

## Chapter II

# Women's Health Informatics: The Ethical and Legal Issues

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### ABSTRACT

*Principlism (derived from common sense morality) is the most common theory used within the health-care sphere. The elements of this theory are explored and discussed in context. A theoretical woman presenting in pregnancy is used to identify issues which can arise and explore the potential conflicts. In the second half of the chapter, health informatics and the law are discussed. Issues such as consent, confidentiality, privacy, and human rights are discussed in general. Legislation in the United Kingdom, United States, Canada, Australia, and New Zealand are discussed in detail.*

### INTRODUCTION

The increasing sophistication of health informatics has brought significant benefits to women's health but the increasing storage and use of confidential data has brought new ethical dilemmas. On first glance it seems unlikely that data can have a moral dimension but the way that data is collected, stored and used does. Fundamental questions like: "Do patients need to know that we are collecting data about them?", "Who does the data belong to?" and "Who decides to what uses we can put that

data?" all need to be addressed. Information and information technology are central to the overall goal of healthcare- to promote health, but the information we use has significant medical, personal, and social implications for our patients and therefore we must find a moral justification for collecting storing and using it.

We start with a sentence or two about rights because they are the currency of the day. We then follow with a brief introduction to a number of important theories of ethics and a description of an approach to medical ethics called

'Principlism'(Beauchamp & Childress, 2001) which we will use to analyse the kind of ethical dilemmas which may arise in the area of health informatics and women's health. You will not find absolute answers to all the questions you might have – that is not the nature of ethics. But this chapter should provide you with an understanding of the basic principles of medical ethics and how they can be used to help you find the best answer.

The law in each country is different and therefore this chapter cannot hope to cover all aspects relevant to all readers. However the major case law and statute law within the Common Law Jurisdictions of the UK, USA, Canada and Australia will be covered as well as the European Convention on Human Rights.

## **HUMAN RIGHTS AND HEALTHCARE**

Man lives in society and therefore must live by rules established for the good of society. To protect individuals within society they are entitled to certain rights. Rights usually entail reciprocal obligations from the State.

A number of rights have been declared universal human rights by the United Nations, in Europe they appear in statute as The Human Rights Act. Generally these rights are negative i.e. rights of non interference e.g., Article 2 the right to life. Article 2 does not establish a right to limitless health resources to prolong life but does establish that every human being has a right not to be killed (unless sanctioned by the law of the country).

The problem is that more and more often individuals couch their rights in a positive way – to demand action from the State. Such rights only have moral force if the reciprocal moral obligation on the State also has moral force. An individual cannot claim a positive right unless every other member of society is also entitled to the same

right. So an appeal to rights does not always help us establish our obligations as healthcare practitioners. A patient may say "I have a right to know" but that does not necessarily translate into a duty to tell.

The individual who claims rights must also claim his obligations (e.g., to pay his taxes and obey laws). Within the therapeutic relationship the patient has certain moral rights: to be treated fairly and compassionately, but also has reciprocal obligations: to be honest with healthcare providers and not putting others in danger. It can also be argued that being in receipt of healthcare entails an obligation to help advance the science of medicine in order for it to benefit others.

## **MEDICAL ETHICS**

Ethics is the branch of philosophy dealing with morality and medical ethics is that branch of ethics which deals with healthcare. Four of the most influential ethical theories are: deontology (which deals with duties), consequentialism (which deals in outcomes), virtue ethics (which concentrates on moral character) and feminist ethics (which puts all of the above into the context of caring compassion and relationships).

### **Deontology**

Deontology has its roots in the Judaeo-Christian tradition but was given a basis in reason by Immanuel Kant. Kant believed that morality could be explained by one overarching absolute rational principle which he called the 'categorical imperative' (Kant, 1785). Deontologists argue that morality may be completely explained by duty. A duty is a rule to guide action. A simple example would be the duty to always tell the truth. Generally speaking many people would agree that telling the truth is the right thing to do. Yet, it is possible to think of a scenario where telling

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