

THE SPECULUM BITES BACK: FEMINISTS SPARK AN INQUIRY INTO THE TREATMENT OF CARCINOMA IN SITU AT AUCKLAND'S NATIONAL WOMEN'S HOSPITAL

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Synopsis – Feminist health activists Sandra Coney and Phillida Bunkle researched and exposed an experiment carried out by Professor Herbert Green at National Women's Hospital (NWH), Auckland New Zealand, involving inadequate treatment of women with carcinoma in situ. Green believed that CIS was not a precursor to invasive cancer. A public inquiry vindicated the claims of Coney and Bunkle and showed the inadequacy of many treatment and research procedures at NWH. It also demonstrated the widespread effect of Green's opposition to a national cervical screening programme in the face of international evidence that screening reduces the incidence of cervical cancer. Three publications that followed the Inquiry, show how medical power was demonstrated in the events and attitudes exposed.

The events surrounding the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters in Auckland, New Zealand between August 1987 and March 1988 have international importance as an example of a feminist challenge to patriarchal medical structures.¹

Two feminist health activists, Sandra Coney and Phillida Bunkle were working for "Fertility Action" a voluntary women's health activist group, on the Dalkon Shield, when their attention was drawn to a paper in *Obstetrics and Gynaecology* on the invasive potential of carcinoma of the cervix (McIndoe, McLean, Jones, & Mullins, 1984). It was written by three male doctors who worked at Auckland's National Women's Hospital (NWH) and a statistician from the local university and raised alarming questions about the "treatment" of some women with cervical smears.

In mid-1986 Sandra Coney made contact with a woman who had been part of an experiment on the treatment (or nontreatment)

of carcinoma in situ, (this woman was known as "Ruth" throughout the Inquiry, and in the magazine article that triggered it) and her story confirmed their concern. They researched and interviewed for more than three years before their article, "An Unfortunate Experiment at National Women's Hospital," was published in *Metro*, a glossy Auckland magazine (Bunkle & Coney, 1987). Public outcry following publication of the story forced the Minister of Health to call a public inquiry, headed by Judge Silvia Cartwright. So what was "the unfortunate experiment?" In Coney's words,

Women with pre-malignant abnormalities in the cells in the neck of the womb had not received conventional treatment for the condition. . . . They had had normal treatment withheld because one doctor, Associate Professor Herbert Green, believed that the abnormal cells were harmless. He argued that the pre-malignant disease, called carcinoma in situ or CIS, did not progress to invasive cervical cancer (Coney, 1988, p. 11).

Green had joined the cervical cancer clinical team at NWH in 1956. For the next 26 years, until his retirement in 1982, he saw “nearly every woman who came to the hospital with invasive cancer and many of those with the earlier or ‘precursor’ stages.” He began to “question established medical wisdom” (Coney, 1988, p.49) about treatment of CIS. For Green, a woman’s fertility was precious and maintaining it first priority. Before 1966 Green was “increasingly concerned at the number of young women undergoing hysterectomy for the disease (CIS) which he regarded as unnecessarily radical” (Report of the Cervical Cancer Inquiry, 1988, p. 26). In 1966 Green submitted to the Hospital Medical Committee, and had approved, a proposal to not treat CIS in women under 35, something he was already doing with some patients. What it all meant was that women with evidence of disease – CIS – were to be left untreated because Green did not believe that CIS was a precursor to cancer.

His ideas and attitudes have had a pervasive and unfortunate influence on the treatment of cervical cancer throughout New Zealand. He and colleagues at Auckland University’s Medical School with similar ideas have kept New Zealand well behind the rest of the world with regard to both treatment and a national cervical screening programme.

