

How does the concept of Cultural Competence affect the practice of Bioethics and Health Law

By

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Abstract

Cultural Competence is one of the competencies required of all Health Practitioners in New Zealand since the enacting of the Health Practitioners Competence Assurance Act in 2003. This dissertation examines what relationship there is between this concept and Bioethics and Health Law.

The dissertation argues that the need for the concept of Cultural Competence comes from the failure of the Bioethics community to adequately address the fundamental ethical issue that non-dominant cultural groups frequently receive inferior care, and have significantly worse health outcomes, than people who are part of the dominant cultural group.

The definition of Cultural Competence is not agreed upon in the literature so I have examined the policies of the sixteen Health Practitioner Registration Authorities in New Zealand to develop a New Zealand definition to work from. The most important triggers for the development of Cultural Competence were the fact that there were significant health outcome disparities affecting non-dominant cultural groups, and people from non-dominant cultural groups do not receive care that is cognisant of their values, beliefs and ways of living.

Cultural Competence is particularly important in New Zealand because we have an increasingly diverse community and there are significant health outcome disparities, some of which are caused by inequitable access to healthcare services. Practising in a culturally competent way is important for non-dominant cultural groups, but also for many people within the dominant cultural group. This is because of the cultural distance between many people and their health care providers, where the explanatory model of clinician and patient are not congruent. An important indicator of this is the level of non-compliance of patients with investigation and treatments recommended by their clinicians.

Most bioethics problems are complex, and if complexity science is applied to them it becomes clear that bioethical judgements are based on an uncertain factual base, change with time and need to be made by the people involved in the problem.

The concept of frame of reference is usefully applied to bioethics problems, understanding that every person will approach a problem from a different (sometimes slightly different, sometimes significantly different) frame of reference. An understanding of the frame of reference of all parties involved in a problem is essential to good decision making.

I will argue that both Cultural Relativism and Moral Objectivism are inadequate positions to deal with a multicultural society and develop a concept of Complex Principlism as a framework for analysing bioethical problems.

Bioethics is a relational activity and it is essential to focus on maintaining a functional relationship with all involved in the problem and understanding how to establish and maintain trust and utilise fair process, rather than just focussing on analysing what you as an individual believe is the right answer to the problem.

We live in a multicultural society but do not value multiculturalism, although New Zealand does value biculturalism between Maori and the dominant cultural group. There is strong evidence in favour of putting the valuing of multiculturalism at the centre of our governance. This would contribute significantly to improving health outcome disparities and is an essential strategy to learn how to live successfully in the modern world.

Foreword

This dissertation is inevitably written from my particular frame of reference and needs to be interpreted as such.

I was born in England of an American mother and English father. My mother is a language teacher, my father a scientist. I am fortunate to have inherited/learned from them these two perspectives on the world. Our family moved to Wellington New Zealand when I was fourteen years old. I unequivocally consider myself to be a New Zealander. I trained as a doctor at the University of Otago first in Dunedin and then in Wellington.

My first hospital job was in New Plymouth and I lived in Taranaki for the following twelve years. After training I became a general practitioner in the town of Waitara, which is an important centre for Maori in Taranaki. As a result of my involvement in environmental politics I became closely involved with the local iwi Te Atiawa and their case before the Waitangi Tribunal regarding the despoliation of their shell fish reefs by a marine outfall discharging human and abattoir wastes. I was privileged to be welcomed into their community, to learn a smattering of Te Reo and much more of the history and customs of Te Atiawa. This involvement was enhanced by my being able to serve many of them as their GP.

I married my wife Lynne and we moved back to Wellington where I have lived since. For the last twenty years I have worked as a general practitioner at Newtown Union Health Service (NUHS); a remarkable practice that provides care for underserved populations in Wellington, particularly people from a refugee and migrant background, Pacific and Maori people and people with enduring mental health problems. My understanding of how to provide cross cultural care was taught to me by my patients who are from more than twenty different ethnic backgrounds. NUHS was a leader in recognising the importance of using interpreters when caring for people of limited English proficiency, and as a result I will have conducted more interpreted consultations than most other doctors in New Zealand.

Six years ago I took up a half time appointment as senior lecturer in the Department of Primary Health Care and General Practice and I am the convener of Professional Skills Attitudes and Ethics for the medical students at University of Otago Wellington. This position has enabled me to pursue my research interest in the use of interpreters but also to gain an understanding of the field of bioethics. These experiences have shaped my view of the world and it is from this position that I write.

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Abbreviations

| | |
|-------|--|
| CIS | (cervical) Cancer in Situ |
| EGIS | Ethical Guidelines for interventional studies |
| EGOS | Ethical Guidelines for observational studies |
| HPCAA | Health Practitioner’s Competence Assurance Act |
| NUHS | Newtown Union Health Service |
| NZMC | New Zealand Medical Council |
| NZNC | Nursing Council of New Zealand |
| RA | Registration Authority |

Chapter 1 Introduction

Bioethics as a discipline grew out of several infamous episodes: Nazi experiments in concentration camps (United States Holocaust Memorial Museum, 2012, p. 154), the Tuskegee Syphilis experiment (Reverby, 2009), Professor Green's unfortunate experiment on cervical cancer (Sylvia Cartwright, 1988)), and many others.

The pivotal New Zealand episode was Professor Herbert Green's experiment into the natural history of cervical cancer in situ (CIS). This was based on the hypothesis that all CIS did not progress to invasive cancer and was done without the knowledge and consent of the women. When the details were made public a commission of inquiry chaired by Judge Sylvia Cartwright, was set up to investigate and report on what changes needed to be made (Sylvia Cartwright, 1988)

Although not described in these terms at the time, these episodes could be described as a lack of cultural competence. The holocaust was an attack on many minority cultures, particularly the Jews, the Tuskegee experiment of a federally funded experiment on African Americans and Professor Green's experiment of a white male doctor exploiting women patients of mixed ethnicity.

1.1 My Thesis

The response to these events was the development of modern bioethics. It is my thesis that the need for the concept of cultural competence stems from a failure of the bioethics community to address the fundamental ethical issue that non-dominant cultural groups frequently receive inferior care and have significantly worse health outcomes than people who are part of the dominant cultural group.

Furthermore as noted by Chattopadhyay (Chattopadhyay, Myser, & De Vries, 2013) 95% of the editorial boards on the leading bioethical journals come from very highly developed countries and Borry (Borry, 2005) found that 96% of investigators in papers published in the leading journals were from high-income countries. The biggest health outcome disparities are between rather than within countries. This bias in contributions and editorial boards must be one of the elements behind this failure.

1.2 The relationship between bioethics and clinical practice

Bioethicists are to clinical practice what anatomists are to surgery. Anatomists study static specimens in detail. This is vital knowledge for surgeons but each operation is on a particular patient (whose anatomy will vary from that in the books) and illness and decisions are made continually as the operation progresses and things change. Bioethicists tend to study and analyse static cases, or contentious issues such as abortion or euthanasia, from a theoretical base. This is vital knowledge for clinicians but each patient has particular circumstances, their values will differ from the clinician, and the decisions will be made over time as new information is found and circumstances change. If an anatomist were called upon to do an operation they would be a lot better than a plumber, and would be more successful doing an operation on a person whose anatomy was the same as in the text books (not badly distorted by disease) and where non-anatomical factors did not disrupt the operation (ex-sanguination, cardiac arrest). My argument is that bioethical analysis is most useful in circumstances where the values and beliefs of the people involved in the case are similar to those of the analysing bioethicist: analogous to the anatomy being true to the text book. The further away they are the less helpful the bioethicist might be. The case discussed in section 9.3 from Saudi Arabia (Adlan & ten Have, 2012) illustrates this point. Bioethics that limits itself to analysis of problems outside of the clinical context has significant limitations. More focus has to be put upon understanding why other people reach different conclusions and particularly from a clinical point of view how best to manage disagreement. Achieving these last two requires the development and maintenance of a trusting relationship. Clinical bioethics is fundamentally a relational activity.

1.3 Bioethics and the legitimate use of power

Clinical bioethics is about deciding how to “do the right thing.” Much emphasis is on working out what the “right thing” might be but it is important to also focus on the doing. As noted above bioethics is fundamentally relational. The clinician or policy setter has the power in the relationship to make choices and bioethics is about either limiting or justifying the use of that power. There are three broad areas of power: (1) the power to act: performing an abortion, performing a genital examination, performing an experiment on a patient.(2) the power of information: informed consent, open disclosure following adverse events, and (3) the power to allocate resources. That power can either be wielded with the agreement or consent of the patient: allowing the surgeon to do the operation, agreeing to participate in a drug trial, or without the consent of the patient with the support of the law: seeking a court order to treat a child against the wishes of their parents, treating a patient committed under Mental Health

legislation. In general, people from non-dominant cultures will have less power within the relationship with a clinician (especially if they do not share a language) and less power in formulating the laws regulations and policies that shape practice.

1.4 The genesis and legal basis of Cultural Competence

Cultural Competence entered the New Zealand medico-legal landscape with the passage of the Health Practitioners Competence Assurance Act 2003 (HPCAA) section 118(i) *“To set standards of clinical competence, cultural competence, and ethical conduct to be observed by health practitioners of the profession”* (Health Practitioner's Competence Assurance Act, 2003). The registration authorities governed by the Act have developed policies relating to this and the concept is slowly filtering into practise in New Zealand. This mirrors activity particularly in the US and the UK. Saha (Saha, Beach, & Cooper, 2008) noted that there were more than 1000 papers published by May 2007 and many more have been published since then.

Reitmanova (Reitmanova, 2011, p. 197) summarised the reasons behind the development of the term for the US and Canada, but the situation applies equally to New Zealand:

North America is becoming more ethnically and culturally diverse than ever before. There is a fundamental need in American and Canadian health care to address this increasingly growing diversity because misunderstanding, miscommunication, and lack of appreciation of cross-cultural variations in the medical encounter can result in patient general dissatisfaction, poor adherence to therapy and care, poor health outcomes, and consequent health and care disparities. These cross-cultural variations may include differences in recognizing and communicating illness, in health- and care-seeking behavior patterns, in understanding and adherence to a prescribed therapy, and in expectations of care.

A similar and related reason for the adoption of Cultural Competence ties it to “Rights” that should be able to be accessed by all without discrimination.(1993; The Code of Health and Disability Services Consumers' Rights, 1996; Whitehead & Dahlgren, 2007)

1.5 Structure of the dissertation

Chapter 2 will examine the definition of “Cultural Competence”, a term for which there is no universally agreed definition. My discussion will include two elements of bioethical practice:

1. The clinician bioethicist (either managing patients or doing research). I will describe what I believe are the attributes of a culturally competent clinician.
2. Bioethics at a community or policy level. This determines the systems within which clinicians work and I will address the ways in which these systems affect the issues that cultural competence is addressing.

Chapter 3 will argue that it is important because of the increasing diversity of the New Zealand population. I will address the detail of health outcome disparity as the main argument justifying more culturally competent care, and then argue that this has wider importance than just the healthcare of non-dominant cultural groups. In developed countries only around 50% of patients adhere to long term therapies. (Sabate, 2003, p. 7). Many of the reasons behind this low level of adherence are the same as the issues relating to cultural competence, and in the clinical setting a patient labelled “non-compliant” often indicates a cultural competence problem in the clinician.

There is an insidious bias within western medicine of a presumption of the null hypothesis: that unless otherwise proven the clinical presentation does not involve “cultural” features (Malgady, 1996), and that ethnic minorities require special attention. This is an assumption that people all share the dominant medical cultural interpretation of health and this disadvantages everyone. Everyone should be assessed in light of sociocultural influences on them. (Ridley, Li, & Hill, 1998, p. 857), and not just those who are perceived as different. The skills inherent in culturally competent care lead to better care for all patients and not just those from non-dominant cultural groups.

Chapter 4 will develop the argument that the moral objectivist position is unhelpful for culturally competent clinical care. I disagree with the moral objectivist premise that there is the possibility of true moral judgements that should be universally accepted by any reasonable and well-informed person. I will go on to discuss uncertainty and complexity to expand on the problems I see with the moral objectivist position. A clinician belief that they know the right answer can be a barrier to further dialogue. It will also mask where there is uncertainty. Most bioethics problems are complex, with the factual base of the problem being uncertain and the problem varying with time. I address the concept of complexity (Section 4.7) and how this should be applied to bioethics.

Chapter 5 will discuss the concept of Moral Circle and discuss the relationship of that to equal moral worth.

Developing a functional relationship with your patient or research participant is a prerequisite of both good clinical practice and good research. This is more challenging when dealing with a person from a significantly different cultural background. Chapters 6 and 7 address the importance of trust and fair process in enabling such relationships to flourish. If a functional relationship has been established then the way is open to finding out and respecting what the other party believes to be the right course of action and if it differs from the bioethicist.

There are similar issues applying to bioethics at a policy level except this involves the relationships between communities and how agreement is reached on setting policies in organisations and enacting laws. In Chapter 8 I will look at the main legal, regulatory and health system structural outcomes of the Cartwright Report and discuss the limitations of the current structure of institutions and guidelines for clinical and research practice in addressing the needs of a culturally diverse community.

Chapter 9 presents two clinical case histories that illustrate many of the preceding arguments. A criticism of the traditional approach is that even if the “ethical” course of action can be decided this does not mean that it can necessarily be implemented. There are many countries where abortion is illegal...but this does not stop all women from having abortions. For some women it leads to a worse outcome of death at the hands of a back street abortionist. I will discuss this issue further when considering the case of Tovia Laufau (Section 9.1). A significant issue is that often the clinician has the power to act (many argued that the clinicians should have sought a custody order in the case of Tovia Laufau) (Brandon, Clarke, George, Jensen, & Paul, 2001). Use of such power will often disrupt the clinical relationship, impair the likelihood of a negotiated resolution, and not necessarily lead to a better outcome: exemplified by the Liam Williams-Holloway case where a court order was obtained to require him to have chemotherapy for his cancer but his parents took him into hiding and he did not receive any further care from the doctors (Brandon et al., 2001). The case from Saudi Arabia (section 9.3) illustrates the value of understanding frames of reference and how this might play out in the clinical setting.

Chapter 10 discusses the way in which the preceding arguments can be applied to the field of research ethics and compares conventional ethics guidelines with guidelines developed by Maori. This is illustrated by a research project which was ill suited to being addressed by conventional research guidelines

Chapter 11 looks at the systemic issues operating from the constitution of the country down that contribute to these outcomes and examines the option of putting valuing of diversity at the centre of policy making.

Chapter 12 concludes the dissertation.

1.6 Summary

In Summary my thesis is that Cultural Competence came in to being because of insufficient attention being paid to the injustice of health outcome disparities of non-dominant cultural groups and the inability of health services to provide services to non-dominant cultural groups that takes into account their language, values, beliefs and ways of living. A belief that there is such a thing as objective moral truth is of great interest to moral philosophers but is of little use in resolving clinical ethical dilemmas which should instead centre on valuing and understanding of diversity. This will require greater focus on establishing and developing a functional relationship by developing trust and using fair process, and acquiring skills on how to either live with disagreements, or work to lessen disagreements over time.

Chapter 2 Definition of Cultural Competence

2.1 Definition

In the literature there is agreement on the problem that is being addressed but no agreement on what “Cultural Competence” is (Reitmanova, 2011), and even less on how it should be taught and evaluated (Kumas-Tan, Beagan, Loppie, MacLeod, & Frank, 2007) Cross’s definition succinctly covers some of the important issues (Cross, Bazron, Dennis, & Isaacs, 1989, p. 13) *“Cultural Competence is a set of congruent behaviours, attitudes and policies that come together in a system agency or among professionals and enable that system agency or those professionals to work effectively in cross cultural situations.”*

In New Zealand definitions of Cultural Competence have been included in policies developed by the 16 Health Practitioner Registration Authorities (RA’s). The two largest authorities; Nursing and Medicine were the first to develop such policies. Many of the other documents have been developed using these two as the framework. To develop a working definition of clinical Cultural Competence based around New Zealand clinicians’ views, I will first examine the Statement of the New Zealand Medical Council (NZMC) and the Guideline of the New Zealand Nursing Council (NZNC), followed by a review of the other RA’s and elements from the literature. I will then address Cultural Competence as it applies to organisations and governance systems.

2.2 New Zealand Medical Council Statement on Cultural Competence

The NZMC definition is: (Medical Council of New Zealand, 2006)

09 Cultural Competence requires an awareness of cultural diversity and the ability to function effectively, and respectfully, when working with and treating people of different cultural backgrounds.

Cultural Competence means a doctor has the attitudes, skills and knowledge needed to achieve this.

A culturally competent doctor will acknowledge:

That New Zealand has a culturally diverse population.

That a doctor’s culture and belief systems influence his or her interactions with patients and accepts this may impact on the doctor-patient relationship.

That a positive patient outcome is achieved when a doctor and patient have mutual respect and understanding.

10 *Cultural mores identified by the Council are not restricted to ethnicity, but also include (and are not limited to) those related to gender, spiritual beliefs, sexual orientation, lifestyle, beliefs, age, social status or perceived economic worth.*

The document then lists many elements that contribute to culturally competent care including:

- Doctors need attitudes knowledge and skills.
- Doctors need to understand their own culture.
- The best outcome is achieved with mutual respect and understanding.

The statement then lists 19 standards under the headings of:

Attitudes: understand own values, on-going development of understanding, preparedness not to impose own values, willingness to challenge bias of colleagues.

Awareness and knowledge: awareness of limitations of knowledge, that general cultural information may not apply to a particular individual, cultural factors influence health and illness, awareness of general beliefs values of particular cultural groups most commonly encountered and how to apply this, an understanding that culture extends beyond ethnicity.

Skills: establish rapport, elicit relevant cultural issues, recognise when actions might be offensive, use cultural information in reaching a diagnosis, work with beliefs values and practises in developing a management plan, include family where appropriate, work with others from the patients culture, communicate effectively including working with interpreters and seeking cultural advice.

2.3 Nursing Council of New Zealand Guidelines for Cultural Safety

The definition used by the NZNC is (Nursing Council of New Zealand, 2011, p. 7):

Cultural Safety is the effective nursing practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability.

The nurse delivering the nursing service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and well-being of an individual.

This is followed by four principles, summarised below:

1. **Aim to improve health status of New Zealanders** through emphasis on health gains and positive health outcomes, and acknowledging the beliefs and practices of those who differ from them; by age, gender, sexual orientation, occupation and socioeconomic status, ethnic origin or migrant experience, religious or spiritual belief, disability.
2. **Aim to enhance delivery of services by:** Identifying power relationship between nurse and patient, empowering patients, understanding the diversity in their own cultural background and the impact of that on patients different from them. Applying a social science concept nursing is more than carrying out tasks but is about relating and responding effectively to people with diverse needs
3. **Cultural Safety is Broad:** recognising that current inequities reflect historical patterns of inequities through history, address historical, political, social and employment status, housing, education, gender and personal experience, accept legitimacy of diversity of behaviour, accept that attitudes and beliefs, policies and practises can act as a barrier to access to services, includes quality improvement and consumer rights.
4. **Cultural Safety Focuses on:** impact of the nurse's own culture and history, examining practice to recognise the power of the nurse over their patient, balancing this power to lead to effective service, prepare to resolve tensions because of cultural differences, understand how to negotiate power differences to provide good care to people who might otherwise be alienated from the service.

Finally they list some learning outcomes:

2.3.1 Cultural Safety Learning Outcomes(p10)

The expected outcome of nursing education will be registered nurses who will practise in a culturally safe manner, as defined by the recipients of their care. Therefore, the learning outcomes for cultural safety education are that student nurses will:

(a) Examine their own realities and the attitudes they bring to each new person they encounter in their practice;

(b) Evaluate the impact that historical, political and social processes have on the health of all people; and

(c) Demonstrate flexibility in their relationships with people who are different from themselves.

2.4 Areas of Agreement

1. Culture is not restricted to ethnicity but includes (and is not limited to) age, gender, sexual orientation, social status, religious or spiritual belief, disability, occupation.
2. Separate statement/guideline on the care of Maori.
3. The statement/guideline addresses the statutory requirement in the HPCAA to provide culturally competent care.
4. Understanding own cultural values and the influence these have on interactions with patients.

5. Preparedness not to impose own culture on patients.
6. Learning about the rituals customs and practises of a cultural group may not apply to the individual patient from that group.
7. Respect for patients and understanding of their cultural beliefs values and practises.
8. Patients' cultural beliefs values and practises influence their perceptions of health, illness and disease.

2.5 Comparison of differences

2.5.1 Cultural Safety vs Cultural Competence Why did the policies develop?

Whilst these documents have much in common there are significant differences in content and in focus. The most obvious difference is in the title: The NZMC uses "Cultural Competence" the NZNC uses "Cultural Safety" This reflects the different genesis of the two documents.

The NCNZ is the largest registration authority and the only authority to have done significant work around cultural competence prior to the enactment of the HPCAA. Without the stimulus of legislative change, the nurses identified significant problems that needed addressing around culture, largely led by Irihapeti Ramsden who coined the term "Cultural Safety" (Papps & Ramsden, 1996) in 1988 and was the leading figure developing the concept.

Ramsden summarized the views of the time "*nurses give service **irrespective** of nationality, culture, colour, age, sex, political or religious beliefs or status*" arguing that "***irrespective***" needed to be changed to "***respectful***" (I. Ramsden, 1993). Her analysis of Cultural Safety was rooted in her experience as Maori and the disadvantage that Maori have suffered and continue to suffer in terms of health and other outcomes. However she clearly enunciated that whilst the term must first be applied to improve the care of Maori it was applicable to all people (I. Ramsden, 1992). Ten years later she went further to suggest separating out teaching of "Cultural Safety" from teaching about "Maori Health" and the "Treaty of Waitangi" (I Ramsden, 2000), an approach which has been adopted by the NCNZ.

In 1991 a Cultural Safety component accounted for 20% of the final exam mark for the State Nursing exams (I. Ramsden, 1992).

The introduction of Cultural Safety was an unashamedly political act aimed at addressing the inequalities in health outcomes experienced particularly by Maori, but also by other non-dominant cultural groups. It was based on an analysis that concluded that non-dominant cultural groups (particularly indigenous) routinely had worse outcomes and less access to health care than the dominant group and that this was unlikely to change without a

commitment to redressing these imbalances and understanding the power of the dominant culture in general and nursing (and other) professions in particular to maintain the status quo. Unlike Medicine they specifically discussed the issue of power in the relationship and how to empower patients, as discussed in the introduction. The tone of the policy is that there is a problem that nurses have contributed to creating and that change is required. The launch of the policy was initially controversial with significant media coverage and attention from parliamentary select committees (I Ramsden, 2000).

By contrast the MCNZ did not of its own volition acknowledge that there was a significant problem to be addressed (despite the highly publicised adoption of Cultural Safety by the nurses). Its statement was developed because of the inclusion of Cultural Competence in the HPCAA. The tone of this statement does not acknowledge that there is much wrong at the moment, but that adopting the statement will lead to improvement.

2.5.2 Inequalities

The NCNZ policy starts with a principle *Principle 1* “Aims to improve the health status of New Zealanders” and “3.1 recognising inequalities within health care interactions” the MCNZ policy is more muted in “*The purpose of cultural competence is to improve the quality of health care services and outcomes for patients*”, with no particular mention of inequalities.

2.5.3 Safety vs Competence; are they comparable concepts?

At the heart of the difference between the NCNZ approach and the MCNZ approach is the use of the word “Safety” rather than “Competence”. Whilst there is no agreed definition for Cultural Competence there is an understanding of what competence means...it is a term used widely in relation to many aspects of medicine.

The Oxford Dictionary defines competence as “the ability to do something successfully or efficiently” (Oxford Dictionaries, 2012). Applied to a procedure (are you competent to drive a car) it is undeniably a helpful concept. The attitudes skills and knowledge required for the procedure can be documented and assessed with reasonable agreement and reliability.

This illustrates the first problem with the difference between competence and safety; just because you can drive competently (and can demonstrate this to assessors) it does not mean that you will drive safely. The concepts are not synonymous and whilst they overlap (if your driving competence is very limited you are less likely to drive safely) they convey slightly different ideas.

The second problem is that the assessment assesses your driving with an instructor in the car under the particular conditions of the assessment: a particular car, city streets, particular time of day etc. You might be competent under those conditions but not under others. The assessment may not validly measure whether you can drive in "real life". Driving is relatively easy to assess and the assessment bears close relationship to the actual task. The same cannot be said of practicing medicine.

This is well recognized by clinical educators, for example :

It is the obligation of academic programs to train competent physicians and to certify that their graduates are capable of providing competent patient care. There is, unfortunately, no universal standard for assessing clinical competence.(Sliwa & Kowalske, 2000, p. 473)

Kumagai (Kumagai & Lypton, 2009, p. 783) describes the problems of applying "competence" to "culture" well:

The term "competence" may be defined as a state or quality of being adequately or well qualified or possessing requisite or adequate knowledge or skills in a particular area. In education, these competencies are often categorized into learning outcomes involving knowledge, skills, and attitudes to allow for educational approaches which address each of these areas. Consequently, "cultural competency" is frequently approached in ways which limit its goals to knowledge of characteristics, cultural beliefs, and practices of different non-majority groups, and skills and attitudes of empathy and compassion in interviewing and communicating with non-majority groups. Achieving cultural competence is thus often viewed as a static outcome: One is "competent" in interacting with patients from diverse backgrounds much in the same way as one is competent in performing a physical exam or reading an EKG[ECG]. Cultural competency is not an abdominal exam. It is not a static requirement to be checked off some list but is something beyond the somewhat rigid categories of knowledge, skills, and attitudes: the continuous critical refinement and fostering of a type of thinking and knowing—a critical consciousness— of self, others, and the world.

Lingard (Lingard, 2009) captures an important element of this issue by describing "Competence" as an individualistic notion that

Invokes the notion that competence is context-free, untied to time and space... In conceiving competence as a state to be achieved, we not surprisingly end up talking about the generically competent practitioner, one whose, say, communicative competence in one situation should predict future communicative performances in other, similar situations. And while cognitive psychology research warns us against the claim that an individual can be universally competent in all contexts, still our competence discourse evokes the notion of generic abilities and generically competent practitioners (p626).

She argues that this provides a lens through which to look at practitioners that selects for our attention particular attributes of the autonomous learner: memory, problem solving and decision making.

To summarize then, 'competence' reflects our individualist healthcare system and education culture. It selects for our attention the individual learner and the knowledge, abilities and values they possess in their heads, hands and hearts (p626).

What, then, does it deflect our attention from? What blind spots does it produce? An example from my own work comes to mind: competent individual professionals can—and do, with some regularity—combine to create an incompetent team. The conventional discourse of competence doesn't really help us grapple with this reality; it deflects our attention from this sticky educational and clinical problem (p626).

Competence deflects our attention from elements that Safety draws our attention towards. Ramsden (I. Ramsden, 1993) sees Cultural Safety as fundamentally relational “*Cultural Safety contends that all nursing interactions are bicultural, that interaction can only be with one person at a time. There is one giver of a message and one receiver.*” An essential element of Cultural Safety is self-reflection: I doubt if anyone would describe themselves as a “competent self-reflector”; this is a never ending process that is sometimes good and sometimes bad.

Safety attracts our attention to knowing the limits of our Competence. Reason (Reason, 2004, p. ii31) describes his three bucket model of error avoidance (safe clinical practice):

In any given situation, the probability of unsafe acts being committed is a function of the amount of bad stuff in all three buckets. The first relates to the current state of the individual(s) involved, the second reflects the nature of the context, and the third depends upon the error potential of the task. While most professionals will have an understanding of what comprises bad stuff in regard to the self (lack of knowledge, fatigue, negative life events, inexperience, feeling under the weather) and the context (distractions, interruptions, shift handovers, harassment, lack of time, unavailability of necessary materials, unserviceable equipment), they are less likely to know that individual task steps vary widely in their potential to elicit error.

This model was developed with clinical safety in mind but that many of the elements in the first two buckets would apply equally to Cultural Safety.

