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DHANGUDE DUNGHUTTI BURRAI
Welcomed to Dunghutti Land: towards a shared
understanding of grief and loss

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of grief and loss**

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RN., Med (Adult Ed.) University of Technology, Sydney

A thesis submitted in fulfilment of the requirements
for the award of the degree of Doctor of Philosophy



**Faculty of Health and Human Sciences
2011**

Thesis Declaration

I certify that the work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text, and that the material has not been submitted, either in whole or in part, for a degree at this or any other university.

I acknowledge that I have read and understood the University's rules, requirements, procedures and policy relating to my higher degree research award and to my thesis. I certify that I have complied with the rules, requirements, procedures and policy of the University.

Wendy Joy Hampshire

A handwritten signature in cursive script, appearing to read 'Wendy Hampshire', written in black ink.

March, 2011

Abstract

*I respectfully acknowledge the traditional owners of this country.
I pay respect to the Elders, past, present and future. The thesis
was made possible because I was made warmly welcome by
the traditional owners of Dunghutti Land.*

Background

There is limited research which focuses on the meaning and experience of Aboriginal grief and loss from Aboriginal people themselves and thus there are currently no clinical Aboriginal models of grief, loss or bereavement on which to base care delivery, or service provision.

Methods

The study is an ethnographic study which was guided and approved by key Aboriginal people living in Dunghutti country, including the Board of Governance at Durri Aboriginal Corporation Medical Service.

Aims

The study aimed to document and analyse the needs of Aboriginal people living in Dunghutti country related to grief, loss and bereavement.

Results

The study has documented the beliefs, values and opinions related to the experience of grief and loss. In addition the study has highlighted the meaning of grief for participants, (which is much broader than the meaning of grief for non-Aboriginal people) and the study has shown that the community involved has a unique history, which shapes the current experience of grief. Therefore culturally safe health care would include this experience. The study has confirmed that Aboriginal people who participated hold strong beliefs and practice rituals in relation to death, dying, loss and grief.

Outcomes from the study are significant, firstly, that the symbolic perspective on Aboriginal grief model developed for the study is unique to this study and could be used for future qualitative health studies. Secondly, the findings of the study could be used to support inter-professional health education related to cultural safety.

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Glossary of Terms and Abbreviations

Aboriginal: In accordance with NSW Health Guidelines the capitalisation is used throughout this thesis to refer to a person who identifies themselves as Aboriginal; is accepted by the Aboriginal community as being Aboriginal and is a part of the Aboriginal race of Australia (New South Wales Department of Health, 2004). The term Aboriginal is used throughout the thesis to refer to Aboriginal people of Australia. However, the term Aboriginal is not typically inclusive of Torres Strait Islander people

Aboriginal and Torres Strait Islander- (ATSI):

Documented as a preferred and inclusive term in accordance with the National Health and Medical Research Council guidelines. However, other NSW guiding policy documents note the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander in acknowledgment that Aboriginal people are the original people of NSW (New South Wales Department of Health, 2004)

ABS: Australian Bureau of Statistics

ACCHS: Aboriginal Community Controlled Health Service

ACMS: Aboriginal Corporation Medical Service

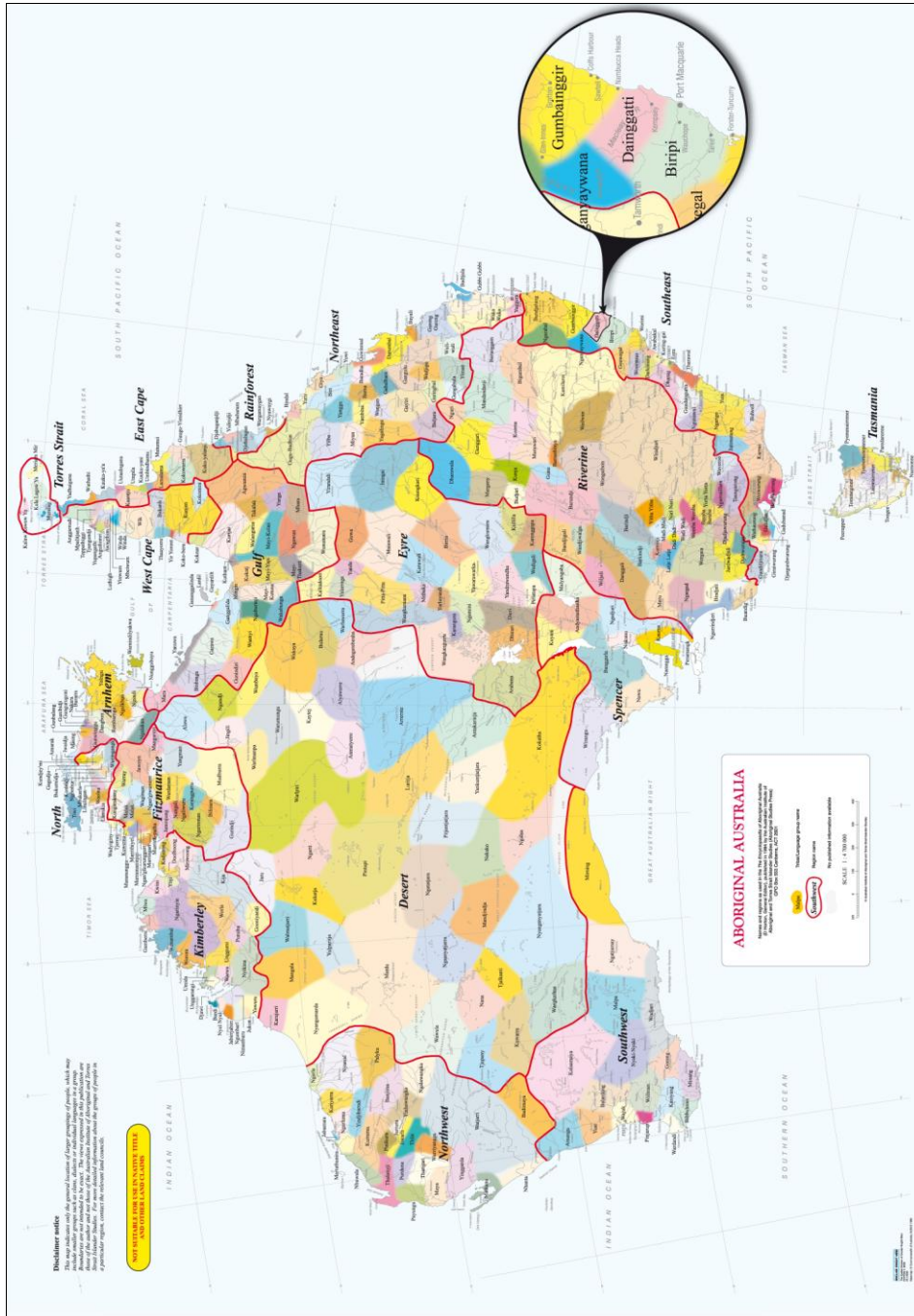
AIATSIS: Australian Institute of Torres Strait Islander Studies

APB: Aboriginal Protection Board

ASGC: Australian Standard Geographical Classification

CEO:	Chief Executive Officer
COAG:	Council of Australian Governments
Community:	In accordance with National Health and Medical Research Council guidelines it is acknowledged the word community is a complex concept in relation to Aboriginal and Torres Strait Islander people. For the purpose of this study, community refers to Aboriginal people living in Dunghutti Country
DALYS:	Disability Adjusted Life Years
Dunghutti:	As noted on the Aboriginal Australia map, the name of the traditional Aboriginal nation where this study was completed
Durri ACMS:	Durri Aboriginal Corporation Medical Service
HREC:	Human Research Ethics Committee
INEWG:	Indigenous Nurse Education Working Group
Koori:	Aboriginal and Torres Strait Islander people from NSW
LGA:	Local Government Area
MNCAHS:	Mid North Coast Area Health Service
MRRAVW:	Many Rivers Regional Aboriginal Violence Workshops
NACCHO:	National Aboriginal Community Controlled Health Organisations
NCAHS:	North Coast Area Health Service
NHMRC:	National Health and Medical Research Council
RACF:	Residential Aged Care Facility
SLA:	Statistical Local Area

Aboriginal Australia Map¹ Showing The Research Location²



¹ The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) granted permission to reproduce this map. The following notation is included in accordance with this permission.
 David R Horton, creator, © Aboriginal Studies Press, AIATSIS and Auslig/Sinclair, Knight, Merz, 1996
 This map indicates only the general location of larger groupings of people which may include smaller groups such as clans, dialects or individual languages in a group. Boundaries are not intended to be exact. The views expressed in this publication are those of the author and not those of AIATSIS. For more information about the groups of people in a particular region contact the relevant land councils.
NOT SUITABLE FOR USE IN NATIVE TITLE AND OTHER LAND CLAIMS

² There are variations of the spelling of the research location amongst various reports cited and from Aboriginal participants in the study. Variations include Daingatti and Thunghutti. For the purpose of this thesis the spelling Dunghutti is used on the advice of the Aboriginal Corporation Medical Service (ACMS) executive where the study was conducted.

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My sincere gratitude is expressed to the Dunghutti Aboriginal Community including staff and the executive board at Durri Aboriginal Corporation Medical Service, Dunghutti Elders Council and North Coast Area Health Service Aboriginal Directorate. Many people so willingly provided me with guidance on culturally sensitive issues. People's capacity to support me as a researcher in addition to their own community roles and employment commitments is deeply respected and valued.

It was with great honour that I accepted the generous offer to use the traditional Dunghutti language in the title of the thesis. My utmost appreciation is extended to the Elders in the community who interpreted the title. I respectfully acknowledge the Welcome to Dunghutti Land given to me.

To the people who participated in this study, this thesis represents a small part of your story. The stories of grief and loss are yours. I thank you for having the trust in me to share them with me for writing of this manuscript.

This thesis could not have been accomplished without the support of both of my supervisors. Dr Anthony (Tony) O'Brien: Associate Professor/Campus Head, Monash University and adjunct Professor Southern Cross University, who was principal supervisor until moving on from Southern Cross University

to take up another position. Thank you for your guidance throughout the development of this research.

Professor Colleen Cartwright, Director of the ASLaRC Aged Services Unit, Southern Cross University, initially my associate supervisor and then my principal supervisor. Thank you for your ongoing support and expertise in Ageing research which has been a much valued contribution. I am also greatly appreciative of the financial support from ASLaRC that assisted with costs associated with the study. This provided me with time away from my academic commitments to allow me to spend extended time with the participants in the study.

To my colleagues at Southern Cross University who supported the study in different ways, in particular Professor Judy Atkinson. Thank you Judy for providing critical feedback and advice during early conversations about the doctoral study.

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CHAPTER ONE:

Introduction to the Thesis: An Ethnographic Study of Grief and Loss in Dunghutti Country

CHAPTER ONE

Introduction

This doctoral research documents an ethnographic study of contemporary descriptions of Aboriginal cultural beliefs surrounding issues related to grief and loss. The research is significant as it focuses on the perspective of the participants who all identify as Aboriginal and who were living in Dunghutti³ country at the time of data collection. The research builds upon existing knowledge of Aboriginal health needs, but breaks new ground by providing original perspectives that focus on the Aboriginal point of view in the context of understanding the meaning of grief and loss. The meaning of grief and loss for participants' was interpreted through an interactionist perspective on Aboriginal grief with a theoretical model developed for the research. This model incorporates Aboriginal symbolism and meanings surrounding participants' life experiences. In addition, the Aboriginal writings, "Dadirri," overarch the model. An explanation of Dadirri is provided on page 7. Consistent with the whole-of-life view of Aboriginal and Torres Strait Islander people the thesis reports on grief and loss across the lifetime and thus also focuses on the view of participants related to Aboriginal ageing and aged persons' associated care needs.

3. Consistent with the theoretical foundations of this study, and where available, traditional terms are used throughout the thesis.

The first Chapter provides an outline of the research, and begins with contextualising the study, followed by an introduction to the theoretical orientations that are central to the research. A summary of Aboriginal demographics, and mainstream and Aboriginal health care services in the study area is provided in Chapter One.

Community and People Involved

Using the Australian Bureau of Statistics (ABS), Standard Geographical Classification (ASCG) (ABS, 2005), the Local Government Area (LGA) and Statistical Local Area (SLA) (ABS, 2006b) where the study was conducted is Kempsey, situated on the Mid North Coast of NSW. In Aboriginal terms the research was implemented on the traditional Aboriginal nation known as the Dunghutti nation, referred to by participants as Dunghutti country (hereafter referred to as Dunghutti country). An Aboriginal Australia map (Horton, 2000) depicting all Aboriginal nations is located on page xv. As acknowledged in the footnote, this map is used with permission from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

Background

The 2006 Census reports that 12, 200 Aboriginal people live on the Mid North Coast of NSW (ABS, 2006c). The main centre of living in Dunghutti country is Kempsey, where the health needs of Aboriginal people are provided by the Durri Aboriginal Corporation Medical Service (ACMS) and Kempsey District Hospital. According to the 2006 ABS Census, the number of Aboriginal people living in Kempsey is 2 441 or 8.9% of the total Kempsey population, which is

27 387 (ABS, 2008). The 2006 ABS Census further reports the Mid North Coast Aboriginal and Torres Strait Islander population as 4.3%. This is proportionately higher than NSW overall which has 138 506 or 2.1% of the Australian national Aboriginal and Torres Strait Islander population. An in-depth and up-to-date community profile is found in Chapter Two: The Literature Review.

Summary of Health Issues

A detailed analysis of Aboriginal health issues is found in Chapter Two: The Literature Review, which focuses on the life expectancy disparities for Aboriginal people in Australia which, at 59 years for males and 65 for females, is 18 and 17 years respectively less than non-Aboriginal people (ABS, 2008a). This difference in life expectancy is further highlighted by the fact that 12% of the Australian population is over 65 years of age, while in the Aboriginal population, only 3% are aged over 65 (ABS, 2008a).

In Canada, Aboriginal people have an estimated life expectancy of approximately 10 years less than the non-Aboriginal Canadian population (Wilkins et al., 2008). In New Zealand, Maori life expectancy is on average 8.2 years less than the non-Maori population (Statistics New Zealand, 2008). Whilst the population characteristics of Indigenous people of Canada and New Zealand are diverse to Australia, the ABS (2008a) confirms that such comparisons illustrate the life expectancy gap of Aboriginal and Torres Strait Islander people is approximately twice that of other developed nations.

Compared to the non-Aboriginal population, disproportionate death rates are evident. The disparity is greatest in the age range 35-45 years, where deaths from a range of causes is reported (ABS, 2008). One example which highlights the disparity is deaths from diabetes. For Aboriginal males the death rate from diabetes is 23 times the rate for non-Aboriginal males and for Aboriginal females it is 37 times the rate for non-Aboriginal females. These statistics are exemplified in the location of this study. For Aboriginal people living in Dunghutti country, death rates have been likened to a war zone, (Cleyworth, Smith, & Sealey, 2006; Jopson, 2000) with the community epitomising many of these inequities. Adding to the complexities of the longevity issues, and the apparent problems with access to health services for people, is the impact of historical trauma for Aboriginal people living in Dunghutti country and Australia generally. This issue of inequity is discussed further in Chapter Two. Compounding the aforementioned issue is the impact of intergenerational trauma and associated grief shown to be directly related to the losses associated with colonisation (Atkinson, 2001; McKendrick & Thorpe, 1998; Sherwood, 2005).

Access to Area Health Services

Mid North Coast Area Health Service (MNCAHS) annual reports depict a health service with a high number of Aboriginal and Torres Strait Islander people accessing mainstream and Aboriginal health services. The MNCAHS access rates by Aboriginal and Torres Strait Islander people are 3.5% compared to other NSW Area Health Service access rates for Aboriginal people of 1.9% (MNCAHS, 2004). Furthermore, reports suggest that Kempsey

has the most prolific growth rate in Aboriginal populations in Australia (MNCAHS, 2004). From a health service provision perspective for example, the projected increase in hospital admissions for cancer-related conditions at Kempsey District Hospital for 2001-2011 is 48.9% (MNCAHS, 2004).

Given the higher proportion of Aboriginal people living in Kempsey it can be estimated that there will be a significant need for Aboriginal and Torres Strait Islander-specific grief and bereavement services over the next decade and beyond. However, no data for Aboriginal people's access to cancer services exists (MNCAHS, 2004), nor is there documentation of culturally-specific needs in relation to grief and bereavement for Aboriginal and Torres Strait Islander people living in Dunghutti country. The ABS reports higher rates of some cancers for Aboriginal and Torres Strait Islander people. A profile of these statistics is provided in Chapter Two.

Reviewing cancer care services and models of clinical care, for example palliative care, provided a useful starting point for reviewing the literature for this ethnographic research. The examination of definitions and guidelines for psychosocial aspects of care delivery in relation to grief and loss are presented in Chapter Two.

It was recognised at the beginning of this study that researching any issues in relation to grief and loss was a highly sensitive area, and one that would require a great deal of compassion and guidance. Compounding the sensitivity of the study, the location of the study was an area where Aboriginal

facilities were established by the mainstream, and to which Aboriginal people were forcibly removed to (Fletcher, 1989a, 1989b) and dispossessed of their land and the Aboriginal spiritual connections with country (Berndt & Berndt, 1978; Blomfield, 1981). The facilities were established by the NSW Aborigines Protection Board (APB) and include the locations of Burnt Bridge, Bellbrook Greenhill and Kinchella, all located on Dunghutti country. In addition to the local dispossession, there was a documented distrust of mainstream research methods in national and international studies involving Aboriginal people (Durie, 1994; Haebich, 2000; Martin, 2008; Smith, 1999; World Health Organisation, 2002) which provided a challenge that made it imperative to work closely with the ACMS executive board and Elders on all aspects of the study from the start.

Guidance for the Study

The impact of colonisation and resultant research, which has often been criticised as a continuation of Western colonising practices (Ashcroft, Griffiths, & Tiffin, 2000; Bhaba, 1985; Said, 1995; Smith, 1999), were vital considerations in designing the study. Furthermore, it was a central component of the design of the research to ensure that the ethnography would be conducted in an ethical way which was respectful of Aboriginal and Torres Strait Islander beliefs, and that the findings would incorporate the oral history tradition of Aboriginal and Torres Strait Islander people (Atkinson, 2001; Kowal, Anderson, & Bailie, 2005; O'Brien, 2000; Wilson, 2004). Guidance was sought and partnerships were formed with the Aboriginal Controlled Medical Service and key Aboriginal organisations in the research

area. An emphasis on partnerships was considered imperative to retain Aboriginal community control over the research process. Aboriginal community control aims to empower and build capacity of local Aboriginal communities (Durie, 1994; Ramsden, 2002) through active involvement in any decisions and in the planning of Aboriginal health care (NSW Department of Health, 1999, 2003).

The key Aboriginal people who provided this guidance, advice and approval were nominated by the Aboriginal Corporation Medical Service (ACMS) Executive Board. The ACMS Executive Board members themselves also provided guidance at all stages of the study, and gave final approval for the research to begin. Details of the partnerships formed between the community representatives and the researcher, are found in Chapter Four of the thesis.

Theoretical Model

This research is theoretically informed by a decolonisation Aboriginal research model, highlighting the concepts of healing, decolonisation and spirituality (Martin, 2003; Smith, 1999). Within this decolonisation model, Dadirri is incorporated. Dadirri is an Aboriginal term that relates to listening and acknowledging Aboriginal peoples' spirituality and their unique and special connection with the land (Ungunmerr-Baumann, 2000). Significantly, an Aboriginal research model (Atkinson, 2001; Smith, 1999) was considered critical to this study to enable the positioning of Aboriginal and Torres Strait Islander beliefs as central to the research. Atkinson (2001) and Wilson (2004) argue that an Aboriginal research theoretical model not only acknowledges

Aboriginal beliefs but privileges Aboriginal beliefs and traditions. Positioning the Aboriginal participants at the centre of the study is a significant aspect of this research, so as not to repeat the effects of Western colonisation so often reported as negative outcomes of Aboriginal research conducted by non-Aboriginal researchers (Bishop & Glynn, 1999; Dunbar & Scrimgeour, 2006a; Durie, 1994; Said, 1995). As Chapter Three discusses the theoretical model for the thesis, only this brief description is provided here.

What This Thesis Adds to the Literature on Health and Wellbeing

This research adds to the current debates about Aboriginal mental health in relation to grief, loss and bereavement (Cleyworth et al., 2006; Ray & Prigerson, 2006) and contributes to the existing and emerging literature on the complexities of Aboriginal grief (Hampshire, 2006b; Hunter, 1998; Kristjanson, Lobb, Aoun, & Monterosso, 2006; Sherwood, 2005; Swan, 1998).

The findings of the study document the Aboriginal participants' experience of grief and loss in contemporary mainstream Australian society, and the analysis of participants' experiences provides the basis for the recommendations derived from the research.

Formulating Aims of the Study

In alignment with the theoretical orientations of the study, the research aims, objectives and research questions were formulated with extensive consultation with the Durri Aboriginal Corporation Medical Service (DACMS)

Executive Board, in both the planning and conduct of the study. Approval and guidance was also obtained from the Dunghutti Elders Council and the North Coast Area Health Service (NCAHS) Aboriginal Directorate before commencement. Full details of the process of devising the aim of the study are located in Chapter Four, consequently only a short introduction is provided in this opening chapter. The following aim, objectives and research questions were agreed on and approved by the Durri ACMS Executive.

Aim, Objectives and Research Questions

Aim

To document and analyse from an ethnographic context, the Aboriginal needs surrounding grief, loss and bereavement for Aboriginal people living in Dunghutti country.

Objectives

1. To identify the needs of Aboriginal families surrounding the death of a family member;
2. To validate the cultural appropriateness of the delivery of end-of-life nursing care to Aboriginal people living in Dunghutti country;
3. To develop a range of culturally safe Key Performance Indicators (KPIs) for nursing an Aboriginal person who is aged or who is dying;
4. To assess the therapeutic benefits of mainstream nursing interventions for Aboriginal people who are living with grief;
5. To identify the nexus between theory and practice in nursing Aboriginal people who are dying and/or chronically ill;

6. To ensure the grief/loss process is facilitated in a culturally safe manner through an examination of current mainstream health care service practices.

Research Questions

1. What is the meaning of grief for Aboriginal people living in Dunghutti country and what are the causes.
2. What are the beliefs, values and opinions of Aboriginal people living in Dunghutti country about death and dying?
3. What is the experience of Aboriginal people who have had a family member pass away?
4. What are the current nursing and health care practices available for loss and grief in this community?
5. What are the specific cultural rites and rituals associated with death, dying and grief processes in this community?
6. What are the spiritual needs in an Aboriginal way, of an Aboriginal person who is dying in this community?

Invited on Koori Country: The Ethnographic Encounter

Typical of ethnographic studies I spent extended time in the Dunghutti community. During my time as a researcher I observed day-to-day interactions of staff, patients and community members at the Durri Aboriginal Corporation Medical Service (ACMS). Comprehensive accounts of the consultative processes, including acknowledging and working with the cultural

complexities in an Aboriginal community, ethical considerations, interview transcript analysis and partnerships, are in the methodology chapter, Chapter Four of this thesis: Walking on Dunghutti Country.

Summary of Key Issues to be Addressed in this Research, and Alignment with Policies, Frameworks and Strategic Plans

1. All Aboriginal groups have diverse and individual needs regarding culturally safe care.
2. This ethnographic study has enabled the documentation and analysis of the social, cultural, and personal needs in relation to grief and bereavement of participants living in Dunghutti country.
3. A review of the literature found there was limited literature which focuses on the identification of the Aboriginal point of view in the context of aged care needs for this large Aboriginal population.
4. Data to quantify the health care needs surrounding grief and bereavement of the Dunghutti people is non-existent.
5. The research addresses The NHMRC Aboriginal and Torres Strait Strategic Framework (NHMRC, 2002) research priorities to fill knowledge gaps in under-researched populations.
6. The National Palliative Care Strategy (Sullivan et al., 2003) is aimed at consistency of care delivery to all Australians requiring terminal care. However, the National Palliative Care strategy has not focused on palliative care of Aboriginal and Torres Strait Islander people in aged care facilities (Sullivan et al., 2003). Federal and State Government funding allocated to palliative care initiatives total \$66 million for the

implementation of The National Palliative Care Program (Sullivan et al., 2003). However, no funding initiatives in the National Palliative Care strategy have been specifically allocated to Aboriginal aged care projects on the Mid North Coast of NSW.

7. The research aligns with the key priorities of the NSW Aboriginal Health Strategic Plan criteria to promote improved practice in primary health care services in consultation with local Aboriginal Area Health Partnerships (NSW Department of Health, 1999). This alignment is strengthened by consulting with key representatives from the ACMS in planning this study about critical issues for caring for Aboriginal people suffering from grief and a range of losses.

8. On a national Aboriginal and Torres Strait Islander health policy level this study addresses service needs priorities identified in the following documents:

- Australian Government. (2005). *Framework Document Overarching Agreement on Aboriginal Affairs Between The Commonwealth of Australia and The State of New South Wales 2005-2010*.
- Australian Government Department of Health and Ageing. (2003). *National Strategic Framework for Aboriginal and Torres Strait Islander Health July 2003-2013 Framework for action by governments*
- Australian Health Ministers. (2003). *The National Mental Health Plan 2003-2008*.

9. The research directly addresses criteria 2.7 of the MNCAHS Strategic Plan which identifies a need for improved care of local Aboriginal people surrounding loss and grief (MNCAHS, 2002).

10. The study addresses strategy 6.3 of the MNCAHS Area Health Service Plan relative to determining local guidelines that are required to meet the needs of individual health care consumers (MNCAHS, Revised 2004).

Structure of the Thesis

The thesis consists of nine Chapters. This Chapter, Chapter One is an introductory chapter which provides a brief overview of the research.

Chapter Two: Literature review. The literature review situates the background of the study and provides a critique of the literature related to Aboriginal grief and loss.

Chapter Three: Theoretical model. The theoretical chapter provides details of the important theoretical considerations and underpinning principles in all stages of the research. The study uses a symbolic perspective on Aboriginal grief which was guided by the Aboriginal writings termed Dadirri. This enabled the analysis of the semi-structured in-depth interviews to be conducted from within an Aboriginal cultural context.

Chapter Four: Methodology. The methodology chapter presents the ethnographic research methods, processes and ethical considerations in the research. This chapter gives a detailed insight into the research partnerships formed between the researcher and key Aboriginal stakeholders. The process of conducting semi-structured in-depth interviews with participants and the analysis of the transcripts is presented in this chapter. Additionally an outline of the analytical method of using a process of grounded theory is provided.

Data was analysed using the structural process of grounded theory, however, this is not a grounded theory study.

Of the remaining chapters, chapters five to eight are findings chapters from the thematic analysis of participant transcripts.

Chapter Five: Findings 1. “So Much Sorry Business” is the first of the findings on the meaning of grief for Aboriginal people living in Dunghutti country.

Chapter Six: Findings 2. Chapter Six presents the key theme “Aboriginal Exclusion” and the associated issues identified by participants.

Chapter Seven: Findings 3. There are two related focal points of Chapter Seven. The first is the special Aboriginal meanings associated with the Aboriginal response when an Aboriginal person is unwell or has died. The sensitive and sacred significance of kinship and the meanings attached to this response are discussed. Secondly, Chapter Seven explores the theme of certain rituals associated with death and dying.

Chapter Eight: Findings 4. Chapter Eight is the final findings chapter and focuses on Aboriginal participants living with loss and the meaning of growing old.

Chapter Nine: Discussion, Conclusions and Recommendations. Chapter Nine, the final chapter, presents a discussion of the findings of this research and lastly, presents recommendations.

CHAPTER TWO:

Review of the Literature

CHAPTER TWO

Introduction

This chapter is a literature review, and begins with an overview of the health and longevity status of Aboriginal people. The review then focuses on Aboriginal worldviews in the context of health and wellbeing, following which the literature relating to Aboriginal grief, loss and bereavement is reviewed and critically examined. The overarching theme of the literature review is the meaning of grief and loss for Aboriginal people within the broad framework of social determinants of health. As introduced in Chapter One, the need for research with Aboriginal people to be contextualised within a framework which incorporates Aboriginal worldviews is affirmed throughout the literature review.

The questions posed in the literature review are:

- What do we know about grief and loss for Aboriginal people?
- What are the gaps? and;
- What is the context in terms of health services and culturally safe health care delivery?

Theories of grief and loss are then reviewed which have informed clinical practice to date. Finally, this review focuses on specific policies and documents relating to cancer services and care delivery. Evaluation of cancer services was a functional starting point from which to examine the literature in the absence of literature in relation to grief and loss from other types of loss

other than death or intergenerational trauma for Aboriginal people in the study. This provided impetus to explore the area of grief and loss in detail, in close consultation with key Aboriginal representatives living in Dunghutti country. These consultative processes, which ensured the research was guided by and approved by local Aboriginal people, are discussed in Chapter Four.

Literature Search Strategy

In the first phase of the study, literature was searched in broad terms related to Aboriginal Health, Aboriginal cancer care, Aboriginal ageing, Aboriginal mental health, and grief. In this phase the North Coast Area Health Service (NCAHS) policies (MNCAHS, 2002; MNCAHS, 2004) and the Australian National Palliative Care policies and strategies (Commonwealth Department of Health and Aged Care, 2000; Sullivan et al., 2003) were reviewed at length to scope the study. Literature searching was conducted using the OVID, CINAHL and Medline databases. The Australian Digital Thesis collection was also searched using the same search terms to account for any recently-completed but unpublished PhD theses. These search strategies and key terms resulted in a limited number of results. The review was then broadened to include all literature on Aboriginal Health, Cancer Care and Aboriginal and Torres Strait Islander ageing.

Phase two of the literature search focused on research and systematic reviews of Aboriginal and Torres Strait Islander grief and loss. Importantly, phase two was implemented following a review of the key areas outlined

above in phase one. This first review was presented to the Durri ACMS Executive Board and other Dunghutti community representatives as advised by the Durri ACMS Executive Board, and the Area Health Service Aboriginal Directorate staff for advice. Following meetings and confirmation from these key community representatives that the area of research was important and meaningful to the community, the research questions were refined and the research methodology finalised. Full discussion of this partnership, participation and protection emphasis for the study (Durie, 1994; National Health and Medical Research Council, 2003, 2005; World Health Organisation, 2002) is found in the method chapter, Chapter Four.

Key contact points for information relating to available documents to guide care provision of Aboriginal people experiencing a range of losses during the scoping phase of the research in Australia were; the NCAHS Aboriginal Directorate staff, NCAHS Service Plans; Durri ACMS Executive Board, Durri ACMS annual reports, and the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). Additional contacts were included on subsequent advice and can be found in Chapter Four. Internationally, relevant health-related literature from developed countries with a history of colonisation that have shown an improvement in the health status of Indigenous people was included. From New Zealand, the Ministry of Health and the Nursing Council of New Zealand Board Cultural Safety policies were reviewed. In Canada, the Canadian Institute of Health Services and the Ottawa Health Research Institute websites were explored for relevant material. Documents from the World Health Organisation were also included in the literature review

to situate these policy documents in the context of global governance of health equality.

In the final stage of the study other historical documents and artifacts such as recordings of Elders stories, pictures and recordings of historical events were searched from local sources where the study was implemented. Sources included the Macleay Valley Historical Society and the local Kempsey Council library. The inclusion of such artifacts is consistent with the ethnographic methods of the study (Bell, 1993; Cowlshaw, 1999; Hammersley & Atkinson, 1995). This material was then reviewed to obtain a complete picture of the historical influences on life today for Aboriginal and Torres Strait Islander people in Dunghutti country.

Finally, stories told through songs written by Aboriginal people were reviewed and relevant excerpts included presenting the Aboriginal perspective in relation to historical events. Ungunmerr-Baumann explains from an Aboriginal understanding, “stories and songs sink quietly into our minds, and we hold them deep inside” (Ungunmerr-Baumann, 2003 in Farrelly 2003, p.1X).

Overview of Aboriginal Health and Longevity

The NSW Aboriginal Health Service Standards (NSW Department of Health, 2005) has focused on six areas in the NSW Aboriginal Health Chronic Conditions Profile. The conditions classified within the NSW Health profile are cardiovascular diseases, diabetes, kidney disease, chronic obstructive

pulmonary disease, asthma and cancers. It should be noted that whilst chronic conditions are reported in isolation:

it is frequently the case that Aboriginal people concurrently experience several of these conditions and other co-morbidities. In addition, people with chronic conditions and complex conditions often present with depression, anxiety or other related mental health disorders as a clinical component” (NSW Department of Health, 2005, p.32).

Thus not only are medical diseases problematic but also, concomitantly, mental health issues exacerbate such conditions and complicate the Health Service presentations made by Aboriginal people. The ABS reports disease and injury for Indigenous Australians using Disability Adjusted Life Years (DALY) (ABS 2008a). DALYs are defined as; “the sum of years of life lost due to premature death and years lived with disability (Vos et al, 2007 in ABS, 2008, p.288) and are described in terms of disease burden. Table 2.1 shows the broad causes of disease and injury for Indigenous people.

Table 2.1 Disability Adjusted Life Years (DALYS), Broad Cause Group, Indigenous Persons 2003

Cause	DALYS No.	Proportion of total %
Cardiovascular disease	16 786	17.5
Mental disorders	14 860	15.5
Chronic respiratory disease	8 587	8.9
Diabetes	8 498	8.9
Cancers	7 817	8.1
Unintentional injuries	6 989	7.3
Intentional injuries	5 395	5.6
Other	27 044	28.2
All causes	95 976	100.0

Source: (ABS 2008, p.128)

Aboriginal people are exposed to a larger number of deaths than their non-Aboriginal Australian mainstream counterparts. Aboriginal people are also more likely to have experienced traumatic losses (Kristjanson, Lobb, Aoun, & Monterosso, 2006; McKendrick & Thorpe, 1998), with a higher incidence of suicide (ABS, 2008) compared to the non-Indigenous population. The National Aboriginal and Torres Strait Islander Health Survey 2004-2005 which reports on the social and emotional wellbeing of Indigenous adults, found that 30% reported being in poor health. Anxiety, depression and suicide are documented as the highest single cause of disease burden for Indigenous males behind ischaemic heart disease (IHD) and diabetes (ABS, 2008a). For Indigenous females the highest single cause of disease burden for females is reported as anxiety and depression ahead of diabetes (type 2), IHD and asthma (ABS, 2008a).