The Inquiry took place in a large office in a government building in Auckland. Sandra Coney gave evidence first, presenting the contents of the *Metro* article. She was subjected to a very hostile cross-examination by Attorney Collins acting for Green, but every statement was fully sourced, she would not be coerced into “yes” or “no” answers to his convoluted questions and gave a wonderful demonstration of how to be an effective witness under hostile cross-examination. A key point that came out was that women were not told that they were taking part in an experiment. (Green insisted that it should not be called that, it was

“treatment” but by the end of the Inquiry everyone was saying experiment.) Green maintained that it was not in the women’s interests to tell them about what he was doing. Patients, he said, were unnecessarily frightened if they heard the word cancer, and should be protected from doctors’ uncertainties! He never seemed to get the point that patients had an even greater right to know when there was any uncertainty. Informed consent was to become one of the major issues of the Inquiry.

The first of the overseas experts brought in by the Inquiry at the government’s expense to give evidence was Professor Ralph Richart, Professor of Pathology at Columbia University, New York. He described Green’s views as “iconoclastic” and different from those of almost everyone else in the world. He stated clearly that CIS is a precursor to invasive cancer. Richart also disagreed with Green’s view that does not favour nationwide cervical screening of all women.

The evidence is irrefutable. While most of the world is trying to reach every section of their population for cytological screening, there is a continuing debate in New Zealand whether screening is effective: maybe all the nations are out of step with New Zealand, but the evidence is dead set against it.²

Women have been calling for a national cervical screening programme for years, and have always met with the resistance of a substantial section of the medical community, so Richart’s evidence about its effectiveness and the need for steps to make the screening reach the entire population were most welcome, and certainly helped to make a national screening programme another major issue. Richart also called for the immediate recall of women treated at NWH for cervical carcinoma by Green for check up and possible further treatment.

At this early stage in the Inquiry many serious questions had been raised: is the training of doctors at NWH jeopardising a national screening programme? What is happening now at NWH? Are there any other experiments that endanger women's health and lives going on? Do doctors at NWH still think that medical uncertainty should be kept from their patients? There were no answers and still more was to be revealed.

The next revelation that created something of an uproar in the mainstream media came from Dr. Dennis Bonham, head of the Postgraduate School of Medicine at Auckland University and Green's boss for most of the time in question. Under cross-examination he admitted that senior medical students were doing vaginal examinations of anaesthetised women without their knowledge or consent. The chairperson of the Auckland Hospital Board, Dr. Frank Rutter, actually said that women were "naive" if they didn't know NWH was a teaching hospital and that by going there they gave something he called "implied consent" to these examinations. The medical boys were sticking together. Human Rights Commissioner Rae Julian condemned the practice as "a form of rape." Here were the attitudes of many doctors towards women laid out for us all to see – patronising and dehumanising.

Bonham was slippery under cross examination. He was in charge of this, but not responsible for that. He had faith in his colleagues. Yes, he chaired the ethics committee that approved Green's treatment programme, but he was junior to others on it at the time. Of course women were given the results of tests and told of treatment alternatives, it was "normal practice" – a phrase he used a lot the day I was there. Statements of some of the women who had given evidence to Judge Cartwright in private were repeated to him: "I cannot recall being told the result. I did not get many answers to the questions I asked."; "I can remember

having photos taken of the inside. I had no idea why they were being taken. I was not told the results."; "I had a biopsy done under anaesthetic. No information was given to me on the results of it."; "I didn't understand why I had to keep coming back to the hospital." Bonham responded that these cases were not under his control and it was "normal practice" for results to be given. Actually, he was just staying off a colleague's patch, in the interests of the "clinical autonomy" that is so precious to doctors. (Never mind the women.)

The evidence against Green's methods continued to mount. Dr. Joseph Jordon, British gynaecologist, said Green's treatment trials should not have been allowed to begin, that he was acting contrary to generally held beliefs at the time and that his forceful personality and closed mind, along with the reluctance of his colleagues to interfere meant that they did not stop when they should have. Jordan also said that in 1971, in Birmingham Hospital where he works, they set up a special meeting to challenge Green, who was visiting, on his methods.

Dr. Colin Laverty from Sydney questioned the overly optimistic classification ("under-calling") of some specimens he had examined. He also commented that at a cervical cancer symposium in New Zealand in 1986 he got the impression that NWH doctors present "underappreciated" cytology and colposcopy. Both these men, as well as Richart, said that the patient "Ruth" should have been fully treated in 1970. All she got was a biopsy in 1977.