The use of the term Safety will deflect our attention from some of the more concrete relevant skills. The NZNC policy makes no mention of the use of interpreters. Ramsden's original formulation (I. Ramsden, 1992) included “*specialized cultural information (taught by people from within the culture concerned)*”. However the NCNZ policy makes no mention of nurses

needing to know any culture specific information (although there is a separate policy on Maori Health).

2.5.4 Cultural Competence Standards (MCNZ) vs. Cultural Safety Learning Outcomes (NCNZ)

An important feature of Cultural Safety is that it is defined by the recipients of the care, putting the power of assessment in the hands of the patient (Nursing Council of New Zealand, 2011, p. 8 fig 2). The idea that the patient must assess safety is at the philosophical core of the concept but the consequence is that it makes the evaluation of the teaching of Cultural Safety more difficult. The NCNZ has a few “learning outcomes” whereas the MCNZ has a long list of “Cultural Competence Standards”. Conceptually it makes more sense to have standards that you measure practitioners against to determine if they are competent; getting every patient to assess the clinician’s Cultural Safety on every occasion is quite impractical. However the focus on learning outcomes by NCNZ has meant that those “competencies” that can be assessed (how to use an interpreter, awareness of the general beliefs of the cultures most often met) are not mentioned. Conversely many of the MCNZ standards (for example development of your own cultural awareness) would be very difficult to meaningfully assess and may have been better described as a “learning outcome”.

2.5.5 The Culture of Medicine/ Nursing

Taylor (Taylor, 2003a) provides an interesting analysis that suggests that medicine sees itself as a “Culture of no Culture” *“Medical knowledge is understood to be not merely ‘cultural’ knowledge but real knowledge.”*(p556) and that “cultural” knowledge contains less valued perceptions to be compared against “real” knowledge. She goes on to discuss how this perception is a major impediment to Cultural Competence teaching and concludes by saying:

“To change this situation will require challenging the tendency to assume that ‘real’ and ‘cultural’ must be mutually exclusive terms. Physicians’ medical knowledge is no less cultural for being real, just as patients’ lived experiences and perspectives are no less real for being cultural.”(p559)

This perception is embraced by the NCNZ in Principle 4.2 *“challenging nurses to examine their practice carefully, recognising the power relationship in nursing is biased toward the provider of the health and disability service”* and 4.4 *“preparing nurses to resolve any tension between the cultures of nursing and the people using the services.”*

The MCNZ does not acknowledge this as an issue at all.

2.5.6 Power Imbalance

The MCNZ policy makes no explicit mention of the imbalance of power in the relationship with patients: the closest it gets is *“A preparedness not to impose your own values on patients”*. This is an important deficit given that by definition the patients that this policy is aimed to help are from non-dominant cultures, for whom many of the issues relating to poor care stem from this power imbalance. The NCNZ guideline devotes nearly a quarter of its content (principle four) to addressing these issues of power.

2.6 Cultural Competence or Cultural Safety?

Both terms have limitations. The development of Cultural Safety contributed significantly to the international literature on this issue. Cultural Competence is the term used in the Act and, whilst definitions are not agreed I would see this as a developmental phase and that in time we will share an understanding of the concept.

2.7 The 14 other registration authorities

The Health Practitioners Competence Assurance Act 2003 amalgamated several pieces of legislation so that all health practitioners' registration requirements were combined into one Act. There are 16 registration authorities. Whilst they are organisationally separate, they do meet together as the Health Registration Authorities of New Zealand and some of them share secretariat. The government is currently doing a strategic review of the HPCAA and has signalled its intent to amalgamate the registration functions into one body, in particular to aid the gathering of accurate health workforce statistics. Many of the more recently confirmed policies on Cultural Competence acknowledge input from the policies of other authorities, particularly those of nursing and medicine. There are differences between the policies, but it is unclear which of these differences reflects a significant difference in belief. This could also be due to the timing of policy development: for example the physiotherapy policy is the most recently developed policy and has adopted elements from several of the other policies. Another factor is that some of the Boards represent health professionals with less substantial patient contact than others: for example the Medical Radiation Technologists and the Medical Laboratory Scientists make no mention of the power imbalance in their relationship with patients or understanding of history and social processes. Finally Chiropractic and Osteopathy are both small relatively recently formed authorities. Neither makes reference explicitly to a cultural competence policy but this may reflect the limited resources to develop policies and not having reached the Cultural Competence policy yet.

A meaningful comparison of the policies is complicated by the fact that Cultural Competence is interpreted by all RA's as being a broad concept, and that elements of what some include in

the Cultural Competence policy appear either in their generic competencies document, or in their code of ethics. Table 1 summarises the policies of the sixteen registration authorities (Dental Council of New Zealand, 2008; Medical Sciences Council of New Zealand, 2007; Midwifery Council of New Zealand, 2007; New Zealand Chiropractic Board, 2010; New Zealand Medical Radiation Technologists Board, 2011; New Zealand Optometrists and Dispensing Opticians Board; New Zealand Psychologists Board, 2011; Occupational Therapy Board of New Zealand; Osteopathic Council of New Zealand, 2009; Pharmacy Council of New Zealand, 2011; Podiatrists Board of New Zealand, 2009) (Psychotherapist Board of Aotearoa New Zealand, 2011) (Dieticians Board of New Zealand, 2006; The Physiotherapy Board of New Zealand, 2011).

Table 1 Registration Authorities

| | No.'s registered | Separate policy | Care of Maori Separated from Cultural Competence | Date of policy |
|----------------------|------------------|-----------------|--|----------------|
| Nursing Council | 50,128 | Yes | Yes | (1990) 2007 |
| Medical Council | 14,333 | Yes | Yes | 2006 |
| Physiotherapy | 4,195 | Yes | No | Post 2006 |
| Dental | 3,689 | Yes | Yes | 2008 |
| Pharmacy | 3,223 | Yes | No | 2011 |
| Medical Sciences | 3286 | Yes | no | 2007 |
| Midwifery Council | 2980 | Yes | yes | 2011 |
| Medical Radiation | 2,367 | No | no | 2011 |
| Occupational Therapy | 2,200 | Yes | No | undated |
| Psychologists | 2,093 | Yes | No | 2011 |
| Optometrists | 769 | Yes | No | undated |
| Psychotherapists | 562 | Yes | No | 2011 |
| Dieticians | 556 | Yes | No | 2006 |
| Chiropractors | 407 | No | No | 2010 |
| Podiatrists | 336 | No | No | 2010 |
| Osteopaths | 384 | No | | 2009 |

Social workers are covered by the Social Workers Registration Act 2003 (2003) which does not mention Cultural Competence. Instead section 100 requires the board to ensure that the aims and aspirations of Maori are integral and on-going priorities and section 101 to obtain views of Pacific and other cultural groups. This is reflected in the competencies that include competence to work with Maori and competence to work with different ethnic and cultural groups. It does not mention the importance of understanding own culture, the link to disparities, or other elements of cultural difference apart from ethnicity.

2.8 Elements of Definition from the International Literature

2.8.1 Equal Moral Worth and Racism

The existence of disparities in health outcome contributed to the development of the concept of Cultural Competence. Hyun (Hyun, 2008), looking at this through an ethical lens asserts: *“Accepting the value of cultural competence in healthcare involves (along with other beliefs) a fundamental normative belief in the equal moral worth of all persons.”* This principle is consistent with section 21 of the Human Rights act (Human Rights Act, 1993), that prohibits discrimination on a long list of grounds but is worth addressing explicitly. I will discuss this further (Section 5.2) showing the relationship between this concept and the idea of Moral Circle.

This links directly into racism defined as *“the belief that all members of each race possess characteristics, abilities, or qualities specific to that race, especially so as to distinguish it as inferior or superior to another race or races:”* (Oxford Dictionaries, 2012).

There is no doubt that some of the health disparities are directly related to racism on the part of health professionals. Australia has documented some of the more flagrant examples (Johnstone & Kanitsaki, 2008). It makes no sense to talk about Cultural Competence without addressing the possibility that some individuals or institutions are behaving in a racist manner.

2.8.2 A Framework for Understanding Culture

Ramsden’s describes “Transcultural Nursing”; an approach where you learn from an authority about the culture of the patients that you see, and discounts it because of the risk of forming racial stereotypes. However, having no knowledge of the normative culture of your patient means that an area of helpful information can be missed. The Pharmacy Council competency standards for example includes: *“1.4.4 Focuses on the influence of a patient’s culture in*

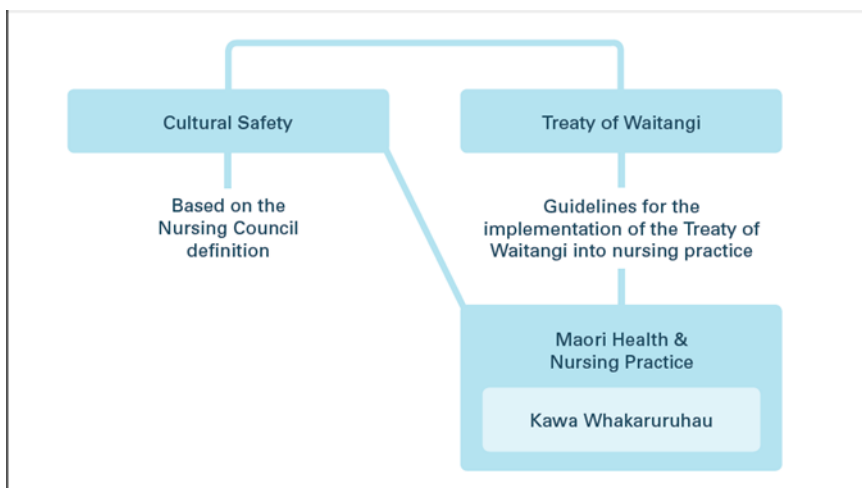
conjunction with their medical condition, to improve adherence to treatment and health outcomes e.g. fasting during Ramadan”(Pharmacy Council of New Zealand, 2011)

Many people have used the analogy between our awareness of our own culture and the awareness of the goldfish of the water in which it swims (Moerman, 2002, p. 67; Psychotherapist Board of Aotearoa New Zealand, 2011). In many settings it is not socially acceptable to make assumptions on the basis of race: this being labelled as “Racism”. Yet the reason that we describe people by cultural labels is that it helps us to function. Providing a framework within which to describe culture can make it much easier to discuss the differences and similarities between cultural groups in a non-judgemental way. One such framework has been developed by Hofstede et al (Hofstede & Hofstede, 2010) and used at the Waitemata DHB as a framework for their training resources on working in a Culturally and Linguistically Diverse health environment (Waitemata District Health Board & Counties Manukau District Health Board, 2010).

2.9 Exclusion of Treaty of Waitangi

I agree with the Nursing Council that knowledge of the Treaty of Waitangi should stand outside of Cultural Competence/Cultural Safety. Figure 1 (Nursing Council of New Zealand, 2011, p. 5) displays the relationship well. To care for Maori patients, nurses need knowledge of Cultural Safety, and the Treaty of Waitangi.

Figure 1 Nursing Council Relationship of Cultural Safety to Treaty of Waitangi and Maori Health



2.10 My Preferred Definition of a Culturally Competent Clinician

1. Cultural Competence is based on the premise that all patients are of equal moral worth and thus equally deserving of the best care we can provide. The concept of “Culture” is not restricted to ethnicity but also includes gender, spiritual beliefs, sexual

orientation, lifestyle, beliefs, age, social status, disability or perceived economic worth.

2. Culturally competent care requires an understanding of the determinants of health and how these affect different people in different ways.
3. Culturally competent practitioners will be able to identify when disparities result from racist behaviours of individuals or institutions, and will act to address this behaviour.
4. “Cultural competence requires an awareness of cultural diversity as well as the ability to function effectively and respectfully with people of different cultural backgrounds than one’s own.”(Waitemata District Health Board & Counties Manukau District Health Board, 2010)
5. A Culturally competent practitioner will have the self-awareness to understand their own cultural values and beliefs and how these might differ from those of the patients they meet. This would include an understanding of the “Culture of Medicine”.
6. Culturally competent practitioners are aware of and sensitive to issues of power within the practitioner/patient relationship, in particular being careful not to impose their own values onto patients.
7. Being culturally competent requires that we have some knowledge of other cultures, and how their practises and expectations differ from our own (Waitemata District Health Board & Counties Manukau District Health Board, 2010).
8. Culturally competent practitioners need to understand and apply a framework for understanding culture.
9. Culturally competent practitioners have the skills to consult effectively with a diverse range of people, in particular being able to respect difference, and avoid making assumptions about the patient’s beliefs and understanding of the world and way of living.
10. Patient’s cultural beliefs values and practises influence their perceptions of health, illness and disease.
11. Culturally competent practitioners are able to work effectively with colleagues from cultural backgrounds different from their own.
12. Culturally competent practitioners will develop skills in effective cross cultural communication: how to use an interpreter if there is no language concordance, how to adapt to the variation in body language, how to show (dis)respect, modesty, and expressions of disagreement that exist between different cultural groups.

2.11 An illustrative clinical example

Many of these points are well illustrated in Widera’s article about a patient’s mother who hoped for a miracle. (Widera, Rosenfeld, Fromme, Sulmasy, & Arnold, 2011) They describe a case of a homeless man with lung cancer who had refused follow up. Three months after diagnosis he was admitted to intensive care in respiratory distress and put onto a ventilator. He was unable to participate in decision making; his physicians believed that no treatment would enable him to be removed from the ventilator, and that treatment was futile. The man’s mother wanted all life sustaining measures to be continued and *‘expresses hope that a miracle will occur that will allow her son to leave hospital. The physician feels frustrated that*

the mother is so unreasonable and is unsure how best to respond to her “irrational” beliefs’ (p120). The paper goes on to describe an approach based on searching the literature. The first thing they discovered was that belief in miracles is quite common; one study citing 79% of 35,556 American respondents agreed that miracles still occur. This enabled them to be more accepting of the views of the mother. Having taken her view seriously they then found literature showing that providing greater attention to good spiritual care fostered negotiated and mutually acceptable plans of care. Other studies *‘emphasized the importance of a communication framework that values and appreciates what families say’* (p123).

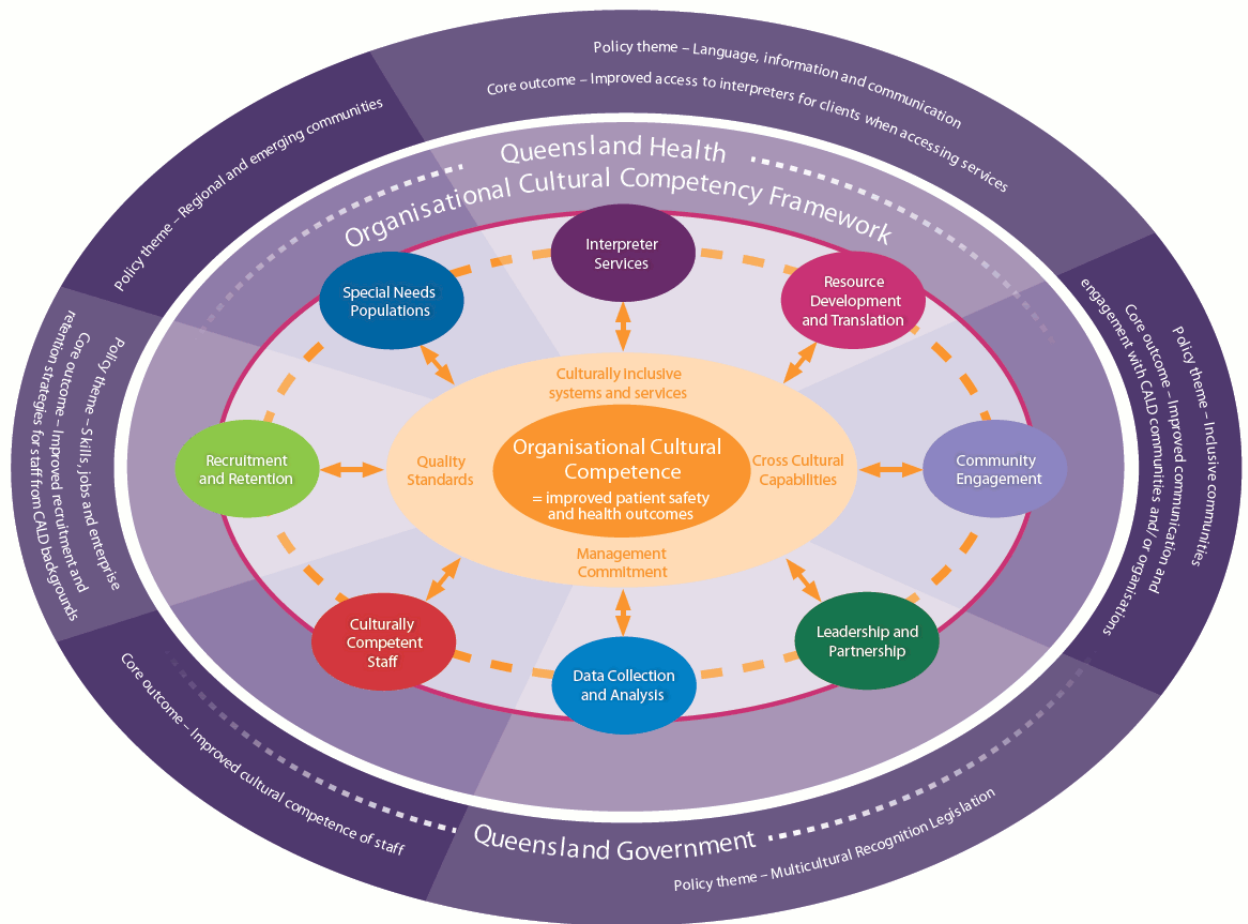
The mother’s belief in miracles was not amenable to reason; that the clinicians “knew the right answer” did not help resolve their differences. They had the power to implement the “right” management, but this would have been at the expense of a functional relationship with the mother. The clinicians’ initial response was that she was unreasonable. However when they determined that many people believe in miracles, they took her views more seriously: they accepted that she had a different frame of reference from the clinicians. Their research suggested greater attention to spiritual care (finding out more about her beliefs) and the importance of communication that values and appreciates what families say.

2.12 Cultural Competence at a Policy and Legislative level.

Implicit in some of the cultural competencies of individual clinicians are institutional policy requirements for a Culturally Competent organisation. Changes at an individual clinician level are difficult to achieve without a supportive institutional and legislative framework. It is often the organisation that provides the budget and access to interpreters for example. It is the law that should establish a framework for accreditation and enforceable ethical codes for professional interpreters. This framework is currently absent in New Zealand (Clark Diana & McGrath Caroline, 2009) so anyone can set up in business as an interpreter and if they behave unethically there is no clear mechanism to address this.

As a clinician, my predominant focus in this dissertation is at the clinical level. I have not attempted an extensive analysis of all the institutional and legal issues that might be involved. Figure 2 (with the detail from the diagram in italics below) from the Queensland Government (Queensland Government, 2012) is a good example of the sorts of elements of a societal system that need to be addressed in order to provide improved patient safety and health outcomes. The inner circle lists the features of a culturally competent organisation and the outer circle policy themes of the Queensland Government.

Figure 2 Queensland Health Organisational Cultural Competency Framework



Action in these core outcomes and foundation areas is essential to the development of a culturally competent organisation.

Interpreter services

A culturally competent organisation addresses the language barriers of consumers. Queensland Health implements a high quality and accessible interpreter service.

Resource development and translation

A culturally competent organisation provides quality resources to build staff cultural competency and facilitates access to services by providing translated information to consumers from culturally and linguistically diverse communities. Queensland Health provides resources for staff which help to build their cross cultural capability and improves the health literacy of consumers by providing translated information about how to access the health system and specific health conditions.

Inclusive recruitment and retention

A culturally competent organisation implements strategies to develop a workforce that reflects the diversity in the general population. Queensland

Health is committed to increasing the workforce participation of people from culturally and linguistically diverse backgrounds, across all occupational streams and areas in the organisation.

Leadership and partnership

Culturally competent organisations provide leadership and support partnerships with key stakeholders to support service provision to culturally and linguistically diverse communities. Queensland Health works in partnership with Multicultural Affairs Queensland and the community sector to improve the health status of culturally and linguistically diverse communities in the state. Queensland Health strategic plans recognise the needs of culturally and linguistically diverse communities.

Culturally competent staff

Culturally competent organisations build the cross cultural capabilities of their staff. Queensland Health has identified five cross cultural capabilities which encompass the skills, knowledge and behaviours Queensland Health expects in its workforce. Queensland Health is committed to providing staff with access to this information through mandatory cultural diversity orientation and standard cross cultural training packages.

Data collection and analysis

Culturally competent organisations work to improve data collection and analysis for culturally and linguistically diverse communities. Queensland Health collects data about culturally and linguistically diverse clients and analyses the results to inform service development.

Community engagement

A culturally competent organisation engages with culturally and linguistically diverse communities in the development of services.

Special needs populations

A culturally competent organisation recognises and responds to specific disadvantaged populations. Queensland Health recognises refugees, Pacific Islanders and Australian South Sea Islanders as populations with special needs.

The outer circle looks at the legislative framework that needs to be in place;

Policy Theme- language information and communication

Core outcome; improved access to interpreters for clients when accessing services

Policy Theme-Inclusive communities

Core outcome: improved communication and engagement with CALD communities and/or organisations.

Policy Theme-Multicultural Recognition Legislation

Policy Theme-Skills jobs and enterprise

Core outcome-improved recruitment and retention strategies for staff from CALD backgrounds

Policy Theme-Regional and emerging communities

2.13 Cultural Competence at a societal level

If the society as a whole does not value diversity then there will be a limit as to how much change can be achieved at either the individual clinician or organisational level. I will address this matter in detail in Chapter 11

Chapter 3 How important is Cultural Competence?

Given how recently Cultural Competence has been added to the responsibilities of health professionals the question has to be asked: How important can it be?

3.1 Diversity

Increasing numbers of New Zealand residents are born overseas – since 1996 the percentage has increased from 17% to 22% or nearly one in four people living in New Zealand. Between 2006 and 2026 the Asian, Māori and Pacific populations are all projected to grow faster than the New Zealand population overall (Statistics New Zealand, 2006), and net migration will become an increasingly significant contributor to population growth (Ministry of Social Development, 2010). The proportion of people from non-English-speaking backgrounds is also increasing; people of Chinese origin are now the second-most common group of migrants after those of English origin, and Chinese and Samoan are the most widely spoken languages in New Zealand after English and Maori. New Zealand’s immigrant population is disproportionately concentrated in the Auckland region. In 2006, over half (52%) of the overseas-born population lived in Auckland, which was home to 32% of the country’s total population. Of the children cared for by the Auckland District Health Board, 13% are Maori, 20% are Pacific, 26% are Asian and just 40.5% are European and other (Aikin & Jelleyman, 2012) New Zealand is one of the more diversely populated countries in the world as measured by proportions of people born outside of the country (figure 3) (Boston J, Callister P, & Wolf A, 2006).

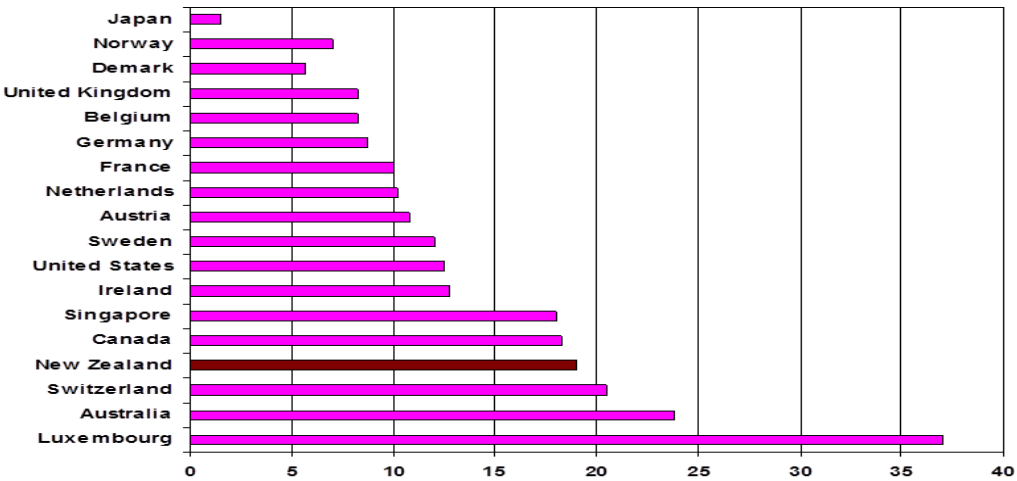


Figure 3 Foreign-born population as a % of total population 2000-2001

3.2 Definition of Diversity

I have used the term “diversity” which has a colloquially accepted meaning, but for the purposes of this thesis more detail definition is needed. Parekh (Parekh, 2002, pp. 3-4) distinguishes between diversity on three different levels:

*First although its members share a broadly common culture, some of them either entertain different beliefs and practices concerning particular areas of life (Gays/Lesbians) or evolve relatively distinct ways of life of their own (miners, fishermen artists.) They all broadly share their society’s dominant system of meaning and values and seek to carve out within it spaces for their divergent lifestyles...I shall call this **subcultural diversity**.*

These are people of the dominant culture with some particular differences. They may suffer from health outcome disparities if they are subject to discrimination or (as with Gay men and HIV) if they are more susceptible to particular conditions. This group would benefit from Culturally Competent care.

*Second, some members of society are highly critical of some of the central principles or values of the prevailing culture and seek to reconstitute it along appropriate lines. Feminists attack its deeply ingrained patriarchal basis, religious people its secular orientation....These....represent neither subcultures, for they often challenge the very basis of the existing culture, nor distinct cultural communities living by their values and views of the world, but intellectual perspectives on how the dominant culture should be reconstituted. I shall call this **perspectival diversity**.*

These people may or may not be disadvantaged by disparate health outcomes, but as a group are generally not a significant area of diversity for the focus of Culturally Competent care.

*Third most modern societies also include several self-conscious and more or less well-organised communities entertaining and living by their own different systems of beliefs and practices. They include the newly arrived immigrants, such long-established communities as Jews....various religious communities and such territorially concentrated cultural groups such as indigenous peoples....I shall call this **communal diversity**.*

These are the groups that most people think of when we talk about Cultural Competence. In this dissertation most of the examples that I will use come from this group. However each of these three groups has values and beliefs that vary from the dominant culture and as such may not receive optimal care unless their non-dominant views and beliefs are taken into account. When I talk about a tolerance of diversity I am referring to all three types of diversity.

3.3 Pluralism, Multicultural and Multiculturalism

New Zealand is a culturally plural society (Berry, 1997, p. 8) and could accurately be described as a “Multicultural Society” (Parekh, 2002, p. 4), or as a society that experiences “Pluralism in

fact” (Michel Rosenfeld, 1998). Berry usefully observed (Berry, 1997, p. 8) cultural groups are not equal in power (numerical, economic or political), and that these differences have led to terms such as “mainstream” and “minority”. He recommends using the term *cultural group* to refer to all groups and *dominant* and *non-dominant* to refer to the relative power, to avoid assumptions about “minorities” and “mainstream”. I will be adopting this convention.

3.4 Disparities in Health Outcomes

An important stimulus for the development of the concept of Cultural Competence internationally was concern about health outcome disparities (Beach et al., 2005). In New Zealand Pearce (Pearce, Davis, Smith, & Foster, 1984) showed that disparities in health outcomes for Maori were not explained on the basis of their lower socioeconomic status but that for all socioeconomic statuses Maori had worse outcomes than for non-Maori. Despite efforts to address this, these disparities remain. At the most basic level there is a significant and continuing difference in life expectancy for Maori and Pacific New Zealanders compared to the rest of the population (Smith Barry, 2012).

