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Who cares? Aboriginal and Torres Strait Islander Health Care Choices and Access Barriers in Mount Isa.

Thesis submitted by

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in the Schools of Arts and Social Sciences and Medicine

James Cook University.

Statement on the contribution of others.

Nature of assistance	Contribution	Names, Titles and Affiliations of Co-contributors
Intellectual support	Cultural Mentorship: • Guidance on research conduct with Aboriginal and Torres Strait Islander peoples	Dr Louis Peachey, formerly of MICRRH, now of Atherton Hospital, Queensland Health Mr Shaun Solomon, Indigenous Studies Co-ordinator, MICRRH Mrs Catrina Felton-Busch formerly of MICRRH, now Indigenous Health Unit, James Cook University
	Cartography: • Creation of Map 1 • Creation of Map 2 • Source copy of Map 3	Map 1: Adella Edwards, Cartographer, James Cook University Map 2: Geraldine Hollyman (GIS Cadet), Mr Bhan Pratap (CEO), Mount Isa City Council Map 3: Shireen Lazaro, Office of Health and Medical Research, Queensland Health
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All research procedures reported in the thesis received the approval of the relevant Ethics Committees as specified in the declaration to follow. There has been one publication to come from this research to date, co-authored by Professor Craig Veitch. His contribution was in general

Declaration on Ethics

The research presented and reported in this thesis was conducted within the guidelines for research ethics outlined in the *National Statement on Ethics Conduct in Research Involving Humans* (1999), the *Joint NHMRC/AVCC Statement and Guidelines on Research Practice* (1997), the *James Cook University Policy on Experimentation Ethics, Standard Practices and Guidelines* (2001), and the *James Cook University Statement and Guidelines on Research Practice* (2001). The proposed research methodology received clearance from the Queensland Health Townsville Health Service District Human Research Ethics Committee (approval number: 47/3) and the James Cook University Experimentation Ethics Review Committee (approval number H2806).

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Mrs. Kristin Emma McBain-Rigg   (Date)

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To my mother and father, Kerry and Pat: thank you for being great parents, who have always encouraged me to 'be the change I want to see in the world', and to follow the intellectual paths

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Plate 1. The family (l-r): Louis with Impella, Talia-Joy, Kris, Jacob, Shahla-Rae and Tess Peachey.

Abstract.

This thesis presents an illustration of the access barriers to health care as experienced by Aboriginal and Torres Strait Islander peoples in Mount Isa, Queensland, Australia. This examination is conducted via fieldwork observations and the narratives of Aboriginal and Torres Strait Islander peoples in Mount Isa, as well as the stories of the health professionals that care for them. In particular, this thesis attempts to unpack the term 'cultural barriers' as used in health and medical literature in discussions of access.

Stories are placed within the context of Australian rural health issues and considerations of global issues affecting rural, minority and Indigenous populations. The research represents a distinct blend of anthropology and health services research principles and practices. This perspective is developed utilising principles from the 'Mindful Bodies' approach within Critical Medical Anthropology, which seeks an understanding of human health issues via examination at three levels (or bodies): the individual body, the social body and the body politic (Scheper-Hughes and Lock 1987). Critical issues of concern with regards to health service provision in Mount Isa are examined using Penchansky and Thomas's (1981) taxonomy, the 5As of Access. This taxonomy allows for a nuanced discussion of access by unpacking the term and identifying the various aspects that create access: Availability, Accessibility, Affordability, Accommodation and Acceptance. Dedicated ethnographic fieldwork was undertaken in Mount Isa from October 2007 to August 2009.

An examination of the ways that Aboriginal and Torres Strait Islander peoples in Mount Isa express their understandings of the barriers to health care has two advantages. First, such discussions at a local level align with and illuminate the barriers that affect Aboriginal and Torres Strait Islander populations nationally. Second, the significance assigned to such barriers, and examination of what may constitute a cultural barrier (as discussed in health literature) highlights the ways in which cultural difference becomes constructed as problematic in health system encounters.

Culture should not be seen as a barrier to health care, but should be seen as an opportunity for increased awareness, understanding and improved personal care for patients in the health system.

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Glossary

Bulk-billing	A payment option under the Medicare system where patients assign payment rights to their health care provider who claims 85% of care costs from the government. Patients are charged via their Medicare card and usually no money changes hands between provider and patient.
Centrelink	The welfare agency of the Commonwealth government of Australia, under the Commonwealth Department of Human Services.
Community Controlled Health Services	NACCHO define these services as incorporated Aboriginal organisations, initiated by and based in a local Aboriginal community. These organisations are governed by an Aboriginal body which is elected by the local Aboriginal community. They are charged with delivering a holistic and culturally appropriate health service to the Community which controls it.
Dilly bag	An Aboriginal cultural artefact. Dilly bags are traditionally bags woven from grass or other natural fibres, used to carry collected items.
General Practice	The RACGP defines general practice as providing person centred, continuing, comprehensive, co-ordinated whole-person health care to individuals and families within their communities. This is considered the equivalent of family medicine in the USA.
Indigenous Australians	Refers to Australians who identify themselves as being of Aboriginal and/or Torres Strait Islander descent. In this thesis , the term 'Aboriginal and Torres Strait Islander peoples' is used in preference of 'indigenous'.
Medicare	Commonwealth government service provider responsible for the delivery of key programs such as the Pharmaceutical Benefits Scheme, The Australian Childhood Immunisation Registry and the Australian Organ Donor Registry.

	Under the Commonwealth Department of Human Services.
Pannikin	A tin cup/mug.
Pharmaceutical Benefits Scheme	This program provides access for Australian residents to prescription medications, through cost subsidies from the Australian Government. Medicare Australia (as defined above) is responsible for the administration of the PBS.
XXXX Gold	A Queensland-brewed full-strength beer. XXXX (pronounced "four-ex") is a brand name.

Acronyms.

A&E	Accident and Emergency (Department in hospitals)
AARN	Association of Australian Rural Nurses
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACCHS	Aboriginal Community Controlled Health Service
AGPAL	Australian General Practice Accreditation Limited
AGPN	Australian General Practice Network
ASGC	Australian Standard Geographical Classification
AHMC	Australian Health Ministers Council
AHW	Aboriginal Health Worker
AMS	Aboriginal Medical Service – term often used interchangeably with ACCHS (Aboriginal Community Controlled Health Service)
APHCRI	Australian Primary Health Care Research Institute
ARIA/ ARIA+	Accessibility/Remoteness Index of Australia
ATSIHS	Aboriginal and Torres Strait Islander Health Service
BP	British Petroleum Company

CAT/CT	Computerised Tomography Scan (Formerly known as CAT scans)
CBD	Central Business District
CCT	Cross Cultural Training (also known as Cultural Awareness Training)
CHIC	Connecting Healthcare in Communities
CMA	Critical Medical Anthropology
CRANA	Council of Remote Area Nurses of Australia
CSDH	Commission on Social Determinants of Health (World Health Organisation)
DoHA	Commonwealth Department of Health and Ageing
ECG	Electrocardiogram
ED	Emergency Department (of the hospital)
GP	General Practice/ General Practitioner (equivalent to family medicine in the USA)
HACC	Home and Community Care (division of Queensland Health)
IOLs	Intraocular lenses
Km	Kilometres (Metric unit of measurement)
MIACCHS	Mount Isa Aboriginal Community Controlled Health Service (trading as Gidgee Healing)
MIATSIHS	Mount Isa Aboriginal and Torres Strait Islander Health Service
MIBH	Mount Isa Base Hospital (called Mount Isa Hospital as at 2010)

MICRRH	Mount Isa Centre for Rural and Remote Health
MRI	Magnetic Resonance Imaging
NACCHO	National Aboriginal Community Controlled Health Organisation (formerly NAIHO – National Aboriginal and Islander Health Organisation)
NAHS	National Aboriginal Health Strategy
NATSIHC	National Aboriginal and Torres Strait Islander Health Council
NHMRC	National Health and Medical Research Council
NRHA	National Rural Health Alliance
NSFATSIH	National Strategic Framework for Aboriginal and Torres Strait Islander Health
NSW	New South Wales (Australian State, south of Queensland)
NSWGP	Trading name of New South Wales Divisions of General Practice
NWQPHC	North & West Queensland Primary Health Care
OATSIH	Office of Aboriginal and Torres Strait Islander Health, Commonwealth Department of Health and Ageing
PBS	Pharmaceutical Benefits Schedule (see glossary)
PHCRED	Primary Health Care Research Evaluation and Development
PHCRIS	Primary Health Care Research Information Service
PhD	Doctor of Philosophy – a university degree characterised by research and the production of a doctoral thesis.

PTSS	Patient Travel Subsidy Scheme
QAIHC	Queensland Aboriginal and Islander Health Council
	(formerly QAIHF –Queensland Aboriginal and Islander Health Forum)
QAS	Queensland Ambulance Service
QLD	Queensland
RACGP	Royal Australian College of General Practitioners
RDAA	Rural Doctors Association of Australia
RFDS	Royal Flying Doctors Service
RRMA	Rural, Remote and Metropolitan Areas index
RSL Club	Returned Servicemen's League Club
SARRAH	Services for Australian Rural and Remote Allied Health
SNAP (framework)	Smoking Nutrition Alcohol Physical Activity framework
TGH	Townsville General Hospital (change of site led to a change of name in 2001 – now called The Townsville Hospital (TTH)
UDRH	University Department of Rural Health
WHO	World Health Organisation
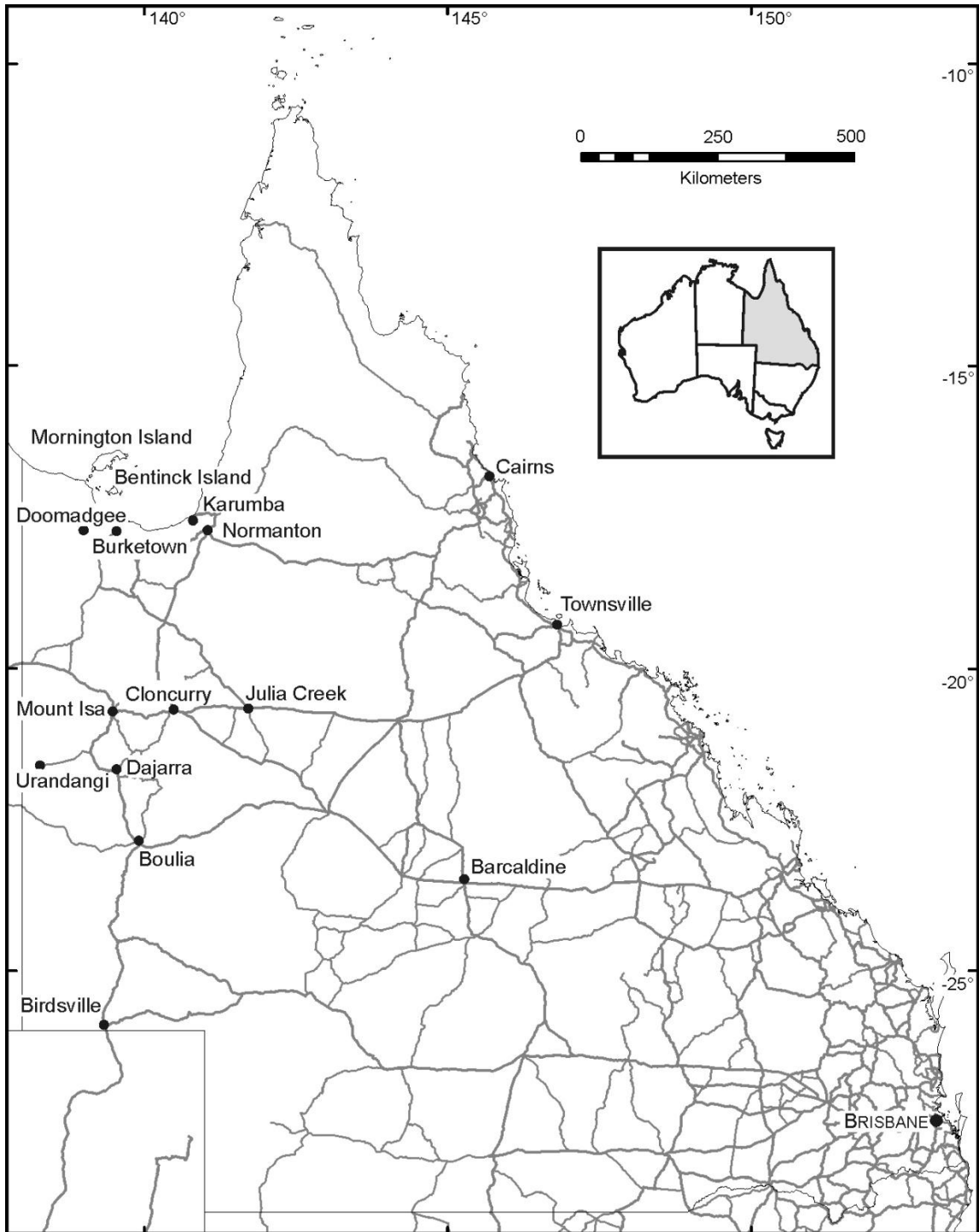
Map 1. Queensland, Australia (Adella Edwards 2011).

Map 2. Mount Isa City, showing significant places and General Practice services (Geraldine Hollywell 2011).

Map 3.   Queensland Health Service District Boundaries (Queensland Health 2008).

Note on language use.

Use of the terms 'Indigenous Australians' and 'Aboriginal and Torres Strait Islander peoples' in text.

It is important to note that, in Australia, the indigenous inhabitants of this country are often referred to as 'Indigenous Australians' in the collective. The capitalisation of the term is politically significant, as in this way it is properly used as a noun, where the non-capitalised word 'indigenous' is used as a adjective. While I have used the term 'Indigenous Australians' in places throughout the thesis, my preference is to use the collective term of 'Aboriginal and Torres Strait Islander peoples' in order to make a clear distinction that Australian Indigenous peoples are from two geographically distinct groups, which have their origins in mainland Australia (Aboriginal peoples) and the islands of the Torres Strait Peninsula (Torres Strait Islanders). These are political choices driven by current discourses around the representation of Aboriginal and Torres Strait Islander peoples, and my desire to be respectful to the identities of those who participated in my research. These choices are in alignment with the ideologies of the Aboriginal and Torres Strait Islander participants in my research project. Further discussion of the problems of collective representations of Aboriginal and Torres Strait Islander peoples is provided throughout the thesis.

The terms 'Aborigine' and 'Aboriginal' are used specifically in reference to those people who identify as or are identified by their community as being of Aboriginal descent. Those people who identify as being of Torres Strait Island descent are called 'Torres Strait Islander'. However, due to the small population of Torres Strait Islanders in Mount Isa, the use of this exclusive term does not feature often in the thesis.

Italicisation and different font choices in text.

I have used italics in this thesis according to the standard use to add emphasis to a statement, such as in quotations, and to indicate direct quotations from my interviews. I have used a Times New Roman font to distinguish between fieldwork notes from the main text throughout the thesis.

Chapter 1

Introduction: Burden or opportunity?

Despite the huge differences between developing and developed countries, access is the major issue in rural health around the world.

Strasser 2003, p.457.

Equitable access to health care is considered to be a universal human right. However, as identified by authors such as Strasser (2003) and Farmer (2005), this equitable access is also considered to be one of the fundamental issues affecting health status of people around the world. Indeed, even reaching consensus on definitions of equitable access has proven problematic (Oliver and Mossialos 2004; UNRISD 2006 for discussions on equitable access). Many of the rhetorical devices employed in discussions regarding equitable access to health care are confusing or partially defined. These partial definitions make it difficult for policymakers to translate research on 'equity' and 'access' into policy directives (Oliver and Mossialos 2004).

However, issues of accessibility of health care can be most concerning for those already disenfranchised and disengaged from the societies in which they live. For such people, accessibility issues are experienced in mundane, painful ways and have tangible and immediate outcomes with far-reaching consequences. Increasing levels of chronic disease among the poor around the world, and specifically the deepening divide on all social determinants between rich and poor in neoliberal societies (such as contemporary Australia) means that the burden on health care systems is growing, often without commensurate growth in resource allocation (Marmot 2011). The tensions for governments between creating low tax thresholds and sustaining fair and equitable health and social welfare systems may in part be responsible for this increase in ill-health (UNRISD 2006).

In Australia, contemporary discourse holds considerations of the health and wellbeing of Australia's Indigenous peoples, Aboriginal and Torres Strait Islander, as paramount, due to the recorded gaps in health outcomes apparent in comparisons between them and the rest of the Australian population (see Thomson et al. 2010, AIHW 2011 for recent overviews and examples of the statistical differences across major health indicators). These disparities in health outcomes are most noticeable in life expectancy rates, infant mortality rates and low birth weights for Aboriginal and Torres Strait Islander babies (Thomson et al. 2010; AIHW 2011). Increasing gaps between Aboriginal and Torres Strait Islander peoples and other Australian populations are reported on other social and economic indicators like income rates, employment rates, housing and education indicators (Calma 2008, Thomson et al. 2010, Marmot 2011). Equitable access to health care is fundamental in efforts to improve the health outcomes of Australia's Indigenous peoples. Yet, efforts to improve access to health care are often left wanting, not least of all because of a continued failure to fully examine what constitutes 'access' and because 'culture' is presented as a 'barrier' to accessing health care.

It is well-recognised in the literature that those who inhabit rural and remote areas are exposed to inequitable access to health care services, often due to their geographical location (Veitch 1994, Humphreys et al. 1997, Strasser, 2003, Alston et al. 2006, Wakerman and Humphreys 2008). This geographic isolation from metropolitan areas is also associated with levels of income, education and opportunity (Lichter et al. 1993, McLaughlin et al. 2001, Zimmerman et al. 2008, Vafaei et al. 2010). Many of Australia's Aboriginal and Torres Strait Islander peoples live in areas classified as rural or remote (ABS 2010). Available health services in these isolated and sparsely populated regions may be incompatible with the health needs of Aboriginal and Torres Strait Islander people.

The title of this chapter references a publication that has proved to be pivotal in the development of my ideas and forms the basis of my approach to issues of Indigenous health[1] (Peachey, McBain and Armstrong 2006). The editorial argues that Indigenous Health should be treated as an

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[1]The lead author, Dr. Louis Peachey has been a major influence in my attitudes toward issues concerning Indigenous health in Australia, and is my adopted kinship brother.

opportunity for practitioners to make tangible differences in the lives of their current patients and subsequently to the lives of younger generations of Aboriginal and Torres Strait Islander peoples. Treating and managing an Aboriginal grandmother's diabetes now has a significant flow-on effect to her children and her grandchildren.

> An extra 5 years for a 'nanna' can mean that these children do not have to lose the single most important adult figure in their lives during the vulnerable adolescent years; this could translate into many more years of health for future generations (Peachey, McBain and Armstrong 2006, p.484).

Treating nanna's chronic illness should not be seen as a burden by the health professionals she relies upon, but an opportunity to find solutions for the most disengaged and disenfranchised members of Australian society, and create innovative solutions to health care for all Australians.

This research project explores the access barriers to health care in Mount Isa, Queensland, Australia, with a particular focus on the experiences of local Aboriginal and Torres Strait Islander people. Mount Isa was established in the early 20th Century as one of Australia's first mining industry company towns and serves as a hub for the entire north-western region of Queensland. The town provides a unique example of the ways that remote locations contribute to the health of resident populations, and also represents the spectrum of socioeconomic circumstance in one location. Mount Isa exhibits many of the same struggles as other remote communities, including a paucity of usable and reliable data regarding these issues. Rather than simply capture data which indicates the statistical significance of access problems in the region, it is important to also explore the significance that people in this region attach to their experiences of health care, and even more importantly, to the expression of suffering that accompanies exclusion (both explicit and implicit) from health services. In order to capture such data, it was important to acknowledge that both folk and biomedical knowledge systems would be traversed in order to produce a complete illustration of the health care system in Mount Isa. The most pertinent way to achieve a complete representation was to explore access issues via a combination of a critical medical anthropological framework; the interpretive framework of the 'Mindful Bodies" (Scheper-Hughes and Lock 1987),

and a health service research framework; the 5As of access (Penchansky and Thomas 1981). These theoretical frameworks will be elaborated further in Chapter 2.

The study examines the ways that local Aboriginal and Torres Strait Islander people may make decisions about health care, and their experiences of care within the mainstream health network of Mount Isa. In particular this study explores the concept of 'cultural barriers' as reported in health and medical literature, and the ways that local Aboriginal and Torres Strait Islander people understand this term and experience these phenomena. This is an ethnography of the phenomenon of 'access barriers' as viewed through a number of cultural lenses: of the remote mining town, of Aboriginal and Torres Strait Islander peoples, and of the health professionals that choose to practice in a remote mining town with a large Aboriginal and Torres Strait Islander population.

In this thesis, the perspectives and experiences of various health professionals working within the health care network are also considered. Their perspectives on the way the health system operates, the collaborations and gaps in service provision, and the ways that they assist their Aboriginal and Torres Strait Islander clients through the network are discussed. The examination of the perspectives and experiences of Aboriginal and Torres Strait Islander peoples and health professionals are all set against the backdrop of Australian rural health issues more generally, providing a broader contextual understanding of local issues.

1.1. Aims and Significance.

The specific aims of the study are to:

- Document and examine access to health care in Mount Isa as expressed by local Aboriginal and Torres Strait Islander peoples and health care providers.
- Explore the concept 'cultural barriers' as discussed in health and medical literature, through the perspectives of local Aboriginal and Torres Strait Islander peoples and health

care providers. In so doing, provide a nuanced definition of what may constitute a 'cultural barrier'.

- Explore Mount Isa Aboriginal and Torres Strait Islander peoples' understandings and expressions of their health needs, aspirations, rights and experiences, including strategies used to enable access to health care.

- Examine the views of health care providers on facilitated co-ordination of health care in Mount Isa, and concerns for their patients.

- Illustrate the intimate relationships between micro-level and macro -evel influences on health across populations in Mount Isa.

The research combined anthropological and health services research principles and practices. Primarily, the research uses ethnographic methods, including participant observation, interviews with key informants and informal discussions with local people to create a deep, contextualised understanding of the issues. The ethnographic fieldwork period was between 2007 and 2009. The ethnographic methods and data analysis techniques are outlined in Chapter 2.

1.2. Chapter Breakdown.

Chapter 2 provides a brief history and description of Mount Isa, including recent demographic data. This is followed by a consideration of my place in this research and the ethnographic approach used to conduct it. Principles from Critical Medical Anthropology were applied in formation of the research questions, while the Mindful Bodies approach of Scheper-Hughes and Lock (1987) has informed my data analysis and the organisation of the thesis. Inherent in my theoretical frameworks is the desire to identify and conduct research that is locally valued and meaningful and that ultimately provides evidence for action to improve the health outcomes of those in the most need.

Chapter 3 begins with an exploration of the taxonomy of Penchansky and Thomas (1981), the 5As of Access. This taxonomy informs the analysis of data regarding access to health care services in Mount Isa. As Penchansky and Thomas (1981) discuss in their work, it is evident that the term

'access' has not been fully explored by many of those who seek to use it in discussions about health services. Those who do explore the issues often do so in a piecemeal way, having not thoroughly elucidated what this term actually means and the various aspects that define how access experiences are shaped and influenced. Therefore, I employ this taxonomy as a conceptual basis for unpacking notions of access barriers to local health services and to further refine my discussion of access issues in Mount Isa.

It is first necessary to review some examples of access barrier studies in international and Australian literature in order to demonstrate the value that a cross-disciplinary approach (Critical Medical Anthropology and Health Services Research) can bring to studies of access barriers and the expressions of health and illness in a rural setting among Aboriginal and Torres Strait Islander people. Experiences of exclusion or barriers in attempts to access health care appear very similar, especially across minority populations. This exploration of the health and medical literature concludes Chapter 3.

Chapter 4 provides a discussion of remoteness; in particular, issues of formal definitions of rurality and remoteness with regards to health care service provision and funding allocation. It also explores the idea of a 'rural' Australian culture, centred on a legendary vision of the pioneering frontiersman whose mystified characteristics may play a central role in how Australian nationalism functions. This chapter is designed to take readers from international and national discussions of the theories of access to the ideas that inform practice on the ground in rural and remote communities, and provides examples of how formal definitions can impact on the lives of those who live in such areas.

Chapter 5 addresses the first of the three Mindful Bodies: the individual body. This chapter contains three case studies, individual stories of illness experiences in the Australian biomedical health system. The first is the story of an Aboriginal man (Douglas) caring for his sick, elderly mother. This is followed by the story of an Aboriginal mother (Anna) whose frustrations with the public health system were crystallised through a number of personally problematic encounters.

The final story tells of a non-Indigenous man (James) and his journey through chronic back pain and private treatment. This chapter highlights how distance, rurality and culture play a major role in illness experiences in places like Mount Isa, and, that conflicts based around cultural differences are but one aspect of the frustrations that impact on the health and wellbeing of rural and remote Aboriginal peoples.

Chapter 6 begins an examination of the second of the Mindful Bodies: the social body. The focus of the chapter is a number of stories drawn from a fieldwork session with local Ambulance crews, which provide insight on the social realities of Mount Isa. The stories testify to Mount Isa as a contact zone. While variations among the stories exist, they are crosscut with illness and disease experiences, bringing otherwise divergent lives together. This chapter provides insight into the local social scene through deep description. The stories include the juxtaposition of an elderly, middle-class white woman suffering from dementia and an elderly, lower-class Aboriginal woman suffering respiratory problems. These two women are long-term residents of this town and experience connectedness to this place in similar, yet culturally distinct, ways. Their stories are followed by that of a middle-aged, working class white man suffering chest pain, who works hard and drinks even harder, and a young Aboriginal mother whose baby is finally being returned home after a long absence due to illness.

Chapter 7 begins discussion of the access barriers data in detail. The data are examined using the 5As of Access taxonomy as a conceptual framework for analysis and deeper understanding of access issues. In Mount Isa, many of the phenomena characterised as access barriers are quite obvious and well-known, but by utilising the 5As of access taxonomy, those barriers that are often obscured from view or a little more complex are highlighted, which provides for a more nuanced understanding of what many of the accessibility issues are in Mount Isa. In discussions of access with participants, issues of availability featured heavily, and were conceptually compartmentalised. Chapter 7 specifically addresses the availability of services in Mount Isa and outlines some of the roles and functions of the major players in the town and the region.

Chapter 8 addresses the four remaining categories in the taxonomy. Conceptually, these themes are more closely interrelated in the data, and thus create a story that sits alongside issues of availability. Considerations of accessibility include examination of the fact that medical treatment outside of Mount Isa is made more or less accessible by provisions such as the Queensland Health Patient Travel Subsidy Scheme. Affordability and the relativity of the term 'cost' are examined, alongside discussion of aspects of Accommodation and Acceptability among health services in Mount Isa, addressing issues of appointment systems, gender differentials and the difficulties in navigating a complex set of bureaucracies, only one of which is the health system. Some of the issues that fit under these labels appear to be culturally related. If people raised issues as being of impact at an operational or organisational level, they were included in Chapter 8. If they were specifically identified as a cultural barrier (either explicitly, or were discussed in ways synonymous with the ways 'cultural barrier' is used in the health literature), they are discussed in more detail in Chapter 9.

Chapter 9 discusses and analyses 'cultural barriers', and specifically highlights this concept as represented in formal interviews with Aboriginal people and health professionals in Mount Isa. This chapter incorporates data from the categories set forth by Penchansky and Thomas (1981), and refines the discussion of cultural barriers by breaking down issues into further categories. While all of the data identified could technically fit under a broad definition of what constitutes 'culture' it is important to recognise that many are in fact structural or social issues that need to be separately identified, understood and dealt with, differently to those that are defined as 'cultural' (in the layperson's sense). This chapter highlights the concern that many issues and barriers are being claimed or relegated to the cultural realm, when in fact that serves to hide the role and responsibilities of structures at the social and institutional level in the health of Aboriginal peoples.

Chapter 10 addresses the third of the Mindful bodies: the Body Politic. This chapter outlines a brief history of Aboriginal Affairs policy, and specifically examines two major Aboriginal health policy pieces at a National and State level. The language of these policies is examined, and in particular the rhetoric of cultural safety and awareness is illuminated, followed by a brief

discussion of the history of cultural awareness training. Through the work of Wright (1998), Torgerson (1986) and Garvin and Eyles (1997), this chapter touches on the ways that Aboriginality in Australia has become thoroughly politicised. This politicisation of Aboriginal identity has occurred through historical constructions of Aboriginal cultures and identities, and the full integration of the concept of 'cultural awareness' and its importance in health care. The thorough integration of these ideas into everyday parlance and conversation is significant, and can work in both positive and negative ways for Aboriginal peoples in Australia. This chapter also includes a case study examining the ways that agents of the state enact policy in practice, further politicising patients through 'lifestyle risk factor' interventions in health care settings.

Chapter 11 is the final chapter, drawing together the key findings and arguments. This chapter also identifies future research required for the northwest region that has emerged from this work. Ultimately this thesis illustrates the factors that influence health care service provision and access to those services in rural and remote areas, with a special focus on the impact on Aboriginal and Torres Strait Islander people.

Summary.

There is a need, especially obvious within the medical literature, to examine in further detail the ways that Aboriginal and Torres Strait Islander people regard biomedical health care, how people access these services and why they access these services. It is also crucial to understand the significance and meanings that Aboriginal and Torres Strait Islander people assign to experiences of barriers to or exclusion from health services, so that we might create biomedical health services that are more sensitive to, and able to deal with, the health needs and aspirations of Aboriginal and Torres Strait Islander patients. A potential theoretical framework to conduct such research is proposed here.

Critical Medical Anthropology, especially the 'Mindful Body' approach (Scheper-Hughes and Lock 1987), allows a nuanced understanding of the relationship between individuals, social and cultural groups and the health system as a whole, regarding the experiences of individuals as a

cornerstone in understanding the transmission and reinforcement of knowledge about health systems, while also providing a detailed account of the political economy of health systems. Combining such anthropological approaches with the 5As of Access taxonomy of Penchansky and Thomas (1981) provides a more pragmatic and broadly meaningful discussion of access barriers that may not be possible when considered independently.

In writing this thesis I have adopted a style that acknowledges that my audience is not only an anthropological one – part of my dedication to this topic was a determination to write a thesis that was accessible and meaningful to anthropologists, medical and health professionals and the community. While anthropology has provided theoretical principles that guided my work, it is my intention to make this thesis accessible to many audiences, unfamiliar with anthropological discourse.

Chapter 2

Background, Methods and Ethnographic approach.

The principles of Critical Medical Anthropology suggest that research should be conducted as needed, where needed and should ultimately provide evidence that forms a call to action. In this chapter I outline my approach to research and introduce Mount Isa as the ethnographic field. My approach throughout the study has been guided by the principle that my work should provide evidence of the need for greater access to health care services for the people of the Mount Isa region. The chapter has three sections. The first section provides some national, state and local demographic data, followed by a brief history and description of the Mount Isa region. The second section provides insight into my standpoint or my place in the research and the theoretical approaches that informed the development of the research questions. The third section details the methods used to collect and analyse data for this research.

2.1. Background.

According to the data collected at the 2006 Australian Census[2], Indigenous Australians account for over 455,000 of the approximately 19.8 million people in Australia (Australian Bureau of Statistics 2007b). Queensland is home to approximately 127,000 Aboriginal and Torres Strait Islander people, which is approximately 28% of the total Australian Indigenous population (ABS 2007b). The ABS projects that the Indigenous population of Queensland will be the fastest growing of all States and Territories in coming years, at a rate of between 2.6% to 2.7% per year to 2021 (ABS 2009).

The Indigenous population is much younger than the non-Indigenous population, and the most recent ABS estimates suggest that, at a national level, an Indigenous male born in 2005-2007

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[2] Conducted by the Australian Bureau of Statistics in 2006. This was the most recent data available at the time of writing, as the 2011 census data had not been released. However, current estimates as of December 2011 place the resident population of Australia at over 22 million (ABS 2011a).

could expect to live approximately 67 years, while his non-Indigenous counterpart can expect to live to about 79 years (ABS 2010). An Indigenous woman born in the same period can expect to live to about 73 years of age, while her non-Indigenous counterpart can expect to live to about 83 years old (ABS 2010). These statistics have attracted international attention for the gap in life expectancy, alongside poor infant birth weights, and increased morbidity throughout Australia's Aboriginal and Torres Strait Islander populations.

In 2008 the state-level life expectancies were consistent with national rates: an Indigenous male born in 2005-2007 in Queensland could expect to live approximately 68.3 years, while his non-Indigenous counterpart can expect to live to about 79 years (Queensland Health 2010, p.23). An Indigenous woman born in the same period in Queensland can expect to live to about 74 years of age, while her non-Indigenous counterpart can expect to live to about 84 years old (Queensland Health 2010, p.23). In a 2009 report, the median age at death[3] for Mount Isa Health Service District's Indigenous men and women (between the years 2002-2005) was 48 years old for both men and women (Queensland Health 2009, p.27). This was approximately twenty years lower than the median ages of death for non-Indigenous men and women both in the Mount Isa Health Service District and in Queensland overall (Queensland Health 2009, p.27). Table 1 provides a review of some demographic details about the Mount Isa population, and compares selected data from the most recent ABS census (2006) between Aboriginal and Torres Strait Islanders and non-Indigenous residents of Mount Isa.

The 2006 census reports Mount Isa's population at 19,663 people, and 3268 (16.6%) of the total population are Aboriginal and Torres Strait Islander Australians (ABS 2007a). The Aboriginal and Torres Strait Islander population is the largest of the minority groups in Mount Isa (ABS 2008). Approximately half of the Aboriginal and Torres Strait Islander population is aged less than 25 years. Post-secondary schooling education levels are low, and less than half of Aboriginal and

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[3] Median age at death: the age at which exactly half the deaths registered (or occurring) in a given time period were deaths of people above that age and half were deaths of people below that age. (AIHW 2007).

Torres Strait Islander peoples aged under 24 are registered as attending an educational institution (ABS 2008).

Table 1. Mount Isa demographic information summary

Topic	Aboriginal and Torres Strait Islanders	Non-Indigenous Australians
Population size	3268 consisting of: • 3052 Aboriginal; • 148 Aboriginal and Torres Strait Islander; • 68 Torres Strait Islander	16, 395
Average age of population	19 years	31 years
Median weekly income (individual)	$381	$742
Median weekly income (household)	$1133	$1585
Average household size	3.6 people per household	2.5 people per household
Average number of people per household per bedroom	1.4 people per bedroom	1.1 people per bedroom

Summarised from ABS (2008)

The top three industries of employment for Aboriginal and Torres Strait Islander peoples are the mining industry (156 people); health care and social services (97); and public administration and safety (87). Among Aboriginal and Torres Strait Islander peoples in Mount Isa, there are more women in the workforce than men. The earnings of these women tend to cluster around income brackets $150-599 per week, while employed men have a greater variance between brackets. Overall, the majority of Aboriginal and Torres Strait Islander peoples in Mount Isa tend to earn within the lower four income brackets (between $1-599 per week) (ABS 2008).

The average household size among Aboriginal and Torres Strait Islanders is slightly larger than other households. Ninety-five Aboriginal and Torres Strait Islander households reported that they owned property. Eighty-two of these households reported owning separate houses outright. However, the majority of households were renting separate houses from State Government (238 households) at $0 – 224 per week (which was a similar rate of rent for other households renting housing from government) (ABS 2008). Eleven households had ten or more people inhabiting a

three bedroom house. A further twenty-four households had between seven and nine people inhabiting a three bedroom house.

2.2. The field site: Mount Isa.

Mount Isa is a remote mining town in the north-west region of Queensland, Australia (refer Map 1, see Plate 2). It is over 1800 kilometres from Queensland's State Capital, Brisbane, and almost 900 kilometres from the nearest major regional city, Townsville (refer Map 1). In 2006, the resident population of Mount Isa was approximately 21 000 people, but more recent estimates place the population at closer to 22 000 people (ABS 2007a, ABS 2011b).

Mount Isa has played a crucial role in the economic history of Australia, and in particular in the economic and cultural development of Queensland. It is a major regional centre, has a sizable Aboriginal population and is the centre of a health services district that includes towns that are either discreet Aboriginal communities or have a large Aboriginal population. These towns include Burketown, Doomadgee, Normanton, Urandangi, and Dajarra (refer Map 1).

The hot semi-arid climate dictates the kind of scrubby vegetation in and around Mount Isa, settled among the picturesque Selwyn Ranges. The hills are vibrant red rock speckled with silver-green Spinifex grass; the hills look almost purple in the summer sunsets, when the bright blue sky turns orange and gold. The surrounding environs of the city are what are typically called 'the bush' in Australia, but typify both the bush and the nearby desert areas of the Northern Territory: red dirt hills and plains covered by native grasses, Gidyea trees and other native scrub.

Plate 2: Mount Isa Aerial Photo (Courtesy of Mount Isa City Council).

Mount Isa is a place of extremes in weather. Instead of the traditional four seasons of summer, autumn, winter and spring, Mount Isa has two seasons, anecdotally called the wet season and the dry season. The wet season occurs over the summer months, from November to March, characterised by high rainfall in a short time, often to the point of flooding, high temperatures, and hot winds. Temperatures range from the low 20°Cs to the high 30°Cs and sometimes exceed 40°C.

The dry season occurs from June to August, when the temperatures drop, averaging from around 12°C overnight to maximum temperatures in the mid-20°Cs, but the lowest recorded overnight temperature is 2.9°C. There is very little rainfall at this time. The months of April and May are a transition from summer to winter; the scorching heat of the sun turns to a softer heat, and finally into the cold winter winds.

A search through the few specific history books available on Mount Isa (see Blainey 1970, Kirkman 1998) leave little doubt of the important part Mount Isa has played in the economic history of Australia in the past century. The town was established on the basis of mining – in 1923, John Campbell Miles discovered an outcrop rich in lead, and began the process of prospecting one of the richest lead deposits in Australia (Kirkman 1998). By 1924, Mount Isa Mines Ltd. was established as a company and rapidly became one of Australia's largest mining companies. The town slowly built up around the mining pursuits, and became a major centre for surrounding pastoral districts. Commercial endeavours began as the town itself settled at the very base of the mine, mere meters from its perimeter (Kirkman 1998, pp.4-24).

Xstrata Plc, a Swiss based mining group currently has 100 percent control of the Mount Isa Mines holding. Xstrata took control over the Mount Isa Mines lease in 2003, after a takeover of MIM Holdings Ltd[4](Xstrata Copper 2011). The Xstrata Company is split into groups according to the

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[4] As part of this acquisition, Xstrata also took control over the McArthur River Mining project in the Northern Territory, a site which was surrounded by controversy when in 2005, the Northern Territory and Federal Governments approved mining activity conversion from underground to Open Cut mining of copper, lead and zinc, which would see the diversion of a 5.5km section of the McArthur River. As popularly reported, this activity was legally challenged (and won) by the

kinds of commodity they produce: this includes Xstrata Copper, Xstrata Zinc, Xstrata Alloys, Xstrata Coal, Xstrata Nickel and an Xstrata Technology services arm (Xstrata 2011). Xstrata Zinc and Xstrata Copper are the two groups present in Mount Isa, with a production focus on zinc-lead-silver, and copper. There are copper and zinc processing facilities on site (and a copper refinery and export port located in Townsville – see map 1). The Mount Isa mines site employs a combined total of over 4500 employees and contractors, and many more Mount Isa residents are employed in related support industries, making mining the largest employment industry in the region.

The presence of the mine in Mount Isa is palpable and heavy, as it impacts on all of the human senses. One sees the mine - it is a looming, constant and orienting landmark; indeed, many people who visit the town know that as long as they can see the iconic candy-striped copper smelter chimney stack, they will be able to find their way around the town. It is audible and felt – every morning at 7.55am and every night at 7.55pm, there is a shudder that runs under the town, coming from the underground charges blasting new cavities for exploration and production. People living in the town take great amusement in watching the shocked faces of tourists and newcomers experiencing their first blast, following up their stifled giggles with the time: "It must be five to eight, no need to wear a watch in this town". The mine is smelt and tasted – as despite all efforts to control it, the sulphur dioxide fumes from the acid plant occasionally float on the breezes across the city. It has a gritty, dirty elegance to it, with cruel twisted steel illuminated by safety stripes and the reflective tape on the workers' uniforms by day, and home to a golden luminescence at night, a spectacle of light, shadow and relentless productivity. The mine is embodied, even for those who do not work within its boundaries - increased efforts are required to reduce dust in homes all around the city. This is especially important for pregnant women and those with young children. Significant exposure to lead can damage developing brain and nervous

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Northern Land Council on behalf of local Aboriginal peoples, but the Northern Territory Government rushed through retrospective legislation which allowed the court ruling to be overturned. The McArthur River Mine was said by Xstrata to contribute approximately $350 million to the Northern Territory economy each year. These are significant businesses that contribute heavily to state economies (Xstrata Zinc 2005).

systems in unborn and young children, and has been linked to significant learning and behavioural problems in children (Canfield et al. 2003, Lanphear et al. 1998, Needleman et al. 1978).

There have been legal proceedings launched against Xstrata by a small number of residents whose children have experienced exceedingly high blood lead levels, (Xstrata MIM 2010; also popularly reported by the Australian newspaper for example, McKenna 2010). One of the outcomes of this was the establishment in 2008 of a local group, the 'Living with Lead Alliance' which is constituted by Xstrata Mount Isa Mines, the Mount Isa City Council, Queensland Health, Queensland Department of Environment and Resource Management and other organisations, and whose primary purpose is to educate the community on ways to reduce their exposure to lead in the home and around the town. This includes advice on diet, home maintenance and hygiene.

The mine is a focal point in the lives of many residents. There are many here who have come to make their fortunes, riding the wave of Australia's mineral resource boom, and as a result the town was somewhat sheltered from the effects of the Global Economic Crisis of 2008-9, even recording economic growth through the period (Mount Isa Chamber of Commerce 2011). The mine and the companies who control it have an intimate place in the community, and Xstrata are particularly renowned for their community engagement and support efforts. Their engagement with local Aboriginal groups, and especially their interactions with the Kalkadoon (traditional owners of the Mount Isa region) appear to be well-established. Certainly, in joint media releases, the relationship seems strong and all parties are interested in further development of the relationship (Xstrata MIM, Kalkadoon Community Pty Ltd, 2009a; 2009b). Xstrata, in their 2009 Sustainability report, state that they provided the Kalkadoon Community Pty Ltd the use of an Xstrata owned property for the community group to run its administrative and cultural heritage and economic development arm (Xstrata MIM 2009). In July 2010, Xstrata was fined $80,000 "in respect to inadvertent damage to cultural heritage objects while a contractor worked to upgrade a road in Mount Isa in 2008...We take the issue of protecting Aboriginal cultural heritage very seriously and deeply regret this incident" (Xstrata MIM 2010). The company does provide employment to Indigenous youth from the region through a number of cadetship programs.

However, while Xstrata have an established role for a dedicated Indigenous Community Liaison Officer, the role has seemed to suffer from a fairly consistent turnover of staff.

The relationship between the mines and local Aboriginal people is somewhat reflective of the relations between Aboriginal people and the rest of the Mount Isa population at large. While there is a strong respect emphasised publically, and there is an accepted civility evident in most encounters between white and black, there are still signs of a latent fear and/or open repugnance among some non-Indigenous residents regarding Aboriginal alterity (Povinelli 2002), especially true in the face of radical cultural difference (Povinelli 2002, Lea 2005, Kowal and Paradies 2003, Kowal 2006). These relations appear to manifest in similar ways to other outback towns (see Cowlishaw 1988, 1993, 1999, 2004 for excellent examples). They feature vocal public disapproval of racist language used in sporting matches, socially unacceptable behaviours perpetrated against Aboriginal people, or as openly hostile racially motivated attacks on the most vulnerable among the local Aboriginal population, the riverbed dwellers (paintball guns were fired from cars that were chasing down riverbed inhabitants in late 2008). They also manifest as the violent acts of Aboriginal others, 'rioting' in the streets, or the assertion of the desperation of many Aboriginal residents by those in social services or welfare services

Mount Isa sits in the heart of traditional Kalkadoon (Kalkatungu; Galgatungu)[5] country (see Plate 3). The Kalkadoon had extensive trade networks across the region with their neighbours including Pitta Pitta, Waluwarra, and Waanyi[6].

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[5] As with many early written records of Aboriginal cultures in Australia, there are various spellings and pronunciations offered for 'Kalkadoon', including these.

[6] For a visual representation of language group neighbours, see AIATSIS map created by David Horton 1996.

Plate 3 Kalkadoon Country sign next to the road into Mount Isa (Photo: Kristin McBain-Rigg).

Their sovereignty in the region was challenged with the settlement of the north-west by pioneers and ex-convicts coming north to find a new life away from the penal settlements of Sydney and the south. There were major skirmishes recorded between the Kalkadoon and settlers, the most popularly reported being at Battle Mountain, which depending on the source, either decimated or completely eliminated all Kalkadoon peoples (Armstrong 1980). This statement of elimination has made the struggle for recognition and ownership of the lands of Mount Isa and surrounds quite difficult for the Kalkadoon, many of whom have been the target of characterisations such as 'the last of their tribe' (Furniss 2001). However, on the 12th December 2011, the Kalkadoon people were granted Native Title over 39 000 square kilometres of claim area which included Mount Isa.

In contemporary times, Aboriginal people from all over Australia (especially from the Gulf of Carpentaria in Queensland and the Northern Territory, along with a small community of Torres Strait Islanders) live in Mount Isa. Traditionally, ethnographic descriptions of Aboriginal peoples of Australia have isolated a single tribal or language group, describing their social institutions and stories in depth. However, Mount Isa (along with many other places in Australia) is not home to one tribal group, but many, interacting and changing over time. Thus, the representations in this work do not concentrate solely on the experiences of the Kalkadoon people, but encompasses stories from individuals of other Aboriginal language groups.

The socioeconomic status of individuals within the local Aboriginal and Torres Strait Islander population is incredibly varied. Hence, it is crucial to capture and discuss this heterogeneity in an attempt to more fully represent the diversity of the Aboriginal population in Mount Isa. Aspects of the socioeconomic status of the Aboriginal and Torres Strait Islander population are explored further in Chapter 7.

The strength of Aboriginal identities in the town could be linked to the strength of family connections in the town and region, as much as in sheer numbers; the Aboriginal and Torres Strait Islander population constitutes approximately 17% of the total population of Mount Isa. This strong assertion of Aboriginal identity has influenced many valuable services and initiatives being established and sustained in Mount Isa, aimed at improving the lot of Aboriginal people throughout the town and the region.

2.2.2. Reflections on the choice of field site.

Mount Isa is my home, and has been since September 2005. After I had finished my undergraduate degree at James Cook University, I applied for a position in the research unit at the Mount Isa Centre for Rural and Remote Health (MICRRH). The Mount Isa Centre for Rural and Remote Health is funded by the Commonwealth Department of Health and Ageing and is a University Department of Rural Health (UDRH) affiliated with James Cook University. I was attracted to the position for a number of reasons: I had just graduated from university with an honours degree in anthropology, with a special interest in, and an honours thesis about, Indigenous health status in Australia. The programs that the MICRRH Research Unit was involved in appealed to me, as they focused on social health research. It was an opportunity to begin specialising in medical anthropology, in a medical school. As it turns out, the Director of the Centre had always wanted an anthropologist, and so I was given a chance.

It was not until I moved to Mount Isa that the enormity of health issues in the bush[7] became a real part of my life. Living on the coast, even in northern Queensland, creates a kind of myopia: it is possible to be aware of and sympathetic to the issues raised by rural people, but it is not until one spends some time in a rural or remote area that the reality of the situation becomes clear. One becomes a part of it – sitting in crowded waiting rooms to see medical professionals that are stretched to their limits, hearing about people who have been sent away to Townsville or Brisbane for treatments that one would believe should be provided in a major (albeit regional) city. Injury and death seems all the more intimate here. So often I know those people who are injured (or worse) during times of extreme risk-taking behaviour or people injured just doing their job. I often read about cars that veer off the road because drivers are tired trying to get from grazing properties (often called 'stations') or from one town to another to access treatment. The close social networks that create this community mean that rural residents are all touched by these experiences, often with very few steps between the injured and ourselves. They are our families, our neighbours, or our workmates; very rarely are they strangers.

2.2.2.1: Researcher's standpoint.

I strive to be non-dualist (Evens 2009), and anti-positivist (Bourdieu 2003) in my interpretation of the data and adopt a phenomenological (Merleau-Ponty 2008) approach in my research. This translates as a set of values and beliefs based on the ideas that the distinction between subject and object is ambiguous and imperfect (Evens 2009) and such that subject and object are only distinct from each other in a relative way, social reality is constructed in the names, labels and concepts that are used to structure reality and that all that exists are particular objects, that the knower and known are interdependent and that social science is subjective (Bourdieu 2003, Evens 2009), the social world can only be known by occupying the frame of reference of the participant

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[7] Bush – an Australian English slang term used to designate rural and remote areas distant from cities, usually characterised by sparse populations and (seemingly) natural environs. Also related, is the term 'outback'.

in the action (Merleau-Ponty 2008), and that values mediate and shape what is understood, but can be suspended for the purposes of deeper understanding and reflection (Merleau-Ponty 2008).

I was born and raised in Townsville, North Queensland and had extensive family networks that spread throughout the North West region. At university, I found anthropology in my first semester and never looked back. Anthropology explained my world to me, fed back my familiar experiences in ways that made sense, and showed me the infinite possibilities of the human condition. I found comfort in kinship structures that exposed the importance of connection, and was stunned by the diversity present among humans all around the world. History became more real, and the impacts of historical actions started to make more sense, moving beyond chronology of significant events to the everyday conditions of those affected by war, conflict and peace.

I became increasingly interested in medical anthropology and the study of various traditions of healing and illness experiences around the world. In particular, I was interested in understanding the plight of Aboriginal and Torres Strait Islander peoples of Australia, and to examine the differences in experience that were purported to cause such dramatic differentials in health status within my own country. I was intensely interested in the ways that contemporary national debates and discourses related to my own experiences and the experiences of my Aboriginal and Torres Strait Islander friends, especially such issues as native title, in particular the Mabo case (which was well documented and followed in Townsville) and the Wik plan[8],the 'Stolen Generations' report (Commonwealth of Australia 1997) and the Royal Commission into deaths in custody (Johnston 1991), calls for reconciliation and the establishment of a National Sorry day. It could be said that I reflected (and perhaps still do) an affect fairly typical of middle-class, young, idealistic, white Australians, a predilection toward a liberal multicultural politics, or as Povinelli (2002, pp.4-5)) describes it, a 'moral sensibility, of the social fact of the feeling of *being obliged*, of finding oneself under an obligation to some thing – or to a complex of things" (original emphasis reproduced).

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[8] For discussions of the Mabo case and its impact on Australian race relations politics, see Sanders (ed.) 1994.

This is an ongoing internal debate that I have with myself, and also one which I have been allowed to explore through my academic and employment journeys.

The next critical step in my epistemological journey was the move to Mount Isa and my employment at MICRRH. I have been allowed and encouraged to explore these issues, in a health education context, and to share the knowledge and experiences I have with health science students. Additionally, my time at MICRRH exposed me to the everyday world of research, particularly engaging my skills in qualitative research, co-opting them in projects that were often based on an interesting mix of qualitative research, evaluation methods and health service research principles. I have been influenced and inspired by the projects that brought me to this place and that kept me interested for over seven years. These projects included a major rural and remote road safety project (Sheehan et al. 2008), the evaluation of a community organisations partnership[9] to enhance the journey of Aboriginal people suffering from alcohol abuse (AERF 2006), development of an Indigenous Australian Cultural Awareness training package for the Australian College of Rural and Remote Medicine, the adaptation of the Lifescripts brief intervention tool for use with Indigenous Australians (DoHA 2008), subsequent development of training resources regarding Lifescripts package for General Practitioners and health staff, The Research Capacity Building Initiative component of the Primary Health Care Research Evaluation and Development program (funded by the Department of Health and Ageing from 2005 to 2011) and many other small evaluation and research projects along the way.

I was also strongly influenced by the 'growing up' (both professionally and personally) performed by my Aboriginal colleagues, most notably from Dr Louis Peachey, Shaun Solomon and Catrina Felton-Busch. These were the people that vouched for me, and found a degree of synergy between the beliefs and values that I held and their own. They would often claim me as being

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[9] The partners were all organisations working to protect Aboriginal people who were suffering from the effects of alcohol abuse, homelessness and were considered to be at increased risk of imprisonment for drunken behaviours. These organisations were: The Kalkadoon Tribal Council Night Patrol, the Arthur Petersen Special Care Centre (diversionary centre), Jimalaya Topsy Harry Centre (temporary accommodation and dry-out centre) and the Kalkadoon Aboriginal Sobriety House (alcohol rehabilitation).

'black where it counts' (i.e. in my beliefs and ways of understanding the world), seeking to minimise the interfering effect that being a young, white, female anthropologist could have in an Aboriginal health context. As a white anti-racist (Kowal 2006, 2011), I worked well with my Aboriginal colleagues, but according to them, what set me apart was my ability to deal with radically different Aboriginal people, and a sense that my privilege was truly earned through personal (yet intensely public) struggle. That I could relate to those who struggled was due to the kind of interrupted upbringing I had experienced, an upbringing that was different to other white, working-middle-class people. I trust them in their assessments of this, but am not sure if I entirely agree.

This doctoral project was developed out of a sense of obligation to the community of Mount Isa. There was a paucity of qualitative research and other data being collected in Mount Isa on health (with some notable works e.g. Kelaher et al. 2001a, Kelaher et al. 2001b, Kelaher et al. 2003, earlier in the decade). The community had welcomed me, and provided me with significant opportunities in my early career, and I felt it only right to repay that by contributing my skills in research on a long-term project (3 or 4 years is a long time in current funding environments) that could have tangible benefits for the Mount Isa community long after I was gone.

When I arrived in Mount Isa, it became increasingly obvious that the health of local Aboriginal people was an issue of significant concern for health professionals. However, I was surprised by the attitudes and misinformation about these access issues. Many non-Indigenous health professionals helpfully informed me that there are no barriers to accessing services and that service providers cannot do any more than they currently do; that Aboriginal people need to take responsibility for their own health.

It seemed that every work meeting I attended included discussions of Aboriginal health status. Often this was through discussion of various programs and initiatives designed to increase 'uptake' of health services by Aboriginal people. Frequently, there were discussions of the frustration at the apparently 'constant non-compliance' of Aboriginal patients. Health professionals would blame

'cultural barriers' as the source of misunderstanding and non-compliance, but rarely did they try to explain what they meant by this. These early anecdotal complaints would range from Aboriginal people not turning up for appointments, to not taking their medications on time (if at all), to language differences, patients being non-responsive, patients not speaking for themselves, or patients being belligerent and rude to health professionals.

The role of the Aboriginal Health Worker has been introduced in many health care settings around the region. One of the primary aims of this role is to reduce the complications in health care interactions and to make Aboriginal people feel more comfortable in health care settings. In Mount Isa, Aboriginal Health Workers are frequently and heavily relied upon by non-Indigenous health professionals, to act as mediator and interpreter in any interaction with Aboriginal patients. This reliance often led to fatigue or complete burn-out of Aboriginal Health Workers throughout the region.

Overwhelmingly though, local Aboriginal and Torres Strait Islander people and health professionals I talked with during my early employment all agreed that there were some definite issues that prevented Aboriginal people from accessing health care in Mount Isa. It was suggested to me that the most obvious issues were a lack of transportation and money. However, as I was soon to discover things were a lot more extensive than that and I became inspired to do more research into access issues in health care systems. I was awarded an opportunity to take up a Research Development Program grant with MICRRH which allowed me to do a small start-up project. I conducted a literature review of national and international medical journals, seeking information on access barriers to health care. The results of this search informed the basis of my enquiries for this project. A selection of the literature identified in the search is included in Chapter 3.

2.3. Ethnographic Approach.

This thesis is an interpretive phenomenological ethnography. Interpretive phenomenology sets out to explore detailed understandings of individual life experiences and the meanings that individuals

attach to these experiences (Benner 1985, Eatough and Smith 2008, Merleau-Ponty 2008), while ethnography is the study and description of the everyday lives of people, the meanings of which are primarily constructed as cultural (Seymour-Smith 1986). In health services research, ethnography does not hold the kind of epistemological primacy as it does in anthropology but is subject to far more pragmatic considerations as a research choice. Ethnography, as a method in health services research, is one of many research methods used to deeply explore an issue to find answers (Sobo 2009).

In this project, interpretive phenomenological ethnography is an approach that lends itself to understanding the individual lived experiences of health care access (or access barriers), from the perspectives of various individuals, from various social and cultural groups, including Aboriginal and Torres Strait Islander peoples, health professionals and residents of rural and remote areas of Australia. It was possible to provide local contextual meaning to enrich the stories of individual experiences by exploring the meanings given to the phenomenon of health care access, using phenomenological techniques in combination with ethnographic methods and considerations. This combination of interpretive phenomenology and ethnography has been used successfully in other exploratory health research projects (Maggs-Rapport 2000, Norris et al. 2010, Norris et al. 2011).

Therefore, this thesis does not represent a traditional ethnography, but rather presents what might more accurately be called an 'ethnographic narrative'. I adopt both anthropological and population health theoretical approaches to understanding my data. While my methods could be primarily characterised as ethnographic, these same methods are now quite popular (and often adopted) in health research circles. I specifically chose to intimately entangle these two disciplines, as I believe that this creates a space to converse in mutually meaningful ways about the relationships between culture and health.

Theoretical sensitivity to this topic was heightened due to my long-term immersion in the community of Mount Isa, and in particular through my experiences as an anthropologist working in health research. In a sense, I performed my research "at home" (Messerschmidt 1982, Jackson

1987, Peirano 1998, Morton 1999) – not literally in my house, but within the community that I called home from 2005 onward. This is not an unusual experience, and serves a number of purposes. Not only does this approach create a link between local and global realities in health care, it also forces the researcher to critically interrogate their own reality, everyday. It is quite easy to be seduced into thinking that one truly knows the situation one is in, but by critically examining the everyday assumptions that creep into familiar places and faces, it is possible to uncover a more detailed experience of our 'webs of significance' (Geertz 1973, p.5).

I employ the term 'community' in this thesis in a number of ways. In Mount Isa, it is impossible to define the community without reference to our physical surroundings – Mount Isans truly are a group of people who are bound by a discrete, shared physical reality (being so physically isolated from other towns and communities). Many people experience this bounded reality, talking about 'getting out' or 'escaping' to other places. However, within the Mount Isa community are a number of other 'communities' bound by other relations – by kinship, by occupation, by shared experiences.

My place within the community was established around the fact that I worked at the Mount Isa Centre for Rural and Remote Health (MICRRH). Many of my initial contacts and informants were met through work meetings, and many community members recognised me from my work at MICRRH. Living and working in the field site prior to starting the PhD, as well as participation on community boards, and going to many health and anthropology conferences means that my reputation as a researcher and community member were intimately tied to one another. This did create some boundaries with regards to the ways that informants engaged with me. I tried to create solid trusting relationships with all the research participants in my project, and am told that I have become known around town as someone who 'tells it like it is', leading people to feel comfortable with me, and able to discuss issues in an open, straight-forward, but protected manner.

Participant observation is often considered synonymous with ethnography; this practice was developed by Malinowski as a response to the often piecemeal use of anthropological data early in the discipline's development. It is defined by extended periods of fieldwork where the researcher aims for immersion in the everyday lives of the people being studied, minimising the interfering effect of his or her presence (Seymour-Smith, 1986, p.215). This should permit a full appreciation of the cultural meanings and the social structure of the group with all its functional interrelations between customs and beliefs, which at first sight appear inexplicable and incoherent. This method is suited to studying small, relatively stable human populations and continues to be the foundation of anthropological research (Seymour-Smith, 1986, pp.215-216). The observations that are the outcome of this work are often recorded in fieldwork diaries, and include the details of informal discussions, details of participation in community events and observations about community life.

There are some obvious limitations with this kind of research approach, including whether it is possible for a loitering, unfamiliar person to 'minimise the interfering effects' (Seymour-Smith, 1986) of merely being there, and whether those being observed may alter their practices or opinions to normalise the situation and present the researcher with a sanitised or regulated view of the everyday experience of life. In the case of this study, too, traditional participant observation that is normalised by anthropologists (i.e. living in the home of an Aboriginal family in order to truly live the experiences of an Aboriginal household) was not possible nor ideal, as I had my own home in Mount Isa and did not wish to impose upon the lives of others in such an intense way, given that I was seeking a specific set of experiences (that of health care accessibility). This could be seen as a limitation to my work. Although I did not live in the homes of my Aboriginal participants, I did spend many hours of the day with them, either working or in social relations. I cared for children, I helped with errands and transport, I performed favours and asked for favours in return. I celebrated, I mourned and I talked with Aboriginal people, but also with health practitioners. These two worlds would often merge and create a reality which was very much lived, and every day. It immersed me fully – this was my social world. And, as a woman who

became pregnant during the course of fieldwork and life in a remote Australian community, I also experienced the phenomenon under examination in this thesis.

Interviews with key informants are an important ethnographic research technique. In-depth interviews are pivotal in phenomenological studies, as they permit a general insight into the descriptions that people give to their experiences and perceptions of a particular phenomenon. Opportunities to discuss general observed behaviours and information with informants who are deemed representative of the community[10] or in some way knowledgeable about these practices informs the ways that anthropologists make sense of their data (Geertz 1973, Seymour-Smith 1986). It is important to confirm the formal rules of a group and the opportunities for breaking or bending these rules in everyday practice.

Semi-structured interviews allow for the free flow and exchange of information in ways that value the narrative style of the informant. This means that the informant can include information or discussions that they consider important, and are not necessarily bound only to the questions of the researcher. In this study, those who became key informants included 'elders'[11] of the Aboriginal community (see footnote) and who speak from a position of authority. Beyond elders, many knowledgeable others within the Aboriginal community shared their personal stories and opinions, but who would never seek to speak on behalf of the community as a whole. This was accompanied by discussions with people within the larger Mount Isa community and especially

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[10] This is usually defined by a process of observation of community interactions and discussions with many community members. This is one of the advantages of performing immersive participant observation activitiy, as it is through living in a community that the significance of social relationships and the tensions present between social actors that anthropologists must take account of in recording the social realities of a community.

[11] Elders within many Aboriginal communities are usually the oldest surviving generation of Aboriginal people in a community, that are the holders of information about their tribal/language group, including understandings of kinship and local history, and the political realities of the local scene. Elders are looked to for advice and guidance on cultural and social matters, both within the Aboriginal community, and by others outside of the Aboriginal community. Elders usually have the inherent right to speak authoritatively on behalf of those they represent (Aboriginal people of their tribal/language group).

with intimate outsiders (in this case health professionals who had extensive experience of providing health care in rural areas and with Aboriginal and Torres Strait Islander people).

To add to this, I would consider the key informants whose stories appear frequently throughout this thesis, to have been the "good ethnographers" (Mol 2002, pp.15-20) among all of my informants. These informants discussed issues articulately, deeply reflecting on their experiences and the experiences of others. Like Young (1982) I did not interview or discuss illness and disease with patients in waiting rooms and hospital beds, due to the differences that these experiences bring to rational and reflective thought. However, I chose to discuss such events with people outside of those settings, so as to give them the space to reflect upon and recount the events of their illness or the illness experiences of those for whom they cared. By situating these discussions in settings which were closer to their preferred and potentially more 'real' lives, there was room for interviewee reflection and for this reflection to be more critical. Thus, these became discourses based in the reality of situations, revealed through events, but not subject to the prying eyes of practice or care regimes, or the effects of feeling unwell.

It seemed that these key informants also often represented a unity within their disciplines in the case of health professionals. For example, the aboriginal health workers who feature in the thesis express views which align strongly with other aboriginal health workers that I spent time with, and it appears that consensus has been reached among this group with regard to issues of access and cultural constraints. The same occurred among ambulance officers, nurses, medical practitioners, and other practitioners, who seemed to create their own disciplinary unity through language and discourse that they revealed in conversations. This unity is most likely an illusion, given the idiosyncrasies of each interviewee. However, these views were being repeated, frequently, in conversations. Mol (2002) discusses the unity that has been represented in medical sociology and medical anthropology as the 'western medicine' phenomena (here described as 'biomedicine' as is conventional in Critical Medical Anthropology). However, Mol (2002) discovered that this unity was further broken down into sub-unities. According to Mol (2002), each discipline that made up the biomedical whole had their own approaches and perspectives on the reality of illness and disease

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processes. Each discipline also exhibited commentary of the social realities that impacted upon those processes (Mol 2002).

Personal contact was made with potential interviewees face-to-face, to request their participation and explain the study. HREC approved consent forms and information sheets (written in plain English) were made available to participants. Verbal consent was also used where necessary on a number of interview tapes. For an overview of questions used to create discussion in these formal interviews (see Appendix A).

In all, fifteen formal key informant interviews, including one group interview with five participants, were conducted between 2007 and 2009 (averaging two and a half hours each). While this is a small number of key informant interviews it encompassed a range of people with various perspectives. There were nine men and ten women, ranging in age from 30 to 62 years. Eight of these key informants were Aboriginal and Torres Strait Islander peoples. They were from a range of occupations including general practitioners, health service managers, paramedics, emergency nurses, senior aboriginal health workers, administrative and government workers, academics, and community board members.