Furthermore, findings from other National Australian reports including the 1997 Human Rights and Equal Opportunity Commission (HREOC) report documenting the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families, depicts the traumatised psychological status of Indigenous people as a result of forcible removal and separation from family and lands. Aboriginal peoples' suffering in terms of evidence of trauma and psychological distress (Atkinson, 2001; McKendrick & Thorpe, 1998; Swan, 1998) also persists from the actions associated with colonisation (McKendrick & Thorpe, 1998; Sherwood, 2005; Swan, 1998). Issues such as those outlined above have highlighted the need for research into grief related to Indigenous people, as called for following the Australian

Systematic Review of the Literature on Complicated Grief (Kristjanson et al., 2006, p.7) to:

examine the links between assessment, intervention and outcomes that are targeted to well defined patient populations at well defined phases of bereavement framed within a public health agenda.

Community Profile of the Study LGA

The Kempsey local government area is situated on the Mid North Coast of NSW with a land area of 3,379.6 km² (ABS, 2006a). The NSW reported land area is 800,642 km² (ABS, 2008b) and the total land area in Australia is reported as 7.7 million km²; (ABS, 2008b). In summary, Kempsey LGA land area is 4.22% of the total NSW land area.

The total population in Australia reported by the 2006 Australian Bureau of Statistics (ABS) census is 20,061,646 (ABS, 2006b). According to the ABS the population as of 10th June, 2008 is estimated to be 21,324,105 (ABS, 2008a).

Reporting of Aboriginal and Torres Strait islander data is both complex and inconsistent for a number of reasons including; ATSI peoples' reluctance in general to disclose ATSI status and others who may not be aware of their ATSI identity. The total Aboriginal and Torres Strait Islander population in Australia is estimated to be 455,031 (ABS, 2006b) which is slighter lower than the preliminary 2.5% Indigenous population estimates of 517,200 reported in the 2008 ABS Yearbook.

The data presented in Table 2.2 (p.24) and Table 2.3 (p.26) and the related discussion which refers to Aboriginal people in the study area, is primarily derived from the 2006 ABS Census data. The ABS Yearbook Australia, 2008 was also used for clarity in some areas and is referenced accordingly. Local Aboriginal and Torres Strait Islander figures are not available in some domains, and in others discrepancy exists.

Data from the National Aboriginal and Torres Strait Islander Health Survey, 2004-05 was also included where specified. The ABS reports this survey of Aboriginal and Torres Strait Islander people as “the largest health survey conducted by the Australian Bureau of Statistics” (ABS, 2005, p.1). Whilst this survey provides useful information regarding a broad range of health related issues it is noted by the ABS; “the sample size was 10,439 persons (or about one in 45 of the total Indigenous population” (p.1). This data is not consistent with ABS Census data, making comparisons inconsistent. This adds further complexity to evaluating Aboriginal and Torres Strait Islander population data.

Table 2.2 Kempsey LGA Community Profile

	Numbers	% Profile	Comments
Total Population	27 387		
Males	13 783	50.3% of persons in region (LGA)	No breakdown of male/female of Indigenous population.
Females	13 640	49.71% of persons in region (LGA)	
Aboriginal & Torres Strait Islander Population	2 540	9.3% of persons in region (LGA)	2.3% of the total persons in Australia identify as Aboriginal or Torres Strait Islander

Source: Adapted from (ABS, 2006, Quickstats Kempsey LGA)

Drawing on the World Health Organisation social determinants of health framework (Bonney et al., 2003) this review of Aboriginal health now focuses on social and economic disadvantage, in the areas of income, employment, housing and environment as measures of health inequities.

A health-disparities framework described by Stuart and Napoles-Springer (in Kilbourne et al 2006, p.2113) has two components; firstly a public health/global view which encompasses the social determinants of health, and secondly a focus on the health care system. Social Determinants of Health frameworks highlight the link between psychological and social influences on health and longevity (Wilkinson & Marmot, 2003).

Indicators of Social Determinants of Health

Table 2.3 (p26), presents the Kempsey profile and was established using the World Health Organisation classifications on the social determinants of health (Wilkinson & Marmot, 2003). These include education, employment, and related indicators of income and housing status. The Kempsey LGA profile created for the purpose of this study therefore includes these indicators. These indicators also mirror some of those described as headline indicators for overcoming Indigenous disadvantage which have been documented by the Council of Australian Governments (COAG). The table highlights the gap in Aboriginal and Torres Strait Islander data, which is yet another challenge for researchers as the ABS data is incomplete.

Table 2.3 Profile of Social Determinants of Health for Kempsey LGA (As at 2004)

	Kempsey LGA	National Profile	Comments
Education			
Year 12 Completion	21%	62% Males 73% Females	No breakdown of Aboriginal & Torres Strait Islander education attainment by LGA
Employment			
Full Time	48%	60.7%	No breakdown of Aboriginal & Torres Strait Islander Employment
Part Time	33.4%	27.9%	
Unemployed	11.7%	2.6%	
Income Per Week			
Median Individual	319	466	No breakdown of Aboriginal & Torres Strait Islander income
Median Household	614	1 027	
Median Family	737	1 171	
Housing			
Home Ownership – homes being purchased	25.1%	32.2%	Indicators of Aboriginal home ownership are not available for the Kempsey LGA from the ABS

Source: Adapted from (ABS, 2006, Quickstats Kempsey LGA)

Contact with the NSW Aboriginal Housing Office also confirmed that a profile of Aboriginal home ownership was not available for the Kempsey LGA (Field Note: July 29, 2008).

Social Exclusion

In relation to the social determinants of health profile, closely related and interlinked with social determinants of health is social exclusion. The Productivity Commission of Australia defines, social exclusion as:

a shorthand label for what can happen when individuals or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown (Banks, 2007, p.3).

As noted in Table 2.2, compared to the National average the Kempsey population overall has high rates of unemployment. Educational attainment at school level, and therefore skill levels, are also low in Kempsey and incomes fall well below the median national profile generally. Wilkinson and Marmot (2003) describe relative poverty as having less than 60% of the median national income. For those living in the Kempsey LGA it is apparent that many households live in relative poverty. Median household incomes equate to 59.78% of the median national household incomes. Marmot & Wilkinson further describe the effects of relative poverty to ultimately deny people access to housing, education and transport. Adding to the profile of disadvantage in Kempsey, the ABS also reports Kempsey ranking 6 out of 10 in the most socio-economic disadvantaged LGA's in NSW, as shown in Table 2.4. (p28)

Table 2.4: Index of Relative Socio-economic Advantage and Disadvantage in NSW Local Government Areas

Rank in NSW	Local Government Area (LGA)	Usual Resident Population
1	Brewarrina	1 945
2	Central Darling	1 938
3	Walgett	6 944
4	Richmond Valley	21 312
5	Coonamble	4 210
6	Kempsey	27 386
7	Nambucca	17 896
8	Wellington	8 122
9	Broken Hill	19 363
10	Tenterfield	6 533

Source: (ABS 2006, Socio-Economic Indexes for Areas)

In addition to socioeconomic disadvantage, crime rates in Kempsey are high by comparison to the NSW average. An increase of 64% is noted in offensive conduct in the Kempsey LGA in the years 2006-2007 (Bureau of Crime Statistics and Research NSW, 2007). There is however no breakdown of Indigenous and non-Indigenous statistics.

The latest publicly-available corrective services data reports 2080 full time Indigenous inmates, accounting for 21% of the total full time inmate population (NSW Department of Corrective Services 2009). When considering the meaning of health for Aboriginal people the statistics in relation to longevity, causes of illness and burden of disease cannot be viewed in isolation in terms of understanding the meaning of health and wellbeing from an Aboriginal

perspective. For example incarceration separates people from their families and Aboriginal kin.

Aboriginal World Views

Whilst Indigenous peoples' worldview has no equivalence in Western terminology (Atkinson, 2001; White, 2007), it is shaped by individuals' experiences, histories, culture and values (Atkinson, 2002; Haebich, 2000). An in-depth discussion of Aboriginal worldviews in terms of the theoretical orientations for this research is found in Chapter Three. The following section of the literature review focuses on the Aboriginal context of grief and loss in relation to health and wellbeing.

Influences on Aboriginal Health and Wellbeing

Aboriginal people's health and wellbeing is shaped by the history of colonisation. It can be argued that providing health services and models of care to acknowledge this history of dispossession is a challenge. Findings from an Australian National Health and Medical Research Council funded Palliative Care study with Aboriginal and Torres Strait Islander people in the Northern Territory support this viewpoint. As McGrath, Holewa, and Kail-Buckley (2007) confirm, many Western medicine and care models fail to acknowledge Aboriginal people's belief systems, which helps to explain why Aboriginal people have a preference for Aboriginal Health Workers because:

of the cultural fear of white people and clinical biomedicine...Indigenous people stated honestly and clearly that they experience fear when being cared for by non-Indigenous people in the hospital setting (McGrath et al., 2007, p.432-433).

Theories of Grief and Loss

It is generally agreed that the area of grief in general is a complex issue (Stroebe et al., 1993), with varying outcomes for individuals (Genevro, Marshall, & Miller, 2003). It is argued that, in order for health care professionals to care for those who are grieving, an evidence base must be established which is firmly based in strong theoretical foundations (Stroebe et al., 1993). To date the theoretical foundations of the research on grief and loss for Indigenous communities have drawn from a range of disciplines including sociology, psychology, social work and anthropology (Kristjanson et al., 2006). From a theoretical perspective the theories of grief identified in Kristjanson et al., (2006) systemic review all focus on loss through death. These are: “the grief work perspective, attachment theory, meaning making and meaning reconstruction, cognitive stress theory and the dual process model” (Kristjanson et al., 2006 p.22). Contemporary definitions used in the bereavement literature reviewed fail to encompass losses other than death. For example, bereavement is described as ‘the objective situation of having lost someone significant’ (Strobe et al, 1993 p.7).

These theories and definitions have absolutely no alignment with the Aboriginal view of health and wellbeing. For example, in terms of the need for further research to document Indigenous issues in relation to grief and loss, Kristjanson et al, (2006, p.7) state that to date, “the bulk of the research material related to Indigenous peoples focused on intergenerational grief, historical grief, or grief associated with the stolen generation.”

Whilst there is no Aboriginal theory of grief and loss, Rosenblatt (in Stroebe et al. 1993 p.110) proposes that understandings of grief must be based on the social and cultural context in which it occurs. He describes the social context as including family, personal relationships, culture and ethnicity. Kellehear (2002) further supports the need for a greater understanding of the cultural interface in understanding grief. However it is noted that “Literature is only presently emerging that specifically explores trauma within Aboriginal and Torres Strait Islander contextual frameworks” (Atkinson, 2001, p.23).

Cultural Safety

In terms of a tangible measurement of outcomes of health care in relation to grief and loss from the consumer or patients’ viewpoint, an important issue is cultural safety. Whilst cultural safety originated with examinations of nurse-patient relationships in nursing and midwifery (Crisp & Taylor, 2005; Ramsden, 2002) the focus is much broader and is described by the original author:

However I began focusing on national issues surrounding Maori identity and ethnicity, formal and informal in order to explore the historical relationship between the status of Maori health and the Treaty of Waitangi and health services in New Zealand at the time of cultural safety’s development (Ramsden, 2002, p.83).

Ramsden (2002) suggests that for both non-Indigenous and Indigenous health care providers to respectfully provide care, an awareness of cultural safety is paramount. The Nursing Council of New Zealand have incorporated cultural safety into the national nursing education guidelines, and define the measurement of cultural safety as an outcome with “safe services to be

defined by those that receive the service” (Nursing Council of New Zealand, 2005, p.5). In Australia, the Indigenous Nurse Education Working Group (INEWG) has recommended that Nursing undergraduate and post graduate course accreditation be contingent upon the inclusion of cultural safety content and assessment (Miller, Spring, Turale, Goold, & Usher, 2005). In the 2005 report: *Dadirri: A Nursing Guide to Improving Indigenous Health*, the INEWG recommended that the health professions registration board stipulate that:

Schools of nursing provide evidence that Indigenous content and cultural competence content has been developed through consultation with Indigenous midwives, nurses and Indigenous communities (Miller, Spring, Turale, Goold, & Usher, 2005, p.52).

In addition to patients experiences of receiving care, cultural safety has further developed to encompass a range of social justice issues (Ramsden, 2002; Taylor & Guerin, 2010) power, prejudice and attitude at all levels of health care. Ramsden further proposes that finding these imbalances within health services is one of the challenges of overcoming the crippling effects of cultural inequalities. Whilst this thesis is not intended to be a comprehensive overview of nurses knowledge, the discussion of cultural safety is an important consideration when viewed from within a decolonisation context. Cultural safety addresses social issues including personal and institutional racism and power positions (Kirkham et al., 2002; Ramsden, 2002). This research addresses the issue of cultural safety by focusing on the Aboriginal perspective in the analysis of the qualitative data.

The Meaning of Health for Aboriginal People

Health from an Aboriginal perspective incorporates a whole-of-life outlook which not only focuses on the social, emotional and cultural wellbeing of the individual but of the entire community (Eckermann et al., 2006; McGrath, Watson, Derschow, Murphy, & Rayner, 2004; MNCAHS, 2004; Prior, 1997; Sullivan et al., 2003; Talbot & Verrinder, 2005). This whole-of-life outlook includes the cyclical life-death-life concept (National Breast Cancer Centre and the National Cancer Control Initiative, 2003; NHMRC, 2002; Status of Women Canada, 2004). For health care from Aboriginal people's perspective the focus is on a community and family focus of care (Bourke, Bourke & Edwards, 1994 in Bin-Sallik & Ranzin 2001).

Family structure in Aboriginal culture holds ultimate respect and honour (Atkinson, 2001, 2002), with the strong relationship between family and kinship being the centre of Aboriginal wellbeing (Aboriginal Health and Medical Research Council of NSW, 2007; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; NHMRC, 2005). Indigenous structure of family extends beyond blood relationships to include extended networks of people who, through a range of relationships, care for and nurture each other (Maddocks & Rayner, 2003). Aboriginal family relationships have a critical role to play in an array of health care decisions. Thus, facilitating the inclusion of family relationships would be a vital consideration for culturally safe health care for Aboriginal people.

Family Decisions

With respect to decisions relating to medical treatment, Maddocks and Rayner (2003) assert that for Aboriginal people this is a family decision. For example, decisions such as who should have access to information about the health status of the person, the person's position or role in the community and the perceived reasons for any illness are areas considered by the family (Maddocks & Raynor, 2003). Similarly, there are complex issues associated with death and dying for Aboriginal people.

Each Aboriginal community has their own ceremonies and customs that surround death and the dying process (Hotson, Macdonald & Martin, 2004). The concept of spirituality also differs for each Aboriginal person (Maddocks & Rayner, 2003; McGrath, 2006; McGrath et al., 2004). The limited available literature on Australian Aboriginal customs following death supports the notion that Aboriginal people believe it is of utmost importance for ceremonies to be conducted with their own chosen people, and the care and handling of the deceased body are issues requiring great care and respect (Maddocks & Rayner, 2003). Smoking ceremonies in the room where an Aboriginal person has died are culturally significant for some Indigenous communities (Maddocks & Rayner, 2003).

Spirituality

The connection with land and the relationship with health and wellbeing previously described in this literature review is a critical issue for Aboriginal people in terms of death. It is usually of cultural significance for Aboriginal

people to die in their home country. Studies of Aboriginal communities in Canada and Australia have found that the majority of Indigenous people want to die in their own community, even though in some cases medical services were reported to be more adequately resourced in cities (Hotson et al., 2004; McGrath et al., 2004). Findings from international studies have also shown that in many cases health care professionals, including doctors and nurses, did not know the local Aboriginal traditions regarding death and dying (Hunter, 1998; Kristjanson et al., 2006; Lobb, Kristjanson, Aoun, & Monterosso, 2006). Recent Australian nursing research (McGrath & Phillips, 2008, p.57) reports findings from a Northern Territory Indigenous palliative care study, which also confirmed the “significant cultural gap between Westernised Australians and Aboriginal cultures, especially in regards to the care of the dying.”

Indigenous beliefs about the causes of disease are also vital considerations in the planning and delivery of culturally safe nursing and health care from an Indigenous perspective. For example some treatments, including pain management, may be considered inappropriate by some Aboriginal communities as pain may be considered to be a necessary process associated with sickness (Maddocks & Rayner, 2003). Aboriginal people may believe that the cause of disease is because the person was removed from their homeland or from being exposed to a metaphysical force (Maddocks & Rayner, 2003). Connection with homeland for Aboriginal people is documented in the song by Carmody (2008), an Australian Aboriginal singer; “the land’s our heritage and our spirit, here the rightful culture’s black”.

Grief and Loss for Aboriginal People

Combined with facing death at a young age and exposure to a greater number of traumatic deaths, the meaning of grief and loss for Aboriginal people is a multifaceted issue. In terms of grief experienced following death or from other causes, Aboriginal people are reluctant to access mainstream Australian health care facilities where grief counsellors are employed, because the counsellors are perceived not to understand Indigenous protocols and ways of grieving (Kellehear, 2002).

Palliative and Cancer Services

Whilst this thesis does not focus entirely on palliative care or cancer care, as identified in the overview of Aboriginal health section of this chapter, it can be estimated that the need for palliative care services in Aboriginal communities would be greater than in the mainstream. The World Health Organisation defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2004).

Similar definitions are used by Palliative Care Australia. However, to date the literature to support care of Aboriginal and Torres Strait Islander people in Australia within the palliative approach is new. On a national level in Australia, palliative care studies documenting some psychosocial aspects of the needs and viewpoints of Aboriginal and Torres Strait Islander people have been conducted in the Northern Territory (Sullivan et al., 2003). In NSW, as a part

of the National Palliative Care Strategy, a scoping study on the palliative care needs of Aboriginal people was conducted but did not focus on specific grief, loss or bereavement issues, or on the social and emotional service delivery issues (Sullivan et al., 2003). However, Sullivan does confirm the need for further investigation into grief, loss and bereavement services:

“Mainstream counsellors tend to avoid Aboriginal clients and put it on untrained Aboriginal workers. There is a need to recognise the role of Aboriginal health workers in providing counselling. Training for health workers needs to be hands on. On the job. Aboriginal health workers and Aboriginal liaison staff carry a large burden-providing informal counselling and support with no training, support or debriefing” (AMS Health Worker, South Australia cited in Sullivan et.al. 2003, p.131).

The model of care for cancer-related service delivery used by the Mid North Coast Area Health Service (MNCAHS) is based on mainstream values, articulated by the guidelines provided by the NSW Health Clinical Service Framework for Optimising Cancer Care 2003 (MNCAHS, Revised 2004). The Mid North Coast Area Health Services (MNCAHS) Plan 2000-2005 reports that palliative care services are linked to the cancer services model, despite the claim that they are a separate service stream (MNCAHS, Revised 2004). At the time this study was conducted the area health service was Mid North Coast Area Health Service. Since then a statewide restructure has occurred and the Area Health Service is now known as The North Coast Area Health Service. The focus of care delivery is on the continuum of care for each client by a multidisciplinary team, which includes case coordination and case management. The multidisciplinary team incorporates allied health, nursing and medical services (MNCAHS, Revised 2004). There are currently three

main base hospitals coordinating cancer care service delivery within the MNCAHS with links to the outlying district hospitals. Dunghutti country is an area that incorporates one of these outlying district hospitals.

Aboriginal people living in Dunghutti country, who have a diagnosis of cancer, are currently required to travel to Port Macquarie or Coffs Harbour—approximately one hour travelling time from each centre—to access the services of medical practitioners with expertise in cancer management,. In an area with limited public transport and high reports of financial disadvantage, this is evidence of yet another barrier to health care for Aboriginal people. Indigenous people in the Kempsey area are reported to be twice as likely as non-Indigenous to be in receipt of a government health care card (ABS, 2008a). Additionally, at the time this study commenced there were no outreach clinics operated in Kempsey by metropolitan cancer treatment centres (MNCAHS, Revised 2004).

The MNCAHS identified that the needs of Aboriginal patients and families with a diagnosis of cancer and other terminal illnesses need to be considered in the 2004-2007 period (MNCAHS Revised 2004). However, at the time this study commenced on 20/7/2004 no funds had been allocated to this need (MNCAHS, Revised 2004). Data for Aboriginal and Torres Strait Islander peoples' access to palliative care is both limited and sketchy (Sullivan et al., 2003). Key findings of Sullivan et al., (2003) analysis of Aboriginal access to palliative care services in Australia indicate that palliative care assessment forms usually are not explicit in asking for Indigenous status and most

palliative care service providers could not access information to ascertain the Indigenous status of clients because their systems did not allow it. For example, although Indigenous status was often required on hospital admission forms, it was not always asked and if the person then became a palliative care client the information was not always linked (Sullivan et al., 2003). Further compounding this incomplete picture of access to palliative care services is the fact that many Aboriginal Community Controlled Health Services (ACCHS) do not keep records of the number of palliative care clients accessing their services (Sullivan et al., 2003).

Indigenous Aged Care

The needs of Indigenous people in residential aged care facilities (RACF) are also poorly reported. Little is known about Aboriginal and Torres Strait Islander occupancy rates in mainstream aged care facilities (Sullivan et al, 2003; Cartwright et al., 2008). As of June, 30 2006 of the 154,872 recipients of permanent and respite care in Australia, 1.7% (2 632) identified as Aboriginal or Torres Strait Islander, however Indigenous status was not identified for 10 986 people (AIHW, 2007). A recent scoping study of the health care needs of older Aboriginal people on the Mid North Coast NSW (Cartwright et al, 2008), identified only 4 Aboriginal residents (2 long-term care, 2 respite care) in only 2 of the 23 RACF facilities surveyed.

The importance of culturally safe, Aboriginal-specific health and aged care facilities is evidenced by the formation of the Booroongen Djugen Aboriginal Corporation (BDAC) in Kempsey, NSW situated within the LGA of this study.

The BDAC is a culturally significant community corporation which operates a RACF with both Indigenous and non-Indigenous residents. This RACF employs in excess of 70 staff, both Indigenous and non-Indigenous, and coordinates the care of 20 low-care and 40 high-care residents (BDAC, 2010).

A report into the aged care needs of Indigenous people in South Australia (Bin-Sallik & Ranzin, 2001) has also confirmed the gap in research on ageing in Aboriginal communities. Bin-Sallik and Ranzin (2001, p.11) report:

Virtually no research has been performed into the psychosocial aspects of Aboriginal ageing whereas there is a vast national and international literature on all aspects of ageing in non-Aboriginal populations, including the medical, biological, sociological and psychological domains.

Locally, needs surrounding grief and bereavement of the Aboriginal Dunghutti Elders is also essentially unreported. By documenting the Aboriginal Elders perspective of the grief and bereavement needs of this densely populated Indigenous community, this study will address the research lacuna surrounding grief and loss at a community level.

Summary

The literature review shows the Kempsey LGA as one the highest socio-economically disadvantaged, poorest and socially excluded communities in NSW, in terms of the social determinants of health. For care delivery and health services to be culturally safe, this literature review has highlighted the need to understand from an Aboriginal perspective, consumers' experiences and needs related to grief and loss. Meanings attributed to health and well-being are unique and special for Aboriginal people. In moving towards an

understanding of the meaning of grief and loss for Aboriginal people, an understanding of the experience of grief and loss must be situated within an Aboriginal worldview. Thus, the review has argued that health policy development in relation to Aboriginal people must include measures of cultural safety. The following chapter, Chapter Three, presents the theoretical model of the thesis.

CHAPTER THREE:

Theoretical Model

CHAPTER THREE

I will tell you something about stories.
They aren't just entertainment.
Don't be fooled.
They are all we have,
All we have to fight off illness and death.
You don't have anything if you don't have stories.
(Meyers in Atkinson, 2001, p.142)

Introduction

This chapter presents the theoretical model for the thesis which was used to analyse and interpret the data of the study. A symbolic perspective on Aboriginal grief theoretical model was developed for the study and used to interpret the meanings attached to grief and loss by participants, who shared their stories in semi-structured in-depth interviews. The theoretical model is a synthesis of three theoretical underpinnings, comprising symbolic interactionism, Dadirri - an Australian Aboriginal conceptual model, and decolonisation. This eclectic merging of theory enabled an Australian Aboriginal culturally-sensitive theoretical model to emerge, which has been guided by the literature supporting culturally sensitive research involving Aboriginal people.

There are a number of publications which support the importance of ethical considerations in research with Aboriginal people (NHMRC, 1999, 2003, 2005; World Health Organisation, 2002), in addition to research articles documenting

the implementation of ethical considerations (Dunbar & Scrimgeour, 2006a, 2006b). However, an Australian theoretical model for non-Aboriginal and Aboriginal partnerships guided by an Australian Aboriginal cultural model is unique to this research.

At the forefront of considerations when formulating the theoretical orientations was an acute awareness of the impact of previous research involving Aboriginal people. Western research methodology underpinning Indigenous research has been heavily criticised (Anderson et al., 2003; Atkinson, 2001; Durie, 1994; Fanon, 1995; Martin, 2003; Mohammed, 2006; Prior, 2007; Said, 1995; Sherwood & Edwards, 2006; Smith, 1999; Wilson, 2004). Smith (1999, p.6) asserts that:

Research is probably one of the dirtiest words in the Indigenous world's vocabulary...the ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the world's colonised peoples.

Indigenous academics Atkinson (2001) and Smith (1999) have likened the effects of Western research methodologies to a reinforcement of colonisation (Atkinson, 2001; Smith, 1999). Alternate models, such as Indigenous models of research have emerged, subsequently, decolonising research methodologies (Durie, 1994; Smith, 1999) have been supported due to the alignment with Indigenous worldviews (Atkinson, 2001; Kirkham et al., 2002; Martin, 2003; Prior, 2007). Australian palliative care nursing research by Prior (2007), using a decolonisation model, suggests a shift towards reconciliation in research.

Koori Worldview - Epistemology

It is consistently reported that, for Indigenous people, ontology refers to a relational ontology (Atkinson, 2001; Martin, 2003; Wilson, 2004) where the interrelatedness of individuals is with their greater surroundings (Thayer Bacon in Wilson 2004, p.206). It is argued that a connection with the land, in the physical and spiritual sense, underpins Indigenous ontology (Atkinson, 2001; Eckermann et al., 2006; Martin, 2003; Smith, 1999). Indigenous peoples' belief and absolute highest regard for kinship, the land, spirituality and rituals surrounding ancient beliefs are interconnected and have a direct relationship with health and wellbeing (Atkinson, 2001; NHMRC, 2003; NSW Department of Health, 1999; 2003; Status of Women Canada, 2004). In addition to respecting these Indigenous beliefs, Aboriginal Community Control (ACC) was another key consideration of formulating the theoretical construct of this study:

ACC means the empowering of a community through the adoption of appropriate organisational structures which enable all Aboriginal people in the local Community the opportunity to be represented as members and to be involved in the decision making process and, therefore, the right to participate and contribute to the goals, structure and operation of its health services (Aboriginal Health and Medical Research Council of NSW, 2007, para. 3).

The partners in this study (described in Chapter Four - Methodology) confirmed the importance of people telling their stories related to grief and loss rather than a quantitative designed study. Traditional Aboriginal history is one of an oral history tradition (Atkinson, 2001, 2002) therefore there is little available published literature that describes Aboriginal knowledge from an

Aboriginal point of view. The following passage expresses one Aboriginal person's view of the mainstream counterparts in relation to stories:

Their evil is mighty,
but it can't stand up to our stories.
So they try to destroy the stories.
Let the stories be confused or forgotten.
They would like that.
They would be happy,
because we would be defenseless then.
(Meyers in Atkinson, 2001, p.142)

Indigenous interrelationships and belief systems are portrayed in the writings of Ungunmerr-Baumann, which the author, an Australian Indigenous woman from the Daly River region of Australia's Northern Territory, has termed Dadirri (Ungunmerr-Baumann, 2000; Atkinson, 2001; Derrington, 2000; Farrelly, 2003).

Dadirri - The Aboriginal Gift

Dadirri is an Aboriginal term that Atkinson (2002) describes as relating to inner deep listening. The writings and paintings which the author and artist termed Dadirri are by Miriam Rose Ungummner-Baumann, an Australian Aboriginal woman who identifies from the Ngan'gikurungur tribe (Derrington, 2000; Farrelly, 2003; Ungunmerr-Baumann, 2000). Farrelly (2003) describes Ungummner-Baumann as a respected author, Elder, artist, teacher, storyteller and writer. Dadirri, (the written works⁵), overarches the theoretical model – discussed later in this chapter. As a non-Indigenous researcher this

⁵ The written form of Dadirri is referred to throughout this thesis. It is acknowledged that Dadirri is also depicted in Art form. It was considered that to interpret art works would not be culturally respectful unless the artist provided the interpretation.

provided a culturally safe position as Dadirri assisted with understanding Aboriginal ways.

What I want you to know about is another special quality of my people. I believe it is most important. It is our most unique gift. It is perhaps the greatest gift we can give to our fellow Australians. In our language it is the quality called Dadirri (Ungunmerr-Baumann, 2000, p.113).

Understanding Aboriginal Ways

Understanding Aboriginal ways, and in particular the generation of health research which is underpinned by Aboriginal belief systems, was considered imperative in understanding the personal effects of disparities such as social exclusion, marginalisation and isolation from mainstream advantages highlighted in the literature review. An inclusive partnership approach was considered paramount for this study. Early anthropological research *on* Indigenous people rather than *with* Indigenous people resulted in criticism and ensuing academic debate in relation to researchers placing rigid definitions on cultural identity (Mohammed, 2006; Said, 1995; Slemon, 1995). The resultant anthropological objectified study of cultures other than one's own as natives or Others has resulted in much criticism (Ashcroft, Griffiths, & Tiffin, 1995; Fanon, 1995; Min-ha, 1995; Mohammed, 2006; Said, 1995). The view of Others as natives or exotic cultures, to be viewed under a lens and then interpreted, is typical of the way there was adversity to early ethnography (Fanon, 1995; Said, 1995; Bishop in Smith, 1999). This added further to the research oppression of Indigenous people and negated the very nature of the positive objectives of the research (Bishop & Glynn, 1999; Martin, 2003; Smith, 1999). Similarly, the meanings attached to the concept of culture have

been criticised due to the fixed associated totalising (Hunter, 1998) nature of some definitions by researchers (Bhaba, 1985; Fanon, 1995; Smith, 1999; Wilson, 2004). This is in contrast to Aboriginal people's worldview and their intuitive connectedness to land, community, relationships, kinship and spirituality. Thus, inclusion of decolonisation aspects into the theoretical model was an important consideration.

Towards an Understanding of Aboriginal Grief and Loss

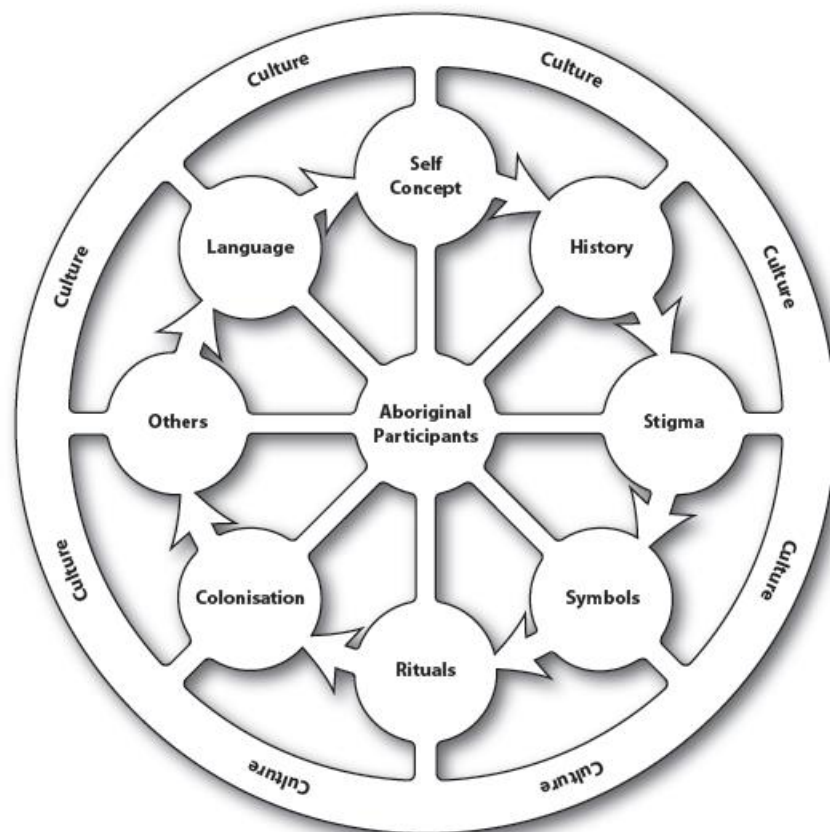
Similarities are recognised between a number of Indigenous research models developed by Indigenous researchers including; Smith's (1999) Kaupapa Maori model, Martin's (2003) research model and the Canadian Holistic Framework for Aboriginal Policy Research (2004). This study builds on these principles of Indigenous research and includes principles identified by Martin (2003). She identifies as a Noonuccal woman, and is an Aboriginal Australian academic. Martin defines the principles of Indigenous research (which she terms Indigenist research) as follows:

- Recognition of our worldviews, our knowledges as distinctive and vital to our existence and survival;
- Honouring our social mores as essential processes through which we live, learn and situate ourselves as Aboriginal people in our own lands and when in the lands of other Aboriginal people;
- Emphasis of social, historical and political contexts which shape our experiences, lives, positions and futures;
- Privileging the voices of experiences and lives of Aboriginal people and Aboriginal lands.
(Martin, 2003 p.205)

A common theme evident in all of these research models is that holistic Aboriginal research is situated within a spiritual, cultural and historical model (Martin, 2003; Status of Women Canada, 2004).

The model developed for interpreting the interview transcripts is depicted in Figure 3.1 and the following discussion describes the significance of each component.

Figure 3.1 A Symbolic Perspective on Aboriginal Grief and Loss



Overarching this model is Dadirri.