Figure 4 New Zealand Life Expectancy at Birth by Ethnicity and Gender

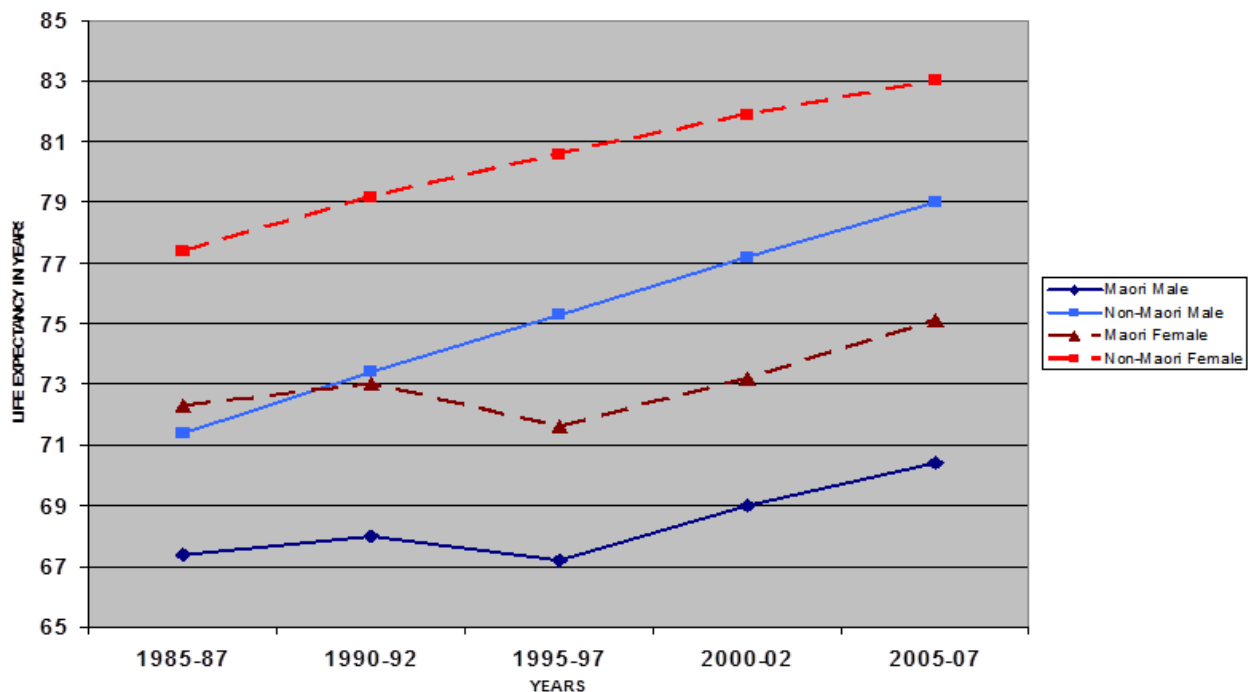
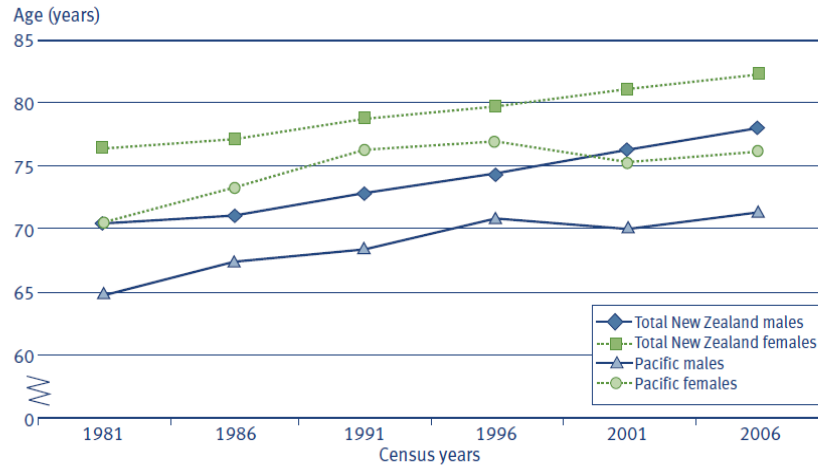


Figure 4 shows that in 2006, life expectancy at birth was 70.4 years for Māori males and 75.1 years for Māori females, while life expectancy at birth for non-Māori males was 79.0 years and for non-Māori females 83.0 years. Overall, in 2006, Māori life expectancy at birth was at least

eight years less than that for non-Māori for both genders (New Zealand Ministry of Health, 2010).

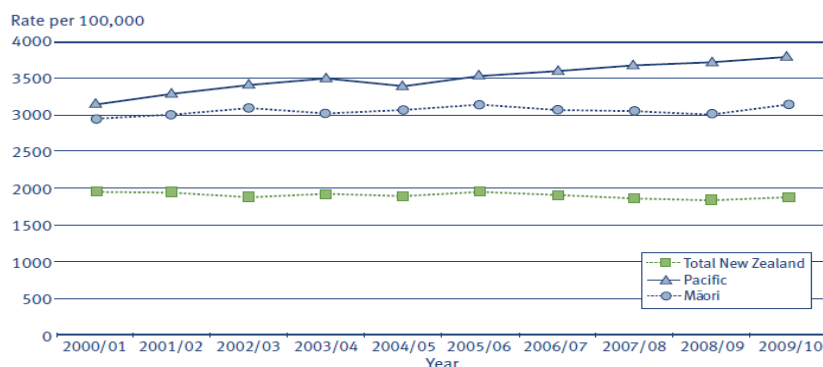
Figure 5 Life Expectancy at Birth, Pacific and Total Population, by sex 1981-2006



Source: Ministry of Health, based on adjusted Pacific mortality (unpublished)

Figure 5 shows that In 2006, life expectancy for Pacific males was 6.7 years less than total males and for Pacific females it was 6.1 years less than total females (New Zealand Ministry of Health, 2012, p. 25). These disparities have not been controlled for other variables such as socioeconomic status in the way that Pearce et al did so some of these disparities will be related to factors other than ethnicity, and not things that can be affected by the health system. However other indices are more within the control of the health system.

Figure 6 Ambulatory-sensitive hospitalisation rates, Pacific (across seven DHB's) Maori and total population aged 0-74 years. 2000/01 to 2009/10 (age standardised)



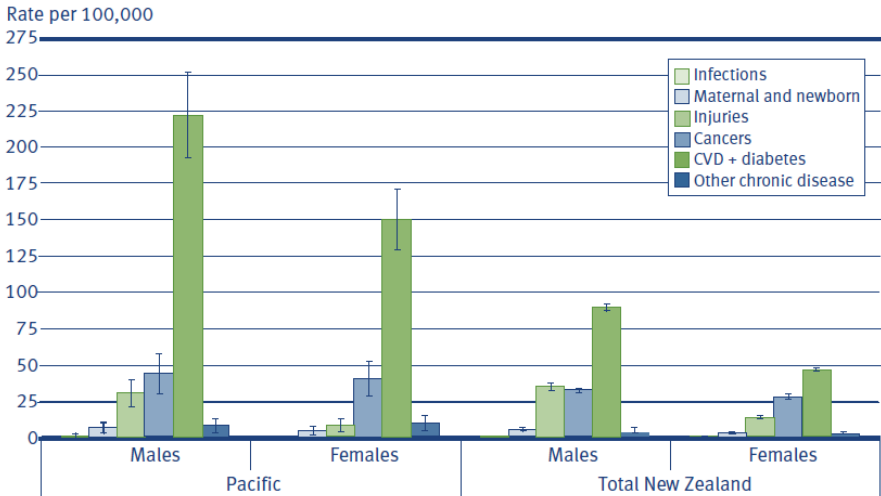
Source: Ministry of Health (National Minimum Dataset)

Figure 6 shows that after adjusting for age, the ambulatory-sensitive hospitalisation rate for the Pacific population (0–74 years) increased between 2000/01 and 2009/10, while the rate for the total population fell slightly. The differences between Pacific and Maori ambulatory-

sensitive hospitalisation rates have increased since 2005/06. These results suggest increasing disparity in access to effective primary health care for the Pacific population (New Zealand Ministry of Health, 2012, p. 29).

This data is explicitly suggesting that there are poorer health outcomes for Pacific and Maori, that the extent of disparity is increasing and that those poorer outcomes are the result of poorer access to primary care for these populations.

Figure 7 Amenable Mortality Rate (applied to deaths under the age of 75 years), Pacific and total population, by cause and sex, 2008 (age standardised)



Source: Ministry of Health (Mortality Collection Dataset)

Figure 7 shows that, after adjusting for age, cardiovascular disease (CVD) and diabetes were the major causes of amenable mortality in the Pacific population, and at a significantly greater rate than for the total population (applied to deaths under the age of 75 years). The amenable mortality rate for CVD and diabetes for Pacific males was 2.5 times the rate for total males and for Pacific females it was 3.2 times the rate for total females (New Zealand Ministry of Health, 2012, p. 30).

Adjusting for age, Māori have higher under-75 mortality rates than non-Māori (for both mortality categories and both sexes). The ethnic rate ratio is around three-fold for amenable causes and around two-fold for non-amenable causes (in each category, slightly higher for females than males). The fact that the relative inequality is wider for amenable than non-amenable causes is indicative of the contribution of health care to the ethnic inequality in health (New Zealand Ministry of Health, 2010, p. 28).

The pattern for Pacific people is similar, with the standardised amenable mortality rate ratio around 2 and the corresponding non-amenable ratio around 1.5 (both sexes).

In New Zealand a particularly stark example is the incidence of rheumatic fever. New Zealand has some of the highest rates in a developed country. *“Compared with New Zealand European and Others, rate ratios were 10.0 for Maori and 20.7 for Pacific peoples. Of all cases, 59.5% were Maori or Pacific children aged 5–14 years, yet this group comprised only 4.7% of the New Zealand population”* (Jaine, Baker, & Venugopal, 2008).

3.5 Improvement for Maori

There have been significant changes in the targeting of health services towards Maori over recent years. As shown above this has not brought Maori levels of ill health down to the level of the majority population, although the fact that Maori levels are better than Pacific levels, could be a reflection of improvement (or it may be deterioration for Pacific). An important area where change has occurred is in infant mortality. *“The infant mortality rate was 4.2 infant deaths per 1,000 live births in 2012, down from 4.7 in 2011 and 5.6 in 2002. The lower infant mortality was due to a decrease in the number of Māori infants dying (82 in 2012, down from 123 the year before). The mortality rate for Māori infants dropped to 4.7 in 2012, down from 7.0 in 2011 (Statistics New Zealand, 2012).* The drop has been attributed to the development of an educational campaign that was designed for Maori (McMillan, 2012) and in particular encouraging the use of woven flax sleeping baskets.

3.6 Interpreter use

The Code of Patient Rights (The Code of Health and Disability Services Consumers' Rights, 1996) has a right to effective communication:

RIGHT (5)

Right to Effective Communication

Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.

Without effective communication it is inevitable that health care will be compromised. New Zealand has an increasing number of citizens from a Non English speaking background, many of whom have limited English proficiency. A recent Christchurch study showed that *“For the years 2008-2010, approximately 10,742 consultations per year involved a non-English speaking patient, yet in only approximately 74.8 (0.7%) consultations per year were interpreter services utilised.”*(Kara Seers, Lynley Cook, Gillian Abel, Philip Schluter, & Paul Bridgford, 2012). This

was in a setting where interpreters were available at no cost to the practitioner or patient. Since 2000 Australia has had a nationwide free telephone and on site interpreting service that has had a priority line for doctors and has similar problems of poor uptake (Huang, Phillips, Huang, & Phillips, 2009). Both papers discuss what strategies might improve uptake of interpreters (more publicity about the service, training of clinicians on how to use interpreters, funding for longer consultations) but none of them explicitly address the probability that these patients are not seen as part of the clinicians' moral circle and what strategies might address this (see Chapter 5). Without an interpreter many of the other rights are not available. They cannot be fully informed (Right 6). I have argued elsewhere (Ben Gray, 2011) that it is not possible to achieve informed consent (Right 7) in patients with limited English proficiency without a professional interpreter. Services of an appropriate standard (Right 4) cannot be provided and the right to complain (Right 10) would be hard to achieve.

The lack of use of interpreters is a good example of a cultural competence problem that has its genesis at many levels of the system. New Zealand has no agreed syllabus, nor registration or accreditation of interpreters so it is hard to determine quality of interpreter (Clark Diana & McGrath Caroline, 2009). Availability of interpreters is variable around the country. Funding for interpreters is not guaranteed. Many clinicians have limited experience of using interpreters.

In the only report of an HDC investigation that discusses use of interpreter (Health and Disability Commissioner, 2002b) a breach of the provision of the code relating to interpreters was not found. On writing the report on the case the Commissioner concluded that communication issues were central to the clinical problems, but because it was not complained of by the patient nor raised by his clinical advisors, it had not been part of the investigation and he felt he could not find a breach of the code on this matter. Instead he *"made extensive comment about these issues throughout this report."*(p2) It is significant that the patient made no comment about his inability to communicate because of the need for an interpreter, nor did the Commissioner's GP advisor. The commissioner makes the comment: *"With the benefit of hindsight, it is apparent that Dr A should have arranged an interpreter for Mr C"* (Health and Disability Commissioner, 2002b, p. 13). The Commissioner had found no evidence that Dr A's service had the capacity to either determine the need for an interpreter, or know how to find one. It is quite lenient for him to say this was a problem that only came to light with the "benefit of hindsight". This was a breach waiting to happen.

It is possible that one reason for this lack of provision of interpreters has its root in seeing people who are not English proficient as having fewer rights (Burnside Julian, 2010). The greater the power imbalance in the clinician/patient relationship, the greater the ethical risk. This is most extreme where there is no language concordance.

3.7 Non-Compliance

In 2003 the WHO published a detailed report on “Adherence to long-term therapies” (Sabate, 2003) They identified that: *“In developed countries, adherence to long-term therapies in the general population is around 50% and is much lower in developing countries”* (Sabate, 2003, p. 7). They rejected the term “compliance” as it *“implies that the patient is a passive, acquiescent recipient of expert advice as opposed to an active collaborator in the treatment process.”* (Sabate, 2003, p. 3) noting that that term implies that the problem is caused by “patient factors” ignoring the clinician and system factors. The report goes on to outline that this problem disproportionately affects the poor. Many of the factors contributing to non-adherence reflect “cultural difference”: the patient has a different understanding of the illness, the patient does not understand how the medicine works; medication is too expensive to buy (doctor is not aware of this). It is very likely that the worse outcomes for non-dominant cultural groups for conditions like rheumatic fever are related in part to “non-adherence”.

In her landmark book “The Spirit Catches you and you fall down” Fadiman (Fadiman, 1997) describes the story of a Hmong girl who despite the best efforts of her paediatricians has uncontrolled epilepsy that ends with her being in a persistent vegetative state. At one point in the story the doctors decide that the problem is “non-compliance” and they refer her to child protection for her to be fostered so that she would get her medication as prescribed. There was a bad outcome, despite the doctors being diligent. Taylor (Taylor, 2003b) notes that *“The Spirit Catches You has quickly become a canonical text for burgeoning efforts to impart ‘cultural competence’ to health care practitioners.”* I think that this is in large part because clinicians can see that the bad outcome was because of “non-compliance” but that the problem was with the clinicians and the health system rather than the patients. Non-Compliance as a term continues to be used not infrequently. In a recent student assignment that I set here at University of Otago Wellington 90 4th year medical students had the choice of 6 essays to write in relation to Fadiman’s book. One of the essay topics was *“Find a patient who has been labelled ‘non-complaint’ by the doctors treating them and discuss why you think the patient was not cooperating with the doctor’s treatment plan.”* Fourteen students wrote such an essay describing a patient labelled by other clinicians as non-compliant, most of which found important clinician factors contributing to the “non-compliance”

3.8 Summary

The New Zealand population is increasingly diverse. Health outcomes for some non-dominant cultural groups are significantly worse than for the dominant cultural group. The failure to provide interpreters for people with limited English proficiency is a significant breach of the code of patient rights. The high level of non-compliance with treatment is symptomatic of a medical culture that has been unable to reach concordance in treatment plans with many patients. Lack of Cultural Competence is a significant problem.

Chapter 4 Moral Objectivism, Moral Relativism and Cultural Competence

In his article about ethics as they apply to Cultural Competence, Hyun asked: *Must clinicians become ethical relativists to provide culturally competent care?* (Hyun, 2008, p. 154)

Cultural Relativism is the view that moral truth is relative to a culture or society: Harman (Harman, 2007, p. 5) describes this: *“There is no single true morality. There are many different moral frameworks, none of which is more correct than the others”*.

Moral Objectivism is the view that there is the possibility of true moral judgements that should be universally accepted by any reasonable and well-informed person.

There are a number of concepts I will discuss to illuminate the debate between these two positions.

4.1 Frame of Reference

Harman compares moral relativism with Einstein’s theory of relativity, *“that two events that are simultaneous with respect to one frame of reference can fail to be simultaneous with respect to another”* (Harman, 2007, p. 11).

Park (Park, 2011, p. 161) goes on to develop the idea:

“Imagine that a driver and a passenger are in a car, and the car travels at 50km/h with respect to the ground. In such a situation, the driver also moves at 50km/h in relation to the ground, but he is at rest in relation to the passenger. Notice that the driver is in motion or at rest depending on what the frame of reference is. If it is the ground, he is in motion, but if it is the passenger, he is at rest. Furthermore, there is no fact of the matter as to which frame of reference is better. It is false that the ground is a better frame of reference than the passenger and vice versa. Harman says that the same is true of morality. Morality is relative to a moral framework. An action that is moral with respect to one moral framework might be immoral with respect to another.”

Two people might reach a different moral conclusion if they come from different frames of reference: a term that could easily equate to different cultures. Unlike Harman I think that the idea that a frame of reference might be “correct” is unhelpful. This implies that the person operating from that frame of reference has adopted that frame to the exclusion of all others. Within the car the person will behave as if it is not moving, talking to the passenger, passing sweets etc. However they are perfectly able to recognise that there is another frame of

reference and that if they want to pass sweets to a person outside of the car, that they will have a problem if they open the door and get out presuming that they are stationary. Park (Park, 2011, p. 167) then addresses the dilemma raised by Pojman (Pojman, 2007) of a woman with two conflicting frames of reference: as a Catholic and as an American citizen. In considering an abortion her Catholic frame may oppose this and as an American citizen this is legal behaviour. Pojman sees this as a problem with Cultural Relativism as he has an expectation that there is a morally correct choice, and that the woman is forced to make a “wrong” choice (in relation to one or other of her frames of reference). However all Catholic people do not hold exactly the same beliefs, any more than all people of any cultural group. All Americans do not think abortion is OK even if it is legal. Instead I think there is the best or least bad choice available at the time balancing the values of the two frames of reference, or more accurately reflecting the complex frame of reference of that particular individual. We all have multiple different “cultures” that we belong to: work based, sexuality based, religious based.

Pojman notes that the “notion of culture or society is notoriously difficult to define” (Pojman, 2007, p. 18). Consequently any “definition” of the beliefs of a culture or society will always be qualified. The exceptions would be accurately described as “fundamentalists” “strict adherence to the basic principles of any subject or discipline” (Oxford Dictionaries, 2012), for example a Jehovah’s Witness carrying a card describing what their faith proscribes in the way of intravenous treatment. Typically this is the only frame of reference they address when considering the issue of blood products. Their “cultural” views are clearly defined although some Jehovah’s Witnesses do alter their views when faced with the possibility of death (Henderson, Maryniak, & Simpson, 1986).

4.2 Discourse Systems

This concept of a person having multiple frames of reference is discussed and analysed through the lens of discourse analysis applied to intercultural communication by Scollon (Scollon, Scollon, & Jones, 2011). They use the term “discourse system” as a way to get beyond the culture-equals-nation problem imposed by the term “culture”. They say that “discourse systems” contain “*ideas, beliefs about the world conventional ways of teaching other people, ways of communicating using various kinds of texts, media, and 'languages', and methods of learning how to use these other tools*”(p8) and that people simultaneously belong to multiple discourse systems: gender, generation, workplace, family, ethnic, country. This is analogous to the concept of “Frame of Reference” that I have developed above. They go into some detail analyzing particular discourse systems and the way in which the ideology behind a

system might alter the way that people within those systems relate to the world. They compare a “Confucian” with a “Utilitarian” (or capitalist) ideology and look at how that alters the perceptions of people operating within that ideology. This is not a book about ethics but the framework of discourse systems is of importance in considering ethical frameworks; it describes the diversity of discourse systems and that an individual may make different responses depending on which discourse system they might be in at the time. The response to a particular question whilst at the Church’s Session meeting might be different to the response whilst at the rugby club. The individual will have to deal with coherence and integrity. Behaving in a sexist way that is acceptable in the rugby club, may still cause problems for the person when they go to the Church Session. Implicit in the discussion is that the “right” answer depends on which discourse system you are in at the time, overlaid with the person’s need to have a coherent sense of self. Most of the time our discourse systems will be coherent with each other; a red neck sexist rugby supporter is less likely to be a member of the Church Session. Christians with Jewish friends in Nazi Germany faced an unenviable dilemma in maintaining a coherent sense of self; being true to their relationship with Jews or risking persecution themselves.

This analysis neatly deals with another important issue. It talks about discourse systems rather than people. It is thus meaningful to say that the Catholic discourse system precludes abortion, but does not imply that all Catholic people abide by everything in the Catholic discourse system, because they are all simultaneously part of other discourse systems. As individuals we develop our moral sensibility by having to resolve conflicting demands from different parts of our lives. It is also the way in which cultures adapt and grow, by members adopting some values from other discourse systems and challenging the prevailing view of their own system. Finally it is ideally how nation states develop their laws by providing a forum to discuss and find an acceptable resolution for what the law of the land should be (see Chapter 11).

4.3 The Limitations of Moral Objectivism

A Moral Objectivist might claim that as a result of their detailed study and bioethical excellence that their frame of reference is “true”. Rachels (Rachels & Rachels, 2010, pp. 29-31) raises two cautions in relation to this position. Firstly he points out that *“there are many...matters that we tend to think of in terms of right and wrong that are really nothing more than social conventions”* A problem with a “right” moral code is the risk that it will reflect the social conventions of the person writing the code, as well as including the fundamental moral code. Secondly he quotes a story from Herodotus about how the Greeks

practiced cremation and the Callatians ate the bodies of their fathers. This story ends with the quote:

For if anyone, no matter who, were given the opportunity of choosing from amongst all the nations of the world the set of beliefs which he thought best, he would inevitably, after careful consideration of their relative merits choose that of his own country. Everyone without exception believes his own native customs, and the religion he was brought up in, to be the best.

Any ethical problem is inevitably seen from particular frames of reference; the values beliefs and understandings of the people viewing the problem. The frames of reference of those people are very unlikely to be fixed: as in clearly defined and unchanging, and it is likely that they as individuals will have several conflicting frames of reference. Thus a clinician faced with ethical disagreement with a patient can approach the problem by trying to understand both the patient's and their own frame of reference to determine whether there is in fact a disagreement on principles, or whether there is something important about the frames of reference that explains the disagreement. This approach can be taken without even entering a discussion about whether there is a "right" moral code and what it might be.

Until now I have been discussing the making of moral judgements and whether these judgements should be relative to a particular culture or whether they should be absolute. Seah et al (Seah E, 2002, p. 22) in their detailed tool on how to provide cross cultural mental health care point out that doing an adequate assessment of a patient "*requires an understanding of the behaviours and beliefs of the client within the parameters of the client's culture rather than the clinician's culture – cultural relativism. Adopting this process is a pre-requisite for negotiation between clinician and client in health care settings.*" Before any judgement can be made of the moral correctness of the patient's position that position has to be understood relative to the patient's culture. Cultural Relativity in understanding is essential in clinical assessment.

4.4 Understanding Cultural Frames of Reference

Respecting autonomy is widely asserted to be a principle of ethical behaviour. In "The Principles of Biomedical Ethics"(Beauchamp Tom L. & Childress James F., 2009) there is no discussion about whether these principles might be coming from a particular cultural perspective; on the contrary they assert that these principles apply to all cultures.

Hofstede et al (Hofstede & Hofstede, 2010) provide an analytical framework for looking at cultures of different countries, based on 30 years of extensive surveying and analysis. In contrast to Beauchamp and Childress they explicitly acknowledge that it is from their own

frame of reference as Dutch and Bulgarian people. They describe cultures varying between six different pairs of attributes or dimensions: Power Difference; Uncertainty Avoidance; Individualism versus Collectivism; Gender Difference; Long Term Orientation; and Indulgence versus Restraint.

Significantly, in relation to this discussion, out of 76 countries the USA is the most individualistic. For an American to assert that autonomy should be a universal principle is unreasonable. Most of the people of the world live in countries where collectivism is the norm. NZ Maori as a generalisation are a collective people. The NZ Ministry of Justice commissioned a report "He Hinatore ki to Ao Maori *A glimpse into the Maori world*" (Clarke, 2001, p. 40) "to help develop an understanding of traditional Maori perspectives on justice, which involves the identification of cultural values and beliefs in relation to Maori practices and tikanga." They addressed these issues explicitly:

"Collective Responsibility

Maori society was largely based around collective responsibility. Individualism and individual responsibility was uncommon. If an individual wronged against another individual or kin group, the whanau and hapu of that individual would have to take responsibility for those actions."

Hofstede et al's studies are based on survey data comparing the values of different countries. They qualify all of their writing by noting that these are generalized averages, and do not necessarily apply to any particular individual from each of those countries. In Scollon's terms they are better seen as "discourse systems" described at a country level. There are problems for example for countries like New Zealand where Maori have different values from other ethnic groups in the population. They are not pretending to "define" different cultures. Instead they have identified dimensions of culture that commonly vary between cultures, and have mapped that variation. We unconsciously know these variations when we attribute particular characteristics to particular nations. The movie "Cool Runnings" (Turteltaub, 1993) follows the fortunes of a Jamaican bob sled team, and contrasts them with a German team. The humour in the movie is based on a shared understanding that the Jamaicans are likely to be happy go lucky compared to the Germans who are precise and organized. It would not have made sense if the Germans rather than the Jamaicans had lost the final race because their bobsled fell apart for lack of maintenance.

A study of the manner in which different cultures vary leads to the conclusion that values differ between different peoples and that will influence the weight they might put on any

particular ethical principle. I have described the example of autonomy, but there will be similar variation in relation to many other ethical values.

4.5 Hierarchy of Needs

Another framework that helps to understand cultural frames of reference is Maslow's hierarchy of need (Maslow A.H., 1943). If a person's physiological and safety needs are not secure, then securing those needs is much more reliably done as part of a collective of people; tribal society. There are many behaviours that ethicists decry that stem from the desire to enhance group cohesion. A simple example would be the Jewish practice of male circumcision.

Acts 11: 1-18

Now the apostles and the believers who were in Judea heard that the Gentiles had also accepted the word of God. So when Peter went up to Jerusalem, the circumcised believers criticized him, saying, 'Why did you go to uncircumcised men and eat with them?'

From my frame of reference, it is hard to characterise circumcision as anything other than male genital mutilation, but it is seen as an important mark of being a member of the Jewish faith, and in a world where anti-Semitism still exists group cohesion is an important value for them.

