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Informed Consent
or
Consent on a Form
An ethical or *legal* dilemma?

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fulfillment for the requirements for the degree of

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Lucy Casey

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Abstract

Informed consent is a worthwhile concept but in my view it does not work within the hospital institution in New Zealand. Why?

- Because the continued emphasis in theory and in practice is still on consent rather than choice and so the focus of the healthcare professional continues to be a signed consent form rather than the process of informing leading to choice?
- Because, to 'fully' inform and to ensure a person 'fully' understands is impossible...fully should be replaced with 'substantially' to make informed consent possible.
- Because the underlying principle of the present model of informed consent is autonomy, a Western concept centered on individualism, a view that is not held by all healthcare professionals or all healthcare consumers. A combination of autonomy, cross-cultural approach, 'ethics of care', and feminist perspective needs to be incorporated within moral theory that informs bioethics – ensuring the patient is viewed as autonomous and relational.
- And lastly, to accommodate true informed consent/choice a different approach to the relationship within the clinical encounter needs to happen; one of effective communication, collaboration and shared decision-making.

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Introduction

There is a plethora of literature on informed consent from philosophy, ethics, bioethics, history, law, medicine, nursing, quality, information services and the social sciences. Literature is abundant from countries that offer points of comparison with our own such as America, Canada, Europe, England and Australia. So you might wonder why a whole thesis on the same topic?

My background is midwifery and anthropology and as a midwife I have worked for many years within the hospital environment. I currently work on a daily basis with midwives, nurses, patients and their families, general practitioners, obstetricians, anaesthetists and paediatricians. Informed consent is the keystone of our relationships with patients and with each other. Informed consent is the key to the restructuring of the power relationships within the healthcare system.

However, I am increasingly concerned at the lack of application and understanding of informed consent within the clinical encounter. Informed consent is the proverbial idea whose time has come. As Victor Hugo (1802-85) said "You can resist an invading army; you cannot resist an idea whose time has come." In reality informed consent simply does not work, though there are no insurmountable reasons why it shouldn't. There is a dearth of understanding and a distinct lack of application within the clinical encounter by all healthcare professionals. This is based on my personal experience as a healthcare professional and on numerous discussions with healthcare colleagues.

Biomedicine is still a Western hegemonic system and the healthcare professional/patient dyad is a social process shaped by Western ideologies that have been formed by forces inside and outside medicine. Incorporated in this thesis is a viewpoint based on the perspective of Baer *et al* when they advocate examining these structures from the patient's point of view in order to amend the assumption that "because power is concentrated in macrolevel structures, the microlevel is mechanically determined from above. Missing from this understanding of the construction of daily life is an appreciation of the capacity of the microlevel to influence the macrolevel" (Baer *et al*/1997:32).

I like the concept of informed consent. I believe it is possible to look people in the eye and tell them the truth. I like the breath of fresh air it brings to the relationship between healthcare providers and the public. I don't like the way informed consent is being reduced to a simple ritual in which the law is satisfied and responsibility ends when the requisite papers are signed and dated. If it is to play a role in enhancing the relationship between health providers and recipients, informed consent must be more than a bureaucratic gesture.

So, if informed consent is such an admirable concept, why does it not work?

- Because the continued emphasis in theory and in practice is on consent rather than choice and the focus of the healthcare professional continues to be a *signed consent form* rather than the process of giving information to facilitate choice.
- Because, to 'fully' inform and to ensure a person 'fully' understands, as is required by New Zealand law, is impossible. 'Fully' needs to be replaced with 'substantially' for informed consent to be achievable.
- Because the underlying principle of the present model of informed consent is the Western individualistic concept of autonomy and many healthcare professionals or healthcare consumers do not share this viewpoint. A more eclectic approach from a cross-cultural and care-focused perspective should be incorporated within the moral discourse that informs bioethics. The patient could then be viewed as both autonomous and relational.
- Because in order to accommodate true informed consent a sea change must happen within the clinical encounter, one of effective communication, collaboration and shared decision-making.

The concept of informed consent has held primacy for only seven years in New Zealand and I believe it is time to reconsider its strengths and weaknesses and move it along to its next level – that of an efficient functional tool.

To justly consider the future of the concept it is essential to consider its past, its origins and its modifications over time. My thesis is, for me, a beginning, a literature search to identify areas that need further exploration through ethnographic or empirical research. Globalization and multicultural societies

are here to stay so there is a need for cross-cultural research into informed consent using an anthropological or ethnographical approach in order to fully understand the contextual relationships within the clinical encounter and how they can be improved.

Working in the field of healthcare my intention is to find practical solutions to the obvious lack of informed consent rather than a purely critical or theoretical analysis of the concept. There is to date no research within New Zealand into the dynamics of the process of informed consent as it takes place within the hospital clinical encounter. Before one can embark on such a journey one needs to understand where 'informed consent' is located within New Zealand. To that end I have structured my thesis in the following way.

Chapter one traces the legal history of informed consent. Recent publications maintain that New Zealand's legal framework is more advanced than that of most Western countries in the matter of informed consent (Donnelly 2002, Thomas 2000, Skegg 1999). This framework consists of an enforceable 'charter of patient's rights' and a corresponding duty imposed on health providers. Both are sanctioned by the Health & Disability Commissioner Act 1994. In addition there is a defined process by which consumers may lay complaints. But the current framework is not perfect: it has its weaknesses and strengths. For example to 'fully inform' is one of the requirements of the Health & Disability Code but that is a daunting prospect for any healthcare professional.

Chapter two examines the progress from medical ethics to bioethics, a process driven by complex cultural forces endeavoring to protect individual rights, a concept whose development can be traced historically through philosophy, law and ethics. I examine various approaches to ethics and how healthcare professionals can move from principle to practice to improve relationships within the clinical encounter. Informed consent is based on the Western view of respect for the autonomy of the individual, an ideology that does not sit well with feminists and non-Western cultures for whom collectiveness and altruism are as important as individual autonomy.

Disease knows no cultural boundaries but there are marked boundaries between the cultural beliefs and values of those who suffer disease and those who treat it. Is there a single ethical approach or a single principle that should be appealed to? Many authors suggest that all principles are inextricably linked to the Western value system allowing socially orientated values to be ignored or dismissed. Because the principle of respect for autonomy is at the core of informed consent I will discuss it at length in chapter eight.

Chapter three examines why the 'ethics of care', cross-cultural ethics and feminist viewpoints have been slow to be adopted and accepted into bioethics alongside the deeply entrenched Western ethical principles of autonomy, maleficence, non-maleficence and justice. The ethics of care presents a person as both an autonomous person and a relational person, emphasising such values as caring, empathy, compassion, friendship, love and relationships. Cross-cultural ethics emphasises collectiveness, community values, differences and other values held to be vital to interpersonal relationships. It is because of feminist reflection and discussion that 'care' has entered mainstream bioethics, despite the fact that Kant believed that women were incapable of theoretical reasoning. Without the inclusion of the ethics of care and cross-cultural ethics there is a distinctly limiting ethnocentric view of ethics.

Chapter four follows the history of informed consent. 'Consent' had been a quasi-legal part of medicine for two hundred years until its more recent merger with 'information', which led to the development of informed consent as the guiding concept within the clinical encounter. It is now a deeply embedded ethical and philosophical tenet within the Western healthcare system but, alas, not within clinical practice. One of the strengths of New Zealand law is in the wording of the Health & Disability Code which emphasises the word 'choice' rather than 'consent', enabling the person to choose to consent or refuse. In this chapter I also examine the elements necessary to ensure informed consent and identify and discuss the more problematic concerns.

Chapter five analyses how information is disclosed and interpreted - too much information can leave a patient as confused as too little information. I ask if any healthcare professional can be a neutral presenter of information and question whether any healthcare professional can possess full knowledge of all aspects of disease. It is an accepted fact that there is cognitive and emotional inequality between patients and healthcare professionals leading to limitations in understanding clinical input (Doyle 2001:129-130). There is also a strong tendency for healthcare professionals to believe that an informed patient is automatically a consenting patient and that a signed consent form demonstrates that a patient has been "fully informed". However, it is vital to stress that there is also a level of responsibility with the patient during the information exchange.

Chapter six declares communication to be the key to a successful relationship between the healthcare professional and the patient within the clinical encounter. Doyle (2001:132) presents evidence that healthcare professionals are poor communicators. Patients and healthcare consumers must both take responsibility for effective communication within the clinical encounter. Therefore education in communication skills is needed for both the public and the professional. Though paternalism is still strongly evident today it is being slowly eroded by moral and bioethical arguments. The decline of their power within the clinical encounter is not easy for healthcare professionals to accept, especially as medicine is steeped in a culture of decision-making. So can healthcare professionals adapt to the shifting focus of control from them to the patient?

Chapter seven discusses models of relationships within the clinical encounter. I examine several of the models that exist and ask which one has the structure to promote change of the power imbalance within the clinical encounter. I examine the model of "partnership" but find it does not reflect the unequal relationship that exists within the clinical encounter. My choice is a model that includes collaboration, negotiation and shared decision-making and recognises the asymmetry of information and the inequality of power within the clinical encounter. I also examine the cultural construction of the patient within the

hospital environment and the clinical encounter. This analysis demonstrates the relevance of an anthropological approach which recognises shared beliefs and values expressed in social practice and traditions. The structure of the hospital institution, strongly influenced by medical hegemony and political manoeuvrings, undermines patient autonomy rather than uphold it. Consumers and patients need to participate more actively in healthcare decision-making to alter the power structure.

Chapter eight discusses autonomy as the central premise of informed consent. Autonomy and individual rights are inextricably linked, but how these rights are respected depends on the social, cultural and political environment in which they exist. However, autonomy, a distinctly Western ideology, does not appeal equally to all users of healthcare because it does not transcend cultural boundaries. Neither does it transcend the illness and wellness spectrum, perhaps because, as White suggests, the “essential problem lies in the fact that the philosophical notion of autonomy is not a phenomenologically accurate description of the condition of the person who seeks medical help – the map is not the territory” (White 1983:99).

Chapter one

"True consent to what happens to one's self is the informed exercise of a choice..." (Canterbury v. Spence, 1972)

Informed Consent and the Law: New Zealand's distinctive perspective.

The term 'informed consent' was first coined in 1957 following a one hundred and ninety year uneasy liaison between medicine and law. According to medico-legal historians the troubled relationship between law and medicine began in the year 1767 when the courts first acknowledged the responsibility of a physician to obtain a patient's consent for medical treatment (Faden & Beauchamp 1986:116). This consent was a very different from the 1957 concept which incorporated respect for autonomy based on an individual's rights.

Respect for individual autonomy is deeply embedded in Western philosophical values and is the essential component that shaped the development of the legal doctrine of informed consent. Though the roots of the principle of respect for autonomy go back over two thousand years, the principle as it is understood today is a more recent development in law and political philosophy.

Historically, medicine was free from legal input, regulated by its own moral and ethical tradition which had its roots, according to Jonsen, 'in Hellenic, Hellenistic, and Roman medicine, beginning in the fifth century BCE' (Jonsen 2000:1) and was first mooted in *Epidemics 1*. Many authors attribute *Epidemics 1* to Hippocrates, though Jonsen points out that the Hippocratic Collection was made up of some 70 treatises written over the course of five hundred years. The Hippocratic model of the clinical encounter originated in the fifth century BC and still has significant influence today.

The mixture of religion and magic practiced prior to the fifth century BC declined in popularity under the influence of the early Greek philosophers in search of natural causes of disease. Hippocrates, philosopher and physician, began teaching a medicine based on four characteristics: 1) natural knowledge, 2) superior techniques and skills of physician, 3) observation of patients within their environment and 4) beneficence. These elements became the essence of

the paternalism, which developed and grew over the next 2000 years to become an integral part of medicine until challenged in the 20th century.

In the traditional clinical encounter the patient visited a physician and could choose whether or not to follow the physician's recommendation. This act implied consent and suggested an agreement to treatment, though with no requirement for explanation or justification. During the second half of the twentieth century a culture of consent began to develop as individuals became increasingly vocal about their rights, which significantly impacted on medicine and research. It is generally accepted that there were several major reasons for this. One, the atrocities committed against humanity by German doctors experimenting on prisoners, in the name of science. Two, the acceptance of the ruling of the Nuremberg Code (1947), which declared that for research on any human subject, voluntary, competent and informed consent was an absolute essential. Three, the adoption and integration of the Nuremberg judgments by the Helsinki Declaration of the World Medical Organization in 1964. Four, the activities of civil rights campaigners in North America and Northern Ireland and five, the emergence of a strong consumer rights movement.

In 1767 the courts first acknowledged the responsibility of a physician to obtain a patient's consent for medical treatment in the case of *Slater v Baker and Stapleton*. The defendant doctor re-fractured the plaintiff's leg against the patient's wishes. The doctors were said to act improperly because 'a patient should be told what is about to be done to him, that he may take courage and put himself in such a situation as to enable him to undergo the operation' (Donnelly 2002:10). The patient, Mr. Slater, complained that he had not consented to treatment and the judge ruled that the physician should indeed have been cognisant to the wishes of the patient. It was in 1914, in America, 147 years later that consent assumed significant importance in medico-legal terms. One of the first precedent-setting cases in 'autonomy as legal self-determination' was *Schloendorff v. Society of New York State*. A woman undergoing an exploratory examination under general anaesthetic asked that she should have no surgery performed, just an examination. The surgeon finding a fibroid tumour removed it. Justice Cardozo, the presiding judge

rejected a 'beneficence-based' account stating "every human being of adult years and sound mind has the right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages" ... but went on to state that there was an exception in the case of an unconscious patient (1914. 211 N.Y). This was induction of consent and autonomy into legal canon. But there was little significant legal input into 'informed consent' until 1957 because the "justification of practices of disclosure and consent-seeking were strictly governed by what we shall call a 'beneficence model' rather than an 'autonomy model' of the physician's responsibility for the patient" (Faden & Beauchamp 1986:59). The concept of consent developed in England, America, Australia and New Zealand becoming embedded in their legal systems, albeit in different ways.

Martin Pernick, a historian, and Jay Katz, a psychiatrist, framed two competing historical analyses of informed consent. Pernick claims that truth-telling and consent have "long been part of an indigenous medical tradition" whereas Katz believes that "the history of the physician-patient relationship from ancient times to the present...bears testimony to physicians' inattention to their patients' right and need to make their own decisions" (Faden & Beauchamp 1986:56). However, both agree that informed consent, as we know it, began in 1957. Pernick did acknowledge that the notion of consent in the nineteenth century was not rights orientated but tended to be justified by therapeutic considerations. Cases that did go to court took action in the law of battery and North American courts became very concerned at the ease under this law to establish criteria for liability so, in 1957 they began to allocate actions involving informed consent to law of negligence.

The notion of informed consent was first verbalized in the case of *Salgo v Leland Stanford Jr. University Board of Trustees* in USA in 1957. The term 'informed' became attached to consent, making the theory of consent a much more complex legal concept. In this case the physicians were held liable for breach of 'duty to disclose' facts which were necessary to form the basis of an intelligent consent by Salgo to specific treatment. This landmark case marked the embryonic development of the concept but the real foundations for informed

consent came in the USA in 1972 in *Canterbury v Spence* which laid down the basic legal principle that a physician had a 'duty to disclose' as well as a 'duty to care'. This court also held that a physician still had 'therapeutic privilege' not to provide information to a patient if the disclosure of such information would be detrimental to the condition of the patient but the court warned that this privilege must be executed with due care.

In the same year as the landmark American case, there was an equally famous ground-breaking case in England. It was the case of *Bolam v Friern Hospital Management Committee* from which the '**Bolam test**' has evolved, a test that has taken on a hallowed respect. Skegg states that the Bolam test inferred that "practitioners are not negligent if they act in accordance with a practice accepted at the time as proper by a responsible body of medical practitioners" (Skegg 1999:144). England's development of the concept of informed consent is based on an appropriate standard of disclosure, sometimes called the 'prudent physician' standard. Though the Bolam test was instigated in 1957 and was appealed to in a few cases, it was not truly endorsed by the House of Lords until 1985 in the *Sidaway v Board of Governors of Bethlem Royal Hospital* when the *Bolam test* was applied to the disclosure of information about risks associated with a specific procedure. According to Skegg little has changed in the English common law approach to informed consent since the *Bolam test* more than forty years ago in comparison to the progress and changes in the other common law countries of America, Australia and New Zealand. Marj Milburn (2001:28) agrees stating that the jurisdiction of England has been the least progressive of common law jurisdictions.

Most parts of the United States moved away from 'prudent physician' to 'prudent patient' standard in 1972 when the court rejected the practitioner-based standard in *Canterbury v Spence* putting the onus on the courts and not the medical community to decide what was the appropriate standard of disclosure. Healthcare professionals must disclose all risks and hazards associated with any medical treatment, which might influence a prudent person to make different choices. USA lead the way with significant numbers of court actions involving 'failure to inform' but such cases did not appear in the English, Australian or New Zealand courts until the 1980s.

Australia rejected the 'prudent physician' standard in a landmark High Court case *Rogers v Whitaker* 1992, accepting that physicians had not only a duty of care and skill but a duty to provide information to enable the patient to make an informed choice about accepting or rejecting treatment. They had a duty to disclose material risks inherent in a proposed treatment – a risk is judged to be a material risk if a reasonable person warned about the risk would attach significance to it. In this case a woman undergoing eye surgery asked about risk to her sight. She was not told about a 1% chance that as a result of the surgery she might lose the sight in her eye. Most patients would not expect to be told of a less than 1% risk factor except for the fact that this woman was already blind in the other eye, so this risk was especially relevant to her.

There is, unfortunately, ambiguity as to what constitutes a rare risk. Thomas identifies a rare occurrence/risk if the probability of its occurrence is less than 1%. If the patient has been told the risk then the adverse outcome occurs it is not regarded as a medical mishap. This led Thomas to suggest, "the risks which need to be disclosed to a patient are those which exceed a 2% probability, either in respect of all such treatments, or because of the particular vulnerability of the patient" (Thomas 2000:9). The emphasis on the degree of risk necessary to comply with the 'fully informed' aspect of informed consent in New Zealand is problematic, suggesting certain limitations of the doctrine of informed consent, as it exists.

Ian Dunn (1993) argues that Whitaker may have been successful in court only because of her insistent questioning before the operation as to the risk involved to her sight by her operation. If this was the case then 'prudent physician' standard was not being upheld because a prudent physician should answer all questions raised by a patient that relate to a proposed treatment. According to Milburn this ambiguity still remains following the case of *Chappel v Hart* 1998 when Hart voiced her concerns about possible damage to her vocal cords by recommended surgery. Her cords were damaged but her physician had not informed her that this was a possible risk. "This conservative emphasis on 'question-asking' may unduly influence future court decisions" (Milburn 2001:13). What *Rogers v Whitaker* did establish was that consent given without

adequate information is meaningless because a true choice has not been made.

Thomas (2000:5) describes subjective and objective tests attached to this ruling: The subjective test - the physician has a duty to provide information that the physician knows is relevant to the specific patient. The objective test – the physician must warn against all risks that would be relevant to a reasonable patient. New Zealand law is based on the subjective test which protects the people who may not know the right questions to ask and that liability should not depend on 'question-asking'. However, this is a catch twenty-two situation because a person must have an adverse outcome in order to prove they have not been properly informed! In New Zealand, patients who have no adverse outcomes, but have not been adequately informed, can lay a complaint with the Health & Disability Commissioner, but how would they know to complain? This implies that quality improvement cannot happen until after an adverse incident. In the law of averages most cases will not end as worst-case scenario but that should not sanction the physician to renege on the duty of disclosure of information.

Legal development of informed consent in New Zealand

In New Zealand the turning point on informed consent occurred later than in many first world countries, but is currently considered to have progressed further. It has moved from focus on duty of care to focus on the patient's right to make informed choices. However, this pioneering advancement came at a price to 948 New Zealand women who were exposed to non-treatment for invasive cervical cancer without informed consent.

The 1990s was an era of sweeping changes within New Zealand's healthcare services and the legislative framework that governed them. The implementation of the current legal principles and framework that govern informed consent followed three major events. One: A twenty-year long research at National Women's Hospital, which began in 1966. Two: an exposé by Sandra Coney & Phillida Bunkle in *Metro* magazine in June 1987. And three: the Cartwright Report (1988), which included the findings from the Cartwright Inquiry into the National Women's Hospital research and recommendations for major changes

to the New Zealand health system. Coney & Bunkle's article raised public awareness while asking serious ethical questions about the research project at National Women's Hospital. That research began in 1966 and continued despite strong challenges over several years from colleagues and international evidence that carcinoma in situ (CIS) becomes invasive if left untreated. However, general reaction to the 'unfortunate experiment' was not spontaneous and in fact politicians, women's groups, the media and civil liberty groups were all initially conspicuous by their silence. Only the work of a small number of journalists and radio commentators who continually highlighted the situation led the New Zealand Prime Minister to move for a 'very rapid inquiry'.

Herbert Green, Associate Professor of Obstetrics and Gynaecology at National Women's Hospital, who headed the research, did not agree with international trends and left many women untreated as part of the research with blatant disregard for their informed consent and their health. The absence of 'informed consent' for all the women in this research trial directly contradicted the requirements for ethical research laid down by *The Nuremberg Code* in 1947. A number of ethical principles were violated during this research – women were not given information so they could make a choice, several women died because of the conservative treatment the research dictated, and all were the subjects of research instead of clinical treatment. Despite the misgiving of colleagues, and research overseas that negated Green's claim, the project continued for 20 years.

Within weeks of Coney & Bunkle's article the Minister of Health set up a Committee of Inquiry headed by District Court Judge Silvia Cartwright. The Cartwright report was released one year later, and together with Coney & Bunkle's "The Unfortunate Experiment" article in Metro, was pivotal in compelling New Zealanders to re-evaluate their understanding and awareness of individual rights within the healthcare system. The report recommended extensive changes to Healthcare practice of research and medicine. A more subtle change at the time was that it made it "politically acceptable to question the medical establishment" (McLoughlin 1993:59).

The report also led to major changes within the medical profession by its own professional body. The most significant change was a shift in 'power' from

healthcare practitioner to the patient – changing the balance of power within the clinical encounter. This “case was to destroy the view that doctors could be trusted to look after their own ethics.” (Snook in Davidson & Tolich, 1999: 71). This inquiry also highlighted several other disturbing details of questionable medical practices that had gone unchecked in New Zealand. One such revelation also happened at National Women’s Hospital, where 2200 newborn female babies had a vaginal swab taken without parental consent. What the inquiry did show was that a number of nurses as well as doctors were involved in both researchs. They carried out practices dictated by the research leaders without questioning their actions and without being held accountable. This, to me demonstrates the hegemonic power relations within healthcare institutions. Little blame was apportioned to the nurses by the commissioner, which reinforced the medical constraints on nurses by medical institutions and continuing the ‘hand-maiden’ of the medical profession image.

Since the Cartwright inquiry, the Ministry of Health, the New Zealand Health Council and the Medical Council have all published papers on consent. Ethics and research committees have been formed by District Health Boards. The Nursing Council of New Zealand has incorporated informed consent in its Code of Conduct for Nurses and Midwives. In 1990, the Medical Council clearly directed “that (except in an emergency or related circumstance) the proper sharing of information, and the offering of suitable advice to patients, is a mandatory prerequisite to any medical procedure instituted by a medical practitioner. This applies whether the procedure is a diagnostic one, a medical or pharmacological regimen, an anaesthetic, or any surgical, obstetric, or operative procedure” (Medical Council of New Zealand 1990:1). This statement followed the 1989 *Green v Matheson* case when it was judged that any failure to adequately inform a patient about treatment or research may be ‘medical misadventure’ if the healthcare professional acted negligently in failing to obtain informed consent. In 1990, the Medical Council also wrote “a unique feature in New Zealand is that it will be to the Medical Council and associated Disciplinary Tribunals that we can look for guidance, not the courts” (1990:23).

New Zealand does not have one single written document as its constitution but is influenced by a variety of legal frameworks; common law or unwritten

constitution, the Constitution act 1986, the New Zealand Bill of Rights 1990 and the Treaty of Waitangi 1840. The legislative framework encompasses common law and provides legal guidance under the Act and the Code. The right to refuse medical treatment is preserved in the Bill of Rights 1990. "The basic principle underlying consent is that every sane adult has the right to say what shall be done to his or her own body", this consent can be written, oral or implied. New Zealand differs from all other countries as the statutory compensation system (Accident Insurance Act 1998) prevents people suing for medical misadventure. The focus is on the patient's rights rather than 'therapeutic' judgment imposed on the patient. Section 36 of the Accident Insurance Act clearly distinguishes between error from negligent treatment as result of failure of duty of care and error as result of failure to obtain 'informed consent'. The Accident Insurance Act answers claims in tort for those who receive personal injury and pays a settlement for injuries that result from medical misadventure.