Symbolic Interactionism and Koori Grief:

Symbolic interactionism is situated in the social theories categories (Clagett, 1988; Haralambos, van Krieken, Smith, & Holborn, 1996; Willis et al., 2007).

It is argued that symbolic interactionism is both a theoretical perspective and a

method (Willis et al., 2007). Denzin (2003, p.99) assert that: 'methodologically, symbolic interactionism directs the investigator to take to the best of his ability the standpoint of the studied'. This is a pertinent issue as the aim of this study was to understand the meaning and experiences of grief, loss and bereavement from participants themselves. The research questions have been previously outlined in Chapter One. The literature review has discussed the literature relating to on-going grief effects of intergenerational trauma (Atkinson, 2001; Hunter, 1998; McKendrick & Thorpe, 1998). However, this study is unlike these studies as it focuses on the meanings of grief and related issues for participants.

From a symbolic interactionist perspective meaning is seen through the way individuals view reality and recognises the uniqueness of each individual's experience (Blumer, 1969; Meltzer, 1972; Prus, 1996). Thus symbolic interactionism allows a focus on the micro level of day-to-day interactions (Blumer, 1969; Haralambos et al., 1996; Meltzer, 1972; Prus, 1996). The importance of interactions for Aboriginal people through listening and story telling are described by Ungunmerr-Baumann (2000, p.113):

stories are told and sung, over and over, as the seasons go by. Today we still gather around the campfires and together we hear the sacred stories.

Understanding the day-to-day interactions of participants in this study draws from the core theoretical concepts of symbolic interactionism.

Core Concepts

Of the variations of symbolic interactionism, three principal concepts remain at the centre. (Blumer, 1969; Haralambos et al., 1996; Meltzer, 1972; Prus, 1996). Firstly, participants act towards things in ways that have individual meanings for them (Blumer, 1969; Clagett, 1988; Meltzer, 1972). Secondly, individuals' meanings arise from social interactions and, the third principle identified from a symbolic interactionist perspective, meanings are processed by individuals through an interpretive process. Additionally, from a symbolic interactionist perspective, reality is seen through the way individuals view and interpret reality and symbols, including rituals and language (Blumer 1969; White 2007), all of which support individuals' understanding of reality (Hollingsworth 1999 in White 2007). These core principles of Symbolic Interactionism guide this study and Dadirri provides the basis of a deeper understanding from an Aboriginal perspective. This study applies the dramaturgical approach to Symbolic Interactionism advocated by Goffman (1959).

Dramaturgical Approach/Model

Erving Goffman (1959), a graduate of the Chicago School, writes from a symbolic interactionist perspective, emphasising a qualitative analysis of the components of the interactive process (Blumer, 1969; Prus, 1996). Goffman defines the interactive process or face-to-face interaction, as "the reciprocal influence of individuals upon others when in others immediate presence" (Goffman, 1959, p.26). Goffman's 1959 text, *The Presentation of Self in Everyday Life* gives a detailed account and analysis of the process and

meaning of individuals' interactions. Goffman's theory of interpersonal interactions was developed from his seminal work and uses a dramaturgical metaphor to focus on the everyday experiences of the individual or actor and the meanings attached in a micro context (Clagett, 1988; Goffman, 1959; Meltzer, 1972). From a symbolic interactionist perspective, knowledge is generated through social interactions with actors, and the interaction is viewed as a performance (Goffman, 1959; Haralambos et al., 1996; Meltzer, 1972). A concept further elaborated on by Goffman is that performers' roles in day to day interactions affect how others perceive them.

The dramaturgical imagery is described by Meltzer (1972, p.72) as 'a device used by the analyst to focus attention upon the effects of the actor's behaviour upon the perceptions of him/her by others.' Goffman described the use of dramaturgical imagery in his seminal work (Goffman, 1959) as useful in describing and analysing roles in society. This is pertinent from the perspective of applying symbolic interactionism in analysing the role of identity in the formation of self for participants in relation to their experiences of social exclusion. Using Goffman's dramaturgical theory enables a microsociological analysis of meanings and day-to-day interactions of participants (Goffman, 1959; Meltzer, 1972).

Symbols and Rituals; Spirituality and Ceremonies

Symbolic interactionism also focuses on how people use symbols to establish meaning, communicate and establish their world views (Blumer, 1969; Meltzer, 1972; Prus 1996). Whilst there is little published literature in relation

to Aboriginal people in this area, the literature that is available reveals spirituality and related customs and ceremonies for Aboriginal people are highly sensitive issues, to be discussed with and performed only by specifically chosen people (Hotson et al., 2004; Maddocks & Rayner, 2003).

Symbols, rituals and language in relation to the whole-of-life-view of Aboriginal people are also portrayed in the writings termed Dadirri:

We wait for our young people as they grow, stage by stage through their initiation ceremonies. When a relation dies we wait for a long time with the sorrow. We own our grief and allow it to heal slowly. We wait for the right time for our ceremonies and meetings. The right people must be present. Careful preparations must be made. We don't mind waiting because we want things to be done with care. Sometimes many hours will be spent on painting the body before an important ceremony (Ungunmerr-Baumann, 2000, p.115)

In addition to the underlying concepts of symbolic interactionism previously described, self is an underlying tenant in all symbolic interactionism (Blumer, 1969; Meltzer, 1972) The central concept of self is further elaborated on in the following section.

Front Stage/Back Stage and Self Concept

Goffman (1959) asserts that whilst a person or actor is in view of others they adopt characteristics according to the setting where the interaction occurs (Goffman, 1959). For example 'many classes of persons have had many different reasons for exercising systemic modesty and for underplaying any expressions of wealth, capacity, spiritual strength or self respect' (Goffman 1959, p.47). Goffman believes a person/actor adopts their own position within a continuum of extremes of self, ranging from either taking on the role or

displaying cynicism about the role (Goffman, 1959). The meaning of the word “person” illuminates the point:

It is probably no mere historical accident that the word person, in its first meaning, is a mask. It is rather recognition of the fact that everyone is always and everywhere, more or less consciously, playing a role...It is in these roles that we know each other; it is in these roles that we know our self (Park, 1950, p.249).

The roles of self an individual portrays are explained by Goffman (1959) when he refers to the following quote from the philosopher, William James:

...we may practically say that he has as many different social selves as there are distinct *groups* of persons about whose opinion he cares. He generally shows a different side of himself to each of these different groups. Many a youth who is demure enough before his parents and teachers, swears and swaggers like a pirate amongst his ‘tough’ young friends. We do not show ourselves to our children as our club companions, to our customers as to the labourers we employ, to our own masters and employers as to our intimate friends (Translation by William James Jr in Goffman, 1959, p.57).

Others

From a symbolic interactionist perspective, two categories of others exist in the development of self, the significant other and the generalised other (Blumer, 1969; Meltzer, 1972). Taking on roles in interactions from a symbolic interactionist perspective occurs within the context of tacit knowledge. Tacit knowledge refers to what the actors know from memories of past experience (Meltzer, 1972). This was considered to be an important issue in relation to the past experiences of dispossession (NSWALC, 2009) thus both memory and history were incorporated into the model.

History

Respected Maori academic Smith (1999) advocates the need for the acknowledgement and close examination of historical forces and the effects of colonisation on those that have been colonised. Smith asserts that:

constant efforts by governments, states, societies and institutions to deny the historical formations of such conditions have simultaneously denied our claims to humanity, to having a history, and to all sense of hope (Smith, 1999, p.40).

It is the ongoing effects of colonisation that are a causal factor in the health disparities affecting Aboriginal people (Hunter, 1998, Swan, 1998, Mckendrick & Thorpe 1998). History and memory are, therefore, inextricably linked.

Memory Related to Grief

In terms of bringing the experiences of Indigenous people to the forefront of research, Indigenous Australian researchers and academics, Martin (2003) and Atkinson (2001) have expressed, in the principles of Indigenous research, that the experiences and voices of Aboriginal peoples' lives should be privileged. From a wider perspective, other authors also advocate that memory is a significant component of post-colonial research (Atkinson, 2001; Bhaba, 1985; Sherwood & Edwards, 2006; Smith, 1999), with Australian Aboriginal nurse academics Sherwood and Edwards (2006, p.6) going as far as promoting post-colonial perspectives as a "framework for remembering". Smith (1999, p.98) also articulates this point in relation to memory:

The Elders, the women and various dissenting voices within Indigenous communities maintain a collective memory and critical conscience of past experience.

In addition to understanding the historical context which has shaped Aboriginal peoples' lives, the role of loss associated with the social history of the community is critical in understanding identity (Kellehear, 2002). Atkinson (2001) also notes that in order to create healing and strength in individuals the acknowledgment of history is paramount. The impact on health of historical trauma and grief, even if documented, is poorly understood. Findings from this study will assist with understanding this issue.

Limitation of Symbolic Interactionism

Critiques of Goffman's symbolic interactionism perspective have focused on the limitations in scope of the theory (Blumer, 1969; Meltzer, 1972) because of his focus on microanalysis of everyday experiences (Meltzer, 1972; Rock, 1979), without due consideration of the historical influences or institutional contextualization (Meltzer, 1972). Nevertheless, with the merging of approaches, the strength of this study lies in situating the study both within the broad context of a decolonising model, and more specifically, following the principles of Indigenous research. Therefore, history and historical experiences are underlying aspects of this study.

Colonisation – Post-colonialism

In the context of grief and loss, Aboriginal people's health and wellbeing is shaped by the history of colonisation. Aboriginal people continue to be affected by intergenerational grief and trauma as a result of colonisation which is well documented (Atkinson, 2001; Hunter, 1998; McKendrick & Thorpe, 1998; O'Brien, 2000; Swan, 1998).

Colonialism is defined by the NSW Aboriginal Land Council (NSW Aboriginal Land Council, 2009 para. 5) as:

The establishment of control over the original inhabitants of an area by taking possession of their land, introducing colonists and a colonial administration.

Dispossession is defined by the NSW Aboriginal Land Council as referring principally to loss of land. Importantly:

Given the spiritual ties which Indigenous people have to their land, its removal also led to the loss of their culture, language and religions, identity and economic independence (NSW Aboriginal Land Council, 2009 para.7).

Thus the worldview of Aboriginal people is shaped by each individual's experiences, histories, culture and values (Atkinson, 2001; Smith, 1999). The literature review discussed the Aboriginal health and wellbeing literature and identified the absence of a specific Aboriginal theory of grief and loss to guide the study and finally analyse the interview transcripts. O'Brien's (2000, p.14) doctoral study on mental health and Aboriginal youth in rural NSW asserts; "belief in kinship, history, the land and its spiritual significance to the Aboriginal person and his or her community are arguably theoretical perspectives in themselves". Publications by Indigenous people have also stressed the need to include spiritual, cultural and historical dimensions in research models with Indigenous people (Martin, 2003; Smith, 1999; Status of Women Canada, 2004), particularly if healing is the intention of the study or report. As noted in Figure 3.1 (p.47) all of these components are incorporated into the Symbolic Perspective on Aboriginal Grief and Loss Model. Therefore in the broad context of critical inquiry, the theoretical model is also embedded

within the domains of post-colonial inquiry. Critical inquiry seeks to generate “practical, pragmatic knowledge that is cultural and structural and judged by its degree of historical situatedness and its ability to produce praxis and action” (Denzin & Lincoln, 2003, p.249).

Koori Country, Koori Ways

The next Chapter, Chapter Four, discusses the ethnographic methods in depth; however the links between theory and method are introduced here to make the connections explicit. The ethnographic methods adopted included spending extended time in the community, semi-structured in-depth interviews, field notes and participant observation, all of which are complementary to Dadirri. Establishing relationships by spending extensive periods of time in the community is a central component of ethnography. In addition, the ethnographic methods are consistent with relational Indigenous ontology (Atkinson, 2001; Wilson, 2004). Similarly, grounded theory, which was used as a structured approach to data analysis, has foundations in symbolic interactionism and is compatible with ethnography (Glaser & Strauss, 1967; Hammersley & Atkinson, 1995; Lee, 2006; Vidich, 2000).

Summary

This chapter has presented the symbolic perspective on Aboriginal grief and loss model developed for the study. This theoretical model was used to interpret the semi-structured in-depth interviews and is a merging of three intersecting domains. These are symbolic interactionism, decolonisation, and Dadirri (Ungunmerr-Baumann, 2000). Dadirri overarches the model and

provides an Australian Aboriginal perspective to assist with analysis of the data. Chapter Four presents the methodology of the research.

CHAPTER FOUR:

Methodology: Walking on Dunghutti Country

CHAPTER FOUR

Introduction

Chapter Three outlined the theoretical perspective for the thesis and this chapter provides details of the ethnographic methods adopted for the study. Ethnography enabled me to become immersed in the community to gain some understanding of the sub-culture I was working with. Intrinsic to the methodological approach to this research are the principles of community control and partnerships, which have been further developed in the preceding chapters. This chapter discusses the guidance which was provided by a number of Aboriginal individuals and organisations which led to the partnership model which overarches the research.

The ethical considerations of the importance of adopting methods to ensure the study was respectful and conducted in accordance with Aboriginal beliefs and traditions are presented. The steps taken to ensure the research and its findings are relevant to the participants involved in the study are also discussed. The structured approach to analysing the semi-structured in-depth interviews using the principles of grounded theory, whilst not generating theory, is presented in this chapter. Throughout Chapter Four my position as a non-Aboriginal researcher working in partnership with Aboriginal people from Dunghutti country is considered.

A Qualitative Approach: Ethnography

For the purpose of this study the choice to adopt a qualitative approach was based on a number of assumptions. Firstly, the qualitative design is consistent with the aim of the study and research questions, which were intended to gain an insight into the experience of, and meanings attached to grief and loss from an Aboriginal perspective. Secondly, presenting and describing Aboriginal participants' point of view are issues which could not be represented numerically as in a quantitative study. Berg (1989) confirms that qualitative research gives an in-depth meaning that would be lost if represented numerically, as would be the case in a quantitative study. Thirdly, the ethnographic nature of this study respects the oral history tradition of Aboriginal people (Atkinson, 2001, 2002) and has been confirmed as being compatible with Aboriginal ways of being (Martin, 2008; Prior, 1997). Atkinson (2001) affirms ethnography is complementary to Dadirri. The need to understand Aboriginal ways is described in the words of Dadirri:

We still wait for the white people to understand us better. We ourselves had to spend many years hearing about the white man's ways. Some of the learning was forced, but in many cases people tried hard over a long time to learn new ways (Ungunmerr-Baumann, 2003, in Farrelly 2003, p. 1X).

Qualitative research in health care has become commonplace (Mays & Pope, 2000) and is particularly relevant to Aboriginal and Torres Strait Islander health research in the context of understanding 'social, behavioral and cultural contexts of health' (NHMRC, 2002, p.8). Qualitative methods and interviews as a means of participants sharing their stories or narratives have been used in a number of recent Australian studies which focus on Aboriginal and Torres

Strait Islander health and wellbeing. These include, but are not limited to, Atkinson's (2001) study on intergenerational trauma, McGrath's (2006) study which investigated participants experience of relocating for end of life care; O'Brien's (2000) study on the development of Mental Health in Koori Adolescents; and Prior's (2006) study which examined Aboriginal women's insight into cancer. McDermott (2006), an academic and Koori psychologist, explains further:

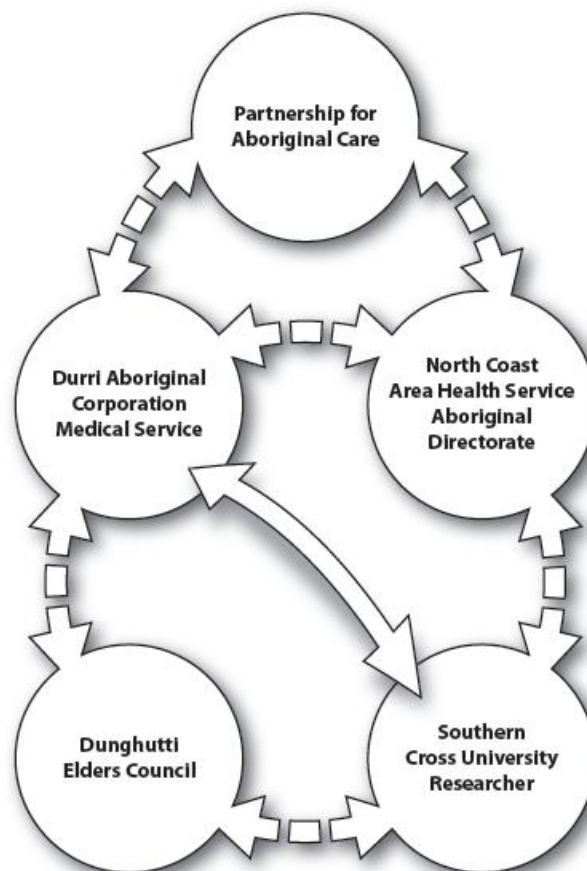
... narrative can carry a complexity that epidemiology lays out as so many bones. Coolly useful as data are, when statistics have real human faces there's a chance that a lost emotional resonance might return. For Gubbas (non-Aboriginal Australians) to come to grips with what's happening in Aboriginal health in this country doesn't require a bleeding heart. It does require new means to "de-Other" Aboriginal Australians — to situate us, and our experiences, inside the national consciousness. Blackfella health won't change until we are no longer the exotics of our own land (McDermott, 2006, p.184).

As discussed in Chapter Three, the positioning of participants at the centre of this study is consistent with the decolonisation intent of the theoretical framework (Durie, 1994; Fanon, 1995; Mohammed, 2006) underpinning the study. Additionally, as introduced in Chapter Three, the underlying principles of partnership with the Aboriginal community, participation by representatives of the Aboriginal community in decision-making regarding the broad area of research and protection of Aboriginal cultural integrity (Durie, 1994; NHMRC 2003, 2005; Orange, 2004) all guided the study. In terms of applying these principles to research methods and practice, firstly relationships had to be built. Relationship building was the first step in beginning to understand the Aboriginal ways of being (Martin, 2003, 2008; Wilson, 2004) through the ethnographic methodology.

Partnerships to Guide the Study

Relationship building in this study was primarily through the formation of partnerships and subsequent guidance for the study by the various partners as depicted in Figure 4.1.

Figure 4.1 Research Partnerships Guiding the Study



The following section illustrates the significance of forming research partnerships to guide all aspects of this study. Participants in the study have not been included in the diagrammatic representation in Figure 4.1 as the partnerships in this case refer to partners that provided guidance for the study.

However on reflection, after being interviewed participants did guide the study by speaking about the study in the wider community.

As introduced in Chapter Three, with respect to implementation of the research, researchers from outside Aboriginal communities making claims and interpretations on Aboriginal knowledge has previously resulted in criticism of ethnography when a researcher studies a cultural group other than their own (Bhaba, 1985; Durie, 1994; Smith, 1999). Smith (1999) further adds, from a Maori point of view that a person would not necessarily need to be Maori themselves to study a Maori community if they had a mentor from within the community being studied. Whilst I had knowledge of the need for a mentor I was unsure at the start of the study how to arrange this. Guidance from the partners was an important aspect in this regard. In addition, the partners provided important advice on the view of previous research at a community level. Thus respectful methods that were agreed by the partners were used. The following field note, which was written early in the study following a conversation with a community member regarding research in general, illustrates this point:

[That university] have been saying they're coming for years but I never see them. They keep promising, that boss fella never does what he says he's going to do. Oh it's not only [that university], I get people ringing up all the time, consultants, but now I just say no. Cause they never give anything back to us Aboriginal people.
(Field Note, August 17, 2004)

Data Collection Methods

Typical of ethnographic studies, semi-structured in-depth interviews were undertaken and field notes of observations and reflections were recorded for the duration of the study. The field notes were coded according to the date recorded.

As is accepted in referencing style guides, field notes were considered as an example of unpublished raw data (APA, 2001). Thus, field notes are referenced according to this example, (Field Note; February 22, 2006). A summary of field notes is attached as Appendix A.

Koori Country Koori Permission: Seeking Community Permission

Permission to conduct the study was a careful and respectful process which required a great deal of negotiation, consultation and meetings with key Aboriginal stakeholders. This process began from the moment when the Durri Aboriginal Corporation Medical Service (ACMS) Executive were approached and asked if they would allow the research to be conducted at the Medical Service.

Although I had worked as a Nurse in Australia since 1984 and had experienced nursing many different cultural groups, including Aboriginal people, at the start of this research I felt I lacked the knowledge to work considerately in partnership with Aboriginal people. I realised that I knew very little about respectful ways to relate to Aboriginal people or Aboriginal belief systems. Consequently, working with Aboriginal people represented

considerable challenges to my existing cultural knowledge. As a non-Aboriginal researcher, this is captured in a field note written early in the study:

It's like I am walking on land that is not mine, and in a way I feel like I need to actually somehow walk above the land. I need to ask permission from the traditional owners of the land where and when I can put my feet down. (Field Note, October 27, 2004)

With these thoughts in mind, from the conceptualisation of the project I began to seek advice on culturally safe (Ramsden, 2002) practice from key Aboriginal community representatives, with the premise that the research needed to be guided by respectful Aboriginal ways, which was consistent with Aboriginal community control. Key NSW Health policy documents were also reviewed including the NSW Health Aboriginal Impact Statement (NSW Department of Health, 2003). Additionally, I sought advice from the same Aboriginal representatives on what would be expected of me as a researcher on Dunghutti country and the ways in which we could work together so the study could proceed in meaningful ways. A field note highlights a portion of this early advice from a national Aboriginal and Torres Strait Islander organisation in response to a general question I had asked in relation to any extant guidelines on ways to conduct respectful research from a non-Aboriginal point of view:

Find Aboriginal leaders to seek permission. Do this gently, incrementally and seek advice from these leaders and form partnerships.
(Field Note, July 22, 2004)

Partners in the Study: Choosing the Site

Initially I had been advised by a number of Aboriginal advisors when scoping the study that the Kempsey-based Durri was an important ACMS to contact, to gauge interest in being included in a study with a focus on grief and loss. Guidance for the research was sought initially from the ACMS Chief Executive Officer. The importance of seeking advice from the ACMS early in the research planning was critical to the research questions addressing issues deemed important by the Executive Board. The names of these advisors and precise details are not included to maintain confidentiality. All advice given in these preliminary planning stages was subsequently endorsed by the Durri ACMS Executive when the full research proposal was viewed.

Durri ACMS is an example of an Aboriginal organisation that Dunbar and Scrimgeour (2006) describe as representing the community members' interests in a range of negotiations. Up-to-date national and international literature highlights the ability and potential impact non-government and community organisations have on generating and using research to reduce health and social inequalities (Dunbar & Scrimgeour, 2006; Sanders, Labonte, Baum & Chopra, 2004).

On further discussions with the ACMS Executive a number of critical key considerations emerged. These considerations reflected the importance of firstly choosing a field setting which would enable the theoretical underpinnings of the partnership model, which are embedded within a number

NSW Health Policy documents, to be implemented. For example, the NSW Health Aboriginal Impact Statement and Guidelines, which advocates a partnership model through community participation in relation to Health Policy development for Aboriginal and Torres Strait Islander people states:

The Aboriginal health principles which should be applied in all relevant health policy initiatives are

- a whole of life view of health
- practical exercise of the principles of self determination
- working in partnerships
- cultural understanding
- recognition of trauma and loss

(NSW Health, Aboriginal Health Impact Statement 2003, p. 5).

Secondly, Aboriginal community control was an important consideration in the research process. Durri ACMS is one of 44 members in Australia of the National Aboriginal Community Controlled Health Organisations (NACCHO). The criteria for NACCHO membership includes governance guidelines which state that a NACCHO must be “governed by an Aboriginal body which is elected by the local community” (NACCHO). The NACCHO definition of an ACCHS is:

a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it (through a locally elected Board of Management).

<http://www.naccho.org.au/definitions/ams.html>

Aboriginal community control in health services is additionally described by the Australian NACCHO:

The term Aboriginal community control has its genesis in Aboriginal peoples' right to self-determination.

An Aboriginal Community Controlled Health Service is:

- An incorporated Aboriginal organisation
- Initiated by a local Aboriginal community

- Based in a local Aboriginal community
 - Governed by an Aboriginal body which is elected by the local Aboriginal community
 - Delivering a holistic and culturally appropriate health service to the Community which controls it.
- <http://www.naccho.org.au/definitions/communitycont.html>

Whilst this forementioned definition and national guidelines (NMHMRC, 2002, 2003, 2005) provided guidance to the methodology, the local partnership formations were vital to ensure the research was both meaningful, and respectful to the community. The following field note provides an example of advice from a key National Aboriginal and Torres Strait Islander organisation in relation to culturally safe research practices:

It's inappropriate for anyone to provide culturally appropriate advice. You need to seek local advice. (Field Note, July 22, 2004)

Thus, extensive guidance and support was gained from key local Aboriginal representatives in the Dunghutti community on ways I, as a non-Aboriginal researcher, could work in partnership with an Aboriginal community. Therefore, the methodology was ultimately guided by recommendations from key local Aboriginal people from Dunghutti country as well as an extensive literature review related to culturally safe research practices.

Seeking Permission

In the year leading up to the first participant interview, I spent on average two days a week visiting the community and talking with people about the proposed research. After meeting with Durri ACMS Executive and spending days talking with staff at the Medical Service about the study and generally

getting to know people, ACMS staff began to show a great deal of interest in the study. Subsequently I was invited by the CEO to spend more time talking with staff at the ACMS staff meetings about the proposed study. Staff willingly spoke about the need for specialised services. At one staff meeting I was handed a typed note which read:

One of the main things I see as a support worker is the need for specialised Koori grief and loss counsellors as there is not one in our area. The need for both female and male counsellors is a must to service both genders, these counselors will attend to the needs of family, extended family, relatives, friends and the community, they will be there in times of need at homes, aged care facilities, hospitals, funerals and wakes. Their availability before and after the event is a time process which can take days, weeks, months and years to come to terms with. Counsellors can also educate the community by doing grief and loss workshops to help alleviate the pain of losing a loved one or another form of grief and loss. (Field Note, October, 27, 2004)

The introductory processes before community permission was gained to conduct the study included:

- attending meetings with Dunghutti Elders' Council which I had been invited to after contacting the Elders' Council on the advice of the ACMS Executive;
- attending staff meetings at Durri ACMS which I had been invited to attend by the Durri ACMS CEO. On the advice of the Durri ACMS CEO and Executive, at these meetings I presented the draft study outline to staff;
- on the advice of Durri ACMS CEO and Executive spending days talking to staff in general about the study;

- extensive consultations, conversations with Mid North Coast Area Health Service (now North Coast Area Health Service, NCAHS) Area Director of Aboriginal and Special Programs Directorate;
- on the advice of MNCAHS Aboriginal and Special Programs Directorate staff, preparing and presenting a summary brief of the study to the MNCAHS Aboriginal Partnership Board Executive; and
- on the advice of MNCAHS Aboriginal and Special Programs Directorate a NSW Health, Aboriginal Impact Statement (Appendix B) was prepared and tabled at a meeting of the MNCAHS Aboriginal Partnership Board Executive.

Whilst I have documented every meeting in a formal, Westernised way, the meetings occurred much less formally than I had previously experienced.. Significant planning for the study occurred over cups of tea and shared conversations with representatives from local Aboriginal organisations. The Aboriginal research agenda has been likened to being somewhat like a ceremony (Atkinson, 2001; Wilson, 2004). Certainly I found this to be the case, and felt humbled to be invited to participate in shared conversation and planning for the study with members of the community. On several occasions individuals from the ACMS staff made remarks about returning to the community on the completion of the study, such as this comment from a respected community member and staff at the ACMS, made in the friendly, lighthearted fashion I became familiar with, during the study:

There is a saying amongst Aboriginal people here, that if you drink the water from the Macleay you will always come back to visit. You have

now had so many cups of tea with us Koorie people that I reckon you'll always come back. (Field Note, August 10, 2005)

Upon reflection, such remarks at this time indicated that I felt a growing level of support and a level of understanding was developing between all the partners. These thoughts were recorded as field notes:

I felt OK as a white woman now, because I understand (or am beginning to understand) the respectful processes and have followed them explicitly. I don't feel whiter than white that I felt on my first visits, which was very intimidating. (Field Note, November 24, 2004)

The description of myself as a white woman rather than a non-Aboriginal person is not intended to describe the Aboriginal and non-Aboriginal relationships in the study. This field note, written in my early fieldwork, indicates I still had a great deal to learn about respectful language and terms to use.

Whilst the research proposal was being finalised, I continued to seek advice from the CEO of Durri Aboriginal Corporation Medical Service and the Dunghutti Elders' Council on procedures that I would need to follow for the study to proceed. More widely, North Coast Area Health Service Aboriginal Directorate staff were also consulted.

The Aboriginal Grapevine: Spreading the Word about the Study

Whilst preparing the full research proposal and Human Research Ethics Committee (HREC) submissions, further advice was given from the ACMS Executive that the wider community should now be informed about the study. Again, I was advised by the ACMS Executive to seek ideas from the Dunghutti

Elders' Council and Aboriginal health workers who were staff at Durri ACMS, about ways to let the wider community know about the proposed study. These people were all very supportive and made the suggestion of distributing an information sheet about the study.

Information letters providing an overview of the proposed study (Appendix C) were distributed to staff at the ACMS and the Dunghutti Elders' Council. Information sheets were also distributed widely in the community via Durri ACMS staff. I was invited to talk about the study again at staff meetings at the ACMS. The following field note describes advice I was given prior to a staff meeting with key staff about appropriate processes:

The next step is to speak with staff to let them know about the project. You can come and speak to staff at either a staff meeting or an in-service meeting. You should keep in touch about the progress of the ethics submission. Just give one to two weeks notice when you are coming to present to staff...really it's up to the staff to see if they like you, to see if they can relate to what you are saying. (Field Note, August 17, 2004)

And two months later, a summary of my field notes from a phone conversation are provided to indicate the increasing intensity of interest in the study and advice on how to distribute information further throughout the community:

- Asked to email a flyer about the study to a contact person at Durri ACMS who would also distribute information to staff and within the community;
- Advised to be visible in the community, spend time talking
- Advised to meet again with Elders' Council
- Suggested mechanisms from ACMS Executive staff put in place for counselling referral for participants. (Field Note October 27, 2004)

I realised that I needed to have confidence in the steps that I had taken to seek permission from the Dunghutti community to undertake the study. I was told by Aboriginal community leaders that processes within the community were taking place to see if I had the patience to respect the processes of the community. I believed I had followed the advice I had been given and therefore needed to trust the community processes that were occurring as I waited for permission to continue the research process. This was also the advice I was given:

I'm happy with the process you have taken so far. Keep talking to everyone, don't assume that the Durri Board will approve until you finally have their approval. Even though this project needs approval from Mid North Coast Area Health Service the *final* approval comes from the Durri Board. (Field Note, October, 27, 2004)

Ethics Approval

In addition to following the specific cultural communication and consultation process described, the NHMRC (2003) "Guidelines for Research with Aboriginal People" were followed explicitly, in addition to the guidelines within the National Statement on Ethical Conduct on Research Involving Humans (NHMRC,1999). Additionally the NHMRC Road Map "A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research Human Research" (NHMRC, 2002), provided guidance. Ethics approval was gained from Southern Cross University Human Research Ethics Committee (Approval No ECN-04-181) and North Coast Area Health Service Human Research Ethics Committee (Approval No 285). However, most significantly, final approval for the study was sought from the Durri ACMS Executive Board. On advice from the ACMS Executive Board members the Elders' Council

were kept informed of all aspects of the study through letters and face-to-face meetings.

Koori Community Processes: Sitting Under a Tree

During the process of waiting for final approval from the ACMS Executive, it was explained to me that if I was in a remote community or in traditional times, when an outsider comes into the community they would be “sitting under a tree and being watched” until the community accepted that I had suitable attributes to have permission to conduct the study (Field Note, October 27, 2005). It was explained to me that I needed to wait whilst the research was considered further by the community. Although I had confirmation from key people in the community that this research was a very much needed and important study, this was an anxious time. I had spent a year talking with the community, preparing an extensive research proposal and submissions to two Human Research Ethics Committees and following the guidance I had been given by the community representatives. I knew this was a critical time and the community processes were not visible to me as an outsider. It was explained to me by the Durri ACMS CEO that the study could not proceed without the final endorsement from the community.

Final Approval is Community Approval of the Study

Five months after I had gained HREC approval from SCU, final approval for the study was given by the Durri ACMS Executive. Twelve months after I had begun talks with the community I was offered office space to use for the duration of the research and beyond if needed.

Approval was given verbally; “We’ve got that research room that you can use, you’re welcome here, take as long as you like” (Field Note, May 12, 2005), followed by a formal letter. When this approval for the study was given from the Durri ACMS Executive Board, I was allocated an office or research room. I soon realised this was my link to the community. Within days, participants began volunteering to take part in the study, akin to snowballing (Minichello, Aroni, Timewell, & Alexander, 1995). The aim of snowball sampling was to generate a sample which was representative of the population studied (Minichello, Aroni, Timewell & Alexander, 1995) and to gain insight about participants’ experiences of grief and loss. The process of snowballing from an Aboriginal perspective was described by a community member:

People in the Aboriginal community do talk, it’s better than the newspaper, it’s better than television. The Aboriginal grapevine you know and the community. Yeah, what’s said here today is probably heard up at Coffs Harbour this afternoon or somewhere like that. (Field Note, June 10, 2006).

As a non-Aboriginal person I felt extremely privileged to be working as a researcher at Durri ACMS. I quickly began to feel accepted and was made welcome by all of the staff in all of the time spent at the Medical Service. This was highlighted when I was on a community visit and I was introduced by a respected Aboriginal community member as “being from Durri”. Whilst I recognised that essentially I was an outsider conducting research which had the permission and direction provided by Durri ACMS Executive, comments such as this were an affirmation of the acceptance of Durri ACMS by Aboriginal people living in the Dunghutti community. Moreover, it was also

confirmation of the important link I had established through Durri ACMS to the wider Aboriginal community. On visits to the wider community, people seemed to know who I was, although I had not been introduced to all people in the community. I was advised by ACMS staff that the Aboriginal grapevine was working.

Aboriginal Mentor

As I settled into days at the Medical Service interviewing participants and talking with staff and the community, there seemed to be a particular senior staff member, a respected community member who was always around. This person was there to greet me on my arrival in the morning, asked when I would return and generally inquired about my well-being and the progress of the study. This person asked daily if they could help in any way or if I was having any problems in relation to recruiting participants. This person would also come and sit with me and advise on how important the study was.

