and somehow lost count. There was a missing tampon. The realisation dawned on me that there was one stuck inside. I had to find a female doctor to remove it as I certainly didn't want to approach a male doctor. She was totally unsympathetic as she couldn't understand why, if I was not menstruating, I was using tampons. She located bits and pieces of it and removed it and then did a pregnancy test. She advised me that I was not pregnant. As a matter of procedure I went to the IVF clinic for the pregnancy blood test and found out the next day that I was indeed very pregnant. As far as I know I was the only one to conceive on that program.

We just couldn't get rid of this feeling of dissatisfaction over the way the whole program was conducted and a short time later we started trying various avenues to get answers from the medical profession with regard to our treatment. Most of the time we were patronised, patted on the head, and told many times over "You've got what you wanted, a pregnancy, so why all the fuss?" In the end we went to a solicitor and we believe, he was so bamboozled by the medical terminology given to him that $1,000 later he advised us that it was useless to proceed.

We went to the Health Services Commissioner.[3] The investigator was unsympathetic. She made an application to the doctors on our behalf but also advised us that it was pointless to proceed. She tried to convince us that simply by the department's interest the doctors would consider they had been reprimanded. As if that was the end of it. I would like to add at this point that I wouldn't want to deter anyone from using the Health Commissioner as a place to lodge complaints. It was just that in our case it wasn't productive.

My husband had a meeting with his surgeon. After being approached by both the solicitor and the Health Commissioner, the surgeon would not see him on his own. He was accompanied by another member of his team and proceeded to try to cajole my husband into both of us becoming promoters of his wonderful new program. I don't need to tell you my husband's reaction to this; we of course refused. At this meeting the surgeon also commented to my husband that the quality of my eggs were very poor. This immediately conjured up in my mind visions of giving birth to a grossly deformed baby. I never really alleviated this fear until after the baby was born.

Eight months later after a very stressful year and a very difficult pregnancy, we had a very beautiful boy. Six months later we nearly lost that very beautiful boy. It appears he was born with a congenital abnormality. He had two stomachs; one which worked, the other growing and subsequently squashing his lungs and heart. He underwent major surgery and thankfully is now thriving. A specialist in the hospital mentioned that this might have occurred as a result of the hormones I was taking during the IVF program. When I questioned him later on this he backed off and claimed that it most probably wasn't the case. We have been advised that we need to keep an eye on our son as there may well be more problems in the future but they have no way of knowing that now. I have, since then, tried to find out the effects of the some of the drugs I was taking on the program and cannot, at this point in time, find any information that would indicate they were responsible. Nor that they weren't. This, for us, was just another blow.

Many people have asked us why, when we have a child from the program we are still dissatisfied and angry. Why don't we just thank our lucky stars that we got the baby we wanted? That we both recovered from the surgery, that there was no apparent permanent damage to any of us?

We're angry at being taken for fools; we had not consented to the injection of sperm into my tubes nor my husband's reversal. We're angry at having been treated in such an undignified manner, at the belief that we don't need our questions answered, that we don't need to know. By all accounts the literature on the program was rosy. So many of their claims were, in fact, untruths. We believed we went into it informed, rational, and calm. We came out of it confused, irrational, and angry, and

yet ultimately we got what we wanted. But that doesn't excuse the treatment. The unempowering of the process of achieving the end goal, of the means justifying the end, doesn't excuse the condescending attitude that we should be grateful. I don't know how to make these people realise they are dealing with real people, with real feelings, not just eggs and follicles, charts and numbers.

There has been absolutely no follow-up from the doctors who had initially treated us as so special. No congratulations on our new baby, no "we want to help iron out these problems and make it better." Nothing. And so it seems we really weren't so special after all.

END NOTES

1. The "Information Night" was a meeting of all participants in the program. The 20 couples who would enter the program, the surgeons, gynaecologist, the radiographers, the biologists, and the nursing staff. They all contributed a piece on what their part in the program was. Videos were also shown on the procedure of taking eggs via a vaginal pick-up. The meeting went for about 2 hours and we were all encouraged to have drinks after wards and mingle.

2. *The Baby Machine: Commercialisation of Motherhood*, Essays by Ten Internationally prominent Women. 1988, McCulloch Publishing.