The response from parliament to the 'unfortunate experiment' was the New Zealand Bill of Rights Act 1990 which affirmed "the right not to be subjected to medical or scientific experimentation" without informed consent and "the right to refuse to undergo any medical treatment". This Act was closely followed in 1993 by The Human Rights Act which prevented discrimination against individuals with disability, against youth and against the elderly; ensuring equality for all within the healthcare system. 1993 also brought the Consumer Guarantees Act, which gave healthcare consumers guaranteed rights to reasonable care and skill. In 1994 came the Privacy Act known, as the Health Information Privacy Code, preventing the disclosure of an individual's information to anybody without explicit permission of the individual. This act also gave an individual access to personal medical or clinical records.

The Health & Disability Act was also enacted in 1994, creating an office of Commissioner whose role was to protect and promote the rights of healthcare consumers and to facilitate "the fair, simple, speedy, and efficient resolution of complaints – together with a national network of independent advocates, under the director of Advocacy and an independent prosecutor, the director of Proceedings." (HDC website)

The Code of Health & Disability Services Consumers' Rights (hereafter referred to as 'the Code', and reproduced in appendix 3) became law on July 1, 1996 as a regulation under the Health and Disability Commissioner Act.

Robyn Stent, the first commissioner saw the 'the code' as a quality improvement tool or 'blueprint' by which the principles would be incorporated into the practices and training of all healthcare providers and professionals (Paterson: HDC website 2001). Clause 1 of the Code provides that 'every consumer has rights in this code' and 'every provider is subject to the duties in this Code'. There are 10 rights conferred on the consumer that impose a legal duty on the providers of healthcare services to give effect to those rights. The Code is a regulation under the Health & Disability Commissioner Act 1994 and codifies patients' rights and provider's responsibilities. It encompasses all healthcare providers, including alternative therapists. The obligation under the Code is to take '*reasonable actions in the circumstances to give effect to the rights, and comply with the duties*' (HDC). The basic principles that are encoded are standard of care, information disclosure, consent and complaint procedure. Skegg (1999:153) reminds us that the code cannot stand alone, it can only be understood with reference to the Health & Disability Act 1994. For example to understand the extent of the term 'provider' one needs to explore both the Act and the Code. What makes the New Zealand legislative framework different from other countries is the focus on patients' rights and information rather than on therapeutic judgment imposed on patients.

It is Right 7 of the Code, - *Right to make an informed **choice** and give informed consent* that is specific to informed consent, but it is essential that no right in the Code is taken in isolation, all other nine rights must also play a part. However, the combination of Right 5, *Right to effective communication*, and Right 6 – *Right to be fully informed* play a major part in duty to disclose and both Rights are essential to understanding and legitimising informed consent. The emphasis on the word *choice* within this legislation is what gives New Zealand the power to make the concept a working possibility, it suggests discussion, disclosure and decisions to consent or refuse, but thus far it is confined to theory not practice.

Right 5(2) of the Code also states that every consumer must have an environment that is conducive to open communication – an almost impossible scenario in any public hospital where a patient is rarely in a room alone and most conversations take place behind a closed curtain!

The intended result of the overall legislation is twofold, to give the patient greater protection from exploitation or manipulation within the healthcare services, and to give legal protection to health care professionals and healthcare institutions. There is debate around the positive impact of the 'deterrent effect' of tort liability on the improvement in quality of care, but according to Brennan there is not enough empirical data to confirm or deny. He does, however, suggest that institutions are in a better position than an individual practitioner to put strategies in place to protect both patient and practitioner from complaints (Brennan 1998:723).

The New Zealand Act and Code together create a form of civil liability and most complaints are dealt with without proceedings being instituted (Skegg 1999:153). The Health & Disability Commissioner is responsible for investigation of complaints but he may refer a case to an advocate or to the director of proceedings who can institute civil proceedings before the complaints review tribunal. The investigation of a complaint is free to the consumer. It seems that the combination of the Act and the Code place emphasis on prevention, reconciliation of complaints and arbitrated decisions. Complaints are also viewed by the Commissioner as a method of improving the healthcare sector standards of care, in fact the Commissioner declared at a Quality conference in Australia, that quality improvement is the major *raison d'être* of the office of the Commissioner.

There is substantial obligation placed on healthcare providers to ensure the Code is widely available to the public, however the 1999 report on the Commissioner's website states that though the existence of the code is widely known, the public have little knowledge of its content. This is despite it being clearly displayed and available in the majority of public hospitals, GP's surgeries and 24-hour accident and emergency buildings. It is a mammoth task to educate the general public and healthcare professionals about the Code to ensure all healthcare consumers access their rights. It is too big for the

individual healthcare provider and will require government resources to increase public awareness and increase communication skills among health professionals. As patients begin to understand their rights they will become more confident and purposeful in their questioning which will lead to improved communication within the clinical encounter because true communication is always a two way process.

An especially significant difference in New Zealand law from other countries is the emphasis on informed *choice* rather than consent within the Code. According to Thomas (2000:13) "the requirements in the Code that a consumer must make an "informed choice" are wider than the concept of informed consent" because it also stipulates the need for information about alternative therapies. I view this emphasis on choice rather than consent as one of the major strengths of the New Zealand legislation. The word consent implies a need to gain consent to a treatment rather than provide patients with options, alternatives and information and allow them to make a choice. I believe that the word choice implies the ability to give an informed consent or an informed refusal to a specific treatment. However, the public and educational emphasis within New Zealand is unfortunately still on informed consent, which is probably the main reason why most healthcare professionals and public still focus on consent rather than choice. If the emphasis became informed choice rather than informed consent, a much needed paradigm shift might take place within the healthcare system, changing the way healthcare professionals equate informed consent with a signature on a consent form rather than with patient's choice.

Another significant difference from Australia, Canada, USA and England, is that in New Zealand, under the Code, a person can complain even if the result of treatment were satisfactory but the patient believed that a significant risk had not been explained to them prior to treatment. By not being informed of such a significant possible risk the individual could not make an informed choice, so the process of informed consent was meaningless.

One of the major weaknesses of the New Zealand system is the reliance of the Act and Code on the consumer, or family of consumer to lodge a complaint. This is especially significant if according to the Commissioner (2001:5) patients

have little knowledge of the content of the Code. The media reminds us constantly how many errors or mistakes are made within the healthcare system but if the public do not understand their rights fully they may not know to complain, especially if they are from a marginalized groups. According to the Health & Disability Commissioner Ron Paterson, there were 544 patient instigated complaints, another 296 complaints initiated by friends or family members, and 38 providers or institutions made complaints on patients' behalf in the year 2002/03 (Peterson 2003 personal communication). This seems to me to be a very small number considering the number of people in hospital on a daily basis, for example there are approximately 3200 births per year in the hospital at which I work. This maternity section is part of a moderately sized general hospital, which in turn is only one of many hospitals throughout New Zealand. I can only speculate that from the experience of working within hospital for many years that there are several errors made on a daily basis in each moderately sized hospital.....

In USA, England and Australia litigation is very high and there seems to be general consensus that the legal history of informed consent has focused almost solely on the clinical encounter instead of research mainly because of compensation and litigation for adverse medical outcomes. One could conclude that the law has popularised informed consent, but it also serves as a strong reminder to the medical profession that uninformed consent is unacceptable.

Law too has its theories and contra theories – legal positivism is the prevailing legal theory in English speaking common law jurisdictions – believing that questions of morality are totally separate from law, making law rational and impartial. The evolvment of the critical legal studies movement in 1970s, inspired by Roberto Unger, called “for major changes to a legal system seen to be protecting power and privilege behind a façade of professed impartiality” (Milburn 2001:93). In most countries common law is still driving the concept of informed consent, but one wonders whose interests are being upheld. From my involvement in the process I believe the movement towards true informed consent is deviating into a legal gambit to protect any healthcare professional who has obtained a signature on a piece of paper. Is legal action becoming focused on avoidance of action rather than on the fundamental issue of benefit

to patients? Milburn argues that the “law in liberal democratic societies should protect the vulnerable citizens from rights violations. However, common law jurisdictions in Australia, Canada, the United Kingdom and the USA have failed to fulfil this obligation in relation to informed choice” (Milburn 2001:x). She sees the imbalance of power as the area to be targeted for some law reform so that there is a change in the balance of power in the clinical encounter.

Summary:

Consent has been implied throughout the history of medicine. It only became a medico-legal issue as part of a shift in attitude towards individual rights and the safeguard of individual autonomy. The culture of consent changed quickly and dramatically in response to universal recognition of the lack of respect for the individual in medical research and experimentation. Because of this universal shift in attitudes the concept of information became linked to the concept of consent and, in 1957, became the legal doctrine of informed consent.

The legal framework for informed consent developed at different stages across the world progressing from physician-focus to patient-focus. In New Zealand a sense of urgency on the issue was prompted by the exposure of the unscrupulous research on hundreds of uninformed women carried out over many years at National Women’s Hospital. New Zealand’s legal framework changed dramatically to ensure that such an event could not happen again.

In my view New Zealand’s legal framework of informed consent has strengths and weaknesses. The vital use of the word ‘choice’ instead of ‘consent’ within the Code is one of its greatest strengths. If this emphasis could be transferred to the clinical setting and into the process of informed consent I believe the relationship between healthcare professional and patient would change dramatically for the better. This change of emphasis needs to stem from the macro level of management, politics and law in order to be incorporated at the micro level of the clinical encounter. The personal emphasis of healthcare professionals must be changed from consent on a form to informed consent.

Choice is a wider concept than consent as it focuses on the patients, their choices, available alternatives and the information and understanding needed to make a choice. Most significantly it suggests a more equal power balance

within the clinical encounter. A major weakness within the Code is its reliance on patients or consumers to make complaints. Though many will, if they have an adverse outcome, minor adverse outcomes, bad practice or inappropriate treatment are much less likely to be exposed.

This is further complicated by limited awareness on the part of the public of their rights under the various laws and even less awareness of the intent of those laws. Not only are the public not aware of their legal right to informed consent but the attitude of medical authoritarianism that still exists within the healthcare institution also deprives them of their moral right to informed consent. To close this gap between law and morality we need to identify the various approaches that inform bioethics and the clinical encounter.

Chapter two

"If the perennial problem of the gap between principle and practice is to be solved, the meaning of principle needs to be clarified" Jonsen 1994:15

Moral Principles and Approaches that inform ethics and bioethics

We face moral dilemmas every day; reading the morning newspaper, watching television, listening to the radio or when confronted at work with a 'difficult' situation. We are troubled by situations that are unfair, immoral, cruel or wrong – but how do we decide what practices are morally acceptable or unacceptable and how do we resolve such issues? The moral principles we appeal to when we attempt to resolve our daily dilemmas are the values, intuitions, beliefs and behaviours shaped by the culture and society we live in. These are defined in each society in the form of rights, rules, obligations, laws, fairness, specific virtues (honesty, compassion, loyalty), benefits to society and are also embedded in our daily actions and rituals. These moral principles are the combination of culture and ethics. "Culture and ethics are inextricably bound to each other. Culture provides the moral presuppositions and ethics the formal normative framework for our moral choices" (Pellegrino 2001:535). Common morality is a code of rules and regulations based on the tradition of the right and wrong of human actions within a social institution. *Specific* morality relates to actions of right and wrong within a specific profession.

Medicine has had its own code of ethics since the formulation of the Hippocratic Code which committed members of the profession to non-maleficence – *above all do no harm*. But the birth of medical ethics as a philosophical field dates from the Enlightenment and is attributed to John Gregory and Dr Thomas Percival. Gregory's publication of his "Lectures on the duties and Qualifications of a Physician" in 1772 was an intrinsic part of the development of medical ethics. He stressed the need for all physicians to be humane: "it is as much the business of the physician to alleviate pain, and to smooth the avenues of death, when unavoidable, as to cure diseases" (Gregory in Freeman 2001:xvi).

Dr Thomas Percival coined the phrase 'medical ethics' and argued that non-maleficence and beneficence: "fix the physician's primary obligation and triumph over the patients rights of autonomy in any serious circumstance of conflict"

(Beauchamp in Gillon 1994:5). In 1803 he published "Medical Ethics; or, a Code of Institutes and Precepts, Adapted to the professional Conduct of Physicians and Surgeons." This became the theoretical justification behind the American Medical Association's first code of ethics. The principles of non-maleficence and beneficence were the landmark principles that gave shape to bioethics or healthcare ethics. The USA took them up with enthusiasm and until recently they remained the dominant values of the clinical encounter within medical ethics (Beauchamp1994:5). More recently, however, the emphasis of the physician's responsibility has moved from the traditional duty of care towards respect for the rights and autonomy of the patient.¹

Bioethics

Bioethics developed from medical ethics in the 1970s, bringing with it a range of complex moral dilemmas and practical problems within healthcare, which, neither moral philosophy nor moral theology were ready to deal with. This was because the discipline of moral philosophy had been a scholarly field for the previous 100 years; medical ethics was merely an academic interest lacking any practical means to solve ethical problems. But as healthcare became more complicated and medical resources became scarce and non-economic, it became essential to have a means to resolve moral dilemmas and bioethics moved into that vacuum.

Bioethics is an attempt to apply general ethical theories to conduct and moral judgements in clinical situations within the healthcare system. Today, bioethics encapsulates all aspects of morality relating to healthcare including health professionals, institutions, administrators, government, economics and the law. The principle at the centre of bioethics is *respect for autonomy*, which is rooted in the recognition of individual freedom and choice.

After WW2 Western societies underwent a general shift away from their historic homogeneity at the same time as movements such as civil rights, consumer

¹ In this thesis I use the traditional term "patient" because for me it has connotations of dignity, caring and protection with implicit ethical obligations, whereas the current fashion for "client/consumer" is business jargon with connotations of profit and loss rather than health and caring.

awareness and feminism played increasing roles. Jonsen lists three major events in the development of bioethics at that time. Firstly, there was the establishment of a hospital ethics committee in Seattle, USA in 1962. This committee, consisting of lay people as well as medical personnel, was formed to allocate renal dialysis because of excessive demand for this scarce resource. Secondly, the article published by Dr Henry Beecher exposing unethical research methods in twenty-two studies. One of those studies was the Tuskegee syphilis experiment, which demonstrated total disregard for the well being of its research subjects. This government sponsored study lasted for 40 years in an attempt to follow the natural course of syphilis. The subjects were poor, rural and black. They were not told they had syphilis but were told their treatment was free. But they received no treatment, only blood tests and clinical examinations. This regime continued despite the fact that early in the study a guaranteed cure for the disease, namely penicillin, became widely available. Thirdly, the first heart transplant performed by Dr Christian Barnard in 1967 raising the question as to when a donor could be considered dead before the heart was removed (Jonsen 1993:S1-S4).

The 70s brought political unrest, social movements based on ethical critiques of Western society, universal recognition of human rights, and major ethical dilemmas because of the rapid technological advancements within biomedicine. Many advanced treatments and technologies in the area of renal dialysis and organ transplants came to be seen as routine. The public began to voice concerns about the resolution of ethical dilemmas, especially in areas where there was a need to harvest organs from cadavers or where the availability of treatment appeared to favour white middleclass moneyed people. Bioethics became a separate discipline, though not without major philosophical and legal discussions and analysis. Meanwhile the universal human rights movement encouraged patients to become aware of their rights within the clinical encounter and there was a worldwide growth of scepticism about medicine, drugs and the ability of healthcare professionals to maintain a high level of knowledge about technological innovations.

However, bioethics is not a monolith. It has subcategories such as medicine and nursing. As these are the two groups most directly involved in the clinical encounter I outline their relationship within bioethics.

Nursing was established as a profession in the 1860s but the first book on nursing ethics did not appear until 1901. Dock, an early advocate for a code of ethics for nursing, was advised by an American physician: "Be a good woman but do not bother with a Code of Ethics" (Dock in Johnstone 1994:1). Johnstone argues that medical ethics and nursing ethics are two distinctly separate "specialised fields of inquiry" and are "a subcategory of bioethics" (Johnstone 1994:38). The field of medical ethics was considered distinct from the field of nursing ethics "naturally born of the practices of medicine and nursing respectively" (Johnstone 1994:38). Both professions interconnect, overlap and link in many areas but their ideology is different; medicine with a cure-focus, nursing a care-focus. Removing the word medical from ethics and using the more generic name bioethics allows nursing to take its place as an equal subcategory of bioethics just as medicine and other healthcare professions have done.

Is there a universal ethical theory?

Because Western countries were largely responsible for the philosophical discussions within bioethics its literature is strongly Eurocentric. Though the principle of individual autonomy is taken for granted by the West this is not the case for non-Western ethical systems which tend to place greater emphasis on "cultural, communal or family autonomy" (Freeman 2001:xxvii). "In biomedical ethics (the) transcultural challenge is vastly complicated because medical science and technology, as well as the ethics designed to deal with it's impact, are currently Western in origin. They are deeply engrained with three sets of values distinctly Western – the values of empirical science, principle-based ethics, and the democratic political philosophy. Such values are often alien, and even antipathetic, to many non-Western world views" (Pellegrino 2001:535).

Mainstream philosophy has not succeeded in developing a single unified moral theory despite the fact that the power and influence of modern medical

technology continue to grow and spread through all cultures. This is further complicated by the fact that cultures are increasingly intermingled within formerly homogeneous societies. Pellegrino reminds us that disease knows no cultural or geographical boundaries so every nation has a stake in its neighbour's health. The corollary of this is that culture also flows across geographical boundaries to the point where every citizen must be aware of his neighbour's culture. This is magnified within practical every day healthcare where professionals of a multiplicity of cultures treat patients who are equally multicultural.

The lack of a single unifying theory is a tenet of cultural relativism which has its origin in anthropology. This states that there is no universal moral standard or principle that can be applied to all cultures (Leininger 1990:49-66, Elliott 1992:28-35). Cultures differ widely in their moral practices; practices that are considered morally acceptable in one culture may be condemned in another, which begs the question as to whether there are any universal moral principles? Moral differences across cultures raises an issue in ethics - the concept of ethical relativism which holds that morality is relative to cultural norms (www.scu.edu/ethics). In other words there are no universal moral standards.

Many ethicists reject this notion, claiming that although practice may differ from culture to culture the fundamental principles underlining the practices do not. Once again this is probably a Eurocentric view, but the concept does raise important issues for healthcare professionals reminding them that their personal beliefs are deeply influenced by their own culture and may be significantly different to those of their patients.

The multicultural status of both healthcare professionals and patients point towards an urgent need to attempt to produce a unified ethical theory that incorporates a cultural perspective, and a feminist perspective (both care and power focused), within a less individualistic view of the concept of respect for individual autonomy. This all encompassing transcultural ethic may allow people from all cultures to feel more connected and involved in the clinical encounter and to have more effectively communicate of differences in values and beliefs to ensure an informed consent. A reshaped transcultural ethic may include a vision of respect for autonomy which includes care-focused attitudes

of sympathy, empathy, love, interdependence and family; power-focused attitudes of gender (and other) equality and lack of oppression; and transcultural attitudes of respect for differences, collectiveness and community involvement. In a nutshell this perspective is advocating a less individualist and more relational approach to autonomy, a notion that is emanating from current literature from ethics to anthropology – so why is it not being heard?

Pellegrino believes that the central problem is the moral status of 'cultural autonomy' with what seems to be a *prima facie* obligation to respect all cultural values no matter how they deviate from our own, "to violate a person's cultural beliefs and practices is tantamount to assaulting his or her very humanity" (Pellegrino 2001:537). Pellegrino suggests finding a middle ground that would avoid locating any difference as culturally 'superior' from a Western perspective but could still also maintain cultural identity. He suggests a 'metacultural' ethic that would 'ameliorate cultural relativism', a metacultural ethic that is grounded in "something more fundamental than culture – the deference owed to all human beings qua human beings" (Pellegrino 2001:538). According to Pellegrino, patient determination, in spite of its propagation as the central tenet of Western bioethics, should be universally recognized because of its metacultural justification. "The dignity of the human person is not something that can be continually asserted or denied. It transcends culture because it resides inalienably in what it is to be a human being" (Pellegrino 2001:539). In my view, respecting the dignity and autonomy of a person within their environment transcends culture. If we respect a person we respect their relationships, their social environment and their moral practices....even though they are different from dominant Western beliefs.

Approaches to Ethics

Approaching ethics brings to mind the old adage that there is more than one way to skin a cat. However, if we wish to consider the future of a concept like informed consent we need to acknowledge our personal approach and understand where others might be coming from. I will briefly summarise commonly held approaches to the resolution of ethical dilemmas.

The Rights Approach (Duty-Focused): Each person has a fundamental right to be respected and treated as a free and equal rational person capable of making his/her own decisions. This approach had its roots in the eighteenth century philosophy of Immanuel Kant whose main focus was the rights of the individual. In deciding what action should be taken we must ask if the action respects everyone's rights?

The Utilitarian Approach: An action is considered to be right or wrong based on its consequences. When analysing an ethical issue we need to discern the various courses of action and the effect of each action on individuals or groups. We then choose the course of action that will generate the greatest benefit for the largest number of people and the least harm to least number of people.

The Virtue Approach: There are certain ideals that benefit humanity. Virtues are character traits that enable us to act in a way that develops our highest potential, and once we acquire a good trait it becomes part of our character. When solving an ethical dilemma we need to ask what kind of person should we be to develop the best character trait in both the environment and ourselves? The ethics of virtue has its roots in the teaching and writings of Aristotle and Plato who believed in the nurturing of virtuous character traits.

The Justice or Fairness Approach: Justice and fairness also has its roots in the saying of the ancient Greek philosopher Aristotle who wrote 'equals should be treated equally and unequals unequally'. We ask which course of action treats everyone equally unless there is a morally justifiable reason not to do so. We ask how fairly or unfairly our actions will distribute benefits and burdens to all members of a group or society in general.

The Common-Good Approach: We consider our society more important than its individual members. Faced with a moral dilemma we search for the answer which will benefit society, not which will benefit ourselves. In other words the social forces or structures and their policies, social systems, institutions and environments, are beneficial to all.

The Legal-Based Approach: This is a modern approach and difficult to summarize in a pithy sentence. Respect for autonomy and patients rights is central, but the resolution of dilemmas within this approach requires a tricky balance between the rights of the professional and the patient, when both have

rights defined and protected by laws. However, it is important to remember that laws can deviate from what is ethical, for example the recent apartheid law in South Africa could not be considered ethical neither could the pre-civil war laws of slavery in America.

The Feminist Approach: There are several feminist approaches to ethics, which, to differing degrees, are “filtered through the lens of gender” (Tong 1997:37). Tong divides this approach into two main groups: care-focused and power-focused. Both approaches are sensitive to all women’s moral concerns, and to the moral disempowerment that occurs in an environment where there is an imbalance of gender power. Though this approach has been labelled sexist most feminists argue that an approach to ethics may be gendered without being sexist (Tong 1997:52), as it includes values and issues that many male individuals could claim as theirs.

The Ethics of Care Approach: This is also a feminist influenced approach. It questions the universality of traditional approaches based on male research and on the Western concept of self and morality. The ethics of care presumes all individuals to be both rational and relational individuals who live complex emotional lives within families and communities and place emphasis on values of sympathy, care, interdependence, collectiveness, relationships, empathy, love and connectedness. Both feminist approach and ethics of care approach are crucial to my thesis so will be discuss further in the next chapter

Traditional Western Principles that inform bioethics

Ethical rules for healthcare professionals are framed within four principles but “principles are general guides that leave considerable room for judgment in specific cases and that provide substantive guidance for the development of more detailed rules and policies” (Beauchamp & Childress 1994:38). The four principles are: *Respect of autonomy* – obligation to respect the decision-making capabilities of an autonomous person, *Beneficence* – the obligation to provide benefits and to balance benefits against risks, putting the welfare of the patient as the primary objective of health care professionals, *Non-Maleficence* – the obligation to avoid causing harm to a person. (Recently the two principles of beneficence and non-maleficence have merged, because in trying to benefit a

person there is a risk of unavoidably harming them). *Justice* – the obligation to equal distribution of benefits and risks. (Gillon 1994 xxii-xxxi, Beauchamp & Childress 1994:36-40).

Gillon, a self professed enthusiast for the four principles, summarises their use stating “(I)n brief, the four principles... approach claims that whatever your personal philosophy, politics, religion, moral theory or life stance, you will find no difficulty in committing yourself to four *prima facie* moral principles plus a concern for their scope of application” (Gillon 1994:xxii). Gillon believes the four principles can be applied to almost any moral issue that may arise within healthcare. These principles are starting points, judgments may be based on one or on all four – they are useful but are not a canonical framework for healthcare ethics.