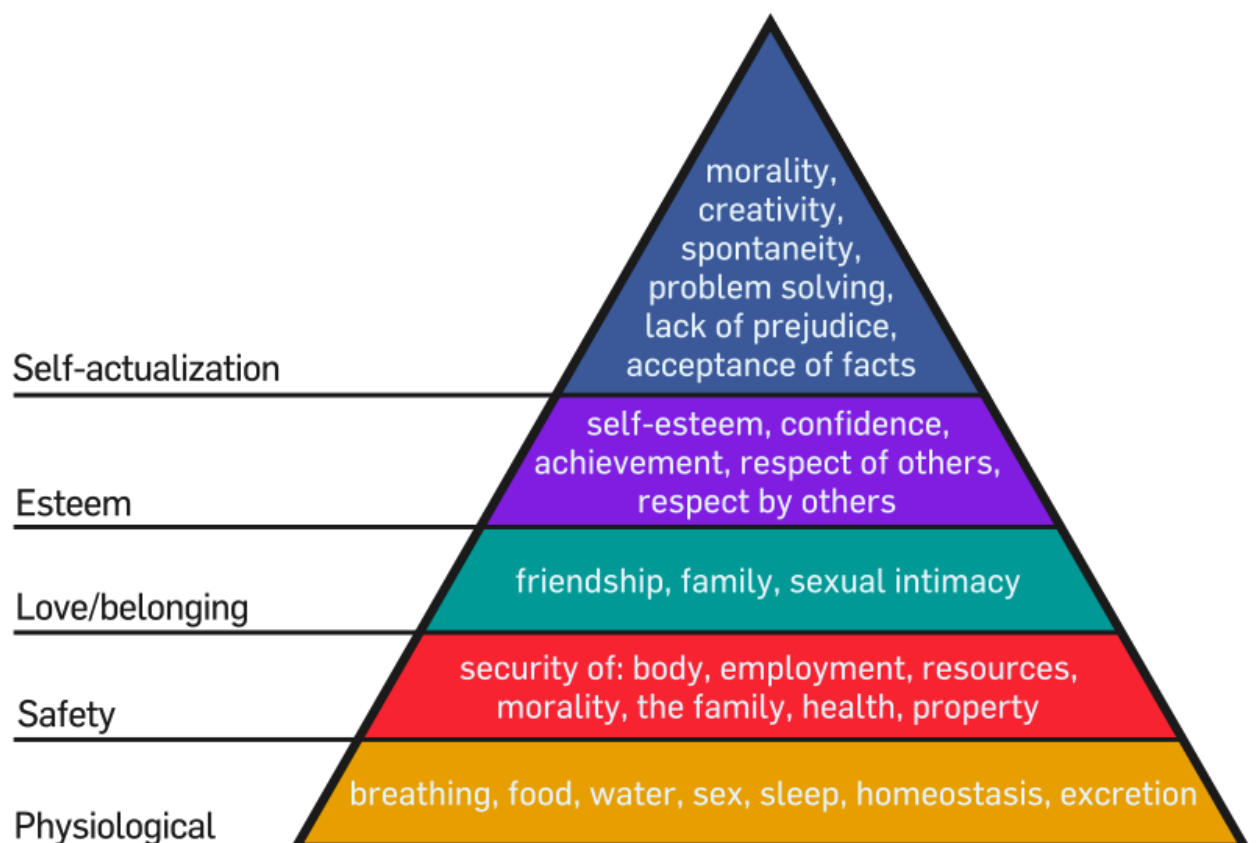
Macklin (Macklin, 1999, p. 7) tells the story of some Chilean indigenous people:

...there remain a few scattered indigenous groups outside the large cities. One such group continues to practice a traditional ritual in which new born infants are sacrificed. The government of Chile forbade the practice by law and succeeded in bringing it to a halt. But when the region where the indigenous group dwelt experienced a severe drought, causing suffering and hardship to the people, they contended that the gods were punishing them for their failure to carry on the ritual sacrifices required by their religion and blamed the state for its prohibition of human sacrifice.

She uses this as an example to decry "cultural relativism" on the premise that infanticide is an activity that she believes should be universally proscribed. This example illustrates the points I want to make about frame of reference. It is very likely that the child mortality rate was normally much higher within this tribe than in the USA so that the death of a baby is more accepted. If we look at the hierarchy of needs the very existence of these people is threatened. From a purely rational perspective practicing infanticide at the time of severe famine makes a lot of sense. If the babies were not killed there would be a high chance of them dying anyway as a result of lack of food. Babies are the least able members of a community and are unable to contribute to providing the necessities of life, so if there is

insufficient food for the whole community then killing babies makes more sense than killing adults or even the elderly. It is entirely plausible that this group of people developed this strategy and that it has successfully enabled them to survive in a harsh environment where other tribes that did not practice this died out. Rachels (Rachels & Rachels, 2010) tells a similar story in relation to Eskimos who also practiced infanticide to illustrate that despite difference in practice the core values might not be all that much different. Another important aspect of this story to note is that the Chilean people believed that the Gods were punishing them. This is a non-rational position, similar to the mother who believed in miracles (section 2.11), but there are many “religious” beliefs that require behaviour that is in fact able to be supported rationally, but are acted on because of “belief”. A blanket rejection of belief based codes of practice on the grounds that ethical behaviour needs to be “reasoned” is too simplistic, particularly when the systems of reason involved are predicated on an individualistic, competitive, “objective” and monistic reading of reality.

Figure 8 Maslow's Hierarchy of Needs



Any judgement on the morality of behaviour must take into account where on the hierarchy of needs the person may sit. I have met a Somali refugee who told lies about his identity whilst in

the refugee camp in Kenya and as a result was accepted as a refugee into New Zealand. Now in New Zealand where he is safe and well fed, lying cannot be condoned, and there is a difficult problem of whether to correct the lie, at the risk of being deported. It is hard to argue that lying is always bad if there is a choice between staying in a refugee camp with all the risks of starvation, disease and physical and mental trauma, and lying to get out. However the fact that this lie continues to have consequences illustrates the dynamic nature of some ethical choices. The other party to this ethical decision is the New Zealand immigration service. They wish to run a fair system of selection of refugees and if all refugees lied then this aim would be subverted. This illustrates the importance of cultural relativism to **understand** the reasons behind a particular act. There remains a **judgement** to be made, by the man as to whether to now tell the authorities the truth, and if he does tell the truth, by the authorities as to how to respond to his admission. He is faced with the problem of how to maintain his own integrity and coherence in the new setting.

Cultural practices change over time. Some practices may have persisted from a time when the cultural group was further down the hierarchy of need and had positive value in helping secure basic needs. Once those basic needs are fulfilled those practices may become less tightly held, and some practices will be abandoned. The Chilean community had abandoned infanticide prior to the drought returning.

4.6 Complexity

The concept of complexity and the understanding of systems developed in the new physics and some of the basic sciences like ecology (Capra Fritjof, 1996) and later in management (Senge, 2006) and has also been applied to medicine (Glouberman & Zimmerman, 2002). The central idea is that problems can be divided up into simple, complicated, complex (and chaotic.) Glouberman and Zimmerman describe the concepts well:

Simple problems like following a recipe may encompass some basic issues of technique and terminology, but once these are mastered, following the recipe carries with it a very high assurance of success. Complicated problems contain subsets of simple problems but are not merely reducible to them. Their complicated nature is often related not only to the scale of a problem like sending a rocket to the moon, but also to issues of coordination or specialized expertise. Complicated problems, though generalizable, are not simply an assembly of simple components. Complex problems can encompass both complicated and simple subsidiary problems, but are not reducible to either since they too have special requirements, including an understanding of unique local conditions, interdependency with the added attribute of non-linearity and a capacity to adapt as conditions change. Unavoidably, complex systems carry with them large

elements of ambiguity and uncertainty that are in many ways similar to the problems associated with raising a child. Despite the uncertainty associated with complexity, all three kinds of problems can be approached with some degree of optimism: we do look forward to raising a child despite the complexity. Our contention is that many health care experts implicitly describe complex problems as complicated ones and hence employ solutions that are wedded to rational planning approaches. These often lead to inappropriate solutions because they neglect many aspects of complexity.(p1-2)

A feature of complex problems compared to simple or complicated problems is that they do not have a “correct” answer: there is no correct way to raise a child that will work for every child.

Complicated problems can have solutions that are external to the system. It is possible for an engineer not involved in the space programme to analyse problems with the rocket and come up with answers to technical problems. By contrast they argue that for complex problems the solution has to be part of the system. Whilst there are some problems in child rearing that can be solved by external experts (for example diagnosing rickets and treating with vitamin D) the complex problems of child rearing have to be solved by the players in the system: how to control tantrums, how to help a child who is being bullied. A clinician managing these problems has to develop a relationship with the parent and child in order to understand the problems, and their efficacy in improving the outcome may well depend on the extent to which they are able to build the trust of the parent and child to implement their suggestions; they have become a part of the system.

This has an interesting resonance with Levi Strauss’s thoughts (Lévi-Strauss & Eribon, 2009):

“Cultural Relativism affirms that one culture has no absolute criteria for judging the activities of another culture as “low” or “noble” However every culture can and should apply such judgements to its own activities because its members are actors as well as observers.”

Glouberman and Zimmerman point out that complicated problems are solved by developing adaptations to what is presumed to be a static environment: again the rickets example. By contrast complex problems involve interaction with the rest of a dynamic environment: the tantrums may be related to discord between the parents, having a new teacher at school, lack of sleep because of a persistent cough, or more likely all of the above in varying proportions.

Beauchamp and Childress's schema of principles that are specified and then balanced bears a striking resemblance to classical Cartesian approach to science of analysing, breaking down into parts with a mechanistic weighing to reach "the answer". Pojman (Pojman, 2007, p. 21) uses similar language "*We are to (judge right and wrong) on the basis of the best reasoning we can bring forth.*" Although he qualifies this by adding "*and with sympathy and understanding.*"

This can be contrasted with a more modern scientific approach that relies on understanding systems, where there is always uncertainty of information, the system is dynamic, and at the subatomic level there is no "answer" only probabilities "*In quantum theory we never end up with any things; we always end up with interconnections.*" (Capra Fritjof, 1996, p. 30)

Another concept from quantum physics is that the act of watching affects the reality (Buks, Schuster, Heiblum, Mahalu, & Umansky, 1998). The observer is part of the system and affects the outcome.

I would argue that bioethics is about complex problems. There is no one correct answer. The solution needs to be developed within the system. The observer affects the outcome of the problem, and the problems are dynamic rather than static.

4.7 Uncertainty

Complex systems inevitably involve uncertainty. Outcomes are probabilistic rather than deterministic. Causation is multifactorial and incompletely understood, and there are recognized elements of unpredictability (Glouberman & Zimmerman, 2002). By contrast complicated problems have less uncertainty, and that uncertainty is often able to be overcome by getting more information. There is an assumed predictability. The Cartesian scientific approach presumed that problems were complicated, that they could be understood by looking in ever more detail and that with enough information the truth could be found. Quantum physics permanently undermined that proposition, not only had we not found "the truth" Heisenberg's uncertainty principle established that for some problems certainty could never be achieved;

***uncertainty principle**, also called Heisenberg uncertainty principle, or indeterminacy principle, statement, articulated (1927) by the German physicist [Werner Heisenberg](#), that the position and the velocity of an object cannot both be measured exactly, at the same time, even in theory. The very concepts of exact position and exact velocity together, in fact, have no meaning in nature.(Britannica Academic Edition, 2013)*

Bioethics case studies are often simplified to focus on the central ethical problem. This is of considerable value in elucidating ethical principles and developing ethical reasoning but of limited help in solving real clinical dilemmas. A good example is Judith Jarvis Thomson's "A defence of Abortion" (Thomson, 1971) which is regarded as a watershed event in 20th century ethics in America (Pence, 1997). She successfully argues that an innocent person can have a right to life and still, in some situations be permissibly killed (Thomson, 1971). The article approaches the problem of abortion as a complicated one that is solvable by an external agent with rational argument. It exists to try to shoot down the straw man that "abortion should not be allowed." In my view the major argument in favour of legalized abortion has nothing to do with the ethics of abortion per se and everything to do with the risks of illegal back street abortions, and the inability of communities all over the world to prevent abortion from happening. Thus any argument about the morality of a particular woman considering an abortion has to take into consideration all the circumstances that affect her at that time in her community, considering the options that are actually available to her. It is of little help to a particular woman living in a community where abortion is illegal to be armed with a paper from Thomson arguing that abortion should be allowed.

4.7.1 Clinical Stories too "certain"

Many clinical stories used to support ethical arguments are either drawn from legal judgements (thus a retrospective analysis where all information is now certain or at least agreed upon) or from edited hospital scenarios where the medical information is presented as "certain". For example Beauchamp and Childress (Beauchamp Tom L. & Childress James F., 2009) talk of a "*life threatening pneumonia (p 139)*"; "*she had a massive stroke and made no recovery nonverbal, limited range of purposeful behaviours (P160)*" and in discussing the rule of double effect "*needs a hysterectomy to save her life because of cancer. (p 162)*" This misses one of the most difficult things in making ethical judgements, the problem of managing uncertainty. The framework they provide looks towards how to make "right" or "ethical" decisions. In most clinical situations all that is possible is to make the best decision available given the circumstances.

Bioethics cases tend to be presented as static, rather than dynamic: see the example above about the refugee lying in the refugee camp.

Nicholas & Gillett expanded on these ideas when they described a narrative approach to bioethics that emphasised the importance of the detail of the story that "*adds a richness to a medical situation that helps to clarify the ethical issues*" (Nicholas & Gillett, 1997, p. 295).

Hurwitz (Hurwitz, 2012) describes how the way a case is presented can significantly alter the moral and ethical interpretation of a case.

4.8 Is there ever a “right” answer to ethical problems?

Cultural Relativism and Moral Objectivism are based on the idea that there could be a “right” moral framework: Moral Objectivism believing that there is one that is “right” for all, and Cultural Relativism that there are many “right” frameworks and more particularly that within a particular “culture” there is an agreed “right” framework.

If we consider Bioethics problems to be complex then the concept of “right” becomes less useful. Is there a “right” way to bring up a child? This does not mean that we do not know a lot about how to raise children, nor that we cannot delineate some principles that provide guidance to increase the likelihood of good outcome. A judgement can always be made in retrospect. Einstein did not speak in sentences until the age of three (Pais, 2005). At the time his parents could well have been criticised for failing as parents. In retrospect it was not a problem.

Furthermore if we think of Bioethics in relation to systems theory the idea that somewhere there might be a framework of moral truths that are absolute, ignores the question that if such a framework were true then why does it not exist?

There are two responses to this: firstly that it does exist and it is a particular culture (American, Scandinavian, New Zealand?) but no living culture would claim that there are no problems with the way they run their lives, or that they could not learn how to do things better. Hofstede (Hofstede & Hofstede, 2010, p. 25) puts this succinctly having studied many different cultures: *“There are no scientific standards for considering the ways of thinking feeling and acting of one group as intrinsically superior or inferior to those of another”*. By contrast Beauchamp and Childress (Beauchamp Tom L. & Childress James F., 2009, p. 3) assert that there is a *“Common Morality” that is a set of norms shared by all persons committed to morality, that is found in all cultures (At least in all cultures in which there is the requisite core of morally committed persons)*. This is a circular argument essentially that there is a common morality that covers all people who agree with it, and the others are not “morally committed persons”. They fail to precisely delineate what the “Common Morality” might be let alone why they have included some principles and excluded others.

Secondly the idea that there might be a “right” code is a chimera. Any bioethical principle has to exist as part of a complex living system, so the idea that we might be able to set up a new

system made up of just our favourite principles and create the perfect society denies our ability to predict the outcome of such a society because of the uncertainty of how people might respond. Elliott (Elliott, 1999) argues convincingly that consensus on such a framework would be undesirable even if it were possible. A world where moral consensus was reached would lack moral reformers, conscientious objection and we would no longer need to make up our own minds, merely learn “the rules”. A moral objectivist could arguably be labelled a fundamental rationalist, comparable to fundamentalist religious adherents who believe that they know the one truth. It is interesting that there are theologians comfortable with a pluralistic world:

I have slowly come to realise that there is no such thing as unchangeable Christian truths. Indeed, there is no such thing as absolute truth. Truth is not a thing - something that remains constant and unchangeable for all time. Truth is a quality or a value, like love, compassion and honesty. Values always hide a subjective component, for what is of value to one person may not be of value to another. It is because of this subjective element in the very concept of truth that the expression of truth in human language is always subject to change through the centuries. There can be no unchangeable truths, divinely revealed or not (Geering, 2012)(Sermon on the 70th anniversary of his ordination).

I will not attempt a review of the literature on post modernism but just observe that the argument above is consistent with that discourse, well-illustrated by Cheek (Cheek, 1999, p. 385);

Postmodern approaches provide a challenge to the view that it is possible to represent any aspect of reality in its entirety, speak for others, make truth claims, and attain universal essential understandings. In so doing, postmodern approaches challenge the way that reality has come to be represented. Thus, sometimes postmodern approaches are described as emanating from a crisis in representation. With an emphasis on the plurality of reality, postmodern approaches recognize the multiplicity of voices, views, and methods present in any representation or analysis of any aspect of reality, including the reality of health care. Such recognition encourages health practitioners and researchers to engage in a form of reflexivity, in which the analysis of practice involves multiple layers, multiple truths, and multiple voices. There is no natural or given way to do things or to understand things in a postmodern approach. Thus, with respect to health care provision, postmodern analyses might ask questions such as, “What are the taken-for-granted assumptions and understandings of health care practice that have shaped the way practice settings operate?” “Whose assumptions and understandings are they?” and “Why were other views excluded or marginalized?”

Harman (Harman, 2007) Pojman (Pojman, 2007) and Hyun (Hyun, 2008) see the debate between Relativism and Objectivism as dichotomous. There is a well-developed alternate position summarised by Galston (Galston, 2009, p. 804):

(1) Value pluralism is not relativism. The distinction between good and bad, and between good and evil, is objective and rationally defensible.

(2) Value pluralists argue that objective goods cannot be fully rank ordered. This means that there is no common measure for all goods, which are qualitatively heterogeneous. It means that there is no single summum bonum that is the chief good for all individuals. It means that there are no comprehensive lexical orderings among types of goods. It also means that there is no "first virtue of social institutions", but rather a range of public goods and virtues whose relative importance will depend on circumstances.

(3) Some goods are basic in the sense that they form part of any choice worthy conception of a human life. To be deprived of such goods is to be forced to endure the great evils of existence. All decent regimes endeavor to minimize the frequency and scope of such deprivations.

(4) Beyond this parsimonious list of basic goods, there is a wide range of legitimate diversity--of individual conceptions of good lives, and also of public cultures and public purposes. This range of legitimate diversity defines the zone of individual liberty, and also of deliberation and democratic decision making. Where necessity, natural or moral, ends, choice begins.

(5) The denial of value pluralism is some form of what I will call "monism." A theory of value is monistic, I will say, if it either (a) reduces goods to a common measure or (b) creates a comprehensive hierarchy or ordering among goods.

This approach is more consistent with a "Post Modern" approach where there is no expectation of coherence of values, and much closer to an approach that I would support. My main disagreement is in the opening statement's appeal to "Reason" (objective and rational). The implication here is that values held on the basis of belief are not to be accorded the same status. Many people hold ethical positions based on belief (for example that abortion is wrong) and a framework that disallows such positions is unhelpful. The mother's belief in miracles (section 2.11) needed to be accepted as valid in order to achieve a satisfactory outcome.

4.9 Complex Principlism

I believe that there are principles of ethical behaviour, but as with Value Pluralism there will be variation as to how much weight is given to each principle.

Bioethics is a relational activity; it is about resolving disagreements between people or communities. In any ethical discussion the relevant principles are those held as important by the people involved in the discussion. A comprehensive list of principles applicable to all people is hard to complete but easy to start.

4.9.1 The Principles

As discussed by Rachels (Rachels & Rachels, 2010) truth telling and prohibition of murder are values without which human society would not function. Beauchamp and Childress: (Beauchamp Tom L. & Childress James F., 2009) advocate Justice, Autonomy Non-maleficence and Beneficence. I would add the Well-being of the Collective and Sustainability of the Planet. Thompson et al (Thompson, Faith, Gibson, & Upshur, 2006) in relation to pandemic planning advocate Equity, Individual liberty, Privacy, Proportionality, Protection of the Public from Harm, Reciprocity, Stewardship, Solidarity and Trust. Nussbaum (Nussbaum, 2000) talks of capabilities summarised under the titles; Life, Bodily Health, Bodily Integrity, Senses, Imagination and Thought, Emotions, Practical Reason, Affiliation, other Species, Play and Control over One's Environment. Rarely mentioned in bioethical discourse (Engelhardt being an exception (Engelhardt, 1996, p. 36)), is the importance of the principle of abiding by the tenets of one's religious conviction. As in the example above of the Jehovah's Witness this may be an over-riding principle for some people.

In addition there is the Universal Declaration of Human Rights (United Nations General Assembly, 1948) which is not just a theoretical or rationally argued set of rights but a declaration that has been accepted by all member states. Although this is agreed at an international level this does not mean that it has been implemented and there continue to be breaches of the Declaration around the world (Human Rights Watch, 2012).

4.9.2 The weighing

None of these principles are absolute. In Beauchamp and Childress's terms there are "*Genuine Moral Dilemmas*" (Beauchamp Tom L. & Childress James F., 2009, p. 24). However unlike Beauchamp and Childress I would argue that *whenever* people disagree about a moral issue, that there is a moral dilemma. I think it is unhelpful and arrogant for one party to decide whether a dilemma is "genuine" and if they think it is not genuine, to declare that the other party is "not moral".

As with Value Pluralism there is no agreed ranking of these values. Some values will have widespread support such as truth telling and the prohibition of murder, but there will be others of high importance to some but low importance to others: Article 24 of the Universal

Declaration of Human Rights “*Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.*” (United Nations General Assembly, 1948) would be highly valued in Western Countries and irrelevant in countries with subsistence economies.

Whilst it may seem self-evident that “*Some goods are basic in the sense that they form part of any choice worthy conception of a human life.*” (Galston, 2009, p. 804), I disagree with Value Pluralism in drawing a distinction between this category of values and the “*wide range of legitimate diversity--of individual conceptions of good lives*” (Galston, 2009, p. 804). This concept in fact implies a ranking. In the same way as there is no agreement on what all the principles are, it is unlikely that there will be complete agreement on this basic list.

4.10 Complex Principlism and Cultural Competence in the consultation.

I will now discuss how this theoretical approach might affect a particular consultation based on the premises that: both parties will approach the problem from their own frame of reference; neither is necessarily right, and ethical problems are complex, then a reasonably clear course can be charted. It is unhelpful to divide disagreements into “moral” and other, the process for resolving them is the same.

Where a clinician and patient disagree, the starting point is to accept that the problem is being seen from two different frames of reference, and that the differences need to be understood. Such a consultation might proceed with the clinician outlining their understanding of the information values and beliefs behind their views, seeking to understand the information, values and beliefs behind the patient’s views and trying to determine what the difference was. This might lead to a resolution by either patient or doctor changing their opinion on the best course of action in light of the new information, or acceptance of the merits of the beliefs of the other person. Alternately it might establish that there is an impasse. The premise is that clinician and patient each have a different frame of reference and that a judgement that one is superior or inferior to the other is unhelpful and unable to be established (except possibly in retrospect). The patient and clinician then have three options on how to proceed: to keep talking and continue to try to find a resolution, agree to differ, or end the relationship.

Where clinician and patient disagree and the clinician believes they are right, the presumption is often made that the disagreement is because the patient “does not understand” so the clinician will then “educate” the patient, to understand why they were misguided. This might lead to a resolution by the patient changing their opinion. Alternately there might be an

impasse. With this approach the doctor is likely to make a judgement that the patient is wrong. As before there are three possible options on how to proceed: to keep talking and continue to try to find a resolution, agree to differ, or end the relationship. If the clinician is only interested in “educating the patient” as opposed to understanding why they believe something different then it is less likely that further talking will resolve the problem. If the clinical issue is trivial then the clinician may agree to differ, but it is more likely that the patient will either agree and then not comply or end the relationship.

This theoretical approach is more easily understood by considering a clinical example:

A 39 year old Maori woman was referred to hospital by her GP for investigation of pelvic pain and vaginal bleeding. She was seen by the O and G registrar and had a number of investigations. These were completed late in the evening when the registrar went to see the woman and her partner. He informed her that she was pregnant, but that the pregnancy was in her fallopian tube and that this required an operation and theatre had been booked for the following morning. The woman replied that she had been trying to get pregnant and was pleased to hear that she was pregnant. She was not quite ready to end the pregnancy, and any way she had to be in court the next day to support her cousin. She wanted to go home. The registrar was annoyed with her for not listening to him but followed the usual procedure which was to get her to sign a discharge note that acknowledged that she was going home against medical advice. She was admitted in shock 3 days later to the intensive care unit following rupture of the ectopic pregnancy.

The registrar approached this problem from the perspective that the medical management was right. He attempted to educate the woman, did not accept the validity of her frame of reference, and saw the problem as being that she did not agree with him, therefore there was nothing more to do until she did agree with him. The patient felt she had not been listened to. Her already limited trust in the health system was undermined as she felt that her value on the importance of supporting her cousin was not appreciated by the registrar. She left angrily not wanting to see the doctor again.

Had the registrar approached this from a Complex Principlism stance, he would have had a consultation where he described why he thought the best management was theatre the next day and explained that he needed to understand why she disagreed with him. Such a conversation would have confirmed that the woman was worried about her health (why else had she come to the hospital?) but she placed high value on her other concerns. The doctor might have been able to admit that they did not know in her particular case how likely a rupture would be, or when it might happen. They may well have been able to agree to meet again the following day after the court appearance to review the problem and talk more. The

registrar could also have expressed his concern and given the woman a cell phone contact to ring in the event that she developed more symptoms and wanted to discuss them. Alternately the registrar could have contacted the referring GP to determine whether he would be able to follow up with the woman.

In this scenario the registrar was “right”. The patient did need to have an operation and without it her life was threatened. However the woman was also “right” in that she was able to attend court the next day without harm. The safe compromise resolution was not found. The woman did not trust the judgement of the registrar. If we consider the ethical principles in this case, the registrar was clearly relying on the woman’s autonomy to make an informed decision as to what to do (even though it was going to lead to a bad outcome). He failed to even consider the importance of affiliation or wellbeing of family as being relevant and did not understand that for the woman at that time that principle was the most important.

Such an approach had a higher chance of leading to a better outcome and would have been more congruent with Cultural Competence as I defined in the first chapter:

4.11 Summary

Cultural Relativity and Moral Objectivism both fail to address the problem of how to manage Value Pluralism. Bioethics is a relational activity of resolving differences between people or communities. In a particular bioethical dilemma the principles behind the choice of action of each party needs to be made clear. Next the relative weight applied to each principle needs to be clarified and once that is achieved a negotiation as to what resolution of the dilemma is possible. As ethical problems are often complex, have uncertain elements and continue over time agreement may be limited to the immediate next step, as opposed to a complete resolution of the conflict. If the dilemma is important then it will be revisited time and again when new information comes to light or when the circumstances change. The priority has to be on maintaining the relationship so that discussions can continue.

Chapter 5 Moral Circle

5.1 Moral Circle

Peter Singer coined the idea of the moral circle, as being the circle of beings for whom a person has moral regard (Singer, 2011, pp. 111-120).

Reed and Aquino use the concept of “circle of moral regard” and describe the circle as being more or less expansive: from a narrow set (family, kin, fellow citizens) to a larger set that in the extreme might include all humanity (Reed II & Aquino, 2003). A corollary is that those who are not part of the circle of moral regard are the “out group”. If we relate this to Hyun’s proposition (Hyun, 2008) regarding equal moral worth, it is likely that I will consider all the people within my circle of moral regard as of equal moral worth. Burnside discussed the extent to which Australians do not accept all people as being of equal moral worth by considering the experience of Aboriginals in Australia, Asylum seeking boat people, and the Bali bombers all of whom are treated by the dominant culture in Australia as being of less worth, and he goes on to say:

“The answer I think is this: Australians subconsciously divide human beings into two categories: Us and Other. We think, perhaps subconsciously, “My rights matter, and so do those of my family and friends and neighbours, but the human rights of others do not matter in quite the same way because, (without quite saying it) the Others are not human in quite the same way we are”. (Burnside Julian, 2010, p. 10)

Engelhardt (Engelhardt, 1996, p. 7) describes the idea of moral friends and moral strangers and argues that moral friends are people who “*share a content full morality that provides substantive guidance regarding what is right and wrong*” and are thus able to resolve moral controversies either by rational argument or by appeal to a mutually accepted and regarded moral authority. “*Moral strangers must resolve moral agreements by common agreement, for they do not share enough of a moral vision so as to be able to discover content-full resolutions to their moral controversies.*” He views communities as composed of moral friends and societies as being a combination of communities, with some inevitably being moral strangers to each other.

As will be discussed in Section 6.7 Maori cultural traditions include the idea of Whakawhanaungatanga which is the process of accepting visitors into the family: accepting them into the moral circle. A

All of these approaches have in common the idea that there are people that we are closer to and people that we are further from. Whilst Hyun might assert that we should all be of equal moral worth, the reality is more complicated than that and it is probably more accurate to think of there being a graded continuum of worth.