3. Health Services Commissioner: The Health Services Commissioner in Victoria is an organisation set up to deal with the complaints against health professionals by the users of the health system. It is meant to deal with these complaints on an arbitrary basis and, if necessary, refer them for further action.

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THE AFTERMATH OF THE CERVICAL CANCER INQUIRY IN NEW ZEALAND: AN ANTIPODAL ABERRATION OR UNIVERSAL STRUGGLE?

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Synopsis — Feminist Health Activists in New Zealand have worked tirelessly to bring about the structural reform of the New Zealand health care system. Much of this has occurred in the public arena since the release of the Cartwright Report into cervical cancer treatment at National Women's Hospital in Auckland. The issues that arose in the New Zealand Inquiry are also of relevance and interest in Australia and elsewhere. In particular, the issues of patient rights, consumer representation, patient advocacy, and patients' access to independent complaints systems have implications for the protection of human rights internationally. The Cartwright Inquiry's examination of the ethnical dilemmas emerging with the involvement of patients in clinical teaching situations also raises many questions about informed consent. The women in New Zealand who have engaged in this public debate have been very effective in using the media to raise public awareness of these issues. However this has been at great personal cost to them. Sections of the New Zealand media have recently launched a series of particularly vicious attacks on the credibility and integrity of feminist health activists. It is reassuring to note that, thus far, New Zealand feminists remain undaunted by these smear tactics.

The Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and Other Related Matters (hereafter called the Cartwright Inquiry) was announced on 10 June 1988. It followed the publication of an article by two New Zealand feminists, Sandra Coney and Phillida Bunkle, in the New Zealand current affairs magazine *Metro* (1988, p. 45) earlier the same month. In the article Coney and Bunkle alleged that there was a failure to adequately treat cervical carcinoma *in situ* (CIS) at National Women's Hospital, and that research involving an experimental control group had been conducted from 1966 to 1987 into the natural history of CIS of the genital tract without the full and informed consent of participants.

The article by Coney and Bunkle caused a considerable stir in the community, because, in a very public arena, it courageously addressed issues of patient rights in general. The impact of the revelations contained in the *Metro* article is well documented by Rosier (1989, p. 121). Coney and Bunkle (1988) raised many important questions that many women had asked many times before with little public response or support.

In pursuing the issues raised by Coney and Bunkle, the Cartwright Inquiry asked what steps were necessary to improve the protection of patients involved in research and/or treatment programs at the National Women's Hospital. It raised questions about whether patients were properly informed of the treatment and options available to them and, if not, what steps needed to be taken to see that they were. Significantly, the inquiry also raised questions concerning the nature and quality of training provided to medical students (past and present) in relation to CIS. Perhaps most importantly, under its final term of reference, the inquiry was

required to examine any other matter which was relevant to the detection and treatment of cervical cancer and pre-cancerous conditions of the genital tract. It was this term of reference that gave the Inquiry the power to examine so many other critical, complex, and subtle issues that had previously been trivialised. Due to the enormity of the issues raised by the Cartwright Inquiry, this paper focuses only on aspects of patient rights.

PATIENT RIGHTS

The discussion surrounding patient rights in New Zealand raised many concerns which are equally relevant in other parts of the world. If one considers the matters raised in the New Zealand Inquiry and examines them in the context of new reproductive technologies, many thorny but important questions emerge: informed consent, the blurring of boundaries between clinical treatment and research, the necessity for the protection of patient rights when involving patients in clinical teaching or research, and the importance of independent patient advocacy. Each of these issues becomes even more contentious when overlaid with themes such as the necessity for consumer representation in decision-making structures and the hazards of a self-regulating health system.