What healthcare professionals need, is a range of *prima facie* obligations. I use the term *prima facie* in W.D. Ross’s sense that a principle is binding unless it conflicts with another moral principle. These obligations would guide the healthcare professional to 1) maintain a professional standard in care and studies, 2) individualize patient treatment and care – the net-benefit for one patient may not be suitable for another (i.e. giving blood to one patient may save their life but giving blood to a Jehovah’s witness may harm them spiritually and mentally and may be viewed as an assault), 3) show respect for patient autonomy, 4) follow research-based medicine and practice to ensure maximum benefit to patients, 5) clearly weigh up the risks and probabilities of benefit and harm to individual patient and 6) identify clearly “*whose* benefit and *whose* harms are likely to result from a proposed intervention” (Gillon 1994:xxiv).

In the current debate regarding which principle should dominate the clinical encounter – *beneficence* or *respect for autonomy*, Timko argues that there are problems with both and neither should be considered more important. He maintains that a broadly constructed principle of non-maleficence supplemented by the principle of due care is “sufficient ethic for clinical medical practice” (Timko 2001:1). Timko questions the elevation of the concept of autonomy within the clinical setting without paying due attention to its natural limitations, but paying too much attention to the rights of the individual, while ignoring the community they live in. I am very much inclined to agree with him and believe

he has an interesting perspective on autonomy, born from an extreme illness during which he had ample time to talk to fellow patients and examine his own situation. He believes a patient's relatives, friends or significant others have rights to be heard by both the healthcare professionals and the patient, even when those views oppose the patients.

While he was ill it became clear to him that his dependents 'expected' him to get better because they felt it was his duty to do so. He found that other patients felt similar duties to loved ones, families, parents and even their students. He suggested that the traditional emphasis on patient's rights placed too much focus on the individual to the detriment of the well being of the patient's community. If we are urged to "enshrine autonomy, we can lose sight of our natural and basic dependency on others" (Timko 2001:x). I have a strong affinity with this notion having spent many years within the healthcare system, though thankfully not in Timko's role as a patient. I believe Timko's view presents a cultural bridge between the traditional Western view, with its emphasis on a relationship between health care and the patient as an individual, and non-Western traditions which defines the relationship as being between health care and the patient as part of the community (Timko 2001:x). His argument finally expresses the cross-cultural ethic of collectiveness and interdependence.

Renee Fox's position reinforces Timko's insight in seeing the weakness of the Western emphasis on individuality. She states that the four principles are linked to the American "value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of justice" (Fox1990:206) – and points out that the social orientated values of responsibility, obligation, kindness, caring and empathy are the losers when such weight is placed on individualism. She warns against assuming that these principles of individuality are transcultural.

There seems to be growing awareness between ethicists, feminists and anthropologists that we need an ethical code that transcends boundaries and cultures – a 'metaethics'. Pellegrino sees it as supplying a "foundation for a common morality by which different ethical systems may be judged and through which transcultural cooperative efforts can be transacted" (Pellegrino 1992:15).

This would have a significant effect on the practice of healthcare by changing the individualistic, rational, act-centred professional into a relational, caring, listening, and responsive person.

This change in attitude could bring a workable bioethical approach into the heart of the clinical encounter empowering both healthcare professional and patient. It might also relieve the tensions between ethical theory and clinical practice. In this vein I appreciate Jessica Muller's insistence that "moral decision making is contextual" and "moral dilemmas and the means to resolve them cannot be separated from the institutional, political, economic, social and cultural contexts in which they are embedded" (Muller 1994:454).

Summary:

Appealing to the cultural and ethical framework embedded in the society in which we live help solve our daily dilemmas. However, bioethics needs a different ethical and legal framework to enable resolution of complex moral issues that emerge within the healthcare system. Of the four principles that are generally accepted by Western morality to guide moral judgment in healthcare ethics; non-maleficence, beneficence, justice and respect for autonomy, it is the latter that is most relevant to the process of informed consent. This will be considered in depth in chapter eight. However, despite an overall general commitment to the act-centered Kantian view of autonomy there is neither a deductive or inductive approach being championed by the proponents of the four principles.

Lack of a universally acceptable ethical theory makes the resolution of many issues within healthcare problematic, mainly because of the already deeply entrenched Eurocentric approach to ethics in the Western medical system. Attempts to resolve bioethical moral dilemmas may be made by appealing to several traditional Western approaches to ethics, but these traditional approaches do not hold all the answers in a world that is increasingly culturally intermingled from the village level right through to the United Nations.

What is needed is a merging of several approaches: aspects of Western approach to autonomy, aspects of power-focused and care-focused feminist theories and cross-cultural ethics. We can then move towards a universally

acceptable 'metaethic'. In the next chapter I discuss what elements of cross-cultural ethics and feminist ethics might be valuable attributes to a 'metaethic'. Timko's experience while in hospital depicts, in my view, the need most people have when ill and vulnerable, the need to be part of a community where values such as love, empathy, sympathy, interconnectedness and collectiveness are as important as rational and act-centred autonomy. Timko's experience illustrates how small a division really exists between the rational and the relational. The distance between Western and non-Western views of the healthcare relationship is bridgeable, it is not a mighty chasm.

Chapter three

“Consider the difference between playing music as an expression of individual achievement and playing music as a social, shared activity.....” (Held 1993:185)

Feminist Ethic, the Ethics of Care and Transcultural Ethics

Since the 1980s both feminist and non-feminist moral philosophers have debated the merits and implications of an approach to morality called the ethics of care. The principle focus of the ethics of care is centred on the values embodied in close personal sentiments such as compassion, trust, love, friendship, sympathy and loyalty. It imposes obligations of responsibility by virtue of relationships and emphasises aspects of moral reasoning that were not part of Kantian ethics or Western moral theory.

It was not until 1994 that Beauchamp, perhaps the most prolific current author on bioethics, together with Childress began to include the ethics of care in philosophical discussions of morality. But it was mainly feminist theorists who championed the inclusion of the ethics of care into ethical theory. This inclusion of feminist philosophers or ethicists in philosophical or moral discussion is a very recent phenomenon. In 1992 Hilde Lindemann Nelson remarked that “bioethics had largely bypassed feminist insight” (Nelson 1992:8), because philosophy as a discipline has largely circumvented feminist scholarship. There were a few pioneering feminists who dared to engage in discourse within the hallowed ground of the ethical, philosophical and moral arena before the 70’s but most were excluded from mainstream philosophy primarily because philosophy and rationality were declared to be outside the sphere of female thought by philosophers such as Aristotle, Kant and Aquinas.

For generations many male philosophers believed that women had no place in philosophy declaring women to be inferior to men both rationally and morally. Kant believed women incapable of theoretical reasoning, arguing, “women’s morality should essentially be one of sentiment, governed by irrational moral feelings of aversion and beauty” (Morgan 1988:149). This statement and many similar statements by male philosophers over many generations removed women from any involvement in the expansion of discourse around moral life.

Mary Ellen Waithe spent 18 months researching early women philosophers and discovered that over one hundred women philosophers had been omitted from Philosophical reference texts. She mentioned to a male colleague that she had located writing by Pythagorean women philosophers to which he replied “but weren't they writing about.... home economics?” (Waithe 1987:xi). The message from these early women's philosophising was *harmonia* which Waithe described as “applied ethical theory” (Waithe 1987:xi). Theano 1, the wife of Pythagoras was one of the earliest recorded women philosophers. She and other early women philosophers had much in common with the contemporary feminist moral theorists with their emphasis on friendship, compassion, justice, wisdom, kindness and care, which symbolize *harmonia*. These women suggested that *harmonia* should apply both to the running of the state and the running of the family because the family was considered to be a microcosm of the state. It is ironic that over 2500 years later women are attempting to include a *harmonia-type* theory into Western moral philosophy.

Over the past ten years the ethics of care has steadily had an increasing presence within mainstream bioethics. Writers such as Johnstone (1994), Sterba (1998), Held (1993), Clement (1996), Bowden (1997), Sevenhuijsen (1998) Tong (1997) and Cates & Lauritzen (2001) have debated the ethics of care from different standpoints. The ethics of care has been one of the most important contemporary challenges to Western views on morality. The persistence of many feminist writers has insured its inclusion in debates and philosophical discussion.

Cates & Lauritzen, attempt to answer some of the general criticism of mainstream Western moral philosophy by feminist theorists. Questions such as: Why Kantianism and utilitarianism are so act-centred? Why they represent individuals as “separate and independent centres of moral agency who ought to be unconstrained in their decision making by everything but their own rational powers”? (Cates & Lauritzen 2001:xiv). Why people must reason objectively, without emotion and without consideration for their own identity or the identity of their family or significant others? Other criticisms have been that Western moral philosophy is too abstract to be relevant to everyday living, that it

privileges the welfare and concerns of the white middle-class male and marginalized all other groups.

In 1982 Carol Gilligan critiques former collaborator Lawrence Kohlberg's six-stage theory of moral development because of a male bias within Kohlberg's research. He indicated that the moral stages defined by his research were applicable to all society, but his empirical research was on male subjects only. As a result girls whose moral development were measured by these stages appeared morally less mature than boys. Gilligan questioned the validity of measuring girls by a male defined standard and presented a female standpoint (a vision of the ethics of care) from her research on moral development in female subjects. This was one of the first times a female academic openly challenged male orientated morality (Gilligan 1982). Later, Gilligan, herself received some contra criticism, being accused of making the same error in her research that she accused Kohlberg of making – false universalism in which she stereotyped women as he had men.

Another impact of Kohlberg's research was that his results helped to continue and reinforce the myth that reason and rationality were morally superior to 'care' or sentiment. Gilligan also contributes to feminist ethical philosophy by drawing a comparison between the caring perspective and the justice perspective. The latter is about individuality and reason and the former is about being a caring person because of the process of caring for and being cared for. The traditional Western ethics of justice regarded emotions as harmful to the reasoning process whereas the ethics of care brought emotions to the centre of the decision-making process alongside rational application to other ethical principles. It was not surprising that these two ethics were poles apart, though recently there has been a blurring of the edges, a faint recognition that one cannot exist without the other, but it needs to become less of a blur and more of a defined combination where neither is superior to the other.

Beauchamp & Walters belatedly stated that "(A) morality centred on care and concern can potentially serve health care ethics in a constructive and balanced fashion, because it is close to the processes of reason and feeling exhibited in clinical contexts" (Beauchamp & Walters 1999:17). That was what feminists have crusaded for through discourse and authorship for some years, but in

terms of Western moral and philosophical dialogue this acknowledgement is vital to encourage open debate. It helped place the ethics of care into the thick of philosophical, ethical and medical anthropological moral discussion.

The framework of the ethics of care within a multi-ethical approach fits the complexities of caring for patients and their families within a hospital or healthcare environment and ensuring informed consent. This approach would be especially useful as part of the problem-solving and decision-making aspects of the clinical encounter. Such encounters involve discussion, information giving, making choices, and being aware of the family, family relationships and family dynamics, while also working within a multidisciplinary team.

Some power-focused feminists make it clear they do not want 'care' to be identified with all feminists because the original feminist movement in the 60's was a rebellion against female activities that were 'woman's destiny'. Caring was regarded as "dull, monotonous and traditional, and thus as an obstacle to self-fulfilment" (Sevenhuijsen1998: 5). Tong describes two types of feminist approach to ethics – a care-focused approach and a power-focused approach. Feminist philosophers are almost equally divided between these. Each approach is sensitive to women's moral concerns and to their moral disempowerment because of the gender bias within society. Feminist ethics have been accused of being sexist in their philosophising but the main focus of both approaches is directed to gender inequality, which is not necessarily sexist. Also the approach is sympathetic to similar issues that arise with marginalized groups, ethnic groups or disadvantaged groups. "An approach to ethics becomes sexist only when it systematically excludes the interests, identities, issues, and values of one or the other of the two sexes, and feminist ethics has no plans to do unto men what non-feminist ethicists did unto women" (Tong 1997:52).

Tong, who advocates an eclectic feminist approach, states that all feminist approaches share a common methodology – the methodology of feminist thought, but her vision for the future is that all approaches might share a common philosophical framework "flexible enough to accommodate a very wide range of feminist politics, ontologies, epistemologies, and ethics" (Tong 1997:93).

I believe the ethics of care is not comprehensive enough to become a single moral framework for bioethics, it needs to encompass such moral values as justice, autonomy, elements of power-focused feminist ethics and transcultural values - an encompassing quintessential framework that includes the most appropriate elements so that the clinical encounter is a safe place for people of all cultures.

Andolsen (2001), Reeder and Gudorf in Cates & Lauritzen (2001), all examine the network of relationships that link care, justice and community and all articulate the need to understand that the ethics of care is both separate from, and interdependent on justice and other principles. The ethics of care should not become undermined or weakened by its inclusion alongside other ethics, as each approach can support, strengthen and inform the other. A multi-ethical framework could contribute to an adequate moral perspective, where each ethical principle or approach could be identified as both a complementary and essential component of morality.

Michael Freeman quotes an especially descriptive definition of care ethics by Joan Tronto & Berenice Fisher:

a species activity that includes everything we do to maintain, continue and repair 'our' world so that we can live in it as well as possible. That world includes our bodies, our selves and our environment, all of which we seek to interweave in a complex life-sustaining web. Thus conceived, care is not 'a marginal activity of life but one of the central procedures of human existence'" (Freeman 2001:xxiv).

True enough, but it cannot stand alone, it needs to be strengthened by the multi-ethical framework I have described. A major risk of having the care model of ethics as a stand-alone ethics within the health care system is that there is a fine line between care and paternalism which might result in the rights of the patient to autonomy and informed choice being pushed aside. Since this is the core tenet that informs informed consent, this is precisely what must not happen.

There is, to date, no single comprehensive feminist theory that can be used within bioethics, but Susan Sherwin (1992) has offered an eclectic approach very different from Tong, drawing from liberal, radical and Marxist feminism.

She distinguishes feminist ethics from both traditional ethics and 'feminine' ethics. She points out that all traditional theories such as deontological and consequential theories place 'autonomy' as the central tenet and traditionally demean women, insisting that men are rational human beings and women are empathetic human beings. 'Feminine ethics' (care-focused ethics), according to Sherwin, has attempted to prove that women bring a different moral point of view from men, but one that is equally valid. She identifies this type of ethics with Gilligan and Noddings. Sherwin differentiates 'feminist ethics' (power-focused ethics) from 'feminine ethics' by describing it as having derived "from the explicitly political perspective of feminism, wherein the oppression of women is seen to be morally and politically unacceptable" (Sherwin 1992:49). So feminist ethics, according to Sherwin, is more about the political critique of oppressive practices than about understanding and accepting that women are distinctively different than men. She rejects autonomy as the central tenet of ethics, instead she asks that any resolution of a moral dilemma needs to consider how the specific issue relates to patterns of oppression of women. This aspect of feminist ethics could be used to argue for a change within the balance of power - the unequal power relationship that exists between medical authoritarianism and the patient.

The unequal power relationship within the clinical encounter in biomedicine is central to feminist bioethics, which calls for a critical assessment of patterns of oppression. Patients within hospital institutions could be considered an oppressed group because of the imbalance of power within the clinical setting. Medical anthropologists have also tackled the unequal power relationships within the clinical encounter. Baer *et al.*, believe that the arm of anthropology called critical medical anthropology has begun to make "micro-macro connections – ones that link patients' suffering to the global political economy" (Baer et al 1997:19). Critical medical anthropology attempts to "understand who controls biomedicine and what the implications are of such control" (Baer et al 1997:27). This is where I, as an 'insider', having worked in the healthcare system for many years, can say that medical authoritarianism and paternalism is alive and well within the healthcare system, which is one reason why the

process of informed consent is not working. The concept of consent has not changed in the eyes of healthcare professionals and neither has control.

A more recent and forceful critique of feminist ethics has come from Daryl Koehn (1998) in which she discusses the weakness and flaws at the centre of the ethics of care. She believes that feminist ethics has similar problems to traditional male ethics in that it tends to support the perspective of the caregiver not the receiver of care. Implicit in this approach is the lack of respect for the individual differences of other people. She stresses the need to accept differences – each person being different because of experiences and life's challenges. She advanced a *dialogical ethics* where we accept differences and openness of an individual within a community of individuals. We may even disagree with an individual person but if this individual speaks in a different voice - we need a different ear. "We require a discerning way of listening capable not only of attending to the plurality of perspective in our human community but also of assessing their truth and relevance to the good life" (Keohn 1998:19). Though this may not be a well-developed theory of ethics it is an approach that could be valuable within the clinical encounter to help understand differences, reminding both parties within the encounter that everyone comes with their own cultural beliefs, values and differences.

So at this time there is no unified voice or canon for an approach to bioethics emanating from mainstream philosophy, transcultural ethics and female philosophers. But one is greatly needed, a canon that encourages recognition of differences, eases the power imbalance within the clinical encounter and recognises that we are all interdependent human beings.

Transcultural ethics:

The fact that there is not a unified ethical voice reflects the range of professions that have contributed to the ethical theoretical framework. Until recently, most discussion was from outside biomedicine, but despite this superfluity of discourse there was little guidance for practical application. However, there are some rare embryonic notions/theories that cross cultural biomedical and philosophical boundaries. One such notion is 'respect for persons' which could be one "of the universally applicable ethical standards" (Levine 1999:146). This

indeed is true, but not in the traditional Western individualistic sense, it would need to incorporate the relational self.

Leininger notes, "culture has been the critical and conspicuously missing dimension in the study and practice of ethical and moral (sic) dimensions of human care" (1990:49). Johnstone reiterates the Eurocentric view of ethics, which she describes as been 'culturally constructed' from Western moral philosophy and feminist philosophy (1994:138). Johnstone quoting Marshall states, "transcultural ethics, like feminist ethics, recognises the problematic of genuine moral problems in human life being 'confronted as abstraction rather than experiential realities'" (Marshall in Johnstone 1994:153). Helman, an eminent medical anthropologist, notes that one of the dangers of focusing on the patient as an individual is that it may be the family or the community "who are pathological, not the individual" (Helman 1990:119), hence focusing only on the individual may risk overlooking wider issues that might make sense of the patients symptoms. Cultural factors impact on health and illness and can often only be understood in terms of the culture they occur in, this might include the political and economical issues which can contribute to specific illness within a community. The other danger is that the opposite can happen; a healthcare professional may assign an action or symptom to the patient's culture whereas there is, in fact, some underlying mental or physical disorder.

Most theorists reject the theory of cultural relativism which holds that morality is only relevant to the culture from which it originates and which shapes the beliefs of what make an action right or wrong. In other words, rightness and wrongness of an action is dependent on specific cultural beliefs so the notion of a 'universal' moral high ground depicting acts as right and wrong is meaningless unless they are examined within the cultural context within which they arise. Cultures differ widely in their moral practices and many anthropologists have written about practices which are accepted in one culture but totally rejected in others, practices such as genocide, polygamy, torture or infanticide, yet these practices exist in one culture but are morally abhorrent in other cultures. So how then can there be a 'universal' morality? Some claim that though practices are very different, the underlying fundamental moral principles are not. For example some societies kill parents before they get too old to be physically

active and vigorous when they take their place in the afterlife, other societies keep their old people alive for as long as they can, though these actions seem to be at the opposite end of the morality spectrum, the moral principle underlying both action is duty to care for parents (www.scu.edu/ethics).

The transcultural challenge to find universal moral ethics becomes problematic “because medical science and technology, as well as the ethics designed to deal with its impact, currently are Western in origin” (Pellegrino 2001:535). Pellegrino reminds us, and rightly so, that placing too much emphasis on differences presented from a Western perspective, may tend to ‘foster claims to cultural superiority’, however, if we emphasise similarities then we could lose cultural integrity – what is needed is a middle ground where some common characteristics can be identified and make compromises that do not endanger ‘cultural identity’ (Pellegrino 1999:537).

Johnstone believes that transcultural ethics, unlike other ethical critiques offers a positive outlook because of its suggestion that “acceptance of and achieving a harmony of moral diversity offer the key to sustaining the existence and purpose of morality” (Johnstone 1994:154). This could be the basis on which we learn to be moral in a world of diverse and competing viewpoints. Everyone is an individual – an ‘other’, in spite of community sameness and ethnic origin. The ‘other’ or individual is different, not inferior, not irrational, not illogical, just different. We need to listen with ‘a different ear’ and not trivialise or generalise. Barry Hoffmaster in his essay ‘Can Ethnography save the life of medical Ethics’ suggests a more situational and contextual approach to ethics. “Ethnography needs to be integrated into a revived practical philosophy that, in the words of Toulmin, is interested in the ‘oral’, the ‘particular’, the ‘local’ and the ‘timely’” (Hoffmaster 1992:531). As Leininger (1991) states the missing link in the ethics of care is culture.

Summary:

The ethics of care has been part of feminist discourse for many years stressing empathy, caring, friendships and family relationships which had been marginalized within the act-centred, relational, rights and obligation male ethical model. However, it was not until 1994 that this feminist care-focused approach

made its way into mainstream biomedical ethics because the “care ethic provided a needed corrective” (Beauchamp & Childress 1994:92). The ethics of care focuses on the relationship within the clinical encounter, whereas traditional Western ethics has historically focused on the individual.

Some feminist writers consider the ethics of care to focus too much on the traditional role of women and not enough on the power imbalance with traditional ethics. Considering the power imbalance within the clinical encounter this suggests a valid argument. But there is still one missing link – a cross-cultural ethics, which focuses on interdependence and differences.

From a medical anthropological perspective, a perspective that has its roots in medicine, health and the social sciences and draws from all three disciplines, I believe there is a moral framework that crosses cultures yet still maintains cultural integrity. An eclectic or polygonal model incorporating elements from each ethical approach; the *ethics of care* for its caring, sentiment focus, *feminism* for equality and power focus, *autonomy* for its respect for individuals, the *cultural* emphasis on community, collectiveness and interdependence and *justice* for fairness and equality.

Healthcare professionals have not significantly changed their concept of consent despite a legal and ethical framework that demands they do so. They are still in control, a situation no longer ethically or legally acceptable. However, the use of a metaethical approach and the use of the word choice instead of consent could begin the process of change.

Many crucial elements are similar within the ethics of cultural and the ethics of care, but one of most important element needs to be recognised from ethnographical study of other cultures – that is the celebration of differences, the need to emphasise differences and.....to listen with a different ear.

Chapter Four

"As soon as questions of will or decisions or reason or choice arise, human science is at a loss"
Noam Chomsky

Informed Consent or Informed Choice? The culture of consent within the clinical encounter

Informed consent as it is currently understood began in 1957 when the word 'information' was linked to 'consent' following legal acknowledgment that an individual was not sufficiently expert to consent to an action if they did not know what they were consenting to. (*Salgo v. Leland Stanford Jr. University Board of Trustees* 1957). Though the term 'informed consent' appeared in literature in the 1950's, discussion around the use of the term, as it exists today did not begin until as late as 1972 (Beauchamp & Walters 1999:118).

As the concept began to develop, the focus moved from the narrow focus of the physician to the wider focus of the relationship between the healthcare professional and the patient. It is now widely accepted that every healthcare professional has a moral obligation "not only to tell patients the truth, but to help them decide important matters that affect their health" (Beauchamp & Walters 1999:118). Justice Michael Kirby, now an Australian High Court judge, was one of very few judges who have defined informed consent since it was first coined. He stated, "An informed consent is that consent which is obtained after the patient has been adequately instructed about the ratio of risk and benefit involved in the procedure as compared to alternative procedures or no treatment at all" (Skegg 1999:140).

The elements of consent are grounded in the Western ethical principle of respect for autonomy, which incorporates the quality of being self-governing and respect for the individual person. Immanuel Kant is considered the main developer of the concept of respect for the individual, stating "so act to treat humanity, whether in thine own person or in that of any other, in each case as an end withal, never as a means only" (Kant 1972:57).

Historically, the development of the concept of informed consent took place within the context of medical experimentation on human subjects. Atrocities committed by German scientists in Nazi concentration camps during the 1940's were "the grim stimulus for the development of the concept of 'informed

consent” (Milburn 2001: 1). It is now presented as an essential element in the healthcare decision making process within the clinical encounter. Developed within the framework of law, philosophy and politics the concept of informed consent has been greatly influenced by historical events, social movements and social changes. It is “simultaneously a legal doctrine, an ethical concept and a clinical practice, it is not surprising that a review of the literature on informed consent and associated issues reveals a recurring tension between what is morally desirable, what is legally required and what is feasible in clinical practice” (Schermer 2002:24).

The entire concept of informed consent is fraught with misconception, confusion and tension, perhaps because people outside the clinical area developed the concept, people such as philosophers, politicians and lawyers, with minimal input from the people using it. This meant that healthcare professionals did not take ownership of the concept, leaving it susceptible to exploitation or disregard by professionals within the clinical encounter. A culture of medical paternalism, which had existed for over 2000 years, and which defined the nature of power within the clinical encounter, was not going to be altered easily by anyone, and certainly not by non-medical personnel.

Though the notion of informed consent is fundamental to the principle of respect for autonomy, Beauchamp & Childress (1994:143) believe that some authors have reduced the concept of informed consent to a shared decision-making between healthcare professional and patient, thereby making shared decision-making and informed consent synonymous. This notion that has agreement from Jay Katz (1984) who believes that the primary goal of informed consent within the clinical encounter is to enable patients to make autonomous choices about the consent or refusal of medical treatment.