There were many other informal interviews and conversations, with Kalkadoon and other Aboriginal elders (both men and women) and their families, with young Aboriginal women[12] at the local women's group. Further to this, I spoke with Church leaders and church workers at the Catholic parish, with board members, managers and staff of the Aboriginal Medical Service and other local services (specifically the Arthur Petersen Special Care Centre), with colleagues at MICRRH, with aboriginal health workers from North and West Queensland Primary Health Care and from Community Health at Queensland Health, allied health staff from NWQPHC and Queensland Health. I also conversed with project officers at the local Indigenous Co-ordinating Centre, members of the board from Kalkadoon Community Pty. Ltd., police officers, fire and rescue

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[12] Ranging in age from 17 to 45, and the two elders that organised the sessions (a Torres Strait Islander woman and local Aboriginal woman) and church elders, as well as other prominent elder women from the local region and a local senior AHW at NWQPHC.

workers, and community members at large. While informal conversations were recorded in fieldwork diaries, transcripts of the formal interviews were offered to participants to ensure they were accurate. To date, none of the interviewees have requested to keep copies of the transcripts[13]. Further to this, observation and time spent with key informants acted as another form of follow-up, and as a triangulation method for much of the interview data.

The interviews with key participants were developed in accordance with the values of Dadirri-style semi-structured interviews. The Dadirri style of interviewing was named and developed by Ungunmerr[14] (Miriam Rose Baumann), and further by Atkinson (2002), as a culturally safe way of researching, but more importantly, as a way of life. Atkinson (2002, pp.16-17) discusses the principles and functions of dadirri as:

> A knowledge and consideration of community and the diversity and unique nature that each individual brings to community; ways of relating and acting within community; a non-intrusive observation or quietly aware watching; a deep listening and hearing with more than the ears; a reflective non-judgemental consideration of what is being seen and heard; and, having learnt from the listening, a purposeful plan to act, with actions informed by learning, wisdom, and the informed responsibility that comes with knowledge....dadirri is not a research methodology in the Western scientific tradition, but a way of life. It gathers information in quiet observation and deep listening, builds knowledge through awareness and contemplation or reflection, which informs action.

Another set of data is that of the case studies provided in Chapter 5. These case studies were chosen from interviews with informants as pertinent and demonstrative of the many issues this thesis addresses. Case studies are an important aspect of the Critical Medical Anthropology theoretical approach (specifically the 'Mindful Bodies' approach as discussed in the following section of this chapter). Case studies are critical to the approach, as they provide the opportunity to hear individual stories of illness and suffering in the medical system, and with careful analysis demonstrate the impact on individual lives of macro-level (social and political) influences and institutions, and vice versa. It is also considered critical to complete understandings of health

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[13] Therefore, confidentiality has not been breached in any way as all data resides with the author.

[14] Ungunmerr is the Aboriginal name of Miriam Rose Baumann, a Ngangikurungkurr woman. Ungunmerr was born in a small community (Nauiyu) on the Daly River, Northern Territory.

phenomena, as the power of narratives often lies in the language people use to capture the emotional experience of health care.

Data collection was accompanied by ongoing analysis and write up of the data during the fieldwork period. This was due largely to the fact that I was solely responsible for collection of all data, diary records and transcription of interviews. This allowed me to confirm that my interview questions were working, and allowed me to develop a series of memos about the themes that were emerging from all of my data sources. The construction of philosophical arguments was concurrent with the data collection and analysis, and some of my initial results and arguments have been presented at conferences in both the health and anthropology sectors (see Appendix A for details). This provided many opportunities for me to discuss my work including my initial findings and analyses with knowledgeable and expert others in both anthropological and health science disciplines.

Data reduction began in earnest in May 2009, with the creation of the initial formal analysis of data. Manual, open coding was used initially to identify major (and most obvious) themes across the data. This was done by identifying statements that related to access barriers across fieldwork notes, interview transcripts and local media, health and historical documentation. In the initial analysis, it became evident that the framework of Penchansky and Thomas (1981) (as outlined in detail in Chapter 3) provided definitions consistent with some of the phenomena present in observational, informal and formal interview data. However, 'cultural barriers' identified in my data required further elucidation. Additional categories were identified to assist with the analysis of cultural difference. These are presented in Chapter 9.

The data collected are people's perceptions, stories, beliefs, values, opinions and experiences – there are no 'confounding factors' in life stories, or indeed in illness narratives. Triangulation was performed, by utilising data from direct and indirect observations, key informant interviews and literature including local media coverage of events and phenomena. Alternative interpretations of the data have been sought from knowledgeable others, including cultural mentors, supervisors,

and colleagues within health research and in various other fields. In keeping with the phenomenological tradition, the final result is a composite of health access phenomena. The focus is on providing a general description of the typical experiences of Mount Isa residents (especially Aboriginal and Torres Strait Islander peoples) when it comes to accessing health care.

I have drawn on a variety of data throughout this thesis, but have chosen to privilege the words of participants over other data. The words of participants are solid evidence about phenomena, while observations and other materials are often subject to interpretation and context. Thus, these other data have been used to assist data triangulation. Statements made within many interviews captured the essence of other data, reflecting deeply the events of everyday life that I experienced with others, the everyday attitudes and beliefs evident in informal conversations and observations. These interviews also reflected the ways that the community (in its varying iterations) made sense of issues regarding health care accessibility in social expressions (either through meetings, local press and media, artwork, rallies, violence, programs/interventions and funding applications).

There were times when these methodological approaches clashed with ethical considerations, usually preventing timely research outcomes. There were times when it was inappropriate to conduct such work with Aboriginal families, such as in times of mourning (which occurred frequently), or more often, because people didn't want to commit to a formal interview. Most people were happy to talk with me, often many times over, about these issues, but did not want to be on a tape recorder, or be presenting grand statements about 'their mob', preferring to talk only about themselves or their families' experiences and understandings. Therefore, there are fieldwork notes about such conversations, which have been integrated into the findings, but which were not used for direct quotes. This is important in an interpretive phenomenological approach, and is ethically responsible, especially in research with populations who may be considered vulnerable, due to historical oppression and ongoing power differentials associated with various socio-economic indicators. While I am unsure that many of the participants in my study considered themselves as 'vulnerable', they were structurally defined in this way, and thus it was

my duty as a researcher to be aware of this classification and act accordingly, so as not take advantage of the participants, nor misrepresent them.

2.4. Theoretical perspectives: Critical Medical Anthropology.

Critical Medical Anthropology (CMA) emerged as a distinct theoretical perspective in the 1980s, from a Marxist, political economy of health perspective on experiences of health and illness (Singer and Baer 1995). This approach challenged established theories and approaches in medical anthropology, largely seen from within the discipline as a practical and applied science. Traditionally, medical anthropologists were involved in research concerning pre-industrial societies, documenting cultural explanations of health and illness. They also worked on international aid programs, public health and population health research, promotion, and program development. These early approaches to issues of health and illness often saw the anthropologist shy away from direct work on disease. Instead, they focused on illness categories, as the patient's experiences and narratives of illness episodes were often considered to be more appropriate domains of the social scientist, whereas disease was for the health professionals (Singer and Baer 1995).

Medical Anthropologists provided a bridge between cultures with different concepts of the body, health and illness, finding ways to articulate biomedical procedures and treatments with ethnomedical systems. Critical Medical Anthropology challenged the very foundations of biomedical thought and practices, instead focusing on the links between the individual micro-level experiences of health and illness, and the macro-level political, historical and economic influences of established systems and institutions in society (Singer and Baer 1995; Baer, Singer and Susser 2003; Joralemon 2006). The approach advocated for changes in attitudes and against culturally inappropriate practices found in the biomedical system, often at a political or system level, to recognise the broader social, historical, political and economic factors that impact on the lives of individuals (Singer and Baer 1995).

Critical Medical Anthropology is a theoretical framework which provides researchers with a "perspective and set of concepts for analysing macro-micro connections" in the context of medical systems (Baer, Singer, and Susser 2003, p.32). This framework advocates for research that takes into account the political, economic, historical, social and cultural realms in which medical systems develop, change and function. Two of the original leading theorists, Baer and Singer, advocate strongly for the adoption of political economy theories into the medical anthropological realm, to demonstrate the relative connectedness of health care systems on a local level with global multinational health systems, especially taking note of those who control (financially and ideologically) and monitor health and health care systems around the world[15].

Singer (1995, p.81) asserts that CMA has often been criticised as being too academic for an applied discipline that is so often required (by funding bodies, by politicians and by people in need) to produce outcomes and solutions. However, Singer has also postulated that it is possible to take CMA beyond the academy and demonstrate its place in applied situations. Singer (1995, p.82) asserts that many critics have assumed the stance of CMA and critical praxis nearly always "...begins and ends with advocacy of global transformation; anything less would amount to little more than system maintaining-reformism". Singer (1995, p.83) addresses the two dilemmas that confront those wishing to employ critical praxis:

1. if, as critical medical anthropologists, among others, have suggested, powerful social classes ultimately control the health care system, is the whole notion of critical praxis in health an exercise in futility?
2. if the health care system both reflects and reproduces the wider system of social inequality and social control, is critical praxis a contradiction in terms?

Singer discusses this in light of Gorz's distinctions between two types of reform. While Gorz categorises these as "reformist reform" and "non-reformist reform", Singer employs the terms "system-correcting praxis" and "system-challenging praxis". Singer (1995, p.88-90) defines

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[15] For more information on the early debates in the development of Critical Medical Anthropology, see Johnson (1995), Huertin-Roberts (1995), Hopkins-Kavanagh (1995) in response to Singer (1995). These were critical arguments in the formation of the theory. More recent work includes Linder (2004) and Young Leslie (2005).

system-correcting praxis as "…conscious implementation of minor material improvements that avoid any alteration to the basic structure of social relations in a social system" and system-challenging praxis as: "…concerned with unmasking the origins of social inequity…strives to heighten rather than dissipate social action and to make permanent changes in the social alignment of power."

Singer asserts that the applied critical medical anthropologist would ideally work toward system-challenging praxis, stopping just short of complete structural transformation. It is the act of uncovering and making transparent the origins and transformations of social inequity that is the important part. Because, while complete structural change may be necessary, it is often perceived as a long-term and progressive goal in health, one which fails to recognise the importance of immediate action in times of crisis. The immediacy of chronic health conditions which need solutions in the present are seen as the place where action is required – a young child dying of a preventable childhood disease requires treatment now, and cannot wait for complete structural change. However, Singer would advocate that the employment of system-challenging praxis is most important at these times of crisis, to avoid reflecting and reinforcing systemic inequity for the sake of a quick fix. Without appropriate consideration of macro-level, structural issues, the medical assistance received may only serve to reinforce and cause further inequity in the future.

Comment on Singer's works, while often critical, commended his identification of principles such as enhancing democracy and eliminating mystification of culture (biomedical culture included) (Johnson 1995, p.108). He was also commended on his call to action in opposing those who see critical stances as irreconcilable with praxis (Huertin-Roberts 1995, p.110), that critical stances that serve to demystify biomedical and cultural knowledge are important pursuits of medical anthropologists (Hopkins-Kavanagh 1995, p.119). However, there were many criticisms of the stance. Huertin-Roberts (1995, p.111) took issue with Singer's stance that medical anthropology is conventional, neutral or a "handmaiden of biomedicine". She questions how different conventional and critical anthropology really are, and argues that those working in applied settings often attempt to rally against injustice or inequity.

While in agreement with Singer over the need for anthropologists to actively work within health settings, Huertin-Roberts (1995, p.111) identifies the problems of working within institutions that one seeks to change, including facing "systemic constraints and possible co-optation". However, it is arguable that the knowledge of these very issues makes for a more critically-aware and active anthropologist – knowing, recognising and acknowledging these factors and being reflective on them would possibly lead to a way of understanding your own practice and stance as an anthropologist. The need for self-awareness in critical praxis is of central importance – being aware and able to reflect upon one's own motivations and actions within health settings, taking account of systemic constraints and their impact on one's praxis, is surely imperative to any truly critical pursuit.

Huertin-Roberts (1995, p.111) also asserts that critical studies always "begin from a position of assumed power imbalance, focussing on economics and class structures". Huertin-Roberts (1995, p.111) continues:

> There is legitimate power and oppressive power. No one wants a powerless physician or other healer; power is necessary for healing. The problem is how to extricate power in service of healing from power in service of domination.

Johnson (1995, p.108) also argues that Critical Medical Anthropologists need to question and avoid reification of the 'truths' of the theory. Johnson (1995, p.108) raises the need to question "whether CMA's reality is just as culturally constructed (i.e. life as a constant battle between powerful and powerless) as any other reality".

> What does our unconscious identification with the disenfranchised say about our view of ourselves? How much does this identification become a source of distortion in both academic and applied domains? (Johnson 1995, p.108).

Of course, the realities of CMA are equally as culturally constructed as any other. However, it is in the recognition of such realities that nuanced understanding can be achieved – CMA theorists need to be not only aware, but critically aware of the cultural conceptions that underpin our relation to others, especially our relation to those considered as the 'fringe dwellers' or 'underdogs' of societies. We should, as a matter of anthropological 'fact' and transparency of process, announce our (often unconscious) identification with the disenfranchised peoples of the world, and demystify

whether this identification becomes a source of distortion in our work. Scheper-Hughes and Lock (1987) have taken the CMA approach to a more interpretive level that also places emphasis on the experiences and life stories of individuals, incorporating classical anthropological pursuits and Foucaultian notions of power, control and surveillance. One of the core values of this research approach is valuing the stories of individuals, in their own voices, to make the vital connection between micro-level and macro-level relationships.

2.4.1. The 'Mindful Body': embodiment in medical anthropology

In 1987, the new series of *Medical Anthropology Quarterly* was released. The lead article in the first edition was by Nancy Scheper-Hughes and Margaret Lock called: *The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology*. This was a major work in the ongoing theoretical development of CMA. The Mindful Bodies approach of Scheper-Hughes and Lock (1987) was a response to calls that CMA was far too focused on the political economy of health and that more attention should be given to the individual embodied experiences of health and sickness and the links between this micro level and discussions of power and medical hegemony. This approach attempted to introduce anthropology of the body, of lived experiences and of emotions in relation to health and sickness.

Scheper-Hughes and Lock (1987) intended to demonstrate that medical anthropology could be an applied science, but that if body concepts were not problematised, it would inevitably fall prey to the biological fallacy and related assumptions common in biomedicine[16]. Scheper-Hughes and Lock (1987) aimed to challenge medical hegemony, and the many basic conceptual categories that biomedicine is based on. These categories are historically and culturally constructed and are not

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[16] The biological fallacy to which Scheper-Hughes and Lock (1987) refer is the belief that there is a biological basis for human illness and suffering as discussed by Hippocrates. Of course, Hippocrates and his scholars were attempting to provide a rational basis to healing that they perceived was threatened by the charlatans and magi-folk healers of the time. In Hippocrates' urging to treat only the observable and palpable, there became a division between what was the real, observable (biological) basis for illness, and the unobservable, spiritual, mindful experience of the illness. This biological fallacy has been perpetuated by Cartesian dualisms that suggest a separation of mind/body, spirit/matter, real/unreal etc. which has further perpetuated the biological fallacy in biomedicine (Scheper-Hughes and Lock 1987, pp.8-10).

universal, although they are often constructed to appear so. This is one of the grounds for miscommunication between biomedical professionals and lay people, especially across cultures (for example, Fadiman 1997).

In this approach, there are three 'bodies' which represent three separate yet overlapping conceptual and analytical categories. The Individual body is the micro-level of analysis, "understood in the phenomenological sense of the lived experience of the body-self" (Scheper-Hughes and Lock 1987, p.7). A phenomenological exploration of the ways that people experience their bodies in times of health and illness through narrative forms of embodied experiences, are primary and crucial sources of information.

The phenomenological approach to understanding the experiences of individuals allows for the exploration of cultural epistemologies of sickness through individual experiences and understandings of sickness. . The recognition of various conceptions of self, often not dependent on the identification of the individual or ego (sociocentric vs egocentric), and explanations of illness that come from these varied conceptions of self are central to understanding how individuals experience their world. However, Scheper-Hughes and Lock (1987, p.10) observe that we are currently without a precise language to describe the embodied experiences and epistemologies of some cultures. They (Scheper-Hughes and Lock 1987, p.10) examine the work of Eisenberg and his attempts to distinguish biomedical conceptions of disease from the language of illness as a patient experience and the impact of this work:

> …one unanticipated effect has been that physicians are claiming both aspects of the sickness experience for the medical domain. As a result, the "illness" dimension of human distress (i.e. the social relations of sickness) are being medicalised and individualised, rather than politicised and collectivised.

This process is often referred to as 'medicalisation'. The appropriation of the illness experiences of patients into the domain of biomedical healing greatly diminishes the power and autonomy of people who express protest about their lives and circumstances through their bodies. It also means that social issues and unrest can be easily controlled through the power delegated to medical practitioners; if a biological basis can be identified (no matter how tenuous), behaviour

can be labelled as pathology, remedied or rehabilitated or reformed with medical treatment and surveillance. The medicalisation of women's sexual urges came with the label of 'hysteria', which was widely 'treated' by medical practitioners and psychologists with various techniques of surveillance, control and submission of women's minds and bodies in the 18th and 19th Centuries (and some would argue continues to this day) (Maines 1999). This is only one example of medicalisation, which was largely driven by Victorian social and cultural beliefs regarding the 'proper' behaviour and temperament of women (docile, submissive bodies, largely inferior in comparison to men) (Maines 1999).

The Social Body is the more traditional domain of social anthropology, combining structuralism and symbolism in analysis of the events and conceptions of social and cultural collectivities. It refers to "the representational uses of the body as a natural symbol with which to think about nature, society and culture" (Scheper-Hughes and Lock 1987, p.7), the constant exchange of symbols and meanings between the natural and the social. An example is biomedical discussion of the body using mechanical metaphors. This may be a reflection of capitalist forces co-opting biomedicine as an agent of surveillance and control of docile, productive worker-bodies, designed to keep the system reproducing and reinforcing these productive bodies. We often talk in mechanistic terms about our own bodies, bodies that are "worn out", "wound up", "turned off" and "tuned in" (Scheper-Hughes and Lock 1987, p.7). This is a reflection and reinforcement of the biomedical concept of the body as productive machine. But these reflections are not universally shared; they are culturally and socially constructed.

The Body Politic is the space of discussion about power and control. Post-structural analysis is common at this level and often features discussion of hegemonic forces in the vein of Gramsci and Foucault's notions of power and surveillance. It refers to:

> ...the regulation, surveillance and control of bodies (individual and collective) in reproduction and sexuality, in work and in leisure, in sickness and other forms of deviance and human difference...In all of these polities the stability of the body politic rests on its own ability to regulate populations (the social body) and to discipline individual bodies. (Scheper-Hughes and Lock 1987, pp.7-8)

The transformation of dissent and unrest into medicalised and labelled pathologies is the transformation of embodied acts of protest into passive acts of 'breakdown' (Scheper-Hughes and Lock 1987, p.27). Scheper-Hughes writes in her own monograph, *Death Without Weeping: The Violence of Everyday Life in Brazil,* of the constant and fierce deprivation that leads to nervous sickness through hunger, called *nervoso* (Scheper-Hughes 1992, p.168). Scheper-Hughes (1992, p.168) writes:

> Hunger and deprivation have set the people of the Alto do Cruzerio on edge, have made them lean, irritable and nervous. Their lives are marked by a free-floating, ontological, existential insecurity. There is not enough, and it is almost inconceivable that there could ever be enough to satisfy basic needs…Nervos, a rich folk conceptual scheme for describing relations between mind, body and social body, is appropriated by medicine and transformed into something other: a biomedical disease that alienates mind from body and that conceals the social relations of sickness. The madness, the delírio de fome, once understood as a terrifying end point in the experience of angry and collective starvation, is transformed into a personal and "psychological" problem, one that requires medication.

In this way, hunger is isolated and denied, and an individualised discourse on sickness comes to replace a more radical and socialised discourse on hunger.

Further to the three bodies, Scheper-Hughes and Lock (1987) advocate for the incorporation of the anthropology of emotion into these analyses, in order to take the final leap into understanding the ways that emotions "affect the way in which the body, illness and pain are experienced and are projected in images of the well or poorly functioning social body and body politic" (Scheper-Hughes and Lock 1987, p.28). Scheper-Hughes and Lock assert that this may be the missing link in our attempts to reconcile the dichotomy of mind/body and the links between the individual, social and body politic. They challenge anthropologists to move beyond studying emotions in formal, public, ritualistic expression to studying it at the level of individual experience.

Scheper-Hughes and Lock (1987, p.31) conclude:

> What we have tried to show…is the interaction among the mind/body and the individual, social and body politic in the production and expression of health and illness. Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication – the language of the organs – through which nature, society and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity, and struggle.

The Mindful Bodies approach values and bases its analyses on the perspectives of individual and social groups, and demonstrates ways of approaching issues of health and illness that emphasise interconnectedness, something that is a core feature of Aboriginal and Torres Strait Islander lives – interconnectedness between country, family and community, language and culture, and shared aspirations for good health.

While the CMA, and in particular the Mindful Bodies approach to medical anthropological study has been criticised for being too political, for being too focused on implicit relations of power to be of use in situations where disadvantaged populations require immediate action for the betterment of their health/lives, I disagree. I, in keeping with Singer, argue that true change is not only possible through intervention (or interference) in the lives of others, but through engagement with higher level political and social processes that may prevent change from being sustainable or even viable. Without a clear and critical engagement with the structures that create power imbalance in our society, coupled with an engagement with people in an everyday sense, through exploration of individual experiences and perspectives, any changes wrought may be fleeting or create further imbalances.

In the Mount Isa context, I will use the CMA Mindful Bodies approach is to demonstrate issues of health care access among Aboriginal and Torres Strait Islander peoples. This approach forced me to question the structures in place in Mount Isa that may contribute to the phenomenon under study, and to unpack how those structures create and reinforce inequities in the town. I use the Mindful Bodies approach to demonstrate and explain this phenomenon as it was lived by patients and carers in Mount Isa, and for those that work within the health system. These perspectives are important in understanding the phenomena of access, as it is in these stories that the frustrations and emotional experiences which inform engagement with the health care system lie. In knowing these experiences, in studying them alongside examination of the health care system in the local setting, and the political context of health services provision in Queensland and Australia, it is possible to get a sense of how this phenomenon becomes reality in the lives of so many Mount Isa residents.

These individual perspectives are woven throughout the thesis, in the case studies and quotations throughout. They represent the major dataset in this research, and have been set within a consideration of the social, cultural and political realities of health care provision in remote Australia. As health interventions become ever more personal and individualised, it is critical to understand the stance of those individuals that will be affected most. The following chapter provides insight into the health services research principles that I utilised in understanding the data from this research. In combination with the Critical Medical Anthropological and Mindful Bodies approaches discussed above, the 5As of Access taxonomy developed by Penchansky and Thomas (1981) has been a critical guiding principle in this work. Examination and critique of the 5As of Access taxonomy will be accompanied by a review of health and medical literature regarding issues of access to health care services. This literature is from international and national sources and considers the access issue from the perspectives of consumers and providers of health care. The review of health and medical literature is crucial in establishing the parameters for my considerations of access. In particular, this literature had significant influence over my decision to concentrate on the concept of 'cultural' barriers.

Chapter 3 considers how health researchers and practitioners regard evidence of access barriers and how they consequently construct understandings of what constitutes a barrier. This leads to discussion of the concept of cultural barriers which features frequently in that literature, and the possible implications of such a categorisation. Considering culture as a barrier constructs minority populations as problematically different, and may increase disengagement of minority populations from mainstream health systems.

Chapter 3

Access barriers to mainstream health care facing minority populations: the literature.

If patients' expectations or health beliefs are not in line with what is proposed by the care provider, they may experience barriers to the use of health services. When the end result is not in line with the treatment received, barriers may also come into existence.

Scheppers et al. 2006

As highlighted in previous chapters, equitable access to health care is considered a human right and fundamental to affecting changes in health status for minority populations all over the world. In order to create more accessible health care systems, it is first necessary to understand what is meant by the term 'access'. According to work by Penchansky and Thomas (1981), the term 'access' requires unpacking, in ways not previously considered within health research. This chapter outlines the work of Penchansky and Thomas (1981), and is followed by a consideration of the health and medical literature on access from 1996 to the present.

3.1. Access to health care: what does this mean?

There have been a number of attempts to better define the term 'access' (Andersen and Newman 1973, Donabedian 1973, Aday and Andersen 1974, Penchansky and Thomas 1981, Frenk 1985, Millman 1993, Andersen 1995). However, for the purposes of my research, and in particular to assist in the analysis and discussion of the complex circumstances reported to me in the course of my research, I settled upon the Penchansky and Thomas (1981) definitions as set out in their 5As of Access taxonomy. This taxonomy examined five aspects of consumer access to, and satisfaction with, health care services (see Figure 1).
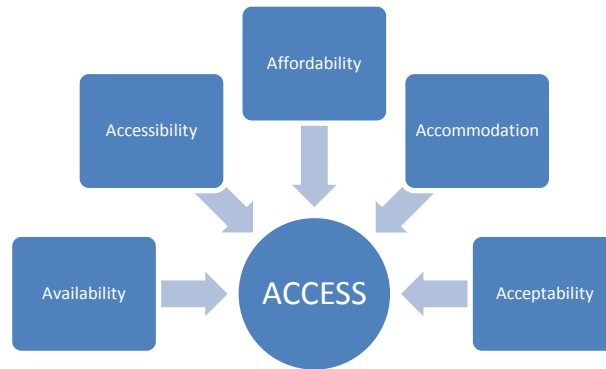
Figure 1. Penchansky and Thomas (1981) 5As of Access taxonomy.

Penchansky and Thomas's (1981) examination and discussion of access as the best fit between patient and provider was a ground-breaking effort at unpacking an important and very popular term in contemporary medical literature that had been previously ill-defined.

According to Penchansky and Thomas (1981), the five A's approach improves discussions of accessibility in the medical and health literature by providing a more comprehensive examination of the various categories that define access.

3.1.1. Availability.

Availability refers to:

> The relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs. It refers to the adequacy of the supply of physicians, dentists and other providers; of facilities such as clinics and hospitals; and of specialised programs and services such as mental health and emergency care. (Penchansky and Thomas 1981, p.128)

Possibly the most obvious aspect of access is availability; or, an examination of the services available for patient use. Availability, as Penchansky and Thomas define it, suggests a degree of social responsibility on the part of health practitioners - the need to provide health care that *actually* serves a population; the design of which is centred on the needs and size of the population. It is one thing to have plenty of health care providers in a town, but if none of these

providers are catering to the needs of patients, this will have a significant impact on uptake of services and patient satisfaction levels, not to mention the health status of the population.

3.1.2. Accessibility.

Accessibility refers to the 'relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost' (Penchansky, and Thomas 1981, p.128).

Accessibility is especially relevant in small regional, rural and remote towns, where there are often large distances between the location of the service provider and the patient. Transportation can cause a great deal of stress and discomfort for patients, especially in towns where there is no public transport (such as in Mount Isa), taxi services are limited and expensive, and the cost of running private vehicles can be prohibitive.

If not recognised and addressed, accessibility problems can lead to under-utilisation of services, even if these services are desperately needed. In some communities accessibility is not an easily recognised issue: for example, in Mount Isa many people do not believe public transport to be an issue, as "most people work in the mines and have a work vehicle or their own car" (King 1996, p.14). However, not *all* people living in Mount Isa have access to a vehicle or own their own, in particular many Aboriginal and Torres Strait Islander families.

These problems also extend to those who need to travel elsewhere for care, due to a lack of available services in the town. This is a major and important issue, and puts strain on many Aboriginal and Torres Strait Islander families, but also on the population as a whole. Studies on transportation and exclusion in Australia demonstrate the impacts that transportation differentials have on uptake of services (Young and Doohan 1989, Newton and Bell 1996, Taylor and Bell 1999, Bostock 2001, Hine 2003, Taylor and Bell 2004, Currie et al 2007, AIHW 2011, Rosier and McDonald 2011).

3.1.3. Affordability.

According to Penchansky and Thomas (1981, pp.128-9), affordability concerns: 'The relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance. Client perception of worth relative to total cost is a concern here, as is clients' knowledge of prices, total cost and possible credit arrangements'.

Affordability of health care is often raised in literature on Indigenous health in Australia. Many Aboriginal families are simply not able to pay the fees charged by private GP services. Thus, in towns without an Aboriginal Medical Service or practices that bulk-bill[17], they are forced to utilise services such as emergency wards at local hospitals (where there is a local hospital available). Publicly-funded mainstream health services that provide free care do much to obviate such issues, and consequently may need to work beyond their capacity in order to serve the needs of their increased patient base.

In rural and remote areas, workforce recruitment and retention also impacts on affordability: clinics need to be able to compensate staff well in order to attract and keep health practitioners in rural and remote towns. In private practices, this can often force the cost of consultations to a premium that is not affordable for many people, especially those of low socio-economic status (most often Aboriginal patients).

3.1.4. Accommodation.

The term accommodation in the 5As taxonomy relates to 'the relationship between the manner in which the supply resources are organised to accept clients (including appointment systems, hours

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[17] As per the glossary, bulk-billing is a payment option under the Medicare system where patients assign payment rights to their health care provider who claims 85% of care costs from the government. No money will usually change hands between provider and patient in this arrangement.

of operation, walk-in facilities, telephone services) and the client's ability to accommodate to these factors and the client's perception of their appropriateness' (Penchansky and Thomas 1981, p.128).

If patient expectations of service operations do not correspond with the actual operational systems of a service, they are unlikely to use that service (Penchansky and Thomas 1981). This issue incorporates discourse about compliance within medical literature. Compliance in health literature refers to the degree to which a patient carries out the instructions/orders/requests of the health practitioner, who is believed to be authoritative in matters of health (Humphrey et al. 2001, p.ix). In this literature patients are often blamed for poor or non-compliance, despite the existence of systems or resources which may not work for them; very rarely is the system found to be at fault in this discourse (Humphrey et al. 2001, p.43). A perceived failure to keep appointments is often identified in literature about Aboriginal and Torres Strait Islander Australians, and is framed as being an issue of compliance, when in fact it may be an issue of accommodation. Appointment systems may not be suitable for use with these patients. It is reported within anthropological, sociological and medical literature that rigid appointment systems simply do not work for all Aboriginal patients, who may require a degree of flexibility that many systems do not have (De Crespigny et al. 2003 p.25; McConnel 2003, Burbank 2006).

In a recent legal case (*Young v. Central Australian Aboriginal Congress Inc.*) the issues of appointment systems failure was highlighted. This case brought claims of negligence against a major and well-established Aboriginal Medical Service. "A finding of negligence was made against Congress [common name of the clinic] for failing to have administrative procedures in place to deal with patients who fail to attend appointments relating to potentially serious conditions – in this case, suspected ischaemic heart disease" (Stevens and Cooke 2009, p.1). This was after a 26 year old Aboriginal man died of coronary thrombosis after extensive ischemic injuries to the heart which had not been properly monitored during his care at Congress. This was largely attributed to

the failure of their systems to flag patients who failed to attend tests and specialist appointments, especially important in practices that do not have a permanent doctor monitoring each patient case. As stated in Stevens and Cooke (2009, p.3):

> The Court found that Congress had a direct duty to the deceased to exercise reasonable care and skill in the administration and management of his treatment and care. As a matter of law, the Court found that Congress was both directly and vicariously liable in respect of that duty…The system at Congress did not provide for referring doctors to be made aware whether or not patients had attended for tests. Congress had a responsibility to put administrative procedures in place to 'catch' non-attendances related to the diagnosis and/or treatment plan for potentially serious conditions. The systems that were in place were ineffective and capable of failure at multiple points.

This kind of legal case has implications for the development and continuation of systems in medical centres. It suggests that inadequate systems that do not fit with patient behaviours and expectations can have significant impacts on health.

3.1.5. Acceptability.

Acceptability is the concept that illustrates 'the relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients' (Penchansky and Thomas 1981, p.129). The authors further refine this, discussing how, in health literature:

> ...the term appears to be used most often to refer to specific consumer reaction to such provider attributes as age, sex, ethnicity, type of facility, neighbourhood of facility, or religious affiliation of facility or provider. In turn, providers have attitudes about the preferred attributes of clients or their financing mechanisms. Providers either may be unwilling to serve certain types of clients (e.g. welfare patients) or, through accommodation, make themselves more or less available'. (Penchansky and Thomas 1981, p.129)

In private practice, practitioners can make themselves more or less available to particular patients. In a capitalist, market-driven society[18], we accept this (often subtle) exclusion, often without question. It is illegal to openly exclude anyone from health care – in fact, access to health care is

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[18] Germov provides a sound definition here: 'market' refers to any institutional arrangement for the exchange of goods according to economic demand and supply. This term is often used to describe the basic principle underlying the capitalist economy (Germov 2001, pp.346-7).

considered a universal human right. Nonetheless, private general practices may make decisions about practice location, pricing of time, and other systems that do seek to subtly exclude particular people.

A study by Hyndman, Holman and Pritchard (2002, p.387) found that within metropolitan Perth attractiveness factors such as ease of making appointments, timeliness, bulk-billing, after-hours servicing and general practice proximity to other services like pharmacies had an impact on patient choice of general practice provider. After stratification for social disadvantage and levels of accessibility of GP surgeries in metro Perth, it was discovered that:

> …Those who were most socially disadvantaged were less likely than those who were better off to bypass surgeries where global access was poor, but more likely to bypass nearby surgeries and to seek out a surgery that bulk-billed where global access was good….adjusting for distance effects and size of surgery, showed within each level of global access and social disadvantage a consistent increase in the odds of attending a surgery that satisfied the attributes desired by respondents. (Hyndman et al. 2002, p.387)

While it is important to note that this study referred to circumstances in a major capital city in Australia, it did reflect a degree of sensitivity to relative social disadvantage, and demonstrates that where people are in better circumstances and in situations that permit them to make choices about where they obtain their health care, they will do so based on a set of desirable attributes.

The implication of the article by Penchansky and Thomas (1981) is that in order to discuss access fully, it is necessary to consider all five aspects to create a comprehensive picture. When applied to the medical and health literature below, it is easy to see how authors can get caught up in the idea of access as an issue, but may fail to consider its many aspects. There are also examples within this literature that challenge the five aspects, pushing definitions to their limits and sometimes, breaking through.

3.2. 'Access barriers' literature.

The literature reviewed here comes predominantly from medical and health databases, and is a discussion of the literature that health professionals are most likely to access in efforts to gather

evidence for their practice. It is important to review such literature, as it is here that the understandings and practice of health practitioners may become clearer. There is a definite hierarchy in the natural sciences and in particular in medical circles regarding what constitutes real evidence, and very rarely do qualitative studies appear. However, in recent years this has been changing, with an increasing number of social science and humanities journals being indexed by medical and health databases, such as PubMed.

In 2006, I was awarded a fellowship under the Primary Health Care Research Evaluation and Development fund to undertake a literature search regarding access barriers to health care. At the time, few social science or qualitative research journals were being indexed by major health databases. If such research does not make it to these indexes, it is likely that it will not be regarded as credible evidence by practitioners, even if they are aware of its existence. The results of my search revealed a paucity of research on access issues in the health (but particularly in the medical) sciences at the time and, in particular, few studies which looked at the ways that access barriers impacted upon Aboriginal and Torres Strait Islander peoples. The findings of the search, along with other literature that was not in the indexes at the time, are reported in the sections below. Scheppers et al. (2006) confirm the results of my study.

Scheppers et al. (2006) reviewed international literature on potential access issues for ethnic minorities. They identified 54 articles conforming to their search conditions[19] that discussed barriers preventing, or potentially preventing, various ethnic minority groups from accessing mainstream health care services. According to Scheppers et al. (2006, p.326):

> A barrier…restricts the use of health services. It is a wall or limit that prevents people from going into an area or doing what they want to do… A potential barrier is a barrier that only afflicts us under certain circumstances or only afflicts some of us, mostly the socioeconomic vulnerable ones.

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[19] Articles published 1990 to 2003 relevant to the study of health services used by ethnic minorities.

Scheppers et al. (2006, p.325) identify potential barriers at three levels: the patient level, the provider level and the system level. The patient level is "…related to patient characteristics, such as sex, ethnicity, income, etc.", while the provider level is related to "…provider characteristics, such as sex, skills, attitudes, etc." (Scheppers et al. 2006, p.326). At the system level are "…system characteristics such as policy, organisational factors, structural factors, etc." (Scheppers et al. 2006, p.326). The potential and actual barriers proposed within the literature were identified for each level. These included items such as: demographic variables, health beliefs and attitudes, personal and community enabling resources, and personal health practices at the patient level; provider personal characteristics; the medical paradigm, consumer-driven systems approaches and organisational factors at the system level.

In many ways the findings of Scheppers et al. (2006) mirror those of Penchansky and Thomas (1981). Scheppers et al. (2006) demonstrate in their reading and analysis of the literature that there are many aspects to access, and there are many factors that contribute to the making of a barrier, real or perceived. All of the detailed items listed by Scheppers et al. (2006) fit into at least one of the five categories set out by Penchansky and Thomas (1981), although some are more challenging than others to accommodate.

Perhaps one of the most interesting features of the Scheppers et al. (2006) categorisation is that the majority of potential barriers fall within the patient level. This suggests that health literature has pronounced patients as the source of barrier creation. The subtle, perhaps unintentional attribution of blame to patients potentially hides larger relationships at play, particularly obscuring the place of providers in their interactions with patients, and also hides from view the influences that systems and bureaucracies have on shaping patient experiences. Given the results of Scheppers et al. (2006) it is pertinent to examine a selection of health literature on access barriers, both international and national examples, in order to get a sense of the origins and style of this discourse, as well as whom and what it attempts to represent.

Much of the international medical literature on cross-cultural experiences of access barriers comes from the United States of America, with the focus on Latino, Hispanic and African American populations. These studies are often carried out via a survey of patients attending clinics or hospital waiting rooms. For example, Flores et al. (1998) write of the barriers within North American health care systems, as cited by the parents of Latino children. They discovered that the major barriers facing parents when accessing health care for Latino children were: language problems (26%); long waiting times (15%); no medical insurance (13%); and, difficulty paying medical bills (7%). When respondents were asked if any factor had ever stopped them from bringing a sick child in for care, they answered: transportation (lack of, or unreliable) (21%); not being able to afford health care (18%); excessive waiting time in the clinic (17%); no health insurance (16%); and, lack of cultural understanding by staff (11%) (Flores et al. 1998, p.1119).

Significantly, these categorisations of responses are similar to the results of many other studies, as reported below, including those regarding adult populations. While this is not an unexpected outcome among minority populations that do not speak English as their first language, there are other factors here that span populations and are not necessarily culturally specific. The role of place (geographical and social) has a significant impact on health.

In a recent literature review of barriers facing Canadian rural women caregivers, Crosato and Leipert (2006) demonstrate the existence of barriers related to the remoteness of their rural communities and locations. These women have many interests competing for their time and attention, not least of which is the health and wellbeing of elderly family members. This often sees women put their own health and wellbeing last, only seeking care when it is absolutely necessary. Not only do these women face access barriers in relation to their own care, but they also have to deal with barriers to accessing care for their elderly charges. Informal networks of care-giving are socially valuable, but can place unwarranted pressures on the caregivers, who often feel isolated and unsupported.

Crosato and Leipert (2006, p.1) identify that while rural informal caregivers often experience similar barriers to their urban counterparts, they also suffer from limited access to adequate and appropriate healthcare services, culturally incongruent health care, geographical distance from regionalised centres and health services, transportation challenges, and social/geographical isolation. Such social aspects of care and the shared responsibilities of health care are crucial elements to access. Health and healing are social activities and are not individual or private events.

3.2.1. Australian literature on rural and remote residents' access to biomedical health care.

In June 2006, 64% of the total Australian population lived in a capital city statistical division – the remaining 36% lived outside of these areas (including rural and remote communities) (ABS 2007b). Due mainly to location, rural and remote populations often experience difficulties actually getting to mainstream health care services. Humphreys et al. (1997) utilised the Penchansky and Thomas (1981) taxonomy in their survey research to "ascertain the importance rural Australians attribute to different factors of accessibility in their decision to consult a general practitioner".

Humphreys et al. (1997) found that participants ranked issues of acceptability as highly important when deciding whether to consult a general practitioner. This was particularly so among elderly rural residents and was more highly ranked than geographical proximity. Alternatively, young and middle-aged people and men living in isolated communities ranked geographical proximity as the most important factor (Humphreys et al. 1997). Thus:

> For rural inhabitants, geographical distance is not the sole or even the most important determinant in their choice of general practice care; rather, they will seek the services of a GP with whom they feel comfortable. Incentives programs designed to recruit and retain more GPs in rural practice must acknowledge the importance of attracting acceptable doctors. This requires that rural doctors acquire suitable clinical and communication skills to meet the diverse needs of their patients, as well as an understanding of rural culture. (Humphreys et al. 1997, p.577)

A study by Veitch et al. (1996) uncovered the non-medical factors that influence the decision making pathways of rural and remote residents requiring specialist medical care away from home communities. Two surveys were conducted, designed to elicit data about the relationship between distance and the health attitudes and help-seeking behaviours of rural and remote residents. The article discusses the factors that influence whether people from rural and remote areas access specialist services in a timely manner, or whether these non-medical considerations impede timely access. Veitch et al. (1996, p.104) state that:

> Highly specialised services can be offered only in large cities or large population centres, and the growth of these services can lead to a parallel increase in locational disadvantage for people in small rural and remote communities.

The authors found that social, economic and emotional considerations played a significant role in the help-seeking behaviours of rural and remote people, often causing anxiety "over and above that generated by the medical condition itself" (Veitch et al. 1996, p.105). Issues under consideration for rural and remote patients in need of specialist care include not only the costs (both financial and temporal) and difficulties related to the journey, but also the problems stemming from extended periods away from home, difficulties experienced in the urban location and distrust of medical services more generally (Veitch et al. 1996, p.105).

Especially significant was the impact of remoteness. Those who were in remote communities or locations were less likely to travel the long distances required to access specialist services. This was often due to considerations involving organisation of home affairs, isolation from family support, expenses experienced while away, transportation and distance from the health care provider and disconnectedness from community (Veitch et al. 1996, p.106-107).

Veitch et al. (1996) highlight important and serious concerns of rural and remote patients that were beyond medical issues – issues that are often considered as beyond the scope of the medical practitioner's concern or control. However, Veitch et al. (1996, p.105) point out that these concerns need to be considered by medical practitioners, as they have significant impact on the

health outcomes of patients, and are crucial to understanding issues of compliance or non-compliance (as the case may be). Help-seeking or health care decision pathways then, are not only determined by medical urgency or need, but are also influenced by social, emotional, cultural and personal non-medical considerations.

Alston, et al. (2006), discuss the health experiences of rural women in Australia and identify the pressures on rural women to maintain their health in the face of many barriers. These barriers again include remoteness and distances from health care services, lack of transport or reliable transport, inability to justify taking time away from domestic and occupational activities to travel long distances unless absolutely necessary, and so on. The study was developed in recognition of the fact that mainstream health servicing often does not attend to quality of life issues or recognise social contexts that create differences in opportunity. The authors report that not only is poor access to health services an issue for rural women, as well as the adequacy of these services. Due to lack of accessible services, 52% of respondents stated that private health insurance is not cost effective in rural areas. Sixty-six percent of respondents needed to travel to regional centres to access health care, yet 84% stated that there was no form of public transport available to get there.

Harris et al. (2004) conducted research with rural and remote patients in attendance at the Townsville General Hospital (TGH). Vignettes of four patient and carer experiences demonstrate the social, cultural and economic impacts on patients and carers. Harris et al (2006) examine the ways that responsibility for care costs and 'inefficiencies' within the hospital system are shifted to patients, carers, community and other health and social welfare systems. The authors (Harris et al. 2006) posited that this may be due to economic rationalism and policies of later admission and early discharge. Issues of transportation, accommodation and other costs for patients and carers were frequently reported, and had a demonstrably disproportionate impact on those in rural and remote locations (Harris et al. 2004, p.1).

Harris et al. (2004, p.2) recommended that more attention be paid to the needs of rural and remote patients' and carers' in the discharge planning process. They also emphasise the need for better communication and information for carers. Referring hospitals and health providers are reportedly expected to provide this information but often do not, or are unable to in the case of emergency situations (Harris et al. 2004, p.9).

Harris et al. (2006) illustrate that specialists or those operating in consultative care situations may not expect to have to deal with social and cultural differences or problems, as these are often considered the domain of those operating at primary or secondary levels (Harris et al. 2004). This may be a reasonable expectation, except that tertiary institutions and staff cannot be certain of the availability (or variability in quality) of primary and secondary care in many rural and remote communities. Thus, the authors (Harris et al. 2006) conclude that tertiary institutions may benefit by creating space in their organisational structures to acknowledge these needs, and many now do so by the employment of Aboriginal Liaison Officers and social workers.

3.2.2. Aboriginal and Torres Strait Islander peoples' access to biomedical health care in rural and remote areas.

A 2004 study conducted by Stamp et al. (2006) highlighted the issues faced by people in rural and remote locations who need to travel to city hospitals for treatment. The study includes documentation of the experiences and perspectives of three Aboriginal Health Workers involved in organising the transportation of Aboriginal patients from Ceduna to major city hospitals in South Australia. The major themes on access emerged: travel and transportation, standards of physical accommodation, privacy and communication (Stamp et al. 2006).

The main argument by Stamp et al. (2006) is that transition of care from one provider to another is crucial to the outcomes of patients in transfer situations. Two important issues were identified: (i) good communication between health professionals ensures smooth transitions; and, (ii), the need for relatively easy and equitable access to available services for patients and escorts, which

are sensitive to the needs of patients. Although there are schemes in place to assist an easy transition, they are often far from adequate (Stamp et al. 2006).

In contrast to patient transfer processes, are health care services offered via outreach programs. Outreach programs are usually based on providing specialist medical care to communities that have inadequate access to medical services locally, as is the case in many rural or remote communities. Gruen et al. (2002) suggest that outreach specialist medical services are a method to offer more equitable access to, or alternatives to, hospital-based care alone. Their research examined how primary health care is supported by specialist outreach services delivered to remote Indigenous communities in the 'Top End'[20] of the Northern Territory.

Gruen et al. (2002, p.518) identified access barriers that remote Indigenous people face when attempting to access hospital-based specialist care. These included the geographical remoteness of patients, cultural inappropriateness of services, poor doctor-patient communication, poverty, and health service structures. Gruen et al. (2002) were particularly interested in the ways that offering outreach specialist health care to disadvantaged populations in remote areas could overcome barriers to good health. The advantages of outreach include reduction in need for patients to travel long distances, improved communication, cultural respect and safety, familiarity between patients and regularly-visiting health specialists, and improved relations between remote clinic staff and visiting specialist (Gruen et al. 2002, p.519).

Of particular concern to the authors (Gruen et al. 2002, p.519) was how to sustain such services, in ways that would not detract from the resources or achievements of primary health care services. "Specialist outreach can only promote equity of access when it considers both the needs of remote communities and the adequacy of the specialist base" (Gruen et al. 2002, p.517). In addition to this they also considered the following to be sustainability requirements: an adequate

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[20] Common reference to the area of the northern most region of the Northern Territory. Darwin is the capital city and hosts the major base hospital and specialist services for the region.

number of specialists, hospital-based specialists who have roles in that hospital alongside outreach responsibilities, and regular, predictable, integrated, and valued outreach activity that is planned to respond to the needs of particular communities (Gruen et al. 2002, p.519).

3.2.3. Initial conclusions.

A general set of access barriers emerges in the literature reviewed above. It is important to recognise that the term 'access' is made up of so many different issues that it is not truly possible to capture with the use of just one word. The literature examined above demonstrates this, and calls for the summation and examination of various aspects of potential and real barriers to health care access. The set of barriers could be summarised as: transportation and distance to services, cost and lack of effective health cover, and language and cultural differences that potentially lead to misunderstanding, miscommunication or inappropriate treatment.

These aspects of access generally correspond with the categories examined by Penchansky and Thomas (1981) of *availability*, *accessibility*, *accommodation*, *affordability*, and *acceptability,* although, as is generally the case with taxonomies, not all issues fit so neatly. Despite this, the Penchansky and Thomas (1981) taxonomy is a comprehensive way to tease out the issues that arise in the individual stories of illness experiences. All of these factors impact on the ways that people access health services, and seem particularly relevant in discussions of rural and remote communities, and Indigenous Australian communities.

While geographic location has undoubted impacts on the health of rural and remote populations, a category of concerns has arisen under the guise of culture. The following section discusses the culture concept in more detail and examines the concept's recent uptake within the health sector and its potential to dissipate blame, subvert agency and potentially hide other factors that may prevent people from accessing biomedical care.

3.3. Cultural barriers effecting Aboriginal and Torres Strait Islander peoples – the health literature.

There is a body of health literature that examines various cultural differences that may be expressed or experienced as barriers to accessing care within mainstream biomedical health systems and services. Some relevant examples are considered here.

Kendall et al. (2004), examined access barriers experienced by disabled Aboriginal patients in rehabilitation services. The authors outline an extensive list of features within biomedical settings and within Aboriginal cultures that cause difficulties in the rehabilitation setting. These include significant differences in the meanings and social construction of disability and illness across Aboriginal and non-Aboriginal cultures. Disability and disease is often interpreted by Aboriginal people: "…according to the imbalance and disruption they cause within families and communities, rather than in terms of personal suffering or physical difficulties they create for individuals" (Kendall et al. 2004). Kendall et al. (2004) refer to Smallwood's (1989) work on the topic, including such details as the types of meals offered in some care settings, the gender and attire of staff, shame and differing communication styles and non-verbal cues as some significant differences between Aboriginal and non-Aboriginal Australians, which may be exacerbated within health and rehabilitation settings. Kendall et al. (2004) argue that health professionals need to establish the level of adherence to traditional beliefs held by individual clients and their families, in order to create an atmosphere conducive to good sensitive communication and treatment.

Similarly, Newman et al. (2007) discussing barriers and incentives to uptake of HIV treatment among Aboriginal people in Western Australia, note that one of the crucial factors in determining access and uptake is based on maintaining good social relationships. Many of the Aboriginal people they interviewed considered it important to "…maintain good social relationships, their

everyday routine and the respect of their family and friends over their individual health *per se*" (Newman et al. 2007).

Gruen et al. (2002) as examined earlier in this chapter, discuss an outreach program trialled in the Northern Territory, designed to bring much-needed specialist services to remote Aboriginal communities. Cultural inappropriateness - "poor appreciation of hospital staff of the needs of indigenous people and communities" and "concepts of health, illness and medicine that may be unfamiliar to patients" (Gruen et al. 2002, p.518) – was identified as an access barrier for remote Aboriginal patients.

Cultural concepts about health, illness and healing vary and there may not be commensurate concepts for particular illness treatments offered by specialists. Moreover, communicating these concepts is based on a biomedical understanding of the body and bodily processes. This is one of the most fundamental issues in communicating biomedical concepts cross-culturally: not all people think about health and illness in the same way as do those acculturated into the biomedical system (Humphrey et al. 2001).

Lea (2005) discusses the issues of trying to communicate western public health messages to Aboriginal people in communities in Arnhem Land, Northern Territory. Her article illustrates how presumptions regarding the superiority of biomedical knowledge can hinder communication across cultures. Case studies examined in Lea's (2005) article highlight health promotion activities which simplify both western biomedical and Aboriginal cultural knowledge in attempts to find 'culturally appropriate' ways to communicate health knowledge. This results in weakened health messages that caused confusion for patients. Patient confusion, in turn, served as evidence of the ever-present need for the 'expert' knowledge of public health officials in remote Aboriginal communities.

3.3.1. Biomedical barriers to health care access.

Andrews et al. (2002) report on a series of consultative meetings held in rural New South Wales, designed to identify and overcome the barriers to Aboriginal people accessing general practice services. They discovered that many GPs in the region were not aware of Aboriginal Health Workers and their roles within communities, and that Aboriginal Health Workers were not confident dealing with GPs, thus a working relationship was rarely established between the two sectors, if at all. According to Andrews (2002), GPs wanted to engage with Aboriginal communities, but found it difficult due to 'poor communication' and 'cultural differences'. Neither of these points was elaborated upon by the GPs. This creates some speculation for me: when these GPs refer to 'poor communication', on the part of whom? What specific cultural differences are these GPs alluding to?

In their conclusion, Andrews et al. (2002, p.200) make a significant statement about the differences in perspective:

> Aboriginal patients in the NSW Central West are of predominantly lower socioeconomic status…want to be bulk-billed…want their doctors to spend more time in consultations getting to know them…want Aboriginal cultural images displayed in general practices to help allay their anxiety about the consultation.

Whereas GPs believed:

> Aboriginal patients have more health problems…want more of the limited general practice resources…want and need the cost to be borne by bulk-billing…For these reasons, Aboriginal health or medical services are seen as an option to provide this type of alternative service.

So, despite a demonstrated need for financial assistance via bulk-billing, the GPs in Andrews et al. (2002) study as a group appear to be unable to deliver. The fact that Aboriginal clients desire a relationship with their health provider that allows consideration of the patient as a whole being, with social and cultural needs and concerns, families, commitments, and so on, appears to make them a problematic group who take up too much of the limited resources general practices have, according to those making comment in Andrews et al. (2002)'s study.

Stoneman et al. (2007) studied pharmacists' perceptions of Aboriginal health issues. They found that many pharmacists in a rural NSW setting did not recognise that Indigenous clients may be uncomfortable in their pharmacies. Many pharmacists believed that staff were friendly, approachable and provided the same treatment and service to all customers. When researchers prompted pharmacists to think about possible barriers that would prevent Aboriginal people shopping in a pharmacy, they admitted that perhaps staff who keep a close eye on Aboriginal shoppers (due to past thefts perpetrated by Aboriginal people) might be an issue. They also reported "…'anger with the system' and resentment toward non-Indigenous people, and failure to understand the importance of carrying Medicare and concession details when accessing prescribed medications" as possible barriers (Stoneman et al. 2007, p.9). A small number of pharmacists identified the following issues (Stoneman et al. 2007, p.9):

> …Indigenous people may not be aware of what services pharmacists and pharmacies provide…Some felt Indigenous patients were less health conscious or may have an issue with privacy and confidentiality. This could be in relation to the pharmacist or concern about other customers listening. The lack of Indigenous pharmacists and pharmacy assistants was also identified by a minority of respondents as a possible issue.

According to Stoneman et al. (2007), pharmacists identified the major barrier to accessing medications as financial, and that this was because of "poor money management" or "low priority given to medication and health expense" (Stoneman et al. 2007, p.6).

Despite being keen to participate in cultural awareness training, most pharmacists in the study reported a lack of time to do so, and a reluctance to commit to expansion of pharmacist roles in Indigenous Health unless financial barriers were removed (i.e. making more medications available through pharmacies for free):

> If the proposed extension of Section 100 of the Australian Pharmaceutical Benefits Scheme goes ahead and financial barriers are removed, it then remains for pharmacists to take up the challenge to increase their own understanding of Indigenous health issues and form collaborative partnerships with their AHW counterparts. (Stoneman et al. 2007, p.1)

An earlier study with Aboriginal Health Workers (Hamrosi et al. 2006) identified that Aboriginal clients felt uncomfortable in many medical settings, including commercial pharmacies, where the pharmacy was considered an extension of the medical setting. AHWs talked about fear and embarrassment experienced (especially by elderly people) within medical settings (especially mainstream medical settings), and believed that those feelings were often applied to mainstream pharmacy settings (Hamrosi et al. 2006, p.5). The Stoneman et al. (2007) study used the recommendations of the AHWs in the Hamrosi et al. (2006) study, to prompt pharmacists to discuss their thoughts on pharmacy information resource development for people with low literacy levels, more collaboration between pharmacists and AHWs and cultural awareness training for pharmacists and staff.

The pharmacists' responses to these suggestions were varied. Most pharmacists believed that low literacy styled resources were not necessary, as the current literature was good enough; Aboriginal clients would just need relevant sections highlighted. Some of the pharmacists believed that 'dumbing down'[21] the information would not be of benefit, and would only alienate people further. This kind of attitude impacts heavily on all people with low literacy skills, not only Aboriginal people, and makes quality use of medicines more complicated across the board.

Most pharmacists were happy to collaborate with AHW colleagues, but had not taken up the opportunity in the past. Again, most pharmacists were keen to participate in cultural awareness training, but some felt it to be a waste of time, due to the small number of Aboriginal clients they had, or felt it an imposition on their staff's time – one pharmacist said that his young staff members were still at school, had study and other extra curricula activities, and that cultural awareness training would be a significant imposition on their spare time (Stoneman et al. 2007, p.9).

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[21] Note: the purpose of providing literature and information in low literacy styles is not to 'dumb down' the information within, but to provide information in ways that are more accessible for people with little or no literacy skills.

It is pertinent at this point to discuss some other key terms and arguments that emerge through the thesis. The concepts of culture, ethnicity, society and social structures are critical terms which must be unpacked here, for the purpose of clarity. Culture is one of the core themes of this thesis, and is here defined as the values and beliefs or underpinning meanings that distinct groups of people give to life experiences. These beliefs are shared by group members, subject to individual idiosyncrasies, are learned behaviours and attitudes and form the basis for social organisation.

Ethnicity is defined as being the "shared sense of peoplehood based on a distinctive social or cultural heritage passed on from generation to generation" (Aranda and Knight 1997). As Mindel et al (1988) assert: "the core categories of ethnic identity from which individuals are able to form a sense of peoplehood are race, religion, national origin or some combination of these categories". However, as Nagel (1994, p.153) adds: " The location and meaning of particular ethnic boundaries are continuously negotiated, revised and revitalised, both by ethnic groups members themselves as well as by outside observers". Aboriginal people in Australia are not commonly characterised as an ethnic group, but rather as a cultural group. Aboriginal identities are often separated from other ethnic identities in Australia, partially as a protest against a minority or ethnic or multicultural model of Australian society (Pettman 1995) and partially due to an entrenched politics of black and white, which according to Pettman (1995, p.72) "...for many Aboriginal people...is still the salient dichotomy".

With regard to Aboriginal people, Pettman (1995, p.75) asserts: "Their politics and relations with both the state and other Australians are routinely seen as separate, even though they...are now embedded...in the same –increasingly globalised- political economy". Statistical representations of Aboriginal health status are a stark example of how Aboriginal people are ideologically separated from the rest of the Australian population, which is often referred to as 'mainstream Australia' and treated as a yardstick by which to measure Aboriginal health indicators. While this is not unusual in a population health approach, and other groups may also be separated by ethnic status for the

purposes of statistical analysis, Aboriginal people are routinely represented in this way, as against the majority (white) population or the recently-termed "Culturally and Linguistically Diverse Groups" (CALD groups).

In this thesis, society is held to represent the social organisation that exists in contemporary Australia. Australian society is characterised as a multicultural, liberal society (Povinelli 2002) and its social structures then, are those institutions that are representative of that social organisation. The construction of health systems reflect the values and attitudes held by a society, demonstrating the importance of healing and care in a society, and the degree to which a state will provide welfare to its citizens (Baer 2008). The health system also reflects attitudes toward power and hegemony, and dominative medical systems are often characterised by a strong hierarchy of professions, and the obvious and active exclusion of other healers (then characterised as 'alternative' healers or alternative medicine – see Baer 2008). These concepts will be explored further in Chapters 8 and 9.

Summary.

When considering the literature presented above it is evident that cultural difference becomes a convenient scapegoat, when it is someone else's culture that is different. Biomedical culture is largely considered by practitioners as the starting point for all health knowledge, and some would argue that, when discussing biomedical settings, it is only fair to assume biomedicine as the basis of knowledge and information. However, this immediately places those of other cultural backgrounds at a disadvantage, frames them as victims and simultaneously blames them for their own 'lack of understanding'. This is a common defence of the biomedical system, an inherent and necessary feature to ensure the ongoing 'successes' of the system (Humphrey et al. 2001).

The taxonomy of Penchansky and Thomas (1981) usefully unpacks the concept of access into five sets of relationships. Understanding these relations and how they function (or not) in various health care settings assists in creating a more nuanced picture of access barriers. The current health literature suggests that the major barriers to accessing health care services facing minority populations are transportation and the distance to services, cost and lack of private health cover, and language and cultural barriers. Each of these barriers can be examined utilising the Penchansky and Thomas (1981) taxonomy. I wish to examine these issues in relation to Mount Isa, and in particular to further interrogate the concept of cultural barriers.

Cultural barriers that appear to be discussed in the health literature include culturally-embedded practices and attitudes that appear to differ from those held by the majority of practitioners within the biomedical system. Culture is discussed as something which is possessed by the 'other', not something which the biomedical system or practitioners themselves have (Humphrey et al. 2001, Taylor 2003). This is a superficial but pertinent reflection on the ways that the biomedical system operates, often reflecting the core values, attitudes and demography of the majority populations in places where the biomedical model has taken a firm hold (Baer 2008).

The following chapter examines issues of distance, and in particular concepts of remoteness. Remoteness is a relative term, and Chapter 4 will examine the ways that the terms 'rural' and 'remote are experienced by those deemed to be living in rural and remote areas, alongside discussion of official definitions of what constitutes a rural or remote place. The chapter also explores the continued use of the term rural by the government and by the general public, despite the fact that this term is no longer used in official scales. This usage of the term rural may be related to mythology tied to Australia's national identity formation.

Chapter 4

Remoteness.

Plate 4. Flinders Highway (Photo: Kristin McBain-Rigg).

In order to better understand the health system and people's encounters within it in Mount Isa, it is pertinent to discuss issues that impact on rural and remote health disciplines more generally. Issues of remoteness feature prominently in the chapters that follow (see Plate 4). Accordingly, this chapter deals with the ways that 'rurality' and 'remoteness' are defined, and the ways this can influence health. Also examined is the perceived existence of a 'rural' culture in Australia, the fundamentals of which are tied heavily to Australian ideals of a national identity. Indigenous identities in rural areas are highly contested and have identified impacts on individual health and well-being, as well as health program design and implementation in rural areas.

The following excerpt is reproduced from my fieldwork notes on a trip to Normanton in 2007. Names have been changed to protect anonymity.

Liam and I took the trip to drop off one medical student and one pharmacy student who were on rural placement with MICRRH. Normanton is approximately 6 hours northeast of Mount Isa by car. So we have to drive along the Flinders Highway to Cloncurry, fuel up and drive north to Normanton (approx 450 km from Cloncurry).

We stopped at the Bourke and Wills Roadhouse, which is approximately 200km south of Normanton. It pretty well sits right in the middle of the trip, and is one of very few fuel stops on the journey. It sits at a junction of the highway that leads south to Cloncurry, North to Normanton and northwest to Burketown.

The Bourke and Wills Roadhouse had a few fuel bowsers, an eatery and pub, and a caravan park area out the back of the pub – it was like a green oasis in the middle of the red dirt and scrubby bush. It was very quiet on the Sunday when we went through, I think only one other couple passed through and they only picked up some beers. We all piled out, while the proprietor filled the fuel tank of the Four-Wheel Drive with diesel. The students and I made our way inside to check the menu for lunch. There was an assortment of snacks and meals available, catering to the many truck drivers who pass through this spot. The café area held a range of souvenirs and memorabilia, postcards, shirts, hats and pannikins[22] with the Bourke and Wills logo on them.

I explained to the proprietor that we had two health students we were taking to Normanton to do placement. We ordered some meals and went outside to wait for them. He came out to us and delivered our food, saying that the usual cook, his wife, was not on today, but that he hoped it would be alright… The man told us that his wife was unwell and had been "medivac-ed" (medical evacuation) to Mount Isa recently. She had been coughing up blood and the doctors reckoned a valve in the lung had ruptured. The man was visibly disturbed as he recounted what he knew…

He had "done his back" twice in a month and had to drive down to Cloncurry for a Chiropractics appointment. While he was there, his wife had fallen ill and started to cough up blood. He was still in Cloncurry when she was evacuated, and could not be reached by phone. It was not until some hours later, when he returned to the Roadhouse, that he was told the news by his staff. On the Sunday, when we saw him

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[22] Pannikin – a tin cup.

this was as much as he knew about her condition and what had happened. He was so upset, and I was shaken to see such a strong and capable man almost reduced to tears. His fears for his wife were obvious, and the pain of being so far away from her and unable to leave to see her was palpable.

This is one of many personal stories that were recounted to me during my fieldwork. This one demonstrates some of the issues of the 'tyranny of distance' (Blainey 2010). In this case, a man living and working in a remote area was isolated from his ill wife. His anxiety over her condition was made worse by his not witnessing the illness event. He sought out the advice and solace of a medical student in order to reassure himself that she would be alright. Given the lack of specific details on her condition or intimate knowledge of the case, our medical student could do little more than provide a sounding board for the man to recount his tale. Emotions can run high in many illness accounts, and are frequently an important part of the rural or remote illness experience narrative. These emotions are intimately tied to issues of isolation and distance from health care services.