Dr. Ellice Pixley came from Adelaide as a witness for Green. At first he said you could not judge whether a treatment was adequate unless you had been there. Yet, when he looked at the files of some individual women who had been in Green's programme he said the treatments were inadequate.

By this stage in the Inquiry (late October) the demand for cervical smear tests had increased by 25% and women were talking

about how they often found the process unpleasant and invading. I heard many stories about the effect of the Inquiry on doctors who were not involved. They ranged from wanting to perform hysterectomies in cases where they were certainly not called for, so there would be no chance of “undertreating” to the patronising attitude that “lay people can’t possibly understand.” I knew that Bonham shared this attitude when I heard him comment during an Inquiry break, “Of course, it’s far too technical for a public inquiry.” There were also reports from nurses that younger doctors were taking much more care about how they spoke to patients and giving careful explanations, so the Inquiry was providing some education that medical training had not.

By mid-November a formal hunt for patients involved in Dr. Green’s treatment programme had begun. But there was a lot of “It wasn’t my fault” being expressed during evidence. Bonham was insisting that Green’s programme was not research (that would have made it his responsibility) and the then medical superintendent of NWH, Dr. Algar Warren, although he had “doubts”, proclaimed himself “just an administrator” and not able to interfere in clinical matters.

The evidence given by local doctors was revealing of their attitudes. Dr. Graeme Duncan, senior gynaecologist at Wellington Hospital and president of the Royal New Zealand College of Obstetricians and Gynaecologists spoke of not wanting to frighten women away from treatment by telling them of every possible complication:

It would be beyond the intellectual comprehension of a considerable proportion of the population. . . . To maintain the confidence between doctor and patient it is important not to frighten the person, and an open, frank discussion of the problem within these bounds is an essential part of medical practice in all disciplines.

I would have thought that the patient was already frightened and the best reassurance would be confidence that she had been given all the relevant information. She can decide for herself whether or not she understands it – how patronising to do that for her (and on what basis?) – and then seek out more information, maybe even from another source, if she dare. These assumptions that women have to be protected from knowledge about *their* conditions and treatment and that they will not understand anyway, are all the more frightening because the doctors do not seem to see anything wrong with them.

The issue of consent came up again in connection with student doctors practising the insertion and withdrawal of IUCDs (Intrauterine contraceptive device) on anaesthetised patients. One nurse said of a trainee doctor she saw doing a “practice internal” on an anaesthetised woman that it looked as though he was “trying to do a tonsillectomy from the vagina” the examination was so vigorous.

Dr. Tony Baird, obstetrician and gynaecologist and head of the New Zealand Medical Association said it was “normal practice” to get consent, “but obviously at times with human failings there are going to be some omissions.” He also said that NWH protected patients through their being able to complain to the superintendent. Two important points not covered were: how do you know you were abused if you were anaesthetised at the time; and who knows about this “right” and how easy is it to make a complaint?

Another local, Dr. Bruce Faris (part-time senior consultation at NWH, retired in 1985) thought everything had been okay too, and criticised the Inquiry for “polarising” the debate into sides resolved to either protect individuals or support the authors of the “ill-conceived” *Metro* article. It is the kind of nonthink that allows someone to blame whoever raises an injustice for the fact that it is there. It was amazing how often Fertility

Action (the feminist group) was spoken of as though it were some powerful organisation, when it is in fact a small group of dedicated, (largely unpaid) women. Sandra Coney was at the Inquiry every day, briefing their lawyer and working most nights on briefs of evidence. She was the only “party to the Inquiry who was there constantly and not being paid a medical or legal salary or fee. (Phillida Bunkle lives and works in Wellington, at the opposite end of New Zealand’s North Island.)