On reflection, although I wasn't aware that this had been arranged, the person was acting as a cultural mentor to help in the study (Smith, 1999). It was this person, as well as the Aboriginal staff members at the Medical Service, who took on the role of cultural advisors during the duration of my stay and subsequent dealings and visitations with the ACMS. Wilson (2004) describes this person as an intermediary, who facilitates rapport between participants and the researcher.

On return visits for community meetings, this person again made themselves available for assistance in contacting people and observing general Aboriginal-specific protocols. The Medical Service staff also willingly provided me with advice on issues like how to contact certain members of the community, and respectful ways to speak with people. For example, I recall being at the ACMS on many occasions and listening to conversations around me and people being greeted by:

Hey brother, hey sister, or, giddy Uncle, giddy Aunty.

Initially I was unsure how I should respectfully address these people. I asked an Elder, a woman, this question and was told:

People (outsiders) need to earn respect and only then is it o.k. for them to call me Aunty. (Field Note, August 24, 2005)

The only publication available to assist NSW Health staff to communicate in a culturally courteous way is the publication, *Communicating Positively: A Guide to Aboriginal Terminology* (NSW Health, 2004). This 32-page booklet did not equip me with the necessary information and confidence to speak with respect to any Aboriginal person. I was exceptionally appreciative of the advice of all staff for both welcoming me and for taking on the roles of mentors. With the assistance of Durri ACMS staff and a cultural mentor to provide leadership in conversing respectfully, the ACMS Executive confirmed that the steps I was taking in the research progression were culturally considerate.

Researcher's Role

Compatible with this ethnographic orientation, my role as a researcher was an informal investigator (Vidich & Lyman, 2000). Typical of ethnographic studies, I

positioned myself as an outsider with an aim to understand and write from the perspective of participants in the study and at no time do I claim to be the voice of the participants; rather my aim is to write and analyse from the participants' perspective (Bell, 1993; Berg, 1989; Hammersley & Aitkinson, 1995; Russell, 2004; Simmons, 2007).

I told people in the community that I was a researcher doing a study on what local Aboriginal people thought were important issues surrounding grief and loss. In fact, many people already knew who I was and in the community people said to me "Ah yes, you're that person for the grief and loss study". I observed day-to-day interactions of staff, patients and community members at the Medical Service. Participant observation in health research observes people in their day-to-day societal cultural setting (Russell, 2004; Whyte, 1955). In addition to the routine activities of the Medical Service, I observed participants at community meetings and gatherings that I was invited to attend. I never intended to become part of the community, although at times I felt that I was and that I was included in conversations that were private and at first, culturally, I didn't always understand fully what was meant. I was at all times open about who I was and made it known that I was a researcher, so as to avoid role-conflict.

As I became more immersed in the community and spent extended time there I began to gain an understanding of many of these initial and subsequent cultural events, particularly in relation to the need to understand historical

influences on the lives of local Aboriginal people. On reflection, this was explained by a participant:

To understand what's happening today, you must first understand the past. (Field Note, June 22, 2005)

Field Notes

Field notes were recorded of my observations of interactions between Aboriginal community members. The field notes were often written after interviews so I could pay attention to what participants were saying or after prolonged periods of conversation and community meetings. I felt this was a respectful way to participate rather than being seen as a person with paper and pencil taking notes at every opportunity, and it allowed me to observe participants in a natural setting (Hammersley & Aitkinson, 1995; Russell, 2004). However, there were times during community meetings that I asked permission of people to take notes rather than assume that this was acceptable.

Field notes are used with caution in reporting this study, out of respect to participants and in an endeavor not to impose my interpretation of events. Rather, participants' points of view and meanings are presented in the findings chapters.

Interviews Began: Stories of the Meaning of Grief and Loss

The first interview was conducted on 26/5/2005. Table 4.1 provides a summary of the lead-up to this first interview, which has been described to this point in this chapter.

Table 4.1: Summary of the main stages of the study up to interviewing participants

Stage of the Study	Key Events of This Stage	Time Frame
Stage 1	Getting to know the community & seeking permission began with first contacts made by the researcher to Durri ACMS Executive	25/6/2004
	Human Research Ethics Committee Approval Southern Cross University	14/12/004
Stage 2	Community Approval Gained	26/5/2005
Stage 3	Interviews conducted over 5 months. Researcher located at Durri ACMS for this time.	26/5/2005-12/11/2005

The volunteering of the first participant to be interviewed in the study was a major milestone in the next phase of the study. On my first site visit to conduct the interview, I stopped on my way to record some reflections in my journal, which was recorded as a field note reflection:

I felt excited and in a privileged position to have gained access to the ACMS. I was given the choice of two offices; the audiometry soundproof office or the designated researcher officers space. I received a letter yesterday from the CEO, with no stipulations at all regarding the use of space for interviews. This was confirmation that I had been accepted and followed the culturally appropriate steps, and sought advice at what seemed like every movement along the way since beginning.
(Field Note, May 25, 2005)

The daily routine of staff at the ACMS was for staff to meet during breaks from the Medical Service routines, and talk together over tea or coffee about a range of issues affecting the Aboriginal community including planned events, sickness of community members, the general wellbeing of community members and funerals. Funerals take place frequently and is a constant topic of conversation. The inclusion of this description of daily activity is important in

describing the ways in which staff interacted and had opportunity to share matters going on in the wider community. Out of respect I have not included details of particular conversations or events that did not relate to this study.

After arriving on this first day of interviews I made tea in the staff room. This was to become daily routine and a way of connecting in conversation with staff. This first day of interviews, I met two female staff members informally in the staff room:

“Ah yes we remember about your study, we got a memo about that”.
Conversation flowed easily between us.
They asked do you know x and y, their X died and they have a lot of grief. This would be good for them, this would really help them. They [are only teenagers]. (Field Note, May 25, 2005)

I explained that I was not a counsellor but a researcher, and that initially the study had Human Research Ethics Approval (HREC) for people over 18 years of age. This was the first of many people in the community who expressed the importance of people under the age of 18 years being included in the study to describe their point of view. At the request of the community and because of emerging themes in the transcripts HREC approval was sought and gained to include participants younger than 18.

After the first interview was completed, it was suggested by the Durri ACMS CEO that I should prepare a flyer about the study for the waiting room and also a letter to the Elders' Council informing them that the study had commenced. On this first day of interviewing, the Durri ACMS CEO also nominated a representative that I could liaise with about any issues or

questions in relation to the study. This person was in addition to the mentor/s that I have previously described. I was then advised by the Durri ACMS CEO representative that the staff member responsible for reception would make up an appointment schedule with the days and times available for interviews. A flyer inviting people to volunteer to participate in the study was displayed in the Durri ACMS waiting room for the duration of the study. Appointments were made via reception or directly to the researcher. The Medical Service staff were very supportive of the study and provided much needed administrative assistance.

Permission was asked of each participant to audio tape the interviews to allow a conversation style of interview to proceed (Berg, 1989; Minichello et al., 1995) This was an important consideration in respect to the advice I received from the community representatives. The literature supported this view in acknowledging the oral history tradition of Aboriginal people (Atkinson, 2001; Eckermann et al., 2006) and aligned with ethical guidelines. Interviews continued and the transcripts were analysed until no new themes emerged or a point of saturation was reached (Glaser & Strauss, 1967).

Consent

Written and verbal consent was obtained from each participant (Appendix D) prior to the interviews commencing. On advice from the Durri ACMS Executive the consent used for youth participants was modified slightly. In accordance with the national guidelines (NHMRC 1999, 2003) participants were fully informed of the aims of the study, the length of the study and

interview and potential risk factors. This information was relayed to participants both verbally and in the consent forms.

Support for Participants

I was aware, and had also been advised by the community, that although they supported the study, the research was of a highly sensitive area. The need to support participants in the case of distress or adverse feelings that could come out during the interviews or afterwards was recognised. The staff at Durri ACMS were available to be present for participant support during the interviews. Participants were also advised that they could bring a friend or relative with them to support them during the interviews if they wished. In planning the research I was advised by the Durri ACMS Executive that this was a culturally appropriate way to proceed. No participants took up this offer, but two participants chose to be interviewed together.

Prior to the first interview commencing, counselling referral was arranged through the usual Durri ACMS referral channels, which in the first instance, was for assessment by Durri ACMS staff, and then if required referral to local non- Aboriginal counselling services. This highlighted the difficulties faced by Aboriginal people in this community because:

Currently North Coast Area Health Service will only see patients with a diagnosed mental illness. No Aboriginal counsellors employed at North Coast Area Health Service. (Field Note, October 27, 2004)

Confidential telephone counselling was arranged with local services, again with non-Aboriginal staff. No participants used this referral mechanism or any of the local services following their participation in the study.

Confidentiality of Information

Confidentiality was maintained and information from the interviews used in the findings chapters do not contain any identifying data. The participant profile, audio tapes, memory cards and field notes were stored in accordance with the National Privacy Principles (Federal Privacy Commissioner, 2000). Table 4.2 provides a summary of participants by age-group and gender.

Table 4.2 Participant Profile

Age Years	Female	Male	Total
15-20	2*		2
20-25			
25-30	3	1	4
30-35		1	1
35-40	1	1	2
40-45	1	2	3
45-50	3	1	4
50-55	2		2
55-60	1	1	2
60-70	2	1	3
70-80		1	1
Total	15	9	24

* Both under 18

All participants identified as Aboriginal and all participants lived in the traditional land known as Dunghutti country.

Location of Interviews

Twenty-one interviews took place at Durri ACMS in either the private office I had been allocated or in the shade of trees overlooking the Macleay River. The choice of venue was made by each participant. In addition, provision had been made to speak with participants in their own homes or other convenient places if this was the preferred option and three participants were interviewed in the community at a venue of their choice. The importance of the safety and comfort experienced by Aboriginal people within the confines of the ACMS was expressed by many informants. This was reinforced by participant comments, recorded as a field note:

I'd be dead without Durri. It's our place, we feel comfortable here.

(Field Note, July 27, 2005).

Interview Format

The wording of the research questions and interview questions were approved by the ACMS Executive prior to the HREC submission. In addition, the questions were piloted with Durri staff who confirmed that they were culturally appropriate. The Interview format is included as Appendix E.

On reflection and review of my field notes I realised that the questions were a loose template and that the agenda for what I would learn was actually set by the community. William Foot Whyte's (1955) doctoral dissertation, an ethnography titled, "Street Corner Society: The Social Structure of an Italian Slum" also identified a similar situation where participants disclosed information they considered important once they became familiar with the

ethnographic researcher. An example that highlights this is the following excerpt from a participant in this study. The findings chapters follow next, however this excerpt is included to give an example of how the community was talking about the study without my involvement at times. This information was given by a male participant as he came in to be interviewed, before he had sat down. I had not asked any questions or given any details about the study:

I know loss of family is different compared to when I was a kid. If you lost a husband, auntie, grandfather anything like that, ... Women would make noise around the place or sing, whistle anything like that. We weren't allowed to. Years ago when I was a kid, people never used to drink through the week, only weekend, on Saturday night was the main issue, but if you made noise you'd get a bit of backside you know – there was no singing out or anything. You wasn't allowed to do that, you wasn't even allowed to go to the pictures. You had to be quiet. Today, it's a whole different thing today. I think people, you know, they go to a funeral, they go to a wake and then they go to the club or pub – in them days they never done that, they never drank. If someone passed away they wouldn't drink for that whole week and come the weekend like their main day Saturday – they wouldn't drink, they just wouldn't drink at all because after that person was buried, you know, funeral was over and the following Saturday they'd have a drink then, you know. We weren't allowed to make noise you know – we got pulled up on that (22:1:1-15).

Data Analysis

The audio-taped interviews were transcribed verbatim to ensure accuracy and completeness of information collection. Field notes were also transcribed. The

transcripts were coded using a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). Whilst the study was not designed as a grounded theory study in relation to generating theory, grounded theory is deemed an appropriate research methodology used for data analysis for a researcher studying a different cultural group to their own (Glaser 1967). The structural process of grounded theory analysis is robust, sequential and previously used in ethnographic studies (Glaser, 1967; O'Brien, 2000).

Transcripts were carefully analysed and the audio-taped interviews were also replayed to recall the depth of emotion in the interviews. Each sentence and paragraph was closely examined for similarities and differences whilst looking for issues that interrelated (Strauss & Corbin, 1998). Simultaneously I was questioning how and why the issues were related. This constant comparative method is typical of a Glaserian approach to grounded theory, and is based on Glaser's set of procedures and techniques (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The initial open coding continued in the same manner to identify similarly grouped sub-categories or axial codes (Glaser & Strauss, 1967; Priest, Roberts & Woods, 2002; Strauss & Corbin, 1998). Selective coding, the final stage of coding, followed, whereby themes from the sub-categories were further analysed to identify the overarching themes or core categories occurring in all of the transcripts (Glaser & Strauss, 1967; Priest, Roberts & Woods, 2002; Strauss & Corbin, 1998).

It is from core categories, in a purely grounded theory study, that theory development occurs. In this study, data analysis ceased when the core categories were developed, because the study was not designed to generate

theory. As this study was not designed as a grounded theory study, this section is not intended to provide an in-depth critique of the variations on grounded theory. However, nursing and midwifery researchers Schneider, Whitehead, and Elliot (2007, p.114) agree that the variations in grounded theory allow a space for researchers to “justify analysis and theorization that suits the researcher’s own philosophical, cognitive and meaning-making processes”

Audit Trail

An audit trail was established to keep track of individual participant interview transcripts and field notes. The method used to identify the excerpts from transcripts used predominantly in the findings chapters is shown in this example;(1:2:3-4). This example relates to interview number 1, page 2 of transcript, lines 3-4.

When coding, initially I began to colour code the categories, but found this to be confusing as many categories emerged quickly on the initial open coding. Instead I began to number and name the codes. On second coding I used a system of numbering and naming the categories. For example 7.0 Marginalization, 7.1 No culturally-appropriate grief counselling, 7.2 Historical treatment, distrust, 7.3 Treatment in mainstream hospital. 7.4 Discrimination, 7.5 Aboriginal Health Workers not trained for roles needed to do. This too became confusing because of the vast amount of transcripts. Finally, due to the large volume of interview transcripts, transcripts were merged into a single word document which totalled 85,199 words. A word search was then

conducted of the core categories by topics that were identified in the open coding.

Authenticity and Trustworthiness

This study is a qualitative study and therefore it is not focused on the issues of validity and reliability as is the case in quantitative studies. In positivist, quantitative studies, validity relates to instruments and measurement and reliability relates to reproducibility and consistency (Denzin & Lincoln, 2003). In this study these concepts are replaced with a focus on authenticity. Authenticity refers to the trustworthiness of information (Denzin & Lincoln, 2003). Criteria embedded into the research processes to ensure trustworthiness are credibility, transferability, dependability and confirmability (Morse, Barrett, Manyan, Olsen, & Spiers, 2002). Strategies that were used to address these criteria in this study are those previously described by Denzin and Lincoln (2003) and included checks with participants through community meetings and extended interaction with the participants.

Feedback: Community Meetings

Once the transcripts had been open-coded I held a community meeting to discuss the broad themes that were emerging from the transcripts. I believed this to be a way of ensuring that I hadn't missed any issues that were important to participants, to ensure the accuracy and completeness of data collection and to ensure that I had uncovered all relevant information (Barnes, 1996; Wilson, 2004). In addition, this feedback from community members provided confirmation that I had interpreted cultural events correctly and that

any subconscious cultural bias would be identified (Strauss & Corbin, 1998). The feedback and authentication mechanism was well received in the community, and confirmed by participants at a meeting discussing emerging themes from the interview transcripts. These comments were recorded as field notes:

It's so good to hear a non-Aboriginal person saying things that we have been saying for years. To many non-Aboriginal people, Aboriginal people are just statistics. You know x percent have heart disease, x percent have diabetes. They just use it to get their grants and none of the money helps Aboriginal people. Statistics alone don't help Aboriginal people.
(Field Note, June 10, 2006).

Returning the Findings to the Community Along the Way

As well as the feedback community meetings described, other ways of building capacity and sharing information were agreed on by the partners in the study. These included shared conference presentations with the researcher and Durri ACMS Executive; ACMS Executive nominee viewing of all publications and presentations prior to publication or presentations.

The practicalities of how to transfer the findings is difficult to articulate as there were few guidelines for practical strategies on how to do so. Sentiments such as these were also expressed by participants, and are exemplified in the following field note:

I see people taking our information getting PhDs and advancing their careers and never coming back. (Field Note, August 24, 2005)

It can therefore be argued that by inappropriately dealing with research findings and not continuing to work within the partnership model developed, that decolonisation would not be an outcome, with the researcher maintaining ownership of the findings.

Building Capacity Through Feedback

As well as confirming along the way that emerging themes were relevant to participants (Barnes, 1996), the feedback meetings were a way of sharing information at all stages of the study to community members, building capacity with the partners along the way, and providing information about all aspects of the research. Another example of the distribution of information from the study to the Durri ACMS partners was the Durri ACMS nominee's involvement in reviewing articles and conference presentations. Although the consent from participants allows publications, seeking further feedback is considered to be important in valuing the ongoing partnerships. An endorsement from the ACMS executive with permission to speak publicly about the study, illustrates the ongoing partnerships described (refer to Appendix F). The final process of feedback for the study was in relation to consideration of the title of the thesis. I met with representatives from Durri ACMS to seek advice regarding the appropriateness of using the words "Walking on Dunghutti Country" in the title of the thesis. I was advised to write to the Elders council requesting to use the local Dunghutti language in the title. I felt honoured and humbled to receive the reply which was translated as Welcome to Dunghutti Land. The letter and my field notes are located in Appendix G.

Limitations

Acknowledging Aboriginal history, traditions and learning about the Aboriginal ways was critical to the study proceeding in a respectful way. Thus the primary strength lies in the qualitative design and the symbolic perspective on Aboriginal grief theoretical model developed for the study. The trust and relationship building between partners has taken four years to develop.

The study has several limitations. The perspectives of participants, although a unique perspective on the experience and meaning of grief and loss, may differ from perspectives of other Aboriginal people. Although the study included a cross section of community members the study is not generalisable to the entire community.

Summary

This chapter has presented the Methodology: Walking on Dunghutti Country. The chapter has described the ethnography and discussed the complexities of the considerations involved in conducting the research to ensure that the study was respectful, meaningful and conducted in a way that was acceptable to the community. In addition, ethical principles and local protocols have been included. The chapter has discussed how local approval from the Aboriginal community itself is contingent to research proceeding. The following chapters, Chapters Five to Eight present key findings from the study.

CHAPTER FIVE:

Findings 1: So Much Sorry Business

CHAPTER FIVE

Introduction

This chapter is the first of the findings chapters and focuses on the meaning of grief for participants. The core category of the meaning of grief is presented in this chapter and is described as “sorry business”, with thematic presentation of the matters relating to dying young, loss of family, loss of culture and loss of land being at the forefront. Finally, the effects of an historical forced dislocation from family, land and culture are a part of day-to-day life for participants who described living with grief.

Sorry Business: The Meaning of Grief

Participants readily identified with the term grief and willingly gave their personal interpretation and meanings during the semi-structured interviews. For Aboriginal people in the study, grief is a complex issue; as one participant observed:

I guess grief, for such a small word has such a big impact. (7:2:7-7)

Atkinson (2001, 2002) explains that Indigenous structure of family goes beyond blood relationships and includes extended networks of people who care for each other. This relationship is described as kinship (Atkinson, 2001; 2002; Eckermann et al., 2006, O'Brien, 2000). Kinship is highly respected and honoured amongst Aboriginal people (Atkinson 2001, 2002). Participants

described the connection between grief and kinship, and as one participant put it, grief is:

It's about sorry business. Sorry business is different to mainstream grieving practices. It's because of the importance of kinship and relationship stuff. In Aboriginal culture, relationships are viewed differently. Some children might have 2, 3 or 4 primary care givers. In sorry business, if there is a basic understanding that relationships are different, there should be a basic understanding by the mainstream that the grief will be different. Also when you look at the statistics and the number of people dying, the number of people dying is huge; there is so much sorry business. (25:8-16)

So Much Sorry Business

The health and longevity statistics discussed in Chapter 2 emphasised the disproportionate death rates of Aboriginal people in comparison to the national Australian average for non-Aboriginal people. The impact on day-to-day working and personal life of the high number of deaths was articulated by participants and is evident in the following example from a participant:

This week we were supposed to have a suicide prevention meeting ...that had to be cancelled because someone had passed away and there was a funeral on Friday. He was only a young fella – 40 I think, he died of a heart attack and that's not unusual looking at the health of the Aboriginal people. (18:3:15-19)

Many participants focused on the grief they experience related to the death rates amongst their people:

I guess there is really a lot of trauma in the Aboriginal community, a lot of deaths of people just too young. The age of Aboriginal people is shocking – at third world level; and it's just not getting any better regardless of what we do. I guess there's also a lot of death in the Aboriginal community – there's always some funeral on - and violent deaths as well. You probably heard about the Bowraville case which is at the moment being re-opened. (18:7:17-23)

Many participants, as well as community members who were not formally interviewed for the study, spoke about what they referred to as the Bowraville murder case and described the grief related to the loss of young Aboriginal people in that community. Bowraville is approximately 48km from Kempsey and is situated within the Nambucca LGA. Participants explained that because of the close relationships between Aboriginal people the grief experienced by people in the Bowraville community is also felt outside that community and also affects the wider Aboriginal community.

Something Dear to You

Connection to land and the social and spiritual beliefs attached to these connections are vital factors in maintaining health and wellbeing for Aboriginal people (Eckermann et al., 2006). The Aboriginal significance of land and culture was identified by participants as they described the types of losses they had experienced in an Aboriginal context:

Something dear to ya, you know I mean just a thing that you've had for years, you know, and lost it. (3:1:12-13)

An older participant added further to the meaning of grief from an Aboriginal perspective:

You know it's something handed down to you from your mother or your father, something like that, something traditional I suppose and to some people I think the loss of their culture is something that a lot of people, young fellas today, grieve about - so you know, that's what I think grieving is all about. (3:1:15-18)

In the main, grief was defined in three categories related to loss, loss of family or close relatives, family breakdown and loss of country. As an older participant put it:

Loss of culture from my experience, so many different losses and I think that's the problem, that people concentrate on grief relating to death a lot but it's not necessarily (only grief relating to death it is also) loss of their country for a start, their freedom, autonomy, employment, things like that as well. Finance, loss of relationships, there's a lot of different issues that have come up. (18:1:11-14)

Participants identified grief and bereavement issues related to losses described in the previous excerpt correlating with separation from land, culture and family. People openly discussed the personal effects of losses that they attributed to previous government policies. For example, the effects of the assimilation policy and the Aboriginal experience related to the grief felt in the present day as a result of these past losses, described in the Bringing them

Home Report, was also described by participants (Human Rights and Equal Opportunity Commission, 1997). An older participant told of their experience:

Lost your language, your culture, its about traditional lifestyle and the fact that you don't fit nowhere. I don't, that's how I grew up, not knowin' until I was 13 that I was Black.

It was really hard. I always wondered why I got shoved from pillar to post before I went to the Home... My mother had been off to heaven and I'd never ever known my father – I met him once when I was 13 so that was when I found out I was Aboriginal. Boy, that was an experience and a half and that was when I ended up in the Homes but if you asked me now if I was ashamed I'd say "piss off" – this was back in the late 50s, early 60s when it wasn't fashionable to be black. And I went from there, I went into the Homes and when I came out, I was one wholly rebellious young woman because I didn't know where I fitted. To my mother's people I was the black one and then when I did contact my father's lot, I was the white one. (17:2:1-14)

Participants spoke passionately about mainstream hegemony (Gramsci, 1929) particularly in relation to the affect that non-Aboriginal people's dominance has on Aboriginal people's sense of self worth. In terms of Goffman's (1959) front stage concept, stigma results in shame which is openly shown, as one participant described it:

It's really sad when as Koori people we have to be ashamed of who we are...When you look at history, we're taught to be ashamed of who we are and that's the sad part. That's why a lot of the young people have

chips on their shoulders – a lot of old people too. When you look at this beautiful country – we originally owned it, but we don't, you know. If I'm standing across the road and I do something wrong or someone says they don't want me standing there, I'm moved on – really strange.
(17:2:1-25)

Knowing Who You Are

In an Aboriginal context, identity and health are closely related, with the effects of intergenerational trauma related to development of mental health issues (Cleyworth, et al.,2006; Hunter, 1998; McKendrick & Thorpe, 1998; Swan, 1998). Identity was viewed by participants as one of the most important aspects in being prepared for life and for being able to function in society. Identity and the importance of knowing which traditional land or country a person is from was a critical issue identified by participants. The following response is from a male participant who was responding to the question: “For a Koori person, what particular things do you see as important for preparing your kids for life, as you say?”

*Ahh, I think knowin' where you're **from** (participant emphasis). Like, and knowin', and for my kids, is knowin' that you're Aboriginal. And being proud of being Aboriginal. (10:12:1-4)*

This 'knowing where you are from' adds to the complexities of the meaning of grief and the types of losses for Aboriginal people in this study, as stated by this participant:

Some of the negative things that are happening are that Aboriginal people need to identify who they are, the young generations of today just don't know who they are. There are some of the Elders in the community who still don't know who they are, where they come from you know, where they belong and that's really sad. If you don't know who you are, how can you progress in life and you know, and it's giving yourself all these wonderful things you know like your social well-being, you know, all those self issues and all that kind of stuff and that's a part of it you know.

(14:2:12-18)

Kinchella Still Exists: The Community Needs to Heal

Participants understanding and experience of themselves or of people they knew in the community with the effects of unresolved grief combined with the fore-mentioned identity issues was clear. The following excerpt from a participant who cried throughout our conversation spoke of grief in a local context:

I keep saying to everybody – non-Aboriginal and Aboriginal people - that in Kempsey in particular, this community is still trying to come to terms with the grieving of our people, like the loss of our land, the loss of our Elders, the loss of our loved ones in the community, the loss of the stolen generation which is right there at Kinchella Boys Home – this community hasn't had time to grieve. I mean all these things are just torn from them and people are not coming to terms with it and that's why you have a lot of different things that are happening in the community, like negative things because nobody has tried to address that and this is the first time

that I have actually seen anybody in Australia who is looking at the actual communities that are part of the grieving and well-being and the wellness of the community you know. Yes, that's why I agreed to do this interview with you because I am very interested in it. (14:2: 3-14)

The same participant went on to explain their view of steps towards healing:

*This community needs to heal – as I said, the government policy that was put in place, the removal of our children like to Kinchella Boys Home and Cootamundra Girls Home and stuff, but within this community **that place still exists** (participant emphasis) and we have a lot of those boys who still live in this community so that process still hasn't even healed yet, hasn't been touched on as yet you know, and what I've been doing in the community is trying to get some kind of memorial in the community for that so the boys names could be on that big plaque or something so we could be reminded that's a part of the healing process. (14:10: 26-32)*

The experience of grief depicted in the previous excerpt was also termed Dunghutti Grief.

Dunghutti Grief

Responding to the question, "What does grief mean to you as a Koori person?" Participants explained there are many levels of grief, with many people experiencing poor socio-economic status and isolation from mainstream advantages. In addition they related the mental health status and

community grieving, being as directly related to grief over loss of culture and what they termed intergenerational grief, that's been passed on. The following excerpt from a participant, whose interview was the longest, lasting almost 2 hours, summarised what other participants had identified. The length of the excerpt is intentional, to capture the essence of the conversation without changing its focus and in keeping with respect for the oral history traditions and theoretical orientations of the study. One level of grief that directly impacts people is:

Like that passed-on grief has been a direct impact from that. So I see grief on that level, whether you want to call it intergenerational depression or whatever you want to call it. I see that there's that grief over that, and the sense of not belonging and the sense of not really having a sense of who we are, and where we are at, this current stage is directly affected by that grief. So I see that grief in one context. Then I see grief in a smaller context. And I would kind of say, especially on the East Coast of NSW, that that's a huge thing, do you know what I mean, Because this is where invasion or colonisation or whatever you want to call it, happened. Where women had no choice around mixed blood children; where children were removed; where language was stolen; where our spiritual base was stolen. So I see that, then I see like I would see Dunghutti grief. (8:2:6-23)

The special spiritual connection with land for Aboriginal people was described by participants. The next excerpt describes a participant's view of the

relationship between grief experienced by Aboriginal people today and the loss of connection with traditional Aboriginal country:

Ok, the fact that there's kind of a lot of conflict within the community - about a lot of things, there's a lot of conflict within the communities. Because, like, a lot of different nations were brought here and placed here. Do you know what I mean? Like especially at Burnt Bridge (mission) there were Kamilaroi people, there were Biripi peoples, there's Gumbainggir people, all dumped on Burnt Bridge mission. And, what I kind of see for them is, whilst they have lived here and their families have been born on Dunghutti land, they aren't Dunghutti people technically. So the Dunghutti people that are traditionally from this land, there's a lot of sense of grief, I think, around the fact that it isn't now seen just as being Dunghutti land. And where a lot of these other people like the Kamilaroi's and Gumbainggir and all different mobs of people, they have a sense of grief over the loss of their, you know their nation. Do you know what I mean? So there's a lot of conflict in that, and a lot of grief over the fact. I see this grief. Grief actually manifests in loss of different ways, over the fact that they are born on Dunghutti land but they are not Dunghutti people, if that makes sense.

(8:2:23-45)

The Meaning of Health

Many participants spoke about the effects of grief on health, and described one of the health issues of Aboriginal people in the community as low self

esteem. Sense of self and self concept is identified by Goffman (1959) who related to poor self concept to stigma (Goffman, 1959):

The health issues are, no self-esteem of people, they're not – because they don't know who they are, they're right down the bottom rung of the ladder in those socio-economic scope – I mean we're right down there at the moment, but still with all these issues people just can't get a hold of themselves. You've got alcohol which plays a major role, I mean where will people go? I mean, our people drink out in the open – they're not wardrobe drinkers and I say this to the wider non-Aboriginal community, you know, when they're having meetings about our people drinking in the street or they had a brawl out in front of the pub the other day – I say "hang on a minute, don't go making judgements because we know for a fact that you guys go home, you drink your wine and you booze up and you're wardrobe drinkers and there's also abuse in that family, so don't go saying that you can't do that because we're an open-minded people you know, we show ourselves to the community, the wider community". And then people start stereotyping saying, "they're drunk" and "they're lazy" and "they're doing this" so that's where that stigma comes from. Your drugs, the drugs issue – I mean a lot of our people in this community are schizophrenic and it's sad - they're traumatised – we're all traumatised in this community because the stolen generation never got (over)... some policies that didn't work, you know the places on reserves and missions and the deplorable health conditions and that, you know, no water and all that kind of stuff and I experienced that, I experienced all that. (14:2/3:2-19)

Expanding on the health effects of grief, another woman described the recurrent themes of alcohol, drugs, depression and anger:

Yeah, losses of you know all those things, like loss of land, loss of identity um all those types of things. Then rather than deal with those things they'll get into alcohol or whatever. Like I have one lady now and I'm looking at getting her into counselling, she's just a lady now who is overweight and whatever, so therefore she hasn't got much confidence. She's getting on in age. Her life now revolves around sitting at home drinking. Now I see her withdrawing each day a little bit more into that world. So what my job is now is to get her out somehow. I don't know ah go to a counselor, let her (talk) freely there, see if she'll start to bring any of these issues out. She's got some mental health issues there because she's blocked all these things out. I've watched her over the past five years. She used to be a bubbly person. Then she had some issues, like she was hearing voices, and they thought that was a culture thing, you know the devil was in her, things like that. I believe it was some sort of manic depression, you know, and she hasn't dealt with that. So rather than deal with that she's just goin' to go back into isolation and start drinking and hope that they solve these issues.

(11:11:1-16)

As well as the alcohol issues described, prominent themes from male participants was confusion about what grief itself felt like. As one participant put it:

Grief, it's just like sort of anger but not anger, might feel stressed, depressed. (16:1:5-6)

Many participants described how they are continually confronted and suffer with their own grief:

It's really strange, like. I find it really hard to grieve. And I don't know, whether it's, like don't get me wrong, like I've always been nurtured as a child and mum's always showed her affection to me, but she was kind of really firm as well. Well it's always been feelings; you know I was always told "control your feelings" and that type of thing. Especially being a boy, where you know "boys don't cry" and that's always been hammered into us. But, I think just recently we did have a loss in our family and, I find meself being really emotional. And it was kind of, like I find as I'm getting older, I find like it is as though I am getting more emotional. Like, you know crying, and that type of thing. Like I found it really hard to cry as a young man. Like it was really hard to cry. (10:2:10-21)

You Never Get Over It: The Impact of Grief

The on-going nature of grief was described as unrelenting. Some participants went so far as saying that grief was so intense that:

Well, I thought of bad things you know, what to do when I lost them, you know. I thought about killing myself and other things you know and then I thought, "no, I've got kids", you know, "and they've got to be looked after", you know. Anyway I started to get nery – I had to get

nerve tablets, I started to jump in me sleep and all that, you know.

(22:8:22-25)

The following participant described the impact of grief:

You never get over it. It always seems like um it's only happened yesterday and you just, it's just really hard to get over it and you think you're good but you're..., and then all of a sudden. You go on every day with life but then somethin' comes up and then you start thinking again and you get really upset and you're really missing that person,...; you feel so, you know, angry and hurt, and it just never seems to go away. And you can't escape it. (2:1:1-7)

Summary

This chapter identified a range of grief-related issues experienced by the participants and described the health and personal well-being impacts that grief has on their present day lives. A major theme that arose was that, even if events happened many years ago, their repercussions are still being experienced today, as part of participants' everyday life. The following chapter, Chapter Six, builds on the themes of the meaning of grief in Dunghutti Country as described in this chapter, and presents the themes of Aboriginal Exclusion.