Even for those who are long-term residents of rural and remote regions of Australia, the fear and anxieties that isolation and distance create are very real, but often are not experienced or given precedence in everyday life until suffered in times of crisis[23]. The experience of isolation is relative, and living out here, people are intimately aware of this physical isolation from other places, but it is not a problem for them in the most part. It is not until something dramatic or significant happens that this isolation is thrown into perspective. Illness episodes that require the relocation of the ill body are such events: when people are forced to relocate due to illness, deep reflection about extreme isolation from particular facilities occurs, alongside reflections on the impacts of social isolation for those who must go away for care.

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[23] Veitch (1994) demonstrated that rural people who had had a negative experience in terms of access/accessibility to health care rated the importance of that issue 2-3 times higher than others who were aware of the potential, but had not personally experienced it.

Another aspect of this fear lies in the interactions of people, time and space in isolated regions. The conditions of travel in the region are often quite dangerous or ruled outright impossible. This can be the case when roads or even air travel are deemed impossible during the wet season, or when extreme weather conditions wreak havoc on the infrastructure and roads in remote regions (see Plate 5)[24].

Plate 5. Normanton road sign under water during early 2009 flooding (Photographer unknown, D Pashen, pers.comms., 2009).

After leaving the roadhouse, we continued north to Normanton. At that time, the country along the stretch of highway between Cloncurry and Normanton was very green. There had been a great deal of rain through the area that wet season, and there had been major flooding some weeks before. In fact, when we reached Normanton, we were told by the Director of Nursing at the hospital that the road further north leading to Karumba had only just re-opened that day so many people had been stuck in Normanton for a week or two. The highway that leads to Normanton often floods and goes under the water, as this area is the channel country – it is very flat with few trees and along the highway, the only indications of a human existence are the herds of cows that graze near the highway, and the kilometres of sparse wire fences to keep them in.

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[24] Veitch (1994) demonstrated that rural/remote people rated the impact of weather and road conditions more highly than distance, time and costs on decisions to seek care.

Many sections of the highway have been re-graded and are now double lanes, allowing traffic to travel on bitumen sealed roads in both directions. But there are still some stretches that are single lane only. This can be a bit harrowing for the novice outback driver and traveller, as the sight of a heavy road train coming straight for you is a bit daunting. In situations such as this, it is the accepted etiquette (for reasons of safety, a very practical rule to observe), that the smaller vehicle must move off the bitumen completely to allow the road train through. In the cases of passing other smaller vehicles, both should move partly off the road and proceed past one another slowly to reduce the incidence of stones flicking up off the unsealed road and cracking the windscreen. Needless to say, the edges of these old sections of bitumen are ragged and soggy in the wet season. This can cause vehicles to bog if not moving at a suitable speed, and tyres can be badly damaged if you do not pull off or back onto the road in a spot where the edge is smooth.

Also of concern for many people is the isolation relative to services. In the following excerpt, the description of the main road in Normanton shows the kinds of services available in town and their physical placement relative to each other. It also provides a common story of the everyday difficulties that many people in isolated areas face, in this case fixing an air-conditioning system that provides cooling to one of the convenience stores in town.

We reached Normanton at about 3:30pm. As we drove down the highway that turns into the main road through the town, I remember seeing a BP service station, a large covered Sports and Recreation centre (there is a swimming pool located next to the complex), a set of tennis courts, a lawn bowls club (filled with older white gentlemen in white clothing, playing a round of bowls behind a high, wire fence topped with barbed wire…I wondered if it was designed to keep people out or to contain the lawn bowlers?), a sport and recreation association, a big green building housing a butchery, an Aboriginal women's centre, a Westpac Bank, a convenience store, some small parks, three pubs, a post office and the State-run community health centre. A small blue sign with a white cross on it signalled the way to the hospital. Once turning off the main road, the road to the hospital would be about 2 km. If you did not know that there would be a hospital at the end of this winding stretch, you might never go down this street. It goes through the mangroves that are a part of the Norman River. But, if you just keep going, you drive straight into the hospital grounds...

Later, we went for a drive around town, as the students needed to get a few essential items from the convenience store. We went down to the convenience store to get some milk, bread etc. As I had previously been told, there was a distinct lack of fresh fruit and vegetables available in the store. In a space no bigger than the average convenience store…most of the food available was pre-packaged, frozen or canned, and a heated display cabinet held a vast array of fried foods. I had a chat to David, who was serving me. He was due to take over the business the next day (Monday). David had come all the way from Newcastle (his wife and kids were still there – his son had just started Uni studies in finance). He was struggling to adjust to the heat, which was only made worse in the shop as the cooling system had broken. It would take six months for someone to come and fix it, which meant that David had to set up a multitude of fans and the staff all had wet towels around their necks to try and keep cool. The heat in Normanton is humid with very high temperatures in the 30s and 40s. The Norman River adds to the humidity in the town, as it winds its way around the north-eastern side of town.

The cooling system in this shop is crucial, not just in providing a more pleasurable shopping experience or a place of respite from the heat outside, but is integral to maintaining the freshness and nutritional value of the food. Given that these foodstuffs often have to travel long distances and thus the nutritional value of many perishable items is diminished in this process, it is important to ensure that these items stay relatively cool while on the shelves. These everyday stressors, especially when occurring in series, are significant in the health and well-being of rural and remote residents, and the shock displayed by David at how long it would take the cooling system to be fixed demonstrates the relativity of isolation experiences. While it was not unusual to us, David, having come from a less isolated place, thought this was cruel and unusual punishment.

In Australia, remoteness is measured in order to distribute funding to different areas of the country, according to relative need and sustainability. An analysis of these remoteness measures is important, to provide a political context for the issues in the story above.

4.1. Rural people as a minority group in Australia.

According to the 2006 Australian census, approximately 36% of Australians lived in non-metropolitan areas including regional centres, rural, and remote areas. Rural areas are not heavily populated (there were 260 Statistical Divisions in Australia with less than 1 person per square kilometre in the 2006 census) (ABS 2007b), and thus rural and remote areas often fail to attract many opportunities or government funds that they may need. The way areas are classified as rural, regional or remote is largely defined by geographical measures developed to represent relative remoteness. The term rural is often missing from these scales, but is represented more strongly in literature defining bush or non-urban identity and culture.

4.1.1. Defining Rurality – are rural places more than simply 'non-urban'?

It seems that, by and large, rurality is measured in terms of deficit and deprivation in Australia. Maps are a politically charged statement about how the world is seen and the kinds of people and places that hold power relative to other people and places. Cartography is an important political tool, especially when it comes to funding distribution for government concerns such as health care.

There have been various geographically-based measures developed to help define and classify what constitute rural, regional and remote areas in Australia. The more recent developments, and those scales most often discussed in the past decade, include the Rural, Remote and Metropolitan Areas (RRMA), the Accessibility/Remoteness Index of Australia (ARIA and ARIA+), and the Australian Standard Geographical Classification (ASGC). All of these scales were, at various points in time, government-approved ways of defining rural and remote areas and populations.

The history of such scales reveals much about the ways that government representatives and policy makers conceive of the Australian total population base, and how decisions are made about funding. The Rural Remote and Metropolitan Areas (RRMA) classification was developed in 1994 by the then Commonwealth Departments of Primary Industries and Energy, and Human Services

and Health and was based on population size and direct distance to the nearest service centre. This created seven distinct categories of capital cities, other metropolitan centres, large rural centres, small rural centres, other rural areas, remote centres and other remote centres (ABS 2003, Kelly and Dade Smith 2007, Wakerman and Humphreys 2008). There were changes made to the classification in 2009, which updated the status of many towns and cities to more 'accurately' reflect their current status under the existing RRMA scale. Mount Isa is still considered remote under this scale.

The Accessibility/Remoteness Index of Australia (ARIA) was developed in 1999 by the then Commonwealth Department of Health and Aged Care and the National Key Centre for Social Applications of Geographical Information Systems. This scale defines remoteness according to distance by road to service centres, and produces a sliding scale indicating remoteness. Remoteness is given a numerical rating, and refers to the ability (or lack thereof) to access a wide range of goods and services, and 'opportunities for social interaction' (ABS 2003, Kelly and Dade Smith 2007, Wakerman and Humphreys 2008). The ratings are a continuum from 0 – 12, where 0 equals major metropolitan areas and 12 very remote areas. While this scale is based on GIS data the use of the continuum model fell into question. The scale was further aggregated into five distinct categories, following criticisms that the continuum model was difficult to interpret and poorly reflected 'rurality' as understood by those who live in such areas. The five categories became: highly accessible, accessible, moderately accessible, remote and very remote (ABS 2003, Kelly and Dade Smith 2007, Wakerman and Humphreys 2008).

ARIA + was a further refinement of this scale released in 2001 by the Department of Health and Aged Care and the National Key Centre for Social Applications of Geographic Information Systems. The ratings went from 0 – 15 due to an extension of the categories, including work on an adjustment factor on the weighting for islands to include Tasmania. The category names changed, to reflect remoteness rather than proximity, and included an extra category. The new categories

were: major cities of Australia, inner regional Australia, outer regional Australia, remote Australia, very remote Australia, and migratory. The word 'accessible' was taken out of the scale on the basis of confusion: 'accessible' indicates the opposite to remote, and in a remoteness scale, this was considered too conflicting (Kelly and Dade Smith 2007). The ARIA + has been developed further, and is the basis for the current derivation of the Australian Standard Geographical Classification (ASGC) updated by the ABS.

The ABS discusses these scales on its website glossary of geographical statistical terms. The ABS distances itself from the RRMA scale, being sure to emphasise the fact that this is *not* an ABS scale (ABS 2003). Kelly and Dade Smith (2007) also discuss the RRMA as being a less sophisticated and inaccurate scale. The scale is still popularly used by the primary health care sector to "measure and manage the distribution of national GP workforce, and a range of incentive and training programs, largely because it remains tied to GP legislation" (Kelly and Dade Smith 2007, p.95).

In 2009, McGrail and Humphreys developed a new measure, an "index of access to primary care services in rural areas" to address some of these issues of measurement accuracy. This method collects data within the smallest possible geographical unit. To do this, McGrail and Humphreys utilised a method called the two-step floating catchment method, combined with a 'distance-decay function' (to measure proximity within catchment areas), and a 'catchment capping function' to deal with more densely populated rural areas.

> …access was assumed to gradually 'decay' beyond ten minutes (up to a limit of 60 minutes) because this was seen as a significant spatial impediment…access was capped at the nearest 100 services, beyond which the likelihood of access was deemed to be negligible. (McGrail and Humphreys 2009, p.419)

While this appears to be a more accurate measure, able to detect more nuanced differences between regions, it has not been widely accepted for use, nor has it been adopted by any government departments or statistical units.

Communities of the rural are small scale societies based on an agricultural or pastoral mode of production, driven by the elements of the environment that surrounds them and sustained by the products of the land, often geographically and ideologically separate from urban neighbours. Often and increasingly, it seems that rural areas are facing an outward flow of people, migrating closer to city locations for employment, education, health care and other needs (Larson 2006). In Australia, too, rural places are still largely defined by their geographical and ideological otherness from urban places. But, in a world that appears to be shrinking due to increased communication opportunities, are rural people in Australia as isolated as they once appeared to be? Sociological literature (Marsden et al. 1990, McMichael 1994, Lobao 1996) suggests that these rural communities have been global for some time, both as producers to world markets and as consumers. However, in measures designed over the past decade or two, Australian rurality, it seems, is most often defined by deprivation and deficit.

Newer scales do not actually define nor use the term 'rural', yet it seems that, due to its use in popular language, it is still a part of health discourse. In 2008, the Rudd Government established the Office of Rural Health under the Commonwealth Department of Health and Ageing Primary and Ambulatory Care Division, despite the fact that rurality had become more of an indicator of the degrees of remoteness in official measures.

What this raises is an interesting perspective on the relative powers of the medical profession and the health industry as a whole. Only in health, and especially when we discuss GP workforce distribution issues, is the 'rural' still highly significant. All other scales and officially recognised forms of geographical classification systems (developed by government departments, recognised national institutions and the national bureau of statistics), are abandoned within health for an 'old and outdated' (Kelly and Dade Smith 2007) model of measurement. The RRMA tie to legislation on workforce placement means that this model remains a legitimate way of seeing regional Australia. And, this allows rural health to remain a legitimate item on the national agenda.

Because we still measure the 'rural' in health, we can focus programs and initiatives at 'rural populations' who respond differently to health initiatives and may even have unique health problems. Wakerman and Humphreys (2008, p.22) discuss the fact that, while rural health has been a recognised issue on the national agenda for some thirty years, the past ten years have seen the most activity on health issues in rural areas.

A significant event for the rural health agenda was the official endorsement of the National Rural Health Strategy by the Australian Health Ministers Council in 1994. This health strategy was designed to: "provide a coordinated framework for ensuring equitable access to effective health care for rural and remote communities." This was going to be achieved in three steps: by 'providing appropriate health services'; through 'promotion of measures to maximise health status among rural and remote residents'; and, with the 'adoption of strategies that minimise barriers and problems that impede the delivery of effective health care' (AHMC 1994).

It is worth noting that this strategy was the first in Australia's history to attempt to systematically target the specific health needs of rural and remote populations. At the same time, "...a number of peak rural and remote health professional bodies became more active...lobbying on behalf of their constituents...including Rural Doctors Association of Australia (RDAA), The Association for Australian Rural Nurses (AARN), Services for Australian Rural and Remote Allied Health (SARRAH), the Council of Remote Area Nurses of Australia (CRANA) and the National Aboriginal Community Controlled Health Organisation (NACCHO)" (Wakerman and Humphreys 2008, p.23).

Many of the programs developed in the early 1990s were retained and rebadged by the Howard-era Liberal Government to make up the General Practice Rural and Remote Program. The Australian National Audit Office in 1998 highlighted the failure of previous mainstream health promotions, initiatives and programs to have the desired effects in rural and remote areas, which led to an 'explosion' of programs specifically designed to target rural, remote and Indigenous populations. At the time that Wakerman and Humphreys (2008) wrote their chapter, there were

more than sixty such programs in operation. However, in more recent years, many lobby groups voiced concerns about the direction that the government was taking, fearing that rural health was soon going to be subsumed within the mainstream and general 'primary health care' agenda.

The Rudd-era Labor Government announced the establishment of a Commonwealth Department of Rural Health in 2008, and one of the initiatives planned were GP Super Clinics, one of which was earmarked for establishment in Mount Isa (but which has yet to be built). Whether this initiative will lead to more general practitioners working in Mount Isa or not remains to be seen, as discussed further in Chapter 6.

It seems that rural health has been placed very firmly on the federal agenda, and in Australia's collective imagination for at least the past 20 years. But the concept of 'rural' is not just the imagining of the health fraternity. Could it be that, Australians need a notion of the 'rural' in order to define themselves as a nation? Perhaps the 'rural' communities of Australia have become a 'discourse community'. As Kapferer (1995, p.70) discusses, identity discourse in Australia is a strong force which shapes communities, and can drive the policy and legislation that in turn bureaucratises and authenticates 'communities' of individuals.

> Discourses in Australia concretise what they construct. They create communities in fact whose social and political reality is forged through the imagination and style of the discourse itself. Encouraged in the administrative and policy shifts of the state, the ever-expanding field of discourse about identity is also integral in forcing the shifts which contribute to the energy of the discourse over identity and, indeed, the construction of discourse communities. (Kapferer 1995, p.70)

The discourse concerning the rural in Australia celebrates a sense of freedom, struggle and often a simpler, more 'quaint' existence. These aspects of rural life are among the popular images portrayed in entertainment and popular culture. While life in many rural communities is far from the ideal, these romantic notions continue to inform popular representations about rural/remote/outback Australia.

4.2. Rurality as culture: Rural identity development in the Australian context.

There is a significant body of literature that discusses the development of rural identity and culture in Australia. The "outback" or "bush" is often referred to and can be related to both rural and more remote areas of Australia. Mount Isa is most often considered to be part of the outback. The concept of "the outback" has been and continues to be a strong component of how Australia as a nation defines itself. Australian nationalism can be traced to European roots as a penal settlement and then to the development of rural industrial pursuits such as pastoralism[25] in rural and remote regions of the country. There was a tremendous dependence on rural industries for Australia's economic growth, certainly from colonisation until the late 1950s (for example, Clark 1996; Blainey 2010).

The "Outback identity" is largely traced back to the early nineteenth century, following the expansion of pastoral pursuits into areas such as north-western Queensland. It is an identity tied to a profession and its ensuing way of life, and the beliefs and values that accompany this line of work, although it has transcended time and professions, to become a more generalised view of 'essentially Australian qualities'.

In considering the development of rural identities in Australia and the resultant impact that these identities have had on the national psyche, it is impossible to move forward without an examination of the "The Australian Legend" by Russell Ward (1966). This book was largely seen as a classic, and examines the development of a myth, a myth of a uniquely Australian identity. Ward points to the development of the Bushman legend in particular as an early example of identity formation of the nation, which has faced challenges from many disciplines, including cultural studies, feminist studies and others, but which in self-reporting may nevertheless retain

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[25] Livestock raising as an economic activity.

much of its original substance, especially with regards to an ethos of egalitarianism and mateship (which Ward believes has carried through from the bushman to the bushranger to the Anzac and beyond with little change).

According to Ward (1966), the archetypal Australian characteristics include practicality, not only valued in the self but also a measure of the strength of others, and an ability to improvise, rough and ready manners, an outright dislike for those demonstrating any kind of affectation, swearing "hard and often", parochial, gambling and drinking heavily, enduring stoically, being sceptical about the value of religion, intellectualism, or other cultural pursuits, egalitarian to a turn, fiercely independent, hating officiousness and authority, being hospitable, cherishing one's mates and sticking by them through it all, even if they may be wrong (Ward, 1966, p.2).

The reasons provided for the maleness of this myth is that it has predominantly been men that went forth to the frontier, as this was largely represented and considered as being 'no place for a woman'. The nomads of the frontier were the pastoral workers, predominantly Irish convicts and ex-convicts, who displayed these traits. As is pointed out by Carroll (1982, p.144), these traits have all come from somewhere else and are not distinctly Australian; this is his main criticism of Ward's work.

There is questionable value in attempting to homogenise people in a particular part of the country and, in particular, trying to summarise their basic character; many authors question the ongoing value and validity of the myth that Ward describes (Carroll, Davison, Dempsey, and Hirst, all in Carroll 1982, Alomes et al. 1991). However, in rural and remote areas of Australia, many of these traits do exist, in men and women, and are self-reported as behaviours and ways of life (Judd et al 2006). Many of the qualities are demonstrated on a regular basis in places like Mount Isa, and at times are excused or, at worst, encouraged, regardless of how offensive or dangerous they may be. The perception and acceptance of these character traits and behaviours as 'natural' and 'naturally right' for Australians (or at least, *some* Australians) could have significant impacts on the

health of rural people and, possibly one of the most damaging aspects of this myth, is that these characteristics may be celebrated and revered when performed by a white 'Aussie' male, but not when they are demonstrated by women or Aboriginal people. In fact, these traits are often viewed as abhorrent and embarrassing when displayed by anyone but a white male in 'the outback'. When women and others exhibit such behaviours, it may act to destabilise the normative rural masculinity that is described by Ward and others (Liepins 2000, Campbell 2006, Courtenay 2006, Alston and Kent 2008, Alston 2010).

Liepins (2000) asserts that Australian men are 'made' in the Australian Agricultural industry, but a similar sentiment could extend to the Australian mining industry (also a hegemonic masculine world of power, wealth and resource control and accumulation). I argue that the mix of agriculture (or pastoralism) and mining industries in this region creates an even stronger normalisation of hegemonic masculinities. Women and excluded others react, attempting to destabilise this condition of rural life, by enacting behaviours which were previously reserved for rural (white) men only, such as those postulated above.

The character trait of stoicism is not only a feature of rural men, but is also widely reported among women, who are expected (if they are good and decent women) to care for their husbands and children first, and never be seen to put themselves before those who need their care (this is a pressure often applied by the women themselves, or comes from other (often older) women in the community) (Dempsey in Carroll 1982, pp.139-141). This has led to women in many rural areas self-reporting that they have often remained ill and tried to struggle through by themselves rather than seek help or medical advice (Crosato and Leipert 2006). This is a significant factor in the uptake and use of medical services, as many people perceive the early consultation of a medical practitioner for many illnesses or disease symptoms as being 'a bit soft', or showing weakness of character.

There may be evidence of a 'culture' of heavy drinking associated with this bush identity, reported in the myth as (certainly among pastoral workers) long periods of sobriety during work followed by extensive and harmful binges of excessive drinking, exhibited in behaviours characteristic of excessive alcohol consumption (Ward 1966, Carroll 1982, Brady 1988). However, it is no longer only alcohol that is cause for concern; illicit drug use and inappropriate use of legal drugs is on the rise in rural and remote Australia, and in excess, can have adverse consequences for entire communities (Australian Institute of Health and Welfare 2002, p.52). These excessive consumption behaviours are characterised within population health discourse as significant risk factors for chronic disease development.

In a more recent study, McColl (2007, pp.107-8) discusses the "historical and current characteristics" associated with bush identity, such as "…self-reliance, resilience, independence and stoicism…rarely admit defeat or ask for help" (all qualities listed in the myth above – practicality and independence, perceived innate toughness) as they relate to the acceptance and uptake of mental health services in outback Queensland. In her ethnographic study, McColl found that bush identities have become a valued part of bush society, and that in themselves, "…the very nature of bush communities could foster mental health problems that are different or unique to the bush. Therefore the treatment of such problems needs to incorporate knowledge of bush culture and tradition" (McColl 2007, p.109). Lack of control over what appeared to be externally generated stressors (economic downturn, closure of businesses in the community, unemployment, antisocial behaviours, resulting in depression, injury and violence) was cited as a major negative impact upon mental health in the subject community. Cultures of self-reliance and stoicism can lead to unhealthy behaviours, where shame and embarrassment at asking for help with 'personal' problems leads to inhibited uptake of mental health services, and in turn can lead to much more dangerous behaviours that cause accidents, injuries, or even death (McColl 2007, p.110).

4.2.1. A rural culture of health care.

Representations of a rural culture and associated health behaviours are evident in my interviews with health professionals, and include themes such as higher levels of need and different coping mechanisms. In an interview with Harry (February 2008), a Paramedic and district Ambulance manager, he noted:

> *People are more resilient out here. They get themselves places...people cut their finger in Brisbane and they need an ambulance, and it had better be an intensive care paramedic! Out here, people lose one leg and go, "No, No, I'm right, I'll drive there". People with horrific injuries drive themselves. People with bloody fish hooks through their arms, not little fish hooks, big fish hooks, and they just get there...she'll be right.*
>
> *A bloke in Barcaldine fell over on Friday afternoon, about half past five. Rings me Monday morning about eight o'clock, he says, "Is it too early to ring?", I said no. He said, "Oh gawd. Do you think you could come around and see me...I fell over in the bath Friday." I said, "What have you still got pain?" And he said, "No, I'm still in the bath"! I said, "Mate, wave". He said, "Why?" I said, "I'm looking out my back window I can see your house. Why didn't you ring?" He said, "Oh it was the weekend I didn't want to disturb you...I don't like the nurses working too hard". I said, "Have you been in that bath this whole time?" He said, yeah....hadn't eaten...just stuck it out.*
>
> *So people are much more resilient out here. And put up with a lot more, and nothing's a problem.*

While this is a good example of the toughness for which rural people are famed, such ideas can have very real impacts on people's health. The ideas in this discourse give pride to the 'little Aussie Bush battlers' stereotype and emphasises the value of stoicism in the face of adversity. The interview also causes recall of the issues raised earlier in this chapter: attitudes towards personal safety and health, while inspiring and amazing to those who find rural struggles inconceivable, may be detrimental to individual and community health status. By staying in the bath, injured, for three days, this man could have become very sick, or caused his injuries to become worse. But, he did it, rather than inconvenience anyone else with his pain and suffering in what could be described as an over-extension of the traditional sick role[26].

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[26] Term developed by Talcott Parsons. As summarised by Germov (2001, p.14): "...social expectations tend to dictate how an individual sick person is expected to act and is meant to be treated." In this case, the over-extension of this role relates to those who continue their normal

Medical providers - who are often amazed at the ways that people in rural and remote areas will put up with pain regularly, and how they sometimes go to extraordinary lengths to exercise agency and maintain their independence – are appreciated in small towns for the services that they can provide. On the other hand, the discourse of rural stoicism undermines the importance of health professionals or that health practitioners are the best people to deal with issues of pain and suffering. It challenges the idea that medical professionals are the experts when it comes to the health and wellbeing of rural people, and reinforces the idea that rural people hate officiousness and authority. By taking the role of care out of the hands of medical professionals until the very last minute, rural and remote people take back control over their lives, circumstances and health (sometimes to their own detriment).

Summary.

Based on the discussions throughout this chapter, it seems that in many ways, representations of rural, remote and Indigenous health issues create a picture of 'slow death' in the vein of work by Lauren Berlant (2007). Berlant (2007, p.754) defines the phrase 'slow death' as the:

> ...physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence. The general emphasis of the phrase is on the phenomenon of mass physical attenuation under global/national regimes of capitalist structural subordination and governmentality.

In spite of the many years of advocacy and program development recognising the specific needs of rural people, rural health is still represented according to deficit, where rural people exist rather than thrive. Such representations of Australian rurality are "simultaneously at an extreme and in a zone of ordinariness, where life building and the attrition of human life are virtually indistinguishable" (Berlant 2007, p.757) but also could be representations of intentional subjects, where "a manifest lack of self-cultivating attention can easily become recast as irresponsibility,

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functions in spite of the expectations placed on them in times of illness, in order to counteract any charge of being considered a lesser-functioning person, and therefore of lesser value to society.

shallowness, resistance, refusal or incapacity; and habit itself can begin to look deeply overmeaningful, such that...just being different can be read as heroic placeholders for resistance to something..." (Berlant 2007, p.757). It is possible to apply a similar conceptualisation to representations of Indigenous health and other remote area political agendas.

Another related point to consider here is that, the historical development of economy in this region (as outlined in chapter 2), and the subsequent systems and infrastructure of health that accompanied this development are a demonstration of a frontier-style of sovereignty (Berlant 2007). Sovereignty in Berlant's (2007) exposition is questioned in the context of the ordinary life time and space, which gestures toward a transformative vision of human agency, where temporality is conceived of as "that of ongoingness, getting by, and living on, where the structural inequalities are dispersed, the pacing of their experience intermittent..." a representation that is reminiscent with popular representations of rural, remote and Indigenous communities in health and other disciplines in contemporary Australia.

Aboriginal people in this region have been variously incidentally included or explicitly excluded from the creation and subsequent retelling of histories of the region. Colonial retellings of the region's history render Aboriginal contributions as merely incidental and of limited economic contribution (or, where this is acknowledged, it is often belittled as being quaint Indigenous knowledge that led to significant frontier discoveries by pioneers, see Furniss 2001). In current health policy environments, it is unlikely that the values of Indigenous Australians in this region will be viably incorporated into health policy. It seems to be of little consequence what concepts like Aboriginal interconnectedness and the relativity of isolation present to a health system that variously disregards or exploits these ideas for economic gain. Rather, the imposition of frontier-styled control over environments, attitudes of life-building, and the subsequent definitions of remoteness applied to regions that Aboriginal people live in, contribute to the continuing slow death (Berlant 2007) (or ongoingness and getting by) that many Aboriginal people in remote

regions are exposed to. These structural developments affected on rural communities may have contributed to the structural ill-health of many Aboriginal people.

Alternatively, this kind of definition of agency or sovereignty could be said to render subjects as nothing more than the victims of locational disadvantage and the slow death of an ordinary reproduction of life in adverse circumstances, where each choice and decision is one more step on the road to an ultimate extinction. However, it could also be a site to consider the ways that structural inequalities have developed historically, and perpetuated this sense of slow, intimate and painful death of rural and remote populations, in particular the ways that these frontier developments have impacted upon the health of regional Aboriginal people. The upshot of such a forecast is that rural, remote and Indigenous communities become especially different, and are allowed to be sites of innovation and change.

Rural health is an intimately political and ideological agenda, and the impacts of this agenda directly affect the lives of rural and remote residents and the livelihood of rural and remote communities. Rural identities, constructed in and about Australia's regional communities, influence the behavior, attitudes and health outcomes of people located in rural and remote communities in Australia, and impact significantly on the ways that Australia defines itself as a nation.

Considerations in this chapter of concepts regarding individual agency turn, in the following chapter, to the first of the three Mindful Bodies concepts: the individual body. The examination of three case studies allows insight into how people experience illness and health, in an everyday sense. It also highlights the ways that government policies and social and cultural events can impact on individual health and well-being, via the exploration of individual narratives featured throughout the case studies.

Chapter 5

The individual body – stories of individual suffering and care.

The stories of individuals and their immediate caregivers provide a poignant and important insight into the impacts that medical practices, procedures, attitudes and system inadequacies have in an everyday, lived sense. The element of individual stories of experience and suffering is central in the Mindful Bodies approach within Critical Medical Anthropology, providing voice to the participants experiencing a phenomenon. This chapter demonstrates the ways that the categories set forth by Penchansky and Thomas (1981) provide arbitrary boundaries around issues that are, in lived reality, far more complex and entangled than they appear when split up according to their taxonomy.

The ways that health professionals and administrators discuss barriers to health care, in terms of small, manageable issues and tasks, is simply not the same as the ways that individuals engage and experience the system itself. Rarely is just one of the issues in the taxonomy *the* problem. The lived experience of journeys through the health system show the ways that all of these issues impact upon one another, ultimately shaping the attitudes of those the system seeks to serve, and determining whether or not these people will return, if the need arises.

An examination of three biographical accounts of pain and suffering reveals that journeys through the health care system are emotive and significant experiences for the individuals concerned. The following case studies from my fieldwork have been selected to demonstrate the often mundane character of illness episodes. The stories come from interviews and observations in the lives of three people and those who surround them. The names of the participants and their family members have been altered to protect their anonymity.

The first story belongs to Douglas, an Aboriginal man caring for his mother who was diagnosed with cancer. The second story comes from Anna, an Aboriginal woman, wife and mother who has

finally had enough of relying on the public system for health care, and who has taken up a limited private health policy. The third story illustrates the journey that James, a non-Indigenous man, and his young family experienced when trying to fix his ongoing and medically chronic back pain. I have included James's story to demonstrate that access issues impact on all rural and remote residents, although they may experience them differently. In James's case, high levels of health literacy and insight into how the health system operates (including having private health coverage) have not exempted him from struggling with the health system. While Douglas and Anna tell stories that are reflective of the experiences of many Aboriginal people, James's story provides an opportunity to examine the effect of living in a remote area even on the health status of people who can afford good health care through private coverage. Each of these stories are similar in terms of the access issues outlined by the 5A's taxonomy (Penchansky and Thomas 1981), yet illustrate the various ways that people from different cultural and socio-economic backgrounds experience those barriers within the same health system.

No one discussed in these stories has died, or even been in particularly harrowing circumstances. Yet, while their experiences of care share many similarities, the stories also serve to highlight glaring differences in experience, which may be related to a number of access factors. The stories show that such experiences may shape further engagements with the health care system. This examination also allows an insight into the ways that critical medical anthropology can add human voices to the statistics that drive the health care system.

5.1. Case Study 1: Aboriginal experiences of the public health system – Douglas's story.

It was often the stories of carers and caregivers that I was exposed to in the course of my research. In this story[27], the carer was Douglas, an Aboriginal man and son of a woman diagnosed with cancer. His story as carer documents many of the issues that are commonly experienced by rural and remote patients in the biomedical system, particularly Aboriginal patients. The impact of remoteness on the health care experience can be profound, and certainly, for those suffering or those caring for the suffering, can have significant impacts on emotional, social, and financial resources.

Over the past seven years, I have spent a great deal of time with Douglas. Mol (2002) regards those informants who have the insight and reflexivity over the events and experiences of everyday life as being very valuable in creation of stories of pain and suffering, despite the assessment of Young (1982) of the need to be wary of the thoughts of ill people. Douglas was not himself ill in this story and had many opportunities to consider the events and experiences that he and his mother had in her time as a patient, and in his time as her carer. Douglas is a deeply reflective man, who describes his life philosophy as being somewhat Buddhist in quality; often calm and reserved, he experiences life genuinely, giving room to emotional responses and then giving equal room to considerations of these emotions. His deeply analytical considerations of the events described below played a major role in my interpretations of these events and the emotional impacts that they had on Douglas's sense of wellbeing.

Douglas's story begins with a visit his mother, Shirley, made to the dentist in July 2008, to check up on some pain she had been feeling in her teeth. She attended the public dental clinic at the

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[27] Recreated from an interview with Douglas in July 2009, and ongoing observations.

hospital, and the dentist there believed that the pain was something more than a toothache. He said she would need to go to Townsville to be checked more thoroughly.

Shirley went to their family GP, who arranged a referral letter and forms to Townsville, for her to have a biopsy on the tooth and jaw. These letters and forms had to be done so that the travel arrangements could be made through the hospital under the Patient Travel Subsidy Scheme (PTSS) (discussed in more detail in Chapter 7, Section 7.1.1.1). While this scheme assists with the costs of travel for care, it can be challenging to negotiate, especially for carers or escorts.

Douglas reported that there were many forms to fill in, and the travel office did not want to accept them from him. They were not keen to send him to Townsville as his mother's escort, as the biopsy was not deemed a life-threatening situation. However, Douglas maintained that while the biopsy was not a life-threatening situation or procedure, he felt strongly that his mother would need support from the beginning of the process, including the early procedures for diagnosis of the problem. He went back to the GP, who wrote another letter of referral to the clinic for the biopsy including a recommendation that Douglas escort his mother on this journey.

Douglas's first encounter with this system was less than satisfactory for him, and the problems continued. With each trip that was required, it seemed there was something else that would get in the way of the travel being a safe and easy process. When it came time for Douglas and his mother to travel back to Townsville to discuss the results of the biopsy, the local travel office was closed for a holiday season break. Douglas called the hospital to try and find out what would happen with the travel arrangements over this period. He was put through to the Nursing Unit Manager (NUM) who told him that her office would organise the travel for them. Douglas walked the forms over to the hospital, and two days later all of their travel arrangements were reported as finalised. However, upon arriving at the accommodation in Townsville, Douglas was told that the hotel had not been expecting him, there was no room booked for him. His mother was booked into a single room, and as the hotel had no spare rooms available, Douglas would have to sleep on

the floor. As Douglas said with some frustration in his voice: "All these little complications come up..." (Douglas, interview July 2009); this was a common theme throughout his interview and his key argument was that it is these small frustrations and complications that all add up to produce a less than satisfactory experience.

These kinds of encounters, while often discounted as being typical of arrangements made within bureaucratic systems, are the kinds of encounters that only add to the pain and frustration of those who have to travel away for health care. While many people would write these encounters off as being unusual or the occasional mistake, for Douglas and his mother they made an already compromising and difficult situation all the more difficult. Veitch (1996) and Kelleher (1996) have both demonstrated that this is not a rare occurrence. Approximately 40% of people in these studies reported having difficulties similar to Douglas's reported problems when they travel away for care (Keleher 1996, Veitch 1996).

While there were many other occasions of trouble with accommodation and travel procedures, one of the other features to stand out about Douglas's story was the sheer number of trips required for his mother's care. There was the travel to Townsville for her initial biopsy, then to receive the results of the biopsy and discussion of the diagnosis, again for the initial treatment period, further treatment due to changes in regime, and ongoing consultations with medical practitioners. There were also two trips to Brisbane for radiation treatments that could not be delivered in Townsville. All of this has punctuated Douglas's life from July 2008 to the present (August 2011).

Other issues that created complications for Douglas and his mother included the cost of being away from home. While the PTSS covers partial payment of accommodation and travel costs, it is a subsidy only, which means that the remainder of the expense for these costs has to be paid by patients or their families. Also, while there was public transport available in Townsville, and Douglas discovered (half way through their longest visit) that there was a bus provided by the Cancer Council to transport patients and carers to and from the hospital for their appointments,

(supplemented with an occasional[28] shopping day), Douglas's experience was that the need for a private vehicle was high.

Besides being a costly exercise for the long term visit, even short stays involved some cost to the traveller. This included taxi fares, from the airport to accommodation or the hospital. The Townsville hospital is now further away from the Townsville airport site than it used to be, and therefore the taxi fare has increased. Taxis were often the only transport option available on these short visits, due to the need to travel quickly from the airport to appointments (because of flight scheduling). The pressure was significant for Douglas if appointments were changed or ran late on occasions when they were due to fly in and out on the same day. There are limited flights between Mount Isa and Townsville, and to miss them would cause considerable cost and inconvenience.

The pace of being in places like Townsville or Brisbane is often perceived as a significant change to the pace of life in Mount Isa, and is often reported as tiring. Besides this, being in an unfamiliar place while dealing with a major diagnosis and illness treatment is a very stressful event for patients and their carers, as discussed in the literature in Chapter 2 (Section 2.2.1, specifically Veitch 1996, Harris et al. 2004).

The burdens of being isolated from familiar social networks and kinship networks places added strain on relationships and can place an unfamiliar level of burden and obligation onto one or two people. In this case, Douglas was deemed the most fit of Shirley's children to cope with this process, and in many ways, he was far better equipped to deal with the health and support systems he faced for his mother than many of his other siblings. As he said, "My other siblings just weren't functional through this process"; they were failing to come to terms with what was happening to their mother, and could not deal with it emotionally.

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[28] Occasional = once a week

Douglas's prior exposure to government departments (having worked in and around many before), gave him some preparation and insight into the kinds of bureaucratic boundaries and barriers that he would experience in helping his mother negotiate the health care system. Douglas also felt that, having dealt with serious illness with other relatives in the past exposed him to issues of grief and loss. He therefore felt he had developed good coping mechanisms for himself around such issues. Douglas is largely seen by his family (and by his own admission) as an advocate, often called upon to assist family members through various crises and dealings with government departments. The pressure of advocacy and agency on behalf of others takes its toll, and although he feels that he only really broke down once in the whole journey, Douglas admits feeling stressed and drained by the entire experience.

Douglas reported struggling with issues of communication, including the attitudes of health staff toward him as a carer and as an Aboriginal man. Douglas is the first to say that "I don't jump to the conclusion that it is because we are Aboriginal, but...sometimes it seems that they don't seem to understand Murris or Murri[29] families". Douglas tried to maintain open and honest communication with all of the health professionals that he met, but did not always feel that they tried to maintain the same with him. As a carer, he found it difficult to remain engaged in the process, as some health professionals blocked his efforts. Despite asking all of the health professionals that he came into contact with if it was okay for him to fully participate in this process with his mother, it quickly became obvious with some health professionals that this was not a familiar or welcome concept.

Douglas had predicted that there may be communication issues between health professionals and his mother, not least of all because she was dealing with a major diagnosis. Clashes between 'murri' English and the language of specialty medical disciplines did cause some concern. Douglas

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[29] A generic term used by Aboriginal people in Queensland, meaning 'Aboriginal'.

reported that his mother had often misinterpreted what the doctors had said to her, and also reported that some of the health professionals he dealt with handled this better than others. He struggled with the variable speed of the whole journey – parts moved too fast, while other parts moved too slowly. Upon diagnosis of cancer:

> *Douglas: So we go to the meeting with the doctor the next day…he says, yes it is cancer. So that's the first sort of acknowledgement that that is what it is. So Mum's dealing with that, and I'm dealing with that as her son and carer, so we're going, "ok…." He [the doctor] says "So what we're going to do is, after here, I'll get you to go over to the cancer unit and the team that will look after you in terms of treatment and the oncologist there will discuss the next step for you". So that's a bit of a shock.*
>
> *So we go over to the cancer unit…we go in [to the consultation room] and there's six people [health professionals] there, so that's a bit confronting, 'cause you've just been told that you've got cancer and then you're confronted with six people and you think, well what's this about?! Must be something wrong…'cause we weren't told…Why they need six people? That's the reaction! That was my reaction!*
>
> *So they introduced themselves, one's an oncology surgeon, one's a chemo specialist and one's the radiation person…one's the registered nurse, one's the speech pathologist and one's the nutritionist, dietician. So we're talking … [long pause] … I asked a question about why a speech pathologist was here, because I didn't understand, so I was thinking something is going to happen to her speech. The speech pathologist goes, "No, my role will be about helping your mother and supporting her during and after the treatment in terms of swallowing." I said, "Oh, okay, that makes sense."*

In his communications with the senior oncologist, Douglas was concerned:

> *I realised he has no…social graces at all…and I think we might have scared him because we are black! So he's talking and I asked him a question and he gets frustrated, and physically frustrated … [shows and describes his physical demeanour] he obviously was nervous. And the other two doctors, reading them, they picked it up straight away … so they responded to my questions. 'Cause I couldn't figure it out, he looked uncomfortable, but maybe that's his character. So, I've been with him for several months now, and I've just worked out he's just got no social graces!*

At the end of the consult with the whole team, the oncologist advised that he would send Douglas and Shirley home to Mount Isa, and then in six months get them to come back again to discuss treatment options. Once the decision had been made, they were advised that there would be a long wait until the treatment would commence. This created quite a bit of anxiety, not only for Douglas and his mum, but also for his siblings and extended family, who all attempted to contact and angrily demand answers from the oncologist. According to Douglas:

We were both just sick of travelling at that point. But, we had to worry because it is so long…cause at that stage they were saying that yes it's cancer…had to go to Brisbane for a CAT scan, but that showed there was no spreading. But if it spreads…it's a very quick progression…to death. So we're sick of the travel but the quicker we can get to it would be the best.

On the following trip (an overnight stay) the oncologist presented them with three treatment options – an aggressive option, a less aggressive option, or to simply do nothing. He waited for an answer. Douglas insisted that he and his mother be given at least twenty minutes to discuss all of the information they had been given, in order to make the right decision for his mum.

Douglas: The doctor said, in a very cold manner too, "You've got three options: aggressive, less aggressive or do nothing". [Nervous yet dismissive giggle from Douglas] So Mum asked: "What's the aggressive treatment?", and he said a combination of radiation treatment, chemotherapy and, oh … well not actually true chemotherapy because of her history she wouldn't take [to] it but they had an experimental drug or something … but he said that will knock you around. It would be intensive over 9 weeks.

So we asked what's the less intensive one? It would be no chemo, cause that would be too rough, but we'd hit you with radiation. But what that would do, that would not be a strategy of trying to get rid of it, because it won't, but what it will do is it will decrease the growth. So you'll come out of that treatment with… the cancer won't be gone but the growth will be smaller and less painful and all that type of stuff. But it will still be there.

Or you do nothing; that was the third option. And he said, "So what do you want to do?" Then I said, "You need to stop…You need to give us time to process what you just told us there." And to allow Mum some space to make a decision there, because she's still dealing with the diagnosis, you know? 'Cause it was only like a couple of weeks after diagnosis and she's still trying to work out what that means.

Douglas's mother chose to pursue the aggressive treatment. In the discussions over what that would mean:

Douglas: Mum tells him [the doctor] aggressive treatment, and we start talking. And then I said to him, and this is where it starts to get, really getting draining…I think when you have awareness of social graces (giggles), you know those quiet times in a conversation where you might raise a question or interrupt or whatever, a quiet space happened in the conversation, so I go, "Oh Doctor, can you…" and he cut me off… So I reckoned well I'll shut up. But then as he finishes the conversation, he says, so do you have any questions? And I went, "Yes I do!" …My first question then was, "Firstly, is it ok for me to ask you about my mother, Doctor? 'Cause I am getting the message that it's not!" Because he basically was implying in that conversation with mum, that this is about you [Douglas's mother], I am talking about you, I'm not interacting with you [Douglas].

Douglas reported that this kind of encounter continued throughout the process.

Douglas and his mother were away from Mount Isa for over four months during the treatment process. Additional personal issues arose for Douglas at that time:

> *So, there's a whole lot of things that came on board for me then. I made a decision, well I have to go back to work, I've got to sort work out. Do I stay with you for these six months? Which meant talking to family, which meant, well, nobody was actually available to be there with mum. And even those ones that could be there shouldn't be there, if you know what I mean.*

Luckily, Douglas's employer had a base in Townsville that he was able to work at temporarily while caring for his mother, and he had a number of weeks of annual leave pay owing to him.

> *Douglas: So we sorted out accommodation. One of the biggest issues then became…transport. Because the treatment then was daily, and then on Tuesdays and Thursdays at the beginning, twice daily. So you had to be getting…she'd do her chemo in the morning, radiation in the afternoon. And for the first five weeks it was going to be chemo twice a week, on those two days, and radiation for the other days [of the week]. What that meant though, is that we had to be up there [at the hospital]. So, back and forth to the hospital.*

Douglas and his mum hired a car for the longest stay, in order to be able to get back and forth for appointments and have a degree of flexibility in their accommodation choice. This also allowed them to 'have a life' outside of the treatment regime, including being able to visit friends and family at will. Douglas needed to commute for work and to go to appointments at support services, such as Centrelink and the Department of Housing. The Cancer Council bus could not provide this level of personal freedom, and the public transport system in Townsville did not fully support their needs and is provided at a cost. Therefore, private vehicle hire was the best option available for their needs.

Halfway through the treatment period, Douglas's stress levels were at a premium. He was working, caring for his mother, transporting her to and from treatment, dealing with other family members and their emotions, and experiencing frustrating and disrespectful encounters with health professionals. Douglas tried to be strong for his mother, but the sombre atmosphere of the various clinics and the people within them made that difficult for him. He tried to keep her spirits up with humour and mundane (but not morbid) conversations, which (he perceived) was seen by

others as being inappropriate in that space. This all contributed to a high level of stress. Douglas felt poorly supported by clinical staff, especially on the particular needs of his mother as an Aboriginal woman. Compounding this stress was a perception that his needs as an Aboriginal man caring for his mother were disregarded.

The role of carer is a complicated one in health care settings (Kessler et al. 2005, Hooper and Ong 2005). It is made potentially more complicated when the recognition of the important role of carers in Aboriginal families is disregarded by health professionals (Kessler et al. 2005, Hooper and Ong 2005, Stoltz et al. 2006). In caring for his mother, Douglas was acting on behalf of his mother and his family. He became witness (often in ways that made health professionals uncomfortable) to the events of the illness experience, and became the conduit of information to the other members of his family. Douglas undoubtedly played a very important role in communicating the illness experiences of his mother to his siblings and other community members. Douglas in most cases was the *sole* witness and carer to Shirley's illness episodes, and thus carried a burden of responsibility.

In Douglas's case, his mother (and siblings by default) had chosen him to be the conduit to facilitate information exchange between herself and the health professionals caring for her. Douglas retained the knowledge and memory of the illness episodes that occurred throughout Shirley's treatment. Even though Shirley was experiencing these episodes, she was not always able to accurately recall the progression of these illness episodes. On the other hand, Douglas, being an observer or witness to such episodes, could recall the time, date and severity of the episode with a high degree of accuracy. His accounts were often discounted by medical practitioners who undervalued the depth of information that he could provide.

Douglas's case is not unique; Devitt and McMasters (1998a, 1998b) recorded similar experiences and journeys in their assessment of the situation of Aboriginal Renal patients in the Northern Territory. The role that family played in worrying for the ill person (particularly in regards to

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communication), and the complementary role played by some members in remembering the information relayed to patients were important elements in the success or failure of treatment periods for these patients. The communication of the disease process and illness experience was a significant issue for families in Devitt and McMasters' (1998a) study. "The research also revealed that many patients communicated little to their immediate families about their illness...and, in turn, the family and relatives worried whether patients fully understood what was being said to them, and happening to them..."(Devitt and McMasters 1998a, p.60). If, as indicated in the studies by Devitt and McMasters, Aboriginal patients were failing to fully understand the information being offered to them by health professionals, this could have an impact on the ability of patients to be compliant with medical instruction, but also the ability of patients or carers to provide an informed consent to treatment.

By comparison to their work, the case of Douglas and Shirley is a little different to many that Devitt and McMasters encountered: Douglas and Shirley both spoke English as their primary language (unlike many in Devitt and McMasters 1998a&b), and Douglas became a communication conduit, between health care providers and Shirley, and his family. He took the time to understand the information being offered, and he would talk this over with Shirley. He would also pass detailed information on to his other family members.

Returning to the point about informed consent, McCoy et al. (2007) wrote a short paper outlining some cultural differences regarding assumptions of informed consent procedures. They discuss the rules of engagement and the ways that vagueness of definition can have a negative impact on the ways that we allow for cultural difference within the biomedical system. The authors discuss how, in times of critical illness and with issues of informed consent for patients who cannot consent for themselves, it is often protocol for clinicians to consult with the family of the patient. While this does leave room for various 'family' arrangements, including acknowledgement and value for extended kinship practices that are very different to the western model of the nuclear

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family, the vagueness of this term actually has the opposite effect, creating a space where these relationships are not fully appreciated or understood by staff:

> This wide and imprecise definition of 'family' can lead to a number of assumptions and problems. It can assume that Aboriginal people have ways of making decisions that remain mysterious to non-Aboriginal people, and that their family dynamics are complex, extensive and difficult to understand. By then giving the public impression that it does not want to offend anyone, it can then fail to support and respect those who are called to exercise particular rights and responsibilities. (McCoy et al. 2007, p.25)

McCoy et al (2007) also refer to the NHMRC guidelines on informed consent for post-coma patients, which talks about respecting and supporting the family of the patients, as well as also respecting and supporting others who have emotional or other ties of care to the patient. McCoy et al (2007, p.25) make an important point: "…it should not be assumed that family ties and responsibilities are equivalent to those that exist within non-Aboriginal society. Nor should it be assumed, that 'other ties of care' are of less importance than those assumed in parental and partner relationships".

According to McCoy et al (2007, p.25) it is important to recognise and support alternative caring roles in health care settings. They believe that this would show support for Aboriginal people's rights and responsibilities, which "encourages people to come forward, to be appropriately informed and consulted and then be allowed to act in the best interests of the patient" (McCoy et al. 2007, p.25). Enabling these care roles shows the ultimate respect for the ill or dying patient, by respecting their culturally distinct beliefs and practices. It also allows for a proper process of mourning to take place for those who should do so, and avoids situations where those who should be mourning are asked to make compromising and difficult decisions. Such alternate caring roles take decision making powers out of the hands of individuals suffering loss, and places them in a community of people. Decisions are made in a communal, shared way, taking pressure off individuals like grieving partners and children.

There is a question of whether this is the same in the case of an illness experience such as Shirley's. While Shirley's disease was potentially life-threatening, it did not lead to a loss of life; in this case, Douglas and Shirley have often had to make decisions between themselves, without being able to call upon the others in their family network for support. The instances of familial grief over Shirley's illness experience came early (at the initial diagnosis stage), and were then revisited upon her return to town. The physically and emotionally demanding treatment of cancer leading to wasting of the body made many of Douglas's siblings uncomfortable, reporting to him feelings of discomfort, revulsion (especially at the site of nasal tubes on their mother), and being afraid of how frail she looked. These emotional responses to Shirley's illness also led to many of the decisions for Shirley's care being left to Douglas and Shirley to consider together, and has led to a continued (substantial) care role for Douglas during his mother's recovery.

Even when providers and carers are of the same cultural group, the carer role can be compromised. There have been many sociological and anthropological examinations of the interactions between patients, carers and health professionals, and in particular the ways that health professionals regard the stories or illness accounts provided by carers (for example, Devitt and McMasters 1998a, May et al. 2001, Mol 2002, Thomas et al. 2002, Ussher and Sandoval 2008).

5.2. Case Study 2: An Aboriginal family's attitudes toward health care – Anna's story.

The following comes from an interview I did in February 2009. A local Waanyi woman was no longer happy to take up curative styles of medicine. She had thought about how to prevent ill health for her family and was in a financial position to take out some private health cover. Anna was about to embark on a journey of preventive health care. This story provides a real contrast to

Douglas's journey and demonstrates a change in the ways that many local Aboriginal people may be seeking health care.

Anna has lived in Mount Isa for the past 22 years. She has care of five children, two teenagers and two primary school aged children of her own, and her nephew who is 13. She is a very practical and pragmatic woman, and is another informant that I shared a great deal of time with. Anna's mother was a health worker and nurse, but Anna feels her mother never got the chance or had the time to pass on much of her knowledge about health. Anna's definition of health is fairly simple:

> Now, it's just me as a person or a member of my household having healthy life. Feeling good about themselves, being able to wake up and know that they can breathe without straining or having some sort of attack or move about freely or not have any restrictions on how you do things on a normal day.

This may, in part be informed by her experiences as a carer for a son with chronic asthma. This is one of the health issues that informs the ways that Anna and her family decide when and in what ways to seek medical care. According to Anna:

> Yeah, and I must say we got different levels or rules that go through in family, but our immediate family, like with my oldest boy, he's a chronic asthmatic. So when he gets very, very unwell, I panic! Nah! (laughs). Well, I do because for me, when he...I kind of think what do I do before I can get somebody here. And I just had, as early as last Saturday, he had a chronic asthma attack, he had 20% oxygen left in his body, I called the ambulance and I'm sort of saying "What do I do to keep this under control before they get here?" So, for me, as a parent, while he was having an attack, and getting that oxygen, he started to go into an anxiety attack as well. All because of the anxiety of not being able to get any, you know, get that feeling of breathing.

> Yeah, so for me, a lot of the times, we used to try and self-diagnose, go, "ok, let's check what's going on". But now what we do is, we head off to the hospital, if we feel it's an emergency we go up there...and I must admit, we do procrastinate about going. Because we know we've got to sit there for hours. And then, we're sort of left at another dead end when we ring, like, another medical centre and they say "we're booked out until next week or end of the week". And you say "but this is immediate" and they say, "Take him to the hospital". So you go, ok....So the choice is, we try to do what we can at home, and like I said before it depends on the illness, like if it's a sore throat, we try antiseptic gargling, and resting and pain relief and if that doesn't improve, like the next day then we think, well it's probably best if we take you to the hospital. And we just have to wait around.

> *So in short, we try to self-diagnose, do what we can, what we know we can do, if it's a minor feeling of being sick, but if it's serious we either call the ambulance, like this is the first time I've ever called the ambulance for my son, my eldest son...or we go directly to the hospital and just wait around. Because, honestly, we found there was no difference in time, waiting at an Aboriginal Medical Service compared to the hospital.*

Availability of health services, for immediate care needs, also determines who the family goes to see for their health care. As Anna notes:

> *It's all got to do with who's available. Like they tell you you've got to find a doctor, go to your own doctor, but ...your best option is to go to emergency at the hospital, because most of the time, you ring your preferred medical service and you just can't get in.*

There is an emphasis here also on the need for continuity of care in primary care situations. Anna visited this idea again later in the interview, when talking about her family's new preventive health care approach, which not only involved shifting to a mindset of being proactive about tracking their health status, but also included an element of self-education:

> *...as a prevention thing, we've been reading now, we've been getting anything we can about asthma and we've been reading it. But a lot of the times, it's like...it's a bit...useless information, because I can't understand a lot of the terminology used in it. So it's really frustrating.*
>
> *And then... feeding back in to your protective role and how you decide where to go for health care, what we do now is we're plotting down all the terminology we can't understand, and we're making it our business, like, my son's not ill at the moment, but I've just decided, no, we're going! We're going once, every month, to have him checked and monitored. And this is what we've agreed to, he's agreed to it.*
>
> *So far, he's had two check-ups where they've gone...and it was interesting, the doctor said, "So what are you here for?" And he (son) says, "I'm here for a whole-of-health check". He (the doctor) said, "You don't come every month for a whole of health check". So that's another of the insensitivies. And we just said, no we're gonna make them responsible, we're gonna make them work for us, because we have a right to go to them – they are in this profession and we have to go. So, I've said just put that aside, and make them speak down to ya!*
>
> *So that's what we've done...we'll see how it goes. So I'm on trial with that for the next six months, and we'll see how it goes, and it's just about being organised and remembering, and so...we just got a calendar that's hanging on the wall that's called the 'doctor calendar', and we've got dates circled and names put in those dates, for each of the kids. And the kids are quite funny, they'd say, "But we're not sick!" And I'd go, "I don't care, we're going! Because it's been a month since we've been to the doctors." And for the little ones who don't really suffer anything serious...we've agreed to go every couple of months. Just send them along for a check up because it's been a couple of months since I was here, just want to make sure that I am going along ok. And I think, the whole idea of this*

> is for support for the older boy, and so they see the importance and relevance of going regularly. Because, being a typical teenage boy, he just sort of went, "oh, oh I'm over this, why are we going to this doctor?" So that's one of the things now that is sort of driving me.

The quality and quantity of information that Anna has received from various practitioners and their perceived attitudes to her proactive approach have helped to determine who Anna chooses to care for her family. As evidenced in Anna's statements below, the attitudes of health staff can play a significant role in whether to go, and where to go:

> ...the quality of information that I'm getting, the quality of support that I receive and I've now probably come to the opinion that you're going to get a lot of information from one doctor, and close to nothing from another. So, you know what – I am going to make them responsible. It's all come back to me now. I've decided, no, I am gonna go there, and I am gonna make them responsible, I'll take some notes and say to them, "I don't understand this, this and this, explain it to me."

> ...I have changed three times now, who I go to locally, and the reason why is that when I get in there, if I see that the doctor has very little interest in my wellbeing, or that of my children, and is not interested in discussing future plans, health care plans, I am concerned. Because if he or she is there just to simply say, "ok, well, here's your medication, take this script, get it filled and you should be okay in ten days", then I'm not happy with that. And for that very reason, because I'm not, especially with my son who's a serious asthmatic, I've been there where...all three doctors, the last ones I've been to, did not even think to do an asthma plan for him. The third one, he said the Asthma plan – it's 'lose weight and you'll be right'. That is the advice he was given so I actually terminated the consultation, I got up and said, "We will exit now" and I said, "You do not have the right to speak to my child like that." I said, "You have no idea the size of the family we come from – it's in his genes, he's a big boned child". But anyway, the doctor just said, lose weight and you'll be right. So that was it for us, we just said Nah.

> I think for me...we got out to the car and I had a second with the older boy and I said, "Mate, unfortunately these are the types of insensitivities that we will cross, as you grow up, as you interact with different types of people. Now, you've got to learn how to best manage that."

Issues of health literacy (see full discussion in Chapter 8 specifically section 8.3.8) were a recurring theme in Anna's interview. Anna felt strongly about the need to have some control over her health and the health of her family. This had come from a great deal of frustration with her situation and the perception that her family were victims of their poor health. Anna expressed this as finally being at the point of taking control over the health of herself and her family, and making health professionals 'accountable' in ways that she had not in the past.

I think, I've had trouble understanding, like help, advice...because sometimes you'll get one that will just give you advice and that's it, they're not interested in explaining anymore, and then, the other side of it is, it's very frustrating when you've got to go home and do a lot of research yourself. And I only do it because...I like to get in and have a look...a lot of other people just go home and say, "oh well that'll do". Wait until you're sick again next time to chase them up.

...because I've sent down a list with the kids, because they had two visits, their second visit I sent a list with them. And I said, this is the list for the doctor, to say to them, when they have completed their heights, their weights, their blood sugar level...anyway, I wrote all these things down, I said please explain to them (the kids) why you do that. Because this child needs to know, why did you weigh me today? Why are you asking my age? And show them how that compares to data that is being collected. That is exactly what I wrote on the piece of paper. The paper didn't come back and I said to the boys, "You should have brought it back", and they said, but they didn't answer anything you had written on the paper, which was really disappointing. Yeah. And because I didn't actually make it to that appointment with them that day, so I was really upset about that.

Anna's experiences of consultations have been such that she and her family now prefer the level of care and information that they receive at the emergency department at the hospital. It is not always about convenience, cost or waiting times, as much as some people may have a preference for the service they receive at their local emergency department over the service they have experienced in other settings. This also shows some degree of flexibility and cultural respect on the part of Emergency Department staff and management in Mount Isa. Preventative health care is not, by definition, emergency care and as such cases like Anna's would not normally be handled at all. But, it is an acknowledged reality of health care provision in Mount Isa that the emergency department at the hospital handles many cases that would not be deemed emergencies, and is especially careful to provide opportunistic care for Aboriginal patients who may not present at other health care settings (See Thomas and Anderson 2006 for a literature review and discussion of Aboriginal patient use of Emergency Departments). According to Anna:

...when I've been to local medical services, the experience has been short. But I think one of the positives I have seen with the team at the hospital, the emergency department is, even when you get a different doctor, they try to explain and walk you through, and the whole aspect of what is going on, and you sort of think, oh okay, right this is great. And that is a positive. That's actually a pat on the back for the doctors at the hospital there, because these guys go in and out, and yet we can't get that level of discussion with our locals. So I must say, that's probably where I've got most of my positive experiences. Where they've sat, and they've talked through and tried to get information for me, and

done referrals...and you might say, well that's part of their job, but what's part of the job of somebody sitting in a medical centre?

So, I think we've kind of been inclined to go back to the hospital, because, one, if it's an emergency, you get seen to...yeah there's a wait period, but we can accept that. But if it's serious you go straight in. That's the positive. And the disadvantage is, with your local GP, you ring up to make an appointment and you say, this is urgent, and you don't get in.

Anna had recently taken out limited hospital and dental private health cover for her and her family. This was in response to not being able to easily afford the kind of care her growing family needed, and to give her more options when they needed to travel away for care, rather than be at the mercy of the public health system. As Anna put it:

And see, this is...a new journey for us this year...I've just taken out some cover, and a dental plan to cover the entire family, so they get physiotherapy treatment, eastern therapeutic treatment included in this, and then there's a whole swag of dental cover that they get. Now, I've had to sit down and say, what is it I want my family to stay in touch with, in 2009, in terms of their health. Well, because of the cover that we've got now, we know we can go twice a year to the dental clinic, and we're covered for anything else...if anything serious happens apart from that. So that's covered.

Now, with the hospital cover, I've said to the kids, and to my husband, well, we're always presenting when we are sick, you know? Let's change that, let's now go, with the eldest boy, it's monthly but with the others, it's either bi-monthly or quarterly. So, you're gonna have four visits to a medical doctor who will just check you over, but if you get sick outside of those four visits, well, fine, we'll do that as well, see what's going on.

...Last year we had three members of the [extended] *family had to be airlifted to Townsville. Basically because they discovered problems that couldn't be operated on and so that was an extremely expensive situation, where we ended up...we were just fortunate we had family there, and we had a motor vehicle to drive across and be there with them. But, just the whole experience of having to leave home and be there, as well, was just...awful. So...that's why 2009 is going to be better! (Laughs)*

...and loss of income because work won't cover, because it's personal issues, you know?

The cost of dental care was a highly motivating factor for Anna in taking out private health cover:

I went to a local dentist here, and I said "I just want to get a simple scale and clean", and half the time you don't really know what they're talking about either, and now, he wanted to refer me to go away to Cairns, which I would have been up there a couple of weeks ago, stuck in the flood waters, but I cancelled it, of course. And it was gonna cost me $1800 to get my teeth cleaned. And I said, "Why can't you do them here?" And he said, "Oh no, it looks like you need some major work", and I said, "Major? What do you mean, major?" Like, I haven't got any black teeth, you know what I mean? So the expense sort of turned my stomach and I thought, you've got to be kidding. First of all, I would be up

for travel costs, accommodation costs, loss of income for those couple of days, and then have to pay on top of that again, to get my dental service?

...So I just think it is such an important service to have and at least at a reasonable rate. It is just...ridiculous what we're paying for dental care.

And we really do need a dental clinic for Aboriginal and Torres Strait Islander people, because you will rarely find them going in to see [local dentist] at his clinic or the other ones, because, first of all it's not a welcoming environment, and secondly, I don't carry a wallet, sorry! So they're like, $200 to get my teeth cleaned – no thank you! You know I've been in there, the youngest one had to get some sealant put on some teeth, two teeth. By the time he come out, it was $650 later, and I almost died! I said, "you've got to be kidding me!" And he says, "Oh, no." He says, he did the general clean, and check and x-ray, and then he sealed two teeth. The fifteen year old, so adult teeth. But $650! And I said, "How much does it cost for an extraction?" He says, "Pardon?" And I said, "It's probably cheaper to get an extraction, that's probably the cost to extract three or four teeth", and he says, "Oh, $200 per tooth". You know? And that's sad. And that's what prompted me to say, I've got to look around and see if I can get some dental cover.

And that's the other thing: how much do you hear about dental health? I mean with people, if their teeth don't feel sore, or they don't feel like they're gonna be falling out, or you got toothache well, they don't see the relevance of what that tooth can do to, how it can affect your quality of health. So, there needs to be a bit of a package done, we need to start letting our families know what quality of health means.

While Anna was aware of some of the major health implications that poor dental care can lead to, she was concerned at the cost of providing proper dental care for her family, prompting her to take out private insurance. There was a dental clinic in operation at the hospital in 2009, but I am unsure if Anna even knew it was there. However, dental care was only carried out when it became obvious to the sufferer, and therefore was not carried out in the family regularly. This was in part due to cost, but it does run parallel to Anna's reasons for taking out health cover at all.