However, Faden and Beauchamp believe that decision-making should be a separate issue from the autonomous action of consenting or refusing a treatment. Essentially, the elements that should make up the concept of informed consent needs to alert healthcare professionals that disclosure of all relevant information alone does not in itself ensure informed consent. A notion that remains firmly entrenched in the practice of healthcare professionals. Harris *et al* (1982) found that 43% of the public and 58% of physicians

described informed consent as the giving of information and the recommending of treatment *not* the actual consenting to the treatment by the patient.

Jay Katz declared that “disclosure and consent, except in the most rudimentary fashion, are obligations alien to medical thinking and practice” (Katz 1999:136). Historically this is because there was never any consideration that the patient would be entitled to the right to choose or share the decision-making process with their healthcare professionals – it was simply never part of the culture or philosophy of the medical profession. Katz calls this the ‘tradition of silence’, a tradition in which medicine has been steeped for two thousand years. When court cases began to appeal for self-determination within medicine even judges did not understand how foreign or alien this concept was to medicine (Katz 1999:136). Many professionals view consent as the means to an end, that is, to the end intended by the professional.

It is hard for most healthcare professionals to accept that it is the patient who must be the definitive decision-maker and it is authorization for treatment by a patient who has received all relevant information that makes consent ‘informed’. A survey published in the *President’s Commission* in Washington USA in 1982 indicated that only 26% of 805 physicians associated the term informed consent with permission to treat whereas 43% of 1,251 members of the public did. The study demonstrated that most physicians assumed that the information giving was the essential part of informed consent not the decision-making of the patient. Perhaps if informed consent was branded as informed choice (which is what it is called within the New Zealand Code) this view might change? The results of that study suggested that physicians placed more emphasis on the information aspect of informed consent than on the autonomous action of consenting (Harris in President’s Commission 1982).

Regarded by many as one of the leading texts on informed consent - “*A history and Theory of Informed Consent*” by Faden & Beauchamp (1986) gives a comprehensive historical account of the legal and philosophical theory that informs this concept. This book is written from an ethical and philosophical stance and presents informed consent as a working doctrine within the clinical encounter. It is not a working doctrine, it does not work within the clinical encounter because the people who need to understand informed consent in

order to make it work do not understand it. As I have said before information is equated with consent and the word consent is not associated with 'choice'. In my view, at the practical level, informed consent still remains a work in progress. Faden & Beauchamp also write from a North American viewpoint giving a legal and philosophical history of informed consent. They do, however, suggest the need for both patients and healthcare professionals to improve communication skills, a notion that has taken hold and is receiving increasing publicity but has been very obvious to those of us who have worked within the healthcare system for many years. However, despite the fact that there is a communication and ethical component incorporated into most medical and nursing study programmes it has not, to date, dramatically improved healthcare professionals' communication skills.

Faden and Beauchamp (1986:276-287), describe two distinct types of informed consent: 'sense-1' and 'sense-2'. *Sense-1 informed consent*, which they regard as the 'true' informed consent, is a specific action taken by an individual patient – called autonomous authorisation. *Sense-2 informed consent*, refers to consent given within a legally or institutionally imposed system where rules or practices may impede autonomous acts. Morally, true informed consent or sense-1 should be appealed to so that autonomous action becomes the objective for the construction of rules, policies and practices within the healthcare system. True informed consent is a theory of autonomous actions but not a theory of autonomous persons, so the essence of informed consent is autonomous authorization. (Faden & Beauchamp 1986:238). For an act to have autonomous authorization it must be performed *intentionally, with competence, without controlling influences, with authorization* to a professional to perform the treatment and with *substantial understanding*.

Beauchamp & Childress (1994:145) break up the concept of informed consent into two separate elements: the information component and the consent component. The consent component includes voluntariness (*without controlling influences*), competence to make a choice, and the giving of consent (*with authorization*) for a specific treatment. The information component includes disclosure of information and comprehension (*with substantial understanding*) of the information. Though all acts are needed for autonomous authorization to

ensure informed consent, the information component of informed consent is again critical to my thesis and is discussed at length in the next chapter.

Intentionally is reasonably straightforward, an act is either intentional or not intentional. It is essentially a black and white situation; there is no grey area.

But the other three elements for an autonomous authorization can be located anywhere along a continuum between being *fully autonomous* or *fully nonautonomous*. Acts are rarely, if ever, fully autonomous, they are generally autonomous to a degree. This means that most acts, which have a high degree of autonomy, can be considered *substantially autonomous*, and therefore autonomous. Faden & Beauchamp dispute the argument that full autonomy is the only instance of true autonomy because full autonomy is not often possible. So if full autonomy was required for informed consent, it could rarely, if ever, be achieved. "To chain informed consent to *fully or completely* autonomous decision-making stacks the deck of the argument and strips informed consent of any meaningful place in the practical world, where peoples' actions are rarely, if ever, fully autonomous" (Faden & Beauchamp 1986:240).

Without Controlling Influences or lack of coercion can also only be substantially achieved because any act can only be totally devoid of control if there is absolutely *no* influence exerted or if influence has been exerted, the person must totally ignore or reject it. This again is an impossible task especially as most patients do not make decisions in isolation they are often surrounded by family and friends. In fact, few people make crucial decisions completely independently because few people live such an independent life that nobody would be affected by the decision made. And in the spirit of 'above all do no harm' most healthcare professionals will present their views and their recommended treatment, which may influence the patient. This is not surprising since that is why the person came to the healthcare professional in the first place – to elicit a form of treatment. However, any form of compulsion, intimidation, duress, bias, force or deception must be absent for consent to be given voluntarily (Faden & Beauchamp 1986: 256-62).

Control can be exerted in many ways from gentle persuasion to degrees of pressure depending on the amount of influence exercised by the healthcare professional. Unfortunately, undue pressure can be applied subtly by playing

on the patient's fear that the professional will not care for them properly if they do not consent willingly and without question to what the professional is suggesting hence many patients consent rather than be labelled 'difficult'. Also ill patients are vulnerable and do not have the strength to be assertive or questioning when informed consent is in process. It is essential for healthcare professionals not to attempt to steer the patient into making decisions that fit comfortably with their professional or personal values, beliefs, advice or hospital's protocols rather than the expressed desires of the patient.

Young (2002) describes a spectrum from coercion, through manipulation and persuasion to complete voluntariness and agrees that the goal is substantial but not complete voluntariness. Healthcare professionals should not pressure patients to make a quick decision or to sign a consent form, but unfortunately in many clinical situations informed consent is perceived as a medico-legal tool and is equated with a written signature on a consent form to document a patient's decision. However, a written consent is in no way an indication of an informed choice. Here again is the emphasis of legal and philosophical literature on consent rather than choice, but consent and choice must be recognized and accepted by healthcare professionals as *separate* issues. Professionals need to speak of informed choice followed by an informed decision to consent or refuse. I believe that most healthcare professionals understand that informed consent implies that a person will automatically consent once information is digested – this is *not* freedom of choice because freedom of choice means an individual is free to *refuse* or *consent* to treatment. Consent may be verbal, implied or written, but whichever form it takes it cannot replace the informed choice process, which is dependent upon the information exchange, communication, and the decision-making process between healthcare professional and patient. If a healthcare professional follows a process that allows the patient to arrive at a carefully considered, specific, value-based preference during the information sharing process, then there is an increased probability that the patient will make a voluntary informed decision. It is important to remember that communication is a two way process leaving room for an opportunity for negotiation if there are underlying differences in values and beliefs between the healthcare professional and the patient.

According to McCullough & Chervenak, it is “crucial to recognize that the informed consent process aims to create common moral ground between”... the healthcare worker and... “the patient concerning the patient’s interests and how they can effectively be protected and promoted” (McCullough & Chervenak 1994:151). To reach the common moral ground the patient must also take some account of the recommendations and clinical judgment of the healthcare professional - the beneficence-based judgments. But also the patient and the professional must be aware of each person’s cultural values and beliefs. If conflict between values of clients and healthcare professional are so opposed then the healthcare professional should withdraw (Pellegrino & Thomasma 1988:29).

A difficult situation can arise if the healthcare professional takes the view that autonomy means total independence and chooses to completely opt out of the decision-making process altogether to ensure that the patient has not been unduly influenced. Such an action can leave the patient feeling vulnerable and confused especially if it is not in accordance with the wishes of the patient. The patient may not have wished to make such a worrying decision alone and if this was the case then the healthcare professional failed to follow the process of informed consent. Communication between patient and healthcare professional could have established clearly the wishes of the patient. By not following the process of informed consent the healthcare professional did not acknowledge respect for the self-determination, wishes, or cultural values of the patient. It is absolutely acceptable for healthcare professionals to give advice and present a reasonable argument about a particular treatment if they believe that the treatment is in the best interests of the patients just as long as they also included alternatives. The difficult task is to know where advice ends and control begins or where informed consent ends and paternalism begins?

With authorization is the recognition that the ultimate choice following the decision-making process is that of the patient either choosing or refusing a specific treatment. This means that the patient has given freely and without coercion the authorization to a specific person to proceed or implement a treatment. The patient accepts responsibility for the choice they have made and then transfers the responsibility for the treatment to the healthcare

professional. "The crucial element in an authorization is that the person who authorizes uses whatever right, power, or control he or she possesses in the situation to endow another with the right to act. In so doing, the authorizer assumes some responsibility for the actions taken by the other person. Here one could either authorize *broadly* so that a person can act in accordance with general guidelines, or *narrowly* so as to authorize only a particular, carefully circumscribed procedure" (Faden & Beauchamp 1999:140).

Competence is fundamental to enable a person to participate in the decision-making process, and the making of an informed choice. Competence means that a person is capable of making a moral, legal and valid choice to consent or refuse a specific treatment. This also means that the person is capable of understanding the description and the distinctiveness of the proposed treatment. Though competence is often listed as a requirement for informed consent, it is in fact a prerequisite for the process of obtaining informed consent. A person who is incapable of consenting to a treatment cannot then give an informed consent; hence a healthcare professional carrying out any procedure with this kind of consent could be found liable in the tort of battery. Competence functions as a gate-keeping concept for informed consent (Faden & Beauchamp 1986, Beauchamp & Childers 1994).

Being competent means having the ability to perform a task, which suggests that competence is task related. "One can be competent to perform a certain task, but this does not imply competence to perform any task. Since abilities and capacities can change over time, competence, too, can change. Moreover, because most abilities and capacities contributing to competence can be possessed in varying degrees, persons can be said to possess different levels of competence" (Schermer 2002:34). Schermer also reminds us that the burden of proof is on the side of incompetence – one is competent until proven otherwise. Donnelly believes that if we take the principle of patient autonomy seriously there are three basic principles that must be recognized when making decisions about the competence of a patient: 1) a decision relating to competence must always refer to a specific task, 2) beside supplying information to a patient, the patient must be facilitated into a substantial understanding of the proposed treatment and 3) there must be no intrinsic

connection between the rationality of a patient's decision and the patient's competence (Donnelly 2002:46-48). If a person makes a decision that the healthcare professionals, the court or the general public disagree with, this does not necessarily mean that the person making the decision is incompetent. "(I)t is very difficult for a medical professional to accept that a person who refuses to accept best advice and earnest entreaties can be competent" (Donnelly 2002:48).

Buchanan and Brock identify two sets of capacities that are needed to ensure competence: the capacity to understand and communicate, and the capacity to reason and deliberate along with a consistent and stable set of values that the person clearly identifies as their own. Presently there are two different views identifying the appropriate threshold level for the desired capacities to ensure competency. The first view is the 'risk-related' standard, which considers that the threshold level must be variable and this level depends on the risks involved in each decision (Buchanan & Brock 1990:52-55). The higher the risk, the higher the level of capacities must be. However, critiques of this view state that the fact a person may be competent to consent to a high risk treatment does not necessarily mean that the person is competent to refuse that treatment – this is termed the 'asymmetry' of competence and is said to be the most problematic outcome of the risk-related standard (Cale 1999:132). The second view requires a fixed minimum level of capacities regardless of the relative risk involved in the decision. The appropriate levels of capacities should be decided, based on the requirements of informed consent.

The Code of Rights in New Zealand state that "Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent" (Right 7:2). The very act of treating a person as incompetent removes their autonomy so it is important to encourage the decision-making capacity of those who appear to have limited ability to give consent. Children, the elderly and mentally disabled people vary widely in their capacity for decision-making. While the healthcare professional must judge whether the person is competent to consent to a specific procedure, they may also take into account the views of parents or caregivers. However, in New Zealand, even if a

person is deemed incompetent they still retain other rights in the Code – the right to receive information in a manner suitable to their level of understanding and the right to respect. Someone with an enduring power of attorney may give consent for treatment on behalf of a person that is deemed incompetent.

The Guardianship Act 1968 deals with consent for or by children. Section 25:3 allows a child's guardian to consent to any treatment deemed necessary for a child. Section 25:1 allows a child over 16 to consent as an adult assuming they are deemed competent. However, healthcare professionals should involve children in the decision-making process as much as possible and direct the level of information to the appropriate level of the child's competence. Section 10 allows the court to remove parents as guardians if deemed unfit. The Guardianship Act can be accessed by healthcare professionals to obtain authorization from the court for the treatment of a child without parental consent.

There are, however, several inconsistencies between the Guardian Act, the Health & Disability Consumer Rights Act and the New Zealand Bill of Rights Act. For example right 11 of the New Zealand Bill of Rights Act allows everyone to refuse medical treatment – but this may not extend to children, even if the children are deemed competent (Bayly 2003:1-6). Also, Right 7:7 of the Code of Health & Disability Consumer Rights 1996 allows every consumer the right to refuse services or to withdraw consent (assuming that these people are competent to make the choice to refuse treatment). Though both the New Zealand Bill of Rights and the Code of Health and Disability Services Consumers Rights clearly give consumers the right to refuse treatment, again this may not extend to children even if they are deemed competent (Bayly 2003). Bayly wonders if healthcare providers or professional need to warn parents about the “potential legal consequences of failing to consent to their child being treated, or removing the child from the hospital. However, the ability for health providers to do this without being seen to coerce parents and therefore breaching Right 2 of the Commissioner's Health and Disability Services, Code of Rights is questionable” (Bayly 2003:6).

Other exceptions to informed consent or the informed consent process are:

One, threats to public health: lack of informed consent is only justified in these cases where there is evidence that there is a high risk of significant harm to others. High-risk situations where a patient refuses treatment that would prevent the spread of a potential life-threatening epidemic. A case in point is the recent outbreak of SARS, which caused many countries to place restrictions on the movements of potential SARS cases to avoid the disease spreading. According to May "What is significant is not that a patient's evaluation that the burden of treatment outweighs the consequences of the disease is deemed poor. Rather, the social effects of this decision impose on others the evaluation of burdens versus consequences and threatens harm to them" (May 2002:23).

Two, medical emergencies: Generally it seems there are three listed factors in which the harm factor outweighs the patient's right to informed consent, a) in which there is clear and immediate danger to life and limb, b) the time needed to gain informed consent could seriously jeopardize the patient's chances of recovery and c) the patient exhibits signs of incompetence, signs such as shock, hypoxia or massive blood loss.

Three, therapeutic privilege: when a healthcare professional decides that withholding information is in 'the best interests' of the patient assuming that either bad news would severely traumatize the patient or full disclosure would lead a person to choose the wrong course of action. Therapeutic privilege is perhaps the most problematic of all the exceptions to informed consent. Put simply, no decision is necessarily 'bad' for a patient, if they make that decision freely with understanding, full disclosure and without undue influences. In *Canterbury v. Spence 1972*, the court ruled that therapeutic privilege "does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forgo therapy the physician feels the patient really needs" (Faden & Beauchamp 1986:38). If this were to happen it would endanger autonomous choice altogether' according to Faden & Beauchamp. A healthcare professional's concern for trauma caused to a patient by giving bad news is even more problematic because different cultures have different ways of dealing with bad news.

In some Asian cultures it is culturally appropriate for the patient's family to receive the bad news instead of the patient because it is their cultural belief that

a person receiving bad news about their health or illness may worsen, give up the will to live or recover much more slowly if burdened with news of ill health. Patients may waive their right to informed choice about treatment in favour of their family, reflecting their culturally held values and beliefs – this could be interpreted as patients asserting their right to informed choice. This situation can also occur if a patient does not wish to make an informed choice about specific treatment but does make an informed choice to defer to the healthcare professional to make that decision, and the circumstances surrounding such a choice reflects the judgment values and beliefs of the individual.

Summary:

The concept of informed consent is relatively young. It's development has moved the focus within the clinical encounter relationship from physician to patient. Respect for individual autonomy is the essence of informed consent. However, despite the concept being 30 years old and embodied in the legal and ethical framework of bioethics, research shows that most healthcare professionals, especially physicians, consider that the next step following disclosure of information is the signing of the consent form. To healthcare professionals the notion of informed consent means the giving of information...not the understanding of it and...not the making of the choice to allow treatment! But informed consent is a two way process and patients need to be encouraged to be more assertive and questioning within the clinical encounter.

The continuing emphasis in theory and practice on the word consent instead of choice, despite the New Zealand Code defining a patient's right to an informed choice, tends to focus healthcare professionals on the consent aspect of informed consent. As a result healthcare professionals equate informed consent with a patient's signature on a consent form. This is legal and certainly the path of least resistance, but it does not do justice to the spirit of the law. Changing the focus from 'consent' to 'choice' might encourage healthcare professionals to rethink their approach to patients and continue the erosion of the embedded history of paternalism.

Patients come to the clinical encounter for expert information and advice, they come with trust in the professional judgment of the healthcare professional to make the most appropriate recommendation for them. Both patients and healthcare professionals bring their own cultural identity, values and beliefs to the clinical situation and each must respect the other's differences and actively be on the lookout for the clues to such differences.

For a person to freely authorize treatment they must do so intentionally, without coercion and with substantial understanding of the information received. It is also important to understand that only some elements needed for autonomous authorization or choice can be totally fulfilled, most can only be 'substantially' fulfilled. It is virtually impossible for a patient to make a decision in isolation and without influence. A 'substantial' lack of controlling influences must also be an acceptable level for a choice to be made. Substantial must also be the accepted level for the other two elements of disclosure and understanding.

Chapter five

"The cruellest lies are often told in silence" Robert Louis Stevenson

The 'Information' Element of Informed Consent:

Disclosure & 'With Understanding'

One of the pre-requisites of informed consent is 'with understanding', the objective being 'substantial' rather than 'complete' understanding. Complete understanding would be an impossible task even for the healthcare professional to achieve. Friendson (1985:11-35) argues that there is no closing of the knowledge gap as patients become more educated because the growth of complex knowledge accumulates at a much faster pace, it is even difficult for the healthcare professionals to keep pace.

In order for a patient to achieve substantial understanding, the information must be effectively communicated or disclosed in a language the patient understands, a language not obscured by medical jargon. It is clear that to have true informed consent, it is not so much the disclosed information that is important but rather the degree of understanding achieved through the disclosure. It is important to remember the legal requirements for disclosure, if certain information is applicable to the patient's circumstances then it must be disclosed. Schermer reminds us that 'disclosure of information' and 'understanding of information' are two separate issues in law and in clinical practice (Schermer 2002:27).

For understanding to occur a patient should receive sufficient information about treatment, risks, expected outcome and alternatives of proposed actions. But once again this is about communication. If facts are not communicated clearly and proficiently there will be minimal understanding. Faden & Beauchamp state: "A person has a *full* or *complete* understanding of an action if there is a fully *adequate* apprehension of all the *relevant* propositions or statements....that correctly describe (1) the nature of the action, and (2) the foreseeable consequences and possible outcomes that might follow as a result of performing and not performing the action" (Faden & Beauchamp 1986:252).

Though this is a complex and apparently sound definition of disclosure and understanding I find their use of 'fully' to be problematic and I also have the

same difficulty with its use within the New Zealand Code. In my professional life I am constantly involved in situations where even the professionals responsible for providing the information would admit they do not always have *'full'* knowledge. In the practical or clinical world, the world in which informed consent will function or fail, *'full'* or *'fully'* needs to be substituted by a requirement that is achievable, such as *'substantial'* or *'substantially'*.

What also needs to be understood is that it is the patient who has the choice of agreeing or *giving* authorization for treatment or declining or *rejecting* treatment, not the healthcare professional. Patients must understand that they are being presented with a choice. For *'with understanding'* to be achieved, it can only be *'substantial'* not *'full understanding'* because substantial understanding makes an act substantially autonomous. However, it is not just all relevant information about proposed treatment that needs to be disclosed, the complexities and concerns surrounding the patient's present state of health must also be clearly understood and discussed. This can only be achieved with excellent communication in the clinical setting.

Currently there are *three* legal standards in vogue by which information can be disclosed to patients: the *professional practice* standard, the *reasonable person* standard and the *subjective standard* of disclosure. The subjective standard suggests a dialogue between patient and healthcare professional that many be envisaged as a form of shared decision-making.

The first standard that emerged within medical ethics was the *'professional practice standard'* from the Bolam test described in chapter one. The second standard is the *'reasonable person standard'*: the patient is given as much information as any reasonable person in the same situation would deem necessary to enable an informed decision to be made. The third standard, the *'subjective standard'*, focuses on the specific person rather than a hypothetical reasonable person.

Presently, Britain uses the *'professional practice standard'*; America uses the *'reasonable person'* standard and New Zealand the *'subjective standard'*. All three standards are fraught with theoretical and practical problems, especially the first two, as they do not require the professional to disclose the amount or type of information that may be required by the individual patient in their specific

circumstances. The 'professional practice standard' emphasises the values of medical practitioners rather than the patient without considering the unique needs and values of individual patients. "This focus fails to grant patient's values their proper role in the decision-making process" (May 2002:18), and helps prolong paternalism.

There is increasing ethical opinion that the 'subjective standard' is the ideal. It gives assurance that the patient receives sufficient information to make a truly informed and autonomous decision. It protects the individual's right to author his or her own life. But this too is problematic, especially within limitations imposed by the hospital, it is difficult for either professional or patient to determine exactly what information is needed. Many professionals do not know the patient well because the first meeting may occur hours or only minutes before the advised treatment so there is inadequate time for the professional to become acquainted with the values, beliefs and expectations of the patient. The patient on the other hand may not always recognize what information is needed until after the clinical encounter.

Many authors believe a major problem with the subjective standard is the perception that the burden of "accounting for idiosyncratic values falls entirely on the healthcare professional. Informed consent is a process designed to foster communication between the patient and the healthcare professional, to ensure that health care treatment is, as much as possible, consistent with a patient's values and desires. In this light, the patient cannot be viewed as a passive receptor of information, but instead must be expected to participate actively in identifying fears and concerns related to health care treatment" (May 2002:20). This view, however, does not release healthcare professionals from their responsibilities because patients cannot be expected to know every medical implication of the recommended treatment. The healthcare professional must make an effort to learn relevant eccentricities and peculiarities of the patients they plan to treat.

Implicit in the informed consent and decision-making process is the belief that a type of partnership exists between the healthcare professional and the patient in which both assume responsibility. I examine 'partnership' in the chapter seven, suffice to say at this point, that I question the use of the concept of partnership

which suggests an equal balance of power which in my view does not exist. The introduction of the term 'partnership', like the use of 'client, might well have originated in an attempt to break down paternalism, but the language of business is simply inadequate to the healthcare situation.

The term 'full disclosure' is unrealistic. Circuit Judge Spottswood W. Robinson 111, the judge in the case *Canterbury V. Spence (1972)* in which the landmark informed consent decision originated, declared it was "obviously prohibitive and unrealistic to expect physicians to discuss with their patients every risk of proposed treatment – no matter how small or remote..... Indeed the cases speaking in terms of "full" disclosure appear to envision something less than total disclosure, leaving unanswered the question of just how much" (Robinson in Beauchamp & Walters 1999: 133). Was "full" never meant to equate to total? Robinson went on to state that the law, not physicians, must set the standard of adequate disclosure, but he later agreed that the content for disclosure rests in the first instant with the physician because with his (sic) medical training and experience he can "sense how the average, reasonable patient expectably would react. Indeed with knowledge of, or ability to learn, his patient's background and current conditions, he is in a position superior to most..."(Robinson 1999:134). It is tempting to see this last position as an indulgence of traditional paternalism embedded in the language of the discussion itself.

Carlton Vogt believes that informed consent is imperative to a person's autonomy, but is cynical about the ability of healthcare workers to inform; saying "there are many ways, besides lying, to misinform". Numerous authors discuss ways that the 'informed' part of informed consent or choice could be removed to "render the term meaningless" (Vogt 2002), and from practical experience I am familiar with many of them.