CHAPTER SIX:

Findings 2: Aboriginal Exclusion

CHAPTER SIX

This chapter is the second findings chapter and describes the core category of Aboriginal exclusion. The chapter contains the emergent themes which contributed to the core category of Aboriginal exclusion. The first theme presented is participants' view of mainstream services which emerged from the theoretical analysis of transcripts in relation to historical memories. Participants described their own memories of health services as well as the memories of other Aboriginal people which had been passed on to them through stories and paintings. Thus, the next thematic representation in this chapter is the participants' contextualisation of the current view of mainstream services based on historical cultural issues. Finally, the chapter concludes with a discussion of the complex roles of Aboriginal Health Workers and the associated grief and loss issues they are faced with daily, which are often not visible to non-Aboriginal people.

Mainstream are “the powers that be”

People in the study spoke freely about the Aboriginal-perceived dominance of direct care providers in mainstream health including medical and nursing staff who often do not incorporate Aboriginal psychosocial needs into assessment and care, despite the fact that some NSW Health policies explicitly call for this to be the case. For example, the NSW Aboriginal Mental Health and

Wellbeing Policy 2006-2010 which guides clinical, allied health, nursing and emergency departments' services for NSW Aboriginal people, promotes an inclusive interagency approach in providing primary care. The policy encourages Area Health Service partnerships with external agencies including "general practitioners, NSW police, NSW Departments of Education and Training; Community Services and Juvenile Justice" (Department of Health NSW, 2007, p.37), to meet the health needs of Aboriginal people with, and within, mainstream health services.

For people in this study, being treated by mainstream health care providers who did not always incorporate the patient's psychosocial needs into assessment and care planning was expressed by participants as being especially distressing. The following excerpt from a well-respected participant exemplifies the point in relation to the psychosocial influences on Aboriginal health and wellbeing by mainstream health care professionals:

'Cause it, the psychosocial stuff, directly impacts on Aboriginal peoples' mental health. ...You know how friggin' ridiculous are they. They do things like, "ok", you know "oh, we'll give them treatment for depression", but there is no addressing the fact that they've got no water or they live in a house that's absolute shit, or that the husband's beatin' the crap out of 'em every second day or you know that they have no money cause he's pissed it up a wall. You know what I mean? It's horrific, and that's what the plan says. But do the powers that be or the mainstream culture care? No they don't. Durri does. (8:14:22-22)

The negative psychosocial and environmental influences on individuals' health and wellbeing which participants described is also articulated in the Diagnostic and Statistical Manual of Mental Disorders Text Revision (DSM-1V-TR, 2000). Housing problems, difficulties with primary support people, financial problems and difficulties with access to health services are identified in the DSM1V, 2000, as stressors that can influence the identification, management and prognosis of mental disorders. Participants explained the difficulties they experienced managing grief and how, at times, mainstream care providers failed to incorporate these stressors into treatment plans. Additionally, from a cultural perspective, being cared for and supported by a person who is either Aboriginal or has a comprehensive knowledge of Aboriginal ways was a critical issue discussed by some participants in achieving a positive outcome.

The significance of verbal communication and trusting relationships between health service providers and clients was an issue discussed by many participants. The need for care providers to understand Aboriginal ways of being was exemplified by participants discussing the disparity between the NSW Aboriginal Mental Health Plan (Department of Health NSW, 2007) and mainstream health service provision in Kempsey. One participant explained the inconsistency between mainstream mental health service and the service's lack of local service provision for Aboriginal grief that was identified by many participants:

What I think is really wrong is that the Aboriginal mental health plan, right, actually addresses social and emotional wellbeing. It is not purely within the psychiatric framework that the mental health plan works.

They don't adhere to that. Unless you have a diagnosed psychiatric illness, well they try and diagnose you with, you know, a psychiatric illness, but you don't fit in so you get no service. Whereas, as we used to, I used to always advocate and say "this fits in here and I am seeing these people". (8:13:2-9)

The importance that Aboriginal people place on trusting culturally safe relationships for health and well-being was compared to mainstream services that participants explained often do not engender such a relationship. This next excerpt explains it:

And I tried to explain to them if they come (to mainstream services), they tell you what they need to tell you, they can talk with you around that, they go away but they don't come back till the next crisis. Even though they don't keep their next appointment, it does mean that you've made some connection, trusted you enough to come back. But, "oh no, that's not good enough, if they're not keeping their appointments, you've failed to attend, we'll put them on the bottom of the list and if we can kind of get around to them we will". And I find that, that is really, really shitty. (8:13:23-30)

This same participant explained further the lack of Aboriginal-specific services in relation to grief and loss, when asked the question "so basically am I right in saying, unless you've got a mental illness you can't be seen?"

Yep basically, unless you have like, they say within the DSM, well that's crap too. Because anxiety disorders, all of those kind of things,

unless you're ending up psychotic, they don't see them either. So loss and grief issues which very much fit into the Aboriginal plan won't cut it in the mainstream mental health system. (8:13:12-15)

The female participant explained that Aboriginal people present to the health system in a different way to mainstream patients. Mainstream policies do not seem to cater for the diversity in this community for Aboriginal presentations:

You know, it's really terrible, I'll see people down town and they'll go, "I need to come and have a yarn with you". Essentially there's not a way, like Aboriginal people presenting within the mainstream system, they, present in a very different way. It's always crisis driven. Ok, Mental Health have this real attitude, if people present once and they don't come back for their next appointment then frig-em, they're off. But that's not how Aboriginal people present. (8:13:18-23)

Putting on a Mask

Participants described how the impact of historical exclusion and racism results in Aboriginal people today attempting to manage their own grief rather than access mainstream services. As well as meeting the kinship obligations and supporting Aboriginal community members who are also experiencing a range of grief and loss interrelated issues. Many participants cried during the interviews as they talked about the effects of grief on individuals and the effect also on the wider Aboriginal community. Participants described how Aboriginal people are suffering because of loss but often do not show this publicly, or as Goffman may well express from a symbolic interactionist perspective,

(Blumer, 1969; Goffman, 1959; Meltzer, 1972) in the front stage of day-to-day social interactions. The next participant excerpt illustrates the issue and gives an example of a local Aboriginal woman:

And this woman used to come to me nearly once a week, I 'spose just to sit and cry at home. But yet out in the community she wouldn't cry, she'd put up this brave face. So why, why do people have to make out there's nothing wrong, when you're aching inside? You're really, really aching and you feel as though you've got to put on a mask. Well you shouldn't have to. (11:8:10-15)

This same participant spoke more about the available health service options where an Aboriginal woman like the one above, suffering from grief, could turn to for help in the local community:

Well they can't go to anyone. There's really nothing for it, and then a lot of Koori people won't go to mainstream, whereas I think this one finished up goin' to a mainstream. Just to talk, and to get it out. I used to say to her, "well you can't bottle it up, you've got to let it out," I said, "and I'm not a counsellor you know, I'm here for ya but I can't do anything". Sometimes when you're really, really close you can't do anything. (11:8:17-22)

Participants identified that mainstream health services dealing with loss are focused on death. However, as Chapter Five identified, Aboriginal people have experienced a range of losses including the dispossession of land and resultant cultural loss which has been strongly linked to Aboriginal grief,

therefore for Aboriginal people loss is much broader (Geneviro, Marshall, & Miller, 2003; Hunter, 1998; Kristjanson, et.al, 2006). The significance of the Aboriginal connection to land in relation to spirituality and the meaning of grief was described by participants and is also reflected in the National Social and Emotional Wellbeing Framework (2004). This policy document guides service delivery for Aboriginal and Torres Strait Islander peoples and recognises that the current determinants in Aboriginal peoples' social and emotional wellbeing are a consequence of a wide range of aspects, including grief. The policy calls for clinicians to:

recognise the impact of cultural and spiritual factors on the way mental health problems present, in order to provide accurate diagnosis and effective treatment (National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004, p.7).

Despite policy documents such as these explicitly calling for the incorporation of Aboriginal cultural losses into clinical care, participants expressed their contrasting experiences and views. A participant with a comprehensive working knowledge of mainstream and Aboriginal health services explained how local mainstream health services do not focus specifically on the care needs associated with Aboriginal loss:

You treat them more as a secondary kind of issue than something one presents with and I think a lot of the time, particularly in mainstream services, that gets overlooked as being a major cause of someone's depression. It presents in a good majority of our clients that I have seen present with some kind of depression – whether that's... Stresses in

their life or clinical, so yes, there is a lot of different issues I think that impacts on grief for people. (18:1:6-14)

Memories of Exclusion

Participants discussed the strong memories they have of being excluded and viewed as inferior because of their Aboriginality. Post-colonial research with Indigenous participants has previously argued that the memory of Aboriginal people is a critical component in understanding Aboriginal people's history (Bhaba, 1985; Bishop & Glynn, 1999; Smith, 1999). Exclusion in a range of domains related to health, community participation, education and living circumstances were spoken about by participants during the interviews.

Memories continue to shape the perception of health services. Participants described their experiences of discriminatory treatment by mainstream health services, and how the past policies continue to resonate and impact on Aboriginal people today. Participants described being isolated from mainstream services. A highly respected community member told of growing up in Dunghutti country. This excerpt follows the question, "Did you grow up on a mission".

No, I didn't. I was a fringe dweller. It was just lucky my mum and dad had us on the outskirts of the mission, you know, with the welfare system we used to go and hide and run away. But those health issues all stem from those policies that came through – the isolation from the wider community and all that - so they had a big impact on the people and you try and deal with it as best that you can. (14:3:14-20)

The government policies this woman and participants in general referred to included the establishment of missions and reserves. In 1883 the government-controlled Aboriginal Protection Board was formed, which resulted in the establishment of Aboriginal Reserves (Berndt & Berndt, 1978; Fletcher, 1989; Haebich, 2000). Telfer (1939) reports from the view of a missionary at the time:

After a preliminary survey, we made an effort to gather the northern natives into a number of large settlements, and a mission station was established at Burnt Bridge, four miles from Kempsey. This became the headquarters of a far-flung parish, extending from the Manning to the Bellinger, and later on to the Tweed, and embracing all the territory between the Pacific Coast and the New England Mountains. The chief centres of native population, apart from Burnt Bridge, were Pelican Island, Fatorina Island, and Kinchella on the lower Macleay; Bellbrook, on the Nulla Nulla Creek, 34 miles from Kempsey; Rollands Plains on the Wilson River; and Wauchope on the Hastings (Telfer, 1939, p. 50).

For Aboriginal people, the forced centres of living referred to by Telfer are mostly located within the Kempsey LGA and Dunghutti nation. Creamer (1980) reports:

In the Macleay River Valley the territory of the Dunghutti people was originally 2800 square km. In 1885 they were confined to 40 hectares on the Bellbrook reserve' (Creamer 1980; cited in RTA Cultural Heritage Assessment Report, 2007, p. 89).

Participants in this study spoke about the relationship between these sites of forced living, which were often not on their traditional homelands, and the grief experienced today. Again, the wider impact of grief throughout the community, as well as at an individual level, was felt, as this Koori participant suggests:

I think it's when you look back into it, into the history of it, these people, like people at South West Rocks, are still Dunghutti people but they have their views and their protocols and procedures as well same as...and Bellbrook and Greenhills and Burnt Bridge and stuff like that but it's all respected and like I say at a funeral or when grieving in this community we come together as one. (14:4:8-13)

Participants explained how stories of discrimination, exclusion and resultant grief are passed on to the younger Aboriginal generation through paintings and story-telling. Ungunmerr-Baumann (2003, p.v111) has described the sacred nature of Aboriginal storytelling, through Dadirri; she writes:

as we grow older, we ourselves become the storytellers. We pass on to the young ones all they must know. The stories and songs slip quietly into our minds and we hold them deep inside.

The generational passing on of grief and trauma through storytelling and also paintings to the younger generations is described in the following two excerpts. The second excerpt provides an example of how local Aboriginal history is passed on by Elders through paintings. In particular the excerpt provides one example of exclusionary policies forced upon Aboriginal people:

I see a generational handover of grief and loss issues from stories being told, even my own [children] who at 8 and 4 know the history of what happened to Aboriginal people, the way the police and soldiers used to slaughter innocent men and women and children.(21:13:28-31)

Well, they wasn't allowed to swim in the pools up here. The pool was shut down. Well it wasn't shut down it was closed for Aboriginals to go in it. There's a painting of people, I think there's four different things on the painting. On one part he's got like black kids, in the traditional paintings, black kids standing behind a fence looking in and watching the white kids swimming in the pool. Another one's a picture theatre and there's a white rope and the black kids up the front and all the white kids up the back. Black kids weren't allowed to pass the rope. That's what went on back then at the Vanbox Theatre up here. Yeah, when they were allowed in all the white kids would go in first and go and sit up the back and the black kids weren't allowed in until the lights went out and then they let them. They let them in after the movie's already started coz the lights were out and the movie had already started and they made them get out before the lights come back on so before the movie finished and they let 'em go out that exit door on the other side...I think it was back in the '60s. Not that long ago, yeah back in the 60s. (16:7:18-34)

As well as being marginalised in the local community, there was a general expression of distrust of mainstream health services by most participants. In some circumstances it is culturally inappropriate for Aboriginal people to disclose personal information to outsiders. This aspect is described by Ungunmerr-Baumann (2000, p.v111); "we own our grief". In some cases participants explained that the past discriminatory treatment of Aboriginal people by the mainstream health services and related unresolved grief has a

flow-on effect today. People in the study were, in the main, very reluctant to seek health care from the local hospital and spoke about being exceedingly fearful of accessing mainstream health services in general. This next excerpt, taken from field notes of a conversation which took place after an interview, is from a woman who described the distrust she felt at Kempsey District Hospital. She described the local area health services as being:

as prickly as a government blanket. Like the government blanket I was issued at Cootamundra (girls' home as a stolen generation child). Blankets are meant to be warm and cosy, but the government issues for Aboriginal people were prickly and provided no warmth. They were made of chaff bags sewn together (Field Note, August 3, 2005).

An older participant who had experienced many losses and was a member of the stolen generation also told of their experiences of mainstream health care exclusion and their distrust associated with mainstream health care workers. They related the experience of prejudice which they reported as being common for many participants at the local Kempsey hospital:

I never had any counselling because of our distrust – there were no Aboriginal counsellors here. You had a hospital that was very prejudiced towards blacks and I use the terminology 'black' and I don't apologise for that – Indigenous and non-Indigenous is too long to say all the time or Aboriginal or non-Aboriginal, so I use black. They were very prejudiced. (17:3:28-29)

Another participant also told of their experiences at Kempsey District Hospital:

When I first came up here you had a general ward (for Aboriginal people), it was 1961-1962. There you had a little ward like this where men, women and children were kept in. You had enamel plates and cups, knives and forks, everything was stamped with ABO on it and that was – I went in with a broken leg and there was another man there dying of cancer and there was an 8 year old child and we'd all be in that one room. The women when they had their babies were on the verandah of the maternity ward with no carpet on the floor – you had the wooden timber – very, very cold. (17:4:1-11)

The memories of exclusion and isolation were vivid for participants and many female participants recalled giving birth at Kempsey Hospital where because the doctors were rotating, participants described how it was difficult to build rapport and confidence with them. In addition, the discriminatory attitudes of some of the staff at the hospital is a painful memory as one participant explained it:

Last one was born in 1971 there...and about 12 months old, I had to take him down there and the doctor came out and looked around – “Oh, no whites to see me today?” I mean I was fair as, with long blonde hair – you’ve got this little Aboriginal baby but he’s milky white in my eyes and the hair was whiter than what my hair is and he says: “no whites to see me today?” and my comment was: “no, am I black?” There was a few swear words in but I can’t repeat that, but, yeh that’s just how they were. (17:4:15-23)

Participants' memories and experiences of the mainstream has resulted in a situation today where participants' explained that many Aboriginal people reluctantly access mainstream services. Service provision was perceived to be not culturally appropriate and services that do exist are difficult to access.

A local woman shared her view:

It's mainstream, very difficult to get in – some people like to tap into that because it's the normal mainstream processes but if you aren't happy with those services that's the only alternative you've got... (14:5:22-27)

Similarly, another woman told of her role within the family combined with her own grief;

With my family... again it gets back to this "mum's the strong one" image. So I am not really sharing my grief ... I am not really sharing what's really going on inside of me. And that is with my immediate family. But if I am really emotional and it's really got me down, I guess, I go and speak to my first cousins,..., or I'll ring somebody at work ...and say " I really need to talk to somebody, I can't handle this any more". So I guess in that sense I call upon a service provider, an Aboriginal service provider. I would not feel comfortable with going and speaking with a non-Aboriginal counsellor. 'Cause it's the stigma. (7:7:1-8)

This woman's view of stigma and the resultant reluctance to seek assistance from outside the Aboriginal community appears to be consistent with Goffman's (1968; p.13) definition of stigma:

The term stigma then will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed.

Aboriginal people interviewed explained that once a person is labeled as inferior or stigmatised, they would not willingly seek help again from mainstream health care providers as the mainstream was then viewed as the perpetrators of the stigma. Thus with a general view of being stigmatised by the mainstream, historical mainstream dominance, cultural fears and isolation, the people in this study acknowledged that they access mainstream health services as a last resort, and went so far as saying that presentations to the local hospital are crisis-driven.

Aboriginal Health Workers Living with Grief

The essential role of Aboriginal Health Workers (AHW) in this community was critical in terms of the meaning of cultural obligations. To protect the identity of participants both community workers and Aboriginal Health Workers are referred to as Aboriginal Health Workers. The traditional community roles of the AHW are described as important cultural brokers in a recent scoping study (which reviewed AHW roles) conducted by the National Aboriginal Community Controlled Health Organisation (NACCHO) and Community Services and Health Industry Skills Council (CSHISC) (2007). Participants described the importance of kinship obligations and explained how AHW are depended on

for support and guidance by the Aboriginal community, which is often outside their paid workforce roles. The continuous chain of deaths, separation from family and country through a range of circumstances, which include incarceration, sickness and losses amongst the Aboriginal community are everyday experiences for an AHW.

Some AHW described how dealing with community grief also affects them personally. Because of the Aboriginal kinship connections, one person's grief affects the extended community, as one participant explained it:

Well, I think its like, being Koori you're kind of like really family-orientated and I think being loss of, loss of family member I think a lot of, you take on a lot of families' grief as well. Like it mightn't be your personal grief but if a family is grieving you've got to take a lot of that on. Like sometimes you don't, like how could I say, like you don't kind of feel it. How could I say, you take it on kind of subconsciously. Like its not out there, I think that you take it on subconsciously, like if you know, your brother may be sad 'cause one of his kids might be put in jail or somewhere like that there, I think that you kind of like own a bit of that grief. (10:3:6-15)

People in the study generally saw grief and loss needs as fitting into a mental health service provision category. However as has been discussed previously, some Aboriginal people are not comfortable accessing mainstream services. Consequently, local AHW endeavor to meet the needs of their people. It was identified that although their intentions were exceptionally good, many of the

workers do not have the appropriate skills to deal with the complex range of losses of the people they are supporting. The need for improved access to education for AHW was identified in the 2007 NACCHO, CSHISC scoping study mentioned above. Progress has been made towards a national framework for Aboriginal and Torres Strait Islander Health Workers (NACCHO, CSHISC 2007; Engelhardt, 2006), however at a local level some AHW are yet to receive the support and education they require to meet the scope of practice they undertake on a daily basis. This excerpt explains the situation:

I'm not putting X down at all but X has no counselling background. You need a lot of that working within Aboriginal Mental Health, so X is kind of out of depth at times and struggles. He/she will ring me and go "Jesus, what'll I do with this?" and will come and talk. In a lot of ways I'm a clinical supervisor unofficially. (8:14:1-5)

For AHW, the effects of supporting the community with grief issues was discussed in terms of frustration, anger at the lack of services and much sadness at the lack of appropriate services in this community. The health workers described the strain they are constantly under:

The grief and loss things, because we live our own lives where we have grief but to have our clients coming in too and we take on their stuff as well, because in the end we are community-focused workers here, but when we go home - no I don't get in the car and go the hell home and then I don't see you 'till I come back in at 9 o'clock. You have people at your door all the time and it's awfully hard you know.

Awfully, awfully hard to say, “no, look you’re going to have to come and see me tomorrow”, because if I started saying that to clients my name would be crap because they would say “oh she’s one of them up-towners again”, but they don’t realise that when you go home you do need a cut off point. (17:8:11-19)

Summary

This Chapter has presented the core category of Aboriginal exclusion. Participants described their grief related to memories of being marginalised and isolated within the community and the mainstream health system. Durri ACMS provides general practice, support services and dental services, however Aboriginal people access mainstream services at Kempsey district hospital for grief-related presentations through mental health services. Participants explained that there is a variance between the culturally acceptable health services currently available and the local Aboriginal needs relating to grief. Participants expressed their cultural preference to discuss the sensitive subject of grief with an Aboriginal person and the reliance on the AHW.

Participants gave details of the importance for psychosocial needs to be met and gave examples of differences between health care guiding documents and care delivery. Accordingly, presentations are made to the local hospital as a last resort, or as one participant described it, they are “crisis driven”.

Following on from the themes presented in this Chapter, Chapter Seven illustrates the Aboriginal experience of dying in Dunghutti country.

CHAPTER SEVEN:

Findings 3:

Responses to a Death in the Community

CHAPTER SEVEN

Introduction

In the previous chapter the themes of Aboriginal inequity and marginalisation were presented. Participants' day-to-day experiences relating to their underlying grief and loss was also discussed. The first section of this chapter focuses on the Aboriginal community response to a person dying. The terms participants used for a person who has died include: died, passed and passed on. It is noted that some participants had a preference for one or another of the terms. However, to represent each and every participant all of the terminology is used interchangeably in this chapter.

The section, "Towards an Understanding of Rituals and Symbols" presents the sensitive and often sacred meanings attached to particular rituals and signs connected with death as described by participants. The ceremonies described are as participants related them to the interrelationship with their whole-of-life view and the spiritual connections, of which death is only a component. Cultural expressions and rituals discussed throughout this chapter are an essential part of life for people in the study.

The chapter concludes with the section, "Drowning Sorrows - Not Knowing Who You Are". This final section focuses on how participants viewed the relationship between identity, losses and grief. Participants described how

these connections are manifested and related the losses and grief to alcohol consumption after funerals, which at times is in excessive amounts.

The Community Gathers - The Extended Family of Kooris

As highlighted in the literature review, family is held with greatest respect in Aboriginal culture (Aitkinson, 2001; 2002). Participants in this study demonstrated how bonds that Aboriginal people have with each other are close and extremely strong. They referred to this as kinship connections, and as one person described it:

And that's not necessarily family – it is a lot of friends, like the extended family of Kooris. (9:5:15-16)

The meaning of kinship is discussed in Chapter Five of this thesis. At times such as funerals or sickness the close ties become apparent to the mainstream non-Aboriginal community when the Aboriginal community gathers publicly to offer support to one another. One participant described what happens in this community:

Family, friends and relations gather, whether they have passed on or whether they are in the process of passing on. Their involvement with each other is strong,... A strong relationship with each other. Whether they have had problems in the past or not, the ties are still there within each other. (1:1:18-23)

Despite many participants or their families being removed from their traditional home country, with the resultant losses and associated grief described in

Chapter Five, the strength of the contemporary Aboriginal community who hold on to traditional spiritual values often not otherwise seen becomes evident to non-Aboriginal people when a person passes on. Goffman (1959) suggests that people have a range of explanations for keeping private the influence which spirituality has on their lives. Explanations include both the individual and sacred nature of when, and with whom, Aboriginal spirituality can be revealed (Maddocks & Rayner, 2003). However, the meaningful symbols of day-to day interaction as described by Goffman (1959) become a focus in the lives of participants as they pay respect through their presence at large community assemblies when a person is sick or has died. The large numbers of Aboriginal people that come together from near and far to offer support for their own people was described by participants:

It ranges from whatever, 80 to 100. (13:5:12-12)

and,

they don't just sort of come around the hospital, they will be there out the front of the hospital sitting on the kiosk steps or down on the steps or just near, standing out the front. It is, it is marvelous to see them and you all know that they all care. They are all affected by it. (12:5:13-16)

As identified in the preceding quote, participants gave details of how the presence of other Aboriginal people made them feel supported and comforted when a death occurs. They described how having Aboriginal community members, the extended family, there to offer comfort and support when someone in the community has died or is sick was reassuring, or as two women described it, as having:

A mile of support (13:5:6-6) and,

They are all there at the hospital to hold your hand and comfort you.(14:5:7-7)

The assembly of Aboriginal people, and the cultural communication channels which participants termed the Koori grapevine, inform people that someone in the community is unwell. Word spreads amongst Aboriginal people. Not only is it a sign of respect but also because of the Aboriginal meaning of the continuing circle-of-life (AHMRC, 2007; Eckerman, et.al, 2006) it is important for Aboriginal people to know if a community member is passing on, or as participants also termed it, coming home, or coming home to rest. The next excerpt is an example of the type of community gathering at the local hospital:

They like gather at the hospital. Like recently we've lost a loved one who passed on who had an accident, not an accident but you know something happened and [x] was being transported from out of town to the hospital. With that in mind the word just spread around the community and the hospital was just packed with bystanders standing out the front waiting on the ambulance to arrive to see what happened and all of that, and to see if [x] was coming home. Unfortunately the ambulance didn't come that way. They went around the back way and people were still standing and congregating outside, to catch a glimpse, to find out what really happened, so you know you're probably looking at about 50 to 100 people at the hospital just standing and waiting for him to arrive. (1:1:25-36)

Participants described fragmented relationships between Aboriginal people, in the context of separation from country, (previously discussed in Chapter Five). This issue of fragmented relationships is put aside when there is a death in the community, as showing respect becomes of highest regard and importance:

I think that it is a community gathering in respect. And whether you talk to the person or not, you've lost that person in the community. So it an automatic reaction as respect. (7:5:9-11)

Participants explained how for Aboriginal people in the community, attending the gatherings at the hospital and also at funerals to offer support by your presence is a sign of cultural respect. The next section of this chapter focuses on the meaning of respect.

Respect through Kinship: The Extended Family of Kooris

The meaning of respect is a significant characteristic of life for people in the study. The large numbers of Aboriginal people that come to show a visible sign of support to others in times of need was expressed by participants as a sign of respect for their culture. Whether it is a tragic event or a terminal illness, people in the Koori community visit the person throughout the illness or the event, right up to the time of death, so as one person put it:

There is always the biggest mob up at the hospital. (7:4:13-13)

Showing respect for each other in response to a death in the Aboriginal community was also seen as a cultural responsibility. The family expectations for attendance at Aboriginal funerals and at the hospitals, as described

previously, is in the main, represented by the large number of people attending funerals compared to most non-Aboriginal funerals. As one participant described the response to a death in the community:

*...you go to a white funeral and there's a few people. You have a black funeral and it doesn't matter who it is, there's like a zillion people there. Yeah, so I guess Aboriginal, my personal (view) is that Aboriginal people are more **respectful** (emphasis in transcript) of people that pass away than white people are. **Far more respectful** (emphasis in transcript). They acknowledge it, you know they acknowledge it by their presence. (4:5:23-30)*

An older esteemed community member also emphasised the point:

Aboriginal funerals are attended by a lot of people; compared to that nuclear stuff. It's a sign of respect. (5:2:1-2)

In terms of relationships with the local hospital executive, participants acknowledged some support of the local hospital in consenting for prayers to be said, as illustrated in the next excerpt:

I take my hat off to the hospital now because they do allow us to come into a little room now. When we've lost someone and the family and friends go into that little room and have prayers – Cause that's what has sort of become part of our lives now with our Catholic upbringing and our Aboriginal Catholic ministers, see the Ministry team. And our priest comes over and we go in and have prayers and that there. (12:5:19-23)

However, there was discussion that sometimes the hospital staff find the numbers of people gathering to pay their respects daunting. The need for cultural understanding within the hospital system is recognised locally with the North Coast Area Health Service signifying commitment to cultural awareness with the implementation of a cultural awareness program for employees (NCAHS, 2009). However, participants explained their views that the hospital staff in some cases have to date not dealt with a number of local Aboriginal care needs. For example the cultural significance of gathering of people is believed by some participant's to be poorly understood by hospital staff. The next excerpt from a woman gives details of this:

I think there has to be more cultural awareness within the hospital system up there at Kempsey itself. I mean I know there is mandatory cultural awareness but there needs to be more understanding that on that day, Koori people are just going to turn up there anyway because it's our way of showing respect to the person that we are losing or that we have lost, and to their family and that. It is acknowledgement of respect. It's not as if we are going to go up and have a big riot, it is not what it is about. But it is the perception that non-Aboriginal staff find difficult to deal with. (7:4:18-26).

Private Aboriginal family gatherings are supplemented by public gatherings including the gatherings at the local hospital described in the previous section of this chapter. At these times rituals and cultural symbols (Goffman, 1959) become paramount.

Towards an Understanding of Rituals and Symbols

It was explained to me that as a non-Indigenous woman researcher, participants in this study may have only been able to disclose some cultural rituals that would be appropriate for outsiders to have knowledge of. The title of this section is named accordingly. Participants confirmed the sensitivity regarding when and with whom Aboriginal spirituality can be discussed, with reference to both Aboriginal and non-Aboriginal people. The importance of not making generalisations about spirituality was an important point, as this next excerpt highlights:

My comment would be that basically I would pertain it to my own family dynamics. Other families would have other ways of letting you know what is traditional. I think you would find that with some of those traditions. X will probably mention them to you – what I've just spoken about, or some of them. (7:23:18-21)

Aboriginal knowledge is passed on to others at particular stages of life through traditional practices. Stories, death, dying and funeral practices are all a part of the traditional and current lives, as this next excerpt highlights:

There are things, like the dreaming stories, that are very specific to each area. There is a storyline that goes through-out the country, the song line. You know about Aboriginal connectedness to the land, well the story is the song line. There are songs, dances, stories that are locally based. (25:2:18-21)

The connectedness to land, which some participants also termed connection to country, is a critical aspect in terms of health, as the literature review highlighted.

A Continuing Circle-of-Life

The spiritual connection with the land and whole-of-life view for Aboriginal people was a significant focus for participants in the context of the response to a death in the community (Farrelly, 2003; Eckermann, 2006; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; NHMRC, 2002; Australian Government Department of Health and Ageing, 2003). Inter-related to Aboriginal family connections are spiritual connections. Spirituality was talked about with pride, respect and caution. The caution was related to the need to take care in documenting the meaning of spiritual connections for different people and not to make generalisations about Aboriginal knowledge. In particular, the sacred meaning of life and the Aboriginal life cycle was explained. The next two accounts give details of the continuing circle-of-life:

I am very spiritual and I believe that the spirit still hangs around and we are born into a continuing circle of life, it is only our body that has gone.

Our spirit still remains. (9:2:6-8)

With spirituality, when a person passes away the spirit will go out of the person and be stored in a special place and when a baby is born that spirit will come into them, the new baby. There is such an important connection with the land and in a spiritual sense if that link is broken that process couldn't be continued. Like for the stolen generation. It's

so different than in Western culture where people try to get more and more land. For Aboriginal people there is no need for that because it wouldn't mean anything because your story would not be related to any other land. (25:2:21-27)

The connection with country and the strength of spirituality was spoken about in the context of important ceremonies that take place when a person dies. One ceremony spoken about is the smoking ceremony. The connection with the continuing circle-of-life is made known through the smoking ceremonies.

Smoking Ceremonies

Traditions, including the smoking ceremonies, are held in highest regard. The ceremonies were described as being an essential spiritual practice. The sacred Aboriginal smoking ceremony is one ceremony that is shown in the front stage (Goffman, 1959, 1963). Ungunmerr-Baumann (2000, p.VIII) explains the connection with smoking ceremonies:

the contemplative way of Dadirri spreads over our whole life. It renews us and brings us peace. It makes us feel whole again. One of the ceremonies that bring about this wholeness is the Smoking Ceremony.

With the smoking ceremonies:

Chosen people perform the role. Generally the priest or another member of the community, an elected member of the Community.
(4:7:6-7)

Participants revealed both the meaning of the smoking ceremony for them and how it made them feel. Participants described how they feel spiritually connected to a person who has passed. The next two excerpts give details of

the point. The first is from a younger woman and the second is from an older man:

Um oh its, its quite calming actually, it is quite calming. So that's just sort of, that's to allow the spirit to go free. That's the purpose behind it. (4:7:3-4)

Our people feel that with a loss of a member, they feel that spirits are there. Smoking ceremonies are to ward off spirits that are hangin' around. I've been to (X) to ward off bad spirits. (5:2:16-19)

Traditional meanings of the smoking ceremony and spiritual connection are passed on to the younger generation as they grow up. Young people have a role in this ceremony. A young participant made the point clear:

Smoking and watering the coffin, and water the coffin as well. It's traditional, it keeps the spirit away and now that they've gone, you know, how could you say, we're putting them to rest and doing our best keeping the bad things away for them and lying them down in their bed now and they are going to be just resting like at peace. What else do they do? Smoke the coffin, some play didgeridoos. Smokin' and they water with a - what do you call them, just with a branch or whatever, just throw the water, the Elders do it. The Elders do the smoking and the watering. And just when they take them to the grave site you'll have a young person in front of them when they carry the coffin with the clap sticks like letting a space to let the other members who are buried around that area know that he or she is coming to rest with youse. (16:6:18-29)

The importance of the smoking ceremony was expressed with general feelings of proudness in the community when traditions are being held on to, as noted by one woman:

So that is very important and it makes me feel incredibly proud when I go to funerals like that. I mean, I know you shouldn't be proud at funerals, but it is proud to pay respect to people that you know deserve to be celebrated in this way. So once the procession then leaves and goes to the cemetery it is smoked again before it is lowered into the ground and is blessed with water and generally a song is sung by an Elder of that country. (9:14:14-20)

The smoking rituals and ceremonies remain a significant cultural practice in the present day, despite the merge of traditional and contemporary practices.

Koori Spirituality and White Man's Religion

Participants gave details of how mainstream policies have affected them, resulting in the loss of some traditions. Older people described how funerals today are not totally traditional, rather they are a combination of what some participants termed "community Christianity" and Aboriginal spirituality. The following two excerpts, highlight the point:

...the Koori component of smoking and blessing the spirit before it goes into the next world is given prior to the white man's religion. (9:14:4-14)
Spiritually here, it's kinda like, there is always a smoking at funerals for Aboriginal people. The Aboriginal Catholic ministry here plays a huge

role in Aboriginal grief. Aboriginal people here tend to be Seventh Day Adventist, much smaller than the Aboriginal Catholic ministry. Father X, he plays a huge part, quite often spiritually. And I've been to lots of these where Father X comes in and there are prayers over the dead person with burning, smoking at the same time. So there is a combination. (8:16:15-21)

In addition to the smoking ceremonies, other cultural symbols including singing and playing some of the old songs was described as having a positive effect for people attending funerals. Amongst the grief, people described a sense of calmness through songs, when during the funeral the focus moves aside from the “white man’s religion”.