Anna's case study raises an interesting point about the concept of preventative medicine and primary health care. Anna has set precarious and somewhat arbitrary boundaries on the preventative care that is necessary to keep her family well. In 2009, the Commonwealth Government launched via the National Preventative Health Taskforce, a national preventative health strategy. However, this strategy was only aimed at reducing obesity, tobacco and alcohol consumption, and acknowledged that by addressing these issues, there could be significant improvements in Indigenous health (National Preventative Health Taskforce 2009, p.8). Anna

never revealed in her interview whether she had accompanied the increased medical surveillance of her family's health with increases in exercise or health eating choices. Or whether there were any additional efforts to improve mental health and wellbeing in their household. Anna also did not mention whether her family were following a regular schedule of immunisations, hand washing practices or other basic practices considered to be preventative health measures. The Royal Australian College of General Practice (RACGP) Green Book (RACGP 2006) in conjunction with the RACGP Red Book (RACGP 2009) and National Aboriginal Community Controlled Health Organisation policy (NACCHO 2005) all feature recommendations of preventive measures and checks for health care assessments. Health practitioners working with Anna could refer to these schedules as a list of core recommendations for Anna when developing her health plan. This may lead to less redundancy in her health plan for her family, and provide her with a sense of being able to contribute actively to health status through every-day, strategic activities and investments.

Anna's story contains many themes, including a focus on feeling in control of personal health to such an extent that Anna could be accused of creating unnecessary work for the health care system, through potentially redundant levels of health surveillance for her children. Ultimately, Anna was no longer content to consider her family as being victims of their poor health, and instead decided to take charge of accessing information and asking questions about the quality of care that her family received.

As Anna herself said, it was important to her that her family take charge of their situation – which is often a rather empowering experience. She was daunted by the amount of work it would take to enact her plan, and yet was committed to trying this approach. This was an attempt to improve the health situation of her family and also to take away some of the stress around, not only everyday illnesses, but also the chronic asthma suffered by her son. The implementation of an action plan and the pursuit of ongoing health maintenance was Anna's way of feeling more in control. For Anna, it had come from feelings of frustration and anger over the ways that her

family have experienced care and treatment for illnesses in the past, and this was evident in her discussion with me.

Anna, like Douglas, experienced a great deal of frustration, and perceived a real need to be far more informed about health care processes and illness processes, in order to demand the kind of care she believed necessary. Also like Douglas, Anna was acting as an advocate for others in her family, and was taking the main role in making positive changes for her health and the health of her family.

5.3. Case Study 3: Back pain and remoteness - James's story.

I interviewed James in December 2009, shortly after the events in this case took place. James is a 29 year old non-Indigenous man, living in Mount Isa with his wife and baby son. James has spent many years living with back pain that, while not severely restricting his lifestyle, has caused him constant pain. James's narrative style is somewhat different to the previous two case studies. His story occurs chronologically and is punctuated heavily by financial and temporal cost considerations. James's story is essentially one of access predicated by high levels of private health cover, which appeared to have little impact on the illness journey he embodied.

In previous years, James says he would experience a short, yet extreme, period of pain in his lower back, followed by a serious displacement (his back would "go out"). This was often righted by spending a couple of days lying flat on the floor at home. However, in the past year, James had been suffering far greater levels of pain; the kind he would expect to have just before his back went out. It had not righted itself in the past 8 months, and it had impacted on his ability to walk comfortably, to sit or stand for any length of time, and was seriously degrading his quality of life. The pain began to radiate down his right leg, and he often suffered some swelling in his ankle and knee as a result. James had been taking ibuprofen and codeine tablets to keep the pain at bay

while at work, and to get to sleep at night, but was concerned about the damage this drug could do to his body in the long term.

James decided to go to the doctor, to find out if there were any exercise regimes he could safely undertake to lose some weight, hoping this would help take some pressure off his back. His GP expressed concern about the problem, and ordered CT scans for James, and put him onto codeine tablets for pain management. The GP expressed surprise at James's tolerance to the pain, adding that most patients with similar problems would have been on high doses of painkillers far earlier than this. He called the PBS office to clear a script for James (he had prescribed over 20 boxes of codeine tablets, and at this level of prescription had to have clearance in the system, or else James would not be able to fill the script at any pharmacy).

James, knowing that the scans were being done at the private x-ray clinic (the only imaging clinic in Mount Isa), called ahead to make a booking and asked how much the scans would cost. According to James:

> I was surprised when they told me the scans would cost $415, and I had to pay it up front. So I called through to [Private Health Fund], to see if I could claim any money back. But they told me no, they were unable to cover these scans, because of federal government legislation that stopped them from covering stuff like that. But I could claim some money back through Medicare…

The report from the scans said that James had a prolapsed disc at the L4 and L5 (his lower back) with bone degradation. His GP referred him to the public neurologist in Townsville, for consultation and action. James said:

> I was really happy with how [GP name] was handling this, he was really working to get it sorted out quickly for me…I hadn't heard anything after 2 weeks, so I called the doc….I told him I hadn't heard from the neurologist, and he asked me then if I could afford to go private [see a private neurologist].

James agreed that that would be the best course of action, and so his GP referred him to a major neurological specialist in Brisbane. Appointments were made, and James was hopeful that action

was taking place and finally, after almost a decade of living with back problems, things were looking up.

James was able, through the help of his GP to access the Patient Travel Subsidy Scheme (PTSS – see section 7.1.1.1) available from the state government health system. As a private patient, the state government would pay for the flights to and from Brisbane. He would not receive a subsidy for accommodation; he would have to pay for the first four nights in the financial year, before being eligible for a partial subsidy. James had to organize and pay for his own accommodation while in Brisbane.

James had to take time off work for his many visits to the GP, for his scans, and now for his trips to Brisbane. He had taken leave earlier in the year following the birth of his son, but had not been eligible for paternity leave (as he had not been with his employer for long enough). This absence had eaten into his annual leave entitlements. Luckily, James was in a job that allowed him to work overtime, and claim it as flexible leave, which he had to draw on extensively for his health care needs.

James travelled to Brisbane for an overnight stay, to see the neurologist. He left work and went straight to the airport for his flight. Upon landing in Brisbane, James reported:

> *I got a cab [taxi]…that was about $50 to get to the hotel. Then it's $200 a night at the hotel, and the reception desk was closed when I got there, because it was after 9 o'clock [at night]. I hadn't eaten at all, so I walked around trying to find somewhere to eat…most stuff in that area was shut, so I went back to the hotel. It was bloody awful.*

The next day, he made his way to the appointment, with his scans in hand. He arrived early and then reports:

> *I had to wait for 2 hours…the specialist was running late. I went up to the receptionist and told her I needed to go in urgently because I had a flight to catch to get home. She told me that the specialist had recently been on holidays, and so he had a backlog of patients to see…And, he was on lunch.*

James had called the clinic before his journey, in order to make sure that the travel component of the trip could be booked in such a way as to match up with the appointment. He had been assured by the specialist's office that he could come down to Brisbane the night before the appointment, go to his noon appointment and make it back to the airport in time for a 3pm flight back to Mount Isa.

As James checked the clock again, and it was approaching 2pm, he was finally admitted to the office. The specialist took a brief look at the scans, announced that he could not make any decisions on action without an MRI scan, that he never made decisions without one and that this would have to be done, and James would need to return then.

> James: I was [expletive] livid! They didn't tell me I would need an MRI, and I couldn't get one of them in Mount Isa even if I wanted to. So, they organized one for me in Brisbane, which meant I had to organize to come back again. I paid $250 for the privilege of 15 minutes with that bloody specialist. By the time I got back to the airport, and managed to claim some of the cost back through Medicare, I was still out of pocket by about $400.

James got back to Mount Isa, and visited his GP to start the process for the next appointment. His GP was disappointed that the specialist had not ordered the appropriate scans ahead of time, and gave James a new prescription for codeine and oxycontin tablets (a highly addictive drug, in the long term). James received a letter from the specialist's office, advising him that they had booked his next appointment, and had booked him in for MRI and Bone Scans at an imaging service in Brisbane. They had not called to consult James on when he would be available to attend such appointments. So, James told his workplace when he would be gone, and went to the travel office at the local hospital to arrange the travel. His flights were booked and he booked his accommodation. He found a hotel closer to the Brisbane hospital where all of his care was being conducted, and which offered a special hospital rate for two nights.

He called through to the x-ray service in Brisbane to find out how much he would have to pay. James said:

And again, I had to pay up front, and each MRI was gonna be $650, so $1300 all up.
They [the x-ray service] could do the Medicare claim there, so that was good. That meant
I would have most of my money back in my account the next day.

The specialist's office assured him that he would be able to make it to the MRI scans, have them completed and ready for his appointment. They also advised him to stay an extra day, just in case the specialist wanted to administer an injection for pain relief into his back.

James did all of this, only to be advised that he would be required to come back for consults every six months and that he could lose weight by going onto a diet consisting of meal replacement bars and shakes. James ceased treatment and over the course of several months, his back pain reduced, as it had so many times before. He was frustrated at the organization of his travel for treatment and the seemingly laissez-faire attitude of his specialist, who seemed to think nothing of recalling James for short consultations despite the major efforts that James had to go to, in order to arrange such trips. This was a case where it was clear that the agenda of the specialist was assumed to take precedence over all other events in James's life.

James took out private health cover, not only for the incentives offered by the Commonwealth government to do so, but also to ensure that he and his family had a degree of choice and control over their health journeys. James's parents had always held a comprehensive private health insurance plan, as had his wife's family. They had held private health insurance prior to coming to Mount Isa, and continued to pay for health insurance while living in Mount Isa, despite a perceived lack of local benefit in doing so. In reality, there are many health providers in Mount Isa that offer private services, including dentists, optometrists, podiatrists, physiotherapists and chiropractors (see Chapter 7 for a list of some of these services). James's wife also admitted herself to the hospital as a private patient when pregnant with their child. This meant that (where available) she would be able to have her own private room, away from the shared ward rooms that most women are allocated after birthing. This couple placed great emphasis on the need to be able to plan and

control health (and illness) events, and for the most part had used their insurance (up until James's incidents above) for preventative or health maintenance procedures.

In James's cultural reality, the presumption that patients will put their lives on hold due to the treatment regimes and advice of their health professionals is unrealistic. It was imperative that he remain a productive member of society throughout his illness experience. It was also important for James to feel that he had a degree of control over the process of consultation and treatment; while private health cover can be seen as an opportunity to assert some control over the medical pathway chosen to enact a disease process, it did not provide benefits to James locally, but did allow him to expedite the process of having his pain addressed[30]. In his view, the assumption by health professionals that illness processes occur in a social vacuum and can be isolated from all other events in an individual's life was demeaning.

It is important to acknowledge here that these stories are joined by a common theme of remoteness and the impacts that distance can have on the ability of people to participate in health care systems. The case studies also serve to demonstrate that while aspects of interaction with the health care system in times of illness may be similar for all participants, their experiences and the manner in which they are interpreted may be influenced by culture and ethnicity. The distinction between ethnicity and culture is an important one and will be discussed further in Chapter 8, but is critical at this point to mention that the practices of ethnicity and the explanatory frameworks that culture creates can make a significant difference in the ways that health journeys are experienced and retold.

All of the stories recounted here are differently focused, and demonstrate the various ways that Australians become health consumers, and the multiple realities of diseases and bodies that enact

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[30] As an aside, James received a letter in November 2011, from the neurosurgery department of the public hospital in Townsville, advising he had made it to the top of the appointment list and that his case would now be seen. James turned the appointment down.

illness. As Mol (2002) suggests, these bodies become multiple, not only in the ways that they are broken down by the health system to treat the diseases or illnesses that they are afflicted by, but also in the ways that they must adapt to form new social realities that are disrupted by illness. Even bodies not particularly experiencing pathology (here that would include Douglas, Anna and James's wife) are impacted upon and drawn into the illness experiences of others, often in a management role.

All three stories demonstrate the roles that families and communities still play in constructing and enacting illness processes. This is especially so in remote settings; the need for family and community to provide support and management (and increasingly, rehabilitation) for patients from rural and remote towns, is now an integrated part of the health care system (as in Harris et al. 2004). However, this integration has not been directly funded as a part of the health care system and many community run organisations in Mount Isa (such as North West Advocacy, Home Assist and others) struggle to find funding to support the increasing demands made upon them.

These stories also demonstrate the pervasiveness of health care messages and health politics. I will give more attention to these themes later in the thesis, but will address them here by saying that all three stories, in line with contemporary state and commonwealth government policies, point to the idea of individual ownership of health journeys, and the need to prevent ill health from occurring at all.

Governments at all levels have invested significantly in promoting lifestyle interventions to patients via the health care professionals that they encounter with benefits of uptake being (at least) two fold; if people act more healthy (i.e. eat better, exercise more, consume less alcohol and tobacco) and perform other healthful activities such as washing hands and washing bed linen, this will (i) lead to better health condition for individuals, and (ii) lessen the burden on health system resources. What individual lifestyle interventions cannot fix and often appear to ignore are the socioeconomically-influenced constraints that contribute to health status.

The philosophy of lifestyle interventions will be addressed further in Chapter 10, but suffice it to say here that such interventions are increasingly popular, as a choice for physicians and health promoters to focus their activities, but also among the public. Public campaigns that promote going for "2 and 5" (serves of fruit and vegetables per day), "Swap it, don't stop it" (a harm minimization campaign regarding nutrition and exercise in daily life), "Slip, Slop, Slap" (an old skin cancer prevention campaign, which has been updated in 2007 by Cancer Council of Australia to include "Seek" i.e. stay in the shade when outdoors, and "Slide" i.e. putting on sunglasses). Such campaigns demonstrate that there are individual actions that can be encouraged and have proven successful in not only decreasing disease rates, but also in infiltrating public imaginings about health (See discussion of Torgerson 1986 And Garvin and Eyles 1997 in Chapter 10 for a more detail).

During my fieldwork, I collected many other stories of individuals who have suffered even more than those recounted above. Many health workers would tell me stories of patients who were let down by the systems designed to assist them, sometimes in major ways, sometimes in mundane, small but frustrating ways. The media also goes to great lengths to tell the stories of patients who are left behind by the health care system. There were often reports in the *North West Star*, the *Townsville Bulletin* and even national newspapers like *The Australian* that told stories of people facing great adversity – such as women delivering babies by the side of the road on a lengthy trip to hospital (ABC News June 7 2006), people who were on waiting lists for treatment being sent home due to technical glitches in appointment systems. Other media reports and health professionals I talked to told of appointment notifications going to the wrong address for patients already waiting in town for their procedures, or an old Aboriginal man being stranded at the airport after a long flight, due to the hospital transport system failing him[31].

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[31] He arrived after office hours, when the hospital transport had ceased operating for the day.

A case well-covered by the media related to the death of a young Aboriginal girl in Doomadgee in 2009. Questions were raised about why the four year-old girl (who it was thought may have been exhibiting symptoms of swine flu) was not transported to Mount Isa for specialist treatment. There were charges of racism directed at Queensland Health when six months later, in January 2010, there had reportedly still been no investigation into the circumstances surrounding her misdiagnosis and subsequent death (Weatherup, 2010). A comment left on the website of the *Townsville Bulletin* dismissed the calls of racism:

> It's not racism for heaven's sake. It's called limiting liability. Admit nothing. Cover your arse at all costs. If the child was white, QLD health would be equally as silent. It's just what they do when they stuff up (Townsville Bulletin website, Ms.Anthropist, Jan 13 2010).

Whether this is an accurate statement, or not, is not the point. While it does downplay the role of racism in everyday encounters, the important point to acknowledge is the lack of faith that everyday people have in the health system in most parts of Queensland. A recent report tells of the high number of complaints received by the Health Quality and Complaints Commission, regarding all health facilities (public and private) in Queensland in the past year; over 2200 complaints were laid in the financial year of 1st July 2009 to 30th June 2010 (Hurst 2010). This could show not only a lack of faith in the health system, but also a disconnect between the expectations that people have about just what the health system can and should provide when it comes to good patient care.

These individual stories concerning navigation through the biomedical health system illustrate a number of recurring themes and issues in my research. By telling the stories of three individuals, differing in their circumstances yet bound together by common experiences, it is possible to get a sense of ways that social and political structures impact on the everyday lived experiences of people, and the compromises that bureaucracies impose on individual lives for the sake of economic efficiency or expediency.

Chapter 6 recounts my experiences during an Ambulance ride-along session in 2008. This was an eye-opening experience, and in many ways captured my perceptions about who makes up the Mount Isa community and the ways that people suffer and cope in this place with regard to health issues. It also made me question some of my previously taken-for-granted perceptions of health care professionals and the systems they work within. For the first time, I questioned my need to find blame and place it at the feet of those who worked in the health care system. Until that time, it had been very easy for me to find fault with the attitudes and behaviours of health professionals, labelling them as cold and uncaring, apathetic and unwilling to act for change in a similarly cold and uncaring system. The frustrations, the complications and the rewards of practising in a health profession in Mount Isa are illustrated in Chapter 6.

Chapter 6

An Ambulance Night Shift: Ethnographic Observations.

The following is a selection from my fieldwork diary documenting a night shift with the Ambulance Service (see Plate 6). The names of ambulance officers and their patients have been altered to protect their anonymity.

I have included this ethnographic observational narrative from my fieldwork to demonstrate a number of issues. First, I feel it gives a poignant description of Mount Isa, not so much as a location but as a contact zone, a place where people's lives differ dramatically within a small geographical location and which collide in often unexpected ways. In this way, this account serves as segue from discussions of literature, research and macro-level issues to more specific, locational, personal, micro-level stories.

Second, illness and disease are factors that bring otherwise disparate lives together, and it is not so much the common illness experiences that matter here, but the ways in which different people and their families deal with and respond to illness and disease. The social capital of families and the loneliness of isolated others create a stark contrast in this story, showing how people cope, and how they organise themselves to respond to family and personal crises. Third, the socioeconomic differences of each case presented during the night shift are Mount Isa writ large – they illuminate the everyday violence of poverty and struggle so often evident in the lives of some Mount Isa residents.

In essence, this narrative illustrates a critical part of my intellectual journey on this topic, and shows the larger issues that affect Mount Isa residents through specific cases. The themes that emerge will be discussed throughout and at the end of the narrative. Although this documents only one nightshift with the ambulance service, I have chosen to include it here, as I believe it demonstrates and represents many of the major issues that the Mount Isa community struggles

with, and that it provides a pertinent opportunity to reflect on the nature of ethnographic field work encounters and the ways that ethnographers must challenge themselves in their perceptions and judgements of the encounters they experience.

Plate 6. The Mount Isa Ambulance Station (Photo: Kristin McBain-Rigg).

On the night of my ambulance ride along, the first crew member I met was Michael. He was a student paramedic and was one of my officers for the shift. He introduced me to Linda, a fully-qualified paramedic supervising him, and me, for the shift. Michael showed me the truck we would be riding in that shift, and gave me an "observer's pack". It was a blue Queensland Ambulance Service bag, with a fluorescent yellow-green vest that had reflective strips and the word AMBULANCE in orange capital letters on the front and back. The bag also had a helmet in it. I did not get too much of a chance to look through the bag very thoroughly, but was told that the vest had to be worn to any call out, to identify me as being with the team at the places we went to. I was also introduced to the other staff members on shift that evening, including Trina and Sally, two senior officers who had been practising as paramedics in Mount Isa for a number of years.

Trina was interested in my thesis and asked me about it. I explained the basic premise, and she and Sally proceeded to recall stories about some of the Indigenous clients they had dealt with on a regular basis (all of whom were now dead or had moved on). Trina told me that it is not usual for them to see too much of the real 'cultural' stuff, which led to a story about a call-out to a job in the riverbed. The woman they attended to was incoherent; she was moaning and flailing her arms around. They tried to ask her what was wrong, but she did not respond, almost like they weren't even there. One of the other riverbed dwellers came over and told them that this woman had been sung. Trina said that the person in the riverbed told them it meant she was cursed, and added that the belief was that, once you have been sung, it signals death, possibly within a very short time. Trina said that she did pass away, only a few days later.

'Singing' and the source act, 'pointing the bone', have been reported on widely in the anthropological literature, but was also popularly reported in 2006, after the death of Palm Island man Mulrunji Doomadgee (Koch 2006). The place of song is fundamental to the transmission of Aboriginal cultural knowledge in Australia, and songs can be used to transmit information, tell stories (both ancestral and contemporary), or be used to ill-effect on those who have committed a transgression. In this case, to 'sing' someone is to place a curse on them for a perceived wrong doing against another, and can be done by an unknown source, from some distance away, by use of particular chanting and singing in a malevolent fashion.

Critically though, this story reveals the ways in which these officers classified such an act as the 'real cultural stuff'. Sorcery is characterised as a social phenomenon that functions to control behaviours and attitudes of individuals for the benefit of social organisation as a whole (Evans-Pritchard 1976, Reid 1983, Cawte 1996). The threat of malevolent acts which originate from an unknown or mythical source as punishment for an individual's social transgressions is well reported in anthropological literature as a form of normalised social control. For these officers, the identification of such exotic or radically different acts represented an authentic encounter with a

'real' Aboriginal cultural phenomenon. This was set against the more mundane, everyday encounters of Aboriginal patients in the town. The two ambulance officers identified that being 'sung', and the outcomes of it as witnessed in the woman they attended, as an act of cultural origin and significance. While the woman was exhibiting symptoms that, to a health professional could have indicated any of many potential illness or disease processes, her campmates had identified it as an episode of sorcery, a culturally constructed act of malevolence. This was a very specific example of something that fits snugly into the realm of 'culture' in the popular sense.

The officers' limited, yet accurate, understanding of the purpose of the act was also encouraging, and interestingly the confirmation of anecdotal evidence to suggest that this is a valid and effective method of sorcery (Trina's confirmation that the woman died only a few days later), is an unusual acknowledgement of Aboriginal cultural beliefs and their efficacy by a health professional. In fact, in my study I think it was the only time that someone spoke in this way about specific traditional or contemporary cultural practices, and certainly was the only time that their efficacy was reinforced.

Although there are other examples in my data of health professionals being privy to various cultural practices (witnessing kinship organisation to influence decision-making, and the importance of kin relationships in place of residence, varying language patterns in English, and so on), these are not explicitly acknowledged or discussed as being cultural phenomena. This suggests that there is a very specific set of issues that are deemed 'cultural' by health professionals that largely relate to concepts of taboo, transgression, extended family structure, values and beliefs. These are often (though not always) some of the most obvious examples of 'culture' acknowledged by health professionals engaged in largely sporadic encounters with Aboriginal people. This is dealt with further in Chapter 9, which discusses the ways that Aboriginal participants and health professionals constructed what might be a cultural barrier for Aboriginal people accessing health care.

I was with Michael and Linda for the rest of the night. Our first call out was to an elderly lady who was experiencing pain and nausea. We pulled up outside a small house with a well-manicured, fenced yard. Once inside we saw Mrs N sitting in a lounge chair. She was an old lady with short, grey and white, curly hair. She looked pale and a little bit frail. Her daughter was talking to us about what was happening. She had been at work while Mrs N was at Respite. Mrs N's husband, Mr N, had received a call from the respite centre during the day, letting him know that Mrs N was not eating or drinking as much as normal and that she seemed a bit off colour. She had pains in her lower abdomen, nausea, and upon questioning had noticed changes in the smell and colour of her urine.

Her daughter was telling me about a fall Mrs N had had recently. She explained that Mrs N has dementia and likes to sleep with the lights on in her bedroom (her husband Mr N now sleeps on the couch because of this behaviour). She had gotten up during the night to go to the toilet and had shut the bedroom door behind her. Because of this, there was no light in the hall and she fell. Her daughter heard her fall, and got up to check on her. She seemed fine, but it had happened on the previous Sunday (we attended to Mrs N on Wednesday), and she was a bit worried it might be related. Mr N told me that recently, Mrs N had started to get quiet, she was not talking as much, was not telling them about anything. His granddaughter was interested in what was happening to her Nan. A young boy came in, covered head to toe in dirt...he had been down the creek near the back of the house, chasing a bull. You could see where his shoes had covered his feet, as there was a line of dirt about where the top of his socks would have been. The kids were very attentive, but tried to stay out of the way as much as their curiosity would allow. They were also clued in to where Nan spent her time, and the kinds of things she needed for her health. They knew about her time at Blue Care respite, and talked to me about how they helped her get dressed and get around the house.

Linda gave Mrs N some aspirin and decided to take her to the hospital. Michael went out to get the stretcher, and we chatted some more. I looked around the house. It was a bit like being at my Grandma's; I suspect this family were long-term residents of the house, as it was well stocked with random memorabilia, sport trophies, photographs, knick knacks, paperwork. There was an old black and white photo of Mrs N, just behind her chair on a display shelf packed with photos and memorabilia. There was a certificate there for Mr N, from the RSL for service to the club, photos of the kids. It was the cabinet that you saw as you walked in the front door.

Michael had the trolley set up and we assisted Mrs N to get from her chair to the front door, down the stairs and onto the stretcher. As we wheeled Mrs N's stretcher out to the ambulance through the front gate, her daughter and grandkids followed. Her daughter kept telling us that Mrs N would get disoriented at the hospital, told me again about the respite centre, discussed the fall again with Linda and I and added that Mrs N had had a bad accident, falling down the stairs when she was six years old that had permanently injured her back. Linda took down their phone number, and told them they could follow up with a phone call to the hospital or come up after us, if they liked. I did not see any of Mrs N's family again that night, but I did see Mrs N being wheeled around the A&E department a couple of times later on.

As we took Mrs N to the hospital, Linda was talking and reassuring her the whole way there. Linda said to me later that Mrs N was a very agreeable patient – which, although helping to get her cared for, it often made it difficult to establish solid facts about her. Linda would ask her questions and she just wanted to agree to everything. She was reporting little pain in the ambulance, and upon reaching the hospital told the nurse she had a pain in her side. She had not told Linda this, but told the nurse after being asked where she had pain.

We finished this, just in time to go to another call out; this time, to Yallambee (see Plate 7). We drove from the hospital down to Yallambee. It was not well lit down this end of town, but I could see enough to get a sense of where I was. There were dogs and kids playing in the small cul-de-

sac surrounded by small suburban houses. They were typical, cheap suburban Mount Isa houses – brick buildings, all the same, raised up about half a metre off the ground. There was very little grass around, certainly no manicured front lawns. You could see that all of the houses with lights on had a lot of people inside them. Many people were moving from house to house, visiting and talking, some staying behind. As we came around the cul-de-sac, a group of five small children came out to wave us down.

Plate 7. Yallambee (Photo: Kristin McBain-Rigg).

As we got out of the ambulance, the smell of smoke from the riverbed burn-off was overwhelming; that smouldering smoky smell of old grass being burned away took over your senses. Every year in winter the fire service go around town performing controlled back-burn in areas that are particularly dry, to minimise the risk of a real, uncontrollable fire breaking out. We were followed into the house by the group of children, who ranged in age from three to eight years old. We had come in through the front door of the house, and the lady we had been called to was sitting right near the door on an old, vinyl dining chair. Next to her was an old couch with one of her daughters and three small children, looking on intently. On another one-seater lounge chair across the room was another of her daughters, nursing a baby. There were three little kids sitting

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on an old hospital bed that they were using as a couch to watch television. There were four or five other little kids running around, and a couple of teenagers.

There were three bedrooms that I could see in the house, and the bathroom was up in the back left corner of the house. It looked like a small bathroom, even for the number of bedrooms in the house. There were some old, faded bed sheets being used as curtains to block the front window. There was a lot of noise in the house, but it was not the same kind of noise as in the last house. When we were with Mrs N, the television was in close proximity and was up very loud. But here, most of the noise was the little kids, playing and squealing at each other. And there were lots of people talking, but not crowding the paramedics.

Mrs H looked distressed, and had been suffering with heavy pain in the chest while breathing. The young girl I was with told me this had been a problem since the back-burn had begun the day before, but it had gotten worse tonight. Mrs H agreed with this. She also had pain in the stomach. The young girl made a joke about her being pregnant on her way out the door to a young man who called Mrs H 'Mum'.

The paramedics decided to conduct and ECG in view of her complaint of chest pains. To put on the ECG pads, Michael had to put his hand up under Mrs H's shirt, which she looked a bit uncomfortable with. She had an oxygen mask on so it was hard to hear her at times, or see her face clearly, but she looked straight to the floor while that was going on. The paramedics decided to take her to the hospital, so Michael stayed in the house with her, while Linda and I got the stretcher. Some of the little kids came out for a look.

We wheeled the stretcher to the bottom of the stairs, and steadied it. Michael helped Mrs H stand up, and the young man at the door said "I will help you Mum", and she reached out for his hand. Inside, the family was figuring out who would go to the hospital with her, and had decided on the daughter with the baby. They asked if the baby could go too, and Michael told them, no, as there

is no restraint for the baby. Some shuffling around was done, and Mrs H's daughter eventually came with us, without the baby. Mrs H was connected up to oxygen, so Michael carried that and assisted her, Linda also assisted and stood on the side of the stairs that had no rail and spotted the congregation of people coming down with them. Most of the people that had congregated in the house and on the veranda came to watch and help where they could. Mrs H said she usually stayed in the house across the road, so I guess she came across when she started to become unwell. I noticed as we got to the ambulance that there was a police car pulled up behind us. It took me back to a conversation with the local Officer in Charge; he had said that his ambulance crews go with a police escort to Yallambee after dark, due to previous violent incidents between officers and residents. I was not sure if that was why they were there, or if they were there independently; regardless, they were there.

I got up into the ambulance to hold the oxygen tank while we pushed the stretcher into the back. The daughter sat in the front with Linda, and I sat in the back with Michael and Mrs H. Then we were on our way. Michael was asking Mrs H various questions about her pain and monitoring her vital signs. After Mrs H's admission to the emergency department, Linda and I then went out to the ambulance, to restock it ready for the next call out. Michael came out a little bit later to get his tough book[32]. They both informed me that that had been a good call out to Yallambee and that I was lucky, as I had gotten a clean house with a nice family. That usually it was a bit rougher than that. It certainly did not fit the stereotypical scenario that I had seen and read about in the local newspaper.

Before I continue, it is pertinent to discuss the stories of the two elderly women, Mrs N and Mrs H which demonstrate similarities and differences in the ways that people in Mount Isa are embedded in this place. While Mrs N lived in what would be considered a well-kept family home, and Mrs H

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[32] A laptop computer that is contained by a hard case, so as to reduce the chance of damage if the computer is dropped or mishandled.

lived in Yallambee, which is largely perceived as being an old run-down relic of the reserves and mission times, both were embedded in this place by their families. While their circumstances differed greatly, they were both bound into Mount Isa's community by their relationships with kin and community.

Mrs N was living in a 'good' part of town, in a well-kept house surrounded by material goods that served as symbols: memories of events, stories and people. Three generations of her small extended family cohabited with her, and had an intimate knowledge of her life and health. She was also embedded in the community through the actions of her husband, who had served in the military and had subsequently provided his services to the local Returned Servicemen's League club (RSL Club). The participation of various family members in sports and other community events cemented the long-term, upstanding residence of a multigenerational family in Mount Isa, a rare yet celebrated occurrence. Those who have lived a long time in Mount Isa (certainly more than 10 years consecutively) are lauded in the local press and anecdotally around town. They become the stuff of legends, much in the same way that pioneering stories are canonised, and are often relied upon to provide a comprehensive history of the comings and goings of the town. They stand as a testament that Mount Isa can be a family home town, flying in the face of the transient nature of most residencies. These are families who have become a part of the town in often very intimate and yet public ways. For some of these families, their embeddedness is also an organic one. They have quite literally become tied to this place through their very engagement with the land (whether it be through employment in the mining or pastoral industries, or in everyday ways like the young grandson chasing a cow in the dry creek bed). These organic experiences of the land tie multigenerational families to this place, often in significant and lasting ways.

Mount Isa seems to have a sense of enduring connectedness, even for those who stay on a short term basis. There are former Mount Isa residents all over Australia that form groups, to celebrate

and reminisce about their time living in Mount Isa. While it is not unusual for people to memorialise places, in a town that often seems so transient and impermanent in its population, there are a lot of people who hold it in very high esteem, especially for the memories they made here, and the people they met and befriended while here. Mount Isa seems to create some lasting ties between people, even when they have left the town, due largely to the shared experiences of living in such a unique and remote place in Australia.

In contrast, Mrs H was embedded in similar yet different ways to Mrs N. Mrs H was living in one of the 'bad' parts of town, in a run-down public housing home. She was not surrounded by an abundance of material goods, but was surrounded by a sea of people; kin and friends whose worth was demonstrated in the ways that they mobilised to help in times of personal crises.

Yallambee (meaning "to dwell at ease" in Kalkadoon language) also known as "the camping area" to some residents, was once what could be called a fringe town camp[33], anecdotally established at the end of the Second World War. Yallambee, Wulliberri and Orana Park were the major fringe camps in Mount Isa. Orana Park was demolished, but Yallambee remained. The Yallambee and Orana Park Corporation fought on behalf of residents to keep the reserve and establish permanent houses in place of the tin huts, tents, dongas and caravans (Hintjens 1999, p.5).

According to Hintjens (1999), Yallambee was a place of rest for many people who had nowhere else to go, alongside the residents who called this place their permanent home. As one resident said:

> Lost people ended up in these areas. There's a whole thing of the lost who found refuge and were accepted into the community, because those people had nowhere, so they would live with us. No question about it. (Hintjens 1999, p.6)

The right to live as they chose was a strong argument put forth by those who fought for Yallambee to become a recognised community. Residents who were moved to the suburbs in the

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[33]For ethnographic definitions and examples, see Merlan (1998) and Collman (1988).

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1980s often returned to the camp community, because of the state welfare department's increased

surveillance of their lives in the suburbs. As reported in Hintjens (1999, p.12):

> When we came off the stations, we came to here. I left the camping ground after that, and I went to a house, up to the suburbs, and we had people from the Housing, and we had people round all the time, in the house. We couldn't live the life that we were living down here. There was no peace…If I knew then what I know now, they wouldn't be getting past the door: That what they done to us, people in and out the house all the time, you don't feel free. …No one could tell us how to live, because it was your own home. That made you feel good, because you clean up when you wanted to clean up, you put things where you want to. They didn't rule us the same.

Yallambee is home to many families who have actually lived there for many generations and who

have a significant connection to this place. Not only are they intimately embedded by long-term

residence, for many this is their 'country', their residential and spiritual home. Their shared

experiences and histories come from and simultaneously reinforce fluid and shared living

arrangements based on kinship structures, and their status as a small sub-community within the

larger Mount Isa community. Yallambee at the time of writing is operated by the State

Government Department of Housing, which provides repairs and maintenance to the houses on

the reserve lands. However, as houses are closed for repairs, residents are moving into the

remaining houses. This movement of people places significant pressure on the infrastructure and

buildings that were not really designed to house more than four or five people in a family. The

state of disrepair was reported by Channel Ten news in 2009 (Ten News Brisbane 20/05/2009)

and these images contribute to the public perceptions of Yallambee, not as a community that has

been ignored and mistreated, but as a dysfunctional community.

The next call-out took us round the back of town, down past the Irish club. As we were driving

along, I looked out the window. The sirens were on and the red light signalling a life-threatening

event was shining out against the corrugated iron fences. The flash of the red light shocked me

every time. Mount Isa looked and felt so different in the back of an ambulance. Each call-out

made me a little anxious – I was trying to prepare myself for things I might see, but thankfully did

not. Inside the ambulance felt safe and secure, yet somehow changed the town I could see

outside – all of a sudden it was a town of many potential problems, but it felt like it was under control. That someone here could do something to start fixing the problems. It was a reassuring feeling.

The place we arrived at was in another cul-de-sac. This cul-de-sac looked a lot more like what I would have expected at Yallambee, had I relied on media or other people's descriptions. There was a child's tricycle upturned in the street, which was also littered with beer bottles and other rubbish. The houses looked run down and the yards were poorly kept – except for one house, which was like new – manicured lawn, warm lighting, and shiny new car in the gated yard. We pulled up out the front of a decrepit, yet functional house. It did not look like anyone was home, except for a lone man sitting on the ground outside the front gate.

The man had his knees drawn up to his chest, and his head in his hands. He was wearing a yellow XXXX (Four X) Gold (see glossary) promotional t-shirt, faded and threadbare black jeans and a pair of thongs. As we went up to him, you could tell he had been drinking. He was disoriented and you could smell the alcohol on his breath. Michael warned me to be aware that the man had been drinking and that it could turn violent. We talked to the man, and found out his name was David. He had pains in his chest and upper abdomen.

We got David into the ambulance on the stretcher and Linda put him on oxygen. She asked him some questions. He was very certain what was causing his pain – it was his ulcer. His doctor had told him he had an ulcer, and gastritis. As we drove in the ambulance, Linda reassured David for a bit. She asked him if he had been drinking, and if he had eaten. He had had a chicken sandwich for dinner, and had been drinking steadily for many hours. She asked what kind of work he did, and he said he worked out bush as a concreter. Linda then started talking to him, about the fact that he knew what the doctors were going to tell him. He knew. He knew they would tell him to lay off the grog. It sounded from the way he talked about it like he had heard it many times, although he was taking little heed of the advice, saying he couldn't give up his beers altogether.

We admitted David and started to get the truck ready again. Linda told me she had picked up David once before for the same thing. That was why she was talking to him about the alcohol.

The stories of Mrs N and Mrs H, along with David's story, also highlight particular perceptions of socioeconomic indicators. State of housing and the relative lack of material goods indicate many things, not just poverty. In Mount Isa, there are many properties owned by people who do not live here, who rent their properties out. In some cases this can contribute to the relatively poor upkeep of the house and property, sometimes due to distant landlords who have little regard for these properties. In other cases, it is difficult for distant landlords to organise and stay on top of overworked local tradespeople in getting repairs and maintenance carried out on properties. Rental prices are at a premium due to a number of factors. Despite a perception of Mount Isa being surrounded by 'empty' space, there is little vacant land available in Mount Isa for new housing development. This means that the relative value of existing properties is at a premium as the population grows and the number of dwellings remains unchanged. This creates a market where supply is far outstripped by demand, creating a space for ever-increasing rental prices, regardless of the state of repair of the dwelling.

The relative condition of homes is therefore not necessarily an indicator of poverty for those who live within. This is also influenced by the level of commitment that residents make to living in Mount Isa. For those who see Mount Isa as a base, a place that they live in temporarily or that they stay in for work, while flying back to their 'real' homes on the coast or interstate, houses tend to be weathered and run down, due to a lack of care or a sense of apathy. For those who do commit to Mount Isa long-term, this can be a source of frustration; houses that are in a state of disrepair may signal to outsiders a sense of a town that is not valued, not cared for, for some this equates with a lack of community coherence.

The stories of Mrs N and Mrs H are juxtaposed with the story of the hard-drinking single male, David, whose isolation was formed after years of living and working in geographically isolated

places, and being socially and physically distant from other people. David's story was similar to the stories of bush legends: David displayed many of the characteristics that were discussed in Chapter 3 (section 3.2, specifically Ward 1966). David professed to working hard which was also evidenced by his physical state; years of working in the sun had aged him prematurely, his skin was sunburned and his hands were tough and worn. David was playing equally as hard on his breaks from working out bush (see Brady 1988 for examinations of group differentiations of drinking styles, and particularly for discussions of tolerance of high consumption behaviours in outback regions). His drinking patterns had been cause for concern before, and had led to the ulcer that he believed was causing his current pain. His dislike and disregard for officiousness and authority was evident in the disdain he showed when Linda discussed his alcohol intake with him. This was a man who had heard it all before, and knew very well that he needed to cut back or eliminate alcohol from his life.

We were on our way again. It was another code one with chest pain. The man was at the phone booth across from the Barkly Hotel. Michael sped out there. We found the man sitting slouched near the one functional phone booth, across the road from the Barkly Hotel. He was an Aboriginal man from Urandangi, and he spoke very softly. Michael kept asking him to speak up, and himself, got louder each time he had to ask. This did not change the way the man spoke, though. I did not hear much of what he had to say, other than he was staying at Arthur Petersen [the Arthur Petersen Special Care Centre, a local diversionary centre], and he had a chest infection. He and Michael got in the back and I rode in the front with Linda.

Linda explained to me that this was one of the downfalls of the kinds of questions you ask in the call centres: it is hard to know when someone says they have a pain in the chest, what exactly it could be. So it ultimately ends up being a code one emergency, even for a chest infection. She had worked in the call centres and knew the sequence of questions, and admits that perhaps we ask the wrong questions, but it is hard to be more precise, when people are in pain.

If one were being uncharitable, it is possible that this man had called the ambulance in order to enact transportation to the hospital, which just happened to be mere meters across the road from the place he was staying. Many of the ambulance officers I spoke with stated that at times, the ambulance was used as a free taxi service, and that people needed to be better educated on the purpose of the ambulance service. I am uncertain that there was a lack of understanding about what the ambulance service does, or whether people know how to manipulate the system to suit their own needs. By calling the emergency services number and asking for an ambulance due to 'chest pain', this man had secured free transportation from a pub to a location conveniently located adjacent to his accommodation. However, he also received care for his chest infection, which may have otherwise gone untreated.

Once we had admitted the man from Urandangi, we took off again, this time to a scheduled Royal Flying Doctors Service flight. We were transporting a baby. The baby boy had been in Townsville for treatment and was coming back in a humidicrib. As we rode along in the ambulance, I wondered how it must feel to do this kind of job all the time. Mount Isa looked and felt different in the back of an ambulance. I felt like I was exposed to the world, and yet totally safe and in control. It was a beautiful clear night with a slight chill in the air. I could see the lights from the mine and the stack blowing waste smoke out the top. Riding backwards through a town gives you a different perspective on it. It is as if Mount Isa was new, despite it being familiar to me. I knew where everything was and should be, but seeing it from the opposite direction to normal just made me more aware of it all.

We reached the airport, and pulled up on the tarmac next to the plane. A young Aboriginal woman had disembarked, and was standing, trying to stay out of the way, looking a little uncomfortable. We made eye contact with each other and started moving toward one another. We talked about her baby. I asked if she lived here, and she said yes. She told me her baby had been away too long. I said it must have been good to get home, and she wearily agreed. Her

name was Becky, and her baby was Billy. The doctor and nurse came out of the plane, and the humidicrib was wheeled down onto a special transport trolley. Becky and I watched closely. He was a beautiful little baby, with big round brown eyes. He was wearing a little green and white stripped knitted beanie on his head, and was wrapped in a blue bunny rug.

We all got into the ambulance once the crib was fixed. I sat in the back next to Becky, and the attending doctor and nurse sat on the stretcher. We all touched the trolley, hoping to keep it a little steadier, even though it was locked in. Billy was awake and looking for Mum. It was just about feed time. There was a little chatter among us, but not too much. We were all a bit mesmerised by little Billy. The doctor asked Becky if she was going to go home that night or stay at the hospital. She replied: "Yes." It was a perfect example of the 'double-pronged question' which has been characterised as problematic in communication with Aboriginal people (see Eades 2000).

We got Becky and Billy to the hospital and wheeled Billy through A&E, through the hospital to the Maternity ward, where he was staying the night. He was going to be swapped out of his travel humidicrib into one in the nursery, and another baby would take his place. The other baby was travelling to Townsville on the RFDS plane at 11:30pm. The Mount Isa Hospital has limited facilities for intensive neonatal care, and thus many babies requiring specialist care are transported to Townsville or Brisbane.

This fieldwork experience produces a number of themes and specific examples that require discussion. These include some of the major themes that run throughout the thesis. These themes include health professionals' perceptions of what constitutes a 'cultural practice' and the ways that people are embedded in communities and larger social processes. The mobilisation of kinship (sometimes including extended kin) networks in times of crisis and patient perceptions of the hierarchy of health professions are other themes. Importantly, the theme of health literacy (see full discussion in Chapter 9) is raised. In this case, health literacy issues concern lay

perceptions of the importance of specific health or life story information in current emergency treatment, as measured against a mystifying biomedical hierarchy of knowledge.

Returning to Mrs N, her daughter and other family members had an intimate knowledge of their matriarch's health and life story. Each member of the family that was present during her crisis (including her grandchildren) was able to contribute information about her life and previous health conditions. Of significant interest though, were what facts each person contributed and the possible reasons for privileging some information over others.

Mrs N's daughter seemed to think it important to provide as much information as possible in the hope that some small piece of the whole story might contribute to an increased understanding of the situation at hand, even to the extent of mentioning a fall that Mrs N suffered as a child that led to ongoing issues with her neck and back. The likelihood of this childhood fall being a causative factor in the current incident is minimal, but her daughter believed it important enough to share with the Ambulance officers who attended. This is a good example of the ways that the mystification of biomedical knowledge operates in an everyday sense. Mrs N was a very old lady, who was most likely displaying symptoms of being a very old lady. However, her daughter in effect denied this as being a factor in the current illness, and attributed many of the recent illness events to the significant impact that falls can have on a person's health, especially those who are old and frail.

This appears to be a common assumption made by lay people not initiated into the ways and knowledge of the biomedical system. Due to a lack of lay understandings of what constitutes medically-significant information, there was a tendency to attempt to recount all possible related information. It was then up to the Ambulance officers, as initiated, knowledgeable practitioners of the biomedical system, to interpret these stories and sift them for meaningful and useful information. It was also up to the officers to ask suitable questions in the hope of obtaining useful and meaningful information.

This also works in reverse. Those experiencing illness can also make active choices in what kind of information they provide to various health professionals, exhibiting an almost hierarchical ordering of the kinds of information deemed relevant to the practice of each kind of health professional. This may also reinforce existing power hierarchy among health professionals. In Mrs N's case, she provided particular information to Linda, the ambulance officer, and provided more information to the emergency department nurse. This caused some degree of difficulty for Linda, who required certain information to do her job, and then discovered she was denied that information by the patient, who chose to share it with the nurse. Alternatively, this may have been a function of the ways that different health professionals ask for information and the corresponding ways that patients are asked to place value on that information. Where Linda had asked about the kind of pain that Mrs N was suffering, the admitting nurse asked her to rate the level of pain on a sliding numerical scale, to which Mrs N seemed far more responsive, and even offered additional information about the location of the pain that she had not provided to Linda. Of course, this may also be related to place: perhaps Mrs N envisages the ambulance journey as purely transportation, not as a distinct episode of care, or the beginning stages of an episode of care. Perhaps for her, the Emergency Department at the hospital (the site of extensive intervention) was the most appropriate place to begin sharing health information.

This chapter also raises some interesting questions about the nature of ethnographic fieldwork and the expectations placed on ethnographic field data. There has been much debate about the role and function of ethnography and what ethnographic data represents (see recent articles such as Forsey 2010, Lillis 2008, Lassiter and Campbell 2010, Koro-Ljungberg and Greckhamer 2005, Boccagni 2011 and Feldman 2011 for discussion of this debate, and Savage 2006 for applications to health care settings). One question such debates produce is whether it is possible to generate sufficient insights from one night's observations. I would not wish to suggest that one night's field work is necessarily enough to generate sufficient insights into anything other than the phenomena under description, but I would suggest that it can provide a number of insights into the place and

positioning of the ethnographer, or the symbolic relationships to be found in a discreet case that are relatable to larger social processes.

If ethnography is characterised as "direct and sustained social contact with agents, and of richly writing up the encounter, respecting, recording, representing at least partly *in its own terms*, the irreducibility of human experience" (Willis and Trondman 2000, p.5, original emphasis), then has this example of an ethnographic artefact (i.e. the text produced as a consequence of participant observation) succeeded or failed in this objective? Has this text sought to essentialise the experience of Mount Isa residents on the back of one night of fieldwork with a couple of interesting examples? In answer to this, one should consider the premise that ethnography is located within the ethnographer's experience of the social reality in which they find themselves:

> The social body is the site of this experience engaging a 'corporeal knowledge that provides a practical comprehension of the world quite different from the act of conscious decoding that is normally designated by the idea of comprehension' (Bourdieu 1999, within Willis and Trondman 2000, p.6).

The narrative presented here was not produced so as to assert that one night with an ambulance crew was enough on which to base my entire thesis about Mount Isa. However, it did reveal an important moment of reflection for me, on my choice of a critical stance which (I thought) had previously cast those who worked within the biomedical system as being intimately tied to and constitutive of that system. This had framed health professionals as those who, in acting as agents of the state through the biomedical system, were to be rallied against. These professional bodies represented the flaws and inadequacies in the bureaucratic structures of the health care system, simply through their embodiment of policies and procedures that either cast cultural difference aside, or denied it altogether in terms of people's experiences of health.

As simplistic as this may seem, such views fit nicely into the naivety of a young, white, middle-class female anthropologist who identified strongly with the so-called 'powerless' peoples in this story. I had unwittingly and unquestioningly placed health professionals into a position of power,

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which they undoubtedly have, but without acknowledging the relatively powerless place that many of them also occupy within the health system. Or the degree to which they could influence and change the structure of the health system, through forms of everyday resistance in practice – by saying and acting in ways which could challenge established norms regarding their practice. Conversely, this realisation also assisted me to better understand the moments in practice where this challenge was denied – moments where practitioners could have chosen to rally against their standard practices to enhance patient care (I am thinking here of the benefit that some flexibility of arrangements could have brought to Mrs H's experience, had Michael and Linda swapped tasks for the sake of patient dignity, rather than maintaining such practice for the sake of equity in their workload).

This fieldwork experience does reveal, when considered in conjunction with long-term immersion in the field itself, several core issues that Mount Isa residents face, which may be shaped by various social realities, both within this location and from much further afield. Alternately, there are many stories which this example does not capture. For example, there were few young people encountered in this narrative, and thus the circumstances of young people in Mount Isa cannot be expected to be elaborated upon here.

What can we reasonably expect from our field data, and why was this example a pertinent one for the development of the core themes of this thesis? As Small (2009) discusses, this ethnography is set within an environment which demands generalisability – intellectually, professionally and politically. By creating an ethnography which is about health, but even more specifically, that grapples with issues of inequality and culture in relation to access to health care, this thesis talks to and will be reviewed by an audience of quantitative observers of the same phenomenon who may share a sense of a unity of method (Small 2009). This is not, and was not created as a purely descriptive ethnography that did not have to contend with questions of generalisability, validity and representativeness. Rather, this ethnography, being guided as it is by a combination of

anthropological and health services research conceptual frameworks, speaks to multiple audiences, and begins to interrogate the ways that ethnography can contribute to health policy and debate. So often, the in-depth descriptions contributed by ethnography to health research are characterised as being merely 'exploratory', not capable of generating data which provides 'real' (i.e. valid) statistical inferences about the representativeness of a community among other like communities, nor providing data which can be generalised across other (unobserved by the ethnographer) communities with like demographics or characteristics (Small 2009).

This specific in-depth engagement with one night's fieldwork has generated some insight into the ways in which Mount Isa residents' realities are shaped by the social realities that bind them together and set them apart. The distinctions between agents in this case study are important micro-representations of some of the demographic categories of this town, and whilst the discussion of these stories is not intended to be representative in any statistical sense, they are intended to be representative in a case-logic sense: upon reflection (and seven years of residence in this place), these cases do demonstrate to a degree some of the social and political influences that shape the everyday experiences of people like Mrs N, Mrs H, David, Becky and Billy. It says nothing at all about those who did not require emergency care that night, it says nothing of the 'well' people of Mount Isa.

However, it does speak about the ways in which local ambulance staff relate to their patients in times of emergency and crisis (which while an exceptional event for some patients, is the everyday mundane existence of an ambulance officer), the ways in which discourses and characterisations of 'culture' become integrated into everyday encounters in emergency health and the ways in which the social and economic conditions of this place engage to create situations of illness and distress for residents of this place. It speaks to data from other studies regarding the health and wellbeing of those people resident in rural and remote communities, it speaks to the statistical

data about self-reported illness behaviours of rural and remote peoples, and it speaks to population health discourses on social inequality and health status.

Perhaps it is like Abu-Lughod (1986, 1993, 2000) asserts in much of her ethnographic work, location is critically important to ethnographic understandings. This chapter represents some of the social 'locatedness' so important to this ethnographic narrative of access barriers to health care in this place – Mount Isa. I also hope, in the spirit of Abu-Lughod (1999) to invoke a discourse of familiarity through the style in which this fieldwork experience (indeed, all of the fieldwork experiences described in the thesis) is conveyed, to bring a sense of honesty and embeddedness to the account that would challenge the ways that ethnographic texts are reproduced in academic texts such as theses. It is important that the reader gets a sense of 'being there' in this ethnographic style, that the opportunity to characterise Mount Isa as truly different or distant to our selves is disturbed and distorted.

This way of writing was also intended to demonstrate the relative incapacity of purely structural analyses to do justice to 'life as lived' (Abu-Lughod 2000). To do this, I have incorporated accounts of fieldwork that create a discourse of familiarity alongside structural frameworks which seek to break apart human lives and experiences for the purpose of newly revealed understandings of particular issues – in this case, access to health care. The following chapters address the data collected with regards to various aspects of access barriers to health care experienced in Mount Isa. These aspects are modelled on Penchansky and Thomas' (1981) 5As of access, as detailed in Chapter 3. By examining various aspects of the experience of access, it is possible to elaborate on the specific circumstances and issues that create barriers to health care. The first aspect to be considered regards the availability of health care services in Mount Isa.

Chapter 7

The 5As of Access – data from Mount Isa.

There are a number of core themes that will be dealt with in chapters 7 through 10, to create a discourse regarding cultural barriers to care. These four chapters will unpack the concept of cultural barriers as it reveals itself in health and medical literature, policy, and everyday expression. I consider representations of access barriers that emerged from interviews and observations during the time of my fieldwork. The Penchansky and Thomas (1981) 5As of access taxonomy is used to demonstrate the ways that barriers to care are manifest in the everyday lives of Mount Isa's Aboriginal and Torres Strait Islander populations. Such taxonomies are a useful way to unpack and examine complex issues in a careful and systematic way. However, it is important to remember that such separations are somewhat artificial, and one must be careful not to misrepresent the complexity and myriad of ways that the concepts overlap and interlock.

The following chapters argue that the creation of a discourse regarding cultural barriers to health care for Aboriginal and Torres Strait Islander peoples is dependent on these interlocking phenomena. While each of these phenomena can be examined separately, each influences the others; the language of policy is influenced by the everyday discourses that are the result of a co-creation of emerging Aboriginal identities and the literature of health and medical practice. Conversely, the language of policy also can be seen to permeate everyday discussions and is often repeated in health and medical literature. By examining the circumstances present in Mount Isa at the time of fieldwork, it is possible to illustrate the ways that such discourse creations occur.

Chapter 7 examines the services which were available in Mount Isa at the time of fieldwork. This reveals the difference between bureaucratic representations of availability and the realities of health practice in Mount Isa between 2007 and 2009. Discussions of the relative availability of necessary services in Mount Isa demonstrate the complexity of service provision in remote regions, while also revealing the necessity of uncovering other factors of access.

My examination of the accessibility of health care services focuses on the provision of transportation (to services within Mount Isa and outside of the town). The adequate provision of transportation can be viewed as a structural issue, particularly with regard to state-sanctioned policies regarding support for transport to services outside of Mount Isa. However, more often transportation has been characterised as being a socio-cultural issue within Mount Isa, casting Aboriginal people as hapless victims in the provision of public transportation services, or as being in need of specialised transportation services.

Chapter 8 continues with an exploration of accommodation of service provision within the Aboriginal community of Mount Isa, and considers appointment systems as an indicator of service rigidity. This consideration reveals discourses regarding Aboriginal concepts of time as different to the ways that western systems compartmentalise time in health care systems. In the creation of a discourse of differing time constructs, Aboriginal people may be cast as ancient and synchronous, when the reality of contemporary Aboriginal lives might suggest quite a different conceptualisation of the reasons for lateness or non-attendance. This creation of a distinct Aboriginal conceptualisation of time is a part of co-creations of Aboriginality on the part of Aboriginal people and health care providers on related issues of acceptability. In particular, constructions of appropriate gender match between patient and provider may essentialise Aboriginal people in Mount Isa and cast them once again as being ancient and synchronous. These issues are often discussed as being immutably and obviously cultural in nature, and which may lead to differential levels of care.

Chapter 9 provides analysis of everyday discourses on what might constitute cultural barriers, as identified in interviews with Aboriginal people and health care providers, interpreted in the context of the field. Many of the issues identified might better be discussed as social, cultural and structural barriers to care, revealing potential ways to overcome some barriers to care. Finally, an examination of Aboriginal and Torres Strait Islander Health policy at national and state levels illustrates disconnects that may occur between communities of Aboriginal people and communities

of policy makers. While the discourses revealed in these policies suggest that community identified needs are integral to service provision, this may be undone at the level of resource allocation, based on formulae that strive for equality and economic rationalism at the expense of equity.

The current chapter tackles issues related to availability of health services in Mount Isa. Here I discuss the theme generally, and provide a brief history of the operations of the local Aboriginal Medical Service as well as information about the other kinds of services that major providers were able to deliver during the time of fieldwork.

Plate 8. Mount Isa Base Hospital (circa 2007) (Photo: Dr Dennis Pashen, MICRRH stock).

Plate 9. Mount Isa Hospital redevelopment 2011 (Photo: Kristin McBain-Rigg).

Plate 10. North & West Queensland Primary Health Care Offices (Photo: Kristin McBain-Rigg).

Plate 11. Gidgee Healing (Photo: Kristin McBain-Rigg).

7.1. Availability of health services in Mount Isa.

The volume and type of health care services and resources available in Mount Isa has been highly variable, which has impacts beyond the boundaries of the city itself. Mount Isa is the health care hub in the region, and Queensland Health provides the majority of health services in the region. When changes occur within the system in Mount Isa, those changes are often felt by communities in the surrounding area, including those as far afield as Doomadgee, Normanton and Mornington Island in the Gulf of Carpentaria (see Map 1).

Volume and type of services and resources can be seen as an indicator of availability. Therefore, lists of service providers and specialist programs offered in Mount Isa provide evidence of (at least theoretical) availability. As at the end of my fieldwork period (May 2009), the service providers and resources available in Mount Isa are represented in Table 2 (see Plates 8-11).

The type and frequency of visiting specialist services can be highly variable and are largely dependent on the availability of specialists willing and able to come to Mount Isa. The workload on visiting specialists is generally high, and bookings are taken well in advance. It is rare for cases to be added to these lists at the 'last minute', although such occurrences are dependent on the relationship between specialists and local service providers, and the patient's diagnosis.

Historically, Mount Isa has had inconsistent success recruiting and retaining staff in most industries, and the health care sector is no exception. The employment market in Mount Isa has typically been dominated by the mines, which offer many positions that require a low level of prior skill or training. Within the health sector, there is competition between state government services, private practices and non-government organisations for staff and resources.

Table 2. List of health services available in Mount Isa as at May 2009.

Type of Health Care Provider	Number of providers
General Practice Services:	
Private Medical Service A	4 General Practitioners (two part-time)
Private Medical Service B	2 General Practitioners
Private Medical Service C	2 General Practitioners (one part-time)
Private Medical Service D	1 General Practitioner (closed down in June 2009)
Private Medical Service E	1 General Practitioner
Aboriginal Medical Service	1 full-time General Practitioner; 2 part-time locum General Practitioners
Private clinic at the hospital	2 General Practitioners (limited GP services available)
Dentistry Services	2 Private Dentistry Services
Optometry Services	2 Private Optometry Providers
North & West Queensland Primary Health Care (largely outreach services)	
Psychology	5 Psychologists
Podiatry	2 Podiatrists
Diabetes Education	2 Educators
Physiotherapy	2 Physiotherapists
Occupational Therapy	2 Occupational Therapists
Dietetics	2 Dieticians
Speech Pathology	2 Speech Pathologists
Queensland Health	Variable staffing numbers over this time
Hospital Departments:	
Accident and Emergency	
Maternity Ward	
Medical Ward	
Surgical Ward	
Physiotherapy	
Occupational Therapy	
Speech Pathology	
Tropical Public Health Unit:	
Communicable Disease Control Nurse	
Immunisation programs	
Health promotion	
Public Health initiatives	
Community Health	
Sexual Health Clinic	
Integrated Mental Health	
Pharmacy	
Pathology	
Podiatry	
Dietetics	
Dentistry	
Social Work	
Aged Care Assessments	
Paediatrics	
Obstetrics	
Private Medical Imaging Clinic	
Off Site services:	
Alcohol, Tobacco and Other Drug Services	
Child Health Clinic	

Other major health service providers include North & West Queensland Primary Health Care (NWQPHC) and the local Aboriginal Medical Service. NWQPHC is the regional division of general practice that co-ordinates and provides support for the region's general practitioners. NWQPHC also organises delivery of allied health care by outreach to remote communities in the region. The offices for the North & West outreach teams are based in Mount Isa. The local Aboriginal Medical Service, currently operated by the Mount Isa Aboriginal Community Controlled Health Service board, is locally known as Gidgee Healing.

There are services that are considered crucial to the region, due to the geographic remoteness of many of the people who live within the health service district. These include the Queensland Ambulance Service and the Royal Flying Doctor Service. Within Mount Isa there are many other service providers that are seen as integral to the health of the population including many support and social service departments. The three major organisations (Queensland Health, North & West Queensland Primary Health Care, and Gidgee Healing) are examined individually below.

7.1.1. Queensland Health.

The major health provider in the region is Queensland Health. Queensland Health is the state government health department, and the region that Mount Isa sits within is the Queensland Health Mount Isa Health Service District[34]. Queensland Health provides the majority of services and medical units in the town and surrounds; in some remote communities there are only Queensland Health facilities available (see Map 3) (see Plate 8 and 9 for pictures of the Mount Isa Hospital).

The Mount Isa Health Service District covers a geographic area of over 300,000 kilometres and provides services west to Camooweal, north to Mornington Island and the communities of the Gulf of Carpentaria, and east to Julia Creek and just to the south of Dajarra (see Map 3). Each of the smaller towns in the region has a small hospital or Primary Health Care Centre available. These

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[34] By area the Mount Isa Health Service District is currently the largest of the twenty Health Service Districts in Queensland.

centres provide various services and accommodate visiting specialist clinics where available. Mount Isa Base Hospital is the major referral hospital for all of these towns.

7.1.2. North & West Queensland Primary Health Care.

Since 1993, North & West Queensland Primary Health Care (NWQPHC) (see Plate 9), originally known as North Queensland Rural Division of General Practice, has been the regional division of general practice, and currently provides support services to ninety general practices in a geographical area covering approximately 776,000 square kilometres. This region has smaller sub-divisions, and Mount Isa and Gulf communities fall within the "North West Place". In their 2008 Annual report, NWQPHC state that they employ approximately 100 staff, "about two-thirds of whom provide outreach allied health services and health promotion activities to remote communities, working in collaboration with local GPs and communities" (NWQPHC 2008).

NWQPHC receives funding from the Commonwealth Department of Health and Ageing and the Office of Aboriginal and Torres Strait Islander Health (OATSIH is an office of the Commonwealth Department of Health and Ageing), Queensland Health, and Disability Services Queensland.

7.1.3. The Aboriginal Medical Service (AMS).

Arguably, one of the most important services for Aboriginal and Torres Strait Islander peoples in Mount Isa is the Aboriginal Medical Service. Mount Isa has its own Aboriginal Medical Service (AMS), currently operating as Gidgee Healing under a local, community-controlled board (Mount Isa Aboriginal Community Controlled Health Service) (see Plate 10). However, this has not always been the case. The local AMS has had a fairly turbulent history, including various struggles for control by local Aboriginal groups. At times, these changes in control through board membership have resulted in disrupted provision of care. In the worst circumstances, it has resulted in complete shut-down for a number of months. A more detailed history of the local AMS, is provided in the case study section below. Despite experiencing many phases of change since its inception, the AMS has always used primary health care model principles with a strong focus on

regular health checks, opportunistic screening and preventative health measures. The availability of such a service is deemed critical in providing culturally appropriate care for local Aboriginal and Torres Strait Islander populations (see Anderson and Brady 1995 for a discussion of the history of the AMS movement in Australia, and the creation of performance indicator measures in such services).

7.1.4. CASE STUDY: History of the local Aboriginal Medical Service.

The history of the Mount Isa Aboriginal Medical Service takes many shifts and turns. In an informal interview (October 2009), Janice, a long standing member of the board of the local AMS discussed the history with me, which is analysed within the context of informal discussions with members of the local community and fieldwork observations. I also conducted interviews (July 2009) with MIATSIHS managers, Sally and William about the years that the local AMS was administered externally due to government intervention.

7.1.4.1. Injilinji and Yapatjarra.

In the early 1970s, there had already been various attempts to organise an Aboriginal medical service for the local Mount Isa community, but it was not until the establishment of Injilinji (a community based organisation) that any real progress was made. The Injilinji Aboriginal and Torres Strait Islander Corporation for Children and Youth Services (1983) was created in response to the movement of local Aboriginal people away from reserves and missions, and was a service designed to operate child and youth services to facilitate community change.

Originating with families from Orana Park in Mount Isa, Injilinji and subsequent Aboriginal organisations around town have often been perceived as clan based, and while this was initially the organising principle to create a groundswell of support and progress, these organisations have since worked hard to distance themselves from this tag. Services such as Injilinji, who now also operate an aged care facility and a community kindergarten, have been running for the benefit of the whole Aboriginal and Torres Strait Islander community for over 30 years.