The following are ways in which misinformation can occur: - no information (none given by the health professional or none asked for by the client). This would be a rare scenario within the healthcare system currently, because most healthcare professionals recognise the need for disclosure of information. Too little information (influence by omission). This is more common, often giving just enough information to get a signature on a consent form. Too much

information, attempting to conceal the truth with information overload causing confusion and impaired understanding and increased vulnerability. Ambiguous information or the manipulation of certain facts to obtain consent, it may come as a surprise to most readers but I believe, as do many of my colleagues, this is one of the most common information giving tactic used within healthcare, it may be because the professional needs to persuade patients to consent to what they propose, this is about power and control – if the patient will not consent to what the professional requires then manipulate, frighten or confuse them so they capitulate. Rhetoric involved in information giving. Rhetoric requires understanding a fundamental division between what is communicated through language and how this is communicated. Aristotle stated that it was the difference between *logos*, the logical content of a speech and *lexis* the style by which the speech is delivered. Hence, the person's style and manner of the delivery of information can influence understanding. *How* one communicates information conveys just as much meaning as *what* one says! Knowledge and information is only as good as the bearer knows and communicates. Misleading information or deceptive truths, when the healthcare professional states a technical truth in such a way that the patient takes the wrong inference from it. Statistical data can be easily distorted to mislead. Distortion of facts can also be done by placing excessive emphasis on risks involved with procedures, for example in Austin's study on induction of labour, she found that some midwives were "using the language of risk to convince women to have an intervention" (Austin 2003:59). "Without sufficient reliable information, framed accurately and objectively....our choices run the risk of not being truly informed choices" and warns that anybody manipulating information in this way is operating "outside the bounds of ethics" (Vogt 2000).

The psychological state of the person receiving the information can have a marked effect on comprehension and memory, especially factors such as stress, fear, anxiety and vulnerability. Although psychological research has made inroads to help reduce these kinds of effects "they can still impair understanding and therefore informed consent" and attempting to achieve 'subjective standard' "is time-consuming and places heavy demands on the professional in terms of communicative skills and psychological insight"

(Schermer 2002:29). It may also be an unrealistic task to expect to substantially inform a person who has no background of health knowledge on which to initiate a discussion or to arrive at a decision. It is equally unrealistic to expect a patient who is vulnerable and ill, to educate themselves immediately and quickly to a point where they can make an informed choice. However, the expectation to substantially inform rather than fully inform allows leeway depending on the competence of the patient. If the patient is very ill then their level of competence or understanding is naturally diminished.

It is vital then that understanding of information is viewed as substantial understanding within the concept of informed consent, otherwise "if the standard of understanding is set too high (...), informed consent simply becomes impossible" (Donnelly 202:22).

The notion of 'fully informed' appearing in many policy documents within New Zealand Hospitals makes the practice of healthcare professions attempting to obtain *true informed consent* an impossible task. I think we need to look towards placing the act of being informed along a continuum, as with voluntariness and disclosure, ranging from fully informed to non-informed but keeping in mind legal requirements. Kenneth Arrow, one of the first to write about the economics of information in 1963, declared that if people have enough information to make themselves fully informed then they would have "as good or nearly as good understanding of the utility of the product as the producer"(Arrow 1963: 951). The notion of 'substantially informing' a patient is achievable, the notion of 'fully' informing is an impossibility.

What is the scope of the information necessary to achieve 'substantial understanding'? First there are the 'core disclosures which should include "1) those facts or descriptions that patients...usually consider material in deciding whether to refuse or consent to the proposed intervention. ..., 2) what the professional believes to be material about proposed intervention.., including the professional's recommendations...and... why the patient ... should take the professional's advice, and 3) what needs to be said to establish the purpose of seeking consent and the nature and implications of consent as an act of authorization" (Faden & Beauchamp 1986:308).

'Materiality' was identified as a legal concept in *Roger v Whitaker* (Australia 1992). A risk is material if: "In the circumstances of a particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it, or if the practitioner is or should be aware that the particular patient, if warned of the risk, would be likely to attach significance to it".

In other words the 'core disclosures' should include – risks inherent in the procedure, risks specific to the individual case, information about success rates of treatment, side-effects of procedure, benefits of procedure, alternative treatments available, the professional's advice and recommendations, who will carry out the procedure and what qualifications and experiences they have, and the expense of the treatment if relevant. These 'core disclosures' will vary with each patient and each treatment. Hopefully, one does not need to work one's way through all the 'core disclosures' just to take a blood pressure!

Ensuring that 'core disclosures' are delivered within a multicultural society can prove difficult and time consuming, as one needs to understand the cultural needs and attitudes of each individual patient. It is essential to adjust the level of information disclosure to the individual's needs, values, beliefs and specific circumstances surrounding the particular clinical encounter. An individual's beliefs are deeply influenced by the culture they live in, and it can often be a worthwhile challenge for healthcare professionals to explore the reasons for underlying beliefs different from their own. Cultural generalities are helpful for background information about patients, but it is inherently dangerous for the healthcare professionals to stereotype rather than treat each person as a unique individual and part of a community.

There is a responsibility on the professional to disclose information that "would be viewed by the actor as worthy of consideration in the process of deciding about whether to perform a proposed action" (Faden & Beauchamp 1986:303). A two-way conversation and attentive listening are needed to accomplish this – listening is an underused but essential feature of informed consent within the clinical encounter. This two-way conversation should also be looked upon as a feed-back loop where the healthcare professional asks the patient what they have understood by the communication. Unless the healthcare professional

asks the patient to recount what they 'heard', they will have *absolutely* no idea how well or how poorly they have communicated the information. Good communication is about more than language and facts. Good communication is about identifying the level of understanding and having an awareness of cultural values such as family values and relationships, and the role family play in the lives of the ill person.

A review of the literature reveals a great deal of discussion around the practical problems that surround different types of disclosure of information. Healthcare professionals do not appear to have one single standard of disclosure despite specific legal requirement within different countries. Realistically, because healthcare professionals are also unique individuals with their own specific values and beliefs, they tend to tackle information disclosure in different ways. There are also enormous discrepancies as to what a specific person under a 'subjective standard' would want to know. No two people are alike, hence each individual might have specific needs that may not be covered by this standard. Most authors agree that effective communication is the key to substantial understanding. (Faden & Beauchamp 1986, President's Commission 1982, Katz 1984, Brock 1987).

Issues of information-giving and opportunities for patients to participate in decision-making are crucial elements in supporting patient autonomy. Waller reiterates that "information is an important element of autonomous control; but unless the patient has confidence and competence to understand, it provokes stress rather than providing comfort" (Waller 2002:257). Schermer reminds us that the disclosure of information can achieve many other clinical goals as well as ensuring the patient is 'substantially informed', "it also enhances patient cooperation, gives reassurance, strengthens the trust relationship and helps the patient adapt to the effects of his illness"(Schermer 2002:29).

All healthcare providers are legally obliged, under New Zealand Bill of Rights act 1990 and the Code of Health and Disability Services Consumers' Rights 1996, to disclose information to consumers of their service. The Code states that; "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive" (Right 6:1, The Code 1996). Implicit in this rights-based approach is the right to know

what the treatment entails in order to make an informed choice and give a valid consent. This approach also recognises that some consumers or patients may wish to receive little or no information preferring to be guided by the professional. There is still scope for paternalism by the clinician if that has been elicited as the distinct wish of their patient. If that is the patient's choice then the professional should abide by these wishes and not compel the patient to listen to the disclosure of information that the professional feels duty-bound to impart.

There is also the question of competence of a non-medical person understanding the intricacies of a complex procedure or even medical personnel understanding the complexities of a procedure outside their area of expertise. Can one really translate medical jargon into layman's language without losing accuracy? Specialized or technical language can be very difficult to translate into layman's terms without losing some subtle meanings, hence healthcare professionals, despite their best intentions use the vernacular and jargon of their profession, disadvantaging their patients. It is also difficult for healthcare professionals to disclose information without any personal bias.

The process of informed choice takes time and skill and the patient must be given adequate opportunities for asking questions because this is the only possible way the healthcare professional can be assured that there is understanding. If the patient is unable to ask questions then a relative or advocate must be appointed to ask questions. The process of ensuring informed choice or obtaining informed consent is about developing a relationship between healthcare professional and patient...even if only for a brief period. Ideally the professional should ask the patient what they believe they have consented to, so that the professional can estimate to what degree the patient understood the whole process. Within a hospital setting this process can and is delegated but it still remains the absolute responsibility of the person carrying out the treatment to "ensure the integrity of the process" (Young 2002:4).

Bad habits can develop with written consent when it becomes a mere formality for healthcare professionals to simply ask the patient to sign a piece of paper without giving due thought to the informed consent process. There is still a

tendency among medical staff to “perceive informed consent mainly as a medico-legal concept centred on the requirement to get a signature on a form” (Jones 1999:105). This in my view is very much still the focus within hospitals although I believe more information is included now than was included five years ago, but whether the patient understands the information is another question.

During the writing of this thesis I was asked by colleagues what my subject was. When I mentioned informed consent, the majority spoke of the ‘written consent’ as though that was the essence of the concept. However, when I questioned them about it they understood the basis of the theory of informed consent while admitting it simply did not happen in a practical sense. I got the distinct impression that their motivation in the process was more legal than ethical.

Some healthcare professionals argue that many patients neither understand nor want information about proposed treatment. But a study carried out in Australia in 1986-87 by the Law Reform Commission of Victoria disputes this. 86.1% of clients surveyed said they always or usually understood the basic information about their illness or treatment given to them. Most people in the survey were very clear about what information they wanted, how it was communicated and why they wanted it. However, healthcare professionals can never be totally certain that patients understand and retain information and several studies have demonstrated that this is a field that requires more research. I believe the following examples demonstrate that there is more to communication in the healthcare setting than one intelligent being explaining matters to another. There is obviously an enormous emotional component working to numb a patient’s understanding. In matters of life and death this is completely understandable.

One study analysed patient’s recall of risks for a specific cardiac procedure in which all patients were counselled using exactly the same method. Several days after the treatment only one person could quote all risks (The Lancet Feb, 20 1999 p.645).

Jones describes several studies pertaining to retention of information in his paper “Informed Consent and Other Fairy Stories”, for example the study by A.P. Armstrong *et al* in 1992 which demonstrated that much of what was told to

patients was soon forgotten and that patients were “notoriously bad” at remembering what they were told about proposed treatment (Jones 1999:126). A study by Byrne *et al* found that between two to five days after an operation, 27% interviewed did not know which organ had been operated upon and 44% could not relate basic facts about their operation. Jones relates another study that suggested that giving information on paper did not improve retention of information. This was a study by Clark *et al* where one group of patients were given an oral explanation of anaesthetic risks and the other group were given both oral and written explanation of the risks, it was found that the group who had received the oral explanation only retained the most information. Oliver *et al* carried out a study in Australia on 100 patients undergoing chemotherapy, all were given written information and a consent form, but only 34 understood the purpose of the consent form and only one considered it a source of information, 75 could not name any of their drugs; 26 did not understand what the aim of the treatment was and only 15 remembered all four major side-effects (Jones 1999:126-128).

A study by Lavelle-Jones *et al* 1993 found that 69% of patients admitted they did not read the consent form before signing it. Jones also relates studies that show that written information can improve understanding and another study that showed that people most often remembered the potential benefits more than the potential risks (Jones 1999: 126-128).

As most of the above studies were about recall it leaves us uncertain as to whether the patient did not understand the information, did not wish to understand the information or the situation was too emotionally intense for them to concentrate on the information or understood the information but once the treatment was finished banished it from their mind. I do not believe these studies reflect a failure of informed consent. They reflect the complexity of the healthcare situation and the limits of our understanding of patient’s mental state in the clinical situation.

Summary:

Disclosure of information to the patient is not enough to ensure informed consent; there must also be understanding by the patient. These two elements

of informed consent are clearly two separate issues, legally and ethically. New Zealand's legal system demands that patients are 'fully' informed, unfortunately an impossible task as most healthcare professionals would not claim to be fully informed. Had the law called for a patient to be 'substantially' informed, healthcare professionals and patients would have been presented a much more achievable task.

Jargon free information specific to the patient is what needs to be communicated in a manner and language the patient can understand. New Zealand's legal disclosure standard is the subjective standard, which means the information must be adjusted to the specific patient. When information is being disclosed the state of the patient receiving the information needs to be considered. Ensuring that specific information is relative to the individual is often problematic in hospitals as many healthcare professionals meet patients for the first time immediately prior to treatment and know little about them. Patients who are ill and vulnerable are unlikely to absorb all relevant information and this is where the feed-back loop is a valuable tool within the clinical encounter.

There are, of course, many ways to inform or misinform - too little information, too much information or misleading information all of which depend on the person imparting the information and their agenda. There is also a need to be culturally aware of the impact of information on individuals or families.

There is still a tendency amongst healthcare professionals to view informed consent from a legal rather than an ethical standpoint and to equate informed consent with a signature on a consent form. From personal experience I do sense that the motivational force within hospitals is indeed legal rather than ethical as there is also a strong tendency to regard the disclosing of information and recommended actions as the essence of informed consent. Breaking a several millennia old culture of decision-making by the medical profession is not proving to be easy.

Studies demonstrating how poorly information is remembered by patients raises concerns about how information can be meaningfully communicated between healthcare professionals, confident and at home in their natural habitat, and anxious patients trapped unwillingly in an alien environment. Communication is the key.....

Chapter six

"Knowledge is the most democratic source of power". Alvin Toffler (b. 1928),

"Knowledge is what we get when an observer, preferably a scientifically trained observer, provides us with a copy of reality that we can all recognize". Christopher Lasch (b. 1932),

"Knowledge is power". Sir Francis Bacon (1561 - 1626),

Knowledge, Power and Communication....

The distinctive evolution of medicine through science and technology has reinforced an extensive history of paternalism and authoritarianism. In reaction to this we now face increased awareness of the importance of patient autonomy and informed consent. Medicine developed a pool of complex knowledge encased in its own protective jargon: "Knowledge itself does not give special power: only *exclusive* knowledge gives power to its possessors" (Freidson 1973:28). Patients were left outside the decision making process and on occasion were the subjects of research without their knowledge or consent.

"Power, at the most rudimentary personal level, originates in dependence, and the power of the profession primarily originates in dependence upon their knowledge and competence" (Starr 1982:3). Most people live their lives deferring to the judgement of people whom they believe to be legitimate authorities. Though Foucault did not address the concept of power at the level of the individual he was concerned with power at the point where it was completely immersed in social practice. He believed that knowledge and power were incapable of being separated insisting that "knowledge is a power over others"...the power to..."define others and control them" (Petersen 1994:5).

Milburn maintains that there is considerable evidence to support the view that medicine's monopoly of healthcare services "is a conscious strategy to access and maintain privileges associated with social and cultural power, and that control of the client group is essential to maintaining this power" (Milburn 2001:57).

Though healthcare professionals acknowledge patient's vulnerability, there is an historic assumption that they know what is best for a patient. The more vulnerable the patient is, the less likely they are to demand information, the more unlikely they are to be able to absorb the information given and the more likely they are to consent 'without understanding', thus increasing their

vulnerability. This is when they need an advocate – either a family member or an independent advocate. This is another right patients are entitled to under the New Zealand Code (Right 10:2c).

Language itself can be a barrier to communication even if healthcare professional and patient share a common language. “Our ability to understand one another depends on the extent to which we understand various accents, colloquial expressions, dialects and slang. Vocabularies differ regionally and are influenced by our experiences and our educational exposures” (Secubdy & Jackson 2000:65).

Two persons sharing a common language may not recognize that they are not communicating and the party imparting information may not be aware of the communication impasse – this is where the use of the feed-back loop is vital to identify lack of communication or understanding. There are even greater gaps in communication when the patient's native language is different to the healthcare professional, even to the point where an interpreter is required, a right that is specified within the Code. However, many healthcare professionals make the mistake of using a friend or relative of the patient to translate. Unfortunately if this person is not a trained interpreter there is a likelihood that they may interpret what they want to convey or even add to the information imparted to them. Education, socio-economic status and cultural beliefs are determinants of health information and knowledge possessed by patients. Healthcare providers need to be open to new information and alternative ways of approaching people in order to gain cooperation, rather than resistance, within the clinical encounter.

In recent years there are a growing number of courses and communication workshops to improve the communication skills of healthcare professionals. Most healthcare training institutes now include communication as part of their curriculum. Communication workshops and facilities have mushroomed in England, America, Canada and Australia in reaction to the growing litigation within healthcare. Though these workshops and courses are currently aimed at doctors and exist mostly in societies with a high medical litigation rate, they are now beginning to include allied health care professionals – albeit on separate courses than doctors.

One such institute in Brisbane, the Cognitive Institute of Australia, the brainchild of Dr Mark O'Brien, claims to have educated more than 4000 doctors and healthcare professionals. For their workshops the Institute makes a distinction amongst various professional groups within healthcare, separating doctors from other healthcare professionals – perhaps an enduring arrogance within the medical profession who may not attend if such workshops were open to all healthcare professionals. O'Brien, when asked in a personal communication why there was segregation for their courses replied,

“the reason we have differentiated doctors from other healthcare workers reflects a number of issues.... Within the UK, USA and Australia, much of the demand for our courses is directly coming from Medical defense organizations, Royal Colleges and Hospitals trying to address the rise in lawsuits against doctors. As most other healthcare professionals rarely get sued or get sued at very low rates in these countries, there is far less demand to provide training to low-risk groups. It is interesting that in our clients' experience when we get called into hospitals where there are significant issues with doctors' behaviour and interpersonal skills, doctors willingness to show vulnerability and to open up and talk about issues and discuss strategies for addressing them is markedly curtailed if there are other healthcare professionals in the room" (O'Brien 2003pc).

In 2003, I attended a lecture given by Dr O'Brien when he was in New Zealand and got the distinct impression that one of the main reasons for the initial development of his education programme was to help doctors reduce litigation. These workshops provide several techniques that help healthcare professionals construct the allotted time for the clinical encounter in order to get the most out of it. Avoidance of litigation was more an issuer than the ethics of the healthcare professional/patient relationship.

Whatever the reasons for teaching a variety of communication skills, O'Brien demonstrated convincingly that they contribute greatly improved interaction within the clinical encounter. He produced interesting statistics that demonstrated the decline in litigation if doctors were up front and honest with their patients when there had been an adverse outcome from treatment. In the event of an adverse outcome, patients ask questions and demand answers.

They expect honesty and time for discussion, if this does not happen they are more likely to sue. He also stated that if quality time had been allocated to these patients before treatment for decision-making and exchange of information - then they rarely sued. All of the above assume excellent communication skills.

The Institute has developed a communication tool in the form of a brochure to educate people how to be a better patient. This was initiated following feedback from healthcare professionals who wished patients could also be educated to take a 'partnership to help' role within the clinical encounter. The brochure is called " Learning the ABC to better healthcare: improving communication with your doctor". The Cognitive Institute's website declares that currently the average patient only asked two questions during an entire clinical encounter lasting 15 minutes. This suggests there remains an immense amount of work to be done on communication amongst healthcare professionals and their patients.

That effective communication is the key concept within the clinical encounter is extraordinary in one specific aspect - it was one of the rare issues in which I found near universal agreement. Barbara Korsch has written several books on the subject of effective communication. Websites are developing all over the world aimed at educating the patient to be more assertive and many specific healthcare groups are providing pamphlets on specific subjects to ensure information is readily available for patients. Effective communication between the patient and the healthcare professional is essential for a successful healthcare relationship; this is the message from Barbara Korsch in "*The Intelligent Patient's Guide to the Doctor-Patient Relationship*"(1998).

Korsch carried out a large-scale quantitative research and found that if physicians wanted to communicate effectively they must first of all be attentive to their patients and listen to their fears, understand anxieties and explore expectations. It is vital that the healthcare professional is non-judgmental and allows the patient to recount their treatment so far and invite description of illness, which includes environmental or relationship difficulties. Korsch warned physicians that they could no longer think of patients as 'passive victims', they must encourage active participation in decision-making. What is loud and clear

from Korsch and other studies is that the patient must also take responsibility for good communication and offers many pertinent points on how they can achieve this (Korsch 1998).

The availability and accessibility of information has changed considerably in the last forty years but is this information reaching all consumers of healthcare? In order to empower consumers to gather knowledge there is a need to study “what consumers know and how they learn with the ultimate objective of designing policies and institutional structures that improve performance of consumers in the medical care marketplace” (Sloan 2001:910). Sloan states that we need to understand how people process health information and recognize ways people communicate their values, beliefs and choices. This is not as simple as it sounds because information is an exceedingly difficult concept to measure. We live in an information technological era, which should produce well-informed patients.

However, no matter how much information patients gather they ultimately tend to rely on their healthcare professional to tie that information to the patient’s particular needs. “All the technological innovations in the world cannot make the informational asymmetry between physicians and patients go away. ‘No Internet site will ever replace the intangibles of the doctor-patient relationship. Data crunching will never eliminate the vast grey areas where technology, medical judgment, and patient preference intersect’” (Millenson quoted in Hass-Wilson 2001:1042). Healthcare professionals and patients, view illness in very different ways, “their perspectives are based on very different premises, employ a different system of proof, and assess the efficacy of treatment in a different way. Each has its strengths, as well as its weaknesses. The problem is how to ensure some *communication....*” (Helman 1994:101).

Seaman illustrates research which shows many healthcare professionals blame patients when communications break down and many have a less than efficient interviewing style. The previously mentioned study by Korsch (1998) found that doctors do more talking than listening. A study in 1999 published in JAMA found that 72% of doctors interrupted the patients opening statement after some 23 seconds, though had the patients been allowed to complete their sentence they would have continued to speak, on average, for only another 6 seconds.

Many healthcare professionals avoided talk of emotional health, steering the patient back to technical talk.

Suchman *et al* demonstrated that many doctors underestimated the amount of information required by the patient while overestimating how much information they give (Seaman 2002:3). Beckman *et al*, found that doctors who did not communicate well were more likely to end up in court, this has been confirmed by other studies which show that 70% of litigation is related to poor communication (O'Brien 2003). Seaman suggests that there is a need to cultivate a patient-centred partnership as patients want to be known and recognized as patients and not the "outer wrappings for a disease" (Lown quoted in Seaman 2002:3). It also seems that healthcare professionals benefit when they use a patient centred approach as they themselves experience a great deal more job satisfaction. Finally, Seaman warns healthcare professionals to respect patients as experts in their particular illness and not as an unreliable resource. She argues that the notion put forward by Rotter & Hall seeking a "patient-centred relationship that accepts the patients 'unique' knowledge as just as important to outcome as the doctor's scientific knowledge" (Seaman 2002:3), is crucial to effective communication within the clinical encounter. Many healthcare professionals view their patients as body parts related to their specific professional specialty and so tend not to view their patients as a whole person. They are unlikely to acknowledge the patient's unique knowledge as being in any way equal to their expert knowledge.

Research on doctor-patient communication has produced substantial evidence that effective communication can greatly improve patient outcomes, patient satisfaction, adherence to treatment and increased understanding of the aetiology of specific diseases (Rosenberg et al 1997, Stewart 1995). Research has also produced evidence that healthcare professionals are very poor communicators, especially when there are cultural or ethnic differences, because there is evidence that race, ethnicity and language have substantial influence on the quality of the clinical encounter (Ferguson & Candib 2002:353). Effective communication is the key requirement for a successful clinical encounter, but if patients are of a different race or culture or speak a different language from the healthcare professional, communication is much more

difficult and it is especially difficult if the patient is not proficient in the healthcare professional's language. Such patients are less likely to "engender empathic responses....less likely to establish rapport... less likely to receive sufficient information, and less likely to be encouraged to participate in medical decision making" (Ferguson & Candib 2002:359).

The Internet is probably the tool that has done most to de-mystify the language of medicine. Amongst the hundreds of resources available are several resources that until recently was only available to members of the medical profession. Now one can 'surf' articles from such prestigious journals as *Journal of the American Medical Association* or *New England Journal of Medicine*. Both consumers and professionals now use these readily available consumer resources. The internet as a source of information brings its own problems, mainly because of the danger of regarding the internet as the answer to all information queries and because the healthcare professionals may spend much of the valuable informed consent process time acting as an information broker. Many people take as 'fact' anything they read or download from the Internet, often not differentiating between what is a professional or a reliable source or what is obtuse or crackpot.

Bidwell *et al* surveyed 314 private and public hospitals in New Zealand in 2000 focusing on the need for a consumer health information service for New Zealand that would give universal access to all consumers regardless of access to internet or not. The results showed that 53.7% of all hospitals surveyed believed that there should be such a service available but could not agree what shape it would take. There was general agreement that this information would be secondary to the information supplied by the healthcare professional – but it would reinforce professional information given (Bidwell 2001:18). The Medical Council of New Zealand 1990 endorsed the 'proper sharing of information' and the New Zealand Code of Rights 1996 (Right 5:1), endorsed the right to effective communication 'in a form, language, and manner that enables the consumer to understand the information provided'. However, Bidwell's survey found the situation in New Zealand to be at best "fragmented, represented by patchy, regionalized services developed as individual initiatives. There (was) no consensus on the direction in which to move to improve this situation, and

this lack of direction has seen the requirement for patient information marginalized and lagging behind international initiatives” (Bidwell 2001:4).