....their favourite songs so they play those around the graveside. Yes that's pretty good and they've got, like their own Aboriginal singers they can get with one of the brothers they play the guitar and a couple of the girls they sing and that, so that's alright too. I enjoy listening to them – it seems to calm everybody down too when they know they got the singers there. Even when you're there they'll all come in and some of them you don't know from a bar of soap but they still come along and say I'm sorry Auntie and give us a kiss and a hug you know, things like that. (15:8:18-28)

Despite the merge between two cultures, participants explained how ancient traditions including the smoking ceremony are important to maintain the spiritual connection with the person who has died. This is another ceremony that takes place publicly, in the front stage (Goffman 1959).

Spiritual Signs, Connection with Ancestors and New Life

In addition to the smoking ceremonies, other spiritual traditions were disclosed that are confidential and take place privately. Some participants have strong family connections and participate in private ceremonies. To use Goffman's interactionist (1959) terms, there are ceremonies which take place backstage. Participants described cultural practices which are essential for their well-being that are not visible to the mainstream.

I mean, we go up the river, we go up there and camp and do all our cultural things that black fellas do. Whereas out at the mall, you don't do it in front of white fellas. We go out to the beaches, you know, we go and visit our ancestors' places and talk about things and tell stories and music and stuff. So we still practice all that, and we are definitely connected with the land as well – very important. (14:7:3-10)

The strong belief that people have in Aboriginal spirituality was evident. Participants described how they feel spiritually connected to their ancestors and others that have passed on. This spiritual connection was explained as going back to the overall view that it is just the physical being that is no longer present. Some people described physical signs of spiritual connections:

It (the smoking ceremony) is a cleansing of the spirit before it goes into the next life so that it comes out pure. And I like I said, it goes back to the overall view of that it is just the physical being that is gone, that person is still with us in the spiritual sense. Even so far, as to say I can feel that person with me... you can feel it. Like there is an old saying

when you get goose bumps and then you say someone walked over my grave. I feel cold with handprints, I feel cold handprints. (9:15:1-6)

People explained that spiritual signs are especially comforting for them and they believe they are being looked after by their ancestors. As one person put it:

The spiritual needs, to me ... what happened within that sense was my way of being comforted from the older people, my ancestors. That was how I was being spiritually cared for I suppose. And you should be privileged ... I have only shared that with you and my husband knew that. (7:6:1-4)

Dunghutti Totems

Within an Aboriginal worldview totemism is central to life. Rose (1996) has previously noted the central role of totemism and spirituality. Rose also notes that discussions of totemism with non-Indigenous Australians have at times been met with skepticism. Anthropologist, Stanner (1979, p127-128) also confirms this:

What is meant by totemism in Aboriginal Australia is always a mystical connection, expressed by symbolic devices and maintained by rules between living persons, whether as individuals or as groups or as stocks, and other existents - their "totems" - within an ontology of life that in Aboriginal understanding depends for order and continuity on maintaining the identities and associations which exemplify the connection.

Older people in this study described their view of spirituality and also confirmed the significant influence totems have on their own personal lives.

One important totem for people in this research is the praying mantis; as one older person described it as:

the totem of the river. It covers the river from Bellbrook down, right up and around Georges Creek (22:1:21-23).

Totems are private, backstage symbols (Goffman 1959) that participants described as being important in times of losses including sickness and death.

This next excerpt is from an older woman who explained the nature of totems:

Dunghutti people have totems – mine is the echidna and we have signs, right, we have spiritual signs and we know for a fact that if we hear a dog moan (this is just my family) or howling, we know that there is something wrong in the community. Or if we see a certain kind of bird, we know that there is something wrong, so we start ringing each other and saying “is everything OK?” because we know that’s a sign and we don’t like those signs. ... the Dunghutti nation people have their own totems. There’s some people that say if they see a bird, you know, someone’s coming home, you know, and that’s what usually happens – so that kind of thing. (14:5:29-37)

As identified in the preceding quote, spiritual symbols such as particular birds indicate for some people that a person is coming home, or as others termed it is in the process of passing on. The signs from certain birds and other animal totems were described as having significant spiritual connections for people.

In this next excerpt an older person also explains the situation:

Spiritually, I won't put up with Mopoke (bird) around the house; a Mopoke is the first sign of death. So if there are Mopokes anywhere, how can I put it, that an Aboriginal person sort of knows that there is something going to happen in their community or something doesn't feel right. The word we use is Booky. It means that there's something not right, something's going to happen. How? White man would put it, "it's the calm before the storm". Yes, that's what it means. And that's just how people will say it. We know when something's going to happen in our community... You know, if you go up and see the old person and that, and if I just happen to go up and see mum and mum will say "I am not feeling well, I'm feeling a bit Booky". Something doesn't feel right, then you know. (7:20:23-38)

It was made clear that in relation to totems, because of losses which people may have experienced including being separated from family, they are individual and the experience is not the same for all people. A broader discussion of handing down Aboriginal knowledge is found in Chapter Eight, however the next excerpt in relation to totems is included here to contextualise the point.

I don't know whether in the whole of the community that those totems have been handed down but I know for a fact that that totem of mine has been handed down from my grandfather down to my mother, down to me and I passed it on to my grandchildren, yeah, and to my sons and daughters....I don't know – you've got to be responsible. I mean you don't get anything for nothing. I mean the cultural needs are there

and the value is there – they're passed down. Through stories, through the cultural activities that you do. There's a few things that I wanted to know from my mother and she will not tell me because she says, no you're not at that stage yet where I can give that information to you. So you know, we don't question why, we don't question why. (14:6:6-20)

The final excerpt in this section is from an older person. They told a personal story in relation to a family member passing on, to convey the significance of the meaning of the spiritual connections for them. In particular they compared their beliefs to mainstream views.

I went around there one morning and... she just said out of the blue that Uncle X was gone. And I said yes we know he's gone, he's missing, because everybody's looking. She said, "no he's gone – I've seen him last night and we said our goodbyes last night". So that's the spiritual connection she shared with me. So from my mother-in-law's point of view, ... so even though Uncle X, in a white man's way has been reported as missing and there is no physical showing of where he is or whether he is dead or alive or not, a spiritual presence was made to my mother-in-law to show that as far as she was concerned he was gone,...he had passed on. So I guess what had happened was maybe he would end up out there behind that log and in that place where he wanted to be. At the end of the day my mother-in-law felt quite comfortable with that.(7:19:1-20)

This section has discussed totems in relation to a death in the Dunghutti community. Sensitive personal spiritual connections with ancestors occur at

the time of losses due to sickness or death. The relationship between losses other than through death and on-going grief has been detailed in the Chapter Five section “Knowing Who You Are”. The on-going grief is compounded with spiritual connections at the time of sickness or death and this aspect becomes in view of the community, or front stage (Goffman,1959, 1963) after funerals. The final section of this chapter focuses on this aspect.

Drowning Sorrows – Not Knowing Who You Are

Participants described how people often consume excessive alcohol after funerals as a way of blocking out grief. Participants expressed the issues associated with the use of and effects of alcohol in this community. Through the stories told at interview it is apparent that alcohol is a prominent theme adversely affecting the lives of some participants. As Chapter Five discussed, identity and health are closely related. The losses described in detail in Chapter Five, including loss of land and identity and “knowing who you are”, becomes more prominent at funerals when through the smoking ceremony and spiritual rituals, connection with country is a focus. When a person is unable to identify with their country, people in the study explained how drowning sorrows has become commonplace on a day-to-day basis for some people living with grief. Drinking becomes a focus for some people after funerals as they struggle to identify who they are. However, this is not the case for all people:

I tell you the truth, I hate it. You're more or less celebratin', celebrating someone's death. There's no way I'm gonna go out and drink if I've just lost my mother. I just don't like it. I'd rather stay at home and be with

family. Especially with the little ones, and be with them, and that's my way - and I've always been like that and I think I'll always be like that.

(2:5:24-28)

The NHMRC's publication Australian Guidelines to Reduce Health Risks from Drinking Alcohol (2009, p.11) defines harmful drinking as "drinking at levels that are likely to cause significant injury or ill-health". The consumption of alcohol is mixed with a celebration of life after funerals. Ongoing grief over other types of losses resurface when a community member dies. Participants in the study spoke of their distress for the practice of getting drunk as the only way of managing grief after funerals, or as some people termed it "drowning sorrows". Drowning sorrows is identified by the NHMRC (2009) as a reason that people drink to escape or forget. A participant explained the point:

Drowning sorrows, blocking out. But it's not really, its still there when they sober up. I remember, a best mate of my husband's actually, he passed on. My husband and I, we were off the grog for about 18 months I think. Well when this best mate died, we got back on the grog and at his funeral, X and I were rowing (arguing). We were on separate sides of the grave. I couldn't even tell ya where this guy was buried, and we turn around and tell ya we respect that bloke. How is that respect? You know it's not, is it? Anyway. But yet people will say " ah that's my mate, I love him". Actually once they get really, really drunk, they wouldn't ave a bloody clue. (11:7:10-17)

Social issues and substance misuse has previously been identified as an area of need for service provision in the 2003 Mid North Coast Area Health Service

Drug and Alcohol Quality Improvement Project (O'Brien, 2003). Durri ACMS provides support to people who are affected by alcohol and other drug addictions (DACMS Annual Report, 2008-2009).

Summary

Despite the related stigma from the mainstream and resulting distress described by participants and documented in Chapter Six, in this chapter an overlay of the strength of connectedness between Aboriginal people themselves was presented. This was described in relation to the community response to a death in the community. The importance of support amongst fellow Aboriginal people was apparent with the attendance at cultural events that occur when an Aboriginal person is sick or dies in this community. Despite many participants being removed from their homeland and being disconnected from their spiritual base by growing up on government reserves, missions or in government-run homes, participants described how Aboriginal spirituality has a strong influence on the lives of some Aboriginal people today.

This chapter has also described Aboriginal rituals relating to a person passing on. Sensitive, backstage Aboriginal knowledge that was considered by the participants to be acceptable to be shared and revealed to a non-Aboriginal researcher was discussed in this chapter in the context of the overarching theme of expressions of Aboriginal symbols and rituals. Participants' views and experiences of the collision of traditional Aboriginal ways and contemporary society in relation to grief have been included. The chapter

concluded with a discussion of how participants described the effects of confusion about Aboriginal identity and the association with alcohol which participants explained often becomes prominent after funerals. Consistent with the Aboriginal view of life described by participants, Chapter Eight the last findings chapter, focuses on ageing and grief across the life-span.

CHAPTER EIGHT:

Findings 4: Transgenerational Loss and Grief

CHAPTER EIGHT

Introduction

This is the final findings chapter and presents the issues that participants identified in relation to ageing and grief. Consistent with the holistic view of Aboriginal health and wellbeing, the chapter presents ageing issues across the life cycle. The themes in Chapter Eight were primarily developed from responses to two interview questions: What does grief mean to you as an Aboriginal person? and, What do you think the aged care issues are surrounding grief for Aboriginal people? The role of Elders in contemporary society is presented in this chapter. The chapter concludes with issues which older people considered important in relation to health services.

Koori Kids

Participants described a cycle of on-going grief that starts at a young age and affects children as they are growing up. Because of the frequency with which death and chronic illness occurs in the Aboriginal community children are exposed to death, illness and grief from a young age. As one participant expressed it:

Grieving starts as young as five, or five onwards. These are the young kids that have probably lost, you know lost their parents or you know, a loved one, someone close like or a brother, a sister and all that and during their life experience of grief themselves and all that at the age of

five; what's happened when they get up to the age of 18. I would tend to say that the grieving process starts at that tender age. It's like being probably adopted, or you know stolen or something like that, and they're given away. They've lived the white man's way. They go through that life-long process of grieving. (1:4:26-30)

Concurrently, children begin to have an understanding of historical and cultural losses at a young age. As identified in Chapter Five, for people in this study, the meaning of grief is about the day-to-day impact of other losses as well as loss related to death. The fundamental role of connection with country and ancestors (discussed in Chapter Seven) is passed on to children. Thus, participants explained how there is a transgenerational hand-over of knowledge and associated grief related to historical events. Passing down knowledge of historical events regardless of whether they are traumatic or not was an important point discussed:

Like, we go for drives to different places to hand on that information about (the history of the ancestors)...And I said X, can you read out that plaque there for X. So she's reading out how all these kids got slaughtered and all that sort of stuff, (kids) got thrown off the edge. (21:13:31-34)

Transgenerational trauma is defined in the DSMIV-TR (2000) as trauma that is passed on from one generation to the next. The concept of transgenerational trauma was originally developed following Danielli's 1998 study with survivors of the Nazi holocaust. The study found that the traumatic

experiences of parents was passed on to their children and refers to parents passing on trauma to their offspring.

As Chapter Seven presented, participants described the high regard for family as a characteristic of being Aboriginal. There was a sense of sadness and grief acknowledged which was attributed to the barriers to the future generation of Aboriginal people succeeding in mainstream society. People compared themselves to the mainstream non-Aboriginal people in relation to the lack of opportunities and barriers for the younger generation to succeed in life. The types of barriers identified by participants include financial hardship. A male participant openly cried during the interview as he compared the future of young Aboriginal people to mainstream youth:

... I think you're more of a unit a lot longer than the general community, where in the general community or the wider community ah, once you get to 18 you kind of, you know, you spread your wings and fly. Where you know through restrictions, there's a lot of financial restrictions (in the Aboriginal community) where you can't really spread your wings and fly.(10:3:21-24)

High school completion rates at Year 12 level in the Kempsey LGA are 12% of the school age population, which falls well below the national levels at 62% for females, and 21% for males (ABS, 2006a). Further details have previously been included in Chapter Two, with a discussion of the social determinants of health. Participants views of the positive influence of education that not all Aboriginal people have the opportunity to obtain, is exemplified in the following excerpt:

With education you get knowledge, with knowledge comes power. Power to change different things, sit around the table and make that decision. (21:15:4-7)

Also noted in the literature review, indicators of social exclusion include high crime rates, family breakdown, poor skills, unemployment, low incomes and poor housing (Banks, 2007). Whilst not all families experience disharmony, participants described the negative effects of family breakdown on some young children. As one participant put it:

(Some) young kids are grieving and they are angry. How they display it is drinking, & drugs. Well they come from very dysfunctional families.... And I'm just finding that I'm dealing with more and more young kids with more and more problems and their parents just don't cope. Their parents come from dysfunctional families (too) and it's just a generational... it's so intergenerational, environmental. From twelve to sixteen... roaming the streets, drinking, drugs, sexually active...Twelve yeah, driving cars, break and enter, stealing. Twelve yeah, roaming round the streets. (4: 1:10-20)

Older People are Burdened

Participants described how some older people are caring for their grandchildren because of family breakdown as well as it being traditional for grandparents to play a role in providing primary care for grandchildren. It is reported that older Aboriginal people commonly have a greater role in caring responsibilities for grandchildren than that of non-Aboriginal grandparents

(Bin-Sallik & Ranzin, 2001). In addition to the care-giving roles, older people in the community themselves are grieving from a complex range of losses. Participants described how some older people in Dunghutti country are suffering from grief as a result of the range of losses described in Chapter Five:

Can you imagine your children being taken from you? The grief that's associated with that and the intergenerational grief and how that impacts on all members of the family. I mean my dad, as I said, he's 72, and he's still got cousins that are coming back now. That he's meeting that he never knew; that were taken... Imagine someone rocking in saying w'ere just taking your kids for the fact that you're Aboriginal. No other reason. So the loss and grief attached to how, to how they were. (8:5:1-14)

Combined with their own grief, participants explained how multilayered levels of grief results in additional suffering experienced by older people. The suffering is constant however and becomes more evident or front stage (Goffman,1959) after the death of a family member. As one participant described the experience of a family member:

Like mums still grieving and it's been two years... Loneliness, isolation, broken heart. Won't talk about her issues. But then we can't give her the answers either, you know. She would have to go to someone else. Some people feel comfortable going to mainstream and some don't. That's people's choice. (11:10:6-12)

In addition, due to the poor health and longevity status for Aboriginal people in general, death and the associated grief has become a part of the contemporary Aboriginal culture. Because death is so much a part of the culture, with people passing away at a young age, people are losing not only grandparents but also their parents. Grief is:

It's kind of almost now, in this culture, accepted to some extent. Do you know what I mean? Yes there is a lot of outpouring of grief. I think that there is so much grief that is around people that have just disappeared out of your life, not only through death, that it becomes too painful to talk about. (8:15:22-25)

Cultural grief that the previous excerpt highlighted was also expressed in relation to the loss of language as a result of mainstream dominance. The next excerpt from an older person describes their personal experience of exclusion in relation to this:

No, where I grew up there was only 5 people that spoke the Aboriginal language and it was never handed down to any of the other family, like the family even now. Years ago they weren't allowed to speak it even out on the reserve – they've taken that all away from us, from the family. Even when I was growing up in Coffs they never let you speak – and the great saying with us lot is, “children should be seen and not heard”. So that meant we had to go if they were sitting down talking...when they used to have all the Aborigine people together, they wouldn't allow them to speak the language so the government's taken that away. (15:9:9-39)

The burden of losses within the community has resulted in some older people being fearful of seeking help from mainstream health services. Some older people in the study expressed concern for the future generation of young people. This next excerpt from an older man describes the point. This person openly wept during the interview as they spoke about grief for older community members.

I think they've got grief, a lot of grief issues with their own family within their own family and that. But they shoulder it because they have to, not because they want to, because they have to because they think about their families issues and their grandkids are more important to them than anything else. And they'll share whatever they've got, they'll give whatever they've gotWell if you look at it they're our future too. Even though there's not much we can do with em but they're still our kids and want to look after e-m, and they're important to us. (3:6:15-21)

Elders

The high regard and importance of Elders roles within the community was evident. The meaning of an Elder was explained by a highly respected Dunghutti man who described himself; he said he was:

a Community Elder because I'm urban. Traditional Elders are initiated, it's all been lost. (5:1:6-7).

Another older person also explained:

The Stats say that because Aboriginal people don't have that long to live so once you hit the 40's and that after 45 well whatever onwards

you are considered to be an Elder. And that's in documentation, that's in all the documentation that floats around with all various service providers and I don't consider myself in that sense[?] I do consider myself an older person and when it comes to young people that I've seen grow up through the years from 2 or 3 that are now about 20's and have got babies and that now. So I'm considered to be an Auntie to them as a sign of respect and as an older person in this community. But not officially as an Elder. (7:2:1-9)

A respected person also gave their viewpoint:

People in the community call me an Elder but I don't think I like to use that term unless my X approves of it.... but people who care to call me Elder, if they're comfortable with it that's fine – I don't portray that I'm an Elder...., see the Elders Council and the Dunghutti nation has indicated and made it a policy that anybody that is over the age of 50 years, bestowed on them as being an Elder. But like I said, I keep saying to myself – I'm not old, I'm not old – because to me if I say I'm an Elder and I keep on that Eldership jargon then, yes I feel old. As I say if people in the community call me an Elder, I'm quite happy to go along with that but I just don't see myself as an Elder.(14:1:5-22)

Another participant who had not reached the age of a community Elder or the position of a traditional Elder recounted their family story:

Because of the definition of what an Elder is – My mother and father were traditional Elders. My father was an initiated man and my mother

was an Elder in her tribe – a princess of her tribe. He was about the last man initiated here in Kempsey, my father. He has been missing now for 11 to 13 years. He wandered off - I reckon he has gone back to the bush. He always used to say that he is going back. He had all the professional markings and everything of an Elder and it was very sacred to him. He wouldn't discuss anything, not with my husband, not with my brother or anything, or his wife or anybody. I've got a tape of mum and her sisters talking about it when they use to initiate young boys bringing them to manhood and they didn't see any of that. They were just put into their little huts in those days. An Elder is not only just turning 50 and being classed as an Elder – it is the knowledge just to respect and your cultural ways - makes them a class of an Elder.

(12:1:8-21)

Passing on Aboriginal Knowledge

Because of the significant cultural role of Elders, participants explained how grief affecting older people is not confined to older people themselves. There was evidence of the lasting effects of historical trauma. The impact of mainstream power relationships over the traditional roles of Elders was a source of great pain and ongoing grief expressed by participants. The following excerpt from a highly respected person conveys the point:

They're heavily burdened with issues that have happened in their lives and that stops them from passing on knowledge and information that's important to the community ... That comes back to their children who are born with other issues. You also have the issue of keeping all this

stuff bottled up inside, a lot of these fellas do they keep it bottled up inside instead of letting people know and the reason why they do that is they can see that the younger Aboriginal people are already burdened enough - they don't want to stress them anymore you know. (21:14:12-18)

Health Service Issues for Older People

Participants identified a number of health service concerns and fears based on their experiences in mainstream health services, which have been acknowledged in previous Chapters. Whilst participants did not express the wish to return totally to traditional practices, they did speak about the difficulties Aboriginal people experience when mainstream service providers fail to have an understanding of Aboriginal customs and the meanings attached to customs. In this community, participants explained that older Aboriginal people are often primary care-givers for young children, therefore the health service issues for grief and loss are different to mainstream non-Aboriginal people. One example which highlights the need for culturally safe care related to grief and loss is the death of a baby in the community. Participant's explained how at this traumatic and emotional time, if care providers are unable to understand the need for cultural compassion and understanding, the families are additionally traumatised. This next excerpt provides an example:

But they still don't have the autopsy report back, and part of its brain is still down there (in Sydney). They've left a hole in the grave, and when the brain comes back, then they just poke it in. You know what I mean

ahhh. And there's no closure... I think that's what hurt the mother really, really bad. That he's not complete and he can't rest until everything is there. (11:9:10-12)

Participants described how some practices such as complex medical terminology within the health services further adds to the distress that families are experiencing and families are left feeling isolated. One older participant described their point of view:

I think there needs to be a lot of reassurance about why some of these things happened – you know coroner's reports come back and people can't read them, you know, the terminology that's used in there – there's no interpretation – say baby had a stroke, this is what happened, it stopped their heart from beating so nothing we could have done because it was inside the baby. (21:9:14-18)

In terms of specific care needs related to grief and loss as a person ages there was an expressed desire to be cared for by people's own family or by trusted people in close relationships with the extended kinship structure. The subsequent transcript is from an older participant who summed up the theme of ageing needs also identified by other participants:

Ah care needs for ageing Kooris; services are not culturally appropriate. You know where the family, the extended family can give care and support and appropriate resources.

Resources: for example educational stuff for carers and families about the needs of the aged. It needs to be in black English, Koori jargon like in those posters for kids I've got up over there.

Financial: for internal home based care. Booroongen as a last resource. The majority of our people here don't get to a RACF because they're not old enough. Or, if they do it's often not the one of their choice.

Counselling: for within family. Look at that over there what do you see? See a fire place; it's the tradition that's gone. The traditional around the fire havin a yarn. Care of the Elderly in their homes would have its benefits, to know their loved ones are in their care and have quality of family values.

Current aged care has taken away people's knowledge and put them in a sterile environment. Taken away knowledge of culture and community. The benefits of having the aged situated in the home or community is that they could pass on cultural and spiritual things.

(5:3:1-17)

Summary

This chapter has provided pertinent excerpts and discussion relating to the experience of grief and loss for older people. The important role of Elders has been discussed. Whilst older people are burdened with their own grief they continue to play an important role in the family and are often involved in the primary care of grandchildren. A number of health service issues in relation to culturally safe practices have been discussed. The next chapter, Chapter

Nine, is the final chapter which elaborates further on all the findings chapters and concludes with recommendations.

CHAPTER NINE:

Discussion, Conclusions and Recommendations: Is Grief the Unconscious Barrier to Aboriginal Health⁷

⁷ Sub-title from a participant's transcript

CHAPTER NINE

Introduction

This final chapter situates the findings in relation to the research questions, aim and current literature. The findings draw attention to the meanings attributed to grief and loss as identified by the participants in this study. The thesis concludes with recommendations related to grief and loss needs for this community, and also in the broader context of multidisciplinary health care, education and research. The findings are not intended to be generalized however they do have currency across numerous reports and other Indigenous research.

Discussion

This study aimed to document the needs surrounding grief, loss and bereavement of Aboriginal people living in Dunghutti country. The theoretical model developed for this study is one key outcome of the research. This model incorporates principles of symbolic interactionism (Goffman 1959, 1963), decolonisation and Dadirri. As a non-Indigenous researcher, the integration of Dadirri (Ungunmerr-Baumann, 2000) was an important inclusion overarching the theoretical model, in that Dadirri assisted with understanding important cultural symbols and rituals and thus provided a culturally safe position to analyse the semi-structured in depth interviews. As noted in the literature review – (Chapter Two) the limited research with Indigenous peoples

in Australia has focused on intergenerational trauma related to the stolen generation, and the need has been identified for community based studies, such as this study, which focus on the effects of grief at a local community level. Findings from this study may well be used as a base to guide culturally safe health care delivery for all Aboriginal people living in Dunghutti Country.

Participants described rituals and associated Aboriginal gatherings as an essential and central part of Aboriginality. Stories and rituals are not always visible to people outside the kinship group and are a part of private Aboriginal life. Goffman (1959, 1963) describes this as backstage rituals. Aboriginal gatherings are further described by Ungunmerr-Baumann, (2000, p. 113) as being where “we hear the sacred stories”.

As both Chapter Five and Chapter Six discussed, findings from this research confirm that for people in this study, loss and grief is much broader than a response to death. Grief also encompasses bereavement and other psychosocial stressors, including poor ratings of indicators of the social determinants of health, including education, employment, income and housing (Wilkinson & Marmot, 2003). Thus participants revealed how grief related to the existence of chronic diseases combined with co-morbidities are only one aspect of loss and grief for Aboriginal people. Chapter Five, (So Much Sorry Business) also presented the meaning of grief and grieving or mourning for participants is in contrast to the meaning and experiences of mainstream non-Aboriginal people.

Grief for people in this study is about “sorry business”. Sorry business was described as relating to a range of losses. Participants identified that the meaning of grief for them is related to loss of land, loss of culture and loss of family. From the perspective of understanding the meaning of health and wellbeing from an Aboriginal viewpoint, these concepts are not static and reflect the whole-of-life view of Aboriginal people (AHMRC, NSW, 2007). In terms of healing, participants explained that the community needs to heal, and that one step towards healing was a visible acknowledgement of the losses that they described. Participants explained how the lack of any formal acknowledgement by the wider mainstream non-Aboriginal community of the type of losses experienced by Aboriginal people in Dunghutti country is a source of pain, anxiety and worry. The on-going nature of distress has similarities with the definition of complicated grief cited in the 2006 systematic review of the literature on complicated grief (Kristjanson et al., p.6) where Complicated Grief (CG) is defined as grief related experiences that are on-going. They include:

- a) separation distress, such as longing and searching for the deceased, loneliness, preoccupation with thoughts of the deceased; and b) symptoms of traumatic distress, such as feelings of disbelief, mistrust, anger, shock, detachment from others, and experiencing somatic symptoms of the deceased.

Although this definition focuses on death, in the absence of an Aboriginal specific definition of grief it provided a useful point to discuss the findings. Furthermore the review acknowledges the need for Aboriginal and Torres Strait Islander research such as this study. Participants in this study described their feelings of mistrust in relation to mainstream policies such as the

Aboriginal Protection Board Policies and the establishment of Aboriginal Reserves (Berndt & Berndt, 1978; Fletcher, 1989; Haebich, 2000) which prevented Aboriginal people's full participation in day-to-day life and have been previously discussed in Chapter Six: Aboriginal Exclusion. Participants described how the resultant power enforced on Aboriginal people by these National policies are a vivid upsetting memory for some people. Other hurtful memories when growing up (previously described in Chapter Six) include exclusion from recreational facilities. For example, some participants described how the local Kempsey swimming pool was closed for Aboriginal people to go in, and the picture theatre where Aboriginal children weren't allowed in until the lights went out and were ushered out before the lights came back on.

As also acknowledged in Chapter Six, another aspect of grief for people in the study is the fear of mainstream non-Aboriginal health services which participants described as continuing to cause hurt and emotional pain. Memories of being marginalised and having traumatic experiences also related to being stigmatised at the local Kempsey hospital. Stemming from the experiences, some participants described their fear and resultant reluctance to access some mainstream health services. Thus Aboriginal grief related presentations and presentations in general to mainstream health services are often crisis-driven and reactive, rather than proactive and preventative care.

In Chapter Seven- (Response to a Death in the Community), the issue of Knowing Who You Are, was discussed. For people in this research the

connection with their own traditional country is a significant part of their Aboriginal identity. The meaning of connection with country was described as being related to the continuing circle-of-life belief and some participants disclosed their sacred, close spiritual connection and how the rituals are interconnected with ‘knowing who you are’ and “what traditional country you are from” which is a critical aspect related to identity. Participants described the ongoing grief and associated distress they are burdened with from not being able to identify with traditional country. Participants explained this as being increasingly distressing and something that never goes away. Rituals such as kinship gatherings in times of sickness, death and day-to-day life are both highly respected and a necessary aspect of being an Aboriginal person.

The disparity between Aboriginal cultural expressions and mainstream expectations was evident where participants described being proud of being Aboriginal but at the same time being isolated from mainstream participation and shamed for being Aboriginal, or being stigmatised. Goffman’s (1963) interpretation of the effects on stigmatised individuals in the presence of those that are not stigmatised, which he terms normals is as follows:

The immediate presence of normals is likely to reinforce this split between self-demands and self, but in fact self-hate and self-derogation can also occur when only he and a mirror are about (Goffman, 1963, p. 18).

Grief related to low self-esteem was also an area of great concern for participants. The use of alcohol and other drugs to cover expressions of grief was described as being prominent at times in this community. The use of alcohol comes into view or becomes front stage (Goffman, 1963) on some

occasions after funerals and in public displays of drunkenness. However, it is evident from the interview transcripts that alcohol use is sometimes not visible to the wider community, or is backstage (Goffman, 1963). Pearson (2003, p. 3) has called on the Australian Federal Government to “make the connection between substance abuse and violence”. It is recognised that recommendations from the Many Rivers Regional Aboriginal Violence Workshops (MRRAVW) held on Dunghutti Country (Many Rivers Workshop, 2004) may not have been implemented since the workshops were funded by the Aboriginal and Torres Strait Islander Commission (ATSIC) which has been abolished.

The care needs of Aboriginal families in relation to grief and loss are different to mainstream non-Aboriginal needs primarily because of the meaning of Aboriginal kinship and the important links with health and wellbeing. As noted in Chapter Six, Aboriginal Health Workers (AHW) have a significant role in supporting people in this community. AHW are called on by the community to support other Aboriginal community members who are sick, injured or bereaved. The significant role of AHW in providing informal counseling to community members was also identified by Sullivan et. al (2003) in the final report of the scoping study for the National Palliative Care Study. The findings of this study confirm that AHW living with their own grief and supporting the Aboriginal community is at times emotionally difficult for them. As noted in Chapter Three—(Theoretical Framework), Ungunmerr- Baumann (2000, p.115) writes of the private nature of Aboriginal grief in Dadirri: “we own our own grief and allow it to heal slowly.”

The central role of Elders was a theme presented in Chapter Eight. The important role of Elders in providing support to their own people who are suffering from grief was evident. A grandmother's group has been formed and this group try to provide support for people who are suffering from grief. The strength of resilience of many older people in this community was evident. The critical role in passing down Aboriginal knowledge to the next generation was explained. However, the range of losses and the meaning of grief for these older people represent some of the ongoing impact of losses and grief for Elders. Participants explained how grief is a barrier to being able to fully participate in life and how grief is something that is always present for them. Chapter Eight also identified a number of concerns related to the care needs of people as they age.

Conclusions

This study has given significant insight into the experience and meaning of grief and loss for people who took part in the research. The research has shown that this Aboriginal community has a unique history which shapes the health care needs for this population. Therefore, as participants suggested, a community-based approach towards healing and intervention is considered an appropriate management strategy of grief and loss.

Participants identified a range of issues related to grief and loss for many people living in Dunghutti country and these are reflected in the recommendations. It is with utmost respect that the following recommendations are provided for consideration by the Board of Governance

of the Durri ACMS. The recommendations are derived from the research data and thus are not intended to be prescriptive, rather they are intended to faithfully represent the participants' viewpoints. The recommendations are provided as they appear in order of chapter development in the thesis and therefore are not ordered in any priority.

Recommendations:

Recommendation One: Visible Acknowledgement of Losses

Acknowledgement of the types of losses in Dunghutti country described by participants in Chapter Five is recommended. One way to suitably acknowledge losses is through consultation with key community groups to pursue the notion of a visible acknowledgement of losses identified in this study. For example, participants suggested a memorial as a formal recognition of the impact of losses and the associated on-going grief. It is suggested that the type of acknowledgement deemed appropriate be at the discretion of the Dunghutti Community representatives.

Recommendation Two: Review of Education Needs and Support for Aboriginal Health Workers

A review of the recently-released (2008) Aboriginal Health Worker National Competency Standards is recommended to ascertain Durri ACMS staff needs. This review would also be complemented with an audit of existing AHW staff skill needs and support funding applications to implement education for all

existing and new AHWs. It is noted in the 2008-2009 Durri ACMS annual report that several staff have recently completed Certificate 111 in health care.

Recommendation Three: Addressing Social and Emotional Wellbeing of Workers

Participants identified the need for support for Aboriginal Health Workers and community workers in addressing their own social and emotional wellbeing.

It is suggested that consideration be given to supporting attendance at professional development workshops. In addition consideration should be given to the ACMS Executive engaging a mental health professional such as a psychologist or psychiatrist with a knowledge of the complexities of grief and loss to support these workers individually. In due course the workers could further support the wider community in building strong, resilient well community members.

Recommendation Four: Supporting Elders

The critical role of Elders in this community is recognised. There is a need to support Elders in addressing their own social and emotional wellbeing, similar to that of Aboriginal Health Workers.