Next up was Dr. Moody, Superintendent-in-Chief of the Auckland Hospital Board from 1963 until his retirement in 1980. His role was “wholly administrative” he said. “On rare occasions only would I have expressed an opinion on a medical matter. As superintendent-in-chief I was not a final arbiter of clinical disputes”. He had lengthy memoes from Drs. McLean and McIndoe disputing Green’s treatment but said they were “insufficiently documented” for him to take action. He felt the matter was best dealt with by the NWH medical committee (the one Bonham chaired and claimed to be a junior member of). Moody also said that doctors “worship” clinical freedom and you cannot have them looking over each others’ shoulders.

The issue of the supervision and discipline of doctors was to become another major issue while the locals continued to replay the theme of clinical freedom. Locals like Dr. Kyle, a part-time visiting obstetrician and gynaecologist at NWH for 32 years, and in private practice, who affirmed Green’s integrity and felt it was not the responsibility of colleagues to follow each other’s actions. “I cannot go around and check on 19 consultants and university staff,” he said, although he also described the situation as “not good.” Maybe being one’s brother’s keeper, in medical circles, means not being critical of those brothers. Never mind the patients.

And still it went on. Former gynaecologist Dr. Bruce Grieve thought that “as a whole”

Green’s safeguards were adequate. The Dean of the Auckland Medical School, David Cole, made much of the burdens on senior staff at the university and the hospital. He said, under cross-examination, that doctors find it difficult to report suspicious or improper practices by colleagues and that he hoped that previously deficient written information for doctors on ethics would be corrected. He made it plain that the line of responsibility for stopping research that was putting patients at risk led directly to Professor Bonham.

A woman who was at the Inquiry on the day that Professor Colin Mantell, head of obstetrics and gynaecology at the post-graduate medical school, gave evidence described it as a “chilling experience.” “He was totally at ease with everything that has happened,” she said. “He thinks nothing has ever gone wrong and that standards of teaching are so high.” He sees pelvic examinations while patients are under anaesthesia as a necessary part of student learning. Apparently, it saves the students embarrassment if the women are out cold. NWH has responded to the outcry about the practice by putting stickers on people’s appointment cards advising them that it is a teaching hospital and doctors in training may be involved in their care!

The Auckland doctors’ unwillingness to commit themselves to criticism of Green’s treatment was not shared by Professor Skegg, Professor of Preventive and Social Medicine and Director of the Hugh Adam Cancer Epidemiology Unit at the University of Otago. His coining of the term “unfortunate experiment” in a medical journal early in 1986 had not been challenged by Green nor any of his colleagues he said, and he thought Green’s own writings indicated that “experiment” was an appropriate word for some of his work. “It was a planned investigation in which conventional treatment was with-held from a carefully designed set of patients.”

Skegg also reiterated the international belief that cervical screening was a very valuable procedure. He had been surprised he said, when returning from overseas in 1980, at the level of ignorance in New Zealand about cervical screening. Challenges on this to medical practitioners often led to them referring to teaching or publications by staff at NWH:

The delay in confirming the malignant potential of cervical cancer in situ contributed to the persistent confusion in New Zealand about cervical screening and the effects of this confusion must be costed in terms of lives.

These comments on cervical screening were reinforced by Medical Director of the Cancer Society, Dr. Allan Gray, in his evidence. He described Green's influence as "profound" and nationwide. "The Cancer Society view is that because of Professor Green's opposition it has not been possible to provide a comprehensive screening programme in New Zealand." He also said:

It is disturbing that Professor Green's retirement has not resulted in any updating of views on cervical screening at National Women's. Dr. Jamieson [Green's successor] represents a new generation of doctors but is presenting views that are over 20 years out of date.

And, a most important point that explains the widespread influence of views held at NWH – "It not only teaches the students, but also trains the teachers." The Ministry of Women's Affairs had been lobbying for a national screening programme for some time, as had Skegg, who sees further education of doctors as a prerequisite. A priority must be the screening of women who have never had a smear, which means removing barriers to the screening of all at-risk women, including those

in minority groups, says Skegg. It is more effective to screen more women than to do the ones already tested more often.