Reed and Aquino (Reed II & Aquino, 2003, p. 1271) discuss the factors that promote the development of out groups, particularly personal “self-image threat” and maintaining self-esteem through group membership. *“Out-group hostility is often triggered when out-group members pose a realistic threat to in-group physical and psychological well-being”*

They cited the example of the negative response by some citizens to Muslim Americans after the attacks on the World Trade Centre, which was contrasted to other citizens who actively went to aid and support Muslim Americans: a good example of the variation in size of the moral circle.

Where a community is more homogeneous the likelihood of everyone sharing a moral circle is higher. The greater the diversity the more potential there is for the forming of groups that view others outside of their group as “out group”, particularly if their group is physically or psychologically threatened. Wilkinson and Pickett (Wilkinson, 2010) show that the greater income inequality in a society, the less trust there is between members of that society: the less likely that the very rich and the very poor see themselves as part of the same moral circle.

This analysis risks falling into the trap of presuming that there are such things as fixed communities that share all the same values, or the obverse that there are communities within a society that share no values the same. This is a simplistic description of reality. It would be more accurate to suggest that each person belongs to several different “moral circles” (frames of reference, discourse systems) that intersect and support the person’s resistance to undue influence from within any of them. The important issue is how accepting they are of diversity, and of people holding different moral views from them. The more rigid they are in their position, the less tolerant they will be of people who disagree on some aspect of their position, and the less they will be able to see similarities. A good example of this would be the discord in Northern Ireland that is ostensibly based around two different interpretations of the Christian religion. They have a lot in common, but certainly in the past have chosen to focus on what to an outsider might appear a trivial difference.

I (as a Presbyterian) participated in an interfaith discussion of practises and beliefs around death with a Sikh, a Jew, a Jehovah’s Witness, a Buddhist and a Hindu. There were clear

differences in beliefs around for example life after death, but it was remarkable the extent to which all were able to identify rituals and practices that had very similar functions. Together we came up with an agreed metaphor that a death causes a break in the woven fabric of the community and the aim of the rituals and practices was to re-weave the fabric of the community in the absence of the departed person to be able to move forward as a community. Prior to the discussion I perceived the other participants as quite different from me and was pleasantly surprised at how much we shared in common.

If the circle of moral regard of all clinicians included (at least) all residents of New Zealand, the need for policies around cultural competence would be significantly reduced. The fact that only 0.7% of consultations expected to need an interpreter in Canterbury actually had an interpreter (Kara Seers et al., 2012) is hard to explain unless a portion of this effect is the result of non-English fluent people being seen as an “out group” and not deserving of the same level of health care available to English speaking patients.

It may be that the issue is whether people value diversity: that of course there are difficulties as a result of people having different values and beliefs, but that these are outweighed by the benefits. The goal of the New Zealand Office of Ethnic Affairs is “promoting the advantages of ethnic diversity for New Zealand” (Office of Ethnic Affairs, 2013).

5.2 Racism

A subset of “other” groups will experience active discrimination, most commonly on the basis of race. Racism is defined as “A belief that some races are superior to others, used to devise and justify actions that create inequality between racial groups” (Bhopal, 1998). It is widely reported to be an important cause of disparities in health outcomes (Bhopal, 1998; Durey, 2010; Harris et al., 2006) despite declarations both internationally and within countries that discrimination on the basis of race should be banned.

5.3 Summary

The political reality is that most people in New Zealand (or Australia) do not consider all residents and citizens to be deserving of equality of health outcome and this can be understood by considering the idea of a moral circle. Some of the disparity is because of overt racism. With the idea of “culture” people belong to more than one culture and the values and beliefs of cultures are not fixed. Similarly with the idea of Moral Circle, there is probably a gradation in strength of a moral circle. If the matter in question was a choice of who amongst a group of people should die and who should be saved, I suspect most people would save their loved family members ahead of others. The current political position in New Zealand is that

there is superannuation fund that is available to all residents irrespective of need, but decreasing health outcome disparities is not one of the Minister of Health's Targets (New Zealand Ministry of Health, 2013). Our increasingly diverse community will be more troubled if we are unable to find a way to think of all residents as deserving of full participation within the society. A good starting point may well be to put more emphasis on valuing diversity.

Chapter 6 The Relationship of Trust and Power to Cultural Competence

6.1 The Importance of Trust

The report of the Cartwright Inquiry did not mention trust per se, although it talked of “protecting patients”. However in a contemporaneous article Paul (Paul, 1988) explicitly refers to the effect of the findings on trust:

The revelations of the inquiry have damaged this trust and good faith not only in the National Women's Hospital but also elsewhere in New Zealand. Many doctors are extremely perturbed about the new lack of trust. Those doctors need to stop and think. The trust that existed has been shown not only to have been misplaced but to have been dangerous to the women concerned.”

“Inevitably, new consent procedures will be recommended, especially for patients concerned in research and teaching. In the past the principal safeguard for the patient has been the integrity and good faith of the doctor. When that good faith is brought into question at the highest levels in the hospital there must be recourse to other mechanisms to protect the patient. Patients will welcome more information and a greater chance to make informed decisions about their treatments, but I suspect that both doctors and patients will continue to worry about the lack of trust. People who are ill need to be able to trust their medical advisers, but that trust is not bestowed with a higher degree; if it has been abused it will need to be earned again.

In this quote Paul highlights the importance of trust to the provision of healthcare, and the damage to that trust that was caused by the events at National Women’s hospital.

Luhmann (Luhmann) argues that the function of trust is “*the reduction of complexity.*”, as it for example saves the patient from having to understand all the details of treatment if they trust the doctor to make good decisions.

The standard work on medical practice in New Zealand “Coles Medical Practice in New Zealand (St George, 2013, p. 11) remarks on the importance of trust:

You should aim to establish and maintain trust with your patients. Relationships based on openness, trust and good communication will enable you to work in partnership with them to address their individual needs.

Lewis and Weigert noted (Lewis & Weigert, 1985, p. 968) *“trust must be conceived as a property of collective units (on-going dyads, groups, and collectivities), not of isolated individuals.”*

Trust is therefore relational in that whether a doctor is trustworthy is primarily judged by the patient, and that trust is sometimes misplaced.

6.2 Definition of Trust

Rousseau’s definition (Rousseau, Sitkin, Burt, & Camerer, 1998, p. 395) following analysis across several disciplines is accepted by many as a good starting point:

Trust is a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another.

Trust is not a behaviour (e.g., cooperation), or a choice (e.g., taking a risk), but an underlying psychological condition that can cause or result from such actions.

Accepting vulnerability is synonymous with allowing the trusted party to have power over you.

Lewis (Lewis & Weigert, 1985) subdivides trust into three types: cognitive, emotional and behavioural.

Trusting an orthopaedic surgeon to do a good hip replacement based on knowing he has an above average record of successful operations would be an example of cognitive trust. Trusting your Oncologist because he was a class mate of your father’s and a family friend would have elements of emotional trust. Trusting your GP because you have been seeing her for the past 10 years and she has always diagnosed and treated you effectively would be an example of behavioural trust. They went on to say:

In reality these dimensions of the phenomenon are interpenetrating and mutually supporting aspects of the one, unitary experience and social imperative that we simply call “trust.” The roots of trust extend to every modality of human experience but it does not thereby lose its unity(p 972).

In addition to these Rousseau (Rousseau et al., 1998) also included institution based trust: that people can build trust in an institution (particular hospital or profession) augmenting the trust in individuals working within the institution through cognitive, emotional or behavioural input.

6.3 Distrust

Lewicki and Wiethoff (Lewicki & Wiethoff, 2000) talk of Calculus-based trust and Identification based trust that correlate with Cognitive and Emotional trust, but add a discussion around distrust. They argue that distrust is different from trust. In trust, one has positive expectations regarding the other's actions, thereby implying a belief in another person. Conversely, distrust is also a confident expectation, however, one that is negative and implies fear of the other. Distrust can be either cognitive or emotional and the idea can be extended to institutions.

6.4 Cognitive Trust and Emotional Trust

Paul refers to more information and being able to make informed choices analogous to cognitive trust. The trust that ill people need to have in their medical advisors not based on authority is emotional trust. She describes the loss of trust in the institutions of National Women's Hospital and in doctors in general but does not specify whether the "lack of trust" extends to active distrust, undoubtedly a factor for the women at the centre of the inquiry and probably for many others.

Parsons (Parsons, 1969) writing more than forty years ago argues that there is a "Competence Gap" between professional and laypeople as a result of asymmetry of knowledge that was bridged by trust. One of the features of trust that he described was shared values.

The Code of Health and Disability Consumer's rights is based around the doctrine of informed consent. (Working Party on the Establishment of the Health Commissioner(s), 1989)

Implicit in this concept is the idea that in order to agree to undergo a procedure or participate in research "all" that is required is information. The presumption is that people make decisions about participation solely on adequate information, weighing the costs and benefits and making a choice.

That belief runs counter to my personal experience both as doctor and patient.

As a doctor I had the experience of a Maori woman with metastatic breast cancer who had severe back pain. She delayed presenting with her extensive breast cancer for many months, and I suspect only came to me because of knowing me from the Marae and because I had been eeling with her husband. She only agreed to see the radiotherapist if I would go with her. He explained the role palliative radiotherapy could have in controlling her pain. She seemed to barely listen to him but turned to me and said "*I will do what you think is best*"

As a patient I (accompanied by my wife) was consulting a surgeon for treatment of a cancer. He outlined the nature of the problem and then proceeded to describe the various alternatives for treatment. Part way through the explanation I can recall thinking that he had done a really good job of explaining in language suitable for both myself and my wife, that he had an understanding who I was, and that I trusted him as a surgeon (partly from my experience as a GP). At that point I decided that I liked him and did not want any more information and asked him to treat me in what in his judgement was the best way.

In the doctor example she was relying totally on “Emotional Trust” in me as her GP. When I was a patient I needed some “Cognitive Trust” but that in the end it was the “Emotional Trust” that decided me and once I trusted the surgeon I had no need for more information.

These impressions are confirmed in the literature. Faden describes a study of 1900 subjects of research who were surveyed and 103 who were interviewed to find out what subjects thought about research (Faden, 1995). In her commentary (Faden, Kass, Schoch-Spana, & Sugarman, 1996, p. no page numbers in the original) she emphasises the importance of trust in the behaviour of the patients. This included trust in the doctor “...get yourself a good doctor and they’re involved in research, they would never steer you wrong”, the hospital “I think I’ve got the best treatment down there at [named hospital]I don’t think I could get any better” and the research enterprise as a whole “They know what they’re doing. They wouldn’t have you do this if they didn’t know what they were doing” “I don’t believe they would offer me anything that isn’t beneficial to me, in my condition”

This also applied to the consent process: “Many participants expressed that their decision to participate had been made before they had been given the consent form to sign. They knew they wanted to participate, they trusted that it was right and the details described in the form were not particularly relevant”

The idea that information alone is sufficient to make a decision is clearly fallacious at least because a judgement has to be made as to the reliability of that information. That could be cognitively based (I know this doctor is a very experienced Otago graduate) but often there are emotional elements. This is likely to be more so in patients like my Maori woman with breast cancer from more collective communities.

There are two important observations in relation to trust that apply to the increasing diversity in our community. Firstly Lewis and Weigert (Lewis & Weigert, 1985, p. 973) noted that:

Consequently, with population growth and greater structural differentiation, a greater number of social relationships are based on cognitive trust than on emotional trust. Luhmann refers to this as a macro change from a social order based largely on personal or interpersonal trust that characterizes small and relatively undifferentiated societies to a social order based more on system trust (i.e., trust in the functioning of bureaucratic sanctions and safeguards, especially the legal system) that characterizes modern, complex societies.

Secondly Anderson (Anderson, 1971 quoted in Lewis p 980) from a study of family structures in 19th century England observed:

... four parameters that we can use to theorize about the level of trust:

(1) The greater the homogeneity of the group, the higher is the level of trust;

(2) The greater the connectedness of a social network, the greater is the level of trust;

(3) The greater the size and complexity of a community, the lower the level of trust; and

(4) The greater the social change, the lower the trust.

6.5 What is the relationship between trust and Cultural Competence?

In many circumstances, particularly when they are ill patients are vulnerable and have less power than the clinician. That gap in power will be greater if culture is not shared, there is no shared language, or if the clinician has racist views believing the patient inferior because of their ethnic background.

In her discussion of a morality involving relationships of unequal power Baier (Baier, 1995, p. 180) talks at some length about the role of trust in these relationships:

trust is appropriately placed in those who for whatever motives, welcome the equalisation of power, who assist the less powerful and renounce eminence of power...

These comments are of particular relevance to Cultural Competence. The need to build trust will be heightened if the patient has less medical knowledge, or does not share values with the doctor. Increasing diversity means that there is more reliance on cognitive trust. However people from collective societies traditionally rely to a greater degree on emotional trust and cognitive trust is harder to gain where there is a bigger disparity in knowledge.

Overall as Anderson notes levels of trust can be expected to go down (particularly for non-dominant cultural groups) because of increasing heterogeneity, decreased social connectedness, increased size and complexity of the community and increased social change. If there is no shared language then trust building is very difficult.

Institutions tend to reflect the dominant culture so that trust in institutions by non-dominant cultural groups is likely to be less, and for some they are a source of distrust, either behavioural (past bad experience of themselves or their family) emotional (as colonised people Maori have less trust in the coloniser's institutions) or cognitive (health outcomes are worse for many non-dominant cultural groups). I had a patient with terminal breast cancer with metastatic disease who had been on the methadone programme for the previous 10 years. Her pain was poorly controlled in part because she did not want to ask for more analgesia for fear she would be thought to be "drug seeking" and in part because some of the staff who managed her did think she was drug seeking: the patient did not trust the staff to care for her well and the staff did not trust the patient to tell the truth.

As discussed in Chapter 11 non-dominant cultural groups are less likely to have been involved in setting the laws and policies of the community and thus less likely to trust them as fair.

Given the complex nature of modern medicine trust is an essential tool to reduce complexity; if you trust the doctor to make good decisions for you, you do not have to understand it all yourself. People from non-dominant cultural groups due to less familiarity are likely to understand the healthcare system less; thus for them to be able to navigate the system, it is even more important that trust is built. In a health needs assessment report commissioned by the Auckland District Health Board on people from the Middle East Latin America and Africa (Perumal L, 2010, p. 120) interviews with health service providers noted "*a lack of trust and fear of Western systems or models of care*"

As for Cultural Safety trustworthiness is primarily judged by the patient. Where there is a significant power differential trust is enhanced if the doctor welcomes an equalisation of power. Simple examples would be that I deliberately dress more casually, expect people to call me "Dr Ben" rather than "Dr Gray" and take care to frequently check that the patient is happy with the plan I am developing and asking for their input into what we should do. For people with a high trust in the profession of doctors, wearing a white coat, calling myself Dr Gray and being very directive in recommending treatment may work very well, but if that institutional trust is not present then it is my experience that behaving in this way makes

effective practise harder. Either way the patient's judgement that I can be trusted could be wrong.

6.6 Emotional Trust the Importance of Relationship and Whakawhanaungatanga

As noted in Section 6.4 people from more collective societies rely to a greater degree on Emotional Trust, rather than Cognitive Trust. If you live in a village trust will be accorded based on knowing a person, and less on knowing that they have completed particular training. Emotional trust is related to depth of relationship.

Maori have deeply held traditions around how Hui (meetings) should be conducted. Whilst this is most clearly expressed on the "Marae" (Maori traditional meeting house and grounds) the way of living implicit in these traditions flows over into all walks of life for Maori. In his book looking at the dynamics of Maori Health, Durie (Durie, 2001, p. 70) devoted a full chapter based around these traditions to try to elucidate Maori psychology.

Seldom however is there full appreciation of the potential of marae encounters for shaping thinking and behaviour and providing guidelines for codes of living.

The Marae atea is used as a stage for clarifying the terms under which parties agree to come together. Formal debate (whaikorero) a hallmark of encounters on the marae atea is essentially about the negotiation of relationships.

Lacey et al (Lacey, Huria, Beckert, Gilles, & Pitama, 2011) have responded to his view that marae encounters can provide guidelines for codes of living by developing the "Hui Process" as a framework for clinical encounters with Maori patients. It contains four key elements:

Mihi: initial greeting and engagement

Whakawhanaungatanga: making a connection

Kaupapa: attending to the main purpose of the encounter

Poroporoaki: concluding the encounter.

The standard system for teaching clinical interviewing at Otago University "Calgary-Cambridge" (Silverman, Draper, & Kurtz, 2005) is an evidence based model of how to conduct consultations. They describe seventy one elements to the consultation under headings of initiating the session, gathering information, physical examination, explanation and planning and closing the session (See Chapter 7 for diagram).The Hui process was explicitly aligned with

“Calgary-Cambridge” but whakawhanaungatanga does not quite map onto any of the elements described in that model:

The primary focus of this stage is connecting at a personal level with the patient and any whanau present. This process is based on a traditional format of engagement within Maori cultural protocol, and is often mistaken as ‘building rapport’. Building rapport is important and is a usual step with all patients; however engagement with Maori patients and whanau requires a further step. Whakawhanaungatanga requires clinicians to draw on their understanding of Te Ao Maori [Maori world] and relevant patient and whanau [family] Maori beliefs, values and experiences. This may be in terms of the patient’s whenua (land) connections, whanau involvements, use of te reo (Maori language). This should not only include identification of these aspects of the Maori patient, but critically should include some self-disclosure of the student/doctor about their own experience of these aspects. At times it may not be fruitful to pursue the medical agenda until this point of shared experience is reached. This is a key point of difference from existing clinical skills teaching and something established clinicians may consider challenging where no self-disclosure has been taught, often as part of establishing boundaries. Similar boundaries exist within Te Ao Maori and the ‘Hui Process’ and obviously limits of self-disclosure must be considered..... It is often noticeable when a connection has been made, for example, as indicated by the patient asking personal questions, change in body posture, or use of humour. It is emphasised that Whakawhanaungatanga is not a one off event and there is a need to attend to connecting with the patient and whanau throughout the consultation (Lacey et al., 2011, pp. 73-74).

The following case study was written as an assignment for me by Rhys Parry, one of my students, where he used the Hui Process (Lacey et al., 2011) as the framework for taking the case history.

Patient:

TW, a 59 year old NZ Māori female, presented short of breath at rest and was admitted after a home visit by a respiratory nurse found her unable to complete short sentences. She had recently been discharged for a similar episode.

Past history:

CHF with Non ST Elevation Myocardial Infarction 2009

Chronic Obstructive Pulmonary Disease

Asthma

Obesity hypoventilation syndrome

Type 2 diabetes (insulin)

Atrial fibrillation

Severely limited mobility due to osteoarthritis and obesity

I met TW in a two-bed room, on the respiratory ward of Wellington hospital. It was Friday afternoon and TW was into her fifth day of a stint in hospital for a flare of pulmonary oedema. I was introduced to her in order to interview a Māori patient as part of the Hauora Māori module.

At the outset, the purpose of this interview, at least in my mind, was to collect as much information relevant Hauora Māori assignment in as little time as possible. I was conscious of my conceived 'heavy workload' – case histories to take, a 'long case' to write up, articles to be read. So, on a Friday afternoon this interview was to be as 'quick and dirty' as possible. It soon became apparent that this was not unfolding as I'd envisaged it to.

I had to take a Māori-specific patient history, based on the principles of the hui process: mihi or introduction; whakawhanaungatanga, the building of relationship; kaupapa, the gathering of information; and poroporoaki, the process of farewell. Following this process put paid to my plans of a quick Friday afternoon chat; if I wanted to do this right it was going to take some time.

As part of the mihi process, we exchanged stories about where we'd come from: TW talked of her childhood; being raised by her grandfather and how she spoke Te Reo at home. Her Ngāpuhi heritage gave an opportunity to create a common bond, as my wife also has Ngāpuhi ancestry. I shared that my wife was raised knowing little of the customs and beliefs of Te Ao Māori (the Māori world), and TW noted that you "have to want to get involved" – even some of her moko (grandchildren) have not connected with their Māori heritage, she said.

As we got to talking and I sat back and actually listened (as opposed to charging in with question after question) I began to discover a lovely and vibrant, but broken lady. The interview progressed in a semi-structured kind of way, loosely following the pattern described above and that of the Meihana model, where health is seen as encompassing six different facets (tinana – physical health, whānau – the family aspect, hinengaro – mental health, wairua – spiritual health, taiao – the environmental aspect, and iwi katoa – the wider societal aspect).

TW stated on more than one occasion, "I feel responsible for where I'm at", referring to her current poor health state. After about an hour, I said to TW that it seemed as if she had come to a point of realisation and that she was starting to take ownership of her health. This seemed to resonate with her, as she broke down in tears, saying that was exactly how she felt and it had taken her a very long time to come to this awareness. She believed she had played a large part in her current poor health state, in that she had neglected to take care of herself, and had deferred seeking help for health concerns. We talked of the opportunity to take ownership of her health and she felt our conversation gave her an opportunity to "get a load off her chest" and that she hoped "people would see a change in her". I felt privileged (and couldn't help but feel a tug at the heart-strings) to be a conduit for TW to reflect on the state of her health and to come to such a revelation, and ultimately play some small role in her healing process.

This case illustrates how the Hui Process can work, and in particular the inclusion of some personal detail from the clinician: the fact his wife was from the same iwi.

The literal definition of *Whakawhanaungatanga* can be understood by splitting the word up into parts (Auckland University of Technology) .

Whaka is *“to cause something to happen.”*

Whanau *“extended family, family group, a familiar term of address to a number of people - in the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.”*

Tanga *“a suffix used to make nouns into verbs.”*

Whakawhanaungatanga “(noun) process of establishing relationships, relating well to others.” Literally it is the process of becoming family.

This is further expanded in *“He Hinatore ki te Ao Maori”* (Clarke, 2001, p. 32):

The close relationship engendered between members of the whanau as a consequence of working together is referred to as whanaungatanga. Whanaungatanga is of fundamental primacy because it determines and connects a person to chosen kin groups from immediate to extended family, to hapu (sub tribe), to iwi (tribe), providing people with a sense of belonging. It developed as a result of kinship rights and obligations which also served to strengthen each member of the kin group, as well as the kin group who shared such values as aroha (love care respect and affection in its widest sense) pono (to have faith and trust, be true to family and tribal values) and tika (be correct, straight, true, direct, keep on a direct course, upright, right, just, fair, accurate, appropriate, lawful, proper.) with each other.”

The key elements to emphasise from this are that it involves shared values and there are rights and obligations.

Whakawhanaungatanga is a key element of the traditional hui on the Marae *“It exists in the speeches delivered during the powhiri (welcome ceremony). The tangata whenua (hosts) and manuhiri (guests) relate to each other and establish their whanaungatanga through the linking of whakapapa (genealogy) (Clarke, 2001, p. 189).* In a traditional sense if you could establish that you were related (part of the whanau) to the tangata whenua (people of the land, hosts) then you literally had standing on that marae. The marae of an iwi is known as their turangawaewae. Literally it is the place to stand *“domicile, place where one has rights of residence and belonging through kinship and whakapapa”* (Auckland University of

Technology). In attending traditional hui having an orator with genealogical knowledge is valued because if there are family links then this deepens the process of whanaungatanga. As part of the powhiri it is essential that the manuhiri describe where they are from and their whakapapa (genealogical links) so that the tangata whenua in turn can identify from their part what overlap of whakapapa there is thus expediting the ability to welcome the guests as “family”. There is a strong link between whakapapa and geography: by definition every iwi has a turangawaewae. This linkage is underlined linguistically. Tangata Whenua means people of the land. An alternate meaning for Whenua is placenta. The placenta is traditionally buried in a special receptacle and buried on the land (Te Ahukaramū Charles Royal, updated 1-Mar-09).

Whanau is used in a broader sense in modern times to include friends or colleagues who are not necessarily related. It is in this sense that *Whakawhanaungatanga* is used in the medical consultation, but the term carries with it shared values, rights and obligations and accountability that exist in the traditional concept. The cultural norm for Maori is that Whakawhanaungatanga precedes Kaupapa and that ignoring this aspect of the encounter not only does not build trust, there is a risk of instilling distrust by failing to value relationship/emotional trust, which is highly valued by Maori. This has clear parallels with the idea of Moral Circle discussed in Chapter 5. It is a very explicit process of establishing inclusion within the moral circle.

Whilst Calgary-Cambridge does not have an equivalent element that maps to Whakawhanaungatanga, building of the relationship is a central feature of the consultation which is based around “Relationship Centred Care” (Beach, Inui, & the Relationship-Centered Care Research Network, 2006, p. S7):

Relationship-centered care is health enhancing. It is founded upon, proceeds within, and is significantly influenced by the web of relationships that promote the well-being, and full functioning of patients. In RCC, the patient is often our central concern, but is not considered in isolation from all others. Instead, while the clinicians' first responsibility is to prevent and alleviate illness, we do this work mindful of the contributions of the family, our team, our organizations, and our community to what can be accomplished.

6.6.1 Summary on Whakawhanaungatanga

The development of emotional trust, which is closely aligned with developing a trusting relationship is seen by Maori as being an essential element of a good consultation with a Maori patient. There is a cultural expectation that this must be attended to prior to the rest of the consultation (or meeting). Whilst the details are culture specific (other cultures do not

emphasise the trust building before starting) the emphasis on relationship in Calgary-Cambridge suggest that developing generic skills in relationship building is needed, and the Hui process may well have relevance with some modification to other cultural groups. Building of relationship is now a central element of the consultation as taught at Otago University and many other medical schools. The Calgary-Cambridge method has only been in the curriculum for the past 3 years, so this is not necessarily accepted as current practice by clinicians trained before this.

6.7 Misplaced Trust

Unlike cultural safety there are times when the patient's assessment of trustworthiness is misplaced: the women in Professor Green's experiment are a clear example. The assessment of trustworthiness is primarily judged by the patient because if the patient judges the clinician as not being trustworthy then the clinical relationship will not proceed smoothly; the patient is unlikely to follow investigation and treatment recommended and may not return. However, because there are elements of trustworthiness that the patient cannot assess, there are professional obligations from the clinician's colleagues to be alert to untrustworthy behaviour and to have reliable systems to respond to any concerns. Systems such as the reporting of "Patient Safety Incidents" and investigations of such incidents, and reaccreditation programmes where clinicians have to demonstrate on-going competence by involvement in continuing education, practice audit and peer review activities have been introduced in recent years to try to address this issue. The complaints system run by the Health and Disability Commissioner is another important system response to try to ensure clinicians are trustworthy; if a patient is unhappy they have an effective avenue to lodge a complaint such that it will be investigated where appropriate and the clinician brought to account if that is necessary.

6.8 Trust at a Societal Level

We can easily forget how fortunate we are in New Zealand. We are relatively free from corruption (Transparency International, 2012) ranking 2nd out of 178 countries. Our police and Judges are not bribed, our medications are safe and comply with the package labels, our health professionals have all been trained properly for the job they do. Developing trust further down into the community is much easier if it is built on a foundation of trustworthiness at the societal level.

6.9 Summary

Trust is an essential pre-requisite of a functional doctor-patient relationship. The greater the power imbalance between doctor and patient, the greater the importance of trust. Increasing diversity undermines emotional trust. More collective cultures rely to a greater degree on relationship/emotional trust, larger diverse more individualistic cultures rely more on cognitive trust. Maori in particular have strong traditions requiring the building of relationship/emotional trust as an essential prerequisite to any meeting. Trust can be misplaced by patients and this risk can be mitigated by professional oversight, expectation of on-going training, and systems for reporting patient safety incidents and responding to complaints. Understanding how to build and maintain trust and repair loss of trust are is an essential element of Cultural Competence.