Recommendation Five: Supporting Aboriginal Clients in North Coast Area Health Service

This study has identified that a number of previously-designated Aboriginal positions have not been included in the restructure and amalgamation of the Area Health Service, (now North Coast Area Health Service). It is recommended that any review of Durri ACMS staff include an analysis of the

North Coast Area Health Service Aboriginal workforce to identify any needs related to Aboriginal-specific positions. It is recommended that the Executive of Durri ACMS liaise with North Coast Area Health Executive to formulate a plan to bridge the gap in supporting Aboriginal patients admitted to Kempsey District Hospital.

Recommendation Six: Grief and Loss Reference Group

It is recommended that consideration be given to forming a grief and loss reference group in the Dunghutti Community. The purpose of such a group would be to formulate a path for the implementation of research findings and to plan for strategies for the future health, healing and wellbeing of the community. It is recommended that consideration be given to establishing links with National Networks such as The Australian Child and Adolescent Trauma, Loss and Grief Network, which was established in 2009 at the Australian National University in Canberra.

Recommendation Seven: Revision of National Policy Documents

There are a number of national health policy documents that are due to be revised, including The National Mental Health Plan 2003-2008, and the (National Aboriginal & Torres Strait Islander Health Council and National Mental Health Working Group, 2004). It is recommended that the community representatives, as considered appropriate by the Durri ACMS Executive Board, liaise with the reference groups associated with the revision of these policies to enable the findings of this research to be considered in the revision.

Recommendation Eight: Education North Coast Area Health

Service

It is recommended that funding be sought to disseminate the findings of this study through in-service education workshops at North Coast Area Health Service. This could coincide with the preliminary planning phases of Recommendation Nine: Need for further research.

Recommendation Nine: Need for Further Research

This research was conducted with great care and in consultation with representatives from the Durri ACMS. While it generated extensive and important findings, much more research is needed to ensure a complete understanding of the issues:

9.1: Research to Identify the Knowledge Base of the Existing

Health Workforce

Further research is needed to identify the existing attitudes and knowledge base of the current mainstream health system workforce in the LGA of this research, encompassing all levels of direct care providers including nursing, allied health and the medical workforce. Specifically, the research needs to measure the knowledge base and attitudes to meeting Aboriginal people's spiritual needs when they are bereaved, suffering from grief or faced with a life-limiting illness. There has been little research concerning nurses' perceptions of cultural practices surrounding death of Indigenous people (Lobar, Youngblood, & Brooten, 2006). As highlighted in the literature review,

the World Health Organisation calls for the palliative approach to enhance the quality of life for patients and their families:

through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organisation, 2004).

9.2. Research to Identify Patients’ Experiences with Particular Service Streams in Mainstream and Aboriginal Controlled Health Services

Further research is needed to review Aboriginal consumers’ experience of the existing health services in this community and in general. Such a review could include an analysis of health service stream usage by Aboriginal people and include barriers and benefits perceived by Aboriginal people. A review of the literature on patients’ and carers’ satisfaction with palliative care services undertaken by Adams (2005, p.12) revealed:

The literature has shown the negative impact of ineffective relationships between health professionals as providers of palliative care services and patients and their carers.

Adams’ review did not include Aboriginal and Torres Strait Islander data because of the limited research with this population group. However, this study suggests that the situation would be similar, if not worse.

9.3. Research to Identify and Track Cultural Safety Learning Outcomes in Health Professionals Undergraduate Degrees

Further research is also needed to audit all health-related higher education curriculum for the inclusion of cultural safety learning outcomes and

assessment criteria. It is considered necessary to monitor the boundaries between graduate attributes of health in the professions and measurements of patients' experiences.

9.4. Research to Identify Psychosocial Stressors at a Community Level

Further examination is needed to study the psychosocial constructs of entire Aboriginal communities to provide a profile for future health care planning, both for the future of clinical care and workforce planning needs. Measurement could include, but not be limited to, the Kessler Psychological Scale used by the Australian Bureau of Statistics. Because of the difficulties and inconsistencies with ABS data, further research is needed to identify psychosocial risk factors for a range of indicators of psychological distress. It is recommended that an evaluation of this nature include a life stage approach which is consistent with the meaning of Aboriginal health and wellbeing. The inclusion of measurements of social capital and the experience of being stigmatised is also recommended.

The Broader Relevance of this Research

As outlined in Chapter Four, building trusting relationships was a central component of this ethnographic study. This relationship building with key community representatives was an important but lengthy process which ensured the study was significant for the community. This research relationship has continued beyond this doctoral study with the Durri ACMS agreeing in 2009 to be a partner in the NHMRC funded study known as the

Koori Growing Old Well Study (KGOWS) NHMRC 510347 (Broe., et al. 2008). The researcher for this doctoral study has worked as a project officer to implement the partnership agreement between Durri ACMS and the KGOWS. A pilot study which included the Kempsey LGA was completed in September 2009. In addition, the knowledge gained in this doctoral study with respect to culturally safe research practices was disseminated through a chapter in a training manual and workshop for fieldworkers and interviewers of the KGOWS study in March 2010 (Hampshire, 2010). Koori Growing Old Well Study: NHMRC 510347 Fieldwork Manual. Neuroscience Research Australia). This is located as Appendix H.

More broadly, the findings of this study could be integrated in health services education in general, to highlight how understanding the experience and meaning from an Indigenous perspective is vital for non-Indigenous Australians in planning and delivering culturally safe health care services.

References

- Aboriginal Health and Medical Research Council of NSW. (2007). Aboriginal Health Information. Retrieved July 13 2007, from <http://www.ahmrc.org.au/AboriginalHealthInformation.htm>
- Adams, M. (2005). Patient and carer satisfaction with palliative care services: a review of the literature *ACCNS Journal for Community Nurses*, 10(2), 11-14.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders Text Revision DSM-IV-TR* (4th ed.). Washington: American Psychiatric Association.
- American Psychological Association. (2001). *Publication Manual of the American Psychological Association*. Washington.
- Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., Khan, K., et al. (2003). "Rewriting" cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 19.
- Ashcroft, B., Griffiths, G., & Tiffin, H. (Eds.). (1995). *The post-colonial studies reader*. London: Routledge.
- Ashcroft, B., Griffiths, G., & Tiffin, H. (2000). *Post-Colonial Studies The Key Concepts*. Devon: Routledge.
- Atkinson, J. (2001). *Lifting the blankets: The transgenerational effects of trauma in Indigenous Australia*. Unpublished PhD, Queensland University of Technology.
- Atkinson, J. (2002). *Trauma trails, recreating song lines: The transgenerational effects of trauma in Indigenous Australia*. Melbourne: Spinifex.
- Australian Bureau of Statistics. (2005). *Australian Standard Geographical Classification (ASGC) - Electronic Publication*. Retrieved April 22, 2008. from <http://www.abs.gov.au/AUSSTATS/abs@.nsf>
- Australian Bureau of Statistics. (2005). *New South Wales in Focus, 2005* Retrieved June 27, 2006. From <http://www.abs.gov.au/AUSSTATS/abs@.nsf/ProductsbyReleaseDate/715DFF6C04542809CA25719A00158806?OpenDocument>.

- Australian Bureau of Statistics. (2006a). *2006 Census QuickStats: Kempsey (Local Government Area)*. Retrieved June 5, 2009. from <http://www.censusdata.abs.gov.au/LGA14350>.
- Australian Bureau of Statistics. (2006b). *National Regional Profile: Kempsey(Local Government Area)*. Retrieved June 5th, 2008. from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/LGA14350Population/People12000-2004>.
- Australian Bureau of Statistics. (2006c). *Population Characteristics, Aboriginal and Torres Strait Islander Australians, 2006* Retrieved March 27, 2009. from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4713.0?OpenDocument>.
- Australian Bureau of Statistics. (2006d). *Selected 2006 Census Facts and Figures*. Retrieved June 10, 2008. from <http://www.abs.gov.au/websitedbs/d3310114.nsf/4a256353001af3ed4b2562bb00121564/5d3cc840c7bcef0bca2573410017db9a!OpenDocument>.
- Australian Bureau of Statistics. (2008a). *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples: National Aboriginal and Torres Strait Islander Health Survey, 2004-05* Retrieved March 3 2008. from <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4704>.
- Australian Bureau of Statistics. (2008b). *Population clock* Retrieved 11th June, 2008. from <http://www.abs.gov.au/ausstats/abs%40.nsf/94713ad445ff1425ca25682000192af2/1647509ef7e25faaca2568a900154b63?OpenDocument>.
- Australian Government. (2005). *Framework Document Overarching Agreement on Aboriginal Affairs Between The Commonwealth of Australia and The State of New South Wales 2005-2010*.
- Australian Government Department of Health and Ageing. (2003). *National Strategic Framework for Aboriginal and Torres Strait Islander Health July 2003-2013 Framework for action by governments*. Retrieved, August 1 2008. from <http://health.gov.au/internet/main/publishing.nsf/Content/health-oatsih-pubs-healthstrategy.htm>.
- Australian Government National Health and Medical Research Council. (2009). *Australian guidelines to reduce health risks from drinking alcohol*. Retrieved August 4, 2009. from http://www.nhmrc.gov.au/publications/synopses/_files/ds10-alcohol.pdf.

- Australian Health Ministers. (2003). *The National Mental Health Plan 2003-2008*. Retrieved from <http://www.health.gov.au/publications-mental-health-plan>.
- Banks, G. (2007). *Overcoming Indigenous Disadvantage in Australia, Chairman of the Productivity Commission of Australia Speech*. Paper presented at the OECD World Forum on Measuring and Fostering the Progress of Societies Retrieved March 26, 2008. from <http://www.pc.gov.au/speeches/cs20070629>
- Barnes, D. M. (1996). An analysis of the grounded theory method and the concept of culture. *Qualitative Health Research*, 6(3), 429-441.
- Bell, D. (1993). *Daughters of the dreaming* (2nd ed.). Sydney: Allen & Unwin.
- Berg, B. (1989). *Qualitative research methods for the social sciences*. Massachusetts: Allyn and Bacon.
- Berndt, C., & Berndt, R. (1978). *The Aboriginal Australians – The first pioneers*. Melbourne: Pitman.
- Berry, J. (1980). Introduction to methodology. In H. Triandis & J. Berry (Eds.), *Handbook of Cross-Cultural Psychology Methodology* (Vol. 2, pp. 1-23). Boston: Allyn and Bacon Inc.
- Bhaba, H. (1985). Signs taken for wonders. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The post colonial studies reader* (pp. 29-35). London: Routledge.
- Bin-Sallik, M., & Ranzin, R. (2001). *Report on a scoping study into the needs of indigenous aged care in South Australia* (Report): College of Indigenous Education, University of South Australia.
- Biripi Aboriginal Medical Service and Mid North Coast Area Health Service. (2002). *Mid North Coast Aboriginal health plan 2000-2005*: Mid North Coast Area Health Service, Lismore NSW.
- Bishop, R., & Glynn, T. (1999). Researching in Maori contexts: An interpretation of participatory consciousness. *Journal of Intercultural Studies*, 20(2), 16.
- Blomfield, G. (1981). *Baal Belbora The End of the Dancing The Agony of The British Invasion of the Ancient People of the Three Rivers: The Hastings, the Manning and the Macleay, in New South Wales*. Sydney: Hogbin Poole.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs: Prentice-Hall.

- Bonnefoy, J., Morgan, A., Kelly, M., Butt, J., & Bergman, V., Tugwell, P., et al. (2007). *Constructing the evidence base on the social determinants of health: A guide*. National Institute for Health and Clinical Governance.
- Booroongen Djugen Aboriginal Corporation. (2000). About Booroongen Djugen Aboriginal Corporation. Retrieved August 24, 2009. from <http://www.midcoast.com.au/~booroon/>
- Broe, T., Jackson-Pulver, L., Chalkey, S., Grayson, D., Daylight, G., Wade, V., et al. (2008). What is the burden of dementia in urban dwelling Indigenous Australians. University of New South Wales, Prince of Wales Medical Research Institute: National Health and Medical Research Council.
- Bureau of Crime Statistics and Research NSW. (2007). Local Government Area Ranking Tool Publication. Retrieved June 6, 2008: <http://bocd.lawlink.nsw.gov.au/bocd/cmd/ranking/lnit>
- Byrne, D., & Nugent, M. (2004). *Mapping attachment: A spatial approach to Aboriginal post-contact heritage*. Sydney: Department of Environment and Conservation (NSW).
- Carmody, K. (Writer) (2008). Thou Shall Not Steal, *Burraay Dreaming Them Home*.
- Cartwright C. (2008). *Seeking a Way to Bridge the Gap: A Scoping Study to Identify the Preferred Aged Care Service Model for Older Aboriginal People in Mid North Coast NSW Report to Commonwealth Department of Health and Ageing*: Southern Cross University Aged Services Learning & Research Collaboration in collaboration with Yarrawarra Aged Care Ltd; Southern Cross University Office of Regional Engagement; Carexcell; and the Enterprise Training Company.
- Clagett, A. F. (1988). Theoretical consideration of integrating social structure into symbolic interactionism: Selected methodological insights. *Social Behavior and Personality*, 16(1), 97-108.
- Cleyworth, S., Smith, W., & Sealey, R. (2006). Grief and courage in a river town: A pilot project in the Aboriginal community of Kempsey, New South Wales. *Australasian Psychiatry*, 14(4), 4.
- Commonwealth Department of Health and Aged Care. (2000). *National palliative care strategy: A national framework for palliative care service development*. Retrieved 31/3/2007. from <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativ ecare-strategy.htm>.

- Commonwealth Department of Health and Ageing Aged and Community Care Division. (2002). *The residential care manual*: Commonwealth Department of Health and Ageing.
- Constitution of the World Health Organization. (1946, 19 June - 22 July 1946). *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*, Paper presented at the International Health Conference, New York.
- Cowlshaw, G. (1999). *Rednecks, Eggheads and Blackfellas: A study of racial power and intimacy in Australia*. Sydney: Allen and Unwin.
- Crisp, J., & Taylor, C. (Eds.). (2005). *Potter & Perry's fundamentals of nursing* (2nd ed.). Sydney: Elsevier.
- Danielli, Y. (1998). *International handbook of multigenerational legacies of trauma*. New York: Peinem Press.
- Denzin, N., & Lincoln, Y. (2003). *The landscape of qualitative research: Theories and issues* (2nd ed.). Thousand Oaks: Sage.
- Department of Health NSW. (2007). *Aboriginal Mental Health and Wellbeing Policy 2006-2010*. Retrieved October 27, 2008. from http://www.health.nsw.gov.au/policies/pd/2007/PD2007_059.html.
- Derrington, P. (2000). *The serpent of good and evil: A reconciliation in the life and art of Miriam-Rose Ungunmerr-Baumann*. Melbourne: Hyland House.
- Dunbar, T., & Scrimgeour, M. (2006). Indigenous health research ethics in Australia: Applying guidelines as the basis for negotiating research agreements in Australia. *Monash Bioethics Review*, 25(2), 53-62.
- Durie, M. (1994). *Whaiora: Maori Health Development*. Auckland,: Oxford University Press.
- Durri Aboriginal Corporation Medical Service. (2009). *Durri Aboriginal Corporation Medical Service Annual Report 2008-2009*. , Kempsey: DACMS.
- Eckermann, A., Dowd, T., Chong, E., Nixon, L., Gray, R., & Johnson, S. (2006). *Binan Goonj: Bridging cultures in Aboriginal health*. Sydney: Elsevier.
- Engelhardt, J. (2006). *Aboriginal and/or Torres Strait Islander Health Workers scope of practice: Scope of Practice Position Paper developed in response to the objectives and strategies of the Aboriginal and Torres Strait Islander Health Workforce National Strategic Framework*. Paper presented at the Workforce Working Group Workshop 2006, South Australia.

- Fanon, F. (1995). National culture. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The Post Colonial Studies Reader* (pp. 153-157). London: Routledge.
- Farrelly, E. (2003). *Dadirri the spring within: The spiritual art of the Aboriginal people from Australia's Daly River region*. Darwin: Terry Knight and Associates.
- Federal Privacy Commissioner. (2000). *The national privacy principles in the Privacy Amendment Private Sector Act*. Retrieved January, 20, 2004. from <http://www.privacy.gov.au/publications/npps01.html>.
- Finlayson, J. (2004). *Success in Aboriginal communities. A pilot study* (Report): Australian Institute of Aboriginal & Torres Strait Islander Studies, Canberra.
- Fletcher, J. (1989). *Clean, Clad and Courteous: A history of Aboriginal education in New South Wales*. Sydney: Southwood Press.
- Genevro, J., Marshall, M., & Miller, D. (2003). *Report on bereavement and grief research*. Alberta: Center for the Advancement of Health, University of Calgary.
- Glaser, B., & Strauss, A. (1967). *The discovery of Grounded Theory: Strategies for qualitative research*. New York: Aldine De Gruyter.
- Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin.
- Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York: Doubleday.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Penguin.
- Gramsci, A. (1929). Prison Writings 1929-1935 In Forgacs, D. (Ed), *An Antonio Gramsci reader, selected writings 1916-1913* (pp.99-239). New York: Columbia University Press.
- Haebich, A. (2000). *Broken circles: Fragmenting Indigenous families 1800-2000*. Fremantle: Fremantle Arts Centre Press.
- Hammersley, M., & Atkinson, P. (1995). *Ethnography principles in practice*. London: Routledge.
- Hampshire, W. (2006a). Investigating grief in an Indigenous community. *Australian Nursing Journal*, 13(7), 42-42.

- Hampshire, W. (2006b). *Indigenous research partnerships*. Paper presented at the Emerging Researchers in Ageing 5th National Conference: Research informing positive outcomes in older persons. The University of Sydney.
- Hampshire, W. (2010). Cultural Awareness. In *Koori Growing Old Well Study Fieldwork Manual (NHMRC 510347)* (pp. 8-14). Sydney: Neuroscience Research Australia. (Hampshire, 2010).
- Haralambos, M., van Krieken, R., Smith, P., & Holborn, M. (1996). *Sociology themes and perspectives Australian edition*. Melbourne: Longman.
- Hong, G.-Y. (2001). Front line care providers professional worlds: The need for qualitative approaches to cultural interfaces. *Forum: Qualitative Social Research*, 3(2), 16.
- Horton, D. (2000). *Aboriginal Australia*. Aboriginal Studies Press, Australian Institute of Aboriginal and Torres Strait Islander Studies, Canberra.
- Hotson, K., Macdonald, S., & Martin, B. (2004). Understanding death and dying in select first nations communities in Northern Manitoba: Issues of culture and remote service delivery in palliative care. *International Journal of Circumpolar Health*, 63(1), 14.
- Human Rights and Equal Opportunity Commission. (1997). *Bringing them home: Report of the National inquiry into the separation of Aboriginal and Torres Strait Islander children from their families*: Human Rights and Equal Opportunity Commission.
- Hunter, E. (1998). Loss and recovery: Indigenous journeys. *Grief matters: The Australian Journal of Grief and Bereavement*, 1(2), 12-14.
- Jopson, D. (2000). The town with a death rate of a war zone. *Sydney Morning Herald*, 22 April 2000.
- Kellehear, A. (2002). Grief and loss: Past present and future. [Editorial]. *Medical Journal of Australia*, 177, 2.
- Kenny, C. (2004). *A holistic framework for Aboriginal policy research*. Ottawa: Research Directorate, Status of Women Canada.
- Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M. J. (2006). Advancing health disparities research within the health care system: a conceptual framework. *American Journal of Public Health*, 96(12), 2113-2121.
- Kirkham, S., Smye, V., Tang, S., Anderson, J., Blue, C., Browne, A., et al. (2002). Rethinking cultural safety while waiting to do fieldwork:

- methodological implications for nursing research. *Research in Nursing & Health*, 25(3), 222-232.
- Kowal, E., Anderson, I., & Bailie, R. (2005). Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. *Australian and New Zealand Journal of Public Health*, 29(5), 3.
- Kristjanson, L., Lobb, E., Aoun, S., & Monterosso, L. (2006). *A systematic review of the literature on complicated grief*. Churchlands: WA Centre for Cancer & Palliative care, Edith Cowan University, funded by the Australian Government Department of Health and Ageing.
- Lee, S. (2006). *Controlling involvement to promote confidence in palliative care decisions: A grounded theory study from the patients perspective*. Unpublished PhD, Edith Cowan University.
- Lobar, S., Youngblood, J., & Brooten, D. (2006). Cross-cultural beliefs, ceremonies, and rituals surrounding death of a loved one. *Pediatric Nursing*, 32(1), 6.
- Lobb, E., Kristjanson, L., Aoun, S., & Monterosso, L. (2006). An overview of complicated grief terminology and diagnostic criteria. *Grief matters: The Australian Journal of Grief and Bereavement*, 9(2), 28-32.
- Maddocks, I., & Rayner, R. G. (2003). Issues in palliative care for Indigenous communities. *Medical Journal of Australia*, 179(6), 5.
- Marker, M. (2003). Indigenous voice, community, and epistemic violence: The ethnographer's "interests" and what "interests" the ethnographer. *International Journal of Qualitative Studies in Education*, 16(3), 361-375.
- Martin, K. (2003). Ways of knowing, being and doing: A theoretical framework and methods for Indigenous and Indigenist re-search *Journal of Australian Studies*, no. 2003: (203)-214, 76,(203), 256-257.
- Martin, K. (2008). *Please Knock Before You Enter: Aboriginal regulation of Outsiders and the implications for researchers* Maleny: eContent Management Pty Ltd.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320, 2.
- McDermott, D. (2006). Unknown family at the taxi stand. *Medical Journal of Australia*, MJA;184 (10):483-484.

- McGrath, P. (2006). Exploring Aboriginal peoples' experience of relocation for treatment during end-of-life care. *International Journal of Palliative Nursing*, 12(3), 102-108.
- McGrath, P., Holewa, H., & Kail-Buckley, S. (2007). "They Should Come Out Here..." Research findings on lack of local palliative care services for Australian Aboriginal people.
- McGrath, P., & Phillips, E. (2008). Aboriginal spiritual perspectives: Research findings relevant to end of life care. *Illness, Crisis and Loss*, 16(2), 24.
- McGrath, P., & Phillips, E. (2008). Australian findings on Aboriginal cultural practices associated with clothing, hair, possessions and use of name of deceased persons. *International Journal of Nursing Practice*, 14, 9.
- McGrath, P., Watson, J., Derschow, B., Murphy, S., & Rayner, R. (2004). *Indigenous palliative care service delivery: A living model*: National Health and Medical Research Council Australia.
- McKendrick, J., & Thorpe, M. (1998). The legacy of colonisation: Trauma, loss and psychological distress amongst Aboriginal people. *Grief matters: The Australian Journal of Grief and Bereavement*, 1(2), 4-8.
- Meltzer, B. N. (1972). *Symbolic Interactionism: Genesis, varieties and criticism*. London: Routledge.
- Mid North Coast Area Health Service. (2002). *Mid North Coast Aboriginal health plan 2000-2005*: Mid North Coast Area Health Service.
- Mid North Coast Area Health Service. (2004). *Area cancer services plan 2003-2004 to 2007-2008*: Mid North Coast Area Health Service, Lismore NSW.
- Miller, M., Spring, L., Turale, S., Goold, S., & Usher, K (2005). *Dadirri: A nursing guide to improving Indigenous health*. Final report of the Indigenous Nursing Education Working Group Project. Council of Aboriginal and Torres Strait Islander Nurses, Bribie Island. QLD
- Min-ha, T. (1995). Writing postcoloniality and feminism. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The Post Colonial Studies Reader* (pp. 264-268). London: Routledge.
- Minichello, V., Aroni, R., Timewell, E., & Alexander, L. (1995). *In-depth interviewing* (2nd ed.). Melbourne: Longman.
- Mohammed, S. (2006). Moving beyond the "Exotic": Applying postcolonial theory in health research. *Advances in Nursing Science*, 29(2), 98-109.

- Morse, M., Barrett, M., Manyan, M., Olsen, K., & Spiers, K. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 2,2002, 6.
- National Aboriginal Community Controlled Health Organisation. (2008). National Aboriginal Community Controlled Health Organisation Definitions. Retrieved June 30 2008, from <http://www.naccho.org.au/definitions/communitycont.html>
- National Aboriginal Community Controlled Health Organisation, & Community Services and Health Industry Skills Council. (2007). *Scoping Report for the development off a Resource Kit to support delivery and assessment of Aboriginal Health Worker and Torres Strait Islander Health Worker qualifications*. Canberra: National Aboriginal Community Controlled Health Organisation.
- National Breast Cancer Centre and the National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Retrieved November 10, 2008. from <http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm>.
- National Health and Medical Research Council. (1999). *The National Statement on Ethical Conduct in Research Involving Humans*. Retrieved. February 20 2007 from <http://www.nhmrc.gov.au> .
- National Health and Medical Research Council. (2002). *The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research*. Retrieved February 20, 2004. from <http://www.nhmrc.gov.au>.
- National Health and Medical Research Council. (2003). *Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. Retrieved July 10 2005. from <http://www.nhmrc.gov.au/publications/synopses/e52syn.htm>.
- National Health and Medical Research Council. (2005). *Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*. Retrieved March 31, 2007. from <http://www.nhmrc.gov.au/publications/index.htm>.
- National Health and Medical Research Council. (2009). *Australian guidelines to reduce health risks from drinking alcohol*.
- Navin Officer Heritage Consultants Pty Ltd. A Report to Parsons Brinckerhoff for the NSW RTA. *Kempsey to Eungai: Upgrading the Pacific Highway: Submissions Report*.

- New South Wales Aboriginal Land Council. (2009). NSWALC Glossary of Terms. Retrieved February 10, 2009, from <http://www.alc.org.au/resources/glossary/Glossary.htm>
- New South Wales Department of Corrective Services (2009) Facts & Figures: Corporate Research, Evaluation & Statistics, 9th Edition, May 2009.
- New South Wales Department of Health. (1999). *New South Wales Aboriginal Health Strategic Plan* (No. AH 99015: State Health Publication). Sydney: NSW Department of Health.
- New South Wales Department of Health. (2003). *NSW Health Aboriginal impact statement and guidelines: Incorporating Aboriginal health needs and interests in health policies and programs* (No. 0 73473529 4). Sydney: NSW Department of Health.
- New South Wales Department of Health. (2004). *Communicating positively: A guide to appropriate Aboriginal terminology*. Sydney: NSW Department of Health.
- New South Wales Department of Health. (2005). *NSW Aboriginal Chronic Conditions Area Health Service Standards*.
- New South Wales Department of Health. (2007). *Drug and Alcohol Plan 2006-2010*. Sydney: NSW Department of Health.
- New South Wales Government Department of Health. (2005). *State Health Plan - A new direction for NSW* (No. 1741870143).
- North Coast Area Health Service. (2009). Aboriginal Cultural Awareness Training Package Information. Retrieved September 2009 from <http://www.ncahs.nsw.gov.au/news/fullstory.php?storyid=681&siteid=142>
- Nursing Council of New Zealand. (2005). *Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health in Nursing Education and Practice*. Wellington: Nursing Council of New Zealand.
- O'Brien, A. P. (2000). *The development of mental health in Koori adolescents: stories and memories from their youth*. Unpublished PhD Thesis, University of New England.
- O'Brien, A. P. (2006). Moving toward culturally sensitive services for Indigenous people: A non-Indigenous mental health nursing perspective. *Contemporary Nurse*, 21(1), 21-31.
- Oliver, P. (2004). *Writing your thesis*. London: Sage.

- Orange, C. (2004). *An illustrated history of the Treaty of Waitangi*. Wellington: Bridget Williams Books.
- Park, R. (1950). *Race and culture*. New York: The Free Press.
- Pearson, N. (2003). *Underlying principles of a new policy for the restoration of Indigenous social order*. Cape York Partnerships
- Preist, H., Roberts, P., & Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data. Part 1 theoretical issues. *Nurse Researcher*, 10(1), 13.
- Prior, D. (1997). *Life-death-life: Urban Aboriginal culture and palliative care*. Unpublished Master of Science thesis, Flinders University, Adelaide.
- Prior, D. (2007). Decolonising research: A shift towards reconciliation. *Nursing Inquiry*, 2(14), 162-168.
- Prus, R. (1996). *Symbolic interaction and ethnographic research: Intersubjectivity and the study of human lived experience*. Albany: State University of New York Press.
- Ramsden, I. (2002). *Cultural safety and nursing education in Aotearoa and Te Waipounamu*. Unpublished Doctoral Thesis, Victoria University of Wellington.
- Ray, A., & Prigerson, H. (2006). Complicated grief: An attachment disorder worthy of inclusion in DSM-V. *Grief matters: The Australian Journal of Grief and Bereavement*, 9(2), 33-38.
- Roads and Traffic Authority of NSW. (2007). Cultural Heritage Assessment Report Kempsey to Eungai: Sydney: Roads and Traffic Authority of NSW.
- Rock, P. (1979). *The making of symbolic interactionism*. London: Macmillan.
- Rose, D. B. (1996). *Nourishing Terrains: Australian Aboriginal views of landscape and terrains*. Canberra: Australian Heritage Commission.
- Russell, C. (2004). Ethnography and participant observation. In V. Minichello, Sullivan, G., Greenwood, K., Axford. (Ed.), *Research Methods for Nursing and Health Science* (pp. 463-478). Sydney: Prentice Hall.
- Said, E. (1995). Orientalism. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The Post Colonial Studies Reader*. London: Routledge.
- Sanders, D., Labonte, R., Baum, F., & Chopra, M. (2004). Making research matter: a civil society perspective on health research. *Bulletin of the World Health Organization*, 82(10), 91

- Schneider, Z., Whitehead, D., & Elliot, D. (2007). *Nursing & midwifery research* (3rd ed.). Sydney: Elsevier.
- Sherwood, J. (2005). Mental health issues from an Indigenous perspective. *Aboriginal and Islander Health Worker Journal*, 29(3), 2.
- Sherwood, J., & Edwards, T. (2006). Decolonisation: A critical step for improving Aboriginal Health. *Contemporary Nurse*.
- Simmons, M. (2007). Insider ethnography: Tinker, tailor, researcher or spy? *Nurse Researcher*, 14(4), 7-17.
- Slemon, S. (1995). The scramble for post colonialism. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The Post Colonial Studies Reader* (pp. 45-52). London: Routledge.
- Smith, L. T. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. Dunedin: University of Otago.
- National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group. (2004). *Social and Emotional Wellbeing Framework: A National Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2004-2009*. Retrieved from <http://www.atns.net.au/agreement.asp?EntityID=4388> August 10, 2009 .
- Stanner, W. (1979). *White man got no dreaming*. Canberra: Australian National University Library Press.
- Statistics New Zealand. (2008). New Zealand Life Tables: 2005-07 New Zealand life expectancy increases Retrieved August 10 2009: http://www.stats.govt.nz/browse_for_stats/health/life_expectancy/nzlife_tables_mr05-07.aspx
- Status of Women Canada. (2004). *A holistic framework for Aboriginal health research*. Retrieved October 19, 2007. from <http://www.swc-cfc.gc.ca/pubs/pubsalpha>.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks: Sage.
- Stroebe, M., Stroebe, W., & Hansson, R. (Eds.). (1993). *Handbook of bereavement theory research and intervention*. New York: Cambridge University Press.

- Sullivan, K., Johnston, L., Colyer, C., Beale, J., Willis, J., Harrison, J., et al. (2003). *National Indigenous palliative care needs study* (Final Report). Sydney: Australian Department of Health and Ageing.
- Swan, P. (1998). Grief and health: The Indigenous legacy. *Grief matters: The Australian Journal of Grief and Bereavement*, 1(2), 9-11.
- Talbot, L., & Verrinder, G. (2005). *Promoting health: The primary care approach* (3rd ed.). Sydney: Elsevier.
- Taylor, B., Kermode, S., & Roberts, K. (2006). *Research in nursing and health care: Evidence for practice* (3rd ed.). Melbourne: Thomson.
- Taylor, J., & Guerin, P. (2010). *Health care and Indigenous Australians: Cultural safety in practice*. Melbourne: Palmgrave Macmillan.
- Telfer, E. (1939). *Amongst Australian Aborigines; Forty years of missionary work: The Story of The United Aborigines' Mission*. Melbourne: Fraser Press.
- Ungunmerr-Baumann, M. (2000). *Dadirri, in The Serpent of Good and Evil. Derrington P, A Reconciliation in the Life and Art of Miriam Rose Ungunmerr-Baumann*. Melbourne: Hyland House.
- Vidich, A. J., Lyman, S.M. (2000). Qualitative Methods: Their history in sociology and anthropology. In N. Denzin, Lincoln, Y. (Eds.), *Handbook of qualitative research* (pp. 37-84). Thousand Oaks: Sage.
- Wand, A., & Eades, S. (2008). Navigating the process of developing a research project in Aboriginal health. *Medical Journal of Australia*, 188(10), 4.
- Warburton, J., & Chambers, B. (2007). Older Indigenous Australians: Their integral role in community and culture. *Australasian Journal on Ageing* 26(1), 5.
- White, N. (2007). *Indigenous womens career development: Voices that challenge educational leadership*. Australian Catholic University, Melbourne.
- Whyte, W. (1955). *Street corner society: The social structure of an Italian slum*. Chicago: The University of Chicago Press.
- Wilkins, R., Sharanjit, U., Philippe, F., Senécal, S., Guimond, E., & Dion, R. (2008). Life expectancy in the Inuit-inhabited areas of Canada, 1989 to 2003 *Journal*. Retrieved from <http://www.statcan.gc.ca/pub/82-003-x/2008001/article/10463-eng.htm>

- Wilkinson, R., Marmot, M. (Ed.). (2003). *Social determinants of health. The solid facts* (2nd ed.). Copenhagen: International Centre for Health & Society.
- Willis, K., Daly, J., Kealy, M., Small, R., Koutroulis, G., Green, J., et al. (2007). The essential role of social theory in qualitative public health research *Australian and New Zealand Journal of Public Health*, 31(5), 438-443.
- Wilson, S. (2004). *Research as a ceremony: Articulating an Indigenous research paradigm*. Unpublished PhD thesis, Monash University, Melbourne.
- World Health Organisation. (2002). *Indigenous peoples & participatory health research planning & management*. Geneva: World Health Organisation.
- World Health Organisation. (2004). WHO definition of palliative care. Retrieved August 20 2008, from <http://www.who.int/cancer/palliative/definition/en/>

Appendix A:

A Summary of Field Notes (Key Dates and Processes)

Key Dates and Summary of Processes:

Notes from Research Journal Wendy Hampshire

25/6/2004 -Meeting Director of Gnibi- College of Indigenous Australian Peoples, Southern Cross University

22/7/2004 1 Preliminary discussions by supervisor with ACMS, Gullumbilla Coffs Harbour and Durri ACMS regarding permission to conduct research in the area.