According to Janice, in the twenty years that followed the establishment of Injilinji, there was much discussion in the community about opening a local medical service to operate and attend to the needs of Aboriginal people. Injilinji established a local clinic which they called Yapatjarra Aboriginal Medical Service. Initially, Yapatjarra was only the name of the clinic and many discussions were had regarding establishing an official Aboriginal organisation or corporation under this name, separating it from Injilinji.

This clinic was often perceived to be clan-based too, given the heavy involvement of particular families in setting up the service; there were in fact many people involved in this process, from many families and with diverse professional backgrounds, including those who had worked in the Aboriginal legal service and other government departments. However, Janice reported that the high visibility of one family during early developments may have created a perception of the service as clan-based among some members of the community, which in turn may have influenced the ways the community as a whole engaged with the early services.

Yapatjarra Aboriginal and Torres Strait Islander Corporation for Health Services was established in 1994 (and was incorporated as an Aboriginal Association in 2002), and was a regional organisation designed to serve the local Mount Isa Aboriginal population and communities in the Gulf of Carpentaria, Mornington Island and as far south as Birdsville.

After a long struggle between the organisation and funding bodies, the government pushed to put Yapatjarra under administration in late 2005 (officially deregistered in November 2005). Janice (and other board members who wished to remain anonymous) stated that internal politics on the board had also undermined the strength of the organisation, and when an administrator was placed in the service, it created a split within the community. Many people were angered at the government for undermining local control processes, while many others watched on, to see what changes would occur.

The administrator made a series of recommendations to the government, including election and establishment of a new board for the service, in order that it could maintain local community control, with a new set of board members. According to the audit report for the service at the time of administration, in March 2006 the Office of Aboriginal and Torres Strait Islander Health advised that funding for primary health care service delivery would cease in July 2006 (Audit report 2006). The service was dependent on this funding for its operations. Withdrawal of these funds rendered the service inoperable. This led to a series of community meetings and petitions protesting the government's decision. But ultimately, the service was handed over in 2006 to Wuchopperen Aboriginal Health Service (based in Cairns) to be administered through a period of transition.

Shortly after my arrival in Mount Isa in September 2005, there was some controversy being reported in the local press about the Aboriginal Medical Service in town. Rumours abounded within the community as to why this had occurred. There were accusations of misappropriation of funds and corrupt board members but, according to Janice, the federal government only found that the board had not met regularly enough and that there was inadequate minute-taking at the meetings that had occurred (Janice pers. comms., October 2009).

The news circulated throughout the community that Yapatjarra was being taken over by the government and would be administered by someone else. There was a series of community meetings and petitions drawn up, citing the reasons that the service should not be taken out of the control of local people. Some people expressed to me their dismay at what was about to take place, while still others saw it as an opportunity for those community members who had felt excluded from the service in the past to finally achieve an adequate level of access to the health service.

According to Janice, this changeover was presented to the community and the Yapatjarra board as a 'transition period' for the service, and created turmoil locally. Many people believed that, even

though the service was going to be run by an Aboriginal organisation, that the board of Wuchopperen (located in Cairns) could not possibly understand the needs and dynamics of the local community. The Wuchopperen and Yapatjarra board members were to meet regularly and discuss an action plan for the eventual transition of the service, back to the local community. These meetings, when held, created some tension at the board level, as Yapatjarra members thought that the transition was inevitable due to government promises, while those on the Wuchopperen board believed that they would continue to run the service for as long as necessary, and that they held a degree of control over when the service would be handed back (Janice, pers. comms., October 2009; Sally and William, Interview, July 2009).

7.1.4.2. MIATSIHS.

On the 3rd of July 2006, the local AMS became the Mount Isa Aboriginal and Torres Strait Islander Health Service (MIATSIHS), auspiced by Wuchopperen Health Services board in Cairns. Sally, an Aboriginal and South Sea Islander woman, was put in charge of the Mount Isa service as the Chief Executive Officer. This remained the arrangement until 30th June, 2008. Sally spoke of the frustrations of the early days of her administration, saying that there was a great deal of hostility expressed about the transition among parts of the community, and most of her time was spent trying to allay fears and earn the trust and respect needed to keep the service going. In trying to establish local credibility and prove trustworthiness, it was important to continue to demonstrate that the interests and needs of the local community were paramount. This meant remaining apolitical and often trying to avoid the local politics within the community, while still respecting the views of local community factions.

According to William, (Health Systems Manager[35] 2007-2008) in an interview I conducted with him and Sally (July 2009):

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[35] William is a 30 year old non-Indigenous man who served as Health System Manager during the MIATSIHS period). When Sally left the service to pursue study leave, William took over as

The issue I have become aware of in my short time in Indigenous health is that essentially, the mob has been burnt so many times before. And whether it has been burnt by white policy, legislation, the policy makers or politicians, or how many times they've had broken promises... when you already have that as a foundation, and then you layer on top of that the idea that you're going to have a mob from a different area step in and try to tell you how to do your job, then you have added issues of mistrust on top of that. Because while indigenous mob to indigenous mob they probably share more in common than indigenous to non-indigenous, at the same time there is still a level of mistrust when, you're not from here...you're not part of us.

Sally confirmed (Interview, July 2009):

Sally: That's true and that's where that degree of credibility comes into play. It's about you portraying to all and sundry that the service that's up and running is credible and is trustworthy and can do the job that it was brought on to do.

In the beginning, Sally believes that "...a good 45-50 percent" of her time was spent on dealing with community relationships, perceptions and politics (Sally and William, Interview, July 2009):

...in terms of the community, that was constant. Every community meeting invite that came across my desk, via email or via mail, I actually accepted and turned up to. Because I knew that if I didn't, there would be discussions within the community that Wuchopperen wasn't interested. So as the public face of Wuchopperen on the ground in Mount Isa, I had to go the extra mile, and the extra mile meant being present, and it meant taking it [abuse] on the chin, and it meant saying the hellos to those who I knew weren't saying nice things about us...it paid off in the end, by doing all of that.

The other major task was to establish systems and processes that would ultimately lead to affordable, accessible and appropriate levels of primary health service and care for the local community, which had to include not only Kalkadoon people, but others as well. It took time to identify the needs of the community and partners that the AMS could work with to ensure a high standard of comprehensive primary health care. Once those partners were identified, the AMS team worked hard to establish solid relationships with those partners, often feeling they had the burden of continually keeping the relationships alive.

One of the schemes that the AMS were approved to administer was the S100 scheme, which they ran in conjunction with a local pharmacy. Many, but not all Aboriginal Medical Services are

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temporary CEO of the service. This was approximately one month prior to the service returning to local community control, at which time William was fired.

approved S100 sites. The S100 scheme refers to Section 100 of the National Health Act 1953 which made "...special provision for supply of medications to clients of eligible approved Aboriginal and Torres Strait Islander Health Services in remote areas (OATSIH 2006, p.59)", and is aimed at addressing the need for Aboriginal and Torres Strait Islander people to access Pharmaceutical Benefits Scheduled (PBS) medications for free at the time of consultation.

According to the Urbis Keys Young 2006 report, *Aboriginal and Torres Strait Islander Access to Major Health Programs*, the S100 works as follows:

> Section 100 medications are ordered through a community pharmacy, but no co-payment is charged. Since the medications are supplied in bulk and the pharmacist has no direct dealings with the client, the pharmacist is paid by the Australian Government at a rate lower than the standard (S85) dispensing fee. ATSIHS [Aboriginal and Torres Strait Islander Health Service] staff are responsible for distributing S100 medications to their patients as needed (Urbis Keys Young 2006, p.59).

This is only one program that has been established specifically for Aboriginal and Torres Strait Islander clients, designed to increase attendance at medical services and enhance health status on a number of indicators. A local pharmacy provided the AMS with the drugs required and sanctioned under the S100 scheme, and was paid by the federal government to do so. The drugs were then prescribed by the AMS doctors and dispensed onsite at the AMS, to facilitate easy patient access. Sally and William explained how important this scheme is for those with chronic illnesses and co-morbidities, and low incomes:

> *Sally (July 2009): When you are talking about making primary health care accessible and affordable and appropriate, that kind of meets all of those needs. You've got the most marginalised group in Australia, who live in an area like Mount Isa, who don't earn a high income, and most of them suffer chronic disease and the cost of those pharmaceuticals for chronic diseases is phenomenal – you know, like $100 for a script to get filled. So when you're talking about every second or third patient being diagnosed with a chronic disease, then you're talking literally hundreds of dollars every time they go to get a script filled. As an S100 site we were fulfilling that need.*

On a similar note, the Aboriginal Medical Service had been advocating to get X-rays provided to their patients at low or no cost from the local service provider. In Mount Isa, the only X-ray facility is a private practice located at the hospital, and unless a patient is admitted to the hospital for

care, they cannot receive bulk-billed (see glossary) X-ray services. Any referral to this service from a GP clinic, including those who bulk-bill and including the AMS, will be charged for the X-ray services provided.

The MIATSIHS team worked to regenerate confidence among the community and other service providers that the local AMS was a useful and functional service. The success of the Wuchopperen administration of the local AMS created space for the transition of control back to the local community board, which occurred in 2008.

7.1.4.3. Gidgee Healing.

On the 1st of July 2008, the Aboriginal Medical Service was handed back to the local community to control. There was a new board (only a couple of historical members, including Janice, were accepted onto the new board to maintain a degree of corporate history), and the organisation became registered as the Mount Isa Aboriginal Community Controlled Health Service (MIACCHS) (Certificate of Registration ASIC 2008). The clinic itself now trades under the name Gidgee Healing, and the staff have been working hard to build connections to other health services around town, and retain (or in some cases, renew) the faith of the local community in their ability to run a functional medical service. While the staff are more than capable of running the service, the chequered past has burned many in the community, and with each change in administration there is the usual struggle to move through community politics and create faith in a service for all of the local mob to access.

MIACCHS has seen a rise in attendance rates, and specialty programs are being developed. Janice (pers. comms., October 2009) says that Gidgee Healing is doing a lot of what Yapatjarra did in the past, and wonders what could have been if the government had not taken the service away from the community. She and other members feel that five years of development were lost because of the handover. But, it could be that the handover created a focal point for the community, effectively banding together those who would not have cooperated with each other in the past, to

unite them against a common 'foe' – often portrayed as State or Federal government – and created the groundswell needed to push the service forward, in ways that the entire community found more acceptable.

7.2. Health Service providers and specialist programs.

The local media frequently reports on the GP shortages that Mount Isa has suffered, which is in a seemingly constant state of flux. When I arrived in 2005, there were issues with not having enough GPs, and this occurred again toward the end of 2008, as more of the town's GPs announced they were leaving town. This was sensationalised by the local press, but was nonetheless accurate.

There is a high degree of variability within staff recruitment and retention efforts, and packages to attract and keep staff in the Northwest region. These packages can include accommodation (either fully supplied or by a subsidized rental agreement), vehicle supply, salary sacrificing, and higher rates of pay than might be on offer in more populous regions. The turnover of staff is popularly reported as generally following a two yearly-cycle, and any staff who stay longer than that are typically characterized as having ties to the region, or have established a life for themselves in the town. The opportunities for young professionals to gain a wide range of skills in a short time, and potentially to gain status in their profession, are also motivating factors for some to stay. However, high staff turnover creates high variability in the availability of services.

As in many rural and remote settings, locum labour is generally perceived poorly by the community, who tend to mistrust those who fly in and out, and perceive it as being a waste of money (see Veitch and Grant 2004). Locum doctors, who provide a valuable relief to the doctors who are stationed in Mount Isa, are often perceived (mainly by other health professionals) as highly demanding, in spite of often being provided free accommodation, and high locum rates of compensation (which are far higher than their stationed and salaried colleagues in Mount Isa).

The management of these perceptions within the community is an important part of the role of managers in the health sector, and is particularly important in even smaller regional communities.

7.2.2. Availability of services from the perspectives of health care professionals.

Health care professionals often have an intimate understanding of availability issues in Mount Isa, and the kinds of behaviours and attitudes that can prevent people seeking care. They are bound up in the same system, and often expressed the same kinds of frustrations as community members about the lack of particular services that they perceived were desperately needed.

Harry (a local paramedic) discussed the ways that the behaviour of health professionals can create barriers to care for potential patients, especially when it came to issues of making public their rates of pay (Harry, Interview, February 2008) :

> *...you've got to be very careful in the communities about...I've pulled up a couple of the paramedics in my time that have been round town, bragging about how much they get paid. And of course the community gets a bit...thinking "they don't do that much work and they're getting paid that much money...you know I work on the council and I'm working all day long"...so yeah, it's a reasonable perception...if you go through Julia Creek now, the nicest house in Julia Creek is the Ambulance house...Because it's brand new. And it's the tallest building in Julia Creek apart from the water tower. But you've got to manage that perception.*
>
> *And it's interesting...that community's really keen and happy that they've got a paramedic and something to retain them, so they look at it as a good thing. But the standard of housing in some of those remote communities is really poor...by what we would accept.*

As identified in the above quote from my interviews, it is important to brief health staff on the standing of their position in many of the small communities in the region, in efforts to manage the perceptions of the community and create a level of trust with health providers. When the newest building in town is a house for the new ambulance officer, the community expectation may be that this person has a privileged place in the community, but may also carry an expectation that, if they are good people and even better health professionals, they will contribute to the community beyond the boundaries of their official position. If this does not occur, it may make service provision difficult.

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Within Mount Isa, some health professionals perceived that there was a real lack of services available, and that there were many services that could easily be provided locally. There was a degree of frustration about this, especially with regard to services at the hospital. As one general practitioner (Kimberley, Interview, January 2008) said:

> *Being a base service, there are some pretty basic things that can't be done here, and so I get very frustrated that a huge amount of money gets wasted transferring people, for things that really could be done relatively easily here. And again, the same thing, not treating, not looking after the staff that are here, paying locums huge amounts to fill in the gap. But, again, that's just sort of a system type thing. But yeah, the fact that so little can actually be done here in Mount Isa, you're almost sort of directly dealing with Townsville. Because the hospital here is so limited in what they can do. And that's very frustrating because it is such a big distance, and I don't think it would be very difficult for them to…provide a few more basic things out here.*

And in the interview with Sarah (general practitioner, Interview, October 2008):

> *Um, I guess, for me, I'm coming up against the same things that come up with every other Joe Blow in town. It's the difficulties accessing people* [health professionals]*, accessing them in a timely interval, not everyone has private insurance, so publicly* [using public services]*, it can be very frustrating, privately it is a lot easier, but still, in a lot of cases, you've got to go out of town. So that means an expense. The hospital does pay for a lot of patient transit, so very often their flight, or their bus, or their train…however they want to go is covered. But it's still the accommodation costs at the end, and seeing the specialists. And even if you've got private insurance, you're still out of pocket. So it can be quite an expensive experience… It's just the issues of whether they've got public or private insurance, whether they've got the ability to travel away. And that's the difficulty in Mount Isa.*

Sarah was a general practitioner who had been working in Mount Isa for approximately ten years, and had seen many changes in the system and the sheer volume of visiting services available to clients over that time. As she noted (Interview, October 2008):

> *When I first got here it was much better. We had a lot more visiting specialists, and it was just that much easier. You know, we had a visiting neurologist, we had two visiting neurologists, we had a visiting neurosurgeon, we had an ear nose and throat specialist coming out every month, and then it went to every two months, and then it stopped…I mean, you had a lot more specialists coming out. So you had a lot more help. And then over time, it's just progressively gone downhill. The system is probably the worst I have seen it, since I've been here. But, having said that, the hospital itself…you can't complain about them coping as best they can, with what they've got. And you've just got to try to work within those limits.*

Some health professionals saw the downturn in specialist visits as a function of apathy and lack of cohesion between the health service providers in the town, while others maintained that, even if the network of health providers was stronger, there would still be a real lack of required services[36]:

> Maree (Aboriginal registered nurse, Interview, November 2007): What I do find is a lot of us work in isolation from one another, and it's...I don't know why that is...I know what's missing...is a forum whereby all the stakeholders in the health system, industry, come together to a table and discuss how we do this better...And, you know, I know for me...it kind of further limits our ability to be able to work in with other services.

Some medical practitioners reported that the health network is functional yet many also expressed frustrations at feeling out of touch with other service providers and the programs available. They all expressed a desire to meet regularly and share program information. Some acknowledged that there may need to be a database containing such information regularly updated and maintained. However, while team case management often occurs for patients within each institution, there may be issues related to privacy and confidentiality of health records that may prevent cross-institutional sharing.

> Kimberley (Interview, January 2008): To be honest...I didn't find the other GPs particularly friendly. Very much tend to work as solo practitioners. Whereas, when I was working in Townsville, we tended to get together on a monthly basis, so there were a lot more friendly networks between the GPs. Um... we saw quite a bit of North West Queensland [NWQPHC], so that's been really good. Again, didn't find community health at the hospital engaged particularly. But again, I wasn't in the hospital so you probably find, community health probably focus on the hospital patients a bit more. There is a decided lack of psychiatric services. Trying to think who else I networked with....there aren't really a lot of other private facilities, there's one physio, and there's a few dentists and things. But again, most people weren't prepared to pay the fees that they charge out here, and the waiting lists...So we didn't tend to work with them.

The waiting lists for specialist care can be long and as stated above are often predicated on the availability of visiting specialists, and this can often be determined by the availability of adequate transportation for these specialists to visit. According to Julie, a 35 year old emergency department nurse (Interview, November 2008):

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[36] For a discussion of the benefits of community health forums in rural settings see Sheehan et al. 1996.

Well, we might be losing our orthopaedics guy, because his clinic of 92 people on Thursday was cancelled because Mac Air didn't fly. And in the heat of the moment he said "Get [expletive], I'm not coming back to Mount Isa again"…and there is only so many times you can have your full day of patients cancelled, and these are patients too coming from all out of the way, they sat in a car for the last eight hours to make it to Mount Isa to have their orthopaedic needs seen to.

These specialists often face the possibility of large case loads when they come to Mount Isa, and the fact that there can be months between seeing a patient for an initial consult and having the ability to actually provide a service. If the procedure cannot be done in Mount Isa, the patient will have to travel, and there are often long waiting lists at other sites around the state, too. Any patients having to go to Townsville may have to wait for the availability of a hospital bed, and there have been cases reported in the local and Townsville media, where patients have been told there is a bed for them, but on their arrival, the bed had to be allocated elsewhere, leaving rural and remote patients stuck in Townsville until a bed becomes free.

Not only are the waiting lists for specialist services long; waiting lists for GP services are often extended. There have been periods of time where reportedly patients have had to wait up to six weeks to be seen by a private GP. This most often occurs when the number of GPs in town is reduced[37], or in times of disease outbreaks[38]. Some community members also complained about the amount of time spent in the waiting rooms of GP and other services. While this is also an issue that spans the realm of how appointment systems are set up and thus also fits under the accommodation aspect, it is often reported not as an issue with the system, but as being largely due to the lack of GPs in town.

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[37] Either due to turnover, lack of locum support, absence due to training offsite, or practitioner burnout.

[38] Often in winter it is more difficult to get an appointment immediately to see a GP; for example, when the swine flu epidemic broke out in Mount Isa, some patients had to wait to see their GP for up to four weeks.

As was the case in Anna's story (Chapter 5), many people attend the Accident and Emergency Department at the hospital for care to circumvent this barrier[39]. According to Harry (Interview, February 2008):

> ...Mount Isa Hospital, through the ED, see a lot of low acuity patients. Probably more so than the other hospitals – the ratio is completely different. But that's a lot to do with the fact that, there's not enough doctors in town, in private practice to see the volume of people, there's not enough clinics, and there has been some work done to establish some more ...so most people present at the hospital. I do. Because my private doctor, if I get the flu, I'll have had three doses of it by the time I get to see him. So I just pop up the hospital...

In the interviews with health professionals, I asked if they had identified any particular services that were not available in Mount Isa that we needed. The services identified included renal care (and specifically in one case, the need for a renal dialysis Aboriginal Health Worker); dental care services; public transport; more Aboriginal Liaison Officers, specifically in the hospital system; more Aboriginal Registered and Enrolled Nurses; ear, nose and throat specialist care (deemed particularly relevant for Aboriginal children); psychiatric and mental health services; eye health services; orthopaedics; and, basic cardiac assessment.

It is interesting to note that, many of these services actually do exist and are offered in town. For example, dental services (both public and private) are available, and many others are offered on a visiting basis at the hospital. This could be further indication of a lack of cohesion or communication between service providers with regards to what is available at any given point in time. It could also indicate frustration at the ways that these services are currently offered.

The one service that was mentioned consistently by general practitioners and other health professionals as being a desperate need was mental health service provision. This was reported, despite the existence of the Integrated Mental Health team, who perform outreach services as well

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[39] Due to the Accident and Emergency Department at the hospital becoming overwhelmed by presentations that could have been handled by a general practitioner, the Optional Pathways clinic was developed adjacent to the ED. The triage nurse can refer appropriate patients through to this clinic, which started operations in 2010.

as provide services in Mount Isa, and the opening of the wellbeing centre by a team of psychologists from North & West Queensland Primary Health Care in 2009 (at any point in time, these psychologists would be in remote locations providing outreach mental health services throughout the region, but there was always someone in the office).

The Queensland Health Integrated Mental Health service in town has been characterized in the past as being "dysfunctional" (Phillips 2004, pp.30-31), and there have been periods where staff shortages have severely crippled this service. However, the ways that GPs discussed the service indicated that they either were not aware of what was available or what was currently being provided by the service, but also that the increased bureaucratisation of the referral process had dramatically reduced their ability (or willingness) to refer patients.

According to hospital staff, mental health patients who present at the hospital, often to the Accident and Emergency Department as a first point of call, are often assessed by a social worker (at the request of Accident and Emergency staff), who then determines whether to refer the patient through to the psychiatrist. This has caused some Accident and Emergency staff to raise concern at the gate-keeping being performed by the social work team, and at the opportunity for patients to be missed or left out of the system due to inadequate diagnosis and referral. One staff member reported a number of issues and concerns about mental health patients in the hospital system, including the analysis of one Aboriginal patient as a significant concern:

> *Julie (Interview, November 2008): And we have a psychiatrist on board now, he doesn't…seem to come down and see patients as much, because it is usually assessed by a senior social worker first as to whether he needs to. And I actually did read notes once that said an attempted suicide was typical Aboriginal attention-seeking behaviour.*

Mental health patients, who are referred for further care at other sites, including Townsville, face issues regarding transportation and the referral procedures between sites. Often there is miscommunication between sites accepting mental health patients, with places allocated to rural and remote patients sometimes being reallocated prior to their arrival. Health professionals have

also reported problems with the transportation process. The Royal Flying Doctors Service is called upon to transport mental health patients, but this can be problematic:

Harry (Interview, February 2008):...if we get a mental health patient here, we can't manage it here for more than a day, so we'll fly it out, we can't fly it out at night because flying doctors don't fly mental health patients at night...the reason is, okay, they've sedated the mental health patient. But if something happened, untoward, their opportunity to land at night is limited. Where, during the day, they can land on a lot more strips...

So, they didn't used to take a patient in Townsville until they had a bed. So you put them in the plane, off you go, A & E in Townsville gets an admission for a mental health patient, they admit them to the ward, while our mental health patient is still in the air. You get told to turn around, bring it back.

...just beat you. So now what they actually do is accept them in A & E, before they make the trip there.

And according to Julie (emergency nurse, Interview, November 2008):

...so, often we are looking after people in emergency that...have got acute mental illness, but because of our lack of RFDS and whatever else, we don't have the facilities here to deal with it. And so these people wait on the backlog for five or six days, in an emergency department, which...isn't the best place for them to be, but the medical wards aren't staffed with the facilities to cope, either. So they...sit down there. And it's not seen as a high priority, because it is not a life-threatening condition...Because the priority is for, oh, this person's got a cardiac condition, so they get first seat on the RFDS plane, then oh, we have space on the plane, we'll take your mental health patient, and then oh no, somebody else has broken their leg, they're going first....so this person's in acute psychosis...

...going through something more life-threatening than the guy with the broken leg?...If they are voluntary patients, and they are calm and everything else, then they can go up to medical ward. But often that's not the case. They are involuntary, they are in acute psychosis, and if we have someone in they have to be nursed, usually in resus [resuscitation bays in the emergency department]. Which, if you know anything about mental health, high stimulus, lots of doctors with their backs to them [the patient], "They're all talking about me right now"...it just does not get treated appropriately out here. Often they are seen by a social worker to have their assessments done. And he's not a psychiatrist. So he doesn't believe in medications.

There are currently no after hours services in Mount Isa; this is handled by the Accident and Emergency Department at the hospital. The issue of afterhours care is one that can have far broader impacts than just those on patients. MIATSIHS had applied for Australian General Practice Accreditation Limited (AGPAL) accreditation in 2007. One of the criteria that they were expected to fulfil was afterhours care for their patients. In efforts to fulfil this criteria (which is based on the

Royal Australian College of General Practitioners (RACGP 2006) guidelines for practice standards), staff were in constant negotiations with the hospital to provide a sanctioned service for the AMS clients. It was simply not feasible, in a practice with one salaried doctor and two locum doctors to provide after hours service, as it would have had significant impacts on the budget of the service, but also on the lifestyle of each doctor.

There are stories among members of the community of what used to be available in the way of health care, and a kind of yearning for some of the simplicity and old home-visit structures to return. Hintjens' (1999) *Stories of Yallambee People*, contains such accounts. One former camp dweller reported to Hintjens about the many 'whitefellas'[40] who would visit the community for health care (1999, p.36):

> The health sisters used to come round with a bus. They'd come down and they'd clean up all sore them kids had. Fruit truck used to come round, selling greens and that. Other sisters used to come round and give out little brown vitamin tablets…this was about thirty years ago. They came in a little white bus, the health sisters…used to come down and treat you, take the kids for needles…They'd take you to the hospital if there was something serious. They would not walk away, they'd stay with you until it was over, and bring you back. Keep up tetanus needles too. It was all sort of done on a ground level.

Aboriginal Health Workers also reported that they remembered times when health care was taken to the people; times when the Aboriginal community was provided services at home, and taken to the hospital in times of crises. Estelle, a Senior Aboriginal Health Worker discussed the 'old days' with me, when health workers from Queensland Health used to visit the town camps and weigh kids on the grocery scales using a dilly bag41. She talked of how people in the camps would not go to the doctor or the hospital because they 'weren't used to the staff down there, they would wait until visits on the Monday and the Health Workers would take them down to hospital'. She was pleased to say that many of these people now 'know the system inside and out', and will go to hospital, or find a general practitioner at the clinic. Another Senior Health Worker told of her early

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[40] A commonly used Aboriginal English term which refers to 'white' people in Australia, generally those of Anglo-Celtic decent.

[41] See glossary.

career: "we used to go down the river, down the camps, sit under the trees, and it worked, it was working." This contrasts greatly with what is on offer now. There have been practitioners in the community that have attempted to bring back home visits as part of their service, with varying levels of success.

7.3. Promises for a brighter future? The Mount Isa Super Clinic.

State and private health services have turned to administering health care from central locations, to which patients make their way; again, with varying levels of success. This approach to health care provision is not set to change in the near future, and one initiative that will seek to further centralise health services will be the proposed Super Clinic.

In 2008, the Commonwealth Department of Health and Ageing announced that Mount Isa had been earmarked for the development of one of the 31 GP Super Clinics proposed by the Rudd Government. In a direct engagement of funding with North & West Queensland Primary Health Care, $2.5 million had been set aside for the establishment of a Super Clinic in Mount Isa. The philosophy behind the Super Clinic concept was to improve access to a range of primary care providers, in places that have traditionally struggled to do so. Some of the services that the Super Clinics would ideally provide included general practice services, various allied health services, after hours clinical care, psychology services, dental services and community education, as well as practice space for visiting specialists. The Super Clinic model was designed to encourage more diverse delegated practice models, including roles for practice nurses and Aboriginal Health Workers (DOHA 2009).

There was a community consultation session held in December 2008, at which Mount Isa's health professionals and community members made the following arguments:

> ...Challenges brought about by distance, land availability, housing availability, service delivery, accommodation and travel costs all contribute to the difficulties of attracting and retaining appropriately qualified health practitioners to work with communities.

> The community participants present emphasised their support for the local health care providers currently in Mount Isa. It was discussed by participants that inducements for attracting health professionals to Mount Isa could include, amongst other things, the provision of subsidised accommodation and an appropriate vehicle.
>
> Local allied health practitioners at the meeting were supportive of a multidisciplinary team-based approach for the Mount Isa GP Super Clinic that included preventative education and support for people with chronic conditions (DoHA 2009)

As pointed out in the Mount Isa consultation session, it is currently difficult to attract and retain staff to the kind of positions that a Super Clinic would offer, and there may continue to be issues doing so, in spite of the existence of a Super Clinic for them to work in. In early 2009, it was publicised that there had been ongoing struggles to identify an appropriate site to house the Super Clinic and that the project had been put on the back burner. It remains to be seen when Mount Isa will get a Super Clinic and where it will be[42].

Summary.

This chapter addresses the first of the 5As of Access (Penchansky and Thomas 1981), by providing an illustration of the issues of availability of health services in Mount Isa. In keeping with the Mindful Bodies approach (Scheper-Hughes and Lock 1987), the examination here of individual and social level data regarding the (relative) availability of basic health services[43]generates insight into the perceptions and realities of health need and health service provision in a regional centre. It is important, according to the Mindful Bodies approach, to consider these social facts in interpreting the individual narratives and experience of service availability to better understand the construction of individual experience narratives. By listing the services that were available during the fieldwork period, it is possible to contextualise and explore individual narratives, while simultaneously exploring the social structure/infrastructure of the health system, exposing inconsistencies and frustrations at both levels.

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[42] As of August 2011, administration of the Super Clinic was handed to Kinetic Medical Inc. The site is yet to be announced but there are strong indications that the site has been set.

[43] Basic, in the sense of the needs these services cater to, not necessarily their level of operation.

The exposure of inconsistencies regarding the services that were actually available versus what health professionals and community members reported to be available highlights a number of potential problems. One such problem is the degree to which the official lists of available services hides the realities of service provision as experienced by patients. It may be that patients and health professionals are exposing the fact that, even though the official version of events shows a wide variety of available services in Mount Isa, it may hide the realities of how available these services were – ultimately, if patients are not aware of and receiving care from the listed services, then they cannot be legitimately claimed to have been truly 'available' according to the Penchansky and Thomas (1981) definition. Also, this reveals that processes of communication between health service providers (re: the wide variety of service available in Mount Isa) requires attention and improvement; health providers in town must have a good working knowledge of what is available in town in order to be able to provide their patients with the best possible chance at receiving care at home, but also in being able to provide patients with local choices in developing multidisciplinary care plans for patients who require such care.

By documenting the role of major health service providers in the region, it is possible to explore the relationships that exist between services that assist or hinder in effective care , and expose the fragility of the relationships between services. In Mount Isa most relationships between health services are enacted at the level of personnel, not necessarily because of established service agreements (although some of these formalised measures may be in place).

This examination also reveals the politics of community identity formation that plays out through the historical developments of the local AMS. This organisation is a critical focal point for community expressions of inclusion and exclusion, rights and responsibilities, ownership and appropriation. The influence of rural location is once again thrown into view with discussions of recruitment and retention of adequate numbers of appropriately qualified health staff. Health professionals who come and practice in the region become intimately aware of their practice capabilities, and of the role they play in the broader community. The expectation of health staff to

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be more than a health professional, whilst simultaneously being inexplicably tied to this role in their community identity, can be confronting in ways that might not become evident in metropolitan settings.

The availability of health care services in Mount Isa has often been characterised as inadequate based on the size of the population in relation to the number of practitioners. This has especially been the case with regards to general practitioner provision in the city[44]. Availability of health services within the Mount Isa Health Service District suffers similarly. However, there are many service providers attempting to supply more suitable services within the region, including outreach service provision. Within Mount Isa, there are many services available, but clinics are often understaffed in relation to demand. The variability of health care service provision may be the underlying problem in Mount Isa, due to the high turnover of staff in the region.

It is important to note here that availability has been treated quite separately to the other aspects of access. This is due to the nature in which availability was discussed in formal interviews and informal discussions. The availability of services was often considered the paramount concern – if the service does not exist, there is an immediate problem for those in need. Further, if the appropriate service does not exist, people consider it as not available to them. Also, due to the density of data on availability of services in Mount Isa it was necessary to treat this issue separately to the other categories. Once participants had established the level of availability of services, this was often followed by discussion of the other aspects of access. The aspects of accessibility, affordability, accommodation and acceptability seemed to overlap with each other, creating complex stories of experience. Participants could not readily separate these aspects in how they discussed their health care experiences.

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[44] It is reported that this is partly due to a concerted effort in the 1990s by local GPs to keep others out of practising in Mount Isa.

The following chapter addresses the remaining four categories in the Penchansky and Thomas (1981) taxonomy. The representation of access barriers in these categories had a great deal of crossover in interviews which demonstrated the interconnected nature of access issues.

Chapter 8

Accessibility, Affordability, Accommodation and Acceptability of health care services in Mount Isa.

This chapter examines data on the remaining four categories of the Penchansky and Thomas (1981) taxonomy: Accessibility, Affordability, Accommodation and Acceptability. Interview data showed the interconnected nature of these four categories, and often it was difficult to determine which phenomena belonged to each category, given their dependence on one another. Participant responses often demonstrated the nexus between accessibility, affordability, accommodation and acceptability in Mount Isa. Many of the issues that may be considered to have a basis in culture would fit best under the category of acceptability in the 5As scheme. However, I have chosen to draw these cultural themes out for further examination in Chapter 9, as a full exposition of these identified issues is one of the major aims of the thesis. Therefore in this chapter, acceptability will include the brief discussion of some fundamental concepts of acceptability and will conclude with a discussion of the important distinction between the terms 'ethnicity' and 'culture' in informing health professionals and their encounters with identified 'ethnically' or 'culturally' others, particularly patients.

The categories of accessibility and affordability in Penchansky and Thomas's (1981) taxonomy relate to the location of available services and the ability of patients to access these services. This includes considerations of patients' ability to travel to such services, the costs of services and the ability of patients to pay for services. In the Mount Isa context, these issues often overlapped in the ways that interviewees discussed them – travel and transport were intimately tied to the ability of patients to afford health care, as much as their ability to afford associated travel costs.

8.1. Accessibility of health services in Mount Isa.

There were two different yet equally important themes that emerged around the issue of accessibility and transportation. One was the theme of travelling away for health care services that are not available in Mount Isa; the other was transportation around the city for health care locally.

8.1.1. Travelling away from Mount Isa.

As is evident in the literature, interviews and observations examined in chapters 3 through 6, there are many instances of rural and remote residents travelling away from their home communities for care. In the case of the Mount Isa Health Service District, people from remote towns like Doomadgee, Normanton and Mornington Island are regularly expected to travel to Mount Isa for health care services. Mount Isa residents often have to travel to centres like Cairns, Townsville or Brisbane for care.

> *Harry (Interview, February 2009): People having a follow-up visit after an incident or an issue, health-wise, and their family has got to take two days off work to drive them there, spend a day there for the appointment and then two days back. Now, some of those appointments last five minutes, and in one case I particularly know, she had a clot in her arm, they took her over to Townsville, they dissolved the clot…fixed her arm. She had to go back in eight weeks to check it. So, a two day drive to Townsville from where they were, five minutes with the doctor, the doctor took her blood pressure, took her pulse, the arm looks alright and says see you later. And two days back…Now that's really, really easy for the doctor, it really hasn't impacted on him too much. But someone has taken a week off work to drive their mother over, there's the cost of accommodation, all these things…*

As demonstrated in the quote above, and in many travel stories, the impact of such arrangements is minimal with regards to the doctors and specialists who consult these remote patients, but the impact on already unwell individuals is high (as examined in Chapters 3 through 5). The costs to individuals and their families are significant. Apart from the financial burdens there are other direct and indirect costs, such as time and disruption to family and work routines.

Depending upon the community one travels from, and the type of transportation available (be it less of a time burden to fly than to get on a train for example), it all takes time, and this is time

away from home, loved ones, community support and the ability to earn a living. If the trip turns out to be an extended one, if treatment runs longer than expected, patients may be left alone, as family and friends need to return to their communities, family obligations and livelihoods. Despite the laid-back pace often associated with life in rural and remote areas, the demands on people's time are largely the same as they are anywhere else. There is anecdotal evidence to suggest that many rural and remote residents, when facing treatment alone or for extended periods, abscond or self-discharge and seek their own way home.

Another cost associated with the journey to and from other places for care, is that of living in another location for a period of treatment. The cost of finding accommodation can be a burden to many, and finding adequate accommodation close to the care facility may not always be an option. People from rural and remote areas can feel threatened or afraid in larger towns and cities that are largely unfamiliar to them. Being unwell and having to navigate the health system can be daunting enough, let alone having to also navigate your way through an unfamiliar environment. If patients are having to live in another location for extended periods, the costs of supporting a family back at home, when income is limited by illness and absence, is a significant burden which can also see people self-discharge or abscond during treatment regimes. This is not only reported anecdotally, but also in health research, as discussed in detail in Chapter 3. One of the ways that the Queensland Government has sought to address issues of expense with regards to travel for health care is the Patient Travel Subsidy Scheme or PTSS.

8.1.1.1. Patient Travel Subsidy Scheme (PTSS).

From 1978 to 1989, the Commonwealth Government administered the Isolated Patients Assisted Travel Scheme (IPATSS), designed to ensure that patients living in rural and remote locations could have equal access to specialist services as their metropolitan counterparts (NACCHO 2000; Parliament of Australia 2007, NRHA 2009). This scheme was transferred to State Government administration in 1987 due to a perception that the Commonwealth Government did not have

sufficient flexibility to deliver the scheme, nor local understanding of the difficulties faced by patients in rural and remote areas in order to administer the system fairly and equitably (NRHA 2009).

All State and Territory Government health services in Australia have travel subsidy schemes designed to assist patients to travel for health care and treatment when it is not available locally. These schemes are all named differently and all have different ways of defining need and the degree of assistance that will be provided to those in need. These schemes are often experienced by both patients and health professionals as ineffectual due to "rigid distance criteria" that limit eligibility (NACCHO 2000), are underfunded, inflexible and thoroughly bureaucratic (NACCHO 2000, Stamp et al. 2006, NRHA 2009), and could be considered to have deficiencies including "grossly inadequate" levels of reimbursement, a lack of uniformity across regions, and a lack of clarity about the level of support for escorts and carers (NRHA 2009).

Queensland Health developed the PTSS to provide "assistance to patients and in some cases their carers to enable them to access specialist medical services from which they are isolated" (Queensland Health 2001). The subsidy provides a partial payment of travel and accommodation costs for patients (and sometimes a carer or escort) to the nearest specialist medical service, if that service is over 50 kilometres from the patient's nearest hospital. In Mount Isa of course, all specialist medical care that is not provided at the Mount Isa Base Hospital is well over 50 kilometres away.

Patients must be a current Medicare card holder, a resident of Queensland, referred for specialist care by a medical practitioner over 50 kilometres away, and this care must be considered essential. Once these criteria are met, a recommendation for the subsidy scheme is made, which is then attached to the application form and sent or taken to the patient's nearest hospital. The hospital is then responsible for determining the travel arrangements (including whether or not a carer or escort will be supported for travel; as was the case in Douglas's story in Chapter 5). This

is not an automatic approval, and if the conditions of travel are not for something deemed life-threatening, escorts or carers may not be supported by the scheme.

The medical care will be deemed essential if it increases access to specialty medical services. A fairly extensive list of what may be deemed essential specialist services is provided, and so the scheme does often provide for patients requiring specialist care to be covered by the subsidy.

The Patient Travel Subsidy Scheme information brochure discusses the subsidy of travel and accommodation:

> Assistance is provided to you, and your approved escort, for the cost of the least expensive form of public transport from the transport terminal (airport, bus station, railway station) in the town where your hospital is located, to the transport terminal in the town to which you are travelling. Private car travel is subsidised at 15 cents per kilometre from the post office nearest the referring hospital to the post office nearest the treating hospital. If you choose a more expensive form of transport, you must meet the additional costs involved. The subsidy remains the same. More expensive forms of transport such as air travel will be approved if necessary for medical reasons. (Queensland Health 2001)

Often in Mount Isa, due to the large distances that would have to be travelled by patients and the significant time it would take to do so by bus or train, air travel seems to be the preferred approved form of transportation. The brochure continues:

> Assistance is provided to you and your approved escort of up to $30.00 per person per night for commercial accommodation, if you are a concession cardholder. If you are not a concession card holder, you must meet the costs of the first four nights of accommodation in a financial year, then you and your approved escort may be provided with up to $30.00 per person per night for commercial accommodation...Assistance of $10.00 per person per night is given if you, or your approved escort, choose to stay with friends or relatives. If you are not a concession card holder, again, you must meet the cost of the first four nights' accommodation in a financial year. (Queensland Health 2001)

In many cases, Townsville is the closest town where most of the essential specialist services are available (sometimes, they are only available in Cairns or Brisbane, as in James's case in Chapter 5, very few smaller towns in between have local access to such specialists). If, for example a patient from Mount Isa needs to travel to Townsville for specialist treatment, the following may occur.

The patient may be referred to a specialist service in Townsville by their Mount Isa general practitioner. If the GP recommends the Patient Travel Subsidy Scheme, they need to complete the application and forward it to the hospital. Queensland Health policy dictates that within approximately two working days, patients will know whether or not they are eligible and travel will be arranged. If the patient is to be flown to Townsville, the flight is booked for the cheapest fare available on the most suitable day for travel, considering the specialist appointments. This fare is covered by the local hospital (or alternatively could be reimbursed upon presentation of receipts – depending upon the decision made by the medical officer reviewing the case). See Table 3 for an example of some of the temporal and financial costs involved in an overnight trip to Townsville for a specialist consultation. Another potential cost in this scenario includes the appointment with a specialist, who may charge for the consultation, depending on whether they are working privately or publicly. The likelihood of encountering serious financial difficulty increases for patients who have to do this a number of times, as does the likelihood of deciding against further care.

Table 3. Temporal and financial costs of travelling to Townsville for specialist care.

Event	Cost – Temporal	Cost – Financial
Flight to Townsville	Approximately 2 hours flying time, one hour in airport for check in and luggage collection.	Supported by PTSS, arranged by home hospital.
Travel from airport to accommodation place	Approximately 15 minute taxi-ride from airport for most accommodation. The hospital is another 10 to 15 minutes in the opposite direction.	Approximately $35 from airport to most accommodation houses. This cost is not supported by the PTSS. Arranged by patient.
Overnight stay required to fit in with specialist appointment schedules	Generally at least 24 hours spent away from home.	Between $90 and $280 per night. If patient has a pension card they are eligible for an accommodation subsidy at $30 per night. Patient is still left to pay the majority of the accommodation cost. Accommodation arranged by hospital (or if a private patient, by the patient).
Meals for overnight stay: Dinner, breakfast and lunch	Time required to either source groceries and prepare meals for self, or travel to restaurants.	Various financial costs, arranged by the patient.
Travel to appointment	Approximately 10 to 15 minutes ride in a taxi.	Approximately $22, arranged by the patient. Added complication: If appointment is after check out patients may need to bring luggage to appointment.
Travel back to airport	Approximately 20 minutes	Approximately $35
Flight to Mount Isa	Approximately 2 hours flying time and one hour to check in and collect baggage.	Covered by PTSS, arranged by hospital.

8.1.2. Transport: issues within Mount Isa.

There is a vast and well-established literature concerning the influence that transportation disadvantage as it applies to low socioeconomic groups has on health outcomes and differentials of health care access (Young and Doohan 1989, Newton and Bell 1996, Taylor and Bell 1999, Bostock 2001, Hine 2003, Taylor and Bell 2004, Currie et al 2007, AIHW 2011, Rosier and McDonald 2011).   Rendered down to its most basic, the argument stands that the poor will universally suffer poor health in part because of a lack of reliable transportation to traverse the distances or difficulties in obtaining health care.

Despite various efforts at various times to establish a public transport system in Mount Isa, there is currently no public transport available in the city. There is a private taxi service available, but it can be expensive if this is the only transportation to which one has access.

While many residents of Mount Isa own and operate their own private vehicles, or have one provided as part of various employment packages, this is certainly not the case for all Mount Isa residents (King 1996). Health service providers have identified transport as an issue for some of their patients, and many have sought various ways to deal with this problem.

The Aboriginal Medical Service had over the course of two different service provision periods, attempted its own innovative transport solutions in recognition that their patients were more likely to suffer disproportionately from 'transport disadvantage' (AIHW 2011) as a symptom of poverty, while also having the highest burden of illness in the community and therefore, highest health care needs.   MIATSIHS provided its Aboriginal and Torres Strait Islander patients with financial assistance to travel to and from the clinic by taxi. If MIATSIHS staff understood that a particular patient had issues getting to their appointments (especially the elderly or those needing frequent visits for care), the taxi fare was paid by the clinic. The clinic helped by booking the taxi, and booking a return taxi home at the end of the consult.

Sally (Interview, July 2009): …we run a taxi service, so that our patients do actually get access to us. We go point to point with that service for them. And you know, a lot of them appreciate that, because out here in Mount Isa the only other choice we've got is taxis…we don't even have bus services…

This had varying levels of success. Some taxi drivers did not want to participate in the scheme; there were some patients who were not at the pick-up point when the taxis arrived, and some patients wanted to use the taxi ride to conduct other business while they had the opportunity, which increased the cost of the fare.

Before MIATSIHS, Yapatjarra had a bus that would collect clients. The bus had run out of registration before MIATSIHS took over, and required a new roadworthy inspection in order to be registered again. The Yapatjarra bus (and other buses owned by various organizations around town), while an effective solution, created its own set of issues for the service with regard to who should drive the bus. Should it be a current staff member, who would have to be properly licensed, or should the service recruit someone to this position? Demand would vary from week to week, and the costs of maintaining a bus, fuelling it and keeping it roadworthy can be a formidable task for many local services.

Home and Community Care (HACC), a division of Queensland Health, also provided a transport service, point to point (i.e. from home or pick-up spot to the hospital and back), for those patients requiring care at Queensland Health facilities. However, it was only available to those who applied for support through the HACC program.

Point-to-point transportation is generally seen as the solution by various health committees and social service organisations that understand transport to be a barrier to full client/patient participation in service provision. While point-to-point transport may improve access by linking people in their personal environment directly to health care services, this transportation solution has the potential for misuse. For those who have no other way of getting around town, pressure may be placed on transport providers to conduct business that is even tangentially related to their

health and well-being in a far broader sense. This kind of behaviour can threaten the financial viability of such an enterprise.

Within the Aboriginal community, access to transport is often dependent on a relationship of obligation and reciprocity. With regards to private vehicles, one can call on other family members to provide transportation in order to fulfil familial obligations. Giving someone a lift into town to do shopping, can turn into trips to the bank, the hospital, and various other locations to do business that is limited at other times.

In a report entitled, *No way to go: Transport and social disadvantage in Australian communities*, Currie and Senbergs (2007) discuss the place of motor vehicles in remote Indigenous communities, and the impacts that transportation issues have on other sources of disadvantage. It was found that private car use in remote Indigenous communities served a number of functions, including providing access to mainstream services, shopping, visiting, and cultural activities. For example, Young (2001, p.52) suggests: '…cars mediate, not only, the constant dynamic of social relations but also, crucially, the strong emotional relationship of people with country', and can evoke strong feelings of autonomy and freedom, whilst simultaneously being a symbol of kinship obligation and reciprocity systems.

According to Currie and Senbergs (2007, sections 09.4-09.6), the state of the vehicles acquired by Aboriginal families in remote communities was of varying standard, but largely these vehicles were second hand, and potentially only had a limited functional lifespan at the time of purchase. These vehicles were used hard and often; many being taken off-road and over dirt tracks to remote locations on a fairly regular basis.

The question of adequate transportation provision presents an area of ambiguity to some health professionals who help patients with transportation on an informal basis. Aboriginal health workers would sometimes appropriate government or corporate vehicles to enact solutions to

transport problems, often covertly. In an interview with a senior Aboriginal Health Worker, for example:

> Mary (Interview, November 2007): We did have a district manager who said "if youse[45] need to transport, just use your own discretion". You know, you don't just go out and pick up willy-nilly[46]. And I thought ok, that's fair enough. But then, as more different managers come through, you don't know where you stand with them.
>
> KMcB: And that would make it difficult then to deal with the people that you had been helping to try and explain, oh I can't help you anymore.
>
> Mary: Yeah. And I…to be honest I never ever said that. If I went down the camp, and they wanted a lift, I'd say, "Look, we're not really allowed to, but I'm going back to the office, so if you want a lift back there and you can walk over" and they'd say "Yep, we can live with that". So that's what I say to the health workers, just say we'll give 'em a lift back here, but I'm not even supposed to be saying that to the health workers. But to me that's just common…you can't let people walk in this heat.

Another health practitioner (Kimberley, general practitioner, interview, January 2008) stated:

> Kimberley: I think a big thing is transport. I think if people were serious about it I think they would have a regular bus that did a route and picked people up and took them to the hospital and the pharmacy, and whatever else they need to do. Because I think transport's a huge issue here.

The interesting point to be made with regards to the above comment is that much research points to the fact that regular scheduled route-styled bus services do not work particularly well for Aboriginal populations, who often require (or prefer) to utilise door-to-door style services (see Currie and Senbergs 2007, Young 2001). But what this interviewee did insist upon was that transportation of this kind not be limited to health services; it was acknowledged as very important that these services be flexible in where they stopped (or stopped close to) so that people could conduct everyday business, including stops near supermarkets for food shopping and social services such as the Centrelink office.

Preference for door-to-door services may be attributable to many factors. I suggest that one reason for door-to-door services being preferred is the fact that this kind of service privileges the patron – it recognises that people are mobile, and does not tie people to particular locations,

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[45] Youse – Australian slang term meaning "you" in the plural sense (you all).

[46] Willy-nilly – An Australian slang term meaning randomly, or without order or purpose.

allowing for a great deal more spatial and temporal flexibility in conducting daily activities, like grocery shopping, attending meetings and appointments and attending to kin, and for pleasure activities.

Many people utilise the buses provided for patrons of clubs and hotels in this fashion. Three[47] of the clubs have door-to-door pick up buses available for members, who ring the bus driver, tell their location, and are picked up and taken to the club, or back home. One of these clubs is located in the CBD area, close to shops, banks and health and social services (a short walk to the hospital). To be a member of these clubs for one year is a fairly low fee ($10 or thereabouts). This entitles members to access the club and its facilities without having to sign in with a member. It also allows members to purchase alcohol at the club bottleshop and provides transport (free of charge) to get from their homes to the club[48].

This kind of arrangement clearly trumps any ideas of upfront-fee-for-service transport provision. It also discourages route-styled services, due to the sheer convenience of being able to be picked up from wherever one chooses to be. While this kind of arrangement allows a degree of freedom of personal movement, it also allows a degree of privacy and invisibility. Being picked up from a home is very different to waiting at a bus stop in clear view of everyone in town. Conversely, it also means that other users know the locations of the intimate relations of fellow users of the bus.

Beyond this, schedules can be difficult to interpret and often do not fit with the pace of life that many Aboriginal and Torres Strait Islander people lead. The need to travel quickly and on demand is often paramount to maintaining kin relations, fulfilling obligations and responding to changes of plan (although many non-Indigenous people perceive the pace of life of Aboriginal people to be much slower and less complicated than it actually is) (Currie and Senbergs 2007). The issue of

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[47] In 2010, one of these clubs closed down.

[48] Despite the fact that technically members have paid for this service, each time they get on the bus it appears to be free of charge, as no money changes hands. This may help people to feel they are getting 'value for money' from their club membership.

demand and almost immediate response, especially with regards to cultural maintenance activities, often precludes scheduled servicing from being suitable.

In an unpublished report for the North West Queensland CHIC Council, transportation innovation was reported as difficult in Mount Isa, often due to the complexities of state and national funding arrangements, which are so often pursued as solutions to the immediate needs of individual services within the town (Jacob 2011). The report identified some 106 buses as being registered to Mount Isa addresses. These transportation resources capture the attention of other services and groups in town suffering from the same or similar immediate needs. The pressure on services with resources to share them with other services who are at a deficit is complicated by funding agreements which silo resources, making sharing almost impossible, or at least highly improbable. The major stumbling block in attempts to resource share the buses held as assets by businesses in Mount Isa was attributed to conflicting insurance policies and funding agreements which meant that these valuable commodities could only be used in very specific ways (Jacob 2011).

Thus, the experience of structural violence and poverty through transportation disadvantage is highlighted and magnified by the glut of resources that exist in Mount Isa, but for bureaucratic reasons, cannot be shared and utilised to their full potential to create equity for those without transportation or with limited transportation options. Discussion of transportation difficulties in Mount Isa highlights the local specificities that relate to what is generally a messy subject – ownership and appropriation of mobility as a human right. As Austin Broos (2011) similarly argues, but in relation to housing, transportation itself may not be the problem, but rather the complex webs of social relations and stratification that transportation is tied into may be the source of much stress and ill health. It is not simply the material condition of transport but the scale of material difference that is actually the better indicator of the social inequalities that must be addressed in order to create transportation solutions in Mount Isa.

In the case of buses provided to particular services for particular needs, transportation may be used as one more way to define Mount Isa people by way of their socioeconomic circumstances, which also leads to increased surveillance and control over these populations of disadvantage. Current funding arrangements seem to further (or rather reinforce) opportunities for inclusion and exclusion of people on the basis of relative needs and deficits, rather than acknowledge the social networks that are utilised for transport, and how these might be strengthened further to increase access to health care.

Ultimately, transportation in Mount Isa as a health issue may not be a case of accessibility, so much as a reflection on the increasing centralisation of health care provision in a neoliberal capitalist imperative to cut cost of health care funding, particularly to already resource poor regions that will not account for major population growth in the State's near future. Transportation as a health related issue then, is more about health care systems than it is about patient deficit. If health care service returned to community and home based care arrangements, then it is possible that transportation of patients would be significantly lessened. Transportation to services is also an accommodation issue: it is another example of the ways that timeliness is critically re-enacted in service systems. Transportation is necessary to get patients to clinics in a timely fashion, and according to appointment schedules.

Many people in Mount Isa will employ various modes of transportation to access health care when they deem it urgent or necessary – motivations are critical in understanding when and why people find transport and make their way to health care services. It may be easier to access a lift from a family member, if there is an obvious and urgent need for care, in the case of running out of a medication, or needing a new script, for example. But mobilising such transport options for preventive care may be a less attractive option, given the obligations that may follow from getting a lift. In these ways, it becomes clear that accessibility in Mount Isa is about more than transportation, it is about mobility within the community, both physical mobility, and social mobility

(or the ability to negotiate and demand transportation and other modes of assistance from kin or related others).

8.2. Affordability of health services in Mount Isa: Socioeconomics of health care.

It is important to acknowledge here that the Australian health system does have many mechanisms in place to support the cost of health care provision to the general public. Medicare is the Commonwealth Government service provider responsible for the delivery of health care support programs such as the Pharmaceutical Benefits Scheme (PBS). The Pharmaceutical Benefits Scheme also reduces or removes the costs of medications from an individual's consideration. The provision of public facilities which are free of charge, via universal health cover (also administered by Medicare) artificially lowers the costs of primary health care services. Private general practices are also encouraged, through Medicare, to bulk-bill patients. This negates consultation cost considerations for individuals in many instances.

In terms of the Penchansky and Thomas (1981) taxonomy, affordability is defined as the cost of services relative to the patient's ability to pay those costs, including considerations of private health insurances, and patient perceptions of worth relative to cost. While issues of cost were often related to travel for care in patient and community discussions (as discussed in the previous section), it is more specifically the relationship of cost for care to the patient that is of relevance in this discussion.

Specific issues of affordability (not necessarily related to travel) in interviews clustered around two general themes: issues of private health cover versus public sector health care and the ability of Aboriginal and Torres Strait Islander patients to pay for services. In the latter instance, this was

often discussed by health providers in terms of a much broader range of socioeconomic factors than was affordability within the general population.

At least one local general practitioner discussed the issue of private versus public health care with me. As quoted earlier (Sarah, Interview, October 2008, p.137), the practitioner considered that ultimately, whether patients were Aboriginal or not, there were concerns about access, more generally, to adequate care and to specialist services. The interview (October 2008) continued:

> *Sarah: Some of the Aboriginal and Torres Strait Islanders are well-educated, earning a lot of money, and it really isn't a major issue for them. They've got holidays and sick pays and stuff like that and they can use it. But some are...they're earning money, but just enough to get by, you know? Particularly, nowadays, people renting in Mount Isa, the rent is just horrendous, which is just really cutting into what kind of free money they have available. Quite often, they might be a bit more sickly, have used up their sick days or holidays already for different things, and so it's just that much more difficult. But...for me, there has been no difference between the Aboriginal and Torres Strait Islanders versus other clients. It's just the issues of whether they've got public or private insurance, whether they've got the ability to travel away. And that's the difficulty in Mount Isa.*

Given that this practice was not a bulk-billing service, the GP reported only seeing a portion of the population who were able (and willing) to pay for services. There is at least one mainstream general practice in town that bulk-bills, and the AMS bulk-bills all of its patients, so within community discussions of local health care consultations, cost did not come up as frequently as it did with medical practitioners.

The perceived cost of health care services may also be a factor in whether or not people feel they have adequate access to other services that reduce their medical costs, be it via rebates from Medicare, private health cover rebates, or health care concession cards. Considering the definition by Penchansky and Thomas (1981), the cost of consultations was not mentioned during my fieldwork as often as I would have expected, while other types of costs were mentioned frequently. This is where taxonomy, while useful, has limits, but nonetheless provides a convenient and adequate conceptual framework to hang these stories upon. Perhaps the cost of specialist care was not mentioned by many people due to the fact that there are so few

opportunities to actually access this care locally. Instead, this may be expressed as discontent with the cost of specialist care wrapped up in stories about travelling away.

Many health providers reported that Aboriginal and Torres Strait Islander people in Mount Isa, even those earning enough to get by, were still struggling with issues of adequate, safe and cost-effective housing, transportation, the legacy of ill-health through generations, and generally poor standards of living. Cost here is defined as a social indicator of Aboriginal and Torres Strait Islander poverty experiences. The formation of such opinions may have been due to the relative visibility of such issues. Many people that I talked to or interviewed referred to 'the Aboriginal community' as made up of those individuals commonly perceived and represented as being the most marginalized in our community. Participants often discussed issues affecting people who live in the riverbed or congregated under the trees or around the telephone booth at the front of the hospital. For them, the 'Aboriginal community' also includes those who lived at places like Yallambee, the Jimaylya Topsy Harry Centre or the Kalkadoon Aboriginal Sobriety House. This renders Aboriginal people as a community of the public space. All of these places and institutions are publically designated spaces where Aboriginal people are assumed to live or congregate.

Participants less often talked about families who were living on the edges of suburbia, at Pioneer in public housing, and those who were working to earn a living for their families, many of whom owned their own homes. The distinction seems to relate, not only to visibility or issues of the public or private spaces that Aboriginal people inhabit, but serves as a kind of ranking system of Aboriginality. Aboriginal people in the public spaces listed above were those deemed most disadvantaged and therefore, most in need. Those Aboriginal people who live in slightly more private spaces were thought of as the betwixt and between; often it was those families living in public housing that were accused of being lazy or of needing to get their lives on track. Aboriginality in Mount Isa is often represented in these terms. This may lead to an ignorance of the emergence of an Aboriginal middle class. This middle class are an increasingly large group, charged with the responsibilities of bringing other Aboriginal people up with them in the

socioeconomic stakes. This middle class is constituted by the health workers and other employed Aboriginal people, seen as the advocates for community, who are at every community meeting and on many committees, trying to make the town a better place for all Aboriginal people.

McKee (1997) and King (2009) discuss representations of Aboriginality in Australia that renders Aboriginal people as "fatal" (in the sense of being dangerously exotic and distinctly different to white people), which precludes Aboriginal people from being considered as "banal" (sharing similarities with white population, and giving access to education, material wealth and advancement without being seen as forgoing their inherently spiritually rich Aboriginality). However, in Mount Isa there is an increasing population of Aboriginal people who have accessed education to a tertiary level, who acquire material wealth, alongside a passionate spirituality and a zest for community advancement. These people are technically the most visible to white people in health and social services as they are the colleagues, the trusted cultural mediators. However, it is these Aboriginal colleagues that become increasingly invisible as Aboriginal people. Instead, they become exceptions to the 'possibility of change' (Simmons and Lecouteur 2008) that modern racist discourse denies Aboriginal people are capable of. And, by extension it is these newly emerging middle class murris that make the others look lazy (a comparative discussion in Jhally et al. 1992 on changing discourses of class relating to African Americans in the United States of America).

This entire discourse exposes poverty as a revelation – relative degrees of poverty reveal various Aboriginal people to the public gaze (Culhane 2003). For Culhane (2003), an increase in wealth buys a decreasing visibility; as Aboriginal people become less fatal and more banal, their invisibility increases as concealment and privacy become accessible, as a result of changes in material conditions. The overexposure of poverty-stricken Aboriginal people inversely leads to 'regimes of disappearance' (Culhane 2003, p.595):

> ...a neo-liberal form of governance that selectively marginalises and/or erases categories of people through strategies of representation that include silences, blind spots, and displacements that have both material and symbolic effects.

In the case of Mount Isa's Aboriginal poor, their visibility is marginal, sensational and collective, to the extent that individuals become silenced, erased from the political landscape. This kind of conflict was identified by Culhane (2003) as a kind of race blindness toward the Aboriginal people of Downtown Eastside Vancouver, but in Mount Isa is a representation of poverty as a *result* of Aboriginal *cultural practices* which create barriers to a better (less pathologised) life. In reality, poverty itself is more rightly a causal condition which may shape the ways that Aboriginal cultural practices are contemporarily lived.

Within the local health community, there is a buoyancy and hope expressed regarding those Aboriginal people (most often colleagues) who engender varying degrees of banality, and sense of hopelessness and overwhelming ambivalence toward those Aboriginal people who, in their expressions of poverty, appear as fatally different (see also Kowal 2006). These co-created experiences of Aboriginal poverty in Mount Isa are integrated into the development of community boundaries of inclusion and exclusion.

Within the Aboriginal community there is often conflict about just who does belong, and who should have access to the services and health care that is provided in Mount Isa. Community members have discussed with me the fact that many of the Aboriginal groups in the gulf area travel down to Mount Isa and do not go home. They are disconcerted by the fact that "...these people are allowed to come here and get medical care and other assistance" (Anonymous, pers. comms., May 2008), asserting that they are taking resources away from local people. There have been many conflicts between Aboriginal people from this region and those from more remote gulf communities, including 'rioting' (a contentious term – due largely to this being an old family fight, with only a few people involved) in the suburbs of Sunset and Pioneer in early 2009 (Nicholls 2009, Rowling 2009, Major, K pers.comms., February 2009).

Some of these fights are old, many are clan-based. But they are often conflicts that are not seen or understood by many outside of the Aboriginal community. Certainly, health care providers have

conveyed to me that they cannot be seen to be getting too involved. The ethos of equal health care for all excludes them from being able to take sides or do anything about the conflicts. Care providers are funded to look after whoever comes through their doors for help, regardless of where they are from, so long as they fit the criteria for inclusion. The anxieties and animosities toward outsider Aboriginal groups may be predicated on the experience of fragility as a result of being made painfully aware of substantial difference in material conditions (experience of poverty), and a sense of only having enough to get by (in the vein of Berlant's (2007) slow death).

Long and Memmott (2007) examined regional mobility among communities in north-west Queensland and the eastern parts of the Northern Territory, revealing that the beats of mobility in the region reflect a larger pattern of connectedness through family and kinship networks, and different motivations for movement in the north-west Queensland region. Many people from Dajarra and other small communities that surround Mount Isa move back and forth to town as needs dictate, in order to fulfil kin obligations, follow sporting and social activities, or pursue education, employment or health care needs as legitimate members/visitors who enact kin relationships with people living in Mount Isa. Long and Memmott (2007, p.5) report that "…the 47 household survey participants from Dajarra and Alpurrurulam made a total of approximately 1000 visits to Mount Isa between them over one year". These visitors would stay in Mount Isa for a short time – usually for the duration of their business here, which took the varying forms listed above (2007, pp.5-6). In conducting their business in Mount Isa, visitors from the local mobility region do access local services regularly, which must be adequately captured in service data so as to advocate for appropriate funding; those services who can monitor and report on the impacts of this mobility on their service provision may have a case for increased funding to accommodate this business, whilst also being able to continue to provide services for the local community.

At the same time, there have been conflicts within the health care community over which services get the funding for Indigenous Health programs, and whether or not they are truly delivering on the promises made in funding applications. Among the Aboriginal community there is a perception

of a long history of the local division of general practice administering what the community call "black money", but not delivering exactly what they said they would. The outreach services to the gulf region are sometimes resented by local community members who feel that these services should be provided as a priority in Mount Isa. Once again, this reflects anxieties regarding ownership and perceived (or real) appropriations of scarce resources. As a consequence, the ability of Aboriginal and Torres Strait Islander people to pay for health care may become less obviously about finance and more of a question of group membership as co-constructed versions of Aboriginal poverty experience.