Chapter 7 Fair Process and Cultural Competence

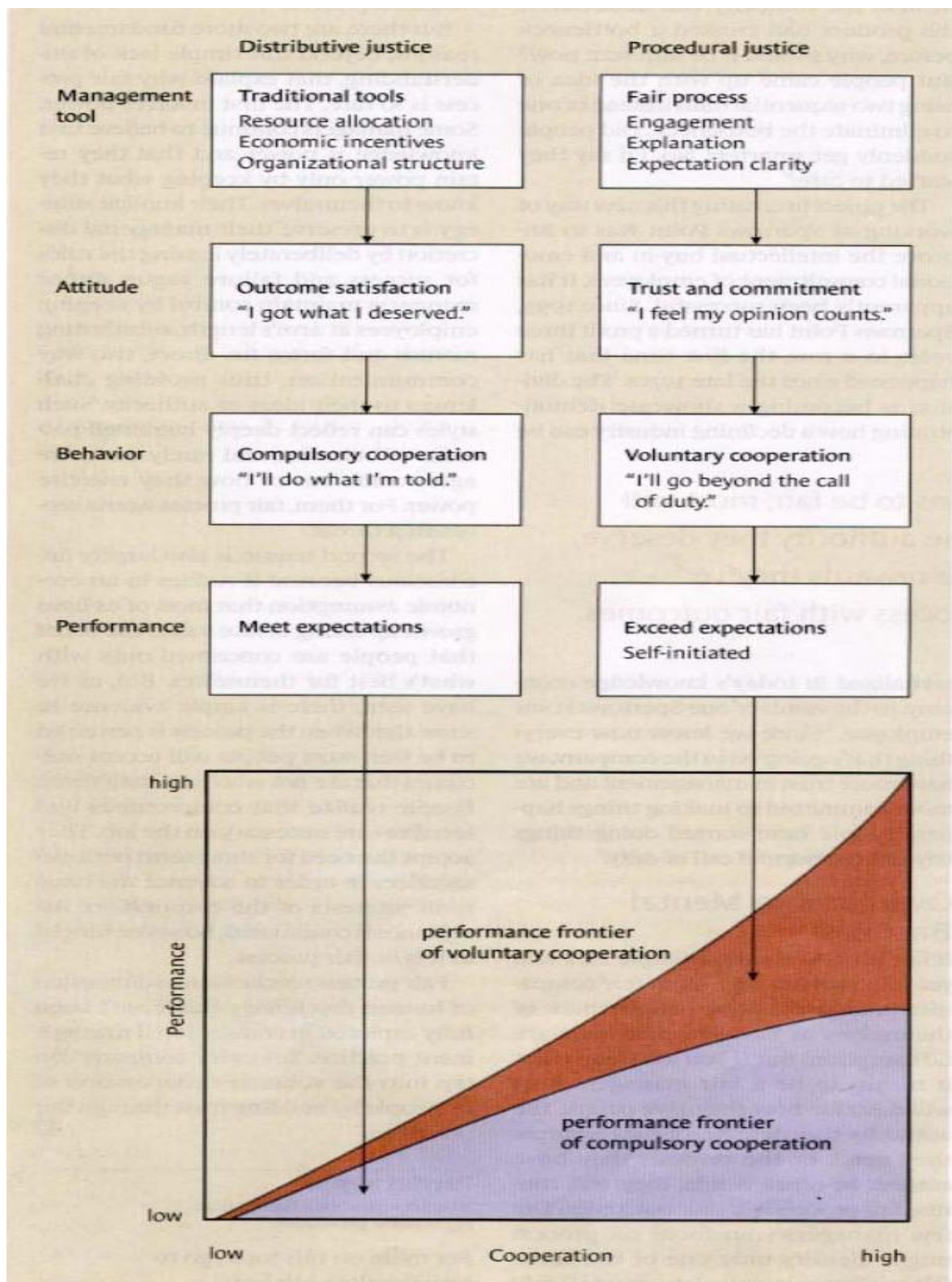
If cultural competence is about lessening health outcome disparities, then this translates into a belief that there should be equality of opportunity. Rawls (Rawls, 1999, p. 75) discussed the importance of “Procedural Justice” as a prerequisite for equality of opportunity. He started by discussing “*imperfect procedural justice*” exemplifying this by looking at a criminal trial. A procedure has been set up to try to achieve the outcome that a defendant is declared guilty if and only if he has committed the offense with which he is charged. In this discussion he notes that whilst there is a “correct” answer (the accused either did or did not offend) the process will not necessarily reach that answer, the procedure is imperfect: an innocent man may be found guilty or a guilty man found innocent. In this formulation the presumption is that there is agreement that the procedure is as good as we can make it and mostly gets the right result. This does not seem to apply well to bioethical problems as it is predicated on knowing that there is a “correct” answer.

More applicable is his formulation of pure procedural justice (Rawls, 1999, p. 75):

Pure procedural justice obtains when there is no independent criterion for the right result: instead there is a correct or fair procedure such that the outcome is likewise correct or fair, whatever it is, provided that the procedure has been properly followed.

Kim and Mauborgne (Kim & Mauborgne, 1997, p. 65) discussed the concept of fair process in their study of business corporations. They noted that people care about outcomes, but “*they also care about the processes that produce those outcomes. They want to know that they had their say—that their point of view was considered...*” Their research with 19 companies found a direct link between organizational processes, attitudes, behaviour, and performance. As shown in Figure 9 they argue that procedural justice in the form of fair process leads to trust and commitment, voluntary cooperation, and exceeded expectations.

Figure 9 Two Complementary Paths to Performance



Applied to the clinical encounter, even if in the end the patient agrees with the outcome decided on by the doctor, not being involved in the process of reaching that decision loses the opportunity of developing trust and increasing commitment. In situations where the strength

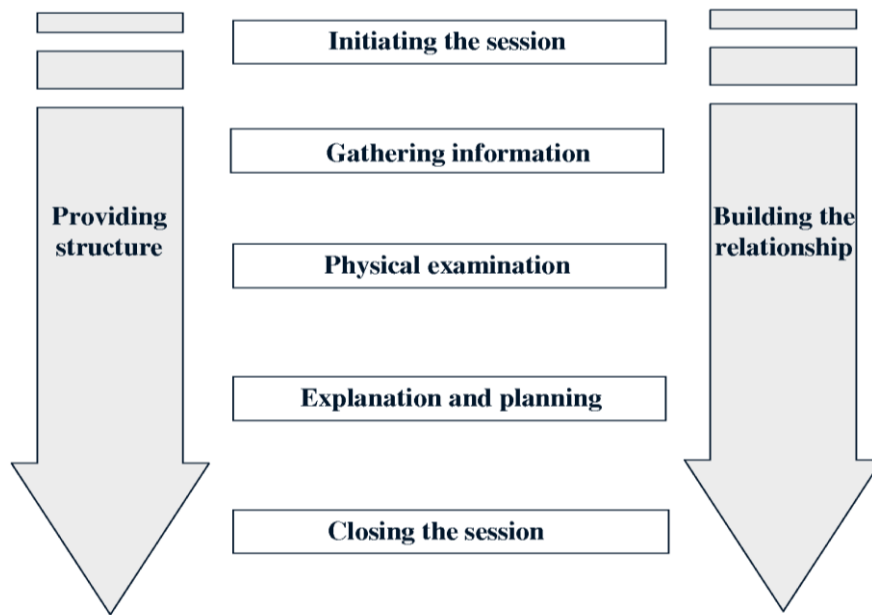
of argument supporting the clinician's preferred outcome is weak, and the patient disagrees, a failure to adhere to fair process is likely to lead to alienation and "non compliance".

Lorenz (Lorenz, 2007) discusses this model as it might apply to brain injury patients. She argues that a focus on fair process means that the patients with brain injury became more involved in their healing. She points out that because of problems with memory and focus that these patients often do not have the opportunity to express their views about management. In this study the patients used portfolios of photos to express the way the injury affected them and as a result felt more engaged with the process. This is an example of what the NZNC describes as empowering the patient. Because of their brain injury there was a larger than usual gap in power in their relationship with their clinician, that was lessened by attention to fair process.

These ideas are not new and have been expressed and acted on extensively. The whole move to "patient centred medicine" (Stewart, 2003) was an attempt to make the process fairer...to include the patient more. Silverman (Silverman et al., 2005) developed the "Calgary-Cambridge" consultation method (see Section 6.6) based on evidence that doctors frequently failed to listen to patient concerns (Silverman et al., 2005, p. 35), did not involve them sufficiently in planning, and did not give them the information that they wanted (Silverman et al., 2005, pp. 41-42). They also emphasised the importance of building a relationship: a task that is much harder in a patient from a different cultural background, particularly if there is limited or no shared language between patient and clinician.

There are significant overlaps between the "Fair process" diagram (figure 9) and the diagram of the "Calgary-Cambridge" consultation model (Figure 10). Fair Process involves engagement and explanation, Calgary-Cambridge initiating and explanation. Fair Process involves trust commitment and voluntary co-operation, Calgary-Cambridge requires relationship building. Fair Process leads to voluntary co-operation and exceeding expectations, which are clearly the goals of a good medical consultation.

Figure 10 Calgary-Cambridge Guide: A Guide to the Medical Interview



It is interesting to note that the Calgary-Cambridge method of consulting with patients was developed from an understanding of cross cultural consultations (Silverman et al., 2005, p. 215).

Attention to fair process will lessen the power imbalance in the clinical relationship and is an important part of Culturally Competent care.

Chapter 8 Cultural Competence, the Code of Health and Disability

Services Consumers' Rights and the Health and Disability

Advocacy Service

8.1 The Code of Health and Disability Services Consumers' Rights (The Code)

The Code came into force on July 1st 1996 (Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations, 1996). It represented a significant step forward in making explicit what patients could expect from health care providers. A particularly important element was the inclusion of “disability services” (as noted by Skegg (Skegg, 2011)) consequential on the government changes whereby disability services became funded under Vote Health in 1993.

8.1.1 The Code as a Whole

In a detailed article assessing the impact of the Code on the New Zealand health landscape, Skegg has concluded that The Code has been a “Fortunate Experiment” (Skegg, 2011), a conclusion that I agree with. My view is that it has been particularly effective for the dominant cultural group but that there are some important limitations to the Code as it applies to some non-dominant cultural groups.

8.1.2 Institutional Trust

As discussed in Chapter 6, trust is centrally important to any doctor patient relationship but particularly so for those not from the dominant cultural group. A major function of the Commissioner is responding to complaints alleging breaches of the Code. A complaint represents a loss of trust and an effective complaints management system is essential to try to repair that trust. The high public profile of the previous Commissioner Ron Patterson meant that the community knew that if complaints were made, they were taken seriously and action was recommended and often followed up on.

8.1.3 Provisions of the code

The following provisions of clause 2 of the code are of particular importance in relation to Cultural Competence:

RIGHT 1

Right to be Treated with Respect

3) Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Maori.

RIGHT 2

Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.

RIGHT 5

Right to Effective Communication

1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.

Of particular significance is the clear conclusion from Judge Cartwright that there was a need for a more patient/consumer centred approach. The concept of Patient Centeredness has been developed over the years since Balint first coined the phrase in 1969 (Balint, 1969). Saha et al (Saha et al., 2008) give a thorough description of the development of Patient Centeredness and then go on to compare and contrast that concept with the concept of Cultural Competence. They argue that whilst there are many similarities between the concepts, there are important differences. The Code reflects the values of patient centeredness and to the extent that there is an overlap with cultural competence, reflects those values as well. However there are elements of Cultural Competence that are not part of Patient Centeredness that are missing from the Code which I will describe below.

8.1.4 Right 5(1)....Where necessary and reasonably practicable, this includes the right to a competent interpreter.

This is the provision of the code that is most troublesome in relation to Cultural Competence. Analysis of the documents prior to enacting the code sheds some light on this. Judge Cartwright's report (Sylvia Cartwright, 1988, p. 213) said:

6 b (i) "There must be greatly improved communication with all patients and improved information available in the first language of those attending the Hospital for inpatient or out-patient treatment or management. Interpreters must be provided wherever possible"

The Health Commissioner Bill (1990) as introduced into parliament explicitly included a requirement for interpreters:

17 Code of Health Consumer' Rights-

(3) In preparing a Code of Health Consumers' Rights, the Commissioner shall ensure that the Code contains provisions relating to the following matters:

(d) The provision of interpreters to ensure that health consumers are able to communicate with health care providers in the health consumer's first or preferred language: (1990).

The emphasis on this in the enacted law (1994) was lessened:

20 Content of the Code

A Code of Health and Disability Services Consumers' Rights prescribed by regulations made under section 74(1) of this Act shall contain provisions relating to the following matters:

(d) The duties of health care providers and disability services providers as they relate to the measures (including the provision of interpreters) necessary to enable ...consumers to communicate effectively with...providers"

In the proposed draft code the clause was "*where needed and where practicable this includes the right to an interpreter*" (Health and Disability Commissioner, 1995b) but the Commissioner did note that

This right makes providers responsible for supplying interpreters. It is not acceptable to expect a consumer to bring family to interpret or for providers to rely on unqualified interpreters such as cleaning or kitchen staff (Health and Disability Commissioner, 1995b, p. 28).

In the draft code that was forwarded to the Minister the clause was changed again following submissions with the commissioner noting:

Many submissions urged that the words "where practicable" be removed and noted that they were unnecessary in light of Clause 3. Hence the words have been deleted.

In her commentary explaining the amendments to the draft code the commissioner said:

I have added the words "and reasonable practicable after the words "where necessary". There will be circumstances where an interpreter is needed but it is not practicable to provide one because there is not enough time eg, in an emergency. It may also be impractical to expect a sole practitioner in a rural location to provide an interpreter. I believe it is important to acknowledge this reality so that both consumers and providers are clear about the matter. I support the presence of interpreters as an aid to improved communication and in many situations I would expect this need

would be anticipated and catered for. However this right should recognise there will be situations where health or disability services have to be provided in circumstances where it will not be reasonably practicable to obtain the services of an interpreter. There would be obvious compliance costs issues if an interpreter was to be provided in every “necessary” situation irrespective of whether it is reasonably practicable to do so (Robyn Stent, p. 3).

The final code wording in the regulation adopted by the Executive Council was “*Where necessary and reasonably practicable, this includes the right to a competent interpreter.*”(Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations, 1996)

The code has been reviewed three times (Health and Disability Commissioner, 1999b, 2004, 2009). On each occasion issues have been raised in relation to the clause on use of interpreters. In 2004 (Health and Disability Commissioner, 2004, p. 34) a majority of submitters supported a strengthening of the clause, which the Commissioner did not support. In 2009 submissions were made asking HDC to implement a national interpreting service, which the Commissioner supported the ideal of but felt it was not within the scope of the HDC (Health and Disability Commissioner, 2009, p. 25) After each of these reviews the government made no amendments to the code in relation to the use of interpreters.

This is the only right within the code which is qualified ***within the right*** by “*where practicable*” in addition to the qualification in Clause 3 “*reasonable actions in the circumstances*”. This could be taken to suggest that providers might be more justified in ignoring this right than other rights; which in fact they do in New Zealand where infrequent use of professional interpreters both in Primary Care and the Emergency Department is “usual practise” (B. Gray, Hilder, & Donaldson, 2011; B. Gray, Stanley, Stubbe, & Hilder, 2011).

This is a matter of considerable concern, because without a “competent” interpreter it is impossible to comply with Right 1 (take account of needs values and beliefs...) Right 2 (3) services consistent with his or her needs, Right 6 to be fully informed, Right 7 to make an Informed Choice and give Informed Consent, and probably Right 10 the right to complain.

I have argued elsewhere (Ben Gray, 2011) that for a significant procedure, valid legally acceptable informed consent cannot be given without the use of a professional interpreter. Unless the qualifications of the interpreter have been validated, the clinician has no idea whether the information discussed has been interpreted accurately.

There has been one HDC Report on a case where the lack of an interpreter was highlighted (Health and Disability Commissioner, 2002b) (see fuller discussion in Section 3.6).

8.1.5 Maori Cultural Competence

Maori are mentioned explicitly in **Right 1(3)**

“Every consumer has the right to be provided with services that take into account the needs, values and beliefs of different cultural religious, social and ethnic groups, including the needs, values and beliefs of Maori.”

This has less emphasis than had been suggested at several stages of the development of the code. The working party (Working Party on the Establishment of the Health Commissioner(s), 1989) wanted a “bicultural” commission with a Maori (and non Maori) commissioner. They wanted explicit reference to the Treaty of Waitangi. The Bill (1990) made no mention of biculturalism but did include

6. Treaty of Waitangi

In exercising or performing any power of function under this Act every person shall take into account the principles of the Treaty of Waitangi.

This clause was dropped in the Act. In the code review of 1999 (Health and Disability Commissioner, 1999b) the then Commissioner recommended adding a “Treaty Clause” to both the Act and the Code. In 2004 (Health and Disability Commissioner, 2004) submissions were made to add a “Treaty Clause” to both the Code and the Act. The commissioner recommended (1.4.3) to add such a clause to the Act but not the Code. No amendment has been made.

8.1.6 Cultural Bias

Whilst the code does explicitly acknowledge the needs of all diverse communities, it none the less has a significant cultural bias. The Kaiwhakahaere (Maori director) from the Health and Disability Commissioner noted:

“The cultural norm for Pacific Island people makes it difficult for them to complain and the concept of the Code of rights is hard to accept.” (Health and Disability Commissioner, 1999a, p. 23).

A broader example is the emphasis on informed consent. *“The core of these patient rights is expressed in the doctrine of informed consent”* (Working Party on the Establishment of the Health Commissioner(s), 1989, p. 2).

This is an approach to decision making that is more acceptable for people from an individualist society and less acceptable for people from a more collective society. Beauchamp and

Childress (Beauchamp Tom L. & Childress James F., 2009, p. 106) hold the view that this is a universally ideal method of decision making and describe a story of the Navajo preference not to discuss the possible negative consequences of treatment because *“thought and language have the power to shape reality and to control events”*. The implicit presumption in this story is that the Navajo are wrong in this belief and that they would be better to comply with the norm of “informed consent”. Had they not presumed the Navajo view to be wrong and investigated this further they would have found that in fact there is sound scientific basis for the Navajo belief well documented by Moerman (Moerman, 2002) in his book on the “Meaning” (placebo) effect.

The case study from Saudi Arabia (Adlan & ten Have, 2012) (Section 9.3.1) illustrates some of the problems of informed consent when there are issues of power disparity.

More recently and more mainstream, Atul Gawande (Gawande, 2002) discusses the balance between informed consent and kindness and competence, suggesting that there are times when “paternalism” is the best course.

Informed consent is an empowering provision. The right to information explicitly lessens the asymmetry of power relating to information where the clinician has more than the patient. This is less effective if the patient does not share an “explanatory model” (see section 9.2) or if there is a large information gap. If the patient does not know they have a gall bladder, being told there is a stone in it is of limited help in understanding.

8.1.7 Respect for Dead bodies

In consultation on the draft code Maori and Pacific Island groups wanted Right 1 to apply to deceased persons (Health and Disability Commissioner, 1995a)(Appendix B p 12).

This was not included in the final code. Including such a clause would have involved other legislative change as under current law deceased persons do not have legal rights. Nonetheless this is an important issue for these groups of people that could have been progressed if government had wanted to.

8.2 Health and Disability Advocacy Service

The Nationwide Health and Disability Advocacy Service was formally established in 1996 under the Health and Disability Commissioner Act (1994). The purpose of the advocates is to make people aware of the code and to be available to advocate for patients to resolve complaints about health or disability services. They managed 26,000 calls last year (Health and Disability Commissioner, 2012a, p. 16).

Forty-eight advocates are located around the country in 25 community-based offices from Kaitaia to Invercargill. Specialist Deaf advocates and refugee/migrant advocates work with these communities to ensure they are aware of their rights, as well as educating health and disability providers on how to make their services more responsive to these consumers (Health and Disability Commissioner, 2012b).

This is a really important addition to the code as a tool to improve the Cultural Competence of the system. Importantly it is reliant on relationships: an advocate supporting the complainant to sort through their problem. The Kaiwhakahaere (Maori director) has noted the importance of face to face contact with Maori and Pacific people and that they are less likely to respond well to telephone advocacy (Health and Disability Commissioner, 2001, p. 15). This shows an ability to appropriately adjust services to meet the needs of different cultural groups. It is significant the way in which it has developed: the range of advocates are heavily weighted towards non-dominant cultural groups: the deaf (2), refugees and new migrants (3), Maori (half the remaining) and Pacific (1)(Health and Disability Commissioner, 2012b).

New Zealand Pakeha continued to make the largest number of complaints (67%) with New Zealand Māori making 13% of the complaints. Pacific people made 2% of complaints in 2011/12. The remainder of complaints were from a wide range of ethnic groups, including a small group of people who declined to provide their ethnicity (Health and Disability Commissioner, 2012a, p. 20).

The ethnic split of complaints compares to proportions of the total populations (2006) NZ European 68% NZ Maori 15% and Pacific 7% (Statistics New Zealand, 2006) (likely to be higher proportions of Maori and Pacific given projections and this data is 7 years old). The proportion of complaints for Maori are close to the proportion in the population, although given the health outcome disparities it might have been expected for complaints to be higher. This most likely reflects the significant efforts made to reach out to Maori and the societal change whereby Maori have been given greater recognition and are exerting more political power. A Maori director “Kaiwhakahaere” was appointed to the senior management team in 1997 (Health and Disability Commissioner, 1997) and each annual report documents significant activity in connecting with Maori groups around the country. The level of complaints for Pacific people is significantly lower than the proportion in the population. The Commissioner is aware of this and there have been several initiatives to increase contact with Pacific people: for example the Moana Ole project to improve awareness of the Code amongst Pacific people (Health and Disability Commissioner, 2002a, p. 14). Despite these efforts the level of complaints received from Pacific people have been consistently around 1-2% (Health and

Disability Commission, 2006; Health and Disability Commissioner, 1997, 1999a, 2001, 2002a, 2011).

The advocates are well trained. The focus is on resolving complaints promptly, where necessary with face to face meetings with the complained of health provider. If they are unable to resolve the complaint then this can be forwarded on to the Commissioner for consideration of a formal investigation. In evaluating the service there is a high level of satisfaction with the service (Health and Disability Commissioner, 2012a, p. 21).

They do a lot of work publicising the code in a variety of fora and make regular visits to health and disability residential facilities.

8.3 Relationship and Trust

Given Paul's emphasis on the loss of trust (Paul, 1988) it might have been helpful for the Code to put more emphasis on how trust, particularly emotional trust, might be built. She noted that the cognitive trust building of more information and better decision making would help, and there is the important element of trust building that results from an effective complaints procedure. The Advocacy Service has compensated for the limitations in the Code by weighting advocacy towards non-dominant cultural groups, and putting more emphasis on relationships. The Code is widely promulgated, the complaint and advocacy services are widely used, and yet we still have all the issues that Cultural Competence was introduced to deal with insufficiently addressed. I wonder whether this is because this system has worked very well for the dominant cultural group that place greater reliance on cognitive trust, but has failed to adequately address issues for non-dominant groups. The language of Rights does not sit well with the language of Trust. For a trusting relationship a Code of Rights is useful so that there is clarity of what each in the relationship expects of each other but the point at which a Right is asserted is often the point at which the relationship is deteriorating. Rights are more available to those who have the political power to assert them. As noted section 3.6, there is only one report on the HDC website when searching for the term "interpreter" (Health and Disability Commissioner, 2002b). Rights work better where the relationship is more equal in power, and less well where there is significant power imbalance. A consequence of the use of "Rights" language is that there is no reference in the Code to any relationship, let alone a trusting relationship. The code obliquely implies relationships by talking about duties of providers in clause 2: you have a duty to someone, but the explicit duties in the code only refer to issues relating to complaints in Right 10. There is also no mention of the word "Trust". Right 4(2) refers to providing services that comply with legal, professional, ethical, and other relevant standards. Issues of trust are addressed indirectly through that provision: as noted in

Section 6.1 the Medical Council requires doctors to “*aim to establish and maintain trust with your patients. Relationships based on openness, trust and good communication will enable you to work in partnership with them to address their individual needs*” (St George, 2013, p. 11), but this seems insufficient to address Paul’s sense that a loss of trust is the central issue.

It does not sit well in a Code of Rights but my suggestion is that the following clause should be added to the Code:

Providers have an obligation to aim to establish and maintain trust with their patients and to develop relationships based on openness, trust and good communication to enable them to work in partnership with patients to address their individual needs.

8.4 Summary

The Code has been effective in improving health and disability services in New Zealand. However, all the issues behind the development of Cultural Competence have either developed or not been effectively addressed during the time the Code has been in operation. The lack of emphasis on the importance of interpreters is a major failing for patients with limited English proficiency and basing the rights around the doctrine of informed consent is culturally biased towards those cultures that rely to a greater degree on cognitive trust, and is problematic in many situations where there is a significant disparity in power or knowledge. The advocacy service has made strenuous efforts to overcome this bias. This has led to significant involvement in the process by Maori, but much less so by Pacific people. The Code makes no mention of the importance of a functional trusting relationship and would be improved if such a clause were included.

Chapter 9 Clinical Case Studies Illustrating elements of Cultural Competence

9.1 The Tragedy of Tovia Laufau was this caused by an absence of trust?

9.1.1 The Case

Tovia Laufau, a 13 year old Samoan boy first presented to the GP in May 1998 with a sore knee. This was diagnosed as an infection and treated with antibiotic. In January 1999 he was seen again with a limp that he attributed to a game of rugby, and was treated with anti-inflammatory pills. He was seen again on Jan 18th, 29th Feb 12th by the GP or locum and then referred to Middlemore Hospital, where he was admitted for ten days for investigations, including a biopsy under general anaesthetic. He was diagnosed with osteosarcoma (a form of bone cancer) on 25th March 1999. The family were referred to Starship Hospital and seen on March 29th. The oncologist at Starship told Mr and Mrs Laufau that with recommended treatment (involving chemotherapy and surgery) Tovia had a 60-70% chance of full recovery; without it he would die. Mr and Mrs Laufau asked to talk to family, and return the next day. They never returned, nor did they seek any further treatment or help from Starship, despite a concerted effort by staff to make contact. (This included their GP, Samoan social worker and Samoan support workers visiting both home and church). Tovia told his family he did not want treatment, and the family put their faith in God, believing He would cure Tovia. Five months later Tovia died (September 1999) after the cancer spread to his lungs. At post mortem, the tumour on his leg weighed 15 kg. Mr and Mrs Laufau were subsequently convicted on the charge of “failing to provide necessities of life” and each received a 15 month suspended sentence. They maintained throughout that Tovia had pleaded with them to not seek treatment, and their failure to do so was because of their love for him. They were acquitted on charges of manslaughter (Brandon et al., 2001; Woolford, 2001).

9.1.2 Analysis of some detail

Mark Woolford (now Justice Mark Woolford of the Auckland High Court) was the counsel for the prosecution who wrote a detailed article about the case explaining his view that Tovia’s parents should have been found guilty of manslaughter (Woolford, 2001). I will highlight some quotes from that account (in italics):

The reasons why Mr and Mrs Laufau objected to the treatment were not explained to the oncologist or the charge nurse....

A culturally competent practitioner would not have proceeded without understanding why Mr and Mrs Laufau objected to the treatment. The implication in this phrase is that the Laufaus were somehow at fault for not explaining this. I would argue on the contrary that this is a basic professional responsibility to clarify points of disagreement and achieve an understanding of the patient's (family's) perspective on the illness.

She stressed to them that no matter what anybody said the family had to know that chemotherapy was the only treatment effective for the disease. The charge nurse made every effort to ensure that Mr and Mrs Laufau understood what she was saying. At one stage she asked them to relay back to her what she had said. Mrs Laufau said in the presence of her husband "Tovia will die if he does not have treatment"

The charge nurse then reported the difficulties they were having in getting Mr and Mrs Laufau to accept the treatment offered to the Pacific Island family support unit attached to Starship Hospital.

This is the complete obverse of Baier's concept of equalisation of power. This is assertion of power accompanied by suggesting fault if Tovia dies because he does not do what representatives of the health system say. Such a stance would not have enhanced trust.

At Middlemore hospital Tovia did not want to have an IV line inserted but Mrs Laufau said "lie down on your bed and do it because it's best for you." For the biopsy Mr Laufau came in from work and told Tovia "If you want to live longer or be with us go through with this" so he did. It appears however that Tovia was upset with Mrs Laufau twice during the 10 day stay and Mrs Laufau decided not to upset Tovia again.

He was terrified of returning because he believed he would die as soon as the cut was made in his neck to insert the portacath. He told his parents he would never ever forgive them if they took him back.

