Lifeline	131114
Gosnells Women's Health Service:	9490 2258	Derbarl Yerrigan Health Service	East Perth: 9421 3888 Maddington: 9452 5333 Mirrabooka: 9344 0444 Mirrambeena:9439 1179

# **APPENDIX F Demographic Information (Health Professionals)**

# **Demographic Information 1**

Please complete all questions that apply to you. This information is confidential and will only be used by the researcher to contact you at a later stage to ensure that the information is presented accurately. Your name or identifying information will not be used in any reports.

1.	Name:					
2.	Contact Number:					
3.	Address:				_	
4.	Employer:					
5.	Current position:					
6.	Are you	a. Aboriginal			[	]
	(Please tick)	b. Torres Stra	nit Islander		[	]
		c. Aboriginal	and Torres St	rait Islander	[	]
		d. Non Abor	iginal		[	]
	Thank you					
	Office use only:					
1.	Interview code Number					
2.	. Consent form completed: Y N					
3.	. Interview date:		//	-		
4.	4. Transcription: Y N			N		
5.	Review Interview date	. Review Interview date:/				

# **APPENDIX G Flyer for recruitment**

Hello,

Are you a Nyoongar woman??

Are you currently pregnant??

Image removed for copyright

reasons

Are you interested in being a part of a research project looking at stress during pregnancy?

If your answer is yes to these questions.... Please contact me;

Kelly Prandl (Research Psychologist)

kelperth@gmail.com

0402 299 050 (SMS/call)

Curtin University 92664149

To thank you for your time each participant will receive a \$25.00 voucher for either Coles or Woolworths.

# **APPENDIX H Consent Form and Demographic information (pregnant/non-pregnant women)**

# **Consent Form 2**

(print full name), have read
ne information sheet on the study exploring stress from a pregnant/non- regnant Nyoongar woman's perspective. I understand the nature and surpose of the study and what my participation involves.
understand that I am agreeing to be interviewed by the researcher on 2 ccasions. I also understand that I can also volunteer to participate in a focus roup.
have been given a copy of the consent form. I understand that my articipation is voluntary and that I may withdraw at any time from the study without penalty and that my antenatal care will not be affected by my articipation or non-participation in this research.
understand that if the researcher has concerns for my safety and the safety of my unborn child she may, in discussion with myself, refer me to a support ervice. If she feels the risk is great she may contact my parent/guardian (if onder the age of 18years) of refer me to a support agency without my onsent.
Signed: Participant
Signed: Participant's parent/guardian (if under the age of 18 years)
Signed:
Researcher  Oate:/

l am	interested in being	contacted at a l	ater date to b	e involved in	a focus	
grou	p discussion	Υ	N	(please	circle)	
3	,			(I	,	
		Demographic	Information			
Plea	se complete all ques	stions that apply to	you. This info	rmation is cor	ıfidential and	d
will c	only be used by the r	esearcher to conta	act you at a lat	er stage to en	sure that the	е
infor	mation is presented	accurately. Your r	name or identif	ying information	on will not be	е
		used in any	y reports.			
Se	ection 1: PERSONA	L INFORMATION	I			
1.	Name:					
2. 3. 4.	Date of Birth: Contact Number: Address:	//				_
s	ection 2: PREGNAI	NCY INFORMATION	ON			
6.	Are you currently p When is your baby	due?	Y /_	N (go to sec /	tion 3)	
7. 8.	Is this your first bab If no to Q7, what no or more		Y ase circle) 2	N 3 4	5 6	
So	ection 3: PREVIOUS	S PREGNANCY II	NFORMATION	I		_
10	Do you have any cl . When was your bal . How many children	oy born?	//	Y NA NA	N	

#### **APPENDIX I Copyright Information**

#### Yarning image

Bessarab, D., & Ng'andu, B. (2010). Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies, 3*(1), 37-50. Retrieved from http://www.isrn.qut.edu.au/pdf/ijcis/v3n1\_2010/Final\_Bessarab\_Bridget\_IJCIS.pdf

http://www.isrn.qut.edu.au/publications/internationaljournal/legalstatements.js

#### **p**

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 From:
 Dawn Bessarab

 To:
 Kelly Prandl

 Subject:
 RE: Permission for use of image

 Date:
 Thursday, 17 August 2017 11:45:33 AM

 Attachments:
 image002.png

image003,png image005,png Importance: High

Hi Kelly

I can't speak for Bridget, but as the first author I am happy for you to use this model. I am sure that Bridget would be ok as well. Rgards

Dawn

Dawn Bessarab PhD, BSW, Hons

Professor|Director| Centre for Aboriginal Medical and Dental Health (CAMDH)| SPARHC University of Western Australia| 35 Stirling Highway CRAWLEY WA 6009
T: +61 08 6488 2038 | F: +61 08 6488 1917 | E: dawn.bessarab@uwa.edu.au | Mb: M303 CRICOS: 00126G



New Publication recently released: International Indigenous Voices in Social Work ISBN(13): 978-1-4438-9468-5

From: <u>Guy, Elise</u> on behalf of <u>info</u>

To: Kelly Prandl

Subject: RE: Other enquiry - Indigenous Australians [SEC=UNCLASSIFIED]

Date: Wednesday, 16 August 2017 9:10:01 AM

Hi Kelly,

Thanks for your email.

Permission has been granted under the Creative Commons Licensing which allows third parties to adapt, disseminate and transform AIHW products/information provided proper acknowledgment is given. Please refer to the <u>copyright page</u> on our website for more information.

Best of luck on your

PhD! Kind regards, Elise on behalf of

#### **The Communications Team**

Australian Institute of Health and Welfare

From: Webmaster [mailto:webmaster@aihw.gov.au]

Sent: Monday, 14 August 2017 5:42 PM

To: info

**Subject:** Other enquiry - Indigenous Australians

Field	Value
Type	Other enquiry
Subject	Indigenous Australians
Message	Hello, I would like to seek permission to use a figure (1 Low birthweight babies per 100 live births, by Indigenous status of mother and state/territory of residence, 2011. Adapted from "AIHW/NPESU analysis of 2011 National Perinatal Data Collection 2016 report" by AIHW, 2016. Australia's mothers and babies 2014-in brief. (Perinatal statistics series no. 32. Cat. No PER 87. Copyright 2016 by Australian Institute of Health and Welfare.) in my PhD Thesis. I am unsure who I need to contact regarding this and would appreciate some guidance please. Thanks, Kind regards Kelly Prandl
Name	Kelly Prandl
Organisation	Curtin University
Business sector	University
Country	Australia
Aust. State or Territory	Western Australia
Email Address	K.prandl@curtin.edu.au