There was one more "scandal" to break, this one a disclosure by Michael Churchouse, hospital cytologist, that from 1963 to 1966 a proportion (later established as one in four) of female newborn babies were given vaginal smears. Green had asked for it, the smears did not give the information he was seeking, so he lost interest after about 200. However, no one told staff to stop taking them so 2200 in all were taken. Media interest in the Inquiry skyrocketed, editors were appalled and outraged. Records were made available to the (now) women or their mothers, but as one said to me, "So what if I was one of the babies to have a smear. I don't remember it, but I sure feel angry that the hospital didn't offer me any protection at all."

Dr. Gabrielle Collison, present Medical Superintendent of NWH, gave evidence in an unhelpful manner. Of course she was defending the hospital, but she did, under cross-examination, seem incredibly ignorant about what happened at the hospital. She made it sound as though there are reasonable complaints procedures at the hospital, when there are not (there was often a difference between what she said and what patients have said they experience), and occasionally made a good point, as in, "It is important not to confuse consent forms with informed consent". Unfortunately, there was no indication that she had any higher opinion than other doctors of women's ability to understand their conditions, treatments, or smear results. Her comments on simple language in pamphlets for patients and some of the examples handed around were insulting to any adult woman's intelligence. She said she was on a learning curve about informed consent, even though she has been a member of the hospital's ethical committee since 1985.

Collison disagreed that a memo she had posted for staff had been a disincentive for

nurses in particular to come forward and give evidence (but that is how nurses had read it) or that she had discouraged social workers from making a submission. She saw no conflict in Bonham being head of the ethics committee (and referred to the honour and integrity of all its members), although Bonham's department is where most of the research emanates from. Under cross-examination she very readily agreed that all sorts of things were a good idea – providing patients with what they want, ongoing review of research, improved consent procedures, consultation with consumer groups – but has never initiated action on any of them. Her tendency to answer questions with “Not that I am aware of made it sound as though she knew very little about the running of the hospital.

She was not aware of nurses having complaints they were too intimidated to bring forward, repeated that she would not bring reprisals against those who did, and expressed sorrow that they had not made complaints in the past, which suggests a very poor understanding of how hospital hierarchies operate. The reprisals that nurses fear are not necessarily open, they fear they will be quietly sidelined and overlooked if they get a reputation for speaking out against doctors. It is impossible to fight that sort of “disciplinary action” because it is so covert. And nurses have, in the past anyway, been thoroughly trained into a place in the hierarchy and a way of thinking that leads many to accept the authority of doctors in much the same way that many women patients do – they do not like it but feel they have to put up with it. This is supported by evidence given later by Stephanie Breen of the New Zealand Nurses Independent Union of Workers, who said, “The hospital institution has a culture all of its own. It's very hierarchical. At the bottom ... are the nurses . . . nurses become acculturated into that culture.”

The final nail was put in the coffin of any credibility for Green's “treatment” programme

by Professor Kolstad, Research Chief of the Norwegian Hydros Institute for Cancer Research. He called it “terrifying mismanagement.” His evidence about when information about the progression of CIS to invasive cancer became available internationally showed that Green was in the wrong from the beginning. He also had some criticisms of what happens at NWH now. For instance, he questioned some classification procedures and the lack of qualified staff to administer radioactive therapy to women with invasive cancer.

After more than 55 days of hearings the Inquiry finally began to hear from women – the YWCA, The Health Alternatives For Women (THAW), a women's group from Glenfield, The Ministry of Women's Affairs, Fertility Action. (Although Judge Cartwright had talked in private with over 80 women patients.) Contained within their submissions are all the changes needed to make New Zealand's health care services work *for* women. But the lack of belief by medical professionals that anything is wrong with the system will make change difficult. As THAW said in their submission, “there is not an awareness among the medical profession that they have something to learn from consumers.”

YWCA representatives Sue Neal and Bonita Chatfield spoke very strongly of the need for patients to be involved in their own health care and treatment. They called for legislative control in a number of areas and emphasised the difficulties for women, including nurses, in coming forward to the Inquiry. NWH is “notorious for the insensitivity of the staff and the system,” said Sue Neal, explaining later that she was referring particularly to medical staff. They also raised the cultural insensitivity of the hospital and its lack of respect for Pacific Island women. “I don't think you can expect Pacific Island women to assert themselves where an authority figure is present and indeed

a lot of women can't do that." The need for advocacy, translation, information, respect, and consent were all emphasised.