The newspaper reported ("Cancer-Stricken boy tried to jump from the car: mother," August 22nd 2000) the determination Tovia had not to return to hospital, including trying to jump from a moving car when his mother tried to take him. They also reported that his mother took him to a Chinese herbalist because he was happy to have medicine without surgery.

There was a chain of trust operating here. The parents had to trust the doctors, and Tovia had to trust his parents. Tovia did not trust the advice being given. The parents were put in the unenviable position of choosing between trusting the doctors and losing the trust with their son, or accepting their son's choice.

In court, the case for the defence was that Tovia was competent to make the decision. Skegg traverses the detail (Skegg P. D. G., Paterson Ron, & Manning Joanna, 2006, p. 191) to the New Zealand law which is that children must be assessed to determine competence and that

that will depend on the significance of the decision (a child of 13 could be competent to consent to suturing a cut but not to agreeing to amputation). In evidence the charge nurse was of the view contrary to the law that no 13 year old was competent to make a decision about treatment of an osteosarcoma:

They would be given a choice if they required different types of feeds or how that would be delivered but I believe to say to a 13 yr old boy the choice of whether you live or die is yours is a suitcase far too big to carry

It is likely from the information provided that if a formal assessment of competence had been made that he would have been found incompetent, but that does not mean that his views are unimportant. Mercurio (Mercurio, 2008) states: *“In early and mid-adolescence we might encounter “the perfect ethical storm” in which the physician’s obligation to beneficence, parental authority and the patient’s right to autonomy collide.”* This was such a storm complicated by cultural difference.

The published record is not explicit about what contact there was between health staff and the Laufau family after the initial attempts to persuade them to have treatment. Woolford implies that there was none. Tovia died in September, five months after he had been in Middlemore hospital. He had no palliative care. Woolford asked the rhetorical question why they did not contact the social worker, go into Starship, or contact their local GP. I think the answer is clearly that either Tovia or his parents did not trust them.

9.1.3 Cognitive Trust

The medical staff were convinced that their treatment was the only reasonable option. This was not necessarily true. They were estimating likely cure rates, and there was a significant chance that had he accepted treatment he may have died anyway. There is evidence to show that doctor’s overestimate the efficacy of their interventions in the treatment of cancer (Temel et al., 2010). It is a value judgement as to what chance of recovery justifies the discomfort and risks of treatment. The estimates of prognosis are based on averages. An important factor in this is the placebo effect. Likelihood of success of a treatment is higher if the patient believes that the treatment is effective and lower if the patient does not believe in the treatment (Moerman, 2002). It is therefore likely that given Tovia’s lack of belief in the treatment, that if he had been forced to have it his chances of recovery may well have been less than averages reported in the literature. The Laufaus had a different explanatory model of his illness from that of the medical staff; they felt that they were able to judge whether he was getting better and that this was happening shortly after his admission. Oncologists would rely

on repeated imaging and blood tests to determine whether a cancer was getting better or worse.

9.1.4 Emotional Trust

The Laufaus had no existing relationship with the staff at Starship. As noted in the chapter on trust, in more collective communities more reliance is placed on trust from knowing the person than cognitive trust. The hospital as an institution did well in attempts to overcome this: offering an interpreter, engaging the Samoan community worker and a Tongan doctor to contact them, visiting them at the church. However there was no reported emotional component to the relationship they had with the clinicians. The events leading up to them going home clearly lead to significant distrust, in that they refused to meet the staff again, even though they were happy to seek further care from a Chinese Herbalist.

9.1.5 Institutional Trust

Tovia was seen many times by GP's before he was referred to Middlemore without a diagnosis being made. This would not have enhanced trust in doctors. It may be significant that they agreed to go to Middlemore, which is their local hospital in South Auckland and cares for many pacific families and not to Starship Hospital which is in central Auckland and serves a much wider population. Our hospitals are still more comfortable and acceptable for the dominant European population than to the Pacific Island population. Convicting the Laufaus for failing to provide the necessities of life is likely to undermine institutional trust amongst the Samoan community.

Henaghan (Henaghan, 2012, p. 104) summarises this well:

The best solution to what happened to Tovia is for healthcare professionals to build trust with families where there are children who need treatment. This can only be done by treating those families as equals, understanding how those families see the world, listening to their concerns and exploring options in a way the family will understand.

This story underlines several of the elements that I have emphasised for Culturally Competent care. The most important is that the first priority has to be the maintenance of a relationship. Published reports do not detail why this broke down, but we do know that Tovia received no care from the medical services for the last five months of his life as he died of metastatic cancer. In their eagerness to implement the "right" treatment, the medical team lost the opportunity to provide any treatment. The story illustrates well how it is much harder to overcome distrust than it is to develop trust in the first place. The family began trusting but that was lost and getting trust back was not found possible. Implicit in the actions of the

hospital team was an expectation of the family trusting the team. Rather than the doctor or nurse that had consulted them going to find them, to try to develop some trust, they sent other staff members. Elements of that approach were clearly desirable; sending a Samoan speaker would seem like a good idea, but it is likely that what the family needed was to develop trust in the doctor who would be providing the treatment. It is unlikely that the staff even asked about the Laufau's explanatory model, let alone gave it any credence. The strategy of getting them to repeat that without treatment Tovia would die would make it almost impossible for the family to express any other view.

9.2 Explanatory Model

A central element of providing good cross cultural care is an understanding of the concept of Explanatory Model (Kleinman, Eisenberg, & Good, 1978; Seah E, 2002). The doctors in this case presumed that their management plan was the only one, and that their understanding of the illness was the only way it could be understood. Kleinman takes the opposite view; that everyone has a different understanding of the cause and management of illness. He coined the phrase "Explanatory Model". In the example in section 2.12 the mother who believed in miracles had a different explanatory model from the doctors who did not believe in miracles. Kleinman and Seah both describe detailed case studies of the management of patients who had significantly different explanatory models from their doctors (in Boston and Australia). One was Vietnamese, the other Chinese. They describe a process of first eliciting the explanatory model and understanding the values and beliefs behind it and then co-constructing an explanatory model that the clinician and patient are both able to accept. In Kleinman's case the Chinese man believed that he was suffering due to "wind" and "not enough blood", the doctors believed he was suffering from depression. The patient wanted medication, the doctors prescribed counselling. In the end the man got better. He took his anti-depressants as well as traditional Chinese treatments. He thanked the doctors, continued to say he had no mental health problem and that maybe the antidepressants were helpful for wind disorders, or that he got better because of the traditional treatments. In Seah's case the Vietnamese man was also suffering from a "wind" disease but this had been brought on by having sexual intercourse whilst in a spiritually weakened state and involved a loss of vitality. The doctor's thought he had a panic disorder, possibly an adjustment disorder, and possibly post-traumatic stress disorder. Again the process was one of spending a lot of time understanding his explanatory model, through the extensive use of an interpreter. The clinicians encouraged him to continue with his traditional "coining" treatments (to release the wind). They described that the process of enquiring into his understanding of the illness and

encouraging him to continue the (harmless) traditional treatments improved the level trust and as a result he revealed more details of his beliefs. Slowly they developed a shared explanatory model that led to him being discharged well. As illustrations these are cases where the difference between the medical model and the patient's model were substantial. Nonetheless the clinical approach of firstly acknowledging and understanding the patient's explanatory model and then working to co-construct a management plan that was acceptable to all seems to be an approach that was missing from Tovia's care. No attempt was reportedly made to understand how Tovia's family understood this illness, nor on what they saw as the best way to manage it. They were forced to repeat the doctor's understanding, but no-one asked them whether they agreed with it and if not why not. Tovia's family clearly believed that prayer was an important strategy in his care. It may have been that if the team had focussed on the family's spiritual care that a relationship could have been developed that could have led to a better outcome.

If a trusting relationship cannot be established and maintained then a good clinical outcome is much less likely. Where there are significant cultural differences between doctors and patients it is important to explore the patient's explanatory model and see how their beliefs can be woven into the management plan.

9.3 The limitations of Informed Consent and Importance of Tribal Values in Saudi Arabia

9.3.1 The Case

Adlan and ten Have (Adlan & ten Have, 2012) described a case from Saudi Arabia. The father and mother had a single child aged 13 who had severe mental and physical challenges that were attributed to a genetic disorder. The family were invited to participate in a genetic study by their treating physician who was also the principal investigator for the research project. The family "*consented and were fully informed that the daughter would not directly benefit.*" Both parents signed consent forms individually. The forms included a clause that "*the family had the right to know all information revealed by the test.*" The research established that the man presenting as her father was not genetically her father. The parents were asked whether they had used any artificial reproductive technologies which they denied. This left the possibility that the child was conceived out of marriage. The authors then provided a detailed discussion of tribal tradition and Sharee'a law both of which provide severe consequences for infidelity; at the worst involving the death of the mother and rejection of the daughter, but also adverse effects on the mother's family that could involve sisters being unable to marry. They then presented argument weighing the ethical value of truth telling; letting both the

father and mother know about the paternity, and the well-being of the family, particularly the mother, the daughter and the mother's relatives. The peer reviewers of the article were anxious about the lack of a rigorous cohesive argument (Komesaroff, 2012) but the journal chose to publish the article with four commentaries from other bioethicists in the same issue of the journal (Komesaroff, 2012; Lingis, 2012; Tsai, 2012; Zabidi-Hussin, 2012), as well as an editorial (Ashby Michael A, 2012).

This case is set in the context of a country that has markedly different social mores from western countries, but with western trained physicians, working in modern hospitals with modern technology. The "cross cultural" ethical conflict is particularly acute in that the physicians are simultaneously a part of the tribal society (with one set of values) and part of the medical community (with another set of values). In the editorial commentary Ashby said *"there is the possibility (however unlikely) for an ethics committee to reach a bioethically based decision in such a case of conflicting obligation that could result in several deaths."* The comment confirms my impression of the difficulty bioethics has in dealing with cultural difference and the case illustrates a number of points that I have made in earlier chapters.

9.3.2 Informed Consent

The authors and commentators all acknowledge that there may have been limits on whether the informed consent was adequate. Firstly whether testing at all was ethical given that the girl could not benefit herself from the testing (Zabidi-Hussin, 2012) and secondly whether the possibility of discovering the paternity issue was discussed at the time of consent. Even if this discussion had been done differently it misses some important points that are inherent in Informed Consent as an ethical concept valued in individualistic societies. In such societies it is assumed that the consequences of any decision are borne almost solely by the individual and that their consent is sufficient to enable the research to proceed. Indeed even where others are acknowledged to be involved, as for example in decisions on sterilisation, individuals are able to make those decisions without the involvement of their sexual partners. This case shows the limitations of this approach in a collective society. The consequences of this decision could affect not only the girl and the parents but also the mother and father's families. Meaningful consent needed to include input from all those who might have been affected.

The next point is that the concept of informed consent comes from a philosophy based around relationships between equals (Baier, 1995). In this example the wife has significantly less power. If this information comes out it will be her and her family that will bear the

greatest consequences, not her husband nor the man who fathered her child. I am presuming that she knew the possibility that her daughter was not fathered by her husband. If she had felt able the sensible thing for her to do would have been to decline to consent to the research, but that of itself created risk that her husband would want to know why she would not consent. The research was proposed by the treating physician. It may have been culturally impossible for her to decline the offer because of her dependence on the physician to care for her child.

It is doubtful whether this study would have been approved in New Zealand given the “vulnerability” of the daughter, and the conflict of interest of the Physician/researcher, but that is by no means certain. If the research had been assessed under Te Ara Tika (of course substituting “this community” for Maori) then on the information provided it would not have been acceptable. The family did not initiate the research, were not involved in the research design and did not have control over any of the results.

9.3.3 Complex Principlism

As a result of the nature of the problem the ethicists did not discuss this with any of the family. They made reasonable presumptions that the mother would prefer not to die, that it would be better for all for the family to remain intact, and in particular that the best interest of the daughter was to continue to receive care from both parents. The conclusion reached was agreed by all commentators, but no clear analytical framework was proposed. Komesaroff (Komesaroff, 2012) looks at the problem as a conflict between three opposing discourse systems (three ways of judging the “right” course of action), but does not go the next step that I am advocating as seeing the role of bioethics to be to mediate between discourse systems, as opposed to believing that their discourse system is right. Tsai (Tsai, 2012) describes how weighting of values would be different in Taiwan. He appeals to narrative medicine as an approach to take which is congruent with my approach but not as explicit. Lingis (Lingis, 2012) shares my view “the concept of autonomy is Enlightenment European” not necessarily as relevant in Saudi Arabia.

9.3.4 A Static Case?

This case suffers from some of the issues raised in my criticism of bioethics cases. It is static. What happened next? I am sure that the information was de-identified for publication but it is not implausible that they might come to hear of the article...then what? They were asked whether their child had been conceived by IVF. How was that question asked in such a way as to have avoided the follow up question “why do you want to know?” It is plausible that they

have chosen not to know. Dwairy (Dwairy, 2009, p. 199) has written about the use of metaphor in the psychological treatment of Arab Muslims:

Attempting to reveal unconscious content and promoting self-actualization may be counterproductive for clients who come from collectivistic cultures. Such treatment goals may expose clients to harsh confrontations with the family. Clients with dependency traits, low ego-strength, and strict families may be helped through metaphor psychotherapy or culture analysis. Metaphor therapy makes it possible to deal symbolically and indirectly with unconscious content; culture analysis can pave the way to reveal unconscious needs and enable clients to establish a new order within their belief systems and within their families. The present article describes these two therapy methods and illustrates their clinical use with an Arab-Muslim suffering from depression.

Whilst this is about “revealing the unconscious” it could equally be about the suppressed conscious. To a western rational person it seems bizarre that DNA testing is not accepted as definitive proof of paternity (as outlined in this case report). Dwairy’s discussion of how people have adapted to living in a culture such as Saudi Arabia underlines how different their explanatory model is and that “truth telling” does not sit well with the way some truths are managed.

Chapter 10 Research Ethics and Cultural Competence

10.1 Introduction

Research Ethics Guidelines have recently been revised with separate documents on observational studies (EGOS) and interventional studies (EGIS) (National Ethics Advisory Committee, 2012a, 2012b). These documents are written from the traditional bioethics approach of protecting the rights of research participants. There is a separate document on Maori Research Guidelines “Te Ara Tika”(Hudson, 2010).

10.2 National Ethics Advisory Committee Research Guidelines

10.2.1 Focus on Inequalities

Inequalities are explicitly mentioned *“Justice involves reducing inequalities. Decision-making about study questions and processes should include consideration of the potential to reduce health inequalities”* (para 4.6 and 5.4 EGIS) Whilst this is not explicitly tied to Cultural Competence it addresses the most important outcome of poor Cultural Competence.

10.2.2 Diversity

Diversity is explicitly mentioned: researchers must make allowance for diversity amongst research populations (para 4.17 EGIS and EGOS). Non-discrimination is noted (para 4.8c EGOS) and in particular participants should be selected for inclusion without discrimination (para 5.26 EGIS).

10.2.3 Collective Consent

There is a specific paragraph (para 6.30 ECOS) on gaining consent in communities where collective consent has importance. Whilst this paragraph is followed by a paragraph explicitly about Maori, suggesting that this was an important stimulus for including it, it clearly applies to communities other than Maori.

10.2.4 Cultural Sensitivity

Interviewers are required to be culturally sensitive (EGOS para 6.9)

10.2.5 Power Inequalities

Power inequalities are recognised as being of major importance in research ethics. They are covered repeatedly, both in general (para 6.18 EGOS) and with specific groups of people (para 11.6 EGOS, 5.28-5.35 and appendices) covering children, those with intellectual disability, the elderly, those with terminal illness, students, employees and prison inmates. Examples are given on how to limit the risks when researching in these populations.

10.2.6 Involving Community in the Planning and Conduct of the study.

Involving community in the planning and conduct of the study is mentioned explicitly for Maori (EGIS Para 4.7) but also for other communities (ECOS para 5.6). In addition it is noted that engagement with the community is more likely to lead to long term benefit for the community (EGOS para 4.15). Researchers are also encouraged to meet obligations to communities by selecting research that addresses important health problems for those communities (ECOS 5.1).

10.2.7 Necessary skills

It is explicitly noted that people have different cultural understandings of knowledge and that researchers need the skills to understand how these different understandings may impact on the analysis and results of the study (EGOS para5.9).

10.3 Omissions from National Ethics Advisory Committee Guidelines

10.3.1 Subjects with limited English proficiency.

As with the Code of patient Rights discussion, provision for the needs of people with limited English proficiency is deficient. Firstly they are classified as “vulnerable”. Whilst it is practically true that research materials and researchers do not make provision for people who are not fluent in English and this could make the subjects more vulnerable, this is blaming the problem on the subjects, rather than seeing it as a responsibility of the researcher. It could be said that the need for an interpreter is implicit in phrases such as:

“Verbal information provided should be tailored to the individual, taking account the participant’s level of knowledge and understanding and the amount of detail they desire. Written information should be tailored to the study population (for example, it should be culturally appropriate for that study population), and should have a reading age appropriate to that population.” (EGIS 6.10).

It is remarkable that such a paragraph could be written without mentioning the possibility of a lack of language concordance. The guidelines explicitly forbid exclusion of participants on the basis of national origin or ethnicity (EGIS 5.26) and yet are silent on the basic requirement of availability of interpreter/translator for people with limited English.

There is a mention of the need for “translation facilities” in the Operational Standards document (Ministry of Health New Zealand, 2006) (para 31) also in the section under informed consent, and in relation to Maori (para 13) who wish to speak in Maori. Those within the interpreting/translating industry would note however that translation refers to the

translation of the written word, whereas interpreting refers to the spoken word. There is a need for both translation and interpreting facilities.

The current electronic ethics application form does not ask whether interpretation/translation will be available even though the version in use (NAF2009 v1) prior to July 2012 had a specific question E3 “*will a competent interpreter be available if required*”

10.3.2 Requirements Relating to Maori

There are a number of specific requirements that are applied to Maori (EGOS):

*4.3 **participation:** involving Māori in the design, governance, management, implementation and analysis of research, particularly research involving Māori”*
***protection:** actively protecting Māori individual and collective rights, and Māori data, cultural concepts, norms, practices and language in the research process.*

And (EGIS):

4.10 Comprehensive, high-quality Māori health research and information can inform both the Government and iwi on the matter of health priorities, and can assist whānau, hapū and iwi to be involved in meeting these priorities.

These are excellent standards aimed at avoiding exploitation of Maori by researchers but why do these standards only apply to Maori. Would not other communities like to be equally involved in design, governance, management, implementation and analysis of research? Might not other cultural groups like the same degree of protection, and is not comprehensive high quality information that can inform on health priorities of value to any community?

10.3.3 Vulnerable Populations

The whole discussion about vulnerable populations comes from a researcher-centric view of research. It would have been as accurate to describe these as populations more likely to be exploited by researchers. Given the lack of guidance on interpreters and the extra costs imposed on the research by the use of interpreters, it is likely that non-English speakers are simply excluded from much research. Internationally there is a problem with pregnant women being routinely excluded from pharmaceutical research because of the risk to the foetus, but that this leads to pregnant women being given treatments that have not been validated, nor have appropriate doses been calculated.

10.3.4 Emphasis on Relationships

As noted above there are scattered references to consulting with communities. There is a separate paragraph about researchers acting with integrity (EGIS and EGOS para 4.15). There

is little focus on developing a trusting relationship. This aligns with O'Neill's discussion of rights where she points out that these are articulated in the absence of relationship. Rights are asserted but it is not clear who is responsible for ensuring that they are fulfilled (O'Neill, 2002). It is implicit in talking about research ethics that it is the researchers that are responsible for enabling them to happen, but the nature of the relationship between researcher and subject is rarely discussed in detail.

10.4 Te Ara Tika Guidelines for Maori Health Research Ethics: A framework for researchers and ethics committee members (Hudson, 2010)

This document was produced by the Health Research Council to provide a Maori view on what good research ethics might be. It was explicitly written by Maori researchers about research involving Maori participants. However this could be viewed as another framework written from a different frame of reference; a Maori frame of reference. This can be compared with the guidelines written from a dominant culture researcher frame of reference.

The Māori ethics framework references four tikanga based principles whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity) as the primary ethical principles in relation to research ethics. Other ethical concepts and principles are located within this framework and the ethical issues within each segment are identified and cross-referenced to the Ministry of Health's Operational Standard for Ethics Committees.

All of the main concepts included within the Operational Standard (Ministry of Health New Zealand, 2006) are covered within the document.

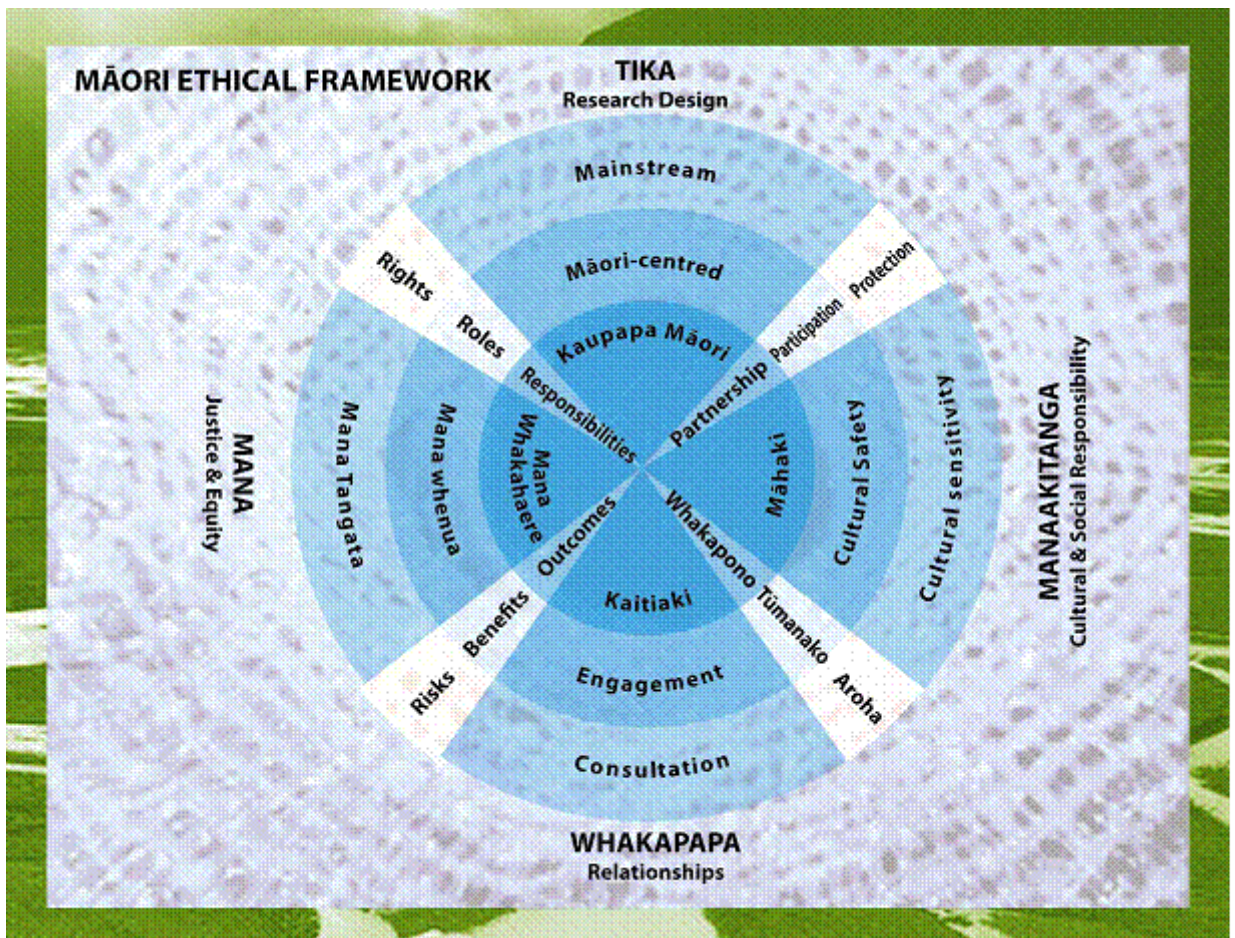
An important feature of the model is the idea of having minimum standards and then more exacting standards. This nicely aligns with the difference O'Neill (O'Neill, 2002) makes between an ethics based around "rights" (which would accurately describe the dominant culture documents) and an ethics based on "obligations". The closer to the centre of the circle (figure 11) the more the researchers accept an obligation to the research subjects; particularly an obligation not to deceive manipulate or harm. Such an obligation cannot be fully carried out without a significant relationship so that both parties understand their respective values and goals and can reach agreement on how to meld them together.

*"The outer quadrant relates to what has been termed minimum standards. The **minimum standards** are expected to have been met by researchers before ethics committee members consider ethical approval for the research project. The middle quadrant refers to **good practice** which indicates a more Māori responsive approach to the research project. **Best***

practice extends the ethical consideration to align with expectations of behaviour within Te Ao Māori.”

Whilst this framework was developed with a view to Maori involvement in research, this idea works very well in dealing with projects where the researcher might be more prone to exploiting the participants (vulnerable subjects). Minimum standards apply when the sensitivity of the research to Maori is low but as the sensitivity increases there is more expectation of a more developed relationship, for the research to be centred around Maori values, and for the research to be guided in significant part by the participants.

Figure 11 Maori Ethical Framework



By comparison the Ethical Guidelines from the National Ethics Committee acknowledge power differences, identify some particular vulnerable populations and provide some specific suggestions on how to achieve better informed consent but unfortunately provide insufficient expectations and guidance around relationships.

10.5 Summary

The Ethical Guidelines for Research are written from the perspective of the dominant culture and have some important deficits particularly around the provision of interpreters. I have emphasised the importance of trust and fair process as being critical to Culturally Competent care. Te Ara Tika provides much better guidance on how to address these particular issues as they apply to Maori. Whilst this has been developed as a “Culture Specific” document the principles it relies upon are of much more general applicability. The Cultural Competence of research guidelines would be significantly improved if “Te Ara Tika” were edited and “Maori” replaced by “the community being researched” and it was used as the guidelines for all research.

10.6 Case Study of research on a “vulnerable population.”

10.6.1 Context

I have worked for the last 20 years as a GP at Newtown Union Health Service, where I have learned “on the job” how to use interpreters and work with people with limited English proficiency. I have developed a relationship with the interpreters at Interpreting New Zealand (A Wellington based not for profit interpreting organisation) and at Language Line (the Government funded telephone interpreting service), through working with individual interpreters but also through attending and addressing some of their meetings. I authored the chapter in Coles Medical Practice in New Zealand on The use of Interpreters (Gray B, 2013). This study was developed to address some of the issues that I became aware of as a clinician.

10.7 The Study: “Observing Communication in Interpreted Health Encounters: Processes and Perceptions”

10.7.1 Research Proposal

There are significant gaps in existing knowledge in the area of healthcare interpreting. Most previous research has focused on clinicians’, patients’, and/or interpreters’ perceptions of interpreted communication using questionnaires, focus groups and/or interviews, so is theoretically rather than empirically based. There is limited empirical evidence on: (a) exactly how interpreted consultations are actually carried out (with both trained and untrained interpreters), and (b) the effectiveness of the various options for interpreting from the point of view of all participants (i.e. patient, clinician and interpreter). Even where actual interactions have been studied, existing research often only investigates one or two participant perspectives or only one category of interpreter.

This study will look at actual consultations between patients and GPs when interpreters are used. We will make video-recordings of meetings and interview the patient, the doctor and the interpreter afterwards to ask them about the consultation. We want to include consultations that use

trained interpreters as well as those where family or friends are used as interpreters.