It is evident that the costs and challenges faced by rural and remote people, as specifically addressed in discussions regarding barriers to care, are considered to be important factors in health care decision-making processes (for individuals and for families). The examples explored above resonate with the cases presented in Chapters 4 through 6 and the literature presented in Chapter 3. While Queensland Health and other institutions have developed schemes of compensation for those patients whose needs cannot be accommodated locally, the value of compensation or support is not adequate, given the substantial direct and indirect costs borne by rural and remote patients.

8.3. Accommodation and Acceptability of health services in Mount Isa.

Accommodation and Acceptability take into account the understandings and perceptions that patients and health providers may have when it comes to providing good quality care. By looking at representations of these issues, it is possible to understand why the term 'cultural barriers' has become popular in the medical literature – it seems that these aspects of care are the ones that can cause the most friction and controversy, especially when attempting to remedy issues of cross-cultural communication breakdown, conflicting attitudes, and ultimately poor uptake of services due to perceptions (from both Aboriginal patients and health professionals) of poor attitudes and

behaviours. The following section will address issues raised with regard to accommodation as defined by Penchansky and Thomas (1981).

8.3.1. Accommodation.

Accommodation refers here to the ways that patients are able to interact with the systems that are set up in practices, specifically those designed to receive and organise patients. During my fieldwork, there were not many references to this aspect of access from the community point of view. Rather, issues that would normally classify as being caused by or prolonged by accommodation problems and the set-up of service resources to accept clients, was often blamed on a lack of qualified health staff in town and the resulting high workloads of the health staff who are here. People did not attribute long waiting times in health service reception areas as being anything to do with the way that the appointment systems were set up or the hours of operation of services.

Health professionals on the other hand, did attribute some of the blame for poor access on issues of accommodation. For some, this even led to discussions on the determination of patients to comply and their willingness to get well and stay well.

The physical arrangement of services was raised a number of times by health professionals, and issues of patient comfort (especially Aboriginal and Torres Strait Islander patients) was discussed. The issue of Aboriginal and Torres Strait Islander patients feeling comfortable in a service strays into the territory of 'acceptance' and will be discussed at length below. But for now, suffice to say, many health professionals believe that a major factor in accommodation is patients being able to access as many services as possible under one roof and the inclusion of symbols and signs that make patients feel welcome and comfortable.

> *Kimberley (Interview, January 2008): I think the environment can to some degree, and again the other thing that has come up so often that I feel maybe it's a bit trite, but they reckon just having Indigenous art up makes a huge difference. So I guess the environment does to some degree…But I think basically it comes down to individuals and*

how they are treated, and in a big organisation like a hospital, it's impossible to control everybody.

Some health professionals noted that their colleagues complained of Aboriginal and Torres Strait Islander patients not presenting for their appointments, or turning up late and still expecting to be seen by the health professional. This was reported as unacceptable to these health staff, but was not reported as being a problem for any of the health care professionals with whom I spoke directly. It seemed to relate to reflections on their colleagues' attitudes and understandings of Aboriginal people. One of the general practitioners that I spoke with related this to possible accommodation issues.

> *Kimberley (Interview, January 2008): I think that patient services need to be a lot more flexible. As I say, they book patients in and then whine that none of them turn up, and so if you had booked in ten patients and only three turn up, why wouldn't you see walk-ins? You know? And most Indigenous people are prepared to wait, if you say to them, well we've got x and x appointment but if you wait we can see you after that, most of them would be happy. But it's that obsessive system related thing.*

While many of the health professionals I talked to identified themselves as culturally competent (Betancourt 2004, p.953) to deal with Aboriginal people, this rhetoric regarding their colleagues' incompetence (which accompanied other aspects of Aboriginal non-compliance as will be explored further in Chapter 9) may be a false attribution based on current standards of social desirability, or a deflecting of responsibility (Tilbury and Colic-Peisker 2006). This discourse may act in a similar way to the discourse explored by Tilbury and Colic-Peisker (2006, p.651) "...to deflect attention away from their own possible culpability" through the employment of 'exoneration utterances' that deferred blame for discriminatory or unsavoury practices and attitudes toward Aboriginal people as being the domain of uninitiated, misunderstanding others (in this case colleagues).

Other than the Accident and Emergency Department at the hospital, the only service in town that I know of that has attempted to address this issue was MIATSIHS, which provided walk-in times in which patients could turn up and be seen. When I asked health practitioners about instituting walk-in arrangements as a solution to perceived issues of 'non-compliance' around an appointment system this was met with shock and often outright denial that such a thing could be achieved or

work in practice. But, it was working well for MIATSIHS; patients knew that every morning, from 8:30am to 12 noon, they could walk in and be seen. While there were appointment slots available for people who wished to make an appointment with a particular doctor at the service, ultimately, if you were ill, and made it in there in the morning, you could be seen without an appointment.

Another aspect of the accommodation of appointment systems by Aboriginal and Torres Strait Islander people came from discussions with Aboriginal Health Workers, who talked about the blurred boundaries of their position in the eyes of the community. It seemed that, unlike medical practitioners and nurses, Aboriginal Health Workers (due largely to their family ties within community), were always 'on the clock'. Their job did not start and end at the clinic and it was often expected that they would know when a family or community member had an appointment, or that they would be able to secure an appointment for someone, outside of office hours, and often in locations remote to the actual clinic.

> *Estelle (Interview, June 2008): But you'll be in the supermarket and they'll come up and say, do you know what time my appointment* [is]*, or have I got an appointment? And I say, 'Hey look I haven't got the appointment book here, I can't remember'! Or they'll say to me at the clubs, 'You make an appointment for me?' So I write it all down on a coaster, and then I forget to make an appointment for so and so! So I come in Monday morning or whatever morning and say 'Oh, so and so's coming down about 10 o'clock for an appointment, can you send a cab for em!'*

One GP who had worked in the AMS also reported that many clients expected that there was a tangible link between various practices and health services, facilitated by her computer. The AMS had a network of computers on site, which provided the storage for patient records, but was not linked to any other services:

> *Kimberley (Interview, January 2008): One of the basic assumptions that I never realised, is that most of the Indigenous clients assume that if you have a computer there and you're looking up data on the computer, you have access to all the data in the world. So they expect you to access the hospital stuff. They call the AMS the little hospital and that [gestures toward the MIBH] the big hospital, and all the other AMSs they've ever visited in Australia, and they assume that you have all of that data on your computer. They don't realise that it is just what we've got on today that is in there. And the differences between Primary Health Care and hospitals and referral pathways, yeah, that really is one of life's mysteries.*

Appointment schedules and often many other systems established in health services are about time and money. While it is important to recognize that the demand for health care is high in Mount Isa, it is equally important to recognize that the nature of how people seek health care may vary from coastal or metropolitan areas.

The literature discussed in Chapter 3 (specifically Crosato and Leipert 2006, Veitch et al. 1996), suggests that many people, especially those who have trouble actually getting to health services, may defer seeking care until they feel they have no other choice. This then creates a sense of urgency. Patients need to be seen urgently and cannot wait a further six weeks for care; they are sick now.

Moreover, many people literally expect to be able to call up their chosen practice and get an appointment within the week, often despite also acknowledging the few health staff (especially GPs) available and their high workloads. Local practices do their best (given the ways that they have established their appointment systems) to accommodate as many people as possible, and offer the services of whichever medical practitioner is available, as soon as possible. As mentioned earlier, many people also attend the Accident and Emergency Department at the hospital for what are often considered minor complaints, because they can walk in and be seen. They may have to wait for over two hours at a time, but ultimately they will accept this, over having to wait six weeks to see their chosen GP.

The navigation of various parts of the health system, often coupled with the need to negotiate through other social support systems, is made difficult for patients because the systems have become increasingly complex, bureaucratised and lack the ability to be personalised or flexible. Maree, a 50 year old Aboriginal registered nurse said (Interview, November 2007):

> ...we've lost the simplicity in how to get and move people through that system because we've become too focused on a whole range of other things, instead of, "Ok, this person doesn't know the system, this person's foreign to the system, how do we then move them through it?" How do we, as individuals within this system, recognise and have empathy

for those who don't understand it? You know, because too many times, you ring up and get fobbed off.

…You're not just dealing with a single entity here. You're actually dealing with a range of different services. Like, if you're dealing with aged care. You've got ACATs [Aged Care Assessment Teams), you've got HACC, you've got Blue Care, you've got Espiritus, you've got North West Queensland Primary Health Care, you've got AMSs in the mix…it's just a whole range of different services you need to deal with if you've got one…frail, aged octogenarian who's got dementia…and you're trying to pull in support services? You know, it's just…not easy.

I don't know…But I know that…I know when I've dealt with the smaller organizations, I've actually got results. So maybe the trick is in having smaller units that actually do know and do personalize their business…maybe that's the trick. Because I know, when I've gone through Queensland Health or Community Health…I just get lost. And I just get fobbed off and I get sent from this person to this person, to this person, to this person…And a week later, nothing.

The rigidity of systems and an atomistic vision of health are frustrating for patients, and the

protection of turfs and medical specialties can be part of the problem:

Maree (Interview, November 2007): …Let me give you an example. My Dad's on dialysis. And I asked if he could have a podiatrist go up and clip his toenails in the hospital, from Community Health, while he is on dialysis. They told me, "Oh, you could ring a private podiatrist and have a private podiatrist visit him at home"…He visits your hospital three days a week…

KMcB: …and you can't clip his toenails? (Laughter)

Maree: …it's a simple request and this is what they come back to you with.

Another issue that was identified frequently was a lack of communication within the system and

with patients. One example was provided in the interview (November 2007) with Maree:

…RFDS do the outreach clinic, eh? They had a patient discharged from here, who we would share normally with the hospital here, anyway. The patient got discharged from here, was sent home, back to the community, and he was a known diabetic. He was sent home with insulin, he went home with insulin, and RFDS seen him about a week later, and he had had no medication whatsoever. And RFDS asked him what he'd been put on, and he told them insulin, and then the first question the RFDS Doctor asked him was, "Do you have a fridge?" And he went "No."…So the insulin was off. So they sent him home with all these vials of insulin…he had no medication for a week.

8.3.2. Acceptability of health services in Mount Isa.

At the time of data collection there was a fairly even split between male and female general

practitioners in private practices and the Aboriginal Medical Service. Among Aboriginal peoples,

there are some general taboos relating to the kinds of health issues that can be discussed and

treated by health practitioners of the same gender. The categories of "women's business" and "men's business", whilst inclusive of a great deal more than just health concerns, refer to gender-specific issues that are of a sensitive nature and are considered to be the intellectual property of respective gender categories (see Chapter 9 of the National Aboriginal Health Strategy 1989).

While Aboriginal Health Workers and some health practitioners are aware of these issues and are respectful of such needs, others are not, or are unable to abide by such rules. The inability to follow such cultural protocols can be generated by a lack of practitioners of each gender, or due to constraints in the ways that service provision is organised and carried out. There are situations when Aboriginal patients will choose to transgress such taboos and seek care from a practitioner of the opposite sex, and in times of the need for intimate care may choose an appropriate person to accompany them to a consultation.

8.3.2.1. Gender differentials among patients and providers.

There is a wide body of literature that relates to the importance assigned to proper conduct according to strict gender rules and taboos in Aboriginal societies of Australia (for example, Berndt and Berndt 1977, Reid 1979 and 1983, Nathan and Japanangka 1983, Toussaint 1989, O'Connor 1993, Merlan, 1997, Peile 1997, Maher 1999). Gender is a signifier of the distinction of men and women in Aboriginal society, across domains of life which are specifically designated as belonging to women or men (often related to functions or modes of production), and is related to the creation of 'constitutive domains of social relationships" (Merlan 1997, p.119) where taboos demonstrate the "link between profound internalised obligation as definitional and constitutive of social relationship, with social distance formalised, and sometimes, constrained access between parties in such a relation" (Merlan 1997, pp.119-120). Taboos related to gender are important to take into consideration with many Aboriginal patients. This is largely dependent on the reasons for seeking health care; things that are particularly intimate issues should be dealt with by a health practitioner of the same gender as the patient where possible. Transgressions on these issues can

be another cause of shame and embarrassment for patients (Maher 1999). The important point for those I spoke to was that Aboriginal patients should be given the choice to be seen by a same-sex practitioner and should be asked for their preference before the consult begins. This was a point often elaborated by Aboriginal Health Workers, as below:

> *Estelle (Interview, June 2008): ...if it's to do with men's business, we as ladies can't do it. This is what happens when they [Aboriginal patients] come through here. If it is somebody I don't know, I say, brother or uncle or whoever it may be, they're not my blood. I always say, am I allowed to do this with you? I say, because otherwise I can go and find someone else that is capable of doing that. I say, but you let me know now... (Laughs). Because I say to them, this is not for a woman, to be seeing a man. And this is why we have male and female (health workers). Yeah. And what I say, these mob here too, if they are my immediate family, they're close to me, I say, if it's to do with any men's business, I'd rather [male health worker] deal with it. But if it's women's, I'll do that.*

This is also discussed by Gracelyn Smallwood (1989, p.9):

> ...one of the oldest traditional Pitjantjatjara elders was a patient when I first arrived, and every Friday he would have to be given a tranquiliser because every Friday he would throw a tantrum. This was the day that two non-Aboriginal female nursing staff were taking him into the shower and washing him and helping him with toileting... and could not understand...why he screamed every time a female was handling his body, particularly the penile area. I then explained that this Pitjantjatjara man was an elder...and that in traditional society no female, other than wives, was allowed to have any contact with a traditional elder...

Gender taboos were often discussed in interviews as a specifically cultural phenomenon and will therefore be elaborated further in Chapter 9.

In terms of access based on attitudes toward providers and vice versa, there is a detailed discussion of this in Chapter 9. Therefore, this section examines attitudinal difference in a more general way. The attitudes that Aboriginal patients have toward particular providers is generally based on personal or familial experiences (negative and positive) of the past (often the recent past, due to the turnover of health practitioners). These experiences predicate the ways that Aboriginal people access health care across generations. While this is not necessarily an Aboriginal-specific phenomenon, it was commonly asserted by the local Aboriginal people I spoke to that this was a common experience, which they also asserted was intimately related to being an Aboriginal patient.   If Aboriginal people perceive that are not welcome or made to feel

comfortable, then there is a chance that the practice will attract a lower number of Aboriginal patients. This holds true, regardless of whether the perception is based on actions, words or the attitudes of staff when Aboriginal people arrived for care. If a practice or practitioner is deemed racist or in some other way not acceptable, then people simply will not go, regardless of how much they need care. Care will either be sought elsewhere (like the hospital emergency department) or not at all.

A number of practices reported having few or no Aboriginal patients (to their knowledge) in regular attendance. One practice manager informed me that they simply "did not get those kind of people coming" to their practice. This kind of language use subtly reveals a latent attitude toward Aboriginal and Torres Strait Islander people, by refusing to acknowledge their culturally distinct identities whilst nonetheless subtly excluding them on this basis. These kinds of attitudes are explored further in Chapter 9.

As discussed in Chapter 7, there were community perceptions that the AMS belonged to a select group of families in town. This constitutes an acceptability issue, as there were many local Aboriginal people who felt excluded due to their perceptions of family power and influence over a service that was meant to serve everyone. Community politics regarding the relative levels of power and influence that came from being a member of the AMS board thus created barriers for some in the community wishing to access the service. The various boards of the AMS have had to work hard to disprove such theories, and ultimately will probably never be able to change the minds of some locals.

Chapter 9 constitutes a separate discussion of phenomena classified as 'cultural barriers'. Focused discussion of these phenomena is required, given the power assigned to 'cultural barriers' in the health and medical literature. In the Penchansky and Thomas (1981) definition of acceptability they include the following:

> The relationship of clients' attitudes about...characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients. In the literature, the term appears to be used most often to refer to specific consumer reaction to such provider attributes as age, sex, ethnicity...

This is the fundamental point: ethnicity is not the same as culture, but in some health literature it seems the terms are used interchangeably. According to Aranda and Knight (1997, p.342), the distinction between the two terms could best be defined, where ethnicity is constituted by "...a group's shared sense of peoplehood based on a distinctive social and cultural heritage passed on from generation to generation", whereas culture is "a group's way of life: the values, beliefs, traditions, symbols, language and social organisation that become meaningful to the group members" (Mindel, Haberstein and Wright 1988, p.5). As Castles and Vasta (2000, p.118) claim:

> ...ethnicity is normally only evoked where it is considered to have some social meaning. It generally concerns minority groups in a situation where ethnic origins, appearance or culture can be linked to other social indicators, such as economic position, education or welfare.

Castles and Vasta (2000, p.118) also point out that Australia's Indigenous peoples reject the idea that they constitute ethnic categories, due to their status as Australia's original inhabitants. They refuse to be categorised and treated as an ethnic group in the same ways as various immigrant groups are treated. So, despite the fact that, when discussing Indigenous Health in Australia we most often refer to what more rightly be defined as an Aboriginal and Torres Strait Islander ethnic category (in creating this collective as an undifferentiated social category which can then be linked to other social indicators), Aboriginal and Torres Strait Islander peoples are constructed as a cultural, not an ethnic, group. This may lead to confusions regarding ideas of Aboriginal culture as responsible for poor health, versus other ethnic minorities, where poverty is a social condition linked to ethnicity, and therefore is amenable to social and structural changes. Health discourse fails to recognise that it has replaced ethnicity with culture in discussions of Aboriginal status, and (perhaps) inadvertently implies that Aboriginal culture results in poverty, rather than poverty being a social condition.

In this way, the category put forth by Penchansky and Thomas (1981) fits well in a discourse of Aboriginal ethnicity, where Aboriginal people are able to claim a shared social and cultural heritage, while simultaneously insisting on the requirement to take each language group as further evidence of important cultural distinctions. It is possible then, that a Pan-Aboriginal ethnicity may be the benchmark used to create some mainstream Indigenous health programs and cultural awareness training packages for health professionals.

As Joralemon (2006, p.101) illustrates in a discussion of cross-cultural awareness training materials, that confuse the terms culture and ethnicity, using them interchangeably and treating these concepts as "a characteristic of the patient that threatens to impede communication".

> Conflating culture with ethnicity encourages medical staff to develop a cookie cutter approach to cultural competency, using oversimplified and stereotypical synopses of beliefs and practices of each ethnic group.

Joralemon (2006, p.101) provides an example of a recent textbook which contained "structured overviews of 16 ethnic groups, with sections on 12 domains of culture". He continued:

> The editors stress the risk that generalisations can lead to stereotyping, but this is exactly what such handbooks are likely to produce in the rushed context of a public health clinic or hospital emergency room.

If health practitioners are engaging in the kinds of simplified encounters based on ethnic stereotyping suggested above, improvements in understanding Aboriginal and Torres Strait Islander cultures and individual experiences of health care may hold the key for improving access to health care for all minority populations. If there can be an intellectual investment in moving health practitioners from a basic level of awareness or stereotyping to a more nuanced understanding of Aboriginal lifeworlds, there are opportunities for innovative health practices to emerge. As Lea (2008, p.109) suggests, perhaps it is "...in our efforts to congeal insurmountable difference into our (non)understanding of elementary societies...that we regress to generalised information about practices that Aboriginal people (perhaps) perform and thus create a moment for the perpetuation of endless summative and piecemeal cultural information and understandings.

There are many researchers (e.g. Devitt et al. 2001 and Carson et al. 2006) who are moving Aboriginal culture through these discussions by placing it within a social determinants of health model, which simultaneously allows for the type of social categorisations that would normally be expressed as ethnicity to be elaborated, whilst also protecting Aboriginal culture from becoming a causal factor of poverty and poor health. By employing this framework, Aboriginal culture becomes a site of regeneration, celebration and strength for Aboriginal people, versus discussions of health which focus on Aboriginal culture as a deficit which predicated poverty and ill-health, or which represent Aboriginality as a 'risk factor' for illness and disease.

Summary.

In chapters 7 and 8, I have presented a composite illustration of the phenomenon of access barriers to health care as experienced and expressed by patients and health care providers in Mount Isa. This was achieved through the adoption of Penchansky and Thomas's (1981) taxonomy, the 5As of access, which describes the conceptual aspects that, in combination, create a comprehensive understanding of the phenomenon of 'access' to health care. The taxonomy provided a model to elaborate the localised understandings of the barriers to health care that Mount Isa residents are subject to in their efforts to be well and healthy. In particular, the utilisation of this model shed light on the burden of access barriers borne by the Aboriginal and Torres Strait Islander populations of Mount Isa.

In Chapter 7, the differences between professed (official version) and experienced (by health professionals and patients) availability of health services illustrated the ways that bureaucratic and lay visions of health care provision clash, creating spaces of confusion and conflict. The examples relating to major health care service providers demonstrated how Queensland Health representations of available services did not resonate with the experiences of patients and health professionals, who were either unaware of available services (due to lack of cohesive

communication between providers), or were experienced as 'variously' available (at the whim of specialists and locum staff).

The case study regarding the AMS showed the ways that community politics can influence perceptions of availability; even though the service was physically available, some people in the community rejected its professed availability, experiencing exclusion on the basis of perceived kinship and relatedness matters. This case study also demonstrated the fragility of the AMS as an institution; at once charged with providing ongoing comprehensive primary health care services that other services failed to provide among a population disproportionately burdened by the effects of poverty and chronic ill health. Simultaneously, the AMS was subject to the demands of government funders through heavy surveillance via extensive reporting processes (Anderson and Brady 1994).

The example of NWQPHC outreach service provision highlights the ways that communities define themselves in relation to other remote communities, particularly in regards to relativity of service need. Comments which sought to exclude more remote communities from receiving services that 'belong' in Mount Isa due to their geographical base being located in town, seem unduly harsh and cruel, given the paucity of services available in communities such as Doomadgee, Normanton and Mornington Island (see Map 1). NWQPHC, due to the kinds of services provided (i.e. allied health and mental health care) were under pressure to provide a high level of care in their base town, due to a perception that Mount Isa lacked these services, too. There was suggestion that this care be provided in Mount Isa at the expense of more regular care for more remote communities. This, and other discussions regarding 'outsiders' coming to Mount Isa and 'using up our services' might be reflective of a generally experienced anxiety caused by perceptions of a resource-poor environment and a fragility related to the shifting nature of government priority and attention on rural and remote areas, a sense of 'get in while the getting is good', because the money and resources could be withdrawn tomorrow.

Chapter 8 continues this sense of anxiety and fragility through discussions of the remaining four aspects of access. In discussions of accessibility and affordability, examinations of transportations issues revealed that the anxieties of travelling away for health care were expressed as a double cost burden for patients, suffering undue financial, temporal and social stresses related to isolation. This was in contrast to discussions about travel within Mount Isa to local services, where anxieties related to the seeming inability to create a comprehensive solution in the face of resource-richness. This situation created anxiety for the committee of health and social service providers charged with remedying this problem, as well as compounding the anxieties experienced by those people suffering from 'transportation disadvantage'. However, by elaborating on the Mount Isa context, it was evident that 'transportation disadvantage' may be a subtle way to shift blame away from inadequate systems (i.e. increased centralisation of care and rigid appointment schedules), creating a 'problem' which required fixing by a coalition of local service providers, who in turn became highly anxious about enacting local wealth (in the form of community buses) and finding that this was almost impossible given the rigidity of funding and insurance arrangements for these assets. All the while, the committee failed to adequately recognise that local people do mobilise in times of urgent need. This cast Aboriginal (and other people subject to transport disadvantage) as fragile, option-less victims, failed to take account of the vast array of social resources available in the community, and ignored the possible motivations related to mobilisation of transport resources.

Affordability turned from discussions about the cost of care and the ability of Aboriginal patients to pay for health care services, to a consideration of the relative visibility afforded to Aboriginal people as a side effect of experiences of poverty. While there was some acknowledgement from some health care providers that the local Aboriginal and Torres Strait Islander population is socially, economically and culturally diverse, this was not conceptually linked to discussions of different needs within the community. Rather, all Aboriginal people were regarded as subject to

poor living conditions, regardless of whether they were employed, had an education, or even owned their own homes.

There appeared to be a degree of disjunction for service providers where, even when recognising the banal commonalities that some of their Aboriginal clients shared with them, all Aboriginal people were regarded as fatal Aborigines (McKee 1997), in the sense of being so exotic and different that they were radically beyond the assistance of health care programs. This struggle to reconcile the fatal versus the banal aspects of Aboriginal lives may be one source of conflict which impacts upon the ways that Aboriginal people approach their decisions to health care.

Those Aboriginal people who, through banal activity (gaining education and employment), decrease the impact of poverty on their life experiences, are not only expected to act as cultural brokers and 'bring the mob up with them', but also were afforded a degree of invisibility when it came to deifying the health needs of Aboriginal populations in Mount Isa. While this invisibility shielded people from scrutinising view, it also meant that they may be looked over in considerations of service provision planning. The sensationalisation of Aboriginal poverty began a process of regimes of disappearance in Mount Isa, in the style discussed by Culhaine (2003).

The Penchansky and Thomas (1981) definitions of accommodation and acceptance incorporate elements of experience that might be considered cultural barriers as per discussions in the health literature presented in Chapter 3. Given the focus of this thesis on uncovering the definition of cultural barriers as they relate to this literature and everyday experiences to create a discourse of cultural difference in health care, it was important to consider these issues in greater detail. In my interviews with Aboriginal people and health care providers, it became evident that there were differently identified, potentially (and specifically) cultural issues that needed to be categorised and addressed separately. Chapter 9 discusses these issues, and further breaks down cultural issues into three categories as they appeared in interviews: cultural issues, social issues and structural issues.

Chapter 9

Cultural barriers to health care.

There are a number of issues that are reported throughout the literature on access barriers, and one of these encompasses 'cultural' barriers – or rather, cultural differences as barriers to the uptake and use of mainstream health services. However, to have a discussion on cultural barriers it is important to acknowledge the history of the term 'culture', in order that it may become clearer what exactly is meant by the term 'cultural barriers' as touched on in the medical literature.

Culture is a term whose use and centrality is still debated in current anthropological circles. It has, however, been generally recognised that culture is the unifying theme that drives anthropological work forward, despite its diversity as a field. Stocking (1968) provides a history of the anthropological conception of 'culture' in *Race, Culture and Evolution: Essays in the history of Anthropology*, and documents the (ongoing) struggles to come to a successful definition. Stocking discusses how definitions of culture, both humanist and anthropological differ:

> Unlike humanist "culture", which was "absolutistic" and knew perfection, anthropological "culture" was "relativistic". Instead of beginning with an "inherited hierarchy of values", it assumed "that every society through its culture seeks and in some measure finds values..." Other antitheses may convey further aspects of the distinction: anthropological "culture" is homeostatic, while humanist "culture" is progressive; it is plural, while humanist "culture" is singular. Traditional humanist usage distinguished between degrees of "culture"; for the anthropologist, all men are equally "cultured". (Stocking 1968, pp.199-200)

Modern anthropology has developed an outlook which privileges the differences between cultures, emphasising the importance of examining these differences before attempting to seek commonalities across cultures. As Stocking (1968, p.200) says:

> But it was precisely in the process of shifting attention to these diverging lines, of focusing attention not on "the features common to all human thought", but on its "differences", of recognising that "before we seek what is common to all culture, we must analyse each culture", that the singular "culture" of the evolutionists became the plural "cultures" of modern anthropology.

Arguably then, two of the most important developments in definitions of the term culture are the change from a humanist to anthropological account of what constituted culture, or the change

from culture as evolutionary stages of civilisation (savagery, barbarism and civilisation) to a recognition of a multiplicity of cultures, where each should be explored on its own merits. Further to this was the change from seeking similarities to examining differences (again, on their own merits) in order to establish the form of a culture.

> Focusing only on those aspects of the change having specifically to do with the culture idea, one might say that it involved the rejection of simplistic models of biological or racial determinism, the rejection of ethnocentric standards of cultural evaluation, and a new appreciation of the role of unconscious social processes in the determination of human behaviour. It implied a conception of man not as a rational so much as a rationalising being. (Stocking 1968, p.232)

This was the beginning of the split between the terms 'culture' and 'race'. As Stocking (1968, p.194) asserts:

> In a broad sense, what was involved in Boas' nominalist critique was the passing of a romantic conception of race – of the ideas of racial "essence", of racial "genius", of racial "soul", of race as a supraindividual organic identity.

However, beyond the field of anthropology, the culture concept took on a life of its own and is today often used in contexts where the word 'race' would earlier have been used[49]. Cultures around the world have become politicised spaces that create tensions over ownership and status of cultural knowledge. Contributing to this process of politicisation are the ways that various health disciplines have integrated cross-cultural communication or cultural awareness training into their curricula. This is an attempt to create skilled graduates able to serve 'others': often this conflates people wholly with the culture of which they are a member, further denying difference or constructing issues as cultural in immutable ways. The reification of culture in this way also obscures from view the cultures of health practitioners and the health system as a social institution. It serves to operationalise difference in ways that often complicate encounters, providing practitioners with awareness, not necessarily better understanding.

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[49] For two excellent works on the historical constructions of race in Australia, see Thomas (2004) and Anderson (2005).

Table 4[50] represents the themes from my interviews with Aboriginal community members and patients, Aboriginal Health Workers, and various health practitioners. Column 1 shows the themes that emerged in interviews with Aboriginal people, and most notably include respect and reciprocity as basic values for good relationships – in life and in health care settings. These are the themes that Aboriginal people identified as being important to them and their families, and whilst all are cultural issues, they can be categorised as being about sociality, cultural and structural concerns. Social structures, which are differentiated here, are the political and bureaucratic systems, physical environments and institutions evident in health and social welfare systems within Australia. It is important to separate these social structures from other social conditions, as it is within these structures that Aboriginal people and health professionals were able to specifically identify systemic violence and failures.

Column 2 shows some of the barriers that health practitioners said influenced Aboriginal patients in their decisions about health care. Many practitioners mentioned that the practice setting was important, but could not really elaborate on any specific qualities that needed to be present in a setting to make it culturally appropriate, other than the presence of Aboriginal artwork. Concerns were often raised around needing cultural awareness lessons in order to better understand Aboriginal culture and the specific concerns and needs of patients. It is important to note that themes were not necessarily addressed by both community members and health practitioners. Where a theme was discussed by both groups, this will be addressed simultaneously in my analysis of that theme.

Possibly the most important point to be noted here is the difference in how various actors frame what they believe to be the issues of concern for Aboriginal patients. While Aboriginal participants identify issues of conduct, respect and reciprocity, health professionals are often more concerned

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[50]This chapter contains information also featured in a recent publication (McBain-Rigg and Veitch, 2011). Some of the content was also presented at the 2nd Annual Rural and Remote Health Scientific Symposium (NRHA Brisbane, June 2010).

with issues of comfort and appropriateness in physical environments, even when they were uncertain of what that would require.

Arguably, what is represented here is a demonstration of the different knowledge of such issues held by different people. While Aboriginal and Torres Strait Islander people described their own embodied experiences and those of their families and friends, health practitioners commented on more general knowledge of Aboriginal culture and social conditions, and also reflected on their own practices and the practices of colleagues that may have created barriers to care.

This chapter is set out according to Table 4. The data are presented according to the categories listed, and are discussed in the order presented, displaying data from Aboriginal and Torres Strait Islander interviews first, then the issues from health practitioner interviews. In some cases, both groups discussed a particular issue. In most cases the themes remained quite separate and different. Where issues were discussed in common, I have indicated this; in all other cases it can be presumed that discussions were exclusively the domain of the group represented in my analysis.

Table 4. Phenomena identified as 'cultural barriers' in interviews.

POPULATION / CATEGORY	Aboriginal and Torres Strait Islander peoples	Non-Indigenous health practitioners
SOCIAL	• Family situation and access to health care • Taking away the sociality of patients (isolating the individual from kin and social networks) • Difference blindness	• Limited ability to pay for services, restricting choice of provider • Difference blindness (examples of)
CULTURAL	• Taken-for-granted lifestyle assumptions • Roles of kin and others in care • Shame • Respect and reciprocity	• Inclusion of symbols and signs (like Aboriginal artwork) and dis/comfort with the physical environment of a service • A perception (or evidence) of poor attitudes or understandings of Aboriginal cultures • Respect and reciprocity • Lack of understanding of Aboriginal kinship structures (evident among colleagues)
STRUCTURAL	• Lack of flexibility in health systems • Lack of communication and understanding between providers and patients • Complex bureaucracies in health and social support systems make it difficult to navigate between systems • Many providers offering many interventions (often overlapping and poorly explained) • Perceived expectation that Aboriginal communities can and will keep pace with changes in medical systems, health care models, and modes of engagement	• Non-compliance with appointment systems • A lack of understanding of separate systems • A lack of health literacy and health systems literacy • Need for many services in one, central location

9.1. Social issues.

The issues discussed here need some clarification. While Aboriginal people spoke about cultural issues of sociality and social realities, health professionals tended to see cultural issues through a 'social determinants of health' lens. Where Aboriginal people would discuss personal stories of illness, suffering and empowerment, health professionals most often tended to discuss socioeconomic status and social conditions in Aboriginal communities and rural communities as a whole.

9.1.1. Family situation and access to health care.

Like Douglas and Anna, whose stories were discussed in Chapter 4, there were other Aboriginal people who reported that they had been conduits for their families in negotiating journeys through health care systems. Many of these informants were in the position of advocate for their parents or other family members. They were seen by their families as appropriate to perform this role, due to past experiences in the health system as either a patient, an advocate or as a health professional.

Maree is an Aboriginal and South Sea Islander woman and also a registered nurse who worked for many years in the health care system. She tells the story of her family's experiences of caring for her elderly father (Interview, November 2007).

Maree's brother and his family lived for 18 years in the Torres Strait. Upon moving back to the mainland, Maree's brother took up the care of their elderly father, who suffers dementia. Her brother struggled to negotiate his way through the health and welfare systems and often relied on Maree for advice regarding their father (Interview, November 2007):

> *And so, they've gone to a range of organisations; first of all, they were told that they earn above the threshold and can't get any services. And so I got in and told them, "no, you're entitled to…you need to talk to …." And they then tried to call and got fobbed off yet again. So you know, if you don't have an understanding of the actual health system, and if you're not au fait with the vocabulary… to use, then how does somebody who is foreign*

to the system actually end up with... a person who can guide them through that process? That seems to be the biggest issue for my brother ...I think if he hadn't had me as a backstop, albeit from Mount Isa, to try and navigate this stuff, navigate them through the system, where would they have turned to, is my question? Because they don't have...an affinity with or knowledge of what to ask for. In terms of extra services.

Such family situations could cause conflict for Aboriginal health professionals, some of whom were called upon to use their position to create more favourable conditions for family, while being expected to toe the line by their colleagues, an example of which is discussed in the previous chapter by a senior Aboriginal Health Worker (Estelle). Her immediate family and other kin often asked her to make appointments on their behalf, in order to short cut the appointment system and gain an access advantage over other patients.

The sense of having an obligation to family, and being asked to exceed the call of duty often meant that Aboriginal Health Workers did not get the chance to switch off at the end of the work day. Most health workers accepted this as a consequence of their position, and saw it as helping, but did portray a sense of guilt at manipulating the system to suit their family's needs.

9.1.2. Sociality and isolation of patients from kin and social networks.

Aboriginal participants often discussed their distress at having a patient become isolated from their social and kin networks for health care, whether it be isolation by distance (when patients travelled away for care) or isolation by institution. When patients could not be close to appropriate kin, it had numerous effects:

> *Maree (Interview, November 2007): Yeah, but then you are taking away from the individual as a whole aren't you? Because you are carving that individual up into sections and pieces when, no...that's Mr. Joseph, who is actually a father to ..., and the son of ya and the uncle of...And although he's got this [condition], he's more than just a patient with this. He's an uncle, he's a father, he's a son of...you know, that type of stuff. He's got connections...*

Institutional rules that precluded large groups from gathering in hospital rooms, while often instituted for practical reasons, made families feel like an imposition. One Aboriginal woman recounted a time when her brother had been hospitalised after a serious illness and a nurse made a snide remark about the number of people trying to crowd into the hospital room. She explained

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the importance that Aboriginal people felt in actually witnessing the patient in the hospital for themselves and used this example to explain why there are often so many Aboriginal people waiting under the large trees (formerly at the front of the Mount Isa hospital). Not everyone who is waiting is waiting for personal care. Many are there to witness the illness of another family member, and provide an extended network of care (Estelle, pers. comms, June 2008). As discussed in Chapter 5, the witnessing of the ill also serves a greater social function. It allows those who are nearby to be able to report on the progression of the illness in discussions with those further away geographically, and creates a community of knowledgeable people who can testify to the event (Sansom 1982).

My interviews with Aboriginal people reveal the frustrations of being isolated within the system and dissatisfaction with the ways that some health professionals would depersonalise patients, talking about them as just another body in a bed:

> Maree (Interview, November 2007): Yeah you are a number at the end of the day. It's not "Hello, Mr. So-and-so", or "Hello, human"…"Hello Jerry, or hello Kim"…
>
> KMcB: Yeah, you just become "the patient with kidney failure" or [both laugh] "the one in room 201", or…
>
> Maree: Or "the daughter of that whinging patient" [both laugh] "The daughter of that whinging patient's on the phone" [both laugh]

9.1.3. Difference blindness.

'Difference blindness', a phrase used in national health ethics documents, refers to an ethos where practitioners treat 'all patients the same' regardless of age, gender, ethnicity or religious belief. Whilst it is important that practitioners do not discriminate against patients in these ways, it is important for them to recognise and understand difference, which can lead to more nuanced practitioner-patient interactions. In this case, difference blindness is used to indicate that some practitioners are not acknowledging that Aboriginal patients have needs and concerns that are

different from other patients, specific to their cultural heritage and historical encounters with medical systems. This was outlined by Mary, (Aboriginal Health Worker and elder):

> *Mary (Interview, November 2007): ...everyone says: "We treat everyone the same way, whether they're black or white". That doesn't help us, because...Aboriginal people have got their fear of the hospital, they have their own culture that sometimes some people don't take that into consideration...if they [Aboriginal patients] walk into a health service...you only gotta find one nurse or doctor who's...very rude to them, so they just think everyone is the same.*

Although this discussion touches on issues of difference blindness, it also highlights perceived attitudes of health professionals toward Aboriginal patients. Perceived attitudes (particularly hostility or indifference) can create major obstacles to Aboriginal (or any other) patients returning to a service. Word spreads through family and community networks about whether particular health professionals are trustworthy, or not. Interestingly, it also points to potential difference blindness among Aboriginal patients, in mistaking one rude staff member as representing the ethos of all staff (this attitude is often based on personal experiences in the past, and so can take some work to change).

There were some challenging comments made by a number of health professionals that relate to difference blindness, that represent views not generally considered acceptable in current discourse as in the example below (Lydia, GP, interview, October 2008):

> *...Aboriginal and Torres Strait Islanders, they get the same (treatment) as any Caucasian or any other nationality and in my opinion they still get that, in fact perhaps in preference to the Caucasians. But it's how they utilise it when they get home, and their determination, their mental determination to... the importance to them to take their pills correctly and toe the line with diabetes, etcetera that is going to influence the outcome. And they don't really have the mindset, on the whole, to be involved with that. So in my opinion that is a great barrier.*

Not only does this practitioner express a degree of difference blindness, they have also gone to some lengths to explain their perception that Aboriginal people have gained a kind of preferential treatment over other patients, determined by virtue of their ethnicity. This is confounding for the biomedical ethos, and creates some obvious tensions in the minds of some providers.

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In this argument, Aboriginal people are blamed for lacking the determination to comply. They are perceived as having a deficit in knowledge that has led to individual poor health which consequently created the need for discriminatory programs aimed at improving that health status. The practitioner (Lydia) discusses the supposed 'mental' capacity of the Aboriginal and Torres Strait Islander population to comply with instruction, suggesting that this population does not deserve extra attention as it has little impact on their health anyway, due to a deficit in their determination to be well. The reasons for this lessened determination may be due to the strictness of the treatment regimes for chronic illnesses (Lydia, Interview, October 2008):

> *...it is important to get it through to them that they do that [comply], especially in relation to diabetes, it's a big ask because it stops their freedom, it stops their way of life, and the very bad ones, who are really ill, go on dialysis and die, or die at an early age, it's because they don't conform, they don't take their pills or their insulin. And they're always out of control. They'll be dying and they're raced to hospital and resuscitated again, and again.*

In this instance the practitioner provides a conceptual link between culture, lifestyle and health, and provides a contrast of opinion to many of her colleagues. Aboriginal people know that these kinds of attitudes exist and that they exist in varying levels with different providers. These attitudes are often understood by the Aboriginal and Torres Strait Islander community and their often subtle expression has significant impacts on this community's uptake of services. If even one community member experiences poor treatment, or perceives or even witnesses these attitudes, word spreads throughout the community that this particular provider is to be avoided to preserve dignity and protect the rest of the community from harm. The element of lifestyle risk factor interventions will be discussed in detail in Chapter 9 with regards to one such federal government initiative. Ultimately though, if lifestyle cannot be controlled, this is seen as non-compliance, just as much as not taking a pill.

Another general practitioner (Barry, Interview, October 2008) recounted an example of what he termed 'reverse racism'. One of his white, lower income patients had required a particular medication for an illness. When the practitioner called through to the PBS office, to see if this patient was eligible for a discount or free medications, he was told no; that with this particular

medication the patient would only be eligible for free or reduced cost supply if he was an Aboriginal or Torres Strait Islander person. Rather than choose to see this as a positive scheme which would improve the health status of an oft-disenfranchised population, the practitioner asserted this was an example of reverse racism, where Aboriginal people were privileged over everyone else.

This practitioner felt quite strongly about this instance, I think not least of all because he felt impotent. He could not assist his patient in as full a way as he deemed appropriate. But, I think it also expresses a deeper concern that few were prepared to openly acknowledge; there are differences within the general population that must be acknowledged by health systems. At times like this one, difference is made to appear as discriminatory in the 'worst' way - against the majority population. Such an attitude does not recognise that whilst people can be medicated similarly, they may not be treated in the same way socially. Sometimes, the fortune falls the way of those in most need. But that is often also interpreted as being discriminatory against other populations with the same perceived need. Part of the reverse racism argument is often bound up in senses of entitlement and egalitarianism, that sense or belief that we are all equal and deserve the same treatment or access as everybody else, despite clear and obvious differences in levels of need or deprivation.

On the part of health professionals, the most discussed social aspect of cultural barriers in interviews focused on the socioeconomic status of Aboriginal patients and their ability to pay for services. Not being able to pay was characterised as significantly reducing the chances of Aboriginal people having any choice in health care providers or in being able to avoid long waiting lists, despite the fact that many services were bulk-billed, including the AMS, or public options. Some interviewed health professionals argued that low socioeconomic status and non-compliance with directions indicates that Aboriginal people simply did not care enough about their health or have the capacity to follow directions due to associated poor education levels.

Humphrey et al. (2001, pp.62-68) discuss the language of cultural difference that emerged in their studies on compliance. They found that the language of cultural difference as expressed by health professionals was "unguarded, clumsy and at times unnervingly blunt" (2001, p.63). Their comments illustrated "...both a culled knowledge of Aboriginal 'ways and values'...and an almost existential uncertainty about how to deal with or even report this knowledge" (2001, p.64).

As demonstrated in the sections above, my experiences of non-Indigenous health practitioners' ability to discuss cultural differences were generally similar to the findings from Humphrey et al. (2001). This inability to communicate or negotiate cultural difference is also evident in Douglas's case study in Chapter 5. Douglas's communications with the specialist were complicated by misunderstandings of Douglas's function as carer and witness for extended kin networks. It was also exemplified in sections of Chapter 6, where Ambulance officers and other health professionals displayed limited knowledge of cultural practices, gender taboos and language differences.

These issues of simplified encounters also extend to previous discussions, such as inappropriate or ineffective appointment systems. For some health professionals, this led to the creation of a composite, heavily reliant on negative stereotypes of Aboriginal ways and beliefs. The following section discusses in more detail the elements of interviews which highlighted differences related more specifically to cultural practices and beliefs.

9.2. Cultural Issues.

Gracelyn Smallwood captured areas of potential cultural misunderstandings in an article from 1989. The article gave an Aboriginal woman's perspective on what cultural barriers may exist within mainstream health systems that may contribute to low rates of attendance from Aboriginal and Torres Strait Islander populations. She provided examples from her time working in an Aboriginal aged and disability care hospital in Alice Springs. There were many practices being carried out in this hospital which were 'culturally inappropriate' and being carried out unwittingly by well-intentioned but ultimately ignorant white staff and administrators. The hospital was

staffed by 80% non-Aboriginal staff, 20% Aboriginal staff (who in Smallwood's words "...were only there to clean up urine and faeces" in the previous years (1989, p.10)), and the clientele were 100% Aboriginal men and women from the Pitjantjatjara homelands in the Northern Territory.

She discusses the old ways and the new changes that she introduced in her role as Matron and Director of Nursing at the hospital (for a comparative summary of these changes, see Appendix C). Smallwood describes the threats she received by the funding body for the hospital, who largely objected to her changes, because they were "...not in line with the Nursing Homes Act" (Smallwood 1989, p.10).

Smallwood (1989, p.9) provides an excellent example of how significantly these issues can impact on the wellbeing of Aboriginal people in care:

> They were also giving him [traditional Pitjantjatjara elder] fish every Friday, and could not understand why he was throwing the fish back in their faces, I then explained that no more heavy western drugs were to be given to any of the traditional people, I also asked some of the staff...why they thought this man was throwing fish in their faces. Not one had realised that there was no sea in the Pitjantjatjara desert – these people had never seen sea, much less eaten seafoods. Their lifestyle is living out on a vast desert, on traditional foods – kangaroo, witchetty grubs, whatever they can get. They had to be put on high-powered western drugs because they felt alien among the non-Aboriginal nurses walking around in white uniforms, white shoes, giving them chocolate cheesecake and roast beef on Saturday.

While the specific details may not apply to all Aboriginal people, the idea that cultural information and practices can be easily overlooked by systems that are not designed to tolerate ambiguity or difference is well demonstrated. There is new evidence from a Tasmanian study that many women from various Asian cultural backgrounds struggle with cultural acceptance within the maternity setting, reporting compromising situations with regards to language difference, food choices (especially being served inappropriate foods for their condition), specific hygiene controls (such as requiring women to shower after the birth), and the role of men in childbirth (Hoang et al. 2009, p.1084). Recognition of cultural difference, provider attitudes to cultural difference, and the ability to incorporate such knowledge into practice may still be elusive goals for some practitioners.

9.2.1. Lifestyle and behaviour assumptions.

In the eyes of Aboriginal people, health practitioners who fail to acknowledge the various roles that family members play in the health of ill individuals, or make assumptions about Aboriginal patients' lifestyles contribute to feelings of mistrust. Many Aboriginal participants felt they were the victims of assumptions made by health practitioners with regards to their lifestyle. Often problems of normalisation of lifestyles would occur, leading to miscommunication and failure of treatments, such as the episode outlined with regards to the old diabetic man who had no refrigerator in the interview with Maree above. The assumption that everybody has (or has access to and electricity to run) a refrigerator is an ecological fallacy - a good example of the ways that people tend to normalise their own situation and project that onto others. Most often these assumptions are made about socioeconomic resources – for better or worse. In this case, it meant that an old man was at risk of becoming more ill, because he did not have access to proper storage for his medication. Had he been asked about this, the problem could have been averted and he would have been given medications more appropriate to his setting.

9.2.2. Roles of kin and others in care.

As discussed in Chapters 3 and 4, it is important to Aboriginal patients that the roles of kin and other community members have in caring for the ill are acknowledged, respected and where possible integrated. Aboriginal interviewees argue that part of the problem comes from health practitioners not understanding Aboriginal kinship systems adequately, and being ignorant of the implications that such tight connections have.

One male General Practitioner (Terry, interview, October 2008) provided a perfect example demonstrating the misunderstandings that Aboriginal people were referring to. This example displays a lack of awareness of the roles of others in the illness experience, but also fails to acknowledge the ways that gender, age differentials and deference to elders inform discussions about sensitive issues:

Terry (Interview, October 2008): The young ones, I notice especially the girls, they do not come alone when I sit down and consult with them; they usually come with an elderly patient. They avoid eye contact, and they don't usually tell me, even though most times, in a diplomatic way, I will tell the elder, not to worry, "let her speak to me, she is old enough to tell me". But I notice that they don't ...I think that is a barrier, what I would regard as a barrier, because they don't actually voice out the main problem, someone will relate the problem to me...

In this case, this action by the patient and carer may be related to issues of gender (a male medical practitioner discussing often intimate issues with young female patients is not generally felt to be acceptable and so, often, an elder is expected to attend), age difference, aspects of shame (a young girl may not feel comfortable talking about women's issues with a male medical practitioner), and as protection, to help her feel more comfortable in the consultation. There may be many other interpretations of this scene, including the possibility of older women translating medical knowledge to young women, acting as a cultural broker between medical practitioner and young patient, or acting in the role of carer or mediator like Douglas or Anna (Chapter 5), or it could be an assertion of power between older women and younger women.

This comes back to who is most appropriate to speak (Sansom 1982, Reid 1983, Devitt and McMasters 1998a, McCoy 2007). In some situations, a young female may not be considered the most appropriate person. Or having an elder present may act as a safeguard, to ensure that appropriate decisions can be made on her behalf. But there was little if any acknowledgment of these issues in the medical practitioner's story. Rather, a sense of frustration and discontent was expressed that an adult would presume to speak for a child and that getting the information from the carer or adult is somehow inferior to hearing it directly from the patient. It denies the important role of carers in illness processes, not just within the Aboriginal community, but in the community at large.

The need to be able to look out for one another in an extended sense of community is important and was expressed in virtually all of my interviews with Aboriginal people. It was especially pronounced in Health Worker discussions, and showed a real valuing of connection through Aboriginal identity, and sometimes through association:

Estelle (Interview, June 2008): And there was another old lady, we were worried about too. I said, 'Doctor, she knows she got an appointment, but because they live by themself too, and if anything happens...they'll end up in hospital you know?' ...And so we panicked there; we was ringing the hospital; we was ringing Blue Nurses eh! So and So told us she had to go somewhere else before she come here. But she eventually come. And we said, we was frantic, we didn't know where you were. ...Cause that makes you worry, eh?...

And if there was ever anybody they was looking for, you just have to say, 'I'm looking for so and so'. And if they're there then they'll tell ya...And not only that too, they'll look after you. Like I say to people, I'm safe here. This is my community and I said, whatever's going down in this clinic and if it's not good it'll go out and family be here. I said I can walk down there (gestures to the riverbed) by myself. Most them mob know me.

The need to look out for those who are in town from other places was discussed. Many stories of how this kind of care can go bad were outlined:

Maree (Interview, November 2007): Well, I mean, I gave you the example of the elderly gentleman coming down from Doomadgee...They fly him down, and he was being operated on Monday morning. And you know, ok, fly him down Friday afternoon, but give him a bed somewhere. Put him in a motel. Anyway, what happened in the end was they booked him in the hospital. But then come Monday morning, what did they do? Discharged him. When was his operation?

KMcB: Monday afternoon?

Maree: Yes...so then we had to send the health workers out to find him...He had nowhere to go, and here he was, sittin' up the main street. With no money and nowhere to go...How do you do that, Kris? How do you discharge somebody, without looking at all the paperwork? Like, this man was out to have his IOLs (intraocular lenses) replaced in the afternoon...and then he was flying home, put on a plane to fly home, Tuesday. I think he may have been in hospital Monday night...but you know, nobody bothered to read on. They just come along, "No you're fine to go home"! And he was like, "Oh, okay." Early stage dementia, so...what do you do? The poor fella didn't know any different.

One Paramedic explained to me that some of his staff simply 'don't understand the aunty, uncle, sister, brother thing...'. He went on to say:

Harry (Interview, February 2008): It's simple... [Other people say] 'Well don't they know who their uncle is?' Well, yeah, and there are more of them. 'Why doesn't the mother look after the child?' Because it's not their role, it's the Grandmother's role to do that. And they just don't understand that.

9.2.3. Shame.

The concept of 'shame' among Aboriginal people is a complex one, but here refers to feelings of embarrassment and indignity when patients simply do not want to go to a service or appointment,

or get caught missing an appointment. It also referred to situations of taboo; of gender (patient and practitioner of opposite sex, especially conflicting in intimate procedures) family roles (e.g. an Aboriginal Health Worker is asked to attend to a patient who is a family member), especially when in an avoidance relationship[51] (son/mother in-law, etc.). When appointments or even consultations and treatments obstruct social obligations, especially to family, this can also cause feelings of shame.

The complex of shame was also a feature in Devitt and McMasters (1998a) work with Aboriginal end-stage renal patients. In their studies, shame was at first thought to be related to issues of individual privacy which may then become a hindrance in patient's understanding of their illness. Upon further inspection, it seemed that some patients experienced shame over having such a serious illness, and some experienced in the reactions of others (relatives) who could not bear to have frank and open discussions about the illness and treatment (such as in Douglas' story in Chapter 5). Thus, shame seemed to be related to cultural conventions regarding the "personalised discussion of serious illness and/or health" (Devitt and McMasters 1998a, p.145).

In my discussions with Aboriginal community members, people also identified a sense of shame related to individual privacy and/or their capacity to respond to health needs. Issues relating to particularly sensitive topics, like sexual health saw a considerable 'cultural conservatism' (Brady 1994), and in discussions of chronic illness, people would express a personal sense of shame at getting sick with a chronic disease at all or being/feeling unable to control their illness.

9.2.4. Reciprocity and respect.

For many informants, the basic values of respect and subsequent reciprocity were highly important in developing good patient-practitioner relationships. Those health professionals who showed

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[51] Avoidance relationship: "...an expression of tensions created by social and kinship structures – in other words, as a mechanism which both expresses and diverts potential conflicts" (Seymour-Smith 1986, p.20). The most commonly known avoidance relationship expressed in many cultures is that of the man/mother-in-law relationship.

respect to their patients, who spent time explaining concepts and treatments, who listened to patient's stories and took note of the important issues in their lives, who remembered and got to know other family members, were deemed good people and had earned respect from the community. When this occurred, health practitioners would be accepted and shown respect through 'gift-giving' or sharing from their patients and their families. This would come in many forms, including food, material goods, and even security.

> *Estelle (Interview, June 2008): We have a yarn, and have a giggle, and (conspiratorial whisper) they used to bring us food, eh! They'd make brownies, one of them old guys, make brownies, and they'd ring Queensland Health, health workers would go and get their share, and they'd ring us and we'd go and get our share, they appreciate what we do.*

It was in these types of relationships that practitioners also felt the most satisfied, and reported feeling like they could really make a difference in people's lives.

> *Kimberley (Interview, January 2008): I do enjoy Indigenous health, in particular, I do find that rewarding. I find the patients…more interesting…and they are probably more grateful, not that you do it for that, but often they are genuinely unwell, so you can genuinely do something for [them], and they are genuinely happy about it. Whereas, otherwise a lot of the 'worried well', you're never going to convince them that there is nothing wrong with them, so they end up feeling dissatisfied, and you end up feeling dissatisfied. So I really enjoy Indigenous health.*

Largely, however, health professionals discussed issues relating to culture in two broad categories: the inclusion of cultural symbols, and communication and attitudes.

9.2.5. Inclusion of symbols.

The inclusion of cultural symbols was a popular theme throughout health practitioner rhetoric, but did not feature in community interviews (with one notable exception from an Aboriginal Health Worker). Including Aboriginal cultural symbols, more specifically in the form of Aboriginal artwork was considered paramount in making a practice 'culturally appropriate'. This is a view that has been encouraged in many cultural awareness training packages. The assumption is that Aboriginal patients will feel more comfortable and secure when surrounded by such artworks. Not all practitioners I spoke with realised that local Aboriginal artwork may have increased resonance for local Aboriginal people than generic "Aboriginal Artwork". However, most of the local practices

that include Aboriginal artworks in their facilities have sourced them from local artists. Not only has this encouraged a vibrant local art scene, but it circulates stories of significance to local people, and shows support for the community.

However, there are limits to the good such inclusions of cultural symbols can do. Including appropriate artwork can provide an indicator of a potentially good relationship with the practitioners of a service, but cannot guarantee acceptance. In a practice that does not foster respectful relationships with Aboriginal patients and their families, all of the artwork in the world will not make people attend. In places where Aboriginal patients have had bad experiences of care, or where they are greeted by practitioners who are rude or uncaring, their cultural symbols are reduced to the status of signs, displaying a token effort at a relationship without putting in the real work.

9.2.6. Discomfort with the physical environment of a service.

As discussed in Chapters 3 and 8, many practitioners brought up the fact that physical environments of practice settings could be unsettling for Aboriginal patients, but struggled to elaborate exactly what they meant by this. Some said that this was related to issues of spatial arrangement; that Aboriginal people required large open-plan spaces, with privacy for consultation areas. Others attributed the colours used in health institutions as being unfriendly or too clinical, making people feel uncomfortable. But largely this notion went unexplained.

9.2.7. Attitudes of Aboriginal people and of health staff: engagement and communication.

Further to the discussion of this issue in section 8.3.1, often, health practitioners believed that they had no trouble understanding or being understood in communication with their Aboriginal patients, although they knew horror stories of colleagues who were not so successful. Non-Indigenous health professionals generally reported being happy with their level of competence when it came to understanding and being understood by their Aboriginal patients. But, they often shared examples of others in their profession who were not so good:

Kimberley (Interview, January 2008): Um, on the whole here I found most of them [Aboriginal people] were quite used to dealing with…white… people. But, we've sometimes had people come through from the [Northern] Territory, from very isolated areas, and then you notice the difference. I think most of them were fairly comfortable with English. You're still aware of the fact that…um…there's a lot of things that you take for granted…um…talking to European patients, that they won't necessarily, that you can't assume. So communication wasn't perfect but we encouraged the health workers to do a lot of building up on that. I mean, there's the occasional client where you just had no idea what was happening, but you get the health worker in and sort that out; but they were fairly few and far between. I think most of them had had a reasonable amount of education, so I think we were mostly on the same page…a lot of them didn't.

I imagine a lot of the medical staff get frustrated because they just can't get any information out of them, but it's not necessarily their fault, they are just in a place where they feel uncomfortable. And I suppose that's going to take a huge amount of work to change their culture and that feeling, because I found even in Townsville, [lowers voice] the nurses used to treat the Indigenous patients so badly, I couldn't blame them for not coming back. You know? They were just rude to them.

And in interview Julie (November 2008):

I found it very eye-opening…communication wise, [pause]…no problem. I found it very easy to adapt to each person, individual…there was a little lady from Bentinck Island and she couldn't speak any English whatsoever, not even pidgin English, so…that was a hard one, trying to stop her from having a ciggie [cigarette] in the cubicles…(laughter)…and then she would talk to me for ages, and I'd be like, "I don't know what…but if you want to come outside, come with me, we'll have a ciggie!" (Laughter). And then you'd sit her back down inside, and she'd be rollin' the next one, in the cubicle, and you'd be like, "What?!?"

But apart from that, no. I have found, especially because we have a lot of foreign doctors here in Mount Isa, they have a bit of trouble a lot of the time, because they (Aboriginal patients) will talk in their boots, or not really pay attention to what the doctors say and they (the patients) look at you like, "Can you help me out here? What? Are they choppin' both legs off, or just doing a dressing on my toe?"…

Some trusted health professionals found themselves in demand by the community. These practitioners were often called upon to help educate new-comers and establish trusting relationships based on strong understandings of local circumstances and Aboriginal cultural particularities. They often expressed frustration at those who just 'did not get it' when it came to Aboriginal cultural values, particularly kinship organisation. These practitioners emphasised basic levels of respect in practices like dressing appropriately, conducting health checks respectfully and, where possible, in same-sex consultations, listening intently, and taking account of family situations and obligations.

Most practitioners I conducted formal interviews with considered Aboriginal people to be very respectful in attitude toward health practitioners generally:

> *Harry (Interview, February 2008): I find the attitudes of some people...I found the people to deal with themselves, really easy. They are a beautiful people, they are more respectful...and I've often made the comment to people, 'tell me which would you rather deal with: A drunken Aboriginal or a drunken White person?' And I can tell you, a drunken Aboriginal is a lot easier to deal with because underlying the whole thing is a high level of respect.*

Respect and reciprocity between Aboriginal community members and the health professionals that they interacted with were common themes. This was most often characterised as being a good and respectful relationship initiated by Aboriginal people. These Aboriginal people were presumed to have some kind of inherent respect for certain (not all) health professionals. It often sounded to me as though there was the existence of reciprocal obligations that characterised these stories. There was a sense of earning trust and respect beyond clinical skill among people who simply did not have to trust nor respect health practitioners.

Earning such respect was seen as a significant achievement among health providers (See Kowal and Paradies 2003, and Kowal 2006), and even community members would discuss the fact that, if you did not show respect to Aboriginal people, or you did the wrong thing in a consultation, you would be shunned by the community more broadly. Often these relationships are dependent on Aboriginal expectations of what various health professionals owe them in terms of treatment, and whether or not the health professional is seen to approach the care situation with a level of deference to the people they were treating. It appears to be about making sure that health professionals know their place and the need to earn trust and respect from their patients. It gives a sense of agency and control back to patients, by seeking to minimise the officiousness and authority of medical practitioners. When this balance is achieved health professionals are often accepted into the community, and seen as trusted allies and providers. They are then often expected to be a conduit to the community, for new staff to develop relationships or as trusted

confidants of the community able to transfer their knowledge and demands of the system back to those in charge.

9.3. Structural issues.

There were many issues raised in interviews that were quite obviously related to structures and institutions rather than cultural specificities or even social concerns. Often these aspects can be hidden in discourses about health status, behind other more obvious or morally-laden issues such as cultural difference. Invariably, these structures are themselves a product of the cultures and societies that create and use them. But systems and structures (and policies as discussed in Chapter 10) are often constructed (at least superficially) in ways that neutralise them, through language, symbolism and appearance.

9.3.1. Lack of flexibility of health systems.

As was also evidenced in chapters 4 through 6, frustrations with a perceived lack of flexibility in systems were often expressed in mundane ways, which also belie a frustration at the protection of 'turf' among health professions. This is not always a matter of ego. Sometimes, it is a function of rigid funding arrangements, bureaucratic structures that silo services, or a way of protecting practitioners from being asked to practice in ways that may contribute to burnout, overburden, or malpractice lawsuits. It does preserve the distinctions between particular care specialities, and in turn can protect the power differentials created between them.

9.3.2. Lack of communication and understanding between providers and patients.

As illustrated by Douglas's story in Chapter 5, communication in one-on-one interactions between practitioners and patients can be a problem. This can stem from differences in language, even when both parties are speaking English. There are significant differences between standard English and Aboriginal English (Dixon 1980; Nathan 1996; Eades 1996), which is further exacerbated when medical English comes into use. In similar ways to the justice system, health

care (and more specifically medical) systems have their own terminology and definitions for words, which can be mistaken for more mundane uses of the same word. In Queensland, the Courts and Justice system has developed a guide to assist in court cases involving Aboriginal people, whose testimonies in court have been misinterpreted in the past (Eades 2000). Language guides could be produced to deal with medical encounters, to assist both patients and providers to better understand each other. Of the issue of language difference, one practitioner said (Barry, GP, interview, October 2008):

> *I see one of the main problems is the push for everyone to keep their own language, especially in early development, it really just decreases communication later on. And we should be about increasing communication in this world, not maintaining discommunication* (sic).

The discussion of language barriers was an obvious source of conflict for this provider, but was ultimately expressed as an agenda of ongoing miscommunication caused by Aboriginal people who insisted on keeping their own languages alive. Apparently this discourse around the necessity of language survival for the ongoing transmission of cultural knowledge was causing real problems in practice. This is despite the fact that (I doubt) any of the Aboriginal people who went to this practice would have expected to communicate with doctors in Kalkadoon or Waanyi, or any other local language, and would no doubt have been speaking Aboriginal English or even standard English. The discourse alone was clearly enough in the mind of this medical practitioner to create hassles in communication, and there was no acknowledgment of the differences between biomedical English, and Aboriginal English and standard English for communication.

This is also an issue of communication on an interpersonal level, in ways similar to Anna's experiences detailed in Chapter 5. Sometimes, Aboriginal patients felt that their individual and family stories did not matter to practitioners, despite providing practitioners with contextual information that could have promoted a solid patient-practitioner relationship, or even facilitated more appropriate care and treatment plans.

Cultural awareness training (or cross-cultural communication training as it is also called) is currently and almost universally accepted as a beneficial way of increasing effective communication and encounters between Indigenous and non-Indigenous Australians. Arguably, cultural awareness training may be a result of the increasing politicisation of Aboriginal cultures in Australia, and serve as one more way to characterise Aboriginal identities as being problematic in interactions between Aboriginal and non-Aboriginal Australians.

The following is reproduced from one of my fieldwork diary entries.

... An Aboriginal gentleman came out to the waiting area, with his foot bound up in a fresh white bandage. He was very quiet and took a seat. He was waiting for the nurse to come with his medications…When she finally appeared about 10 minutes later, she proceeded to explain the medications to him. There was more than one medication to be taken, all in pill form. Although I did not catch all of the details, I did hear her telling him at what time of the night or day they should be taken – around 8 o'clock. The man was not wearing a watch, and I did not notice any clocks in the waiting room. He took the medications from her, and made his way unassisted and alone to a vehicle outside.