Two women from THAW in Christchurch, Corinne Stephenson and Christine Bird, included in their submission many examples of the behaviour of doctors who denied information, refused smears, discouraged second opinions, and generally demoralised their patients. Bird referred to "the injustice of lack of information" and to the use of "extremely complicated language that they [patients] don't understand or language so simplistic that it doesn't actually inform them." Their submission ranged widely over the failure of medicine to serve women, the lack of easy access to records, the inaccessibility of (inadequate) complaints procedures, a frightening lack of information-giving about diagnoses in some cases, the side effects of drugs, bad consent procedures, resistance to cervical screening programmes, and an unwillingness to give smears when asked (which they related to Green's influence), lack of independent ethics committees, the poor training experiences of a lot of medical students and so on and on and on. They included some examples of alternative ways of doing things, such as using conscious, paid, substitute patients in vaginal examination training, ones that will give students feedback on their communication and interaction skills.

The women also talked about how THAW women learned to do cervical smears and other health checks under the guidance of a doctor, and were then stopped by the Health Department following a complaint (about the fact they were doing it, not the quality of what they were doing) from another doctor. THAW has contact with women who have been patients at Christchurch Women's Hospital and it is clear that there are similar problems of consent and treatment to those being examined at NWH.

The submission from the Glenfield Women's Health Co-operative began with one of the three presenters, Therese Weir, saying:

I guess the feelings that have come up for the women who have been involved in this submission have been wide ranging – anger, frustration and also celebration that we are actually talking at long last about some of the things that have been affecting us for many years.

They also referred to "the helplessness we feel once we are in there [NWH] and through that lack of confidence, it is inevitable that there is going to be no challenging, no questioning, no voice even to ask about what are our rights". Their conclusion was:

We believe that medical attitudes serve to create a climate of emotional and physical estrangement, to reinforce the attitudes of acceptance and self-blame for the situations we find ourselves in. This makes it impossible to ask questions or challenge what is happening around our own health and increases the despair and feeling of not being in control. What happens in hospitals can have damaging and permanent physical and emotional effects on women's lives and basically, what we ask is to retain our dignity.

The Ministry of Women's Affairs' submission was in two parts, with a separate statement from Te Ohu Whakatupu (The Maori Women's Secretariat). Miriama Evans, in the introduction for Te Ohu Whakatupu, said:

. . . Maori women are reluctant to appear before a commission such as this. Many are intimidated by the aura of this inquiry. Its mauri [spirit] is unfamiliar and overwhelmingly awesome. It does not have the feel of partnership.

Mary O'Regan, then Secretary of the Ministry was speaking for many, many women when she said:

Central to this Inquiry and the issues which are emerging is the very basic issue of the relationship between the medical profession as "experts" and women as consumers of health services. The dynamic is one of power versus powerlessness.

It is ironic too that the very nature of this forum has mirrored this dynamic. There have been days spent listening to medical experts. A great deal of money has been spent on bringing their expertise and perspective to this Inquiry. But women have not had access to comparable facilities to ensure that their voices are heard. Women all over the country have been outraged by what they have been hearing, especially as they have identified with the powerlessness of the women who entrusted the medical experts with their bodies and their lives . . .

Women must never again be used as unknowing subjects in research projects such as that which is the subject for this Inquiry. When we go to get treatment for a medical condition we must be given the best treatment possible and know what is being done to us. No information or treatment should be withheld from us in order to test a doctor's hypothesis. This is a gross breach of the faith that patients have been socialised to have in their doctors.