If the legal framework of New Zealand and the department of Health and Disability imposes such precise demands on all healthcare professionals, they also need to do strategic planning around health information and its availability to all New Zealanders. There is no doubt that one universal national service should be available to the public as an information back up for all healthcare professionals, whether it be through the hospitals, libraries, community outlets or other user friendly sources. This information would need to be consumer-friendly, accurate, constant and evidence-based. It should also include alternative therapies and major experimental studies in progress. It should be presented without a biomedical bias and should be available in a variety of languages. The content would need to be updated on a regular basis.

One such package available in the UK is the Midwives Information and Resource Service (MIDIRS) Informed Choice Information Pack. Originally launched in 1996 and revamped and re printed in March 2003. This resource is free of charge and is available to all consumers of obstetrics and all healthcare professionals who work within obstetrics. According to MIDIRS editorial staff there was a “plethora of pregnancy related information available to pregnant women and their families and their concern was that the quality of this material is variable, ranging from the soundly evidence-based to the empiric” (MIDIRS website 2003). All information contained in the resource is evidence-based and has been rigorously cross-referenced to give an objective approach to pregnancy, childbirth and postnatal care. All leaflets, which are free of charge, can be sourced in bulk for any healthcare organization or professional group or can be sourced singly by prospective clients. There are two sets of leaflets on a variety of topics available, one set for the patient and one set for the professional, each giving the same information but the leaflet for the professional has much greater detail, both are available on MIDIRS website.

Another such package has been created by A. Gaisser, MD, Cancer Information service, Heidelberg, Germany. A group of experts in cancer have devised and tested three brochures to improve communication between patient with cancer

and the doctor. Besides evidence based research, they include experimental and unconventional therapies available.

Information within hospitals appears in protocols and policies. Though hospital protocols are evidence based they are scientifically biased and leave little room for choices. Schermer, who carried out hospital-based research on autonomy, found that the biomedical perspective is still hugely influential in hospital protocols and policies and is "being enacted, reaffirmed and passed on in everyday routines and interactions" (Schermer 2002:78). Protocols and policies are one way the biomedical perspective is deeply embedded within hospitals, which in turn impacts on everyday decision-making. Protocols within hospital tend to focus on just one right way to act, charting instructions or a sequence of steps about a course of action for specific situations. Protocols are presented as best practice standards to encourage a single standard of practice within a hospital. Though these protocols are evidence-based they are also exclusionary in that they exclude the possibility of alternatives, which is a requirement according to the doctrine of informed consent, and so negate choice because it gives the illusion of a single right answer. Protocols tend to suggest a preferred treatment rather than a series of alternative choices for the patient. There is a right way, and that way is the biomedical scientific way.

Evidence-based medicine, which is defined as "conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients"(Sackett et al in Schermer 2002:80), is according to Schermer, evidence from a biomedical perspective not from a patient perspective, since the priority is given to scientific evidence not patient benefit. This is despite the fact that the New Zealand legal framework places the patient at the centre of the healthcare sector. Schermer also reminds us that choosing treatment based on evidence "causes a bias against those kinds of treatments that have been poorly investigated.....the objectivity and rationality which is part of the rhetoric of evidence-based medicine tends to obscure the fact that values play an important role in the conclusions from evidence-based medicine" (Hope in Schermer 2002:80).

Healthcare professionals within hospitals should encourage a more collaborative decision-making process by which information and options are

tailored to each patient. Schermer describes the collaborative decision-making process as a process that consists of four phases: “the establishment of a relationship, reaching an agreement on the nature of the problem and the goals for treatment, selecting an approach to diagnosis or treatment and deciding on separate interventions, and a follow up including evaluation and a continuation of the exchange of information and decision-making” (Schermer 2002: 188). I believe that this collaborative decision-making model is the model best suited to the clinical encounter and will discuss it in more detail in the chapter on the clinical encounter. Schermer recommends further changes if collaborative decision-making is to succeed and the clinical encounter is to become more patient-centred, suggesting changes to protocols and policies so that the values and preferences of patients are given more prominence. In other words they should become more flexible and open to allow deviation for individual needs. Schermer also suggests a change in attitude development during training in order to be alert to values and preferences of individuals, demonstrating genuine interest in patients goals and life plans leading to a genuine respect for individual autonomy.

Summary:

Communication is the key to informed consent and the New Zealand Code (Right 5:1) endorsed the right to effective communication ‘in a form, language, and manner that enables the consumer to understand the information provided’. But healthcare professionals are notoriously bad communicators, especially when patients are from a different cultural or ethnic background. They have expert knowledge, which carries with it embedded power and this combination of knowledge and power encourages dependence by the patient seeking that knowledge. The fact that patients have expert knowledge about their illness and their body is rarely considered as vital to the clinical encounter.

Historically physicians embodied paternalism, believing they always knew what was best for the patients. The notion of sharing that power, even a little bit, is slow to take hold. Active participation by patients is needed to swing the pendulum. Patients need to take a key role in the communication impasse and many leaflets and books are now available to them on this subject. Medical

information is available through a variety of sources for the patient's edification, but it is not always suitable or unbiased and often requires further explanation from the healthcare professional.

Paternalism and the biomedical perspective are still very much alive and well within medicine both in research and within the clinical encounter. Until we have a patient centered collaborative decision-making process within the clinical encounter with unbiased information available for all New Zealanders, the informed consent process will not work. However, the fault is not just with the healthcare professional, patients and consumer must also take responsibility for their part in ensuring communication – they need to become more active information seekers in order to help change the dynamics of the relationship within the clinical encounter. A relationship, which historically has progressed through many stages and models but amazingly there is still no consensus about which is the ultimate model.

Chapter seven

"Medical practices are not a medley of disconnected and meaningless customs' but rather an integral part of the larger sociocultural system within which they are embedded" (Rivers 1924 quoted in Baer et al 1997:15).

The Institution and the Clinical Encounter

"Nothing in medical ethics has changed so dramatically and drastically in the last quarter-century as the standards of ethical conduct governing the relationship between doctors and patients. In that time the centre of gravity of clinical decision-making has shifted almost completely from the doctor to the patient" (Pellegrino 1994:354). This transformation is most apparent in Western civilization but the social, political and cultural forces that are driving this change are also occurring, though to a lesser degree, throughout the world. The global nature of media, education and communication, growing democracy, waning religion, increased medical technologies, moral pluralism and general questioning of power are fostering this adaptation. Though moral beliefs and practices differ significantly between cultures each specific culture decides what is morally acceptable within that culture and establishes the moral framework that supports the ethics of that culture. However, the ethics of one culture can be quite different from the ethics of another and the recognition of differences in moral beliefs and practices across cultures is important within the clinical encounter and within western bioethics – this has been termed ethical relativism.

The clinical encounter is a social and symbolic process in which two parties are separated by power and knowledge. Both parties bring to the encounter a set of beliefs, expectations and practices influenced by their individual view of illness and health. Both parties approach the encounter from different viewpoints. The healthcare practitioner approaches the encounter from a diagnostic and task orientated position: taking a history, doing a physical examination, ordering blood tests and deciding on a provisional diagnosis. The patient does not necessarily share the professional's culture of medicine but comes to the encounter reliant on professional expertise, dependent on professional knowledge, exposed and vulnerable because of illness and the

need for a consultation and powerless because of the need to seek help. The patient can also be susceptible to the particular culture of medicine practiced by the professional.

Brandt (2000) states that bioethics has grown into an astonishingly vigorous discipline since the 1970s but has mainly concentrated on the clinical encounter to the neglect of the structure of the institution within which the encounter occurs. Brandt also suggests that the bioethics that has emerged in the last three decades may not be a good 'fit' for the moral or ethical dilemmas that occur within biomedicine.

Brandt observations were American based but I believe his comments are relevant to other Western societies. Brandt writes of the 'professional dominance' of the physician and the paternalistic tradition of medicine and believes that the immense progress in medicine has, in fact, reinforced this trait. While medicine advanced and patients gained from this advancement they were excluded from the decision-making process. Bioethics developed its moral and ethical theories while patients began demanding rights. Debate raged about the structure of interpersonal relationships within the clinical encounter and discussion continued about the rights of patients to autonomy, respect, privacy, disclosure, informed choice and self-determination. But the focus was more on "inter-personal relationships than to social structures and institutional structures" (Jonsen 2000).

According to Jonsen "the authority of medical managers has usurped the authority of physicians and the rights of patients. Usurped, in my view, is too strong a term, medical managers certainly have changed and lessened the authority of physicians but they still wield a modicum of power and authority within the healthcare institutions. The use of technology is contingent on policy and financing as much, or more, than on medical need. The rights of patients are debated now, not just by philosophers, but also by politicians " whose opinion is deeply coloured by political ideology" (Jonsen 2000). Jonsen claims that there is an overemphasis on 'autonomy' and a need for a greater appreciation of the ethic of justice. He believes that contemporary bioethicists need to find "conceptual tools to pry open the problems created by the social and economical structures of modern health care" (Jonsen 2000).

Capitalism shapes our western social process, it has “progressively shaped and reshaped social life”, hence biomedicine with its internal and external controls must be analysed within the context of the capitalist world system (Baer *et al* 1997:27). These shaping forces, individualism, rationality, community and interpersonal relationships, are constantly changing. Biomedicine became a dominant power with the event of industrial capitalism fostering a process called *medicalization* along the way. “Medicalization...contributes to increasing social control on the part of the physician and health institutions over behavior” and “underlying the medicalization of contemporary life is the broader phenomenon of *medical hegemony*, the process by which capitalist assumptions, concepts, and values come to permeate medical diagnosis and treatment” (Baer *et al* 1997:14). Because biomedicine has always been physician centred, it will take a massive sea change to shift the emphasis to patient centred within the clinical encounter. This change has begun to take place in theory but has not yet reached the clinical arena.

Baer *et al* remind us that hegemony is the preponderant influence of the state by structural means, as opposed to coercive means, over the cognitive and intellectual life of society - and is achieved by the assimilation, diffusion and practice of societal values, beliefs, traditions, customs, attitudes and legal and moral principles. This control is frequently reinforced within the clinical encounter by the compulsion the patient feels to comply with expert judgment. Inequality of power within the clinical encounter may engender a sense of powerlessness and vulnerability in the patient, which can devalue their sense of autonomy and their ability to make an informed choice. Milburn is not optimistic about the level of informed choice within healthcare because she believes that “medical authoritarianism, as a *culture*, remains deeply entrenched in western societies”, failing to recognise informed consent because “of the traditional western philosophical, political, legal and scientific focus on rationality as *the* major influence on human behaviour” ignoring the central role that personal values and beliefs play in making choices (Milburn 2001:ix). Baer, one of the proponents of critical medical anthropology which seeks to understand who “ultimately controls biomedicine and what the implications are of such

control” asks “how is this power expressed in the social relations of various groups and actors that comprise the health care system?” (Baer *et al* 1997:27). Walsh defines structure as a “recurring pattern of behaviour (that) has a constraining effect” (Walsh 1998:33). Structural issues impact on freedom of choice despite the fact that the very concept of freedom and agency is imposed by social structures. This concept gives the illusion that the macro sociocultural structure’s that have shaped the current notion of autonomy and agency encourages decision-making within the clinical encounter, through a rhetoric that symbolize free choice without constraints. This is the same macro structure that wields the power within the institution creating a power imbalance and constraints in the healthcare professional and patient relationship. Baer *et al* insist that to discuss the impact of power relations within a healthcare system one needs to recognize several levels of power. Foucault believed that power relations existed in all social relationships “permeating society in a capillary way rather than coming ‘down’ from a single centre of control such as the state”, he sees the state as just one instrument of power whereas Bourdieu, on the other hand has a ‘top down’ view of power relations (Gledhill 1994:148).

There are several ways one can explore the relationship between ‘structure’ and ‘agency’, between the ‘macro’ and ‘micro’ levels of society, In *appendix 1*, I have outlined how I see the levels of power within a public hospital in New Zealand. This shift in power relationships is not because the medical profession want such a change but rather because the legal, political and managerial forces are becoming stronger and more influential within hospital institutions and, as Freidson (1984) comments, bureaucratic structures like hospitals generate their sources of power through regulations such as protocols, policies and hospital hierarchy.

Protocols and policies impact on the issues of power within the clinical encounter. Power or lack of it is not an easy issue to deal with. I do not believe it possible for a totally even balance of power to exist within the clinical encounter because of the cultural construction of the clinical encounter. It will always be an episode between a professional and a lay-person. Each party approaches the encounter with a different perspective. The patient is ill, vulnerable and dependent on expert professional knowledge to obtain correct

treatment and is in a situation not of their choice, a situation that they probably dislike, resent or even hate. The healthcare professional is engaged in a job they have freely chosen and probably enjoy.

Hospitals are described as *partial institutions* by Purtilo & Haddad (2002) differentiating them from Goffman's *total institutions* which he describes as a place where "a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life", in which professionals are the sole authority. This arrangement is assumed to benefit the individual or society (Goffman 1961: xiii). Purtilo & Haddad state that most healthcare institutions can be classified as '*partial institutions*' "because they constrain patients' or clients' autonomy in some important ways, but also allow for a varying degree of self-determination" (Purtilo & Haddad 2002:25). If one considers this to be true the very fact that patients are partially constrained must impact on the voluntariness that is needed for informed consent to take place. But if voluntariness needs to be only substantially achieved, then informed consent can take place. However, subtle oppression from the healthcare professionals and from the imposition of policies and protocols could make voluntariness less than substantially achieved.

People change as they enter a hospital; they relinquish their identity as a member of a community to become a patient within an institution. Upon entering a hospital, patients may be constrained, they face certain limitations of personal actions such as restriction on visitors, limited food choices, being confined to a specific bed in a specific area surrounded by two or three strangers, and sometimes having only minimal involvement in decision-making about their treatment. A patient may feel defenceless, isolated from family members and constrained by loss of autonomy because of their inability to ask for a second opinion without fear of retribution.

On the other hand, healthcare professionals entering a hospital are also constrained, albeit in a different way from the patient. They are constrained by hospital management and political policies, by legal framework, by regulations of professional conduct and by managerial expectation of daily workload (Purtilo

& Haddad 2002). The clinical encounter I will discuss here is that which takes place within the culture of a hospital environment or 'partial institution'.

Restrictions in the form of hospital policies or protocols are imposed upon all healthcare institutions either by the government, the legal framework or the Western world systems - the society in which we live. Other more subtle restrictions such as in-house policies and protocols are imposed by hospital management, based on their distinct view of healthcare. Most policies are put in place to protect the institution, the individual or the professional; however, they leave little room for individual choice or variations of treatments. Too many policies, legal requirements and protocols can make professionals feel powerless to carry out their duty of care in an efficient way or powerless to change inadequate or unacceptable policies because change can be a convoluted and complex process.

The balance of power within hospitals is changing; professionals are losing their autonomy while managers are gaining more power. The complex web of rules and regulations enforced because of political, economic or legal pressure can make many professionals impotent and denude them of their professional autonomy. One could question if professional accountability is being eroded or suppressed or shaped by law, by politics or by ethics. The law and Insurance companies wield great power, especially in USA where insurance companies have ruled that a group of hospitals along the seacoast in Portsmouth cannot allow pregnant women to attempt a Vaginal Birth After Caesarean section (VBAC), unless under specific guidelines dictated by the American College of Obstetrics and Gynaecology (ACOG). Research shows that 1% of these women risk rupturing their uterus and if the scar ruptures 50% result in a neurologically impaired infant, a hysterectomy or death (Hait 2001:1). This leaves women without the right to choose their mode of delivery even though many women are frustrated because they cannot sign a consent that would hold *them* liable for their informed choice (Hait 2001).

There is another form of bioethics called the 'discourse of bioethics', that is very different from the discipline of bioethics. It exists in the media, in hospital committees, at political debates, in discussions between patient, healthcare professionals and families about proposed treatment and in corporate planning

of biotechnology companies. It talks about risks, informed choice, rights, benefits and equity. This discourse includes such current dilemmas as cloning, assisted death and genetic engineering and some of this discourse has led to social and legal change. As mentioned earlier, it was the media that highlighted 'the unfortunate experiment' here in New Zealand. If this media discourse had not occurred New Zealand may not be as far ahead as it is with patients rights and informed choice. Within a democratic society public discourses are a major source through which ideas and ideals can move institutional, social and economic powers in the "directions that better reflect those ethical ideas and ideals" (Jonsen 2000).

The Clinical Encounter

The clinical encounter within a hospital could be said to be a culturally created symbolic process. The healthcare professionals enter the hospital wearing a uniform, a stethoscope, a white coat or a hospital identification tag that is symbolic of their profession and identifies them as such. These symbolic acts or items are entrenched and popularised by the media and encourage popular belief in healthcare traditional actions which are in some way suggestive of power – the power to care, cure or alleviate pain. People who become patients also go through a similar symbolic process by being allocated a specific bed in a specific area within the hospital to await treatment, by wearing clothes that identify them as patients, by having personal medical charts and by wearing identification wristbands that acknowledge their status as a patient. For both parties these symbolic acts are part of a process of change: for the healthcare professional, it is a change from being a member of the public to healthcare professional. For the patient it is a change from being a member of the public to a dependant patient. Patients move from independence to dependence, which immediately makes them vulnerable and alters the power relations between them and healthcare professionals. Hence the very act of entering the hospital environment increases the stress level of an already stressed and vulnerable patient and reduced the likelihood of them being active information seekers. Patients admitted to hospital leave the comfort of their home life and enter this strange 'new' world.

Pellegrino (1985) describes three steps within the clinical encounter, the first step is when the person become ill and seeks professional help. The second step is the implied professionalism and agreement by the family healthcare professional to act in the patient's best interests – a relationship based on professionalism and veracity that has been built up over years between the patient and his/her family clinic. The third element is the interaction between the patient and the familiar family doctor/clinic, culminating in a mutual decision about a course of action (Pellegrino 1985).

I believe admission to hospital is a fourth element, when the patient enters this strange environment for further consultation and treatment. With each stage the patient becomes more vulnerable and by the time they reach the fourth stage they are at their most vulnerable. They feel isolated because they are separated from their family or support system and are expected to listen and absorb unfamiliar information, be autonomous and make vital decisions that may impact on the rest of their life. Into this chasm steps the nurse or what Engelhardt (1985) describes as the 'in-between person' who gets to know the patient, building a relationship of trust and care – "the in-between situation of nurses, which is a thorn in the side of those who stress autonomy, is actually a privileged position from which to make moral decisions concerning patient care" (Bishop & Scudder 1990:11). However, from an ethical perspective the nurse or healthcare professional cannot 'make' moral decisions for patients but I do believe they are in an ideal situation to know and understand the values and beliefs of their patient and therefore could and *should* be part of a collaborative decision making group within the clinical encounter.

The success of the informed choice process, which takes place within the clinical encounter, depends very much on the relationship that is established between the patient and the healthcare professionals. Most of the literature about this relationship is centred on the physician and his/her patient. This in itself is fairly remarkable considering the majority of healthcare workers are women and in fact, in the 1992 Boston Women's Health Book Collective's "*Our Bodies, Ourselves*, 85% of all healthcare workers in hospitals in the USA were women, and 75% overall worked in the healthcare sector. Women tend to enter the healthcare system as patients more often than men. Women tend to be the

primary carers for sick children, sick members of family and aging parents. Though the numbers are greatly increased, women physicians are still in the minority but come through a training that is still male dominated and emerge from training “eager to prove that they can be as good as any male physician according to the male-centred criteria of the profession: clinical competence, emotional detachment and financial success” (New Our Bodies 1992:668).

Though nurses spend substantially more time with patients than physicians do they tend to occupy lower-status, lower-paying positions and often have little input in healthcare policies and practices that shape the healthcare experience for patients. Also they are often excluded from the decision-making process of patients in their care.

Model of the clinical encounter relationship

There are several models of both physician-patient and healthcare professional-patient relationships that exist within the hospital environment. Historically the doctor-patient relationship has been the subject of most texts. In 1964 Parson's described an early Western model of the doctor-patient relationship as harmonious, based on the patient's trust and unquestioning acceptance of the doctor's superior skill and status (Parsons 1964). In 1980 Kleinman examined a later model of power imbalance shaped by specialized medical knowledge and higher social status, differences that often lead to a fraught or imbalanced relationship. In 1984, Jay Katz examined the time-honoured belief in the virtue of 'silent care', describing the historical doctor-patient relationship as being based on a one-way trust. He challenged physicians to discourage patients from surrendering their autonomy and advocated a new informed dialogue that respected the rights of both sides.

Other cultures had their own specific models: there was the 'God' model where traditional Muslim healers needed just to see the patient to immediately know their condition – no diagnosis was required. Other healers used pulse symmetry to initiate a diagnosis and in some African cultures part of the healing process was the need to continuously argue with the healer about diagnosis and treatment.

The clinical encounter between healthcare professionals and patients is a subtle but complex form of social interaction and each healthcare group demonstrates different forms of social interaction. I will examine the clinical encounter process from the viewpoint of two of the largest groups of healthcare professionals within hospitals – doctors and nurses/midwives.

Emanuel & Emanuel (1992) describe four models of physician-patient relationship identifying the decision-making process between patient and doctor as a *mêlée* between autonomy and health, between patient's values and physician's values and between the social status of the physician and patient. The first model is labelled 'Paternalistic', where the physician decides what treatment is best for the well being of their patient. This assumes there are shared values between physician and patient and the patient's interests are placed ahead of the physician's own. It has been said that the state of illness diminishes a person's sense of autonomy, which, in turn, invites and endorses the healthcare professional to assume a paternalistic attitude (Harding 2000). The second is the 'Informative' model where physician give patient all relevant information, the physician becomes the technical expert and the patient exercises control over treatment consistent with their own values and beliefs. However, the physician refrains from imposing his/her views or values on the patient. The physician is thus the information giver. The third 'Interpretive' model allows the patient, in discussion with the physician, to identify their values, goals, beliefs and needs and the treatment necessary to realize them. This interpretive process ends with an informed choice by the patient. The last model, considered to be the ideal, is the 'Deliberative' model, which is a collaborative process where "the physician acts as a teacher or friend engaging the patient in dialogue on what course of action would be best...the patient is empowered not simply to follow unexamined preferences or examined values, but to consider through dialogue, attractive health-related values, their worthiness, and their implications for treatment" (Emanuel & Emanuel 1992:2222). Both authors believe that the 'Informative' model is the most dominant model reducing the role of the physician to an information technologist. In my view the most common model in the hospital environment at present is a combination of the paternalistic and informative model. For me

the ideal is the '*deliberative*' patient-centred, collaborative, decision-making, mutual participation relationship incorporating consensus and the 'feed-back loop'.

Engelhardt described nurses as "people in-between" because they "give care under the scrutiny of two rather powerful individuals: the patient and the physician" (1985:71). The power of the physician is sustained by; his/her extensive education and knowledge, his/her legal right to perform lifesaving procedures, his/her right to dispense all types of drug regimes to effect treatment, his/her right to carry out invasive surgical procedures and the physician is also held accountable for the ultimate outcome of any treatment initiated by the physician but carried out by others. The power of the patient come from established rights from the Bill of Rights and the 1996 Code of Health and Disability in New Zealand which grants the autonomous patient the right to choose to consent or refuse treatment. However, the rights, authority and positions of nurses are undefined and ambiguous (Engelhardt 1995).

Nursing models of patient-nurse relationships begin with the earliest traditional model of nursing care the '*Surrogate mother*' role, the traditional role that incorporated the belief that nursing was a vocation, not a profession, a belief today's nursing profession is still fighting to change. In this '*surrogate mother*' role the nurse had great influence over the patient and could often persuade a dependent patient to accept a treatment based on what the nurse felt was best for the patient – not significantly different than the much criticized model of paternalism (Smith 1980). The second model is the '*technician*' model, which perceives the nurse as a technician providing knowledge, and skills without moral or value judgments and the patients make their own decisions, again, similar to the physician '*informative model*'. In today's environment of mammoth advances in technologies, diverse but equally effective treatments and information overload, the nursing profession has sought to find effective ways to ensure patient's rights and to promote the well-being of patients within the healthcare system. Authors such as Gadow (1985), Curtin (1986), Johnstone (1995) and Kohnke (1982) have argued around the notion of the nurse playing a role as patient advocate, a role that is very different from what Sally Gadow calls '*consumer advocacy*' or a 'bill of rights brochure' role.