This is one observed example of how communication can be fraught with misunderstandings and assumptions. Here was an Aboriginal man, possibly in some pain, being given a large range of medications all in pill form. The instruction on what to do with them – take them at around 8 o'clock – was vague at best, but was also complicated by the fact that there were no obvious timepieces available to refer to, nor did the man have a watch, so the dependability of such instruction is questionable.

In order to combat such misunderstandings, many organisations, including Queensland Health have introduced mandatory cultural awareness training for their staff. In a recent text outlining the history of Cultural awareness training (here called cross-cultural training), Morgan (2010, p.60) states:

Cross-cultural training is based on three key concepts, 'cultural misunderstandings', 'cultural sensitivity' and 'intercultural competence'….CCT aims at helping trainees develop 'intercultural competence', or expertise in intercultural communication. Intercultural competence is gained through the development of 'cultural sensitivity' or 'cultural awareness'…The development of intercultural competence, through the acquisition of cultural sensitivity, enables trainees to avoid 'cultural misunderstandings', which are thought to be detrimental to successful intercultural interactions. These processes beg the question: when is a misunderstanding a cultural misunderstanding and why do cultural misunderstandings occur?

Morgan (2010, p.60) continues: "By focusing on dimensions of difference all of these [cross-cultural training] models are implicitly identifying *cultural differences themselves* as the primary causes of cultural misunderstandings and conceptualising diversity as a barrier to successful intercultural communication" [emphasis my own].

In interviews, health care professionals also identified cross-cultural communication as a problem, in various forms. The health professional below found frustrations in poor communication at the hospital level, whether it be in verbal instruction to patients or the technical details of consent forms, as it had a profound impact on patient management at the primary care level:

> *Kimberley (Interview, January 2008): But you go up to the hospital and the number of patients, and again this might be people being a bit cunning and making up excuses, but a lot of them leave before their treatment is finished. I mean, it's an endless problem, and a lot of that's communication, they just didn't understand what was going to happen to them. And so they either left because they were bored, or they left because they thought everybody was finished, or they left because they just wanted a drink or a smoke. But I think they really need someone on their ward rounds who is Indigenous to explain what's going on, what's happening. And I think that doesn't happen at all, from what I can see…*
>
> *…And the other thing is those wretched consent forms for operations. They frighten off all the Indigenous patients. I've had them come back: "So, why haven't you had the operation for your cancer?" "Oh, they said it might kill me." "Well, yes, it might kill you, but the cancer will kill you." It's just not explained to them properly.*

In this study, cultural awareness training was identified by participants as a universal need, but in various ways. Some Aboriginal participants stated that non-Indigenous health staff needed to complete cultural awareness training, while health staff often identified the need for themselves or colleagues to undergo such training, to increase their knowledge of Aboriginal culture. The need for the community to be educated by health professionals or knowledgeable others about the ways

that health care systems functioned was also identified, often to highlight a lack of understanding and compliance of Aboriginal people with regards to health issues.

In terms of cultural awareness training for health professionals, the term was consistently used in interviews to refer to training that provides insight into Aboriginal and Torres Strait Island cultures. It is seemingly not used in this community to refer to any other cultural groups, despite the cultural diversity within Mount Isa (although, this could be a function of the fact that many people understood that my project had a significant focus on Aboriginal and Torres Strait Islander experiences, and that this was my area of interest, and due to my participation in some cultural awareness training at MICRRH).

Largely, this kind of training is characterised as providing knowledge of Aboriginal people's history, attitudes and behaviours, so that health staff can be prepared to deal with their Aboriginal patients. In keeping with many of the kinds of training that health professionals receive, they often expect that they can be given a checklist or set of skills that will help them to deal with individual encounters, but that can be generalized across the population, and that are defined as a set of desirable behaviours on their part that they can employ in such encounters. In my experience, these training sessions are expected to be short – either a half day or full day of training, which is often expected to be provided by Aboriginal people, and will provide a general insight into Aboriginal people and why they do what they do (Beagan 2003).

There were health services that were seeking to actively engage with the Aboriginal community in efforts to improve access to services, and understandings between health service staff and Aboriginal patients. At the organisational level, attempts to be culturally appropriate with how they would offer education about their service and how it worked was common. Rodney, a Paramedic and Ambulance manager said (interview, February 2008):

> *There would probably be a good thirty percent of the emergency calls we receive, to Indigenous areas of town that would quite easily be non-emergencies. But once again this comes back to the education side of things. And they don't understand that when they*

get on the phone and call for an ambulance, what to say. And that's where we have some issues. Now, how are we addressing that, from the QAS side of things? ...We will target the elders first, so they know where we are coming from, what's going on, so they understand why we're in there, in the areas that we will be in. So we're not treading on any cultural...areas, so we're not upsetting people.

After we've finished with the elders and got permission and everything is happy there, we will automatically progress back to the children. Because we have to educate the children, because as the children come through into their teens and adult years; that is where the cultural cycle will change. It is no use talking to the adults at the moment. We need to talk to the kids, because they'll take it home, and all that sort of stuff, so we need to start the cultural change early....

There is potential for cross-cultural awareness training to celebrate the differences and fluid identities of Aboriginal people, but also a danger of inverting the meaning of difference, as a way of examining a separate culture with no similarities to any other cultural group. And whilst this may reinforce the importance of the 'distinctiveness' of cultures, it can also serve as a place to lay blame, and problematise Aboriginals as cultural 'other', constantly misunderstood as a result of their difference to mainstream (or non-Indigenous, or white) Australians. The movement of cultural awareness and sensitivity from the vague language of policy, through to the administration of major institutions and finally into everyday cognisance and conversations signals the politicisation of Aboriginal culture in Australia (discussed further in Chapter 11). However, evidence regarding the impact of cultural awareness training on Aboriginal health outcomes is limited, and while there is evidence of the intangible and indirect outcomes that cultural awareness training provides to students which may contribute positively to Aboriginal health outcomes, this may not be sufficient to sustain such tutelage. In attempting to move practitioners from awareness to cultural safety or cultural competence it will be necessary to address the place where ethnicity and culture meet conceptually, to move beyond social indicators of Aboriginal health and poverty, and simplified encounters based on stereotypes that cast Aboriginal culture as static and slow to change.

9.3.3. Complex Bureaucracies.

Health and social service bureaucracies are intimidating structures that are often very complex. Many Aboriginal people admitted being intimidated by such systems. This was often due to having bad previous experiences in trying to navigate their way through such systems. Feeling trapped or caught out by decisions that they made along the way, after following advice from those working within the system made many participants reticent about engaging with such bureaucracies again. Many participants expressed a desire for better understanding of the machinations of bureaucratic systems; many people felt that if they could only understand the systems a bit better, their experiences would have been better.

Possibly best expressed in the Queensland Health Systems Review Interim Report (2005, p.7), is the way that a complex system creates confusion for patients. The Report attributes much of this confusion to funding arrangements, saying that the Australian health system is fragmented due to each level of government having responsibilities for different health services.

9.3.3.1. Frustrations with the inadequacy of the bureaucratic nature of the health system.

Discussions about frustrations with health bureaucracies featured heavily in practitioner discussion. It was often the case that health practitioners had felt stifled by the health bureaucracy before, and it had prevented them from being able to deliver good quality care and satisfying outcomes for their patients. An excellent example comes from an interview with Kimberley (GP):

> *Kimberley (Interview, January 2008): We've had a lady from Boulia who's been in town for about four, five weeks now. And they've* [Hospital staff and administration] *been complaining that she hasn't turned up to any of her appointments. Where do you think they sent the appointments to?*
>
> *KMcB: Boulia?*
>
> *Kimberley: [Nods head] So appointments keep turning up in Boulia, and no one can find this woman. And she is in town somewhere.*

> *Kimberley: And then after the third one we get a letter saying, "Your patient has missed three appointments and has now been removed from the waiting list."*

This example shows a clash in two ways of seeing the world. The patient in this case was trying to be compliant with the instructions from her health practitioners, and had made her way to Mount Isa from Boulia (over 300 kilometres apart – See Map 1), but bureaucratic process meant that she still missed out on the appropriate care. In her interview, Kimberley also discusses the various processes that have been attempted to assist Aboriginal patients who move around frequently, but these systems are often reported as being less than adequate for keeping contact with patients. Sometimes, it is an active choice by the patient not to be contacted; at other times it is a failure of the system or practitioners to adequately communicate what the next step is, and to assist or advocate for patients, to ensure that step is completed.

9.3.4. Many providers, many interventions.

The interventions of many providers at once in Aboriginal life worlds was a theme that came up in many of the informal interactions I had with Aboriginal people in the community. In the time I spent with women attending a local women's group I heard many stories of frustration and concern about the sheer number of people intervening in Aboriginal lives.

One woman reported to me that, while she was attempting to go through a process of dry-out from alcohol, she was constantly under watch. On the day we spoke, she had been visited by health practitioners to assess her health during her dry-out, followed by an alcohol counsellor who was assisting her to keep on the detoxification program. This was then followed by a social worker who was discussing the state of her relationship with her children who were in foster care. Shortly afterward, a legal representative visited to assist her with criminal charges she was facing in court. Finally her day of interventions ended with her attendance at the women's group (which had been court ordered, and thus her attendance was being recorded to show dedication to 'turning her life around'). She was obviously frustrated and angry about this. She expressed her confusion by saying that she felt like she was never going to be able to sort her life out, with so

many people to answer to. This was not an uncommon story, particularly among those Aboriginal people in the group who were from lower socioeconomic status groups.

Another Aboriginal community worker told me about how these many constant interventions translated into frustrations for her. Charged with running a national program locally, she constantly faced opposition from Aboriginal people who were suspicious of her motives. Despite consistently explaining who she worked for (a government department) she was often asked to explain again, and was often confused by community members with other services because of the kinds of work she undertook. Her work did overlap with some of the things provided by other services that visited homes in the area, and so people were suspicious as to why two different people seemed to be doing the same things on behalf of two different government departments. Not only did they see it as an inconvenience, they were also wary of who was watching them and their kids. Many services in town have been funded to carry out similar projects; there are many overlaps in provision, which can also create gaps in other areas of need. These overlapping services and the intricacies of their funding arrangements do create slight differences in provision, but this is rarely well explained to the community, widely reported by both Aboriginal people and health professionals as leading to misunderstandings and a reluctance to take up services when offered.

9.3.5. Expectations on Aboriginal communities.

Expectations that Aboriginal communities would keep pace with changes in health care models and styles of engagement were experienced as unfair requests by communities and health practitioners on the ground. This was discussed by at least one Senior Aboriginal Health Worker (and community elder) in the following way:

> *Mary (Interview, November 2007): I started in 1982 as what's known as an Aboriginal Health Worker, and in them days it was called "Search and Rescue". In the end, about the late 80's Queensland health decided that no more search and rescue, it would be self-help health care, which was basically Primary Health Care. In saying that, I...I think it was done too quick. Like, one week we were search and rescue, and the next week we were*

self-help health care, and everyone expected our people to just...change, (clicks fingers) like that.

In a population that has seen many changes to the ways they are cared for, these changes were reported as creating further mistrust, fear, and sometimes apathy, as people feel like their health status only matters for as long as it is deemed interesting enough to be funded, or until the next big thing comes along. As the above quotation demonstrates, these changes, while they may be discussed at bureaucratic levels for a long time, are often experienced as sudden and confusing at the patient level.

On the part of health professionals, there was an acute awareness of how health systems could stifle efforts at access, having often been victims of these systems themselves as employees. They discussed issues such as lack of opportunities to access good quality care and frustrations with the bureaucratic nature of various health and social service systems. There was an element of victim-blame in some health professionals' discussions, with regards to issues of compliance, or a perceived lack of understanding and knowledge about health care systems on the part of patients.

9.3.6. Non-compliance with appointment schedules.

Perceptions of Aboriginal people being non-compliant, especially with appointment systems is a common theme in Aboriginal Health literature, and it was raised in my informal and formal interviews with participants. Besides being the experience of many health practitioners, this is often an argument that is put forth as a way of blaming Aboriginal people for the state of their health. It does show an ultimate disconnect between the ways that Aboriginal people and others quantify time, and give value to it. There are arguments in the anthropological literature (For example, Swain 1993 and Humphrey et al. 2001) that suggest that this may be the case, and that due to the nature of Aboriginal concepts of time, as opposed to the linear sequences that mainstream society operates under, appointment systems simply don't work. But perhaps this is not so much about differing concepts of time as it is differing concepts of 'timeliness'.

As discussed by Burbank (2006), if it is truly a case of Aboriginal people only doing things when they feel the need, then there may be very different sets of priorities at play here. For health practitioners though, this is often seen as the ultimate offence, not only to themselves, but also to the systems they work within. However, in my study there were very few people who actively reported that they felt that way themselves; it was generally stories of other colleagues who had expressed such frustrations. For health practitioners who did not take offence at this practice, it was more a matter of this becoming a problem for other patients. Some felt that it was very important that Aboriginal people fit into appointment systems, so that others were not inconvenienced.

I find this argument unconvincing from practitioners and practices which actively set appointment schedules to double-book appointment spots, or book consultations so closely together that patients do not get a quality consultation. Patients often reported feeling rushed in health care settings, where workers are required to work quickly and efficiently for a number of reasons. For example, the demand for service often outstrips the ability to provide service (due to staff shortages). Outputs need to be high to justify existing funding arrangements or (in the case of private practices) turn over as much profit as possible in a short time.

I return to the example, discussed in Chapter 7 and in Chapter 8, of the Aboriginal Medical Service personnel who had a part of their day set aside to see walk-in patients who did not have appointments. This was highly effective for them, and meant that patients who really needed care got it, regardless of the appointment book. Many people told me of Aboriginal patients who had missed appointments and who then did not receive treatment when they did turn up, having to rebook and wait for the next available time. For some patients, this was a frequent occurrence.

9.3.7. A lack of understanding of separate systems.

It was clear to some practitioners that their patients did not have an adequate understanding of separate systems in their lives. Some reported patients asking them about things like checking

their health records in distant locations, checking on welfare payments, bank account details and other information that the practitioners simply did not have access to as discussed earlier in Chapter 8 (section 8.3.1, interview with Kimberley (page 165) provides a pertinent example). This may be one of the observations that led practitioners to discuss the need for multipurpose services for Aboriginal patients. Multipurpose facilities which include health and social service agents have been trialled in some Aboriginal Medical Service settings, including in Mount Isa. Various government departments would send representatives down to the Aboriginal Medical Service on a set schedule, so that patients could conveniently access all of these services in a setting in which they felt comfortable.

9.3.8. A lack of health literacy and health systems literacy.

Health literacy is a specific phenomenon discussed by health practitioners in both formal and informal discussions. Health literacy and health systems literacy here refers to Aboriginal patients' knowledge about illnesses and diseases, disease processes, and the impacts that behavioural risk factors have on disease progression (Devitt and McMasters 1998a & 1998b, Reid 1983, Hamrosi et al 2006, Craig 2000).

One example of this in my interviews (Lydia, GP, Interview, October 2008): included:

> *I would like to think that the moment the children start school or prep, that there would be a time, ten minutes a day on health and from an early age discuss diabetes, heart disease, and...early in the simplest...early grades, so they get brainwashed that, when they are older, it's not a fault to conform and take medicine. I think you need to start at that level, because teenagers who are quite ill, don't conform. And they end up in hospital with diabetes...because I think for too long they've been allowed to get along with what they want to do themselves and we've removed ourselves from it, but I think it's got to be training in schools, and there's no doubt about it, when you're in school, and it gets drummed in everyday, it sinks in. So that, when they're older, they think, 'Oh I've learnt about that, yes...maybe I might conform'. ...But I still think it needs to be a simplistic thing about health. In fact, health should really almost be a subject. Not one for hours on end that stops them learning other things, but it should almost be a subject, and I think it's got to be a little bit daily, rather than weekly. Little and often? ...*

Another general practitioner took a different view, still related to education:

Sarah (Interview, October 2008): I don't think things are a compliance issue, I think things are an education issue. A lot of the times that people aren't (makes a gesture) 'compliant', or so called 'compliant', is when they don't understand. So, often times, if things aren't going the way you'd expect them to go, I think, as a doctor, you've got to stand back a little bit more and go, "Why isn't this happening?" And a lot of the times, it is because you haven't managed to explain yourself properly to patients.

Once again, issues of education came up, but in different ways to the previous interview. Here, compliance was a dirty word, one that did not really portray the truth of situations. Rather, it was seen as being the job of the practitioner to find adequate ways to communicate with patients, and to assist, not force, patients to make active decisions about their health.

Education for this practitioner was not about brainwashing, but about providing patients with information in ways that made sense to them, so that they could make far more informed decisions about their care. And an acknowledgement that often this care is ongoing, and constant, requiring decisions at different stages. Ultimately, it was a difference of practitioners being able to force someone to comply with their advice, and providing patients with enough information to make their own choices, and at times that were appropriate and successful for the patient, not necessarily for the practitioner.

I would argue that most of the Aboriginal people I spoke with had a reasonable layperson understanding of the illness processes that they saw most often in their community, and understood well the impacts that particular behaviours had on their health. This was particularly so among elders, who were often counselling younger people on what they should do to improve not only their health, but their life in general and their opportunities for a better life. Some Aboriginal people have an intimate knowledge and understanding of the processes of disease, often because they are living through it.

There have been many successful programs developed that integrate Aboriginal and biomedical knowledge to create a shared space for better communication (most notably the "Sharing true Stories" initiative in the Northern Territory - Lowell et al. 2005), without compromising either system of knowledge. However, in most of the health practitioner interviews I conducted, it was

believed that biomedical knowledge on disease causation, progression and treatment was required to be taught to Aboriginal patients to improve their health. So many initiatives supported by successive governments have placed emphasis on risk factor behaviour (including the adaptation of 'Lifescripts', as discussed further in Chapter 10), that it is starting to become trite. Aboriginal people generally understand the link between behaviours deemed risky and their health status. A more important emphasis lies in encouraging and enabling people to cease these behaviours at their pace, and supporting cessation or reduction that is truly useful.

9.3.9. One location, many services.

Many practitioners saw the need for services to be located centrally to assist their Aboriginal patients. For some this was directly related to issues of transportation – it was believed that it would be easier for those with limited transportation options to visit one location and get all of their business done, than expect them to run around all over town (especially for health care services). For some it was an issue of cultural appropriateness – it was deemed that this kind of arrangement made Aboriginal people feel more comfortable and less confused or victimised by bureaucracies. The latter was generally the case for those health professionals who had practiced in AMS settings or discreet Aboriginal communities previously.

9.4. Initial Conclusions.

It is important to acknowledge that while access barriers may be the same or similar across cultural boundaries, the experiences and implications of these barriers are often quite different based on a person's class, race, socioeconomic status, history, attitudes, values, obligations and capacities. Interesting points to note in the examples provided (Table 4) are the different ways that concerns of Aboriginal patients are framed. Aboriginal patients, families and communities discussed concepts intimately tied to people and their relationships with each other. By contrast, health professionals often dealt with issues in a more practical, task-based fashion, focusing on the 'things you should/not do' when dealing with Aboriginal patients.

Issues of respect were discussed by Aboriginal people at a conceptual and interpersonal level, while many health professionals believed the most obvious way to show respect was to hang Aboriginal artworks in their practice settings[52]. Although artwork is a signifier of a potential respectful relationship, demonstrating at least an awareness of Aboriginal culture and the significance of stories that artwork tell, it is not the first and last step in creating a trusting and respectful relationship between patients and practitioners.

The classic tale of Aboriginal people not turning up for appointments is still used to justify and demonstrate the 'stark' contrast between Australian Indigenous and non-Indigenous cultures: the differences in concepts of time and the values placed upon it. It is used as a subtle way to blame Aboriginal people for the state of their health, and cast them as the villains in their own downfall. While some local services have managed to find ways around this issue (e.g. open door policy for certain times of the day), others cannot fathom running a practice without a schedule and appointments. Many practitioners maintain an appointment schedule because it suits the needs of the majority of their patients. And, just as Aboriginal and Torres Strait Islander people have the right to choose which practices they attend, so practitioners have the right to decide how they run their businesses. Appointment schedules should not become a way to create blame or false attributions.

A language of non-compliance with treatment regimes is still evident in many of the interviews I conducted, and this too is used by some practitioners as evidence of the 'fact' that Aboriginal people simply do not care enough about their health. In the minds and practices of some health practitioners, Aboriginal people constitute a "problematic and marginal market segment" (Andrews et al. 2002). Culture is often said to be the culprit here. In the minds of some, Aboriginal people

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[52] I do not wish to suggest that practitioners were under the illusion that this was the penultimate way to create comfort at a service, but it was the most obvious choice to begin such conversations for all non-Indigenous practitioners. The reality of their practice situations and the interview data presented here from non-Indigenous health professionals does suggest a much more complex situation.

just have different values that mean that they prioritise the wrong things in life, and health is one of those things. Of course, we also need to acknowledge that our health care system is a reflection of larger, mainstream culture in its own right. Biomedicine is based largely on Western values around morality and mortality and reflects a system of beliefs and values that determine what constitutes illness, how it occurs and how the sick are treated in Western societies (Baer 2008). Bearing this in mind, and the intimate sociality of everyday Aboriginal lives, it is not surprising that relationships of trust and respect feature so heavily in Aboriginal narratives about health. Even in narratives about health care experiences in the biomedical system, these relationships are paramount. The ways that people relate to each other, in the kinship sense and in everyday, mundane interactions, is crucial to understanding the ways that Aboriginal people navigate the health system.

Cultural differences do not have to be experienced as barriers, and in fact can be the source of inspiration for healthful pathways and many useful developments in health care programs and interventions. However, it seems that, for the most part, cultural differences are being characterised and experienced, in an everyday sense, as barriers to equitable health status for Aboriginal and Torres Strait Islander Australians.

Cultural barriers as discussed above and in the health literature (see Chapter 3) are related to specific codes of etiquette or ways of doing things, and also much larger social structures and experiences. It is culture that can inform the ways that we engage with each other and with the systems that humans create, through language, through shared histories, and the impacts such histories have on predicating future experiences. Perhaps when we discuss culture in health literature, we should more rightly discuss it as cultural difference, rather than as cultural barriers. This discussion of cultural difference must be located, "on multiple grids that enable us to see that connection and contiguity...vary considerably by factors such as class, gender, race, and sexuality, and are differentially available to those in different locations in the field of power" (Gupta and Ferguson 1992, p.20). Or, as Brady (1994) and Austin Broos (2011) highlight, in discussions of

cultural difference it is critical to ensure that Aboriginal culture does not become further reified as fixed and unchanging, but rather is represented by a dynamic fluidity shared by the changing representations of culture all over the world.

There are plenty of instances provided in previous chapters (but particularly in Chapters 7 and 8) that lend themselves to the creation of an exotic, ancient, immovable Aboriginal cultural identity, one which fails to acknowledge the flexibility of contemporary Aboriginal cultures. This identity has been co-created within Australia through dialogue between Indigenous and non-Indigenous which has been co-opted and politicised by the State.

The process of politicisation of a culture is determined by the ways that a minority culture interacts with a majority culture over time. Susan Wright (1998, p.7) 'treat(s) the prominence of 'culture'…as itself a cultural phenomenon', and demonstrates a three-stage process of contested meaning-making.

According to Wright (1998, p.7), the first stage in politicisation is to redefine key symbols in order to create an ideology, that is, to take a strong cultural symbol and recreate its meaning and use. The second stage is the institutionalisation of this ideology, moving ideas into 'non-agentive' spaces. At the second stage, the ideology may provide or generate new guidelines for engagement and policy that filter down to institutional practices. The third stage is the normalisation of the ideology, such that these new institutionalised beliefs become the basis for lay understandings of the world.

Once the ideology, through institutional practices, begins to shape the everyday values, perceptions and categories of human lives, the process is complete. Importantly, as Wright points out, at its most secure an ideology appears hegemonic (Wright 1998, p.9). Because institutions and traditional values are at the heart of every culture, members are incited to defend them – and, to defend one's culture from the attack of people 'not of one's own kind' is seen as a legitimate self-defence.

Wright's argument about the politicisation of culture in Britain has resonance with the ways that local Aboriginal people (and others) experience their culture in Australia. Wright discusses three avenues of appropriation and politicisation of culture in Britain. British right wing politicians took up the culture rhetoric in the 1990s to 'talk about nationalism in such a way that they can distance themselves from the taints of biological racism, yet reintroduce exclusive practices in an insidious cultural guise' (Wright 1998, p.7).

In this context the key symbol that has been redefined (repeatedly) is the Aborigine. Aboriginal people and their cultural identity are key symbols in the Australian consciousness (Kapferer 1998; Povinelli 2002). This symbol has been subject to official redefinition time and again over the past 220 years, in a process of politicisation.

Recent interpretations of Australia's colonial past include Aboriginal perspectives and shared histories of violence that were previously portrayed in very different ways. In past histories, Aboriginal people were largely absent from accounts of colonisation, and where they were present were given only token attention, usually treated as a hostile, unknown 'other' that frontiersmen and women battled against, or (less often) worked with in harmonious ways. However, for the most part, Aboriginal people became somewhat synonymous with the natural environment – often framed as hostile, savage and in need of taming (Blainey 1970; Clark 1996; for an analysis of such representations, see McGregor 1997).

These kinds of historical account have flavoured more recent debates about the new interpretations and presentations of Australia's history, and have caused much division in academic and lay circles. The accounts of historians, such as Noel Loos (1982), Henry Reynolds (1995, 1996, 2000), Dawn May (1994) and Russell McGregor (1997 and 2011), provide evidence of the intimately violent encounters of Aboriginal peoples and settlers in colonial contexts, but also emphasise the positive (although largely unequal) relationships that were often fostered by Aboriginal people and frontiersmen and women (Reynolds 1995, 1996, 2000; McGregor 1997).

This is opposed to historical interpretations which downplay the extent of violence in frontier encounters and maintain that the 'black armband' view of history furthers contemporary attempts at creating collective guilt in the majority population (see Windshuttle 2002).

Ultimately, debates about historical accuracy and the utilisation of historical accounts may, at its core, be a representation of Australian processes of nationalism and the ability of those who feel they have a firm place as citizens of Australia to make claims about the cultural 'other'. Kapferer (1998) refers to white Australian nationalism as Anzac nationalism, a nationalism that arose 'within the egalitarian ideology of those First World War Australian soldiers who inspired the tradition of Anzac' and whose 'egalitarianism has been integral in the development of racial intolerance and in the structure of state violence' in Australia. This is an egalitarian ideal that does not tolerate difference. In order for everyone to be considered equal, or treated equally, all people need to be the same. Any expression or assertion of difference is taken to be an offence to this egalitarian ideal (see also Pedersen et al. 2006). In terms of how this relates to non-Indigenous imaginings of Aboriginal identities, Kapferer (1998, p.142) asserts that:

> In recent decades Australian Aboriginals have virtually become symbolic archetypes of the unity of space-land, environment-time. In this white imagination, the Aboriginal concept of the Dreamtime has received particular focus...non-Aboriginal Australian ideas of the Dreamtime are born of the magical thought of a modern Western nationalism. Such ideas have nothing to do with the Aboriginal concept and are mystical in the sense that the Aboriginal's is not.

Morris and Lattas (2010) provide a discussion of the ways that Aboriginal people in the Northern Territory, Queensland and Western Australia have been constructed around the ideals critiqued by Kapferer above. The experience (or opinions) of non-Indigenous Australians regarding Aboriginal existence are predicated on the creation of Aboriginal people as a discourse community, often made 'real' via stereotypes and sweeping generalisations about a traditional mythical past or a wretched mundane present. Ethnographic works long considered out of date have been recently resurrected to recreate Aboriginality anew. In the case of the Northern Territory, this recreation was based on debates about the moral nature of supposedly 'culturally-embedded practices' that may have led to instances of child neglect or abuse in the Northern Territory. The Emergency

Intervention in the Northern Territory has once again opened the chasm of moral divide in Australia over Aboriginal lives, often without considering the social, cultural and political realities of contemporary Aboriginal communities.

Given the history of oppression and intervention that Aboriginal people have experienced in Australia, it is hardly surprising that there is a degree of cynicism among Aboriginal people that changes in legislation over time have had consequent changes in everyday lives: most Aboriginal people have lived through many of the recent policy and legislative changes to their recognition as citizens of Australia and their value as a community in a multicultural society. Many Aboriginal people still feel they are overtly and unnecessarily subjects of state surveillance despite changes in legislation that mean they can now live somewhat free lives.

Smith (2008) observed over years of fieldwork that many Aboriginal people express frustrations at 'still living under the Act'. The government act they are referring to began with the *Aboriginal Protection and Restriction of the Sale of Opium Act (QLD)* (1897) which saw many revisions and amendments until it was finally repealed in 1965. The Act placed restrictions on virtually all facets of Aboriginal lives, including restrictions on residence (confined to special government-run Reservations and banned from towns), movement and travel, control over virtually all rights such as marriage, asset management, guardianship of children, and seeking employment outside of the reserves/missions. Smith (2008) asserts that when Aboriginal people express the opinion that they are "still living under the Act", they are separating the state from their everyday lives in a familiar yet false way. Increasingly the state is not fundamentally separate from Aboriginal life-worlds (if it can ever be claimed to have been truly separate from Aboriginal life-worlds since colonisation), yet rather an intimate part of everyday Aboriginal lives.

Smith (2008, p.202) explains that this assertion by Aboriginal people implies that these effects stem from a state understood as fundamentally disconnected from Aboriginal life-worlds[53]:

> The fact that Aborigines continue to identify as members of a particular culture distinct from settler society cannot simply be taken as a successful resistance to assimilation in either cultural or social terms. Rather, in the current context, identity lies at the heart of the existence of the state in relation to Aboriginal subjects, not least through the way identity is configured within 'the practiced constitution of experience' (Austin-Broos...) – that is, through the interweaving of identity and subjectivity.

Smith (2008, p.202) goes on to discuss the reversal of this argument, acknowledging that Aboriginal life-worlds are distinct from the mainstream and the state identities present within Australia, and this has led to an increasingly complex Aboriginal cultural subjectivity.

There are (at least) two sides to claims of difference in Aboriginal affairs. Whilst difference can be a celebration of cultural diversity and survival, it can also function as an act of exclusion (asserting that cultural knowledge and Aboriginal culture are something only to be truly known by Aboriginal people). This assertion further mystifies Aboriginal cultural practices. And when for so many years, Aboriginality in Australia has been characterised by non-Indigenous Australians as a homogenous pan-Aboriginal culture, where practices have been represented as expressions of an homogenous nationality of sorts, there is a danger that this kind of pan-Aboriginal identity becomes institutionalised and normalised, politicised and legislated. This in turn fosters further hostilities, as Aboriginal peoples in Australia struggle to assert the differences among language groups and regions, while non-Indigenous Australians are content to accept a pan-Aboriginal ideal that simplifies encounters with the Aboriginal other (Povinelli 2002).

Povinelli (2002) asserts that Australia as a nation celebrates 'indigenous tradition' by reducing it to essentialisms: "To be truly Aboriginal, indigenous persons must not only occupy a place in a semiotically determined social space, they must also identify with, desire to communicate…and, to some satisfactory degree, lament the loss of the ancient customs that define(d) their difference"

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[53] Perhaps it could be said that the Lifescripts adaptation was the State's expression of an understanding which is fundamentally yet problematically disconnected from Aboriginal life-worlds.

(Povinelli 2002, p.48). This celebration is embodied in policy and legislation while the suspicion of authenticity remains.

Sutton asserts that there has been an "over-structuration of indigenous ill-health and de-emphasising of indigenous agency" (Sutton 2005). This was discussed by Kowal and Paradies, in their analysis of a workshop dealing with race, racism and culture, which was offered to Indigenous Health researchers. As stated in their report (Kowal and Paradies 2003, p.25):

> …it became clear that participants were uncomfortable with attributing causes of health inequalities to the agency or 'choices' of Indigenous people. They had to be encouraged to come up with the majority of reasons in the 'individual/behaviour' category. And among the seven reasons…that were not "politically incorrect" were tongue-twisters like 'wanting to share in a non-healthful behaviour identity'. This laborious phrase indicates the lengths to which we have to go in order to feel comfortable with the fact that Indigenous people may freely make 'morally-unsound' decisions.

This reluctance is a symptom of the 'bind' that non-Indigenous (especially white) researchers experience in attempting to reconcile their place (and their right to a place) within Indigenous Health. The need for many to establish a moral similarity between themselves and Indigenous research subjects is the only (very tentative) thing keeping them from being different to the 'helpful others' that had come before them, the only thing that separated their practice from those seeking to assimilate Aboriginal people with mainstream society (Lea 2005, Kowal 2011).

And yet, this very notion is assimilationist – an assumption that we would all do the same things in the same circumstances, the assumption that we all want the same things, including a vaguely-defined 'good health status', is the same assumption that prevents challenges to contemporary health interventions and programs. The real challenge to be considered is not whether we should provide more or better interventions in Indigenous health, but whether we should provide interventions *at all*.

In her article: '*From Bedtime to On Time: Why many Aboriginal people don't especially like participating in Western institutions'* (2006), Victoria Burbank takes a slightly different angle to most, by asserting that we need to start moving beyond examining culture as a phenomenon of

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individual or collective belief and practice, to consider the mindful place of culture in cognition –
where culture is understood as a motivational factor, a "...motivational force that either facilitates
or obstructs productive engagement with forms of living in this world" (Burbank 2006, p.3).
Burbank focuses on Aboriginal interactions with the institutions of 'school' and 'work', and utilises
theories of early childhood development in cognition to demonstrate the differences in how
Aboriginal and Western children are raised to be productive members of society.

Utilising theories of attachment and the early understandings of the self with others (the earliest
model of this is the self with family) Burbank shows how these theories can add an extra
dimension of understanding to interactions with institutions. The Western institutions of 'school'
and 'work' are modelled early in a western child's life, with the imposition of schedules and time
controls (like 'bedtime'). These early schedules set the tone for children to enter school and work
life, as children raised to best fit these systems. Burbank (2006, p.7) characterises these
institutions as 'impersonal':

> I would describe 'impersonality' as a focal characteristic of extra-familial Western
> institutions... The personal has little place within them, and personal feelings are not
> recognised, at least as legitimate reasons for action. The contrast that I draw here
> between personal and impersonal is perhaps the best evidence of this characteristic of
> Western culture, because persons, that is people, are a part of institutions, which do not
> exist apart from them. However, the permissible aspects of people in institutions or
> people as institutions...are parsed down to a very restricted version of who the person is.
> School and work are about doing a job, being on time, getting things done. At their core,
> they are not about how the people who function in them are feeling or getting on with
> their lives...that if the personal interferes with getting the job done, something must be
> done about the person(al). It must be changed or people must leave.

Burbank (2006, p.7) asserts that these institutions do not engage Aboriginal people because of a
fundamental "emotional incompatibility of the cultural self with a Western arrangement of others".
Part of this is due to being functional within different constraints: where Western schedules are
set by the external controlling force (parent or institution), in Aboriginal society feeling the need to
do something is more compelling, and is explained as the driving force behind the timing of
activities like hunting, eating, sharing and visiting (Burbank 2006).

Burbank expresses this as the 'sense of senselessness' Westerners often feel when watching Aboriginal people engage in Western activity. While Aboriginal people often see the point of doing something (work in the shop to get money to buy food) they often don't *feel* the point. It may feel good to work one day, but not the next, but the institution requires consistent attendance regardless of how one feels and thus engenders the sense of senselessness. The experience of schedule early on establishes our ability to function in settings that require schedule. It is the early production of people who fit in to the schedules of life that allows Western children less dissonance in the transition of knowledge transference from self with family, to self with other. And, according to Burbank this may be one of the reasons that Aboriginal people do not particularly like engaging with Western institutions.

Summary.

Chapter 9 presents further evidence of a discourse regarding cultural barriers to health care as expressed in discussions with Aboriginal and Torres Strait Islander people and with health professionals in Mount Isa. The analysis of comments from these interviews is situated within the local context using fieldwork observations for triangulation. By examining these phenomena separately to the aspects presented in chapters 7 and 8, this chapter allows for further insights to be generated regarding a discourse of cultural difference in health care. By exploring the everyday narratives of cultural barriers in Mount Isa, it became evident that some of the issues attributed to culture were instead better represented as social and structural issues tied up in a confused rhetoric of cultural difference.

As per earlier discussions regarding the Mindful Bodies approach (Scheper-Hughes and Lock 1987), it is important to explore the everyday narratives of individuals in efforts to illuminate the broader society and culture of which individuals are a part. While earlier chapters contributed to a rendering of the social and cultural realities of Mount Isa as a site, through embodiment, narrative

and observations of illness and health care experiences, this chapter seeks to expand upon and elaborate constructions of a discourse of culture and its place within health care in Mount Isa.

This chapter sought to unpack the concepts hidden behind the label of culture, to assess whether this was the most appropriate and effective way of categorising the problems that people face in accessing health care. By separating culture from social and structural confines, it was evident that some of the barriers identified as being specifically related to Aboriginal culture were more likely social indicators of Aboriginality or related to structures within the health care system that could be altered to revolutionise Aboriginal experiences of health care. It is important to identify social structures separately to other social issues, due to the ways that people could specifically identify structural violence and failures in the systems of health care, but also in order that these concerns may become the site of advocacy for system-challenging (not merely system-correcting) praxis as per Singer's (1995) Critical Medical Anthropological framework.

Performing this deeper analysis of cultural barriers discussions demonstrates that culture was being employed in speech in ways that suggested a catch-all approach to issues of difference. While Aboriginal people discussed the ways in which their specifically cultural needs in health care settings were indeed different to the needs of other patients, health professionals would often discuss social indicators or stereotypes of Aboriginal beliefs or behaviours as being cultural. Some of the key differences between Aboriginal and health professionals' employment of the culture concept came down to a different set of expectations: where Aboriginal patients sought respectful and reciprocal relationships of trust and sharing with health care professionals, health care professionals were concerned with creating spaces of comfort, and therefore, of greater engagement with Aboriginal patients. While Aboriginal people could and did identify some important structural points of difference as being the problem of inadequate systems, health professionals (whilst recognising the same basic set of structural concerns) discussed these as being a deficit in Aboriginal understandings of complex health systems.

Some of the disruption in these narratives could be explained by a shared reliance on Cultural Awareness Training as a solution to differences in understanding. Both Aboriginal people and health care professionals strongly asserted that programs of CAT needed to be provided in order to minimise the gap in understandings between Indigenous and Non-Indigenous people. However, CAT in many of its mainstream forms may not be the most appropriate way to facilitate conversations regarding cultural difference. Beside the paucity of data to suggest that CAT actually has any real effect on the health outcomes of Aboriginal people, it may also be detrimental in moving discussions of Aboriginal health beyond ethnic categories of understanding; many CAT courses rely upon social indicators of Aboriginal health status to predicate discussions of the differential need for health care. While this is not an unacceptable way to start conversations about Aboriginal health, it is possible that this preoccupation may lead to conflation of social indicators to culture (where Aboriginal people are wholly identified as cultural).

Chapter 10 discusses the recent history of Aboriginal Health policy and furthers considerations of the politicisation of Aboriginal cultures in Australia. This politicisation often approaches construction of a pan-Aboriginality that is variously taken up to blame Aboriginal people for the state of their health as a collective, or as an empowering use of white guilt to achieve change for Aboriginal peoples. Recent developments in Aboriginal Health policy are also discussed to determine whether these policies will be able to achieve the kind of changes that need to occur to create health equity between Indigenous and non-Indigenous populations in Australia.

Chapter 10

The body politic – Access and Aboriginal Health Policy.

> *The key question is not "What is policy?" but rather, "What do people do in the name of policy?"*
>
> *Wedel, Shore, Feldman and Lathrop 2005, p.35.*
>
> *...healing and change is a* process *not merely a strategy.*
>
> *Phillips 2003.*

Previous chapters discussed access barriers to health care facing Aboriginal and Torres Strait Islander peoples in Mount Isa. This included discussion of some of the relevant policy initiatives. In this chapter I focus on how major Aboriginal Health policies have contributed (or not) to solutions to access issues. The way that everyday praxis is informed by policy and vice versa is an obvious example of the ways that power relations intimately impact upon everyday lives, and the ways that agents of the State (in this case, health professionals) enact or rework policy directives to fit everyday circumstances.

The content of two key Indigenous health policies (State and Federal policies) and the exploration of a national brief intervention strategy tailored for use with Aboriginal and Torres Strait Islander patients are indicative of the interplay between policy and the mundane world. This chapter addresses the medico-moral and culturalist stances (Seidel and Vidal 1997) present in current debates on Aboriginal Health, specifically focusing on debates between the individual responsibilities for health versus the social determinants of health approaches. This chapter will consider the current literature in the anthropology of public policy, including guiding statements from the work of Shore and Wright (1997), Seidel and Vidal (1997), and Singer and Castro (2004).

The National Aboriginal Health Strategy and its partner document the National Aboriginal and Torres Strait Islander Framework for Health policy are guiding policy documents from the 1980s and 1990s that are still relevant in current debates. These policies were developed at a federal level and have set the tone for state policies to deal with issues specific to state jurisdictions. From Queensland, I will examine the 1994 Aboriginal and Torres Strait Islander Health policy, which still holds currency in Queensland Health today and has formed the basis for many more recent policies of the department. In particular, it is important to consider these documents as directives to action that concern improving access to mainstream health care services for Aboriginal and Torres Strait Islander people. Importantly, it is cultural difference that has been the focus of both of these policies, and of the Lifescripts adaptation discussed toward the end of the chapter.

10.1. What is policy and what do people do in the name of policy?

Policy is generally referred to as a set of "…official guidelines implemented by a social institution to set direction for action" (Singer and Castro 2004, p.xi). Singer and Castro (2004, p.xi) refer to health policy as "…both codified guidelines relative to health…or health-programmatic actions that reflect either codified guidelines or what is often referred to as 'unstated policy' ".

In the case of this chapter, when I discuss policy I refer specifically to artefacts of policy, or the policy document. However, policy can also be the act of putting policy into practice, the art of creating action from seeming inaction and rhetoric, and the ways that people construct themselves and the social relations that tie them together. Policies, in the ways that Shore and Wright (1997) discuss them, are the instruments (documents, ideologies, guidelines for action) by which governing bodies seek to exert control over those governed.

Policy has become an intimate part of modern states and "now impinges on all areas of life so that it is virtually impossible to ignore or escape its influence" (Shore and Wright 1997, p.4). According

to Shore and Wright, policy plays many roles, but two of the crucial elements include policy as political technologies of the self and policy as the neutral guideline:

> …policy increasingly shapes the ways that individuals construct themselves as subjects…From the cradle to the grave people are classified, shaped and ordered according to policies, but they may have little consciousness of or control over the processes at work. (Shore and Wright 1997, p.4)

In the vein of Foucaultian notions of political technologies[54], expert knowledge is employed by governing bodies in a process of increasing surveillance, which ends with the individual constituting "themselves in terms of norms through which they are governed so that although imposed on individuals, once internalized, influence them to think, feel and act in certain ways" (Lukes 1985, p.15). Ultimately this appears to give agency to those governed bodies while simultaneously exerting tighter controls over them. As Shore and Wright (1997, p.9) note:

> Such 'techniques of self', involving the self-regulating capacities of subjects 'normalised' through the powers of expertise, have become key resources for modern forms of government and have established crucial conditions for governing in a liberal democratic way…Liberalism renders its subjects 'governable' by requiring that they become self-activating and free agents.

To achieve this, policy is framed by language that appears to be value-free, neutral, scientific and legal-rational. It is this language that creates a space for policies to be viewed as "mere instruments for promoting efficiency and effectiveness" (Shore and Wright 1997, p.8).

Policy then can be a reflection of styles and systems of governance, where governance is also a reflection of reconfigurations of relationships between the individual and society (Shore and Wright 1997, p.4). This is true of Aboriginal Health policy (and many other policies related to Aboriginal affairs): Aboriginal Health Policy examined historically represents a partial reflection of the changes in styles of governance of Aboriginal people in Australia. It also reflects changes in moral values relating to Aboriginality and the relationship of Aboriginal peoples (individuals and collectives) to

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[54]Foucault defined political technologies as the ways in which power conceals its own functionality, its own operation, and this is a key element of modern power (1977).

broader Australian society. It is possible to note changes in political discourse and often consequent changes in public debates, through an analysis of policy statements.

Aldrich (2007) discusses the changes in political discourses across successive governments in Australia from 1972 to 2001. In Australia, politics has been dominated by a two-party preferred system, and governments have been formed primarily around these two major party lines: the Labor Party (social democrat) and the Liberal/National Party Coalition (conservative). The period under study for Aldrich (2007) saw changes from the Labor Whitlam government (1972-1975), to the Fraser Liberal Government (1975-1983), the Hawke/Keating Labor government (1983-1996) and the Howard Liberal government (1996-2007, but the Aldrich study only considered up to end of 2001)[55].

Aldrich (2007, p.128) discovered four significant discourses which were common to all administrations, but expressed very differently, reflecting political persuasion. These were: competence and capacity, control and responsibility, the "other", and the "problem". Further to this, Aldrich (2007, p.128) finds that the Labor administrations featured a discourse theme of social justice, while the Liberal coalition featured one of progress through pragmatism.

> Politicians' frames within the four continuous discourses changed with each change of government. For example, while the politicians of each administration communicated that Aboriginal and Torres Strait Islander Peoples were 'not like us', this characterization was framed differently: from being exotic and positively different (Whitlam and Hawke/Keating administrations), to being not like 'us' but that if 'they' let go of 'their' ambitions and symbols 'they' could be (Howard Administration). (Aldrich 2007, p.128)

The examples provided in this chapter all demonstrate this trend. Table 5 is adapted from Aldrich (2007, p.133) and demonstrates the ways in which successive governments framed their arguments about Aboriginal Health and Affairs policies.

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[55] Aldrich notes that within the period of her study, there were only 16 years of social democratic government in Australia from 1949 to 2001.

Table 5. Political discourses regarding Aboriginal and Torres Strait Islander peoples 1972-2001.

Discourse	Social Democratic frame	Conservative frame
Competence and capacity	Assumed – Aboriginal people will have knowledge and be able to contribute to building competence and capacity for their needs	Not assumed, needs proving
Control and responsibility	Promoting self-determination	Promoting self-management with government direction
Problem	Structural – solutions require government-driven system change	Individual (solutions require individual behavior change)
Other	Recognised ancient, difference valued	Difference a problem, solved by becoming 'us'

(Adapted from Aldrich 2007, p.13)

The election of the Rudd Labor government in 2007 saw the end of twelve years of consecutive conservative government, under the same political leader. While Rudd's leadership signaled a return to social justice approaches to governance, like previous Labor governments, it can take a long time to challenge the views established after a twelve year conservative reign. Arguably the large margin by which Rudd won power indicated that Australians were ready for a change in governance, and Aboriginal affairs played a leading role in the Rudd campaign. The most obvious signs of a return to social justice was the official Apology offered by Rudd on behalf of the past and current governments to the 'Stolen Generation', a generation of Aboriginal people forcibly removed from their families in the attempt to assimilate them into mainstream Australian culture (from 1910 to 1970). The second was the signing of Australia to the United Nations Declaration of the Rights of Indigenous Peoples, which Howard had refused to do (United Nations 2007).

Importantly, it is critical to acknowledge that the discourses of politicians are simultaneously influencing and influenced by public opinion and debate. As Augoustinos et al. (2002, p.106)

assert, "[t]he privileged access to symbolic resources such as the media places political elites in a particularly powerful position to shape the parameters of public discourse and debate on social issues". Wetherell and Potter (1992) discuss similar issues in their book on discourses of racism in New Zealand. They describe a set of rhetorically self-sufficient arguments that can be used in flexible ways to construct a version of liberal accountability beyond reproach:

> Resources should be used productively and in a cost-effective manner; nobody should be compelled; everybody should be treated equally; you cannot turn the clock backwards; present generations cannot be blamed for the mistakes of past generations; injustices should be righted; everybody can succeed if they try hard enough; minority opinion should not carry more weight than majority opinion; we live in the twentieth century; you have to be practical. (Wetherell and Potter 1992, p.177)

The construction of Aboriginal identities and Aboriginal health policy have in part come from the testimony of expert others, who by attesting to Aboriginal practices and beliefs have co-constructed the ways by which the governing state has kept watch over Aboriginal bodies.

10.2. Entitled to Aspire: Aboriginal Health Policy.

While there have been many policies devoted to Aboriginal health in Australia, this section will discuss two pertinent examples: the 1989 National Aboriginal Health Strategy, and the 1994 Queensland Health Aboriginal and Torres Strait Islander Health Policy.

10.2.1. 1989: The National Aboriginal Health Strategy (NAHS).

In the preface to the National Aboriginal Health Strategy (Office of Aboriginal and Torres Strait Islander Health 1989), John Newfong writes:

> …it has been found that it cannot be emphasised enough that not all Aboriginal communities are entirely traditional anymore, not all Aboriginal communities are the same, and that, because these communities do not conform to some arbitrary norm, there are no general standards that can be applied with any surety in the provision, or assessment of effectiveness of primary and preventative health care programs.

Upon reading the preface to the 1989 National Aboriginal Health Strategy (NAHS) document, one is left with little doubt about the pain and suffering that Aboriginal people were experiencing in 1989, one year after festivities celebrating the 200th Anniversary of the European colonisation of

Australia. This policy document represents the first real, concerted effort at creating a national strategy to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples in Australia.

This national strategy was designed as one of the first 'whole-of-government' approaches to addressing issues of disadvantage, inequity and poor health of Aboriginal peoples. The strategy was comprehensive. It addressed current health status, outlined commonwealth and state level responsibilities for health and called for the coordination of government responsibilities. The strategy identified problems with health services and infrastructure, including funding arrangements, as well as issues with training and education for Aboriginal people in the health sciences. It outlined specific health issues of concern in Aboriginal and Torres Strait Islander communities and called for inter-sectoral collaboration among governments and non-government organisations.

In the 1989 NAHS, there is a strong emphasis on the need for Aboriginal communities to be able to control their own destinies, including the delivery of health care to their communities. The need for community participation at all stages of program development and implementation is strongly advocated as the way forward for Aboriginal health. The report provides many examples of submissions from stakeholders about the need for increased Aboriginal participation and control over health for Aboriginal communities, but ultimately made the point (OATSIH 1989, p.xvi):

> In general, non-Aboriginal people recognised the need for more Aboriginal participation but were noticeably reserved when discussing the need for Aboriginal control. Many had little or no idea as to the implications of Aboriginal community control and were far too entrenched in the current health system, based on the medical model, to promote or contemplate an alternative.

The benefits of community control were outlined (OATSIH 1989, p.xvi):

> Communities become active participants rather than passive recipients, and the development processes that emerge allows from the design of structure to meet the specific health needs of Aboriginal people rather than attempting to "fit" Aboriginal people to the existing system. Community control rids the systems of paternalism, promotes awareness and raises self-esteem...the latter being crucial to the overall well being and health of Aboriginal communities.

The possible benefits of community participation and control according to the policy document included the prevention of covert and overt racism from non-Aboriginal staff working in Aboriginal health. It was argued that the employment of 'culturally acceptable staff' in community controlled health services would increase awareness (for non-Aboriginal people) of Aboriginal social and cultural milieu and would enhance community participation and control (OATSIH 1989). All of these aspects would, presumably greatly improve access to health care services for Aboriginal people. The development of culturally aware and acceptable services and staff was highlighted as a priority, and the use of such terms was about to become popular. The 1994 evaluation of the NAHS (OATSIH 1994) deemed that the strategy was never fully or effectively implemented by the Commonwealth government (despite the fact that the executive summary of the 1989 document also noted the lack of "co-ordinating mechanisms or a comprehensive data base to ensure and measure the success of such a strategy") (OATSIH 1994). In 2003, this was addressed with the design of a "National Strategic Framework for Aboriginal and Torres Strait Islander Health" (National Aboriginal and Torres Strait Islander Health Commission 2003), which built on the original strategy by adding frameworks for action, and evaluation tools and measurable outcomes. This was seen as a constructive step towards finding solutions for many of the issues raised in the initial strategy document.

The National Strategic Framework for Aboriginal and Torres Strait Islander Health (NSFATSIH) emphasised 'shared responsibilities' across government agencies (NSFATSIH 2003). The Framework observed a need for increased levels of health and infrastructure funding due to higher levels of need in Aboriginal and Torres Strait Islander populations. The framework also called for initiatives to improve Aboriginal and Torres Strait islander peoples' access to mainstream and Aboriginal and Torres Strait Islander specific services and programs. Improvements were suggested with regard to data collection and evaluation systems for these program innovations. The 2003 Framework does not supersede the original strategy, but functions as a complementary

document that is intended to advance the agendas of the original strategy document "within contemporary policy environments and planning structures" (NATSIHC 2003).

The 2003 NSFATSIH framework places the National Strategy's original agenda into contemporary policy contexts by creating consistencies with the new framework and The Council of Australian Governments' Reconciliation Framework (COAG 2000). The Reconciliation Framework calls for 'whole-of-government' and inter-sectoral coordination on many issues including community leadership and governance, health, and economic independence for Aboriginal and Torres Strait Islander communities. This is to be achieved through increased partnership between governments and communities to improve the "availability and quality of data" on these communities and their members.

The National Aboriginal Health Strategy and the National Framework have set the tone for further engagements with Aboriginal and Torres Strait Islander communities, especially with regard to their health status. The language of acceptability, availability, culturally appropriate or culturally acceptable services provision, all furthers the politicisation of Aboriginal and Torres Strait Islander identities. These two policies emphasise progress according to community defined need, by utilising extensive ongoing consultation at local, state and national levels and utilising increasingly accurate data from health care services.

10.2.2. 1994: The Queensland Health Aboriginal and Torres Strait Islander Health policy.

As stated in Chapter 2, the ABS predicts that the Queensland Indigenous population will be the fastest growing of all states in the coming years (to 2021). Therefore, it is imperative that Queensland Health service planning for the near future take this into account. However, this may be juxtaposed against the need to placate all Queensland taxpayers, who are the major stakeholders to whom governments are accountable (see Augoustinos et al. 2002, for the rhetorical self-sufficient arguments of 'everybody should be treated equally'; 'resources should be

used productively and in a cost-effective manner'; 'minority opinion should not carry more weight than majority opinion').

Queensland Health[56] developed its Aboriginal Health policy in 1994. The policy still holds currency in the organisation. The document requires examination, as it sets the tone for organisational responses to both state and federal government agendas, alongside the development of an organisation culture of respecting the specific cultural needs of Queensland Aboriginal and Torres Strait Islander populations. The Queensland Health Aboriginal and Torres Strait Islander Health Policy was designed after significant community and stakeholder consultations throughout the early 1990s. This document (Queensland Health 1994, p.3) confirms that Queensland Health "identified the health of Aboriginal and Torres Strait Islander people as its number one health priority".

The policy identified seven key areas 'for future action to improve the health of indigenous people' (Queensland Health 1994, p3). These key areas could be summarised as community control of, and participation in, culturally appropriate primary health care service provision. Another key area suggests a way forward for such an agenda: needs-based criteria for service provision and resource allocation. Overall, the policy aims to:

> …improve Aboriginal and Torres Strait Islander health so that the differences in health status between Aboriginal and Torres Strait Islander people and the rest of the Queensland population are eliminated. (Queensland Health 1994, p.3)

In the policy, there is a section that outlines Aboriginal and Torres Strait Islander community principles, which "present the views of Aboriginal and Torres Strait Islander people who attended a workshop held in June 1994" (Queensland Health 1994, p.8). In section 6.2.1, the Primary Health Care policy principle suggested by community members was: "That this policy reflects the primary health care philosophies that are bi-culturally determined for and by Aboriginal and Torres Strait

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[56] The State level health bureaucracy and organisation in Queensland

Islander communities themselves" (Queensland Health 1994, p.8). This principle demonstrates the relevance given to community consultations by government agencies.

While the community consultation process is a professed important part of policy and program development, often it is little more than a token gesture. In the case of this principle, the language is telling: philosophies that are bi-culturally determined *for* and *by* Aboriginal and Torres Strait Islander communities are effectively government-led philosophies developed *for* the Aboriginal and Torres Strait Islander community, that will need to be taken up *by* Aboriginal and Torres Strait Islander communities, in order to receive favourable funding and support for their services. And even though this list of principles was developed by the community, and takes pride of place as Section 6 of the document (of 8 sections), it has not necessarily informed the rest of the policy.

In the discussion of the key direction of community control of primary health care services, the document urges the need for Aboriginal and Torres Strait Islanders to "control their own destiny and exercise responsibility for decision making for health" (Queensland Health 1994, p.10). The extent to which Aboriginal and Torres Strait Islander people may truly have control over their own destinies (individual or collective) is questionable, given the long and continued history of heavy surveillance of their lives and their bodies. When, or even if, they have the opportunity to 'exercise responsibility for decision making for health' it is debatable whether or not their decisions will be respected by government departments responsible for service delivery.

In the case of this policy though, these ideas of control and responsibility are the framework for increased participation and control over health service planning and provision by Aboriginal and Torres Strait islander communities. The policy does acknowledge that by giving control to local Aboriginal and Torres Strait Islander communities to determine their own health care provision, and by providing "…resources to empower Aboriginal and Torres Strait Islander communities to make decisions regarding the efficient management and effective delivery of primary health care

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services targeting specific community needs" (Queensland Health 1994, p.11), that health status indicators should improve.

The goals stated in the section on community control include empowering Aboriginal and Torres Strait Islander people to determine their own primary health care priorities. This is facilitated by assistance to develop and manage their own health services. Further, there is an expectation that these services would be extended to give better access to Aboriginal and Torres Strait Islander people throughout Queensland (Queensland Health 1994, p.11). Government-supported empowerment toward these goals is facilitated in a number of ways.

In some cases, local community-controlled services are assisted by Queensland Health towards these goals. For example, in 2007 when the local (Mount Isa) AMS held its annual 'flu day' to provide the local Aboriginal community with free access to influenza immunisations, Queensland Health provided the vaccines to the AMS free of charge. When the local AMS was the Mount Isa Aboriginal and Torres Strait Islander Health Service, the Executive Officer discussed with me how many of the benefits that flowed from Queensland Health at a local level were negotiated at that local and regional level, and were often personnel dependent, meaning that when people changed jobs or left town, any negotiations or arrangements that she had been discussing would often have to begin again. It is questionable whether this approach is truly empowering to the local community. However, support (whether in-kind support or in the creation of shared positions or knowledge) was both offered and sought. This is often the first step in a productive health care arrangement for the local community.

With regard to developing and managing community-controlled health services, there are institutions to assist in these processes, including the Queensland Aboriginal and Islander Health Council (QAIHC) in Queensland. However, as was the case with the local AMS, sometimes these processes of empowerment simply fail. In the case of the local AMS (see case study in Chapter 7) this led to a great deal of upheaval and change to health care provision for a community of people

who could least afford to suffer through the changes wrought by the federal government. But, there is a counter-argument that suggests that, had the federal government not taken charge, this same community would have suffered through a decline in service delivery standards.

Of course, this also presumes that the Queensland Aboriginal and Torres Strait Islander 'community' discussed in this document knows or is in a position to determine what is needed to improve their health status. Such policies may be interpreted as an attempt to divert blame to communities if health does not improve. If communities are responsible for setting their own health agendas, and are then funded based on need[57], ultimately it is those communities that would be held accountable if these interventions fail. The question remains: who would be lauded if these interventions succeed?

One of the fundamental concepts in this policy is that of 'culturally appropriate service provision'. Culturally appropriate health service provision in this policy is defined as services "…provided in forms, structures, settings and languages which local Aboriginal and Torres Strait Islander communities can identify and which they will utilise" (Queensland Health 1994, p.11). There are significant challenges with this, especially in service delivery settings that were built before the policy was drawn up. Some facilities and the settings within them will never be considered 'culturally appropriate' nor be meaningful for the local Aboriginal and Torres Strait Islander communities they serve. Some facilities have negative historical significance or associations for communities, posing significant challenges to altering such perceptions.

The policy also acknowledges the need for flexibility around cultural protocols, practices and needs of individual communities in development of health programs and services. One of the goals is to "increase the awareness of Queensland Health staff about Aboriginal and Torres Strait Islander cultures and communities, and the implications of these for the planning and delivery of health services" (Queensland Health 1994, p.12). Queensland Health does provide staff with a fairly

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[57] Needs which are ultimately defined by the State Government.

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comprehensive online cultural awareness training package. Queensland Health also allows staff to participate in externally-run cultural awareness training sessions. However, there is little to no mention of ongoing cultural awareness training or mentorship.

Effective cultural awareness training requires a commitment to ongoing development and learning (Morgan 2010, Trudgen 2004). Some Queensland Health staff reported less than favourable encounters with Aboriginal patients, and took the opportunity of talking with me as a way of de-briefing. The same can be said on the side of the local Aboriginal community, some of whom discussed their encounters with 'racist' or 'rude' Queensland Health staff. This may indicate that, whilst there is a good resource available for initial cultural awareness training, it may be underutilised, undervalued and may not be properly supported as a career-long learning objective. Alternatively, this could suggest that cultural awareness programs do not work as intended or achieve the intended outcomes, as per discussions in Chapter 9.

The next objective in the policy is related to "Needs based criteria for service provision and resource allocation" (Queensland Health 1994, p.12). As the policy states:

> Consistent with working towards self-determination, and participation in health decision making, these needs and the criteria to establish them must be determined in cooperation with Queensland Health, its Regional Health Authorities and Aboriginal and Torres Strait Islander communities…
>
> The Resource Allocation Formula which determines the direction for allocation of global funds to Regional Health Authorities provides a positive adjustment for the proportion of Aboriginal and Torres Strait Islander people living in a particular region. Funding is allocated according to the health needs of populations, as indicated by mortality and morbidity ratios (Queensland Health 1994, p.12).

Ultimately, Queensland Health as the state organisation has the final say on allocation and the needs of a community. There are two goals that relate to this – one discusses the development of "service delivery models and best practice standards for the provision of health care to Aboriginal and Torres Strait Islander people" (Queensland Health 1994, p.13); the other is the development and implementation of "processes by which the needs of Aboriginal and Torres Strait Islander communities can be determined, priorities agreed, and appropriate action taken by stakeholders at

a Regional level" (Queensland Health 1994, p.13). This is a good example of what Ball (1990, p.154) discusses in his work: "Political, ideologically-loaded decisions are choked by bureaucratic-administrative systems and attempts are made to displace issues of moral and cultural identity with the imperatives of administrative efficiency".

Arguably, the service delivery models, best practice standards and processes to determine needs will all be developed by Queensland Health for the communities they serve. While there may be an element of community engagement and consultation, these protocols and practices are standardised at the state level of Queensland Health, to in some way ensure accountability across sites, and parity across regions (and subsequently placate the majority of Queensland taxpayers). This does not necessarily equate with flexibility to deliver and develop health services and programs specifically for the needs of local or even regional communities.

The second goal of developing processes to determine need does not appear to support communities. Again, the first point of speculation is whether these 'processes' will be developed and implemented at state or regional levels. But more importantly, even if developed and implemented at the regional level, this will cause some confusion and discontent across many individual, unique and discreet Aboriginal communities who are competing for funds. While Queensland Health employees may recognise the differences between Aboriginal communities at a local level, bureaucratic procedure may inhibit the ability to narrow the resource allocation formula adequately enough to really deal with localised differences.

Despite what is said throughout the document about communities setting their own health priorities, the Resource Allocation formula relies on morbidity and mortality ratios as indicators to determine funding. This measurement reduces the impact and importance that communities can have over setting priorities for health.

In the Health Systems Review of 2005 (Forster 2005), there are a number of sections dealing with resource allocation, including a section on increasing involvement of clinicians in resource

allocation and budget decisions. In this section, the report states that many clinicians across the State desired more involvement in budgeting and resource allocation within Queensland Health. Physicians perceived that "service delivery priorities which had been established did not match where they considered there to be greatest need, and were unsure of the decision making process" (Forster 2005, p.96). This is a possible indication of incongruence between the resource allocation formulas used at a state level, and the needs as identified at a regional and even local health service delivery level. The report also found that the funding allocations based on a regional allocation formula "shows an inequitable allocation of resources across the districts, particularly in high growth areas" (Forster 2005, p.21). The report also noted that "District budgets are not automatically adjusted to reflect changing demand or community expectations" (Forster 2005, p.21).

In this case, Queensland Health said all the right things – 'empowerment', 'self-determination', 'participation' and 'community control' are all frequently featured in Aboriginal health policy documents. And for good reason; these concepts represent many hard-won battles by Aboriginal people over the course of the last 220 years. But they can also be words that hide the true power relations at play – despite Queensland Health's professed desire to empower Aboriginal communities to adhere to these outcomes, such initiatives may effectively become a case of cost- and or blame-shifting to the communities who are least able to bear the burden.