The aim is to see how these consultations are conducted and to find out what makes them satisfactory or challenging for each of the participants. By comparing what is actually said in the consultation with comments from the doctors, interpreters and patients, we aim to provide information that will help make these kinds of consultations more effective.(Stubbe et al., 2012)

10.8 Reflections on the study

10.8.1 The ethical issues

We were aware of many potential ethical problems in carrying out this study. Informed consent is very complicated. The first problem is that all three participants in the study need to give separate informed consent. One of the participants does not speak fluent English, and there are potential ethical problems of coercion if either the doctor (through the interpreter who is involved) or the involved interpreter themselves do the patient recruitment. Our experience is that this work has to use video, to ensure identification of the person speaking and to pick up on all the other communication that occurs outside of speech. However video recording is significantly more intrusive. For the interpreter (particularly if the interpreter is a professional) and the doctor there are reputational risks of having their practice recorded, depending on who has access to the recordings. Some of the patients come from refugee backgrounds where there was significant risk of persecution. Because of this some of these people can be particularly sensitive to being filmed. In addition this is a medical consultation with the possibility of personal and sensitive issues being discussed.

The participant most open to exploitation by the research is the patient. If we relied on informed consent as the main mechanism for establishing trust we might distribute information about the study to potential participants who were going to be seeing their doctor soon, looking for volunteers. We would then hope that if a patient volunteered that the interpreter and the doctor would also participate. We did not try this strategy as we believed that it would not have worked. It would have involved translating information into many different languages, and we have no knowledge of how literate the patients are in their own languages and thus whether they could read any notice we provided.

Importantly for this project no amount of information can adequately assure them that we will keep the video recordings safely and use the information respectfully. That requires emotional trust and relationship.

10.8.2 Elements of trust

Trust is usefully separated into three types at two levels: Behavioural, Cognitive, Emotional trust at the individual and institutional levels.

10.8.3 Institutional Trust

10.8.4 Newtown Union Health Service (NUHS)

The patients were recruited via the doctors at Newtown Union Health Service. This service explicitly focuses its efforts to provide good care for patients from refugee and migrant backgrounds, and is run by a policy board that has representatives from some of those communities. NUHS has a close relationship with NZ Interpreting and Language Line as a practice has been a leader in advocating the use of professional interpreters in Primary Care.

10.8.5 University of Otago Wellington

The project is being run from the University of Otago Wellington. Patients may well be aware that the University is across the road from the practice, as the practice sometimes takes students and patients may have met students whilst in hospital. Language Line and the Primary Care department have developed a mutually supportive relationship, with Language Line being interested in research being done around the use of interpreters. The staff at NUHS have a close relationship with the University of Otago Wellington as many of them have part time appointments in the Department of Primary Care and General Practice. The two institutions have a long history of collaboration on several research projects, training of students both undergraduate and post graduate and many shared goals around the provision of good care to underserved populations. As a generalisation the idea of a University is understood by many people as being a place of higher learning and thus having more institutional trust than, for example, if the study had been proposed by an unknown interpreting company.

10.8.6 Interpreting New Zealand

Interpreting New Zealand has been established for nearly 20 years as a not for profit incorporated society. They translate up to 70 different languages both face to face and over the phone. They employ people in Wellington and many of the interpreters who work there are well known and in fact are leaders within their communities. They could not succeed as an interpreting organisation without the trust of the communities that they serve.

10.8.7 Language Line

Language line is a government run interpreting service that provides telephone interpreting services to government agencies and health providers. Many patients will have used Language Line when visiting other agencies such as for benefits at Work and Income, or at the hospital.

10.8.8 Staff interpreters

These are often very well known to the patients, with high levels of emotional trust.

10.8.9 Individual Trust

The doctors initially contacted the patients, who were known to them, through the interpreter if needed to see if in principle they would be interested in participating in the study. This was followed up by a formal consent gaining process prior to proceeding with recording a consultation. There is likely to be significant trust between patient and doctor, a combination of all three types. Dr Gray used to work at NUHS and has a personal relationship with all the doctors, and with several of the interpreters.

10.8.10 Shared Goal of Research

The project was developed from University of Otago Wellington. Dr Gray came to understand the issues around interpreting by working at NUHS with these patients and these interpreters. The researchers have an extensive background in research of other health consultations, and have all worked on previous projects either relating to interpreting or to studying consultations. The goals of understanding how well interpreted consultations worked and the effectiveness of the various interpreting options are of real practical interest to the interpreters, patients and doctors (as well as the researchers). New Zealand Interpreting run an interpreter training course and are interested in the outcome of the research for practical training purposes.

10.8.11 Informed Consent

The presence of “emotional” trust does not mean that attention need not be paid to “cognitive” trust elements by gaining informed consent. The ethics approval process provides the “collegial oversight” to decide whether we as a research team had devised a trustworthy project. Information sheets and consent forms were tailored to each participant and explained respectfully by trained researchers. This was straightforward with the doctors and with the professional interpreters who were mostly consented in advance of the consultation. The researcher met with the patient prior to the consultation and with the help of the interpreter explained the detail of the project and if they were happy with this the patient signed the consent form and the consultation proceeded. Where the patient brought a family member to interpret, consent for both the patient and the (family member) interpreter was gained just prior to the consultation. One of the investigators observed that sometimes asking people to sign the form can create a slight feeling of distrust in people who rely on oral communication. A lot of emphasis is placed on having signed informed consent but the benefit of the form being signed is almost all with the researcher. In the event of there being any

dispute about whether the research was properly conducted the fact of the signature would carry significant weight.

One advantage of video recording the research is that we have a permanent record of the whole interaction. With one patient we were able to demonstrate that they had a good understanding of the study and her choices within it, in that she requested that the camera be turned off for part of the consultation to allow her to talk about a sensitive matter that she was not happy to have recorded. When that was dealt with the camera was turned back on again.

10.8.12 Use of Translators to translate interview audio recording

For adequate analysis of the consultations it is necessary to have a transcript of the consultation. This is something that is easily done if the consultation is in English and there are professionals who provide a transcription service. These people do not offer to transcribe languages other than English. In one previous interaction study where we had had an interpreted consultation this transcription was done by another interpreter. We were concerned about reputational issues, as the interpreter community is not large and by asking a second interpreter to “reinterpret” the consultation there was a risk that they might view the original interpreting as being inadequate. We discussed this issue with the trainer at Interpreting New Zealand who pointed out a fact that was not apparent to the researchers: that the interpreting community (who deal with the spoken word) are a completely different community from the translating community (who deal with the written word). The skill sets are different with interpreters needing to be able to remember chunks of conversation and interpret them on the spot, whereas translators have as much time as they need to work on a piece to ensure accuracy. Interpreters have a high need of interpersonal skills in two languages whereas translators often work in isolation. In general you would expect the accuracy of translated words to be greater than the accuracy of interpreted speech. As a result of this discussion we amended the research design so that we now send an audio file of the consultation to a translator and ask them to translate the “foreign language” part of the tape. Interpreting New Zealand believe that this virtually removes the “reputational risk” for the interpreters.

10.9 Conclusion

We applied for and were granted ethical approval by the Central Regional Ethics Committee as an observational study. It is interesting to review the ethics application. There are questions

about “consultation” for which we provided a lot of detail. There is also a question about relationships: *“Is there any special relationship between the participants and the researchers (for example: doctor/patient, student/teacher)?* This question has the clear implication that the interest in a relationship is the possibility of coercion, and that it would be better if there was no “special relationship”. If we had been filling out an application based around “Te Ara Tika” a central part of their process focuses on “Whakapapa/relationships” with the minimal requirement being consultation, an intermediate requirement being engagement and the requirement for fully engaged research being Kaitiaki/guardian/advocate. We see a central element of the ethical safety of our research being the extent of our engagement with the research participants, which is not really captured in the Ethics Application form. The example of using translators rather than interpreters is a great illustration of how the best way to safeguard the interests of participants is to have them involved in the design of the study.

As an observational study the aim is not to change clinical practice, but to just observe what is happening. There is always the potential for a tension between the goals of the clinical encounter and the goals of the research activity, though these are less in observational studies. The safeguards we had in place were the formal consenting process with clear ability to withdraw at any time plus the shared project development such that the researchers, doctors and interpreters (although not the patients) had the opportunity to adjust the design to minimise risks. The biggest safeguard is probably the value of the relationships concerned.

All the participants in this research project have existing relationships of trust: the patients with the doctors and the interpreters, the doctors with the interpreters, and the researchers with all the participants. If that trust is undermined at all it will have significant impacts: patients may no longer be willing to see the doctor or use a particular interpreter, and the researchers will not be welcome to do any further research projects at the practice (which is the closest practice to their institution). The nature of this project is such that there is significant potential for exploitation of the non-English speaking patients. The best safeguard against such exploitation is developing transparent trusting relationships with all those involved, and for it to be seen as a shared project to meet the needs of all participants.

Chapter 11 Cultural Competence and Law

11.1 The Cultural Competence of Bioethical Choices by government

As noted in the introduction the power to make ethical decisions is legitimated in some circumstances by law: seeking a treatment order for treating a child against the parents' wishes. The most important power that affects Cultural Competence in health is the power to allocate resources. A recent Treasury reports (Treasury, 2012) shows an upper middle class household receives on average almost \$11,000 of health services a year, whereas the households with the lowest income receive on average \$6,000 of health services – despite their greater need.

11.2 Government favours the dominant cultural group

It is a truism to say that the law of the country will reflect the make-up of the body that passes those laws; in the case of New Zealand that is the New Zealand Parliament. In 1993 when the Health and Disability Commissioner Act was passed the parliament was far from evenly representing the make-up of New Zealand society. Only 19% of members were women and 92% were European (Statistics New Zealand, 1994). It is hardly surprising that section 20 of the Health and Disability Commissioner Act did not provide a more demanding requirement that the Code impose a stronger obligation to provide interpreters. Table 2 below shows the skewed representation in favour of European people compared to population figures. This has improved since 1993 with the advent of the Mixed Member Proportional electoral system. Despite this improvement given that the parliament passes laws by majority, legislation is likely to be skewed towards the position of the dominant cultural group. In addition many of the laws currently in force were originally passed some years ago, reflecting the parliamentary make up and mores of the time they were enacted. An example of this phenomenon is the recent repeal of the law (first enacted in 1800) banning women from wearing trousers in Paris (Vuk, 2013). My hypothesis is that the law is inevitable “Culturally Biased” towards those with greater political power. No amount of Cultural Competence by individual clinicians can overcome the systemic influences of the structures within which they work. It is essential to address those structures.

Table 2 Proportions by Ethnicity of Members of Parliament Compared to Total Population

| | Proportion of MP's 1994 (2008) | Proportion of Community (2006) |
|-----------------|-----------------------------------|-----------------------------------|
| European | 92% (75%) | 67.6% |
| Maori | 7% (16%) | 14.6% |
| Pacific Peoples | 1% (4%) | 6% |
| Asian | 0% (5%) | 8% |
| Other | | 3.8% |

11.3 Multiculturalism/Comprehensive Pluralism

Parekh (Parekh, 2002, p. 6) defines Multiculturalism:

A multicultural society, then, is one that includes two or more cultural communities. It might respond to its cultural diversity in one of two ways, each capable of taking several forms. It might welcome and cherish it, make it central to its self-understanding, and respect the cultural demands of its constituent communities; or it might seek to assimilate these communities into its mainstream culture either wholly or substantially. The term "multicultural" refers to the fact of cultural diversity, the term "multiculturalism" to a normative response to that fact.

Rosenfeld has the same analysis but uses the term "Comprehensive Pluralism" to refer to Multiculturalism. Berry (Berry & Kalin, 1995) uses Multiculturalism.

Berry, Parekh and Rosenfeld have all reached the conclusion that Multiculturalism is the preferred approach to managing Multicultural societies coming at the problem from three different angles; Law, Political Philosophy and Cross Cultural Psychology. I will summarise their arguments.

11.3.1 Berry Multiculturalism and Canada.

John Berry is a cross cultural psychologist from Canada who has been researching this problem for more than 30 years. He talks of Canada as moving towards being truly multicultural:

Canada is a plural society, and this situation has been officially recognized by the Federal and some Provincial Governments with the establishment of multiculturalism policies. There is some discussion and debate as to whether Canada is more than merely plural, in the sense of having residents from a variety of ethnic origins, but truly multicultural..."(Kalin, 1996, p. 253)

When two cultural groups live within the same society there has to be a process of acculturation. Berry describes four strategies (Berry, 1997, p. 9):

1. **Assimilation:** When individuals do not wish to maintain their cultural identity and seek daily interaction with other cultures.
2. **Separation:** When individuals place a value on holding on to their original culture, and at the same time wish to avoid interaction with others.
3. **Integration:** When there is an interest in both maintaining one's original culture, while in daily interactions with other groups; here, there is some degree of cultural integrity maintained, while at the same time seeking to participate as an integral part of the larger social network.
4. **Marginalisation:** When there is little possibility or interest in cultural maintenance (often for reasons of enforced cultural loss), and little interest in having relations with others (often for reasons of exclusion or discrimination)

He notes that “the integration strategy can only be pursued in societies that are explicitly **multicultural**” and after summarizing a large amount of evidence concludes

*there is now sufficient psychological evidence to support the development of national policies that neither force culture shedding (**assimilation**), nor ghettoization (**segregation**), or some combination of them (leading to **marginalisation**). Instead a policy “balancing act” between these alternatives (the policy option termed “**integration**” here) can be sought. (Berry, 1997, p. 28)*

11.3.2 Parekh Rethinking Multiculturalism

Bhikhu Parekh is a political philosopher. The first part of his book (Parekh, 2002, p. 11) “traces the origins and elucidates the internal varieties of naturalism and culturalism”, in particular providing a critique of moral monism with reference to the Greeks, the Christian Church and Classical Liberalism. The second part sketches the outlines of a theory of multicultural society and:

I discuss the nature, basis and structure of culture, how and within what limits it is possible to arrive at cross-cultural moral principles, how cultures can and should be judged, the basis and limits of respect for other cultures and the reasons why cultural diversity should not be viewed as a brute fact to be reluctantly accepted and accommodated but as a positive value to be cherished and fostered (Parekh, 2002, p. 12.)

He then discusses practical problems of multicultural societies. He observes that:

Multiculturalism is not about minorities, for that implies that the majority culture is uncritically accepted and used to judge the claims and define the rights of minorities. Multiculturalism is about the proper terms of relationship between different cultural communities. The norms governing their respective claims including principles of justice cannot be derived from

one culture alone but through an open and equal dialogue between them. (Parekh, 2002, p. 13)

11.3.3 Rosenfeld Comprehensive Pluralism

Michel Rosenfeld is a constitutional lawyer (Michel Rosenfeld, 1998; Michel. Rosenfeld, 2011) and addresses constitutional issues:

The Cold War ideological battle with universal aspirations has given way to a clash of cultures as the world concurrently moves toward globalization of economies and communications and balkanization through a clash of ethnic and cultural identities. Traditional liberal theory has confronted daunting challenges in coping with these changes and with recent developments such as the spread of postmodern thought, religious fundamentalism, and global terrorism. This book argues that a political and legal philosophy based on pluralism is best suited to confront the problems of the twenty-first century. Pointing out that monist theories such as liberalism have become inadequate and that relativism is dangerous, the book makes the case for pluralism from the standpoint of both theory and its applications (Michel. Rosenfeld, 2011, p. (i)).

He argues that a government based on Pluralism puts the valuing of Pluralism at the centre of the decision making. It is the opposite of a Monistic or a majority driven approach. A Monistic approach holds the view that there is a right way to do things, a single conception of the good, and everyone ought to agree with that. Non-dominant cultural groups are left to assimilate (or leave). Checks and balances can be put in by ascribing some rights and allowing interpretation of the law for particular circumstances, but such a system inevitably disadvantages the minority.

11.4 New Zealand and Biculturalism

New Zealand is gradually developing a variant of a Pluralist approach with the concept of Biculturalism centred on the Treaty of Waitangi. In this regime it is accepted that on any particular issue there may be two conceptions of the good and that the law needs to make provision for both. The two documents on Ethical Guidelines for Research; Mainstream (National Ethics Advisory Committee, 2009) and Maori (Hudson, 2010) are a clear illustration of this approach.

One of the principles Rosenfeld outlines for Pluralism is that where the conception of the good of one community does not impinge on the others, then even if they are only in a minority the encouragement of pluralism is a good reason to enact such a provision. A good example of this is the law around reproductive technologies in New Zealand. Maori place a high value on knowing their genealogy. They tie their identity to the Iwi (tribe) they come from, and the mountain and river that that tribe identifies with. Artificial insemination by anonymous donor

such that the child could not know their ancestry would be offensive to Maori. European people in general feel less strongly about this. As a result of cognisance of the Principles of the Treaty, and a wish to take Maori perspectives into account, New Zealand law in these matters now has clear provisions to ensure that when an artificially inseminated child reaches adulthood they are able to determine their ancestry (2004, pp. sect 47-50). This is in contrast for example to the law in the United States (American Society for Reproductive Medicine, 2012, pp. 7 sect C5-6) there is a requirement to keep records of the donor for at least 10 years although a permanent record is recommended. However the purpose of this is limited to providing information in the event of the offspring having a heritable disease. Donors are assured that confidentiality will be protected (subject to any specific state or federal laws).

Berry Parekh and Rosenfeld are all discussing how to manage diversity at a societal level (although Berry's work is significantly based at an individual level) but their analysis closely mirrors my own management of diversity at a clinical level.

The traditional medical model is to presume that everyone understands health as doctors do (and share views on degree of risk aversion, importance of longevity etc.). Clinicians have a moral objectivist view of ethics and err on the side of believing that they can find the "right" option. They take a history, examine the patient, do investigations and propose a management plan, to which the patient then "consents" , after being informed. "Cultural beliefs" are inserted as an afterthought for those who look or speak differently. People who disagree with doctors are labelled non-compliant and problem patients. There is an implication that the doctor is responsible for fixing the problem and the patient's job is to do what they are told. People are expected to trust their doctors and the importance of relationship is significantly devalued: for example by the way a modern hospital provides care for single patients with large numbers of staff, few of whom have the opportunity to really get to know the patient. The result of this model is the marked disparities in health outcome

This set of assumptions parallels the arrangement of a liberal democracy. There is "one law for all" that is determined by the majority. Judges have the role of considering the details of particular cases where there is dispute and deciding on what is right. "Cultural views" may be added as an afterthought (for example in human rights legislation) but with limited action to implement policy to make those rights a reality (the lack of availability of interpreters for health care being a good example of this). If the values of a non-dominant cultural group clash with the dominant cultural group there may be few avenues for redress. Prior to the Waitangi Tribunal Act Maori in Waitara had no legal way of stopping the discharge of freezing

works waste over their seafood reefs at the mouth of the Waitara River (Waitangi Tribunal, 1983) People are expected to respect the law. The result of this model is a loss of trust in the law being fair and a risk of alienation of significant minorities from the processes of the community and potentially a threat to the stability of the whole system. The Bastion Point protests (Ministry for Culture and Heritage, 2012) were arguably symptomatic of such a threat to stability. They were eventually followed by Waitangi Tribunal Hearings on the matter in dispute (Waitangi Tribunal, 1987) which assisted the process of resolution.

The clinical model I have developed in this thesis is to presume that everyone is different from me, but the degree of difference varies considerably. I have a complex principlist view of ethics whereby I expect that we will make decisions using the same principles with different weights or different principles. Whilst I gather information from the patient I develop a sense of in what way the patient in front of me has markedly different views from me on the appropriate course; a different explanatory model, and together we co-construct an agreed management plan. There will be some management that I will not agree to, and there will be some suggestions for management that I might make that the patient will not agree to. By accepting the co-construction the weight of responsibility held by the doctor is lighter. No longer is there an expectation that the doctor always knows what is “right” (and if it does not turn out well then it is the doctor’s fault) but that together we decide how to move forward. The potential for conflict is significantly reduced. In part that occurs because of a much greater focus on developing and maintaining a trusting relationship as an integral part of the interaction. Maintaining that focus is harder with patients who are very different from me and requires a lot of listening and determining what it is that they and I agree upon and that they believe I can do for them.

This attention to diversity and difference parallels the national approach where there is a presumption that Maori have a different viewpoint on decisions. The degree of difference varies. Maori place different weight on the importance of problems (like the polluting of shellfish reefs) and have a different explanatory model on which they base their views (Roberts, Norman, Minhinnick, Wihongi, & Kirkwood, 1995). There is now much more focus on discussion to resolve differences rather than Government merely decreeing a resolution. This is evidenced by the extensive use of the Waitangi Tribunal (Waitangi Tribunal, 2012), and a greater involvement of Maori in the political process.

In his review of Rosenfeld’s book (Callaway, 2012) Callaway’s main concern is the risk of exaggerating difference. On a clinical level I would argue that the major problem is that we

too often presume concordance. As the doctor has more power the patient is less likely to speak up. However the outcome is worse because the patient may be deemed “non-compliant. At the national level the problem was identified by the Waitangi Tribunal Waitara Claim (Waitangi Tribunal, 1983) the difference had always been there but through lack of power Maori had been unable to voice their concerns effectively.

11.5 Codes of Ethics

Like the law these are mostly developed by members of the dominant culture. The New Zealand Medical Association Code of Ethics (New Zealand Medical Association, 2008) exemplifies this. The code is based on Beauchamp and Childress’s (Beauchamp Tom L. & Childress James F., 2009) four principles and implicitly takes a Moral Objectivist stand point. It makes no mention of cultural differences. The only reference to a relationship with patients in the twelve principles is: “3.Avoid exploiting the patient in any manner.” An insight of how different this might be if the development of such codes was not dominated by the dominant culture is provided by the New Zealand Public Health Association *Te Ture Whakaruruhau Code Of Ethical Principles For Public Health in Aotearoa New Zealand.(Public Health Association of New Zealand Incorporated, 2012)*. It melds western ethical principles with Maori principles. It includes Beneficence, Justice and Truth Telling (but excludes Autonomy) and importantly includes the Maori principles of: “**Manaakitanga** is behaviour that acknowledges the mana of others as having equal or greater importance than one’s own, through expression of aroha, hospitality, generosity and mutual respect. **Whanaungatanga** (see section 6.6) **Rangatiratanga**: is the expression of the attributes of rangatira (weaving the people together) including humility, leadership by example, generosity, altruism, diplomacy and knowledge of benefit of the people.” These principles put the nature of relationships as central to ethical behaviour.

11.6 Summary

In summary there are important features of the way the society is organised that impact on disparities in health outcome and that are external to the “health system”. No matter what changes might be made at a clinical or health system level without addressing the way the society as a whole organises itself disparities will persist. Berry, Parekh and Rosenfeld provide a convincing argument for the adoption of Multiculturalism as a central premise for governance. This provides a theoretical base to the constitutional direction New Zealand has been travelling and it has many resonances with the approach I advocate at a clinical level.

Chapter 12 Conclusions

Cross's definition (Cross et al., 1989, p. 13) "*Cultural Competence is a set of congruent behaviours, attitudes and policies that come together in a system agency or among professionals and enable that system agency or those professionals to work effectively in cross cultural situations.*", is a succinct statement that covers the main elements of cultural competence. My preferred definition is much longer and broader, the most important difference from Cross being the idea that every consultation is a "cross cultural situation": that everyone is culturally different from me.

The need for the concept of Cultural Competence stems from a failure of the bioethics community to address the fundamental ethical issue that non-dominant cultural groups frequently receive inferior care and have significantly worse health outcomes than people who are part of the dominant cultural group.

I share Engelhardt's view that "*Moral diversity is real. It is real in fact and in principle. Bioethics and health care policy have yet to take this diversity seriously*" (Engelhardt, 1996, p. 3). The moral objectivist position is untenable unless this diversity is ignored.

Bioethics is a relational activity both institutionally and in its content, but it has grown from the discipline of philosophy which is a solo enterprise and too many bioethicists have remained too close to these roots. As a result much of the effort of bioethics has been in the analysis of bioethics problems either in a general sense (is abortion right or wrong) or from static cases; law case reports or edited clinical cases. From these analyses have grown lists of Rights such as The Code of Health and Disability Services Consumers Rights (The Code of Health and Disability Services Consumers' Rights, 1996). Both can overlook the importance of relationships. The Public Health Association's Code of Ethics (Public Health Association of New Zealand Incorporated, 2012) show how this could be different.

The greater the cultural distance between clinician and patient (or between disputing communities), the more difficult it is to establish a functional relationship, the more likely it is that there will be a different weighting of values and beliefs, and the harder it will be to either find agreement or find a course of action that all parties are accepting of.

The failure of bioethics to address relationships, understand different frames of reference (discourse systems, cultures) and find ways of living with diversity have contributed to the poor health outcomes for minority populations.

An important contributor to bioethics having failed in this way is a lack of understanding of the concept of complexity. Bioethics problems are complex problems affected by uncertainty, and changing over time, where the solution needs to be developed within the system and there is only a correct answer in retrospect.

Without understanding complexity it is hard to have a meaningful understanding of culture. The debates between Cultural Relativity and Moral Objectivism are based on the presumption that there are such things as definable cultures that have a defined moral code that is able to be codified, applicable to all in that culture. We all belong to many different cultures and the moral views of any of those cultures are not precisely defined. Having a framework to understand cultural variation is essential. A prerequisite of Culturally Competent care is understanding of your own cultural background values and beliefs, and the ability to see these as just your own frame of reference, rather than as being “right”.

Trust is an essential prerequisite of a functional relationship and effective clinical care. It was trust that was the biggest casualty of Professor Green’s “Unfortunate Experiment”. It is common for there to be a power imbalance between doctor and patient and for non-dominant cultural groups this is often the norm. As Baier has discussed (Baier, 1995) much philosophy is predicated on a presumption of equal power between parties; epitomised by contracting. Bioethics needs to place more focus on how we manage these unequal relationships and in particular how we establish, develop and repair trust, and identify the circumstances where trust is misplaced. Only trust will allow a proper development of a doctor patient partnership. Maori traditions on the importance of trust building (Whakawhanaungatanga), are valuable as an example of the way one community deals with this requirement.

At a societal level this equates to the importance of fair process in resolving disputes. New Zealand is exceptional in the lack of corruption in our community, meaning that our ability to find ways forward for difficult ethical problems is greatly enhanced compared to communities struggling under the burden of corruption.

On a clinical level there needs to be a deep understanding of the importance of accepting that everyone sees their problems from a different frame of reference. If the patient’s frame of

reference is not known to the professional offering care then care will be inferior if not impossible. Kleinman's idea of Explanatory Models is a particularly effective tool when managing patients from cultures who understand the body works differently from western clinicians, but it is also useful whenever there is an impasse, as in the story of the mother who believed in miracles Section 2.12. An advantage of the clinician/patient interaction is that there is always something shared, some agreement. The Maori woman (Section 4.12) was worried about her health which is why she came to the hospital. An approach that first identifies areas of agreement before moving on to differences can help to find a way forward.

Clinicians are expected to treat patients as if they are of equal moral worth. Like all principles this does not apply absolutely all the time. In reality we all have different degrees of moral regard; include different people within our moral circles; have different moral friends. Self-awareness of these issues is essential. A person who feels really uncomfortable around homosexual men should not apply for a job at the AIDS foundation.

Sustainable living in a pluralist society is **THE** challenge of the 21st century. If society as a whole shifted to a position of valuing diversity and developing the institutions to negotiate ways forward where values and beliefs are not congruent, we might be moving in the right direction. New Zealand has demonstrated that this approach can work in the way that significant discord between Maori and the dominant culture has been discussed by the Waitangi Tribunal and ways forward negotiated. Most health law and regulations reflect this development. Specific clauses in the Code and the Maori specific research guidelines are good examples. The Code has made significant improvements for most of the population but by relying on informed consent and an inadequate approach to the use of interpreters has failed to be as effective as it could be for non-dominant cultural groups. Maori complaints are comparable to the proportions of Maori in the population but Pacific complaints are much lower (section 8.2), perhaps because Pacific find complaining culturally uncomfortable. There are some encouraging signs that some Maori health outcomes are improving. The Code does a good job of enhancing "cognitive trust" through the provision of information and of building institutional trust through the effective complaints process but it does not address relationship or emotional trust. My suggestion is an extra clause: *Providers have an obligation to aim to establish and maintain trust with their patients and to develop relationships based on openness, trust and good communication to enable them to work in partnership with patients to address their individual needs.*

The concept of Cultural Competence is central to bioethical practice. The need for this concept represents a failure of mainstream bioethics to consider the world from the perspective of someone from outside of the frame of reference of bioethicists. There is an urgent need for us to learn how to live in a functional pluralist society, reducing the disparity in health outcomes would be a good start.

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