Gadow calls this role '*existential advocacy*' in which the nurse helps patients to "authentically exercise their freedom of self-determination" (1985:45) by being an advocate for them because, Gadow argues, advocacy is the "philosophical foundation and ideal of nursing" (1985:42). I am not sure that this role would not become another semi-paternalistic role because nurses like doctors are acculturated into 'medicalization' and therefore it may be difficult to differentiate their own values and beliefs from what they believe may be right for their patient. Johnstone warns that there is much more philosophical groundwork to be done to make advocacy a credible theory but it may be achieved by developing "sound philosophical arguments for its defence" instead of relying on metaphor or rhetoric. She suggests that a possible solution might be to articulate "advocacy as a coherent and comprehensive *moral* theory; that is, as a *subcategory of moral duty* rather than a distinct and separate concept or theory in its own right....nurses must seriously consider the real moral issues at stake in relation to the difficulties experienced by individuals in their attempt to ensure that their significant moral interests are protected and promoted (Johnstone 1995:287).

Partnership model

Many authors have proclaimed the partnership model as the ideal relationship between healthcare professionals and their patients. Though I like the ideology behind partnership I do not see it as a suitable representation for the relationship within the clinical encounter. Currently, the partnership model is an integral part of the profession of midwifery practice in New Zealand based on the unique partnership that exists between a woman and her midwife articulated by Oakley (1986), Kirkham (1986) and Guilliland & Pairman (1995). The partnership model accepts that "each partner has an acknowledged expertise. The midwife for her midwifery intuition, scientific knowledge and experience, the woman for her intuition, intrinsic wisdom, self-knowledge and experience" (Guilliland & Pairman 1995:44). The concept of partnership is that both members have equal status and involves "trust, shared control and responsibility and shared meaning through mutual understanding" (Guilliland and Pairman 1995:7).

The general criticism of this model is that it is unrealistic without evidence-based research. My criticism is the focus on equal status, which I believe does not exist between a healthcare professional and a patient/client/consumer for all the reasons I have described earlier. However, a collaborative client-centred, decision-making, mutual participation relationship incorporating consensus and the 'feed-back loop' would in my view be a more realistic model. Despite these general criticisms the New Zealand College of Midwives have incorporated the concept of a partnership model in their philosophy and code of ethics stating "Midwifery care takes place in partnership with women" (NZCOM 1993:7) believing that the discourse around partnership

"puts feminist concerns about issues of responsibility, control, empowerment, and choice in health/maternity care at the centre of midwifery's definition of itself as a profession with a 'moral obligation to work in partnership with women'. By redefining the professional-client relationship as one of partnership, in which each partner contributes knowledge and experience, it also embraces feminist criticism of the hierarchical power relations involved in the doctor-patient relationship and consequent devaluing of woman's knowledge" (Tully *et al* 1998:248/9).

The principle of 'partnership' in New Zealand goes back a very long way - back to the Treaty of Waitangi signed in 1840 between the Crown and the indigenous Maori people.

Partnership is an ideology held by the people in the 'powerful' position in order to create the appearance of equality while obscuring the reality of a power imbalance. That is not to say that a conscientious and caring midwife cannot aspire to such an ideology. However, partnership holds too many business connotations for me to consider it as a relationship model within healthcare. There are thousands of definitions of partnership available and most are business orientated ... "a cross-sector alliance in which individuals, groups or organisations agree to work together to fulfil an obligation or undertake a specific task; share the risks as well as the benefits; and review the relationship regularly, revisiting their agreement as necessary" (The Prince of Wales Business Leaders Forum).

Embedded in the ideology of midwifery partnership model is respect for autonomy, which is the essence of informed consent. In a research carried out in 2002/3 Austin found that most Lead Maternity Carers (LMCs) were in a relationship with their women that was based “on a *partial* acceptance of autonomy” (Austin 2003:57, my emphasis). She identified threads of paternalism and the use of the language of risk to convince women to have an intervention – she did indicate that this was mainly obstetricians. Despite “a climate of women centeredness and decision making in partnership within the health field this was not always reflected”.. in the study (Austin 2003:56). Austin observed that midwives confronted with elements of paternalism in their interaction with women felt that it was acceptable for them to be paternalistic but did not condone such actions by doctors.

Partnership may be an idealistic and exciting model but is highly problematic when considered from a hospital midwife’s point of view, whose work is fairly rigidly defined by protocols and policies in an attempt to run an efficient and safe facility for women to give birth and for LMCs to bring their women to give birth. I have never seen what I would consider to be a true partnership in obstetrics, neither have any of my colleagues when questioned on the issue. I think that if the concept of partnership could exist within the clinical encounter then midwifery would be where it would be most likely to exist, because there are subtle differences in the dynamics of the relationship between a woman and her LMC and the healthcare professional and a patient. Pregnant women are predominantly well women; they have nine months to become informed about possible outcomes and interventions that may happen during childbirth. There is time to develop a trusting collaborative relationship.

Yet many women come in to hospital to give birth uninformed in numerous areas. As Austin’s study shows 16% of women were unaware of any negative effects of induction of labour, in spite of the fact that it is a medical intervention. Another remarkable finding from Austin’s study was that “managing risk” appeared to “contribute significantly as a motivator for health professionals to obtain informed consent” (Austin 2003:61). A fairly significant number of midwives use hospital facilities for two reasons; one, the majority of women choose to birth in a hospital and two, many midwives prefer to have their

women birth there because of the medical support available there. Though the partnership works partially for some, I see many midwives subtly impose their views on woman during the course of labour – this, of course could be the woman's choice - to abdicate decisions to her midwife. However, the fact that some midwives insist on their women birthing in a hospital facility where the midwife is obliged to follow guidelines for safe practice could negate many of the choices the woman may wish to make.

I also frequently see subtle pressures being applied in the active management of women in labour. Knowledge is still power and it is my observation that many midwives use it and enjoy it more that they will admit. But partnership is a relatively new concept to midwifery so it may take some more time to rid midwifery of the enduring aspects of medicalization.

Can an equal partnership work within healthcare? I believe a close professional relationship does exist between midwife and woman, which Pairman has since articulated as a "professional friendship" (Pairman 1999). Again, the word friendship seems to me to be an inappropriate term to use especially when this relationship often only lasts for the period covering pregnancy, parturition and up to six weeks after birth. I think the relationship within the clinical encounter could be described as a collaborative, decision-making, trustful alliance embracing respect for the autonomous and relational person. To achieve this kind of relationship between the healthcare professional and the patient within the clinical encounter is most difficult within a hospital setting. The GP and his patients usually develop a relationship over many years, the midwife and the pregnant woman have nine months to develop a relationship but within the hospital a healthcare professional has only a specific amount of time to develop a collaborative trusting alliance – this necessitates some efficient and effective communication skills to achieve.

Summary:

Biomedicine became dominant with the advent of Capitalism, which helped to reinforce paternalistic traits and medical hegemony. Bioethics, however, mainly concentrated on what happened within the clinical encounter rather than the growing power of the political, legal and managerial forces within healthcare

institutions. These forces impact greatly on the process of informed consent within the clinical encounter. But despite this specific bioethical concentration, which in my view focuses on theory not on practical issues, there still exists a power imbalance within the clinical encounter. This imbalance of power is created by the expert knowledge of one party and the vulnerability of the other and is further complicated by the growing managerial power within institutional structures. The imbalance of power is maintained by the policies and protocols instigated by the institution. These 'one way to do it' policies & protocols remove many choices for patients attempting to consider informed consent. This is still a form of medicalization. Power is at the macro level, not the micro level.

The clinical encounter is a culturally constructed symbolic process in which both healthcare professional and patient carry out symbolic actions that identify their roles. Both are restricted in their actions by the forces that drive the institution by the subtle oppression of the policies and protocols that specify one right way to do things. Not much autonomy, not many choices. These policies and protocols are in place to protect the patient, but it is easy to make the case that they are in place to protect the institution.

A radical restructure of the relationship within the clinical encounter is needed to ensure informed consent takes place. Paternalism has been the accepted relationship within medicine for many centuries and despite legal frameworks and ethical directives this attitude is extremely hard to change. Many relationship models exist, but in my view the relationship that fits the process of informed consent best is the collaborative model with its central tenet being the respect for the relational and autonomous person. Unfortunately, to achieve this there is need for a paradigm shift away from medicalization and some major changes within institutions. One area that must change is the Eurocentric notion of respect for autonomy which is discussed in the next chapter.

Chapter eight

Our treatment of both older people and children reflects the value we place on independence and autonomy. We do our best to make our children independent from birth. We leave them all alone in rooms with the lights out and tell them, "Go to sleep by yourselves." And the old people we respect most are the ones who will fight for their independence, who would sooner starve to death than ask for help. Margaret Mead (1901–1978), U.S. Anthropologist.

The Many Faces of Autonomy

The ethical principle of respect for an autonomous agent is at the centre of bioethics and ensures that all patients have the right to informed consent. The concept of respect for autonomy was first developed within the Ancient Greek political arena to describe the self-rule or self-government of the Greek city-states. It is a concept surrounded by ambiguity, although there is agreement upon the derivation of the word. It is Greek in origin and derives from two words: *auto*-self and *nomos*-rule. There is general agreement that the concept of autonomy is grounded in the liberal, moral, political and philosophical significance of individual freedom rooted in Immanuel Kant's notion that *persons are always to be treated as ends, never merely as means* (Kant 1972).

Autonomy has many connotations such as rationality, freedom, independence and self-determination (Schermer 2002:ii), but the general concurrence is that autonomy means self-determination, freedom from external constraints and the critical ability to rationalize, form opinions and make decisions. Consequently to respect individual autonomy acknowledges an individual's rights to hold views, make choices and take actions based on personal values and beliefs. A significant consideration for people working within the healthcare system is that respect for autonomy involves respectful *action* as well as a respectful *attitude*.

Several codes of practice within the healthcare professions have incorporated the principle of respect for autonomy within their rules. It is generally accepted as one of the four leading moral principles of bioethics alongside beneficence, non-maleficence and justice, and is commonly agreed to be associated with freedom, privacy, voluntariness, self-determination and independent choice. (Schermer 2002). The moral obligation to respect the autonomous person is "expressed as a principle of respect for autonomy: Autonomy of action should

not be subjected to control by others”, they consider ‘autonomy’ to mean “freedom from external constraint and the presence of critical mental capacities such as understanding, intending, and voluntary decision-making capacity” (Beauchamp & Walters 1999:19).

In 1986 Joe Feinberg described different ways in which the term autonomy might apply to an individual: 1) Autonomy as a *capacity*, the capacity to self-govern depending on the ability to make rational choices. Both the capacity and the condition of self-government is a matter of degrees but one must achieve a minimum level of competence to be able to self-govern. 2) Autonomy as an *actual condition*, to fulfil this, one must have the relevant capacities and the right to govern oneself – the actual condition of autonomy refers to possessions and practice of various virtues which are “united only by family resemblance, and a connection, however far removed, to the generating idea of self-government”, virtues such as self-determination, self-possession, self-legislation, initiative, responsibility for self and individuality. (Feinberg 1986:31). 3) Autonomy as a *character ideal* is shaped by combinations of the previously listed virtues which determine the actual condition of autonomy. “(T)he ideal of the autonomous person is that of an authentic individual whose self-determination is as complete as is consistent with the requirements that he is, of course, a member of a community” (Feinberg 1986:45). 4) Autonomy as a *right* to sovereign authority is the absolute right to govern oneself; the right to choose and act on one’s choice without interference – the right to ‘negative freedom’.

In 1958 Isaiah Berlin distinguished between positive and negative liberty and freedom, ‘negative freedom’ referring to freedom of action and interference from others while ‘positive freedom’ referred to freedom from within – freedom of the will. ‘*Positive freedom*’ focuses on a person’s own capacity to make life choices according to their distinctively held values and goals and is referred to as ‘*autonomy*’. ‘*Negative freedom*’ focuses on a person’s social interaction and the level of interference by others on an individual’s actions and is commonly referred to as ‘*freedom*’. Berlin’s view of ‘negative freedom’ is challenged by many philosophers and ethicists as being unattainable for the majority of people and is similar to the argument put forward earlier in this thesis that most people cannot or do not make decisions alone as it would be almost impossible to live

one's life totally free of external influences. Gerald Dworkin argues the view of 'negative freedom' is incompatible with people's values of "loyalty, objectivity, commitment, benevolence and love" (Dworkin 1988:21), many of the elements that are incorporated within the ethic of care.

Dworkin, argues that autonomy is only one of the foundation values in our lives and depends on; the ability to make independent choices, the accessibility of adequate information and availability of adequate knowledge. From Berlin's 'negative freedom' view, a person who chooses to allow the healthcare professional to make the decision for him/her could never be viewed as autonomous. From Dworkin's view a person can cede decision-making power without losing their autonomous status simply because they have chosen a course of action. "The defining factor is.... freedom to choose even if this choice is to cede..... (one's) own authority" (Donnelly 2002:15). Donnelly describes a study by Carl Schneider, which demonstrates that although many patients want to be kept informed about their medical condition and treatment, many do not want to be the sole decision-maker (Donnelly 2002:16).

If we accept that most individuals are socially and culturally constructed and therefore are still entrenched within the biomedical model, we need to examine the autonomy of an individual from the perspective of a person within a collective environment in which they participate as an individual, not as an independent individual who is not constrained by any political or social forces. The latter would be virtually impossible within the social forces of a hospital environment. Most patients come to hospital accompanied by significant others...family, friends, dependants.....rarely does anyone come alone! I passionately agree with Donnelly that autonomy should be about freedom of choice – no matter what that choice is – rather than intense concentration on independence.

The rhetoric of individualism does not fit every worldview and although respect for autonomy is paramount there is a need to recognise that almost all human beings manifest some forms or aspects of interdependence – "as individuals, cultures, societies, and states" (Pellegrino 2001:537). Recent literature indicates a growing concern about the emphasis placed on individuality or personal choice at the expense of cooperative political action.

According to Beauchamp & Childress (1994) respect for autonomy is the acceptance of an individual's unconditional worth and their right to determine their own destiny. However, Scott (1998) reminds us that autonomy is not synonymous with freedom and that freedom of action is neither necessary nor sufficient to achieve autonomy. Autonomy is not a right to lay claim to but rather a quality that a person has (Scott 1998). Gillon (1994) states that respect for autonomy in healthcare has *prima facie* implications requiring consultation and informed consent before any type of treatment. He also states that patient's entitlement to privacy is also a *prima facie* obligation as part of the respect for the individual autonomy an obligation that must be implicit within the clinical encounter. Embedded in respect for autonomy is the notion of detailed two-way communication by which the healthcare professional learns the values, beliefs and wishes of the patient - whether this is to relinquish the responsibility of a decision to family or to the healthcare professional or to make the choice themselves.

Thomas May suggests that the rights granted to us in a liberal society, which are intended to allow individuals to determine their own destiny, by placing autonomy at the centre of any decision-making process "are most important when an individual's values and decisions differ from those of others"... (May 2002:30). This is especially true when two cultures meet within the clinical encounter and values and beliefs of each party are divergent. What is required then is tolerance, acceptance and mutual recognition of differences. Dissimilar values need not be accepted as one's own but the right of any individual to embrace conflicting views must be recognized.

Within Western society, we must come to terms with the different needs and demands, for example those of Jehovah's Witnesses (JW) and non-JW around blood products. Many non-JW healthcare professionals still feel uncomfortable about the medical decisions made by JW but accept it as their autonomous right. The more exposed healthcare professionals are to various cultures the easier it will become for them to accept 'difference' from their own values and beliefs as the autonomous right of all patients. May warns that is vital to develop a 'level playing field' within any clinical encounter but especially when patient and healthcare professional values differ. "Because patients are more

vulnerable and because remaining neutral would likely result...in the provider's values prevailing, it is important to provide mechanisms to protect the standing of the patient's values" (May 2002:116).

Autonomy within the health care system appears becomes even more problematic when examined from the perspective of non-Western cultures, which identify such virtues as collectiveness and interdependence as being fundamental to their existence. The notion of individualism and independence, which is popularised in mainstream bioethical discourse, is foreign to them. This makes the Western view of autonomy challenging for patients from other cultures using Western healthcare system. The impact of cultural variations on different sociocultural groups influences subjective experiences of health and illness and affects the way these patients seek and accept medical diagnosis and treatment. Johnstone (1995) illustrates this moral dilemma by recounting a case history of an elderly Greek man who spoke no English and before admission to an Australian hospital was totally dependent on and cared for by his family. Following investigations he was diagnosed with cancer of the lung. His physician, immersed in the Western bioethical discourse of respect for individual autonomy, independence and the right to information, told the patient his diagnosis. The physician did not consider that this man's Greek culture determined that it was his family that should have been given the information. Although the physician was well intentioned his actions were culturally inappropriate and caused undue suffering to the patient and his family.

Johnstone states that from a cultural perspective the actions of the physician could be seen to be morally harmful and quotes from a previous work with co-author Kanitsaki (1991) "during a health crisis patients... who are of a traditional ... cultural background, tend to prefer 'the close involvement of their family and value the supportive, protective and therapeutic role that the family can and does play when one of its members is ill..... Indeed the involvement of the patient's family is an essential and integral part of the therapeutic relationship and of the process required to uphold the patient's best interests'" (Johnstone 1995:148).

My own experience working in the Middle East confirms family involvement in all healthcare decisions, in fact sometimes Arab women did not have any say at

all in treatment chosen by the family. This was frustratingly foreign to me but I elicited from many of my patients that this was how they wanted it and they would feel uncomfortable if it were any other way. Also when a person was ill in hospital they were very rarely left alone being almost always surrounded by family members.

Despite the fact that New Zealand has been a bicultural society for over 150 years with two very different cultures living together, and despite the fact that the Maori people place strong emphasis on interdependence, collectiveness, and whanau (family), the legal framework for informed consent in New Zealand is based on the Western view of autonomy. This is also despite the fact that the Treaty of Waitangi signed in 1840 was rooted in the concept of partnership between the indigenous Maori and the British Crown who colonized New Zealand. The last ten years have seen this bicultural society of New Zealand fast becoming a multicultural society as a high number of Asian ethnic groups enter the healthcare system. Many of these cultures have vastly different values and beliefs, so there is a need for healthcare professionals to ascertain the moral-viewpoint of the 'other'.

Johnstone recounts a story of a young pharmacist, a first generation Australian-Italian man whose father, an Australian immigrant of forty years, had been told by his physician he had cancer. This young pharmacist went to extraordinary lengths to have a second set of tests carried out on his father so he could fabricate them and let his father believe that there had been a terrible mistake with the first results. The son said when his father received the news "the life just went out of his eyes and we knew he would die very soon". Following the revised results, the father was taken home, cared for by family and lived way beyond the time limit given from his poor prognosis (Johnstone 1995:150).

Peter Kasenene (1994) states that in Africa the ability to act and think independently is limited by the cultural emphasis on communalism because African communities tend to "emphasize interdependence and an individual's obligation to the community. An individual, who disregards the family or the community and does what he or she thinks to be right, is regarded as anti-social. Thus, excessive individual autonomy is regarded as being a denial of one's corporate existence" (Kasenene 1994:187). He is quick to point out that a

person is still a unique individual but must learn to strike a balance between independence and conformity. He also points out that African societies practice a 'high degree of paternalism' because despite the fact that individual autonomy is respected, this is only the case as long as the individual's actions do not harm others or interfere with their rights, if they do then the community move to restrict the free actions of the individual for their own good. Within a community existence what is harmful to the individual is regarded as harmful to the community thus "paternalistic intervention is justified on the grounds that the experience and knowledge of the elders should benefit the younger or less wise members of the community who might not understand the implications of their decisions or actions. Thus the communalistic value of mutual responsibility and caring often leads to paternalism" (Kanenene 1994:188).

A shared value that all cultures could appeal to is one based on the validity of differences... the reality that no one individual belongs to a totally unified homogenous group. Though individuals share the same social group, their experiences and relationships can be very different, they are unique individuals which are impacted on by different factors such as age, marital status, work status, sexual preferences, hereditary traits, health and wealth to name but a few. Perhaps healthcare professionals should reject the notion of universalism and put emphasis on differences within collectiveness.

Feminists also embrace values of interdependence with family, caring and connectedness, at odds with the historic Western view of autonomy. They question the independence and isolation implicit in autonomy and believe it could only be appropriate for relationships between strangers or professional relationships (Cook 1994). Susan Sherwin is sceptical about the dominance given to autonomy believing that "ethical models based on the image of historical, self-sufficient, atom-like individuals are simply not credible to most women...most women experience the world as a complex web of interdependent relationships, where responsible caring for others is implicit in their moral lives. The abstract reasoning of morality on the rights of independent agents is inadequate for the moral reality in which they live"(Sherwin 1992:47). Sherwin also states theories that give dominance to the concept of autonomy rather than empowering people serve "to protect the

privileges of the most powerful” and sacrificing “the necessary prerequisites for autonomy for others” (Sherwin 1996:53). She believes that individual autonomy cannot be reconciled with needs of the community. Other feminist bioethicists stress the importance of woman's autonomous choice when it comes to making decisions about their own bodies moving away from societies control over women's reproductive capacities (Tong 1997). However, Koehn sees it as ironic that “female ethics criticize traditional ethics' emphasis on autonomy,” when “they themselves treat the self as remarkably free of any political or institutional influence. By equating private and intimate human relations with the political realm, these ethics overlook the role of institutions in these relationships”(Koehn 1998:141). For Koehn the central tenet for feminist ethics is connectedness with people rather than individuality.

It is vital to any clinical encounter that the values, beliefs and individual cultural ethics of the patient are known and considered and any decision-making or discussion is a cooperative effort. It is about accepting the 'other' as different and unique, not inferior or worthless. Because healthcare services embrace a diversity of cultures then healthcare professionals need to embrace a diversity of moral beliefs and values. They do not have to take them on as their own values, simply to be open to the reality of their existence and accept that they have as much value for the 'other' as the healthcare professionals set of moral values and beliefs have for the professional.

Respect for autonomy in my view means respect for a person's actions (their choice, no matter what that choice may be) and a person's attitude (their beliefs, values, and cultural embodiment). For me this encompasses many of the central, cross cultural, feminist and ethic of care values which are: collectiveness, interdependence, community, close family involvement, caring, empathy and connectiveness. Current literature is signalling a slowly changing attitude from a very dominant individualist approach to incorporating some of these values. But we do not want to remove autonomy, because it is a rights based autonomy, one we fought too hard to get. Rather it should be only one of the foundation values alongside most people's values of “loyalty, objectivity, commitment, benevolence and love” (Dworkin 1988:21).

Summary:

According to Maartje Schermer, there are many different faces of autonomy (Schermer 2002). It is not a single unequivocal concept, it is associated with the rights approach of being able to choose for oneself, to have freedom and to enjoy privacy. Some ethicists view autonomy as the 'be all and end all' of ethics; others believe it has been given far too much credence. I believe that the emphasis on the Western view of autonomy within the clinical encounter has obscured the values that are of significant importance to many users of health care, values that are implicit in feminism, ethnic groups and the ethic of care. As I have already said, too many lives were lost winning us our freedom and rights so we do not want to lose respect for autonomy. But it should be just one of the many values that inform the concept of informed consent and not its single defining factor.

Conclusion:

In July 2003 I heard an interview on national radio with Euphemia McGoogan, a visiting Scottish pathologist, who said “New Zealanders are obsessed with privacy and informed consent”. Almost certainly this is a legacy of the ‘unfortunate experiment’ at National Women’s Hospital where both were totally ignored. Worldwide trends towards respect for individual rights also made a significant contribution. New Zealand was innovative in its approach to the ideology of informed consent and is viewed worldwide as having an advanced legal framework for informed consent because of its patient-centred focus (Donnelly 2002, Thomas 2000, Skegg 1999). *But* in the real world of everyday healthcare do we have informed consent or merely signed consent?

I believe informed consent works only partially in its present form. “Like democracy, informed consent is seldom an efficient process but that shouldn’t mean we toss it aside” (Fountain 2003). Instead we need to analyse the flaws in the current situation and endeavour to modify or alter them to create an invaluable tool with which healthcare professionals and patients can develop a collaborative relationship within the clinical encounter and ensure that the ‘relational and rational autonomy’ of each patient is respected.

At present the nascent concept of informed consent is universally fraught with misunderstanding and confusion. Healthcare professionals still equate it with a ‘signed’ consent form while patients are only beginning to grasp some of the subtleties of the rights conferred on them by the Health & Disability Code of New Zealand. The New Zealand legal framework was created for all the right reasons, but unfortunately it fails to meet the needs of the actual people it was intended to benefit.

New Zealand’s legislative framework of informed consent differs significantly from all other countries because of several precise emphases. It is patient-centred, it places emphasis on information, and it uses the term *informed choice* rather than informed consent. The use of ‘*choice*’ rather than ‘consent’ implies a patient’s right to make a choice before consenting or refusing, implying a right to choose between alternatives. *Informed choice* must become culturally

embedded in the system in order to change the focus from consent forms to informed choice.