Advised by acting CEO Durri ACMS to contact Department of Indigenous Affairs.

22/7/2004 2. Google search "*Department of Indigenous Affairs*" reveals *Australian Government Department of Multicultural and Indigenous Affairs*. My notes record the switchboard operator's words "most of the people in this office have moved to another office, try this office OPIC Office of Indigenous Policy Coordination /ATSIS there's a name change in progress".

Referred to Cultural Rights and Justice Department. Phone conversation notes: "This department is now under the attorney generals, it used to be under ATSI now it's under OPIC. I haven't come across this before. It's usually done at local level. Try Department of Health Indigenous Affairs Office at Woden".

The Office for Aboriginal and Torres Strait Islander Health, Office of Indigenous Health were contacted. Advised to refer to the NHMRC publication Ethics in Indigenous Health. Also advised to speak with staff from the

research and data department within The Office for Aboriginal and Torres Strait Islander Health.

I asked about culturally appropriate protocols and was advised by a research team member, "I don't know" ATSIC is broken up; people have gone to 4 corners. This isn't our jurisdiction therefore we can't advise. You should check if the ATSIC regional office is still open. It should be, and seek their advice. There should be someone there to advise you. You need to find Aboriginal leaders to seek permission. Gently, incrementally seek advice from leaders and work in partnership".

22/7/2004 3. Contacted Many Rivers Regional Land Council Coffs Harbour and advised the office was now Coffs Harbour Indigenous Coordination Centre.

Names of key contacts given to me.

27/7/2004 Conversations with key contacts as above, asking for advice. Referred to North Coast Area Health Service (NCAHS) senior staff.

28/8/2004 Phone contact with NCAHS senior staff.

28/7/2004 1. Supervisor phone conversation with acting CEO Durri ACMS. PhD student doing a cultural study and would like to include Indigenous participants. Wanting to seek advice from Aboriginal people. "Ok for WH to phone CEO to talk about this."

28/7/2004 2. Unable to speak with CEO-in meetings.

30/7/2004 Unable to speak with CEO-in meetings. Message left.

10/8/2004 Received advice on processes from NCAHS.

Write to NCAHS Aboriginal Partnership, including a brief summary and include Aboriginal Health Impact Statement. Also advised to write to keep the

conversations happening with key community representatives so all people are informed.

17/8/2004 Face to face meeting with CEO ACMS. Sought advice. Next step is to speak with staff about project. Invited to staff meeting.

17/8/2004 Notes from conversations and meetings with Aboriginal community members not included here to protect the identity of these people.

25/8/2004 E-mail correspondence from NCAHS requesting an executive summary of the broad parameters of the study. Asked who I had been consulting with in the community. I sought advice as to if there was anyone else at this stage.

21/9/2004 Advised by NCAHS that a representative would take the briefing documents to the Aboriginal Health Partnership Executive Committee meeting. Prior to the meeting I was advised that the outcome would be that the partnership would recommend that the studies full proposal go to MNCAHS Human Research Ethics Committee as the Aboriginal partnership seek advice from the MNCAHS HREC. I was further advised that MNCAHS would seek advice from the ACMS executive board for a final decision.

12/10/2004 Letter received from MNCAHS to advise that the research proposal tabled through the Aboriginal Health Partnership Executive Committee. The committee had agreed that the full research submission should be forwarded to MNCAHS HREC for consideration.

19/10/2004 Confirmation from ACMS of invitation to attend next staff meeting with PhD supervisor. Sought advice from CEO at how best to approach this meeting

27/10/2004 Staff Meeting ACMS- Outline of talks : Introductions, Why here i.e. background to the proposed study, key issues as a non-Indigenous person,

cultural safety, benefit to the community, study supervision, the process so far, where to next, sought advice, questions, comments.

Following meeting I was given a letter from a senior staff member outlining key areas of research need in relation to grief and loss.

27/10/2004 Afternoon meeting NCAHS senior staff member.

15/11/2004 Phone call from senior manager at ACMS inviting me back to attend a staff in-service to discuss the project further. CEO had senior staff to assist me with formulating the project to meet the needs of the community. Verbal indication of strong support. Also, advised to speak with Elders Council, contacts given.

15/11/2004 Conversation with Elders council. Advice given to me on communication protocols. Very strong indication of support for a study to be conducted solely in Dunghutti country.

15/11/2004 Phone call from senior staff at ACMS. Advised on culturally appropriate mechanism for participant referral.

20/11/2004 Full research proposal request from ACMS for consideration. Advised to distribute community information letters. Positive feedback via phone.

22/11/2004 Human Research Ethics Committee submission Southern Cross University.

25/11/2004 Met with staff at ACMS to talk and hand out community info letters. No-one attended. Funeral on.

25/11/2004 Meeting with community members, details not recorded here to maintain confidentiality.

27/11/2004 Attended ACMS staff in-service. Much conversation throughout the day with staff. Visited Elders Council.

6/12/2006 Approval SCU Human Research Ethics Committee (HREC). HREC commended this research project and Ethics application.

6/12/2006 ACMS notified of HREC approval.

25/2/2005 Appointments made with ACMS and Elders council.

12/5/2005 Meeting CEO ACMS "researcher room" offered. "Your welcome here. Take as long as you like".

19/5/2005 Letter received from ACMS advising that I had been allocated an office to use for research purposes.

20/5/2005 Meeting Elders Council. Strong support. Advice sought.

25/5/2005 Letter to Elders Council with Executive Summary of the study.

25/5/2005 Further advice Southern Cross University GNIBI-College of Indigenous Australians.

26/5/2005 First participant interview at ACMS.

Appendix B:

NSW Health: Aboriginal Impact Statement

ABORIGINAL HEALTH IMPACT STATEMENT

This Statement and the following Checklist will accompany new policies submitted for approval to the NSW Department of Health's Policy Development Committee and/or the relevant committees at local level. This Statement and Checklist aims to ensure that the health needs and interests of Aboriginal people have been considered, and where relevant, appropriately incorporated into health policies. Note that as well as health policies and policy initiatives, this Statement should be used in relation to major health strategies and programs.

Title of policy: PhD Study: Title (Working title) Living With Death-
Towards an Aboriginal Perspective of Understanding Grief and Bereavement

Please complete:

- Have all items of the Checklist been reviewed and answered? Yes No

If not, give reasons: _____

- Will this policy significantly affect the health* of Aboriginal people? (the Checklist may assist you to answer this question) Yes No

If so, how: This study is significant because it will contribute to the understanding of the health needs of Indigenous people on the north coast of NSW. The study will build upon existing knowledge, of Indigenous health needs but specifically highlight the particular needs of the NSW north coast aged Indigenous population.

- Is this policy likely to lead to a change in the nature or level of resources or health services available for Aboriginal health? Yes No

If so, specify: Potential outcomes from the study will include a report to all Aboriginal and non-Aboriginal organisations involved in the study. This information is highly likely to support future funding proposals for health service delivery and partnerships in Aboriginal health. _____

Statement The health needs and interests of Aboriginal people have been considered, and where relevant, incorporated and appropriately addressed in the development of this health policy.

Head of Unit name _____

Unit name _____

* For Aboriginal people, health is defined not only as physical health, but also emotional, cultural and spiritual well-being of the individual and his/her community.

CHECKLIST FOR THE STATEMENT

This Checklist should be used when preparing an Aboriginal Health Impact Statement for new health policies, as well as major health strategies and programs. To complete the Checklist and to fully understand the meaning of each Checklist item, it is essential to refer to "How to Use the Checklist" in Part 3 of this document.

Development of the policy

1. Has there been *appropriate representation* of Aboriginal stakeholders in the development of the policy? Yes
2. Have Aboriginal stakeholders been involved *from the early stages* of policy development? Yes

Please provide a brief description

The research proposal has been formulated with all, Aboriginal stakeholders being involved to ensure the research is both culturally safe and of benefit to the Aboriginal Community.

Consultations to date have included, Durri Aboriginal Medical Service (Names deleted), Mid North Coast Area Health Service, (Names deleted), (the names of other services consulted have been removed to maintain confidentiality. _____

3. Have *consultation/negotiation processes* occurred with Aboriginal stakeholders? Yes
4. Have these processes been effective? Yes

Explain : Yes following the implementation of recommendations for example staff presentations at Durri, further advice and invitations to extend the process to the wider community have been given _____
to the researcher _____

5. Have links been made with relevant existing mainstream and/or Aboriginal-specific policies, programs and/or strategies? Yes

Explain _____
Refer to research proposal for in depth analysis.

6. Has the policy been endorsed by the NSW Aboriginal Health Partnership where required? No

Comments: An application to the NSW Health Partnership was tabled at the September, 2004 meeting as at Mid North Coast Area Health Service. Recommendations from this meeting were to provide a full submission to MNCCHS ethics committee. This will be tabled at the first meeting in 2005, following approval by Southern Cross University Ethics Committee.

Contents of the policy

7. Does the policy *clearly identify* the effects it will have on Aboriginal health outcomes and health services? Yes

Comments The proposed study is aimed directly at improving the quality of health care service Provision to Indigenous people .The final report could be used to support funding proposals for local health initiatives as identified by the study.

8. Have these effects been *adequately addressed* in the policy? Yes No N/A

Explain :As this is a proposal only, final outcomes are not yet known

9. Are the identified effects on Aboriginal health outcomes and health services sufficiently different for Aboriginal people (compared to the general population) to warrant the development of a separate policy? Yes

Explain. The study builds upon existing knowledge of indigenous health needs and specifically highlights the particular needs of the NSW North Coast indigenous population. Whilst there is much research presently being undertaken by the National Palliative Care Strategy(Sullivan et al., 2003), including indigenous palliative care; there is no current project which focuses on the identification of the Aboriginal point of view in the context of aged and palliative care needs in relation to grief and bereavement issues for this population group.

Implementation and evaluation of the policy

10. Will implementation of the policy be supported by an Adequate allocation of resources specifically for its Aboriginal health aspects? Yes No N/A To be advised

Describe _____

11. Will the policy be implemented in partnership with Aboriginal stakeholders? yes

Briefly describe the intended implementation process

Implementation will be formulated in partnership with all key stakeholders, following completion of the Study.

12. Does an evaluation plan exist for this policy? N/A
13. Has it been developed in conjunction with Aboriginal stakeholders? N/A

Briefly describe Aboriginal stakeholder involvement in the evaluation plan

An evaluation plan will be formulated in partnership with all stakeholders before the implementation of the research

Appendix C:

Community Information Letter about the Study



Information Letter Re: Grief and Bereavement Study

This is a brief letter about some interviews I would like to conduct at Durri Aboriginal Corporation Medical Services next year.

My name is Wendy Hampshire, I am a lecturer and also a student at Southern Cross University in Coffs Harbour. I have met with the CEO at Durri Aboriginal Corporation Medical Services, the Aboriginal Programs manager at the Mid North Coast Area Health Service and community people for the past few months about the need for this type of project in the Kempsey area.

Everyone has suggested I let more staff and the community know about the project. The study will document the Aboriginal perspective regarding death and dying and the suffering of grief. This study is significant because it will contribute to the understanding of the health needs of the Dungutti people.

Background

This project will develop information which identifies specific cultural needs of the Dungutti people surrounding grief.

The past experience of indigenous Australian people and the immense cultural trauma and loss experienced is an area where a great deal of previous research has been conducted. Aboriginal people continue to be affected by past trauma and grief. Aboriginal people's trauma has been relayed across generations from the direct effects of the process of colonisation (Atkinson, 2001).

Outcomes/Benefit

The study will enable the researcher in partnership with the indigenous community to document and analyse the needs of the Dungutti people surrounding grief and bereavement.

The project will develop a Dungutti model of death, dying and bereavement.

This project intends to enable the Aboriginal perspective to be influential in supporting future funding proposals to develop programs such as local grief and bereavement workshops run by local Aboriginal people.

The study could also link to other indigenous projects which document the Aboriginal health care needs perspective and ultimately contribute to the understanding of health needs of all indigenous people.

The interviews

I would like speak to Aboriginal people who have experienced the loss of a family member or friend.

I realise this is a very sensitive area and strict guidelines will be followed which will have been approved by the Durri board and the Mid North Coast Area Health Service Aboriginal Partnership executive and Southern Cross University before the study starts.

An Aboriginal observer who has been nominated by Durri executive is able to be at the interviews to support the participants if necessary. This person will advise and consult on issues of cultural sensitivity and appropriateness. Alternatively participants might want to bring a friend or relative along with them at their request.

Participants will be asked to sign a consent form which says that the project has been explained fully to them and that they have volunteered to participate. The consent form will also say that participants can withdraw at any time, and finally that information from the study may be published only if there is never any identity disclosed. A copy of this form will be given to each participant and the original will be kept in the researchers locked filing cabinet.

Confidentiality will be assured; participants will not have their identity disclosed. Personal details such as name, and addresses or any other information that could identify participants will not be used in the study or in the study report.

If participants withdraw from the study any data relating to the participant will be destroyed, including any audio tape recordings of interviews if they want that to occur.

Information about the project and the tapes and transcripts from the interviews will be stored in accordance with National Health & Medical Research Council guidelines (NHMRC) and the Commonwealth Privacy Act. Tapes from interviews will be held in a locked filing cabinet at Southern Cross University Coffs Harbour, with access only by myself and my supervisor Dr. Tony O'Brien.

More Information: At this stage I don't want people to volunteer to be a part of the study. I am looking for support and for feedback as to how to commence the project. If anyone would like more information I can be contacted on Ph: 0401 309 107 or by e-mail whampshi@scu.edu.au.

A message can also be left for me at Durri ACMS Ph 65621604. If people ring me I will ring them back so the call doesn't cost them.

Dr Tony O'Brien who is my supervisor is also willing to answer any questions, and can be contacted on Ph: 0428 288 3349 or aobrien@scu.edu.au

Kind regards,

Wendy Hampshire

Appendix D:

Consent Form

SOUTHERN CROSS UNIVERSITY

INFORMATION AND CONSENT:

My name is Wendy Hampshire; I am a university student from Southern Cross University in Coffs Harbour,

You are invited to participate in the study to identify the needs of indigenous peoples surrounding grief and bereavement.

The project:

The study will document what Aboriginal people believe are the important issues regarding grief and bereavement. This study is also significant because it will contribute to the understanding of the health needs of indigenous people on the north coast of NSW.

I would like to speak with local Aboriginal people about what they think are the important issues for Aboriginal people and their families when they have suffered a loss through the death of a loved one. Interviews will take about one hour, and will be conducted at Durri Aboriginal Corporation Medical Service.

Confidentiality will be assured; participants will not have their identity disclosed. Personal details such as name, and addresses or any information that could identify you will not be used in the study or report of the study. If you decide at any stage to withdraw from the study, all information will be destroyed and not used in the study if that is what you would like to happen.

Tapes from interviews will be held in a locked filing cabinet at Southern Cross University Coffs Harbour, with access only by me, and my supervisor Tony O'Brien. After the interviews I will type up the content of the interview, and then show you to ensure the accuracy of data collection.

An Aboriginal observer nominated by the CEO of Durri ACMS will be at the interviews to support you if you want them there. Alternatively you might want to bring a friend or relative along with you.

If at any time during or after the interviews issues arise that are sensitive, you can speak to a counsellor confidentially, by phoning Mid Coast Lifeline Services ph 131114. This is a free service that operates 24hrs a day.

Inquiries

Any questions about the study can be directed to me (Wendy Hampshire), or if you would like to speak to someone else Tony O'Brien who is supervising the project is able to answer any questions.

Supervisor Details: Anthony (Tony) O'Brien (RN.PhD).

Southern Cross University
Regional Academic Co-coordinator
Nursing Programs, School of Nursing and
Health Care Practices, Port Macquarie Base Hospital Education Centre
Wrights Road, Port Macquarie, 2444
Ph: 6580 1130 (Mon, Thru, Fri).

Fax: 6580 1110
CHEC Coffs Harbour Education Campus
Coffs Harbour
Ph. 6659 3349 (Tues, Wed) Mobile - 042 828 8526 (Business Hours)
Email: aobrien@scu.edu.au

Researcher Details: Wendy Hampshire, PhD student, School of Nursing and Health
Care Practices, Southern Cross University, Coffs Harbour Education Campus
Ph 66414500
Mobile: 0401309107
whampshi@scu.edu.au

OR if you have any problems associated with this project, please contact:

Mr J. Russell
Ethics Complaints Officer
Graduate Research College
Southern Cross University
PO Box 157
LISMORE NSW 2480
(02) 6626 3705 Email: jrussell@scu.edu.au

Consent:

I have read/ been explained to the above information. I
agree to be a participant in this project and understand that I may withdraw at any time. If
I should withdraw from the project know that audiotapes, and notes will be
destroyed. Futher, I agree that information obtained from the study may be published
provided that any information that may identify me is not used.

.....
Name of participant Date

.....
Name of interviewer Date

.....
Name of witness Date

You will be given a copy of this form to keep.

Appendix E:

Interview Format and Questions

Interview Format Durri ACMS

Checklist

- Introductions
- Role of Observer
- Confidentiality issues
- Interview cessation at any time
- Referral mechanism
- Consent

Participant information.

Age:

Gender:

Country:

Elder Y/N

Community/Traditional

Interview questions

1. What does grief mean to you as an Aboriginal person?
2. What happens in this community when an Aboriginal person dies?
3. Can you describe the sort of care and assistance that has been offered to help you deal with any loss or grief that you have experienced?
4. What are the Aboriginal cultural rites and rituals that help in the grief process?
5. What are the spiritual needs in a Koori sense of someone who is grieving?
6. What do you think are the aged care issues surrounding grief are for Kooris?

Appendix F:

Durri ACMS Endorsement of the Study



DURRI ABORIGINAL CORPORATION
MEDICAL SERVICE

A.B.N. 52 730 046 875

Phone: 02 6562 4919
02 6562 6733
Fax: 02 6562 7069

15-19 York Lane
Kempsey NSW 2440

PO Box 136
Kempsey, NSW 2440

25/10/07

TO WHOM IT MAY CONCERN

Thank you for this opportunity to provide a support letter.

I would like to advise you that as the Chief Executive Officer of Durri Aboriginal Corporation Medical Service and on behalf of the Executive Board members of Durri Aboriginal Corporation Medical Service we support the grief and loss study conducted by Wendy Hampshire and support this presentation.

If you require further information please contact me on the above numbers.

Yours faithfully,

(Details deleted)

Chief Executive Officer

Durri ACMS is a funding initiative of both the Commonwealth and NSW Department of Health

Appendix G:

Correspondence Regarding Welcomed Language

7 September, 2009

Chairperson Dunghutti Elders Council
PO Box 179 Kempsey 2440

Re: Permission to Use Dunghutti Language

Dear x and Members of the Dunghutti Elders Council,

Following recent discussions I am writing to ask permission from the Elders council to use the Dunghutti language in the title of the Grief and Loss PhD study that was conducted at Durri ACMS.

By now some of the members may know that the study is complete and is at the final write-up stage. The first part of the title of the study is *Walking on Dunghutti country*. This part of the title acknowledges my position as a non-Indigenous researcher and highlights the important guiding partnerships on Dunghutti Country that enabled the study to proceed to completion.

As there will be a need to have the thesis bound for examination soon it would be appreciated if the council would provide me with their instructions regarding the wording of the title in Dunghutti language. I will provide the Elders council with a copy of the study report when it has been accepted by the university.

If any of the members have any other questions I can be contacted via email or the phone numbers provided. Alternatively, Dr Tony O'Brien the supervisor of the study can be contacted at the numbers below for any questions.

I would like to take this opportunity to once again personally thank the Elders Council for their support of this study.

Respectfully yours,



Wendy Hampshire
Lecturer, Southern Cross University
Research Fellow, University of New South Wales. Faculty of Medicine, Prince of Wales Medical Research Institute.
Project Officer: Koori Growing Old Well Study A Research Study approved by AHMRC and funded by the NHMRC

Anthony (Tony) O'Brien (RN,PhD)
2006-2009bVisiting Fellow, Southern Cross University
Associate Professor/Campus Head Monash University, Faculty of Medicine Nursing and
Health Sciences,
School of Nursing and Midwifery, Peninsula Campus
Building E, Room E2.42, McMahons Road, Frankston
PO Box 527, Frankston, VIC 3199
Tel +61 3 990 44377
Fax +61 3 990 44130

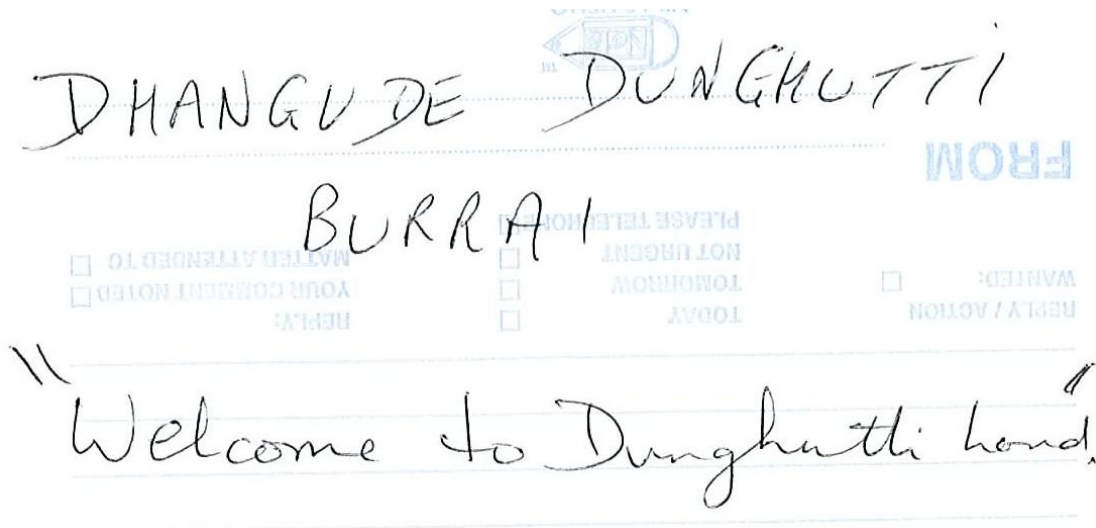
Field Note 26/10/2009:

Received a phone call which was followed up with a meeting with a person who is also an Elder and representative from Durri ACMS. Apologised for not getting the language to me earlier. They explained the recent process of the Elders meeting to discuss the title of the study...all (the Elders group) want to help.

The Elders group have agreed to Dhangude Dungutti Burrari., it means Welcome to Dunghutti Land. I have scanned the document that was given to me and it appears below.

Said: Dungoo Dunghutti Buuri

Reflection: I feel a great honor and in a privileged position to have received this traditional language and warmest welcome.



Appendix H:

Cultural Awareness

Chapter 2: Cultural Awareness

Acknowledgements

This chapter has been endorsed by a number of people who generously provided feedback on the final draft. We acknowledge the support and guidance given by the Directors of Durri board of governance. Thank you also to Colleen Cawood, chair of the Koori Growing Old Well Study (KGOWS) Aboriginal Reference Group (ARG) representing the metropolitan Sydney sites. Appreciation is also extended to Professor Lisa Jackson Pulver, Director of the Muru Marri Indigenous Health Unit, University of New South Wales.

The Purpose of this Chapter

This section of the handbook is not designed to be a comprehensive or prescriptive training manual, rather it is intended to provide interviewers with an introduction to important concepts related to working respectfully with Indigenous participants. In addition to reviewing this chapter and reading the associated recommended readings, interviewers are advised to consult the project team at their study site for on-going advice in relation to local protocols for working with the community⁸.

What is Cultural Awareness

Aboriginal cultural awareness means having knowledge and understanding of Aboriginal people's histories, values, belief systems and

⁸ Community - in accordance with the National Health and Medical Research Council Guidelines it is acknowledged the word community is a complex concept in relation to Aboriginal and Torres Strait Islander people. For the purpose of this study, community refers to Aboriginal and Torres Strait Islander people living in the LGA.

lifestyles. It is not about becoming an expert on Aboriginal culture; however it is about becoming aware of the cultural differences that exist, appreciating and having an understanding of those differences, and accepting them (Weetra, 2001, p.2).

Background to the Final Questionnaire

In addition to the ethics approval, the partnerships between the KGOWS and the communities involved seek to overcome historical criticisms of Western research methodologies. Historical criticism of early anthropological research has often been likened to a reinforcement of colonisation (Durie, 1994; Martin, 2008). Much of the published adversity to early research involving Indigenous people relates to researchers placing rigid definitions on identity and viewing Indigenous people as exotic cultures (Fanon, 1995; Said, 1995; Smith, 1999). Understanding Aboriginal ways and in particular the generation of health research which incorporated Aboriginal belief systems was a significant consideration in refining the project.

The KGOWS questionnaire was finalised with feedback provided by the pilot study participants, key community representatives and the KGOWS research team. The KGOWS questionnaire includes quantitative and qualitative components. The qualitative, open ended questions will record what participants consider important to their overall health and wellbeing as they age.

The Meaning of Health

Health from an Aboriginal perspective incorporates a whole-of-life outlook which not only focuses on the social, emotional and cultural wellbeing of the individual but of the entire community (AHMRC; 2007; Eckermann et al., 2006; McGrath, Watson, Derschow, Murphy, & Rayner, 2004; MNCAHS, 2002; Prior, 1997; Sullivan et al., 2003; Talbot & Verrinder, 2005). This whole-of-life outlook includes the cyclical life-death-life concept (NHMRC, 2002).

Also, with respect to health care from Aboriginal people's perspective the focus is on a community and family focus of care (Bourke, Bourke & Edwards, 1994 in Bin-Sallik & Ranzin 2001).

The role of the Family

Family structure in Aboriginal culture holds ultimate respect and honour (Atkinson, 2002), with the strong relationship between family and kinship being the centre of Aboriginal wellbeing (Aboriginal Health and Medical Research Council of NSW, 2007; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; NHMRC, 2005). Indigenous structure of family extends beyond blood relationships to include extended networks of people who, through a range of relationships, care for and nurture each other (Maddocks & Rayner, 2003). Aboriginal family relationships have a critical role to play in an array of health care decisions. Consequently, the interactions between the KGOWS team, individual participants and the wider family network are an important consideration for interviewers when arranging for the consent to participate.

History

Aboriginal people's health and wellbeing is influenced by the history of colonisation and Aboriginal people continue to be affected by intergenerational grief and trauma as a result of colonisation and the resultant dispossession which is well documented (Atkinson, 2002; Hunter, 1998; Swan, 1998; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004). Colonialism is defined by the NSW Aboriginal Land Council as:

The establishment of control over the original inhabitants of an area by taking possession of their land, introducing colonists and a colonial administration (NSW Aboriginal Land Council, 2009 para.5)

Dispossession is defined by the NSW Aboriginal Land Council as referring principally to loss of land. Importantly,

Given the spiritual ties which Indigenous people have to their land, its removal also led to the loss of their culture, language and religions, identity and economic independence (NSW Aboriginal Land Council, 2009 para.7)

The Gap: A Snapshot of Health and Longevity

The life expectancy gap between Indigenous and non-Indigenous people in Australia is unacceptable gap, and this difference in life expectancy is further highlighted by the fact that 12% of the Australian population is over 65 years of age, while in the Indigenous population, only 3% are aged over 65 (ABS, 2008).

The NSW Aboriginal Health Service Standards (NSW Department of Health, 2005) has focused on six areas in the NSW Aboriginal Health Chronic Conditions Profile. The conditions classified within the NSW Health profile are cardiovascular diseases, diabetes, kidney disease, chronic obstructive pulmonary disease, asthma and cancers. It should be noted that whilst chronic conditions are reported in isolation:

“It is frequently the case that Aboriginal people concurrently experience several of these conditions and other co-morbidities. In addition, people with chronic conditions and complex conditions often present with depression, anxiety or other related mental health disorders as a clinical component” (NSW Department of Health, 2005 p 32).

Thus not only are medical diseases problematic but also concomitantly mental health issues exacerbate such conditions and complicate the health service presentations made by Aboriginal people. The ABS reports disease and injury for Indigenous Australians using Disability Adjusted Life Years (DALY) (ABS

2008). DALY's are defined as; "the sum of years of life lost due to premature death and years lived with disability (Vos et al, 2007 in ABS, 2008, p288), and are described in terms of disease burden. Table 2.1 shows the broad causes of disease and injury.

Table 2.1 Disability Adjusted Life Years (DALYS), Broad Cause Group, Indigenous Persons 2003

Cause	DALYS No.	Proportion of total %
Cardiovascular disease	16 786	17.5
Mental disorders	14 860	15.5
Chronic respiratory disease	8 587	8.9
Diabetes	8 498	8.9
Cancers	7 817	8.1
Unintentional injuries	6 989	7.3
Intentional injuries	5 395	5.6
Other	27 044	28.2
All causes	95 976	100.0

Source: (ABS 2008, p. 128)

What Does this Mean for the KGOWS Team: Connecting with the Community Respectfully

Connecting respectfully through culturally appropriate ways with the community in general and specifically with participants in the KGOWS is a critical aspect of this study. At each study site an Aboriginal Reference Group (ARG) has been established to guide the KGOWS team in community processes. The KGOWS ARG model resulted in successful pilot study in 2009. This mentorship model aims to facilitate the partnership between the KGOWS team and participants.

Through the ARG and/or where applicable the Aboriginal Controlled Medical Services representatives, advice should be sought on issues like how to contact members of the community, and respectful ways to speak with people. It is projected that much of the on-going community liaison work will be carried out by the Aboriginal Research Assistants and interviewer booking staff. Interviewers will be advised of site specific booking processes.

Recommended Reading

Reconciliation Australia (2008). Share our pride: An introduction to Aboriginal and Torres Strait Islander People and their culture, and to building respectful relationships. From <http://www.shareourpride.org.au/pages/topics/welcome-to-share-our-pride.php>

New South Wales Department of Health. (2004). *Communicating positively: A guide to appropriate Aboriginal terminology*. Sydney: NSW Department of Health.

References

- Aboriginal Health and Medical Research Council of NSW. (2007). Aboriginal Health Information. Retrieved July 13 2007. From <http://www.ahmrc.org.au/AboriginalHealthInformation.htm>
- Atkinson, J. (2002). *Trauma trails, recreating song lines: the transgenerational effects of trauma in Indigenous Australia* Melbourne: Spinifex.
- Australian Bureau of Statistics. (2008). *Year Book Australia, 2008*. Retrieved 10th June, 2008. From <http://www.abs.gov.au/AUSSTATS/abs>
- Bin-Sallik, M., & Ranzijn, R. (2001). *Report on a scoping study into the needs of indigenous aged care in South Australia* (Report): College of Indigenous Education University of South Australia.

- Fanon, F. (1995). National culture. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The Post Colonial Studies Reader* (pp. 153-157). London: Routledge.
- Durie, M. (1994). *Whaiora: Maori Health Development*. Auckland: Oxford University Press New Zealand.
- Eckermann, A., Dowd, T., Chong, E., Nixon, L., Gray, R., & Johnson, S. (2006). *Binan Goonj: Bridging Cultures in Aboriginal Health*. Sydney: Elsevier.
- Hunter, E. (1998). Loss and recovery: Indigenous journeys. *Grief matters: The Australian Journal of grief and bereavement*, 1(2), 12-14.
- Swan, P. (1998). Grief and health: The Indigenous legacy. *Grief matters: The Australian Journal of grief and bereavement*, 1(2), 9-11.
- Maddocks, I., & Rayner, R. G. (2003). Issues in palliative care for indigenous communities. *Medical Journal of Australia*, 179(6), 5.
- Martin, K. (2008). *Please Knock Before You Enter: Aboriginal regulation of Outsiders and the implications for researchers*. Maleny: eContent
- McGrath, P., Watson, J., Derschow, B., Murphy, S., & Rayner, R. (2004). *Indigenous palliative care service delivery: A living model*: National Health and Medical Research Council.
- Mid North Coast Area Health Service. (2002). *Mid North Coast Aboriginal health plan 2000-2009*: Mid North Coast Area Health Service.
- National Aboriginal Community Controlled Health Organisation. (2008). National Aboriginal Community Controlled Health Organisation Definitions. Retrieved June 30, 2008. From <http://www.naccho.org.au/definitions/communitycont.html>
- National Health and Medical Research Council. (2002). *The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research*. Retrieved February 20, 2004. From <http://www.nhmrc.gov.au>.
- Social Health Reference Group for National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group. (2004). *Social and Emotional Wellbeing Framework: A National Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2004-2009*.
- National Health and Medical Research Council. (2005). *Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about*

health research ethics. Retrieved March 31 2007. From <http://www.nhmrc.gov.au/publications/index.htm>.

NSW Aboriginal Land Council. (2009). NSWALC Glossary of Terms. Retrieved February, 10, 2009. From <http://www.alc.org.au/resources/glossary/Glossary.htm>

NSW Department of Health. (2003). *NSW Health Aboriginal impact statement and guidelines: Incorporating Aboriginal health needs and interests in health policies and programs* (No. 0 73473529 4). Sydney: NSW Department of Health.

Prior, D. (2007). Decolonising research: A shift towards reconciliation. *Nursing Inquiry*, 2(14), 162-168.

Said, E. (1995). Orientalism. In B. Ashcroft, G. Griffiths & H. Tiffin (Eds.), *The post colonial studies reader*. London: Routledge.

Sullivan, K., Johnston, L., Colyer, C., Beale, J., Willis, J., Harrison, J., et al. (2003). *National Indigenous palliative care needs study* (Final Report). Sydney: Australian Department of Health and Ageing.

Smith, L. T. (1999). *Decolonizing methodologies: Research and Indigenous peoples* Dunedin: University of Otago.

Talbot, L., & Verrinder, G. (2005). *Promoting Health The Primary Care Approach* (3rd ed.). Sydney: Elsevier.

Weetra, C. (2001). *Working with Aboriginal People in Rural and Remote South Australia*. Whyalla: South Australia Centre for Rural and Remote Health, University of South Australia.