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

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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).