The New Zealand framework gives comprehensive guidance on how patient autonomy can be effectively implemented. The major aims of the combined Code of Health & Disability Services Consumers' Rights and the Health & Disability Act, are prevention and reconciliation. Ultimately the application of the Code depends on how effectively communication skills are used within the clinical encounter. Unfortunately, communication skills cannot be legislated, and since good communication is essential to ensure that the clinical encounter works, and since healthcare professionals are notoriously poor communicators, the laws on informed consent have not changed the process of the clinical encounter.

A major ongoing problem with the Code is the emphasis placed on the patients right to be 'fully informed' (Right 6). If patients were fully informed they would presumably be as informed as the healthcare professional treating them, a state that could rarely, if ever, be achieved. This makes the information part of the concept an impossible task and I believe the cause of informed consent and informed choice would be greatly assisted if the Code could substitute the word 'substantially' for 'fully'.

In Western societies the principle of autonomy is central to informed consent. However, this is not a universally applicable concept because much of the world does not share the Western emphasis on rationality and independence. Proponents of the 'ethics of care', including many feminist philosophers, break with the Western tradition that reason and rationality are morally superior to care, collectiveness and interdependence, thereby introducing a middle ground where the concept of respect for autonomy incorporates the fact that all individuals are "inextricably linked to other selves" (Tong 1997:94).

An ethical framework or morality that included elements of the ethics of care and cross-cultural ethics would help balance the complexities of the relationships within the clinical encounter so that both reason and feeling could be freely exhibited. As Pellegrino(2001) points out, the rhetoric of individualism does not fit with every world view, not even with every individual view within

Western society, because almost all humans demonstrate some aspects of interdependence within their environment.

One has to question the implication of the current individualist concept of autonomy within the clinical setting and consider its limitations. One also has to question emphasis on the individual to the disadvantage of the community in which the individual lives. Pellegrino answers these questions by suggesting a 'metaethic' that transcends all boundaries and cultures, a fundamental metaethic grounded in "the deference owed to all human beings qua human beings" (Pellegrino 2001:194).

Milburn (2001) writing about Australian law raises a universal point. She believes the clinical encounter is a power struggle maintained by the law, a conscious strategy to maintain the power and privilege of the medical profession. Milburn sees the law as protecting the medical profession and believes it is a dangerous illusion to presume healthcare professionals are "untouched by flaws inherent in human nature" (Milburn 2001:57). The fact that for 2000 years power has mostly been in the hands of the physicians makes it unlikely they will relinquish it without significant resistance.

Medical authoritarianism creates a power imbalance within the clinical encounter. Historically, and currently, healthcare professionals, especially doctors, struggle with the notion of complaints, regarding them as a direct threat, becoming defensive and attempting to lay blame with the patient rather than using complaints as an opportunity to evaluate and improve their role within the clinical encounter (Moynihan in Milburn 2001). Though many complaints emerge through the Health & Disability Commissioner Office I believe it reasonable to assume that many more are not being instigated because the general public are not adequately informed about their rights within the Code – another limitation within the present system. Fewer than 900 complaints in one year seems a small amount when one considers the number of people accessing the New Zealand healthcare system, so could nationwide education about individual rights within the Code occur?

There are limited resources for public education and Paterson believes that resources are best used to "target providers to effect change" (Paterson 2003:pc). This entails convincing health providers and healthcare professionals

that informed consent is truly worth the effort and means far more than a signature on a consent sheet. Both healthcare professionals and patients must understand that written consent is *not* confirmation that informed consent has taken place.

Some healthcare professional still view the concept of informed consent as an information session, but the disclosure of all consequences of treatment does not, in itself, ensure informed consent. The patient needs to be seen as an autonomous agent who makes choices 'intentionally', 'without coercion' and with 'substantial understanding' to authorize the healthcare professional to carry out treatment. A survey published in the *President's Commission* in Washington USA in 1982 demonstrated a common conviction amongst healthcare professionals that informed consent is the giving of information and the obtaining of consent. Implicit in that mindset is the culture of paternalism and the culture of decision making that has long existed within medicine.

One of the crucial elements ignored in the day to day routine of informed consent is the 'understanding' component. Both disclosure and the understanding of information are equally important to ensure the substantial autonomous action of choice. Though the New Zealand code does not ask that the healthcare professional ensure understanding it does ask that the mode of communication enables understanding. Healthcare professionals are required "to facilitate understanding, but cannot be expected to guarantee patient understanding, and the law makes no such requirement" (Paterson 2003:2).

As with many relationship issues in life communication is the *key*. It is most definitely the key to a collaborative relationship within the clinical encounter so that true informed consent occurs. Alas, communication is not the strong point of either the healthcare professional or the patient, making the process of informed consent a challenging task. To make the process work each party must take responsibility for effective communication. But because of the information asymmetry between the two parties, far more input is needed from the healthcare professional. A shared language does not necessarily mean communication at any level. There is a critical need to educate both public and healthcare professionals in communication skills. Results have clearly shown

that communication workshops improve interaction with the clinical encounter (O'Brien 2003).

Other communication skills are equally important, those of listening, caring, trusting and respecting. "Trust is a vital element...and for trust to exist.." both healthcare professionals and patients...." Must believe that the other party is honest and willing to provide all necessary information..(Medical Council of New Zealand, 2002). The notion that the burden of communication lies with the healthcare professional needs to be altered. As Paterson says, "it takes two to tango" (Paterson 2003:2), however, healthcare professionals need to be cognisant of the numerous ways to misinform (Vogt 2002).

The nature of the relationship within the clinical encounter has had many labels and emphases, one of the most common models referred to is 'partnership'. However, I believe that implicit in the notion of partnership is equality of power, which in my view does not and cannot exist within the clinical encounter for several reasons:

- Patients enter into the relationship because they are ill and need to consult a doctor – power imbalance of health and illness. Being ill generates a state of dependence on both knowledge and competence (Starr 1982)
- Patients enter into the relationship in search of a diagnosis and with the expectation of the disclosure of relevant information to enable choices for treatment – a power imbalance of knowledge.
- Patients may need specific treatment, which is only available at hospital, they have no choice but to enter this 'partial' institution – power imbalance of structure and agency.

A collaborative patient-centred relationship, in which the patient's 'unique' knowledge, and 'unique' views on life are as important to the outcome as the healthcare professional's knowledge, offers a sensible practical model for the clinical encounter. The nurse, the 'in-between' person (Engelhardt 1985), has a vital role to play within the clinical encounter in the mode of Gadow's '*existential advocate*', an advocacy role based on knowledge and experience which enables the nurse as a healthcare professional to help patients exercise their right to self-determination. However, as Austin (2003) found in her research,

midwives, like nurses in an essentially female profession, can unconsciously adopt the paternalism they resent in the medical profession.

Within the clinical encounter in the last ten years there has been a paradigm shift from the healthcare worker as decision maker to the patient as decision maker. But there are still strong elements of medical authoritarianism within the healthcare structure. These elements are reinforced by the phenomenon of medical hegemony (Baer 1997) by which patients feel the need to conform to expert judgment. Walsh defines structure as a "recurring pattern of behaviour (that) has a constraining effect" (Walsh 1998:33) which explains why structures like hospitals tend to impact on freedom of choice despite the fact that the Western worldview is firmly fixed on freedom of choice and respect for autonomy (Walsh 1998). Biomedicine greatly influences hospital protocols and policies that tend to focus on a single course of right action leaving little room for deviation. This makes hospitals symbols of social power and areas of constraint that enact and reaffirm medical knowledge.

Despite the discussion and disagreement around the concept of autonomy within Western philosophy, and especially within its more recent role in medicine, it is exceedingly problematic when viewed from a non-Western perspective of collectiveness and interdependence. Nor does the Western view concur with many feminist bioethicists and moral philosophers who also embrace family values, interdependence, connectedness and caring. Sherwin (1992) states that many Western moral theories empower the already powerful and disempower the less powerful. The Western focus on rationality as the major influence on human behaviour tends to overlook the personal beliefs and values of the individual who is making the choice. Autonomy needs to be about choices, the freedom to choose whether you are an independent individual or an interdependent individual. There is not one individual that belongs to a unified homogenous group,

I work with informed consent, I like it, I think it is a good workable concept whose application is failing as it becomes downgraded to the level of a routine bureaucratic procedure – that of getting a signature on a consent form.

Concepts evolve and I do not believe there is ever an endpoint. Democracy has been evolving for millennia but even among nations we would consider

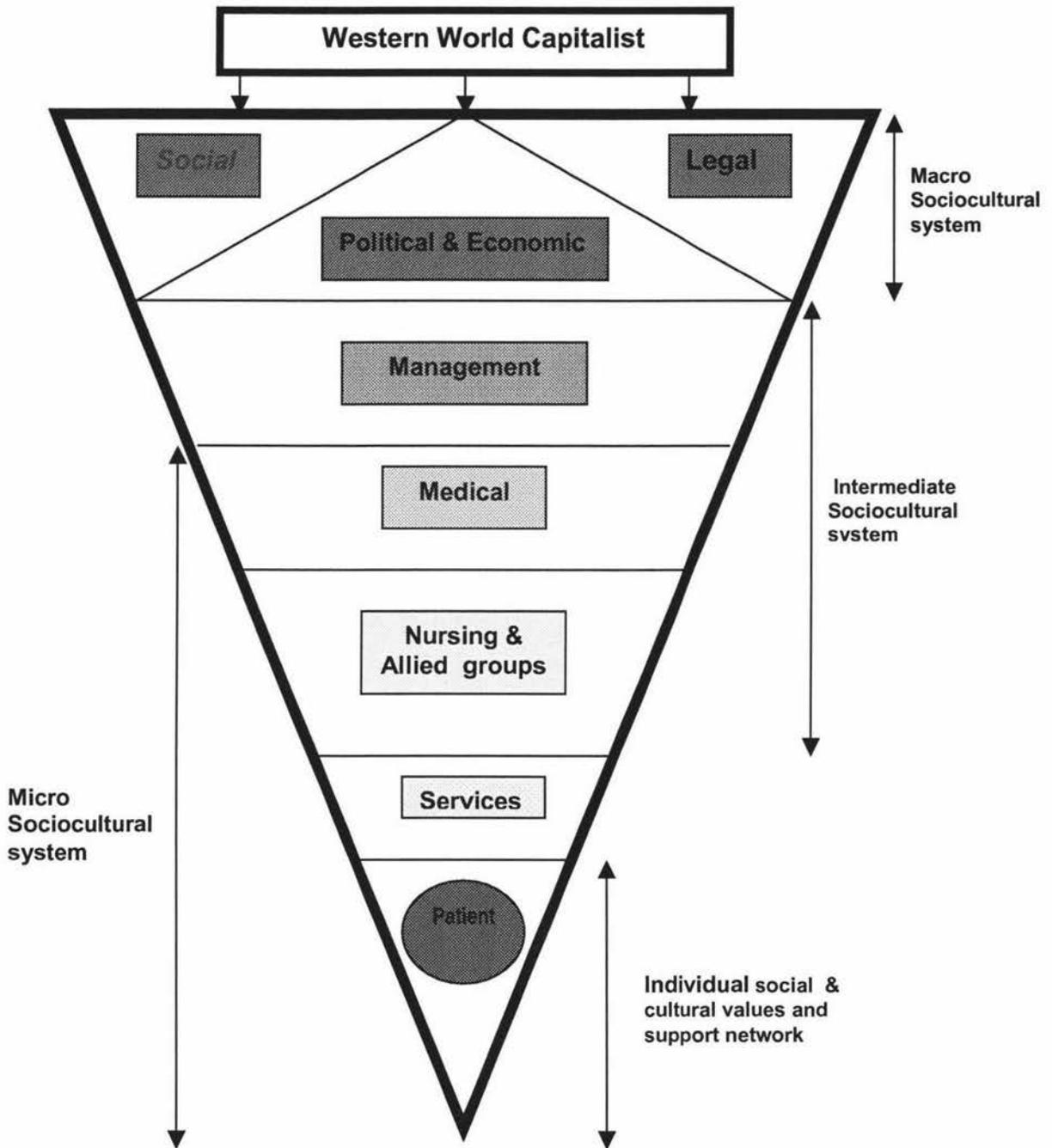
democratic it has different expressions. New Zealand used to be 'first past the post', now we have MMP. Both are expressions of the democratic urge and it would be foolish to declare that MMP was the final achievement and the nation will still be using it in fifty or a hundred years.

I have the same attitude towards informed consent. The concept promised a new relationship between providers and recipients, which is the same as saying, between those with power and those without it in the health system. The concept advanced the cause of a new paradigm of power, but it did not guarantee it, and it is in danger of becoming an idea embedded in the establishment to ultimately strengthen the establishment.

As New Zealand health professionals we must ask what are the strengths and weaknesses of informed consent? I believe the strengths are emphasis on choice, information, disclosure and patient centeredness. I believe the weaknesses are the emphasis on consent instead of choice within the clinical area, the requirement to be 'fully informed', the dependence on communication without the education to ensure efficient communication between both parties and the public's lack of knowledge of their rights within the Code.

Which raises the question of what we can do next to redefine informed consent in the spirit in which it was developed. Informed choice needs to be the 'buzz word' not informed consent thereby removing the emphasis from consent to choice. 'Fully' informed must change to 'substantially' informed and healthcare professionals and providers must be convinced that informed consent is not a gambit to prevent litigation but a valid exercise to right the power imbalance within the clinical encounter. We need to convince healthcare recipients that they need comprehensible information, not power for its own sake. We need to reconstruct the concept of autonomy to incorporate a 'metaethic'. We need to convince government to reconsider their legislation because in the light of current experience, they have to accept that their informed consent legislation did not spring full grown and fully armed like Athena from the forehead of Zeus but must be reconsidered to remain living and meaningful legislation.

Impact of Macro-Social System on structure of power relations within an institution



Macro-social level: Capitalism, Western World View, Political, Economic and Legal Systems all shape and reproduce the structures of power relations (Bae *et al* 1997)

Intermediate-social level: Institutions within which clinical encounters occur, most of the power is entrenched in management, though it is a delegated power from the Macro-social level. Physicians exert a great deal of control but, also subject to hospital bureaucratic constraints. Nurses and nurse managers are constrained by the uneven power relations between them and the physicians and also by bureaucratic constraints

Micro-social level: The clinical encounter occurs at this level as does gate keeping and medicalization of illness and social distress. The relationship that occurs within this encounter is impacted upon by social factors outside and inside the hospital, which, in turn, have shaped the policies and protocols that dictate the relationship of the encounter.

Individual level: All that impacts on the patient – illness, pain, social distress, hospitalization, political and economic forces. (Baer *et al* 1997:25- 33)

Appendix 2

Table of Cases:

Bolam v Friern Barnet Hospital Management Committee [1957] 1 WLR 582

Canterbury v Spence (1972) 464 F (2nd) 772

F V R (1983) 33 SASR 189

Green v Matheson [1989] 3 NZLR 564

Reibl v Hughes [1980] 2 SCR 880, (1981) 114 DLR (3rd)1

Rogers v Whitaker (1992) 175 CLR 479

Sidaway v Board of Governors of Bethlem Hospital [1985] 1 A11 ER 643,
(1985) AC 871,

Wakefield, Re (Medical Practitioners Disciplinary Tribunal), 85-99-42D, 6 October
1999, Cartwright PJ, Chair)

Appendix 3

The Code of Rights

The Code of Health and Disability Services Consumers' Rights became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act. It confers a number of rights on all consumers of health and disability services in New Zealand and places corresponding obligations on providers of those services.

Application of the Code is very wide and extends to any person or organisation providing, or holding themselves out as providing, a health service to the public or a section of the public, whether that service is paid for or not. With regard to disability services, it extends to goods, services and facilities provided to people with disabilities for their care or support or to promote their independence, or for related or incidental purposes. Unlike health services, disability services do not have to be provided to the public in order to be covered by this legislation.

The Code therefore covers all registered health professionals, such as doctors, nurses, dentists, etc, and in addition brings a level of accountability to all those who might be considered outside the mainstream of medical practice, e.g. naturopaths, homeopaths, acupuncturists etc. As well as applying to individual providers, the Code also applies to hospitals and other health and disability institutions and allows the Commissioner to enquire into systems issues across professional boundaries. It does not extend to purchasing decisions or confer entitlement to any particular service.

The obligation under the Code is to take *"reasonable actions in the circumstances to give effect to the rights, and comply with the duties"* in the Code. The onus is on providers to show that such action has been taken. The Code does not override other legislation, and nothing in the Code requires providers to act in breach of a duty or obligation imposed by any enactment, or prevents a provider doing an act authorised by another enactment.

Read a summary of The Code of Health and Disability Services Consumers' Rights in different languages:

Amharic, Arabic, Burmese, Chinese, Cook Island, English/Maori, Khmer, Korean, Niuean, Samoan and Tongan

The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulation 1996

Clause 1

This establishes the duties and obligations of providers to comply with the Code, to ensure they promote awareness of it to consumers and enable consumers to exercise their rights

Clause 2

This details the ten rights of consumers and the duties of providers.

Right 1: the right to be treated with respect

Right 2: the right to freedom from discrimination, coercion, harassment, and exploitation

Right 3: the right to dignity and independence

Right 4: the right to services of an appropriate standard

Right 5: the right to effective communication

Right 6: the right to be fully informed

Right 7: the right to make an informed choice and give informed consent

Right 8: the right to support

Right 9: rights in respect of teaching or research

Right 10: the right to complain

Clause 3

Sets out provider compliance requirements and states that where the rights cannot be met then the onus is on the provider to show that it was reasonable in the circumstances not to have done so.

This reasonableness test will be applied and developed over time.& It is expected that over time, greater compliance will be demanded of providers.& This clause gives some flexibility in terms of a gradual implementation of these rights.

Clause 4

Establishes certain definitions where these are appropriate and elaborates on some of the definitions in the Act.

Clause 5

Notes that in meeting the rights no provider is required to break any other New Zealand law.

Clause 6

Ensures that all existing rights outside of the regulation still apply.

The Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulation 1996

1. Consumers have Rights and Providers have Duties:

- 1) Every consumer has the rights in this Code.
- 2) Every provider is subject to the duties in this Code.
- 3) Every provider must take action to -
 - a) Inform consumers of their rights; and
 - b) Enable consumers to exercise their rights.

2. Rights of Consumers and Duties of Providers:

The rights of consumers and the duties of providers under this Code are as follows:

Right 1: Right to be treated with respect

- 1) Every consumer has the right to be treated with respect.
- 2) Every consumer has the right to have his or her privacy respected.
- 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 3: Right to Dignity and Independence

Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual

Right 4: Right to Services of an Appropriate Standard

- 1) Every consumer has the right to have services provided with reasonable care

and skill.

- 2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.
- 3) Every consumer has the right to have services provided in a manner consistent with his or her needs.
- 4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.
- 5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

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.
- 2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

Right 6: Right to be Fully Informed

- 1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
 - a) An explanation of his or her condition; and
 - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
 - c) Advice of the estimated time within which the services will be provided; and
 - d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
 - e) Any other information required by legal, professional, ethical, and other relevant standards; and
 - f) The results of tests; and
 - g) The results of procedures.
- 2) Before making a choice or giving consent, every consumer has the right to

the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.

- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about -
 - a) The identity and qualifications of the provider; and
 - b) The recommendation of the provider; and
 - c) How to obtain an opinion from another provider; and
 - d) The results of research.
- 4) Every consumer has the right to receive, on request, a written summary of information provided.

Right 7: Right to Make an Informed Choice and Give Informed Consent

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
 - a) It is in the best interests of the consumer; and
 - b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - c) Either, -
 - i) If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - ii) If the consumer's views have not been ascertained, the provider

takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

- 5) Every consumer may use an advance directive in accordance with the common law.
- 6) Where informed consent to a health care procedure is required, it must be in writing if -
 - a) The consumer is to participate in any research; or
 - b) The procedure is experimental; or
 - c) The consumer will be under general anaesthetic; or
 - d) There is a significant risk of adverse effects on the consumer.
- 7) Every consumer has the right to refuse services and to withdraw consent to services.
- 8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
- 9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
- 10) Any body parts or bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer.

Right 8: Right to Support

Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.

Right 9: Rights in Respect of Teaching or Research

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

Right 10: Right to Complain

- 1) Every consumer has the right to complain about a provider in any form appropriate to the consumer.
- 2) Every consumer may make a complaint to -

- a) The individual or individuals who provided the services complained of; and
 - b) Any person authorised to receive complaints about that provider; and
 - c) Any other appropriate person, including -
 - i) An independent advocate provided under the Health and Disability Commissioner Act 1994; and
 - ii. The Health and Disability Commissioner.
- 3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
- 4) Every provider must inform a consumer about progress on the consumer's complaint at intervals of not more than 1 month.
- 5) Every provider must comply with all the other relevant rights in this Code when dealing with complaints.
- 6) Every provider, unless an employee of a provider, must have a complaints procedure that ensures that -
- a) The complaint is acknowledged in writing within 5 working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period; and
 - b) The consumer is informed of any relevant internal and external complaints procedures, including the availability of -
 - i) Independent advocates provided under the Health and Disability Commissioner Act 1994; and
 - ii) The Health and Disability Commissioner; and
 - c) The consumer's complaint and the actions of the provider regarding that complaint are documented; and
 - d) The consumer receives all information held by the provider that is or may be relevant to the complaint.
- 7) Within 10 working days of giving written acknowledgement of a complaint, the provider must, -
- a) Decide whether the provider -
 - i) Accepts that the complaint is justified; or
 - ii) Does not accept that the complaint is justified; or
 - b) If it decides that more time is needed to investigate the complaint, -

- i) Determine how much additional time is needed; and
 - ii) If that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.
- 8) As soon as practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of -
- a) The reasons for the decision; and
 - b) Any actions the provider proposes to take; and
 - c) Any appeal procedure the provider has in place.

3. Provider Compliance

A provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code.

The onus is on the provider to prove it took reasonable actions.

For the purposes of this clause, "the circumstances" means all the relevant circumstances, including the consumer's clinical circumstances and the provider's resource constraints.

4. Definitions

In this Code,

"Advance directive" means a written or oral directive-

- (a) By which a consumer makes a choice about a possible future health care procedure; and
- (b) That is intended to be effective only when he or she is not competent:

"Choice" means a decision-

- (a) To receive services:
- (b) To refuse services:
- (c) To withdraw consent to services:

"Consumer" means a health consumer or a disability services consumer; and, for the purposes of rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer:

"Discrimination" means discrimination that is unlawful by virtue of Part II of the Human Rights Act 1993:

"Duties" includes duties and obligations corresponding to the rights in this Code

"Exploitation" includes any abuse of a position of trust, breach of a fiduciary duty, or exercise of undue influence.

"Optimise the quality of life" means to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances:

"Privacy" means all matters of privacy in respect of the consumer, other than matters of privacy that may be the subject of a complaint under Part VII or Part VIII of the Privacy Act 1993 or matters to which Part X of that Act relates:

"Provider" means a health care provider or disability services provider:

"Research" means health research or disability research:

"Rights" includes rights corresponding to the duties in this Code:

"Services" means health services, or disability services, or both; and includes health care procedures:

"Teaching" includes training of providers.

5. Other Enactments

Nothing in this Code shall require a provider to act in breach of any duty or obligation imposed by any enactment or prevents a provider doing an act authorised by any enactment.

6. Other Rights

An existing right is not overridden or restricted simply because the right is not included in this Code or is included only in part.

Appendix 4

Legal terms

Common law: originated in England in the feudal era. The complainant's clan challenged the wrongdoer and vengeance was extracted from the wrongdoer or his/her family. Feudal lords maintained law and order because of the enormous powers they possessed as landlords. Each lord could hold court for his tenants to settle any disputes. The act of wrongdoing causing physical harm or damage to property was an act against the law of "wrongs" or law of "torts" as it is still called today (Johnson 2000). This acceptance of authority whether it is a rule, a standard or behaviour, is the basic principle of today's law of acceptance of each level of authority within the court system. Each court is "bound by legal principles established by Courts with higher standing than its own" (Jonson 2000:8)

Tort: is a civil wrong committed against another person or property.

Intentional tort: A wrong committed with intent and knowledge that harm would result.

Trespass as a tort: To invade the property, rights or person of another without consent and with the intention, implied or actual of committing a violent act is an actionable wrong at law and can be tried under the law of trespass. This has been a law under common law for several hundred years. Any medical procedure or research on a person without their consent would be a trespass. Assault & battery are two different types of intentional torts or trespass.

Assault: An assault is a deliberate threat to a person to do them physical harm combined with the ability to do such harm.

Battery: An intentional touching of a person against their will or harming them without consent. Battery can occur even when the intention is good. *Mohr v Williams* 104 NW (1905) A surgeon operating on the right ear of a woman who is under anaesthesia, discovers the left ear was more seriously damaged, so following consultation with the woman's GP, who was present at the operation, he made a decision to go ahead with the operation on the other ear. The court ruled that the operation on the woman's left ear was battery.

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