The Executive Summary of the Queensland Health Systems Review Final Report 2005 (Forster 2005) contained the following recommendations and statements:

> Some structures and initiatives to improve the quality and safety of health services are in place but the infrastructure and an organisation culture that foster commitment to service improvement and patient safety are *only in formative stages* [my emphasis]. (Forster 2005, p.xi)

> …Priorities for performance monitoring have focused largely on budget integrity, inpatient activity and waiting lists at the expense of giving attention to patient outcomes, population health and quality and safety. (Forster 2005, p.xi)

While the centralised and hierarchical organisational structure (with many layers of decision making and loss of appropriate accountability and authority throughout) may in fact be partly a response to some of these challenges, it has also contributed to the frustration experienced by many staff and patients on a day to day basis. In this environment, organisational culture has taken on quite negative characteristics as evidenced by reports of bullying and intimidatory behaviour when seeking to deliver patient care in a resource constrained environment. (Forster 2005, p.xi)

The organisational culture of Queensland Health took a battering in this review. However the above points, alongside many others, indicate that Queensland Health as an organisation and bureaucratic structure was in need of an overhaul. The report notes that patient safety measures are only in the formative stages, priorities for measuring performance are not patient-centric; basically the system was assessed as flawed in this review, due mainly to unnecessary bureaucratic complexity:

Queensland Health's services are currently provided through a network of 37 Health Service Districts, the Mater public hospitals and statewide services supported by three Zones and a large corporate office…Queensland Health has a bureaucratic mechanistic structure characterised by highly centralised formal authority and hierarchical layers of decision making and separate directorates which do not support a responsive, integrated and efficient health system. A key problem with the structure relates to bottlenecks in decision making particularly as the position of Senior Executive Director of Health Services is responsible for more than 80 percent of the department's resources. This slowed down the flow of information and the capacity of the organisation to implement new policy or respond to service delivery pressures. (Forster 2005, p.xiii)

According to the Queensland Health website, last updated in 2010 (Queensland Health 2010), it currently operates fifteen Health Service Districts; in 2005 there were thirty-seven Health Service Districts (Forster 2005), in 2007 there were twenty (Queensland Government 2007). The constant nature of system reform and revision creates confusion not only for consumers but also for staff, in trying to keep up with changes in jurisdictions and classifications especially regarding who is in charge of what and to who each staff member reports.

In response to the Forster (2005) report, Queensland Health released an Action Plan in October 2005, outlining details of how they would work toward better health for all Queenslanders. The action plan was designed to "drive reform" (Queensland Government 2007), while the Queensland Health Strategic Plan 2007-2012 contains four strategic directions, two of which align directly with

the Queensland Statewide Health Services Plan 2007-2012: "improving access to safe and sustainable services", and "better meeting need across the health continuum" (Queensland Government 2007).

In the Statewide Health Services plan, it is recognised that the north-west region of Queensland will only account for approximately two percent of the total population growth in Queensland which is a justifiable reason for Queensland Health to invest less resources in this region. It is also recognised that, if this is the plan, the reform will need to "improve networks between the public sector, the private sector and non-government organisations, including Aboriginal and Torres Strait Islander-specific organisations, and (to) identify ways to deliver services through effective partnership arrangements" (Queensland Government 2007, p.7).

There is a section in the Statewide Health Services Plan devoted to access to services for Aboriginal and Torres Strait Islander peoples, which asserts that "Cultural barriers reduce access to mainstream services for Aboriginal and Torres Strait Islander peoples and there is limited capacity (due to geographic, workforce and resource constraints) to provide Aboriginal and Torres Strait Islander-specific health services in all regions of the state" (Queensland Government 2007, p.7). Besides the fact that, once again, the concept of 'cultural barrier' is not defined, there are other inconsistencies across this statement. The majority of Aboriginal and Torres Strait Islander-specific services are provided by Queensland Health in their provision of community health services so these kinds of programs are already accounted for and delivered. Improved partnerships of the kind alluded to earlier in the Statewide plan document might help to combat such issues. This statement also appears to contradict the proclamation in the 1994 Aboriginal and Torres Strait Islander Health Policy, that Aboriginal health is Queensland Health's number one identified priority.

These policy documents make statements about ways forward for the improved health of Australia's Indigenous peoples, which are clearly predicated on increased cultural awareness through training sessions for non-Indigenous health staff. Cross-cultural communication and

cultural awareness training are doubtless issues for consideration and open up spaces for innovation and improvement. And this has been identified not just at the policy level, but by managers and health staff working at a grass roots level. However, whether policy has influenced opinion on this, or vice versa, is debatable. However, theories relating to policy translation may provide some insight into this third phase of politicisation.

Garvin and Eyles (1997) use the case study of scientific discoveries (and uncertainties) regarding the relationship between ozone depletion, ultra-violet (UV) radiation and skin cancer, and how these discoveries were transformed in public health messages in Canada. They (Garvin and Eyles 1997, p.48) assert:

> The action-oriented nature of health policy means that values are necessarily embedded because all action is based on underlying values...in this way, environmental health problems approach Torgerson's (1986) 'third face' of policy making, where the relationship between science, politics and policy making is not necessarily antagonistic. Instead the relationship is symbiotic – a necessary requirement for solving broad problems that are beyond the scope of narrow, technocratic problem solving methods of rational science.

Torgerson's (1986, p.34) discussion of the three faces of policy analysis regards the changing nature of policy through time. The first face of policy was an Enlightenment phase, where public policy was seen as the saviour of the human social condition, whereby the natural sciences would provide evidence of the best way forward, beyond the conflict of everyday politics. The second face regards the fall of this utopian vision of policy making, into a dysutopian world of 'dark foreboding', where policy cannot be accepted without question, and a sense of political neutrality in policy is rendered impossible (Torgerson 1986, pp.37-38). The third face of policy we "glimpse the potential for a relationship in which politics and knowledge are no longer deadly antagonists" (Torgerson 1986, p.39). In this phase, an analyst "must develop not only a knowledge *of* society, but also a knowledge *in* society" (Torgerson 1986, p.40), and the shift is to a post-positivist position in science and policy making. It brings the expert and non-expert closer together, through community consultation and in the ways that experts now lay bare their "frailty and fallibility" in understanding human affairs (Torgerson 1986, p.51).

Indeed, experts take care not to mystify non-experts, and the citizenry guards against mystification. In the communication between expert and citizen, each seeks to identify points where the boundary between expertise and common sense becomes fluid and indistinct; each seeks, that is, to expand the domain in which active participation can educate a broad range of the population for a rational consideration of both specific policies and general social directions (Torgerson 1986, p.51).

As Garvin and Eyles (1997, p.48) point out, in contrast to the above, the uncertainties that have accompanied shifts in scientific philosophies have created a conundrum for policy that is solved with the advent of public health policy statements. These statements take uncertain evidence and create a consensus of moral direction (Garvin and Eyles 1997, p.48):

With the move from absolute proof to persuasion and argumentation, concern in the sun safety metanarrative is concurrently shifted from the less-certain, scientific and medical realm into the more-certain public health message advocating individual control. By shifting responsibility, science is released from its burden of absolute proof and the problem instead becomes an issue of action, values and morality. The result is a public health message that resonate with what the public 'knows' – the importance of individual responsibility and the moral certitude of acting 'right' to prevent skin cancer.

In this model of policy creation, which according to Garvin and Eyles (1997, p.49) "resonates with a message that links back to a traditional European heritage", public health issues are framed as a narrative of morality, whereby "humankind acts in ignorance, falls from grace, and is redeemed through the collective pursuit of 'proper' and 'moral' decisions and through the appropriate execution of the power of free will". In this way, practice is critical to the success of policy to create a moral baseline for behaviour and attitudes toward environmental health issues.

In Australia, the translation of policy into health practice is a driving discourse in current health care research. This was put into action through Commonwealth Government initiatives such as the Primary Health Care Research, Evaluation and Development (PHCRED) program from 2001 to 2011 and institutions such as the Primary Health Care Research and Information Service (PHCRIS) and the Australian Primary Health Care Research Institute (APHCRI). The enactment of the ideals contained in policy documents by agents of the State is a critical step in ensuring full cycles of surveillance and control. Aboriginality adds an interesting dimension to such translations, which directly challenges accepted conventions of how health interventions should work.

Aboriginal identities are wholly 'othered'[58] in the processes of such translation. There is a common assumption in the development of health care initiatives and translations of health policy that Aboriginal and Torres Strait Islander populations require significantly different planning for successful deliveries. While it is important for difference to be acknowledged and accounted for, there is little requirement for such recognition to transform into the 'othering' described by Vidal and Seidel (1997 – see footnote below).

Aboriginal people, Torres Strait Islanders, majority populations and Australian Governments have together created the discourse community that is the 'Aboriginal and Torres Strait Islander population'. While this is predicated on ethnicity, it is more often constructed on the basis of shared cultural heritage (despite the obvious issues of difference between Aboriginal cultures and Torres Strait Islander cultures) alongside recognition of origins and historical circumstance. Like all discourse communities, it entails an ongoing, constant reiteration and re-establishment of the 'selves' of Aboriginal and Torres Strait Islander peoples, within the group membership, by themselves in reference to others, and by others in reference to them.

The co-creation of a discourse community of Aboriginal and Torres Strait Islander peoples (where both Indigenous and non-Indigenous actors have interacted constantly creating new meanings of Aboriginality, see McGregor 2011 for recent discussion of such events) has led to the establishment of specific health care programs and initiatives designed to improve life expectancy and overall health status for Aboriginal and Torres Strait Islander Australians. However, there are two important statements to add to this assertion. The first concerns the creation of the 'Aboriginal *and* Torres Strait Islander' community. This is largely an historical creation of the State, a way of defining and limiting Aboriginal and Torres Strait Islander peoples into a manageable, distinct population group, which has become an acceptable 'discourse community' among non-

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[58]Seidel and Vidal (1997) discuss the process of 'othering' as an act of wholly associating individuals or groups of individuals with their culture, often setting this in opposition to a majority culture. This leads to the construction of minority cultures as 'other' and often as problematically different.

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Indigenous Australians, and has varying degrees of acceptability among Aboriginal peoples and Torres Strait Islanders. Many Aboriginal people and Torres Strait Islanders used this discourse community as the opportunity to forge a kind of 'advocacy coalition' (Sabatier 1988, p.139) to advance the rights of their people in the face of adverse conditions, while others still see this as an unacceptable ethnic aggregation which seeks to minimise differences between these cultural groups.

The creation of such a community harks to similar experiences of both Aboriginal and Torres Strait Islander peoples of colonial conditions and dispossession of lands. Despite variation of experience and the variation of the outcomes, these shared experiences have created a common dialogue between Aboriginal people, Torres Strait Islanders and the Australian State. This common dialogue does not diminish the fact that Torres Strait Islander culture and Aboriginal cultures are distinct cultural milieus.

The second statement is of course that, the Aboriginal and Torres Strait Islander community's discursive practice "generates communities of identity and authenticates their presence" (Kapferer 1995, p.70). As Kapferer (1995, p.70) notes, "It is integral to their 'registration' within the bureaucratic order of the state". The ways that the Aboriginal and Torres Strait Islander communities have created and asserted their identities (as a collective and as distinct cultural entities) have influenced the ways that policies regarding their realities are written. These policies in turn have had significant influences on the ways that non-Indigenous Australians understand and engage with Aboriginal and Torres Strait Islander peoples.

The following section is a case study of fieldwork experience concerning my participation in the adaptation of a national health initiative specifically for use with Aboriginal and Torres Strait islander peoples. The health initiative, called Lifescripts, is a lifestyle risk factor intervention, which assists in the prevention or management of chronic disease. This case study examines the ways that I, as an anthropologist and health researcher, have acted as an agent of the state, as part of

my professional work. It exemplifies some of the content discussed above; particularly the adaptations of a mainstream health initiative for use with a cultural other. The case study begins by describing the public health context that was being created globally with regard to the management of lifestyle risk factors that contribute to chronic disease burdens around the world. I also describe some elements of the consultation and redesign processes that could be interpreted as continuing the process of othering, but is usually interpreted as incorporating specifically 'Aboriginal' or 'indigenous' perspectives into the development process.

10.3. Lifescripts: Policy into Practice.

The World Health Organisation developed a 'global strategy for the prevention and control of non-communicable diseases' in 2004. The WHO has been working towards a goal of prevention and elimination of the major modifiable risk factors for diseases such as diabetes, cardiovascular diseases and cancers. These risk factors have been identified by the WHO as "elevated consumption of energy-dense, nutrient-poor foods that are high in fat, sugar and salt; reduced levels of physical activity at home, at school, at work and for recreation and transport; and use of tobacco" (WHO 2004, 57.17). These risk factors, along with harmful use of alcohol (WHO 2004, 57.16) have been targeted by partner nations for the past decade and put under the increased management of agents of the state in attempts to improve health and reduce the need and cost of health service provision.

In the fifty-seventh resolution (WHO 2004, 57.17) a point is made that is important to bear in mind when considering the actions of nations: "Variations in risk levels and related health outcomes among the population are attributed, in part, to the variability in timing and intensity of economic, demographic and social changes at national and global levels"[59]. Many of the associated WHO documents and resolutions dealing with these issues identify changing patterns of

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[59] It is important to note here that the WHO does NOT attribute blame to cultural difference nor refer to cultural barriers in this document.

consumption and living as associated with rises in cancer, heart disease, mental illness, stroke, and obesity.

Epidemiology provides these agendas with the discourse of 'risk factors' (Kindig 2007) and traditionally and formally define this concept quite broadly, incorporating elements of environmental exposure. However, according to Kindig (2007, p.150), the term is most commonly used in reference to individual level (rather than population level) behavioural and lifestyle factors that may contribute to disease/health status. Kindig (2007) maintains that there is uncertainty regarding the causality of risk factors, which has led to further debate and clumsy refinements of 'primary' risk factors (which are considered to be causal factors in disease processes).

Last (2001) further developed the risk factor discourse by examining what became known as 'modifiable' risk factors, which appear to be those behaviours which Lalonde (1974) would characterise as self-imposed individual level lifestyle choices (Frohlich and Potvin 2008, p.216). These included activities such as tobacco consumption, 'excessive' alcohol consumption and lack of physical activity. Lalonde (1974) recommended that population health activity focus attention on segments of the population which demonstrated the highest level of risk exposure, as indicated through engagement in health risk behaviours or in biological markers (which according to Frohlich and Potvin (2008, p.216) was based on sound evidence from longitudinal studies of morbidity and mortality)(Lalonde 1974, Frohlich and Potvin 2008). This approach has been extensively critiqued, and yet seems to hold some degree of sway over current practices. Part of the Australian response to the WHO-identified issues includes the Lifescripts package (DoHA 2008). Lifescripts is a brief intervention tool developed by a consortium of researchers and promoted by the Australian General Practice Network on behalf of the Commonwealth Department of Health and Ageing. Lifescripts resources assist general practitioners to deliver key health promotion messages to clients exhibiting risky lifestyle-related behaviours that could have serious consequences for their long-term health status, particularly in the realm of chronic disease. The original mainstream Lifescripts resources were developed in 2005, and were reviewed in 2009.

The mainstream Lifescripts kit[60] comprised resources that separately address each of 5 lifestyle risk factors for chronic disease covering smoking cessation, alcohol use, nutrition, physical activity and healthy weight management. For each risk factor there was a set of resources: A prescription pad (one for each factor), a generic Lifescripts methodology card (which outlined the 5As process of Ask Assess Advise Assist Arrange), a methodology card with information specific to each risk factor (national guidelines), and a training manual which provided information on how practitioners might incorporate this kit into their consultations. There was also a marketing kit which contained a brochure, poster, and waiting room checklist which would assist patients to identify pertinent risk factors in their lives that they wished to discuss with their practitioner.

The original kit was designed primarily for use with mainstream general practice audiences, but the Department of Health and Ageing had received feedback from a number of Aboriginal and Torres Strait Islander primary health care organisations suggesting that the kit required further refinement for use in their service settings. These services also indicated that Aboriginal and Torres Strait Islander Health Workers would be best placed to deliver these messages and interventions. Therefore the resources needed to be more user-friendly for Aboriginal and Torres Strait Islander patients and communities, and for Health Workers.

Adaptation of the original set for use with Aboriginal and Torres Strait Islander patients went to national tender in 2007, and MICRRH won the tender process, beginning work in 2008. The Department of Health and Ageing had specifically stated the objective of this project as the adaptation of the lifestyle prescriptions and the 5A guidelines cards, for ease of use with Indigenous patients (Tender document). I was a member of the MICRRH team that conducted a series of consultations and testing to determine what needed to be changed in the original set to

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[60] This was the language used by our MICRRH research team regarding the original set of resources. This was how the research team made the distinction between the original resources and our adapted resources; the mainstream kit versus the Indigenous (or adapted) kit.

make it more culturally acceptable for Aboriginal and Torres Strait Islander patients (Reeve et al. 2008).

The results of the community and stakeholder consultations suggested a range of enhancements and changes to the original set which would make them more useful for Aboriginal and Torres Strait Islander patients. These enhancements included aesthetic and practical changes. Improvements were made to the colour scheme, using brighter tones and more white spaces. Text was adapted to plain language, with less text where possible. The textual improvements made the production of low-literacy resources for use with select patients easier. It also reduced the amount of paperwork in the kit. There was an obvious need to incorporate the stages of change model[61] present in many Indigenous health initiatives. It was also crucial to integrate this kit with existing health promotion activities and health checks.

The end result saw an adapted set which featured resources for patients with low literacy and standard literacy levels. There was a single script pad (now called a lifestyle action plan) for low literacy patients, while the Department of Health and Ageing insisted on maintaining five separate script pads for the standard literacy set. The single script sheet could be adapted to suit whichever risk factor was under consideration, and also allowed for patients tackling multiple risk factors to take one piece of paper home, not five separate pieces. The separate methodology cards had been turned into an A4-sized flipchart allowing practitioners to easily transport it for community visits and opened the process up to the possibility of group consultations. The flipchart also provided practitioners with the information they needed to deliver the brief intervention. The

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[61] According to Bunton et al. (2000), the stages of change model (also known as the transtheoretical model) has been popular in health promotion since the 1980s. The model converges elements of multiple theories of human behaviour change, and isolating common 'stages' of behaviour change. This created a process which allowed for stage-matched interventions to be developed, thus targeting those most likely to change. This supposed success, and the ease of teaching it to practitioners, led to its increased popularity. There is however, little evidence to support the success of the theory.

stages of change model used in the flipchart allowed patients to actively decide on their level of commitment to lifestyle changes.

As per Torgerson's (1986) predictions, community consultations have become a crucial element in liberal democratic governance in Australia, and are featured regularly in the development of many policies, but are deemed essential in matters of Indigenous Affairs. The contract for the adaptation stipulated community consultation as an essential element of the process. The MICRRH team believed the community and stakeholder consultations were highly important, and worked tirelessly to integrate the changes suggested by Aboriginal and Torres Strait Islander peoples and by health professionals. Members of the research team thus muted their role as experts, and laid bare their humanity in attempts to provide a space whereby community members could exercise their expertise of everyday experiences (Torgerson 1986).

The team actively resisted directives that sought to diminish these voices in the development of the adapted resources. The team recognised that, to some extent, this adaptation project was an attempt to exert greater control and surveillance of Indigenous bodies, through the medicalised framework of 'lifestyle risk factors'. The process of consultation with communities (as is often perceived to be the case when governments 'consult' with Aboriginal peoples) could have been little more than another token exercise, had the team allowed it. The importance the team ascribed to community voices was not always mutually recognised by the Department of Health and Ageing, who had their own reasons for resisting some of the changes. The issue of language use provides a pertinent example of the struggles that emerged during the adaptation process.

In Australia, The National Health and Medical Research Council (NHMRC) is responsible for developing national guidelines and advising the federal government on issues of health and wellbeing in the Australian population. Panels of experts create these evidence-based guidelines. The purpose of such guidelines is to guide health practitioners in their clinical decision-making. It was with regard to these guidelines that the team experienced the most protracted struggle.

In the original kit, the national guidelines for each risk factor were included in full on the 5A cards for practitioners and on the reverse of the prescription sheets for patients. These guidelines offer advice to practitioners on important information to transmit to patients, and for patients, offers helpful 'everyday' ways to change behaviours related to the risk factors.

The issue of appropriate language came to a head with the development of the single page low-literacy action plan. The team agreed with the department that the appropriate guidelines for each risk factor would be listed on the reverse of the plan. In their current form, these guidelines were simply too verbose to fit all five sets of guidelines on a single page, and still make them legible. The team's suggestion was to create 'plain language' versions of the national guidelines which would allow for the key messages to be relayed effectively to those with low literacy levels, and would also allow all five sets to be featured on the one page. This suggestion was resisted by two core reference group representatives.

Representatives from the Department of Health and Ageing and the Australian General Practice Network went on record as objecting to changes in the expression of the national guidelines. These representatives presented a number of reasons for their protest, including that these were nationally approved and sanctioned guidelines, and therefore should not be altered in any way, and that the guidelines featured on the scripts needed to provide consistency of message between practitioners and patients. The AGPN in particular insisted that the guidelines remain unaltered, as many General Practitioners had reported not feeling comfortable offering lifestyle advice to patients. There is some evidence to suggest that this is true. Swinburn et al. (1997) found that the majority of general practitioners are not comfortable or confident offering advice on lifestyle risk factor modification.

However, health promotion and education feature heavily in many of the streams of training for Aboriginal Health Workers. In many Aboriginal Primary Health Care settings, Aboriginal Health Workers would be the staff most likely to utilise these resources (as identified in the tender

documents for the project). This was the case according to feedback received by the Department from Aboriginal Health clinics around Australia as reaction to the release of the mainstream originals. Brady et al (2002) and Sibthorpe et al (2002) found that Aboriginal Health Workers often felt the least able to provide such services, due to a sense of being personally invasive whereas GPs were respected outsiders who may be seen to provide more objective (read perceptively less judgemental) advice in the case of brief interventions for alcohol misuse.

The testing period provided some insight into the views of general practitioners being asked to implement such resources and provide advice on lifestyle change. In discussions with the project leader, at least one practitioner described these activities as the domain of Health Workers, while others dismissed the effectiveness of such initiatives outright, blaming Aboriginal apathy for poor health status. This surprised the project leader, as some of these comments came from practitioners in Aboriginal Primary Health Care settings.

The Department of Health and Ageing is primarily responsible for the promotion and distribution of the adapted kit, and continue to make them available. Many general practices have taken up the original kit, and many others have instituted the adapted set to use in conjunction with Medicare items such as the Aboriginal Adult Health Check. However, this resource has not been widely promoted and thus may not be in comprehensive use. The Australian General Practice Network does not currently actively promote or provide the adapted set[62], leaving those who are interested to find the set on the Department of Health and Ageing website.

The adapted resources recently featured in a review of brief intervention tools, and were deemed highly successful due to the inclusion of evidence-based elements that have been proven effective, and in terms of readability, receiving consistently high scores (Clifford et al. 2010). This was also acknowledged in a recent New South Wales Divisions of General Practice meeting, where general

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[62] They were not charged with doing so by the Department, and so merely mention the existence of these resources with a link to the relevant page on the Department of Health and Ageing site.

practitioners reported using the adapted resources with all clients due to their increased readability and ease of comprehension (for themselves and for their patients). They argued that the newly-revised original resources were still far too academic in their language to be useful or meaningful to patients, and therefore would continue to use the adapted resources (NSWGP Lifescripts forum, pers. comms., April 2011).

I have no moral dilemma with the resource we created; in fact, I believe it to be a very useful and well-developed health promotion resource. However, this does not exempt it from critique. While there is evidence to suggest that the most effective strategy for health promotion activity is to aim it at the individual level, I feel it is important to acknowledge that this may not be the entire reason for creation and subsequent adaptation of the Lifescripts resources.

10.3.1. Lifescripts and the body politic.

Egocentric[63] lifestyle intervention is not only considered 'evidence-based practice' in many health promotion or intervention activities, it is also consistent with the outlook of a conservative government style, as outlined by Aldrich[64] (2007). Programs such as Lifescripts question the capacity and competence of Aboriginal people[65] to create good health, it promotes self-management under careful government direction, it depicts the solution to chronic disease as individual and requiring self-activating and free agents to make individual changes, and highlights difference as a problem which could be solved by having all people conduct their lives in a very particular way.

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[63] In the philosophical sense of being centred on the individual 'self' considering this to be the central hub of all experience.

[64] I do not mean this specifically in the ways that Aldrich discusses conservative government but rather in the ways that Foucault (1977) and Kapferer (1995, 1998) discuss conservative styles of modern democratic governance. However, in relation to the Aldrich paper's point, the Lifescripts initiative was developed under a conservative Howard-led Liberal Coalition Government, but has been continued under both Rudd and Gillard-led Labor Governments.

[65] In fact, the original program poses similar issues for non-Indigenous Australians as well. The development of Lifescripts resources translated for different language groups and for pregnant women suggests that there is little faith in the ability of the Australian public to create healthy ways of living without state intervention.

Resources such as Lifescripts are based on evidence of best practice in chronic disease management, and policy on chronic disease outcomes and management styles. However, success ultimately rests with the agents of the state who enact this policy, in this case health professionals. Ideally, these interventions should continually improve population health status with regard to 'lifestyle' related disease and (should) ultimately take pressure off an ever-dwindling health budget facing ever-increasing system demand.

In practice, however, these resources (both the original and adapted versions) are asking general practitioners to provide a level of health counselling (i.e. promotion) that they are often unfamiliar and uncomfortable with. These initiatives ask practitioners to know and apply concepts that (while one might expect a GP to know) they often do not know intimately or do not see this function as part of their role in patient care. Maintaining the official sanctified language of the national guidelines on each risk factor was to protect health practitioners from getting it wrong, and was an integral part of the process for offering advice and support for change. However, it seems that practitioners themselves much prefer plain language versions of the advice in practice, while having the official guidelines close for enhanced clarification.

The MICRRH team were acting as agents of the state in this case. We were taking an original resource and attempting to make it more culturally appropriate for Aboriginal and Torres Strait Islander peoples. We have (knowingly, I might add) contributed to the further official authentication of Aboriginality, through state-mediated and sanctioned operations. We assisted in the construction of Aboriginal and Torres Strait Islander voices in health rhetoric by completing this adaptation. And ultimately, we have succeeded in producing a health resource that is deemed to be successful with Aboriginal and Torres Strait Islander patients, and also with health practitioners. Some of these health practitioners, however, have taken the resource for use with *all* of their patients. If this is the course of action taken in practice, it is contestable whether our changes were truly addressing cultural issues specific to Aboriginal communities. Perhaps there are some

assumptions that need challenging when it comes to so called 'mainstream' populations and the development of health interventions.

In completing the adapted pieces, MICRRH has also contributed to the population health debate with regards to the appropriateness of 'lifestyle risk factor interventions'. Whether we agree that this is a viable and successful approach to health promotion and care or not, we have nonetheless produced resources which will further justify and reinforce the shift in blame for poor health to individuals, without necessarily addressing the socioeconomic and systemic features that may contribute to poor health in the lives of individuals. Nor does it negate the fact that such initiatives are an attempt to shift costs from an increasingly stressed health system back to communities and individuals. Perhaps the positive aspect of this project lies in being able to say that this resource was adapted for use with groups of Aboriginal people, in context. That is, by making the resource easily transportable, Aboriginal Health Workers can take it out to remote communities, and work with families and larger communities to reduce these 'lifestyle risk factors'.

It appeared to the team at the time of the resource adaptation that the ideals that underpinned the original set of resources, and indeed the original premise for state intervention on matters of modifiable lifestyle risk factors was remarkably similar to the sentiments of Lalonde (1974) regarding lifestyle factors as being self imposed and individual level choices. Rose (1992) challenges this idea, by asserting that contextual factors are critical in understanding the distribution of risk exposure, also pointing out that the majority of cases in a population "are represented by individuals with an average level of risk exposure" (Frohlich and Potvin 2008), while Link and Phelan (1995, 2005) assert that these risk factors are actually the expression of one's place in the social structure, or that there exist 'fundamental causes' which are risks that generate exposure to other risks (social and economic indicators like low income, low education levels, etc) (Frohlich and Potvin 2008, p.218).

However, the Lalonde (1974) theorisation appears to reflect the theories that the conservative government of the time of the Lifescripts development and adaptation held with regard to issues of chronic disease management and population health. This package, and way of approaching major health concerns, by focusing on the individual distracts practitioners and patients from the fundamental causes of ill health, including the social, political and environmental circumstances which may contribute heavily to health related behaviours and attitudes.

If the original premise for designing such a resources package was indeed the idea that individuals could modify risk factors such as smoking, drinking, poor nutrition and lack of physical activity due to these being a reflection of suboptimal life choices, then it is possible that the adaptation was also informed by this way of thinking. However, the adaptation allowed these fundamental causes a voice in the therapeutic process: by giving space to the practitioner to have conversations with patients regarding the kinds of goals they could achieve relative to their circumstances and contextual setting, the adaptation attempted to eschew attempts to blame individuals for factors which, while at first may appear to be individual choices, could actually be a reflection of social and structural limitations on their collective lives.

The Lifescripts case study presented here reflects strongly the principles elaborated by Torgerson (1986) in his "third face" of policy analysis, and reflects the "modern morality play" discussed by Garvin and Eyles (1997). The research team at MICRRH clearly took up the position of experts who sought knowledge of society, and knowledge in society (in this case, Aboriginal and Torres Strait Islander societies) in order to create an adapted product that more closely matched the needs of these populations, and to do so in a highly pragmatic, 'common sense' way so as to avoid mystification of non-experts. Alternatively, the communities that we consulted acted to safeguard against mystification, and heavily asserted their own expertise as people living through chronic illnesses and other conditions which might be amenable to the changes suggested by the Lifescripts program. The Lifescripts resources themselves, in whichever form, can be seen not only as political technologies but as the source for enacting redemptive behaviours in a modern

morality play in which no person (least of all an Aboriginal or Torres Strait Islander person) would knowingly make the 'wrong' choice with regard to smoking, nutrition, alcohol consumption, physical activity or weight control. Lifescripts is a perfect example of how science and policy making feed social action (Garvin and Eyles 1997, p.49), or may feed social dissonance (in this case modification to suit the circumstances which arise, as performed by the medical professionals who chose the adapted kit over the originals or translated versions for multicultural patients). The Lifescripts example thus also demonstrates the full cycle of the politicisation of Aboriginal culture and Aboriginal health discourse (Wright 1998). With the recognition of the need for consensus regarding Aboriginal attitudes toward health promotion activities (or the adaptation of current activities to suit Aboriginal peoples' proclivities), the government enacted relationships with researchers, to create a consensus position regarding the approach toward a thoroughly politicised population, wholly associated with its culture and in deemed to be in obvious need of moral direction for better health.

10.3.2. Additional Lifescripts adaptations and reification of Aboriginal 'other'.

There were concurrent developments and adaptations of the Lifescripts kit specifically for use with pregnant women, and translated kits (Italian, Greek, Vietnamese, Chinese, Arab). The pregnancy resources[66] have been developed for use with mainstream audiences (in keeping with the original kit). The translated pieces are wholly based on the originals, and there is no indication of testing to check the reliability or compatibility of these health promotion messages with target populations. This is another indication of how Aboriginal and Torres Strait Islander peoples have been 'othered' in Australia, wholly associated with their culture and perceived notions about Aboriginal everyday lives. As Trudgen (2004, p.157) states:

> There is great confusion out there. The dominant culture plans and implements, then waits for things to change – but nothing ever does! Could it be that the health programs

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[66] As at 18th March 2011, the Department of Health and Ageing had removed the pregnancy resources from their website, saying that these were 'out of date and under review'. The revised editions should be made available some time (exact timeframe not stated) in 2011.

set up to empower Aboriginal people are not understood by the very people they are designed to help?

Seidel and Vidal (1997, pp.72-3) provide a poignant argument with regards to failures of health interventions on cultural grounds:

> ...there is a problem with trying to account for the relative failures of health interventions on the grounds that they have encountered a 'cultural problem'...This is further sustained... by some researchers who are convinced that, if an argument is made out for culturally-based resistance, the problem has no solution. They argue that the reason is to be found in conceptions and health practices different from those developed in the industrialised countries. Conversely, an intellectual position that constantly harks back to 'African values' ignores people's capacity to change and underestimates the factors which do not explicitly derive from cultural tradition...This kind of analysis lends credence to the process of stigmatization and Othering, where the Other is totally identified with their culture.

Moral and political stances on Aboriginal Health status and access have been held over from previous moralistic and political stances about Aboriginal existence. Aboriginal people are alternately presented as problematically different or as valuably different by governments. Yet, they are always presented as a people that pose a problem to the health system, which ultimately needs to be fixed by the health system. Through the lens of many non-Indigenous people, ours is a health system that Aboriginal people are considered to be resistant to, evident in the different health concepts and practice taken from a traditional era of Aboriginal society. Aboriginal people are presented in a homogenous way, wholly identified with their culture, and classified as a high-risk group by health professionals and politicians. Notions of distinctly Aboriginal communities may also contribute to the process of othering, and thus have been easily integrated into the language of policy, as a means of creating a Pan-Aboriginal discourse community, able to be governed with little regard to differences between communities (see also Brady 1994).

The issue of responsibility for one's own health is a common medico-moral agenda pushed through health promotion and primary health care prevention activity, increasing individual responsibility for health care choices, even over aspects of life or lifestyle where there is no choice available (see Plate 11). Arguably, these policies and initiatives are also generated to reduce health spending as chronic illness increases. A shift in emphasis to individual responsibility over lifestyle and Primary

Health Care could ultimately be seen as a response to growing need versus dwindling health funding and resources (including workforce)[67]. This is not to suggest that such shifts are entirely without merit in practice, but the employment of such concepts strikes out at notions of culturally-embedded practices and Aboriginal identity as experienced by non-Indigenous others. This creates a problematic space of practice, where 'othering' becomes essential, and anthropologists are often asked to step in as consultants. As stated by Seidel and Vidal (1997, p.72):

> Anthropology is called upon to explain how a particular pathology has emerged in one group rather than another, and to account for the unwillingness to adopt prevention measures or other treatments which have proved effective elsewhere. This 'elsewhere' refers essentially to a different culture whose distinctive characteristics for adapting to medical advice have been helpful in avoiding, or in limiting, the extent of the illness in question. This leads to a dichotomy of societies, and hence of cultures – those which adapt, and those which resist the changes dictated by a health-promoting rationality. In both cases, this has given rise to the tendency to account for even minor conceptual and attitudinal differences towards a health problem by referring to cultural traits, which in most cases, are presented as immutable.

Throughout the policies discussed in this chapter, and evident in the adaptation brief for the Lifescripts program, the issue of cultural difference between Aboriginal and Torres Strait Islander peoples and the rest of the Australian public was a prominent feature. This cultural difference was often not incorporated into policy and practice in order to acknowledge and celebrate such diversity. It was often performed as an act of governance, an othering which, through health policy and practice (re)created an easily-governed Aboriginal community, whose differences were considered so stark as to need intervention. These issues will be highlighted in the discussion and conclusions presented in Chapter Eleven. The politicization of Aboriginal culture and 'lifestyle' are essential elements that run throughout this thesis, as was evident in discussions of cultural barriers (Chapter 9). The ongoing perpetuation of the concept of cultural difference as a barrier to good

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[67] This idea reminds me of a comment by Morris and Lattas (2010) referring to the Northern Territory Intervention: "Revealingly, the government has moved Indigenous people off community development work programs and onto welfare payments so they can become 'income managed'. When faced with a choice and a conflict between its own moral priorities, today's state, via its policies and practices, affirms the priority and transformative powers not of work but of keeping people in dependent tutelary states of surveillance".

health in the medical literature and the presentation of cultural difference as problematic in policy documents create tensions for health professionals and Aboriginal patients in an everyday sense.

Plate 12. A mission statement of hope: the welcome sign at JTHC, a culturally appropriate dry-out centre with temporary accommodation (Photo: Kristin McBain-Rigg).

Chapter 11

Conclusion: Indigenous Health is an opportunity, not a burden.

Health is dependent on conditions that enable people to live lives they would choose to live.

Marmot 2011, p.512.

Our interpretations (of Aboriginal identity as anthropologists) challenge a public opinion which, in rural Australia at least, is constructed around an aggressive hostility to Aboriginal difference which is seen as breaching the canons of populist egalitarianism. Only recently has the offer of formally equal status been extended to Aborigines; their subsequent assertion of a continuing difference is taken to be an insult.

Cowlishaw 1993, p.184.

Plate 13. Aggressive hostility: the Kalkadoon memorial west of Mount Isa, complete with bullet holes (Photo: Kristin McBain-Rigg).

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In this thesis, access barriers to health care facing Aboriginal and Torres Strait Islander peoples were documented and analyzed from 2007 to 2009. This was done by recording the stories and experiences of local Aboriginal and Torres Strait Islander peoples, health care professionals and members of the general population of the region.

A Critical Medical Anthropological framework was followed, influenced specifically by the Mindful Bodies approach of Scheper-Hughes and Lock (1987). This allowed examination of the issues via three bodies – the individual body, the social body, and the body politic. Also employed was the Penchansky and Thomas (1981) taxonomy, the 5As of Access. This taxonomy assisted in the analysis of data concerning accessibility of health care services in Mount Isa. The categories of availability, accessibility, affordability, accommodation and acceptability provided a means to tease out the finer details of access issues experienced locally, which also corresponded with national and international examples in health literature.

Mount Isa's residents are subject to the same conditions as people living in other rural and remote towns in Australia, but these conditions may be said to manifest in unique ways, as demonstrated in this research. For my research participants in Mount Isa, the main accessibility issues concerned travel, both within Mount Isa city and travel away for care that cannot be provided in Mount Isa. The cost of travel was raised as a significant factor related to accessibility, but it was also a key point raised in discussions of affordability. The specific issues of affordability related to private health cover versus using the public health care system, and whether Aboriginal people could afford to pay for the care they required.

Somewhat peripheral issues featured highly in discussions of accommodation. Most participants perceived that many of these issues were caused by high staff turnover, or periods of understaffing in services. Participants did not often attribute issues of accommodation to the failure of systems. This cannot, however, be considered as an indication of successful systems. Rather, it may be interpreted as the ultimate deception, where inadequacies in local structures of

practice are hidden behind the oft-identified problems that plague health care in remote communities all over Australia. Perhaps rural people are so very accustomed to the conditions of slow death (Berlant 2007) that they do not notice the impact that ineffectual systems can have in creating this slow death in the first place. Alternatively, perhaps participants in the health care system do not have sufficient exposure to the mechanization of these systems to understand or detect this as the key issue in practice accommodation. Health care providers did raise the problem of appointment systems that seemed to be failing with regard to Aboriginal clients, yet many could not conceptualise a way to fix this in a way that would significantly alter current systems of patient bookings.

Acceptability related to issues of patient/provider characteristics. My interviews indicate that differences in gender constructions and rules are an issue. It is however, important to note here the specifics of the Penchansky and Thomas (1981) definition which states that "…in the literature, the term [acceptability] appears to be used…to refer to specific consumer reaction to such provider attributes as age, sex, ethnicity…" etc. Confusions often begin here for many health practitioners; understanding the difference between ethnicity and culture.

Joralemon (2006) asserts this may be a fundamental problem (which also relates strongly to issues of cultural competency): there are times when 'ethnicity' becomes conflated or confused with 'culture'. In some health literature, ethnicity has been used interchangeably with the terms 'race' and 'culture', which inaccurately conflates these terms. Not only is the term 'race' and its variants still in folk use, but it is also, at times, privileged within medicine and other disciplines.

If race and ethnicity are often interchanged at will in medical literature, without a definition or explanation, what is the possibility that 'culture' could also be supplanted (inappropriately) in place of race? Substituting the word race with ethnicity and/or culture to avoid language that may be considered politically incorrect can lead to further confusion for medical practitioners attempting to

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be culturally competent. It is therefore pertinent to provide a separate discussion of what may be understood as 'culture' in the health literature on 'cultural barriers'.

My own examination of how people understand cultural barriers was achieved primarily through the analysis of interview data produced by key informants within the context of several years of field observations. Exploring the ways that health professionals and Aboriginal people conceive of access barriers and particularly cultural barriers, illuminates not only culturally specific issues, but also social and structural issues that impact upon access. While all themes discussed in Chapter 9 related to cultural phenomena, there were elements that, once subjected to such an analysis, seem far more amenable to change than they may have when presented as purely 'cultural'. Given the contemporary (and historical) propensity for government-driven intervention in Aboriginal lives, it is important to distinguish between what are culturally embedded phenomena, and what may have their origins elsewhere, before embarking on a mission of change for practitioners or patients.

There were many phenomena presented by informants as cultural in origin (see Chapter 9) but ultimately the chapter concluded with a call for a change in language from discussing cultural barriers to discussing cultural difference. Culture or cultural difference should not be seen as a 'barrier' or problem, but rather as an opportunity to engage and create new approaches in health care provision. A change in language may lead to a change in attitudes, and a change in practice (Duranti 2009).

Chapter 10 discussed Aboriginal health policies across time and government jurisdictions. In particular, this chapter elucidated the relationships between policy language and the politicization of Aboriginal culture in Australia. Policy contributes to the mystification of Aboriginal cultures in Australia by representing Aboriginal and Torres Strait Islander peoples as possessing a distinct culture which requires awareness by others, but does not encourage ongoing processes required to achieve an understanding of such cultures. Policy also frames Aboriginal and Torres Strait

Islander populations as being homogenous. In some instances, policy presents a pan-Aboriginal cultural group that appears to be without internal differences, all suffering the same injustices in the same ways. This not only reduces a diverse group of people to what is assumed to be a manageable whole, it also subtly seeks to simplify everyday encounters between agents of the State and a culturally-distinct 'other'. The vague and highly symbolic language of policy instead creates tensions and conflict in practice.

If, as is asserted in Chapter 4, there is indeed an affect of slow death (Berlant 2007) associated with rural, remote and Indigenous health issues in Australia, then the current discourse about cultural barriers to health care reinforces this, due in part to the co-construction of an undifferentiated Pan-Aboriginal identity discourse that is present in policy, literature and (at times) in everyday constructions of the state of Indigenous health. It is also a result of state institutional violence that continues to manifest itself in practice and everyday encounters. The concept of slow death (Berlant 2007) is pertinent in discussions of rural, remote and Indigenous health given the statistical evidence that is used to suggest that indeed these populations are physically deteriorating (Berlant 2009), which, is presented as a defining condition of their experience and historical existence (Berlant 2007). Berlant's (2007) concept of slow death is also pertinent given discussions in this thesis of the ways in which a discourse of culture in health is created within literature, practice and policy, and is then enacted through the actions of agents of the state. The discourse questions the capacity of these regions and populations to contribute in a meaningful way to the productive economic community of Australians. Rural and remote populations (and the Indigenous populations within) are continually exposed to processes which seek to attenuate them, physically and morally, minimising their contribution to the wealth of the country, and minimising their worth as sources of vital human capital in the nation's identity. These communities are variously cast as victims of distance, romanticised as a simpler existence, and reduced to a figure of relative population growth by the State government as a justification for discontinued funding in policies that focus on coastal and metropolitan growth potential.

Although it appears that 'slow death' (Berlant 2007) best captures the ongoing character of policy approaches to rural, remote and Indigenous health in Australia, these communities are not without hope. Within regional communities it is possible and is indeed tenable to grow the capacity of the local population toward better health outcomes. While it seems hopeless in situations where services are more often removed than instituted, differential models of service provision are emerging. In the north west, there has been a great deal of advocacy and testing of alternative models of health service and development of delegated roles, including trials for Physician Assistant models of care, and the development of rural generalist streams in medical education at regional universities such as James Cook University. These efforts could be seen as further ways of cutting the cost of providing adequate health services to the bush once again (not really changing, merely shifting focus), these are models that appear to suit the needs of many rural and remote communities. These models continue a long standing tradition of Remote Area Nursing practice and other models of sole practice. The trick appears to be in recruiting and retaining those who are truly suited to these roles, and the kinds of communities that need them.

As Diane Austin-Broos (2011) argues, Australians need to consider the value that rural, remote and Indigenous communities bring to the Australian social landscape. Is the discourse surrounding the cultural otherness represented strongly in Australia by a discourse that separates and identifies Aboriginal and Torres Strait Islander Australians as differently special (or especially different) in need of revision? Could it be that the reification of the culture concept in classical ethnography has itself contributed to creating a barrier to effective health care for Indigenous Australians?

In her book *A different inequality*, Austin Broos (2011) writes "on the side of cultural difference", but not the side that reifies notions of traditional Aboriginal society as the only viable way forward for Indigenous Australians. Regarding the clash of certain anthropological representations of difference and inequality with other representations of Aboriginal lifeworlds, she writes (2011, p.136):

Evidence cited for the anthropologist's position includes Aboriginal people's reluctance to migrate from their homelands, and the flowering of fine Aboriginal art. The latter confirms a sensibility that differs from that of other Australians. The former testifies to the importance of land rights and living remote. Moreover, remote elders often display knowledge, an aesthetic, and a delicacy of spirit that shouts an 'other' history of human experience. The evidence against the anthropologists' position is the suffering incurred by high mortality rates caused by lifestyle illness including diabetes, alcohol dependence, malnutrition, ischaemic heart disease, stroke and hypertension, respiratory infection, and kidney and liver disease. This epidemiology, in conjunction with personal violence and abuse, speaks to conflicting values in communities rather than simply to an 'other' culture. Aboriginal people living on homelands are struggling with different ways of being that are in substantial conflict. Moreover part of their distress is the product of poverty, experienced as such, and not simply the product of inferior services.

Austin Broos (2011) writes about this process of othering with regard to the arguments concerning mainstream education and the outstations created by Aboriginal Australians. In much the same ways that I have explored in this thesis, Austin Broos sees the construction of cultural difference in outstation communities as a construct of shared realities where mainstream society and culture cannot be simply separated by considering Aboriginal people as wholly other:

Rather, the difference I have in mind is more like a conundrum: intimate conflicts within communities and individuals that reflect different histories and forms of tradition. What these communities have in common is the reproduction of cultural difference in the context of marked inequality. The interlinked histories of this form of cultural difference reveal the ways in which law and economy, the state and capitalism, have shaped and sometimes torn apart the attempt at continuity. ...in the remote communities debate, a position that rendered cultural difference as bounded and reified – kin-based versus market-based society – also locked its adherents into a policy position that resisted labour market strategies, including mainstream education. Rather, the proposal was that community-based strategies alone could suffice for remote communities. Austin Broos (2011, p.136)

Whilst I am not discussing homeland communities, nor what could technically be referred to as bounded "remote encapsulated groups" per se, the position expressed by Austin Broos is germane in this region. The acquisition of land in this place was on the basis of the market – at first, the sights of a potentially rich yet rugged pastoral land in the region, followed by settlement on the basis of the discovery of great wealth in the land that required extraction and recreation as precious metals and minerals. The Aboriginal communities of this estate, were only incidentally included (differently valued for their special knowledge of the land, which in these circumstances proved economically valuable) or completely excluded from this history and development of riches,

and many lost their lives in attempts to defend it. Beyond this physical attenuation, the structural violence of the frontier continued; this time in the denial of the continued existence of the Kalkadoon people, the denigrated continuity of other Aboriginal groups in the region, and the creation of a history that denied the needs or rights of Aboriginal peoples in remote regions captured and conquered by the frontiersmen and women of our early shared history.

The development of health facilities and health systems in remote areas has been a history that furthered this sense of exclusion (with the occasional heroic narrative of those who sought to overcome such exclusions). In Mount Isa, along with many other remote communities burdened with economic richness, these systems and facilities were often designed to keep safe and well those who were most likely to be economically viable and sustaining – the workers who produced such riches for the young Australian economy, a capitalist society that defined sickness as the inability to work. If the economic pursuits of Aboriginal people could not be recognised as work, or productive work, then it follows that discourses of sickness and pathology would (and did) prevail in creating Aboriginal policies, when this finally became a policy priority/imperative.

In a more contemporary sense, though, Aboriginal communities face ongoing struggles to retain and strengthen their cultural difference, all the while being expected to find innovative ways of turning tradition into economic gain. Ultimately, Austin Broos (2011, p.140) advocates that it is critical that cultural difference be addressed "in order to move toward an equality of services" and admonishes an Australian public that "...was sufficiently indifferent not to notice that the issue of culture had been hijacked by pathology in league with idealised market solutions" in the development of the Northern Territory Intervention. It is possible to see the relationship with the development of health policy for Aboriginal people, and other marginalised groups in Australian society. These differences must be acknowledged for the complexities that they pose to policy creation and implementation.

Ultimately, in the debate regarding the Aboriginal remote communities, Austin Broos (2011, p.146)

asserts:

> The remote communities debate involved three failures. One was a failure to acknowledge cultural difference and the complexities it brings to policy concerning marginalisation. Another was a failure to acknowledge disadvantage incurred by marginalisation and the suffering it brings to those who wish to live remote. In the remote communities debate, anti-separatists by and large suppressed the issue of cultural difference and anthropologists by and large suppressed the issue of distress. Finally, those anthropologists who did acknowledge social suffering did so by pathologising difference and entirely averting their gaze from the issue of an economic base for remote communities.

In the creation of the discourse surrounding the viability of remote Indigenous Homeland

communities, Austin Broos uses primary education as a critical indicator of potential success. She

advocates that Aboriginal people who are living in these communities must be supported in

obtaining a mainstream primary level of education, in order that they may legitimately exist into

the future, but more critically than that, that they should be supported to receive this as a basic

right of citizenship.

> Generally, education in these terms is not seen as a radical politics. It becomes so in the context of contemporary ideas about efficient markets and the limited role of government in providing even basic services. These ideas have plagued discussions of remote communities along with the widespread view, promoted by the Intervention, that cultural difference as pathology is the cause of remote Aboriginal inequality. In short, an over-optimistic view of markets, a minimalist position on the state and a propensity to individualise and psychologise structural inequality while ignoring real differences have been hallmarks of the remote communities debate (Austin Broos 2011, p.166).

Health, like education, is also a basic right of citizenship, and while it can be costly to administer

health care in remote communities, this is a burden to be borne by governments and societies.

Certainly in Mount Isa, it would be hard to argue that the basic rights to health are not being

delivered. However, it is relatively easy to envisage a more efficient (in an economic and cultural

sense) way of operating. Fundamentally, the differences identified by health care providers and

Aboriginal people that were related to culture, concerned ways of conceptualising each other's

needs and capabilities. While Aboriginal people were asking for more respectful and engaged care

from their health care providers, the providers themselves were quite concerned with creating

environments that were comfortable to Aboriginal clients. Both are working toward the same ends, albeit going about it in slightly different ways.

Health care providers sought to minimise harm for Aboriginal patients by establishing environments that are familiar as clinical places but also engender culturally safe practices. These health professionals simultaneously hoped that this environmental change would lead to a 'cultural change' in staff attitudes and behaviours, further strengthening the culturally safe character of a clinical space. Meanwhile, Aboriginal people were advocating for more socially aware and engaged practitioners, who had the time and energy to invest in ongoing and meaningful health care *relationships* (not merely arrangements) with their Aboriginal patients. Although there was evidence to suggest that comfortable environments were important to Aboriginal peoples too, it was critical that staff and practitioners in clinical spaces were demonstrating their ability to care well for Aboriginal people (or at least show a propensity to do this). As the Lifescripts project demonstrated to our team, the changes for which Aboriginal and Torres Strait Islander people advocated most strongly were also the elements of the kit that led to practitioners using it more broadly, with patients of varying cultural and socioeconomic backgrounds. Additionally, as postulated by Peachey, McBain and Armstrong (2006), it is critical that we get care right for the most disengaged and disenfranchised in our society, as this will lead to truly lasting and innovative solutions to care for all Australians.

Many of the barriers uncovered through my research align with the international and national literature reviewed in Chapter 3. Given the location and particular population discussed, many of the barriers were expected; these barriers, or expressions of barriers, indicate that the local health system has not managed to avoid the issues that face minority populations the world over, but that some of them are managed differently in Mount Isa. There have been ongoing efforts by many non-government organizations, charities and government departments to make changes to

the ways that people access health care in Mount Isa, and even to the ways that health care is delivered in Mount Isa[68].

11.2. Recent Developments in Mount Isa.

Since the conclusion of my dedicated fieldwork period (2009), there have been a number of events of significance that have affected the delivery of health care to local Aboriginal and Torres Strait Islander peoples. Some of these have been mentioned throughout the thesis, including a change of board for the local Aboriginal Medical Service (Chapter 7), changes in staff and management in Queensland Health at the district and local level (Chapter 7), the global financial crisis that changed the shape of the housing market, and the announcement of new mining ventures throughout the region.

There has also been the development of the Optional Pathways clinic - a general practice-style clinic that adjoins the outpatients department and primarily acts as a feeder clinic for those presenting to the Emergency Department with category 4 or 5 presentations - at the Mount Isa Hospital (which is being upgraded). This has taken some pressure off emergency staff, but the Clinic has also suffered through changes in management and staffing arrangements.

Local Queensland Health staff have driven recent research and program development of culturally appropriate care and activities, including a local cultural walking trail to increase physical activity and local cultural awareness. Another program of potential significance is the development of a patient transfer "dillybag[69]". The dillybag contains information of cultural significance that travels with Aboriginal patients from remote regions to Mount Isa, Townsville and Brisbane, for the use of

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[68] Including the increasing use of telehealth, where consultations are conducted via video link. This enables patients to stay in town, and still have access to surgeons and specialists in major cities. It is hoped that this may circumvent the need for costly travel arrangements when telehealth poses a suitable alternative.

[69] See glossary for definition. In this case, the dillybag would be replaced by a specially designed transfer envelope.

the local Aboriginal Liaison Officers and health staff. This initiative turns culture into a significant feature of clinical conduct: cultural safety would become a sign-off matter in care management plans. These two initiatives were led by an Aboriginal Health Promotion Officer and an Aboriginal Health Worker from the region.

One of the local mental health services (coordinated by North & West Queensland Primary Health Care) has lost funding due to changes in funding arrangements. This service provided critical services in a community that has minimal mental health services. Local petitions were organized at the end of 2010 to support the staff in bids to gain funding for the service. The results of this remain to be seen, and for now the team of psychologists has moved out of their office space (centrally located in the CBD) back to the NWQPHC offices, over five kilometers from the central business district.

My research serves the local community in a number of ways. The results provide additional evidence sorely needed in this region to support advocacy for the resources and funding required to deliver technically best and culturally competent care for Aboriginal and Torres Strait Islander peoples. By capturing significant data on cultural differences that are perceived as health barriers, my thesis provides tangible evidence that may be referred to in the development of more culturally appropriate care regimes. In particular, one of the goals of this research was to provide local Aboriginal and Torres Strait Islander people with a nuanced analysis of these issues, to enable them to better advocate their needs to health professionals and health bureaucrats. The Aboriginal and Torres Strait Islander peoples of this region are strong, and have a significant history of advocating for their own rights. Perhaps this work will assist those efforts.

The study results are not necessarily transferable, but the findings do align with the established knowledge from other sites and times. By providing a snapshot in time of the health care system and perceptions of health care access in the Mount Isa community, this work stands as a testimony to events, and is an interpretation of a social situation that exists in many parts of

Australia, and perhaps more generally in rural multicultural towns across the world. It is rarely possible to interpret such data with total objectivity. However, I have striven for a rigorous subjectivity in the style of Wolcott (1994). While the findings of this thesis are necessarily localised, they do have broader implications for the discussion of access barriers in health care generally and especially to the ways that the health literature uses the term 'cultural barriers'.

11.3. Future Research.

The results featured in this thesis indicate the need for further research in the region. Most obviously, a similar analysis is required on the access barriers to health care facing other cultural groups in and around Mount Isa (what some literature and policy refer to as "Culturally and Linguistically Diverse" (or CALD) groups). This should extend even into organizational cultures with a particular focus onto the experiences of pastoralists, for example. While there has been research conducted with these kind of communities (Leipert and Crosato 2006 and Kelaher et al. 2001a), there is a need for targeted research designed to provide a local evidence base for advocacy.

Research is also required on enablers to good health within the community and how that information might translate into local, state and federal policies on health workforce development. There has been some local research performed that assessed the mental wellbeing and resilience of the Mount Isa community (as part of the 'Be Kind to Your Mind' health promotion initiative of Queensland Health, led locally by the Tropical Population Health Unit in 2006). The evidence from that project suggests Mount Isa is generally perceived (from within) to be a relatively safe and connected community. These perceptions could be harnessed to build social capital within the city, and to generate more sustainable health care models by and for local people. This might require quite different models of care and health workforce than current conventional models.

In addition, it is important to highlight the expectations of health consumers in the region versus the realities of health service provision in Mount Isa. While my research has touched on this, it

was not my intention to capture satisfaction levels per se. However, the results from this thesis go some way toward constructing an accurate vision of how complicated service delivery is in Mount Isa and the region. More targeted research specifically looking at these issues would be of value in developing models of care and health professional roles that are more responsive to local consumer demand.

Mapping the health care decision-making pathways of Aboriginal and Torres Strait Islander patients from a cognitive or behavioural sciences perspective might be of benefit to the emerging discipline of Indigenous Mental Health. Importantly, this kind of research should focus on incorporating cultural attitudes and beliefs about different kinds of care, and the place of such interventions in everyday lives. This kind of research with local communities would inform the development of more logical pathways through health care systems for Aboriginal and Torres Strait Islander peoples. This could accompany a more traditional ethnographic documentation of healing practices in the region.

In addition, study of culture in cognition in the vein of Victoria Burbank's (2006) work may be of value in the north-west region. This kind of research may fundamentally change the approach that is taken in health promotion or prevention activity with Aboriginal and Torres Strait Islander populations. By understanding the ways that cultural concepts may influence or motivate particular behaviours it is possible to further separate cultural factors from other social and structural factors in health status.

One of the fundamental arguments put forth in this thesis concerns choice. Not being able to make active choices about health care can have real impact on the health status of individuals and communities. Sir Michael Marmot, in an editorial for the *Medical Journal of Australia* (2011:512-3), asserted that to achieve the conditions conducive to good health required examination of equity across populations in six domains of life.

The six domains of life are: early childhood development, education and skills development, employment and working conditions, minimum income for healthy living, sustainable communities, and social-determinants approach to prevention activities (Marmot 2011, p.512). Marmot (2011) argued that assessment of all of these domains creates an illustration of the degree to which one can take control and give value or meaning to one's life. "If Indigenous Australians do not have the conditions – each of the six domains – that would allow them to live lives that they would choose to live, ill health is an inevitable result" (Marmot 2011, p.513).

Invariably, analysis of Indigenous health status must then be constructed through considerations of exactly what kinds of lives Indigenous Australians would choose to live. These arguments appear to provide an element of choice to Aboriginal and Torres Strait Islander peoples. However, it is important in attempting to apply the findings within social determinants research to acknowledge variation in the aspirations of any population group, and relative levels of accessibility to resources and infrastructure to support success (Marmot 2011, p.513).

The social determinants of health approach to health research and practice has become a crucial element in understanding the needs of underserved populations, including Aboriginal and Torres Strait Islander peoples. However, this approach is also at risk of being co-opted for further politicization of Aboriginal and Torres Strait Islander cultures in Australia, and may not adequately allow for Indigenous voices to be heard in debates about ways of life and health status. This constitutes another area for research in the North-west region. The examination of the six domains suggested by Marmot, and the WHO Commission on the Social Determinants of Health (CSDH) reports, is required to determine whether Aboriginal and Torres Strait Islander peoples in this region have the basic structural conditions that would enable them to choose the lives they wish to lead, and where improvements could be made to improve health status.

Additionally, ongoing research and evaluation of the work of local hospital networks and the developments of the Medicare Local service, to assess the success of these programs in impacting

upon Aboriginal and Torres Strait Islander health status in the northwest Queensland region provides some exciting opportunities for future work.

Summary.

It is critical to acknowledge that so long as Aboriginal life-worlds are constructed as radically different, as dangerously and mystifyingly 'other', disparities in health status will continue. The ambitions and aspirations of most Aboriginal and Torres Strait Islander Australians are not so different to everyone else, but their experiences of their difference are highlighted on an everyday basis, including in encounters with the health system.

Choice is paramount, but we must acknowledge that there are elements in our lives which are beyond our control and where viable choices are limited. However, if those limits are purely structural, social or even cultural constructs, they can be challenged. With regards to health, and the health of Mount Isa's Aboriginal and Torres Strait Islander peoples, these limits are challenged everyday in mundane and sometimes radically different ways. This challenge is expressed in the deeply-seated need for trust between Aboriginal patients and health care professionals through a nuanced understanding of Aboriginal cultural values, and the demonstration of such knowledge in practice encounters. Fifteen minutes can be a lot of time for a consultation, if the right elements of a life are accorded value in the encounter. Knowing an individual is also about knowing their family, their circumstances, their obligations, their struggles.

It is in these sites of challenge where the biggest gains in Aboriginal and Torres Strait Islander health status in Mount Isa and the Northwest region can be made, as these create spaces in the health system for opportunity, in place of burden.

We can look on the terrible state of Indigenous health in Australia, and see a burden for health care, or we can see an opportunity...

Peachey, McBain and Armstrong 2006.

Plate 14. Shahla-Rae and Talia-Joy Peachey with Jacob Rigg (Photo: Kristin McBain-Rigg)

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Appendix A: Publications arising from this research.

Journal Article:

McBain-Rigg, KE, Veitch, C 2011, 'Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa', *Australian Journal of Rural Health*, vol. 19, no. 2, pp.70-74.

Conference Presentations:

McBain, KE 2006, 'Can the Indigenous Australian Residents of Mount Isa *really* choose who cares for them?', Conference presentation at 2006 AAS Conference, Cairns, 27-30 September.

McBain, KE 2008, 'Cultural barriers in medical literature: who owns the culture concept?' Conference presentation at 2008 Mount Isa Remote Health Conference, Mount Isa, 15-17 August.

McBain, KE 2008, 'Rural Health – On whose terms?' Conference presentation at ASA/ASAANZ/AAS Joint Conference, Auckland, New Zealand, 8-12 December.

McBain-Rigg, KE 2010, 'Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa', Symposium Presentation at 2nd Rural and Remote Health Scientific Symposium, Brisbane, 9-11 June.

McBain-Rigg, KE 2010, 'Cultural barriers to health care', Conference Presentation at 2010 Mount Isa Remote Health Conference, Mount Isa, 20-22 August.

Poster Presentations:

McBain-Rigg, KE 2011, 'Who cares? Aboriginal and Torres Strait Islander Health Care Choices and Access Barriers in Mount Isa'. Poster presentation at 2011 Primary Health Care Research Conference, Brisbane, 13-15 July.

Appendix B: Interview schedule.

These questions were used as prompts in interviews and were reviewed as part of the ethics approval process. Not all questions were necessary in all interviews.

In interviews with health professionals :

How long have you been working in your health care profession?

How long have you been working in Mount Isa?

Have you found it easy to work in the health sector in Mount Isa?

What have been the challenges?

What have been the rewards?

Are you aware of other health services in the town?

Do you have formal referral systems that you use with these services?

Have you had to create links to personnel in other services, to get things done?

Do you have any Aboriginal or Torres Strait Islander clients?

How have you found working with Aboriginal and Torres Strait Islander clients?

Have you had any issues in trying to communicate, understand or be understood by your Aboriginal and Torres Strait Islander clients?

Do you know about other services and programs around town that they can access?

Have you had any difficulties in assisting your Aboriginal and Torres Strait Islander clients to negotiate their way through the health network?

Are there any services that we don't have that we need?

Have you identified any gaps in service provision that need to be filled?

In interviews with Aboriginal and Torres Strait Islander participants:

How do you define or describe health?

When you or your family gets sick, what do you do?

How do you make the decision to go to a health professional for care?

How do you decide where to go for care?

Is there anything that stops you going to a doctor or a service?

Have you had any good/bad experiences with health care here?

Do you find it easy to get the kind of care that your family needs?

Are there any services that we don't have in town that you think we need?

Have you or your family ever had to travel away for health care?

Appendix C: Table (referred to in Chapter 9).

Table: Comparative summary of changes in administrative policy (Smallwood 1989)

Old Administration	Smallwood's changes
Occupational therapy: knitting/crocheting in front of television, occasional walks with physiotherapist.	Occupational therapy: every Saturday, all staff and clients go out after "witchetty grubs, yams, or kangaroo" (which would be eaten on Saturday night).
All patients made to sleep in beds with clean white linen	Declaration that elders would not be forced to sleep in beds with white linen
All patients in the same areas together, regardless of gender. All patients attended to by all staff, regardless of gender	Women and men clients separated unless in a sanctioned relationship. Attempt to have same gendered staff attend to clients (women staff to deal with women, men staff to deal with men)
Uniforms – white nursing styled uniforms	Denim jeans and t-shirts
Use of heavy western pharmaceuticals to control patient behaviour	No more heavy drugs used on any of the "traditional Pitjantjatjara people"
Staff spoke only English, while all clients spoke Pitjantjatjara language	All staff to learn basic Pitjantjatjara.
Non-Aboriginal Staff were unaware of Aboriginal culture	Compulsory attendance at staff cross-cultural awareness training, and Aboriginal staff to be considered as 'cultural experts'
Cooking of food done in microwaves	Open fire cooking introduced, microwaves no longer used to cook patient food.
80% Non-Aboriginal staff, 20% Aboriginal staff ratio	50% Aboriginal staff and 50% non-Aboriginal staff ratio

(Information summarised from Smallwood 1989:8-10).