Some particularly smug and deluded attitudes are apparent in many doctors demonstrating their belief that such abuses of power could not happen in Australia or anywhere else. Such views are disturbingly common among members of the medical profession in Australia. For those who do not share such delusions it is a sobering thought to realise that there but for the grace of the goddess go we. This caution was also expressed in a special article by Paul McNeill (1989). As he put it:

> It is tempting to dismiss this cervical cancer study as an aberration in a medical system that is generally reliable. The response may well be that "it could not happen here." However, the extent of disregard for patients' welfare in this case, and the almost uniform refusal by other doctors to examine the issues, must raise serious doubts about the adequacy of systems elsewhere to deal appropriately with misconduct . . . most of the safeguards depend to some extent, on peer review and on the compliance of researchers with review procedures. If doctors do not have the will to confront the issues and to modify dangerous practices, or if they are unable to overcome institutional resistance to scrutiny, then the systems and safeguards will necessarily fail. (p. 264)

In any discussion of patient rights the issue of informed consent must be considered because it is central to the notion of patient rights. It is therefore important to review how the New Zealand courts dealt with the requirement for informed consent and how this differed from countries such as Australia. Currently in New Zealand there exists a system which ensures that the state accepts responsibility for all but the most gross forms of medical malpractice. It is referred to as the No Fault Principle and is embodied in New Zealand's Accident Compensation Law.

Clare Matheson was the patient at the centre of the disclosure of *The Unfortunate Experiment* (Coney, 1988). Following the release of the judge's findings, Clare Matheson made a claim against Professor Herb Green, Professor Dennis Bonham, the Auckland Hospital Board, and the University of Auckland. The claim totalled $1.5 million and comprised three parts: claim for trespass to the person (assault), claim for breach of fiduciary duty (breach of trust), and claim for negligence. This claim was later followed by those of another 18 women. The probability of their claims now succeeding is very small given the decision made recently by the New Zealand Court of Appeal in relation to Clare Matheson.

On 29 October 1989, in Green v. Matheson the New Zealand Court of

Appeal outlined the forms of medical misadventure barred from civil action under the New Zealand Accident Compensation Act. Prior to this ruling negligent advice and incomplete information leading to faulty consent were not regarded as misadventure and could therefore be the subject of civil action. The appeal judgment changed all this when the court took a broader view and defined misadventure from the perspective of the patient.

Now if a case is mishandled, it is regarded as the patient's misfortune or ill luck. Matheson (1989, p. 223) concluded that the appeal ruling on her case left her and most other health care consumers in New Zealand with no civil remedy and therefore no redress in cases of medical misadventure. The Medical Council of New Zealand (MCNZ) (1990, p. 23) did not fail to point out, in support of the decision, that this judgment still allows claims for exemplary damages "in cases of high handed disregard of the (patient's) rights or the like outrageous conduct." Significantly, the MCNZ went on to describe the ruling as a "positive and clarifying finding, . . . [which] removes litigation on consent further than ever from the courts."

In Australia, the scenario is slightly different. Consumers have a greater degree of redress through the civil courts. The Australian Law Reform Commission (LRC, 1989) recommended that the common law standard of reasonable care which now applies to the provision of information to patients concerning a proposed treatment or medical procedure should not be replaced by a statutory standard.

Instead they recommended that guidelines be developed by the National Health and Medical Research Council (NH & MRC) for the provision of information for patients concerning a proposed treatment or procedure. They also recommended that legislation be enacted which gives such guidelines a specified status as admissable evidence in relation to the law of negligence. This is preferable to the New Zealand scenario because it clearly endorses the notion of a yardstick of acceptable clinical practice. The existence of a guideline as a legal yardstick must reduce the doctors' temptation to observe the doctrine of "clinical freedom" to a dangerous degree. Such guidelines will also encourage the use of treatment protocols wherever possible.

CONSUMER REPRESENTATION

In Australia, the composition of those bodies recommended as the appropriate structure to prepare such guidelines is a question that remains unaddressed. The question must be asked in Australia as it was in New Zealand: What representation generally do consumers have in such organisations? And: What representation is provided for women in these structures? After all, women constitute the majority of consumers and workers in the health care system and as such are entitled to proportional representation across decision-making structures.

The question of who controls the agendas in such groups, for what purpose, and to whose benefit was an issue tackled boldly by Sandra Coney in New Zealand. Coney noted that:

> Although consumers initially had great difficulty being included on committees where important decisions were being made, they were persistently invited to make submissions about already written reports. The real power lay with those who had drafted the reports and determined what the topics addressed would be. Consumers were confined to a commenting function, an after-the-fact role which was very time consuming, but usually not very productive. (1990, p. 231)

This is indeed a familiar theme for women living in the patriarchal world.

Another popular strategy of New Zealand institutions to control consumer demands was to appoint lay representatives to the various committees and working parties. A layperson is