Maori women are over-represented among women who die of cervical cancer. Te Ohu Whakatupu argued for knowledge and respect for Maori feelings and beliefs about the body, about the use of any parts of the body, for interpretive services and support, for advocacy, for Maori representation (by at least two) on ethics committees and for Maori liaison staff. Miriana Evans said, "The best conceivable change for all women would be to

have doctors who respected each woman as a living, feeling entity and not just as a patient/client/subject." And, "Trainee doctors need to be given seminars on tikanga Maori [Maori ways of doing things] and Maori attitudes to the body and especially te whare o te tangata." (Literally, the house of the people, that is, the reproductive organs.) Reference was made to the Ministry's work to establish pilot schemes for the cervical testing of Maori and working class women, intended to, "make cervical cancer screening programmes not only physically and financially accessible, but acceptable to women in terms of who does them as well."

The rest of the Ministry's submission continued to reinforce what women have been saying and saying and saying. As in:

In the Ministry's view the flaw that lies at the base of much of the conduct this commission has heard about is that the medical profession in this country is, in effect, accountable only to itself with only token and ineffectual involvement of non-medical people at any point.

Very specific frameworks for protecting patients rights by legislation, including a code of patients' rights that covers research, treatment, and teaching are suggested, along with ways of monitoring research.

It was appropriate that the Fertility Action submission was the final one, and equally appropriate that it be presented by Sandra Coney, who fought constantly to keep the perspective of women patients before the commission. It begins:

It is our view that this Inquiry has been about power: the power of the medical profession and patients' lack of it. This is the framework in which the events of the past must be placed. Changes in the future must have as their primary aim the equalisation of this power imbalance, by

dismantling the power of the profession and strengthening patients' rights. Only then will we feel confident about claiming: "Never again". Women have been ignored, infantilised, treated as a parent might a young child.

The socialisation of medical students was discussed as a political and modelling process, designed to maintain the status quo. "Students witness first hand the way in which their teachers work with patients . . . they see powerful and unchallenged doctors working with usually submissive, frightened and relatively powerless patients." The hidden curriculum teaches that the "best" patient is one who is unconscious, immobile, silent, and invisible – as with the embarrassed patient given a cloth to cover *her* face when students came to see a colposcopy examination (after she had declined permission for their presence).

The submission treated the issue of informed consent in detail. In the section on research, the ethics of research funding, is addressed. How "objective" can research funding by drug companies be?

A widespread public perception had developed by this time, encouraged by some interested parties, that the events being scrutinised by the Inquiry were in the past and that the existence of ethics committees now meant that research was properly over-seen. To evaluate the current situation, Fertility Action surveyed the minutes of the NWH Ethics Committee from November 1984 to May 1987. It found that Professor Bonham never once stepped down from the chair when applications from his own department, or even his own applications, were considered. Eighteen of 38 proposals came from the hospital's academic staff and a further 11 from nonacademic staff. Written consent forms were included in only 12 of 36 studies approved. Nine other studies mentioned consent but there were no forms. In six trials

women were being asked to give consent under duress, such as when they were seeking an abortion or about to have a caesarian section. Fertility Action's evaluation of the minutes showed that patients' rights have systematically been ignored. Blood, body tissues, and foetal tissue were taken for research without the knowledge of the women, women were randomised into trials without their knowledge and many of the consent forms that did exist failed to mention important side effects.

Lay representation on ethical committees, "preferably chosen by the people they represent, and definitely accountable to them," is another issue discussed. So too are medical accountability and the deficiencies of the accident compensation provisions and medical practitioners' disciplinary hearings. The latter leads to the conclusion that:

Doctors who offend against the reputation of the profession are more likely to be sternly treated and publicly censured than those who injure patients and . . . the disciplinary procedures maintained by the profession operate in the interests of the profession rather than the public.

With regard to hospital and hospital board complaints procedures, the Inquiry found that:

. . . the structures presently in place are inaccessible and invisible and . . . the deliberate informality of the process allows too much discretion to hospital and hospital board administrators.

The "medical solution to quality control," peer review, also comes under attack:

Peer review operates from the assumption that all doctors are reasonable people, self-critical and open to criticism, willing to change and admit they have been wrong. This is not the case in the real world.

Doctors Bonham and Mantell were recalled to give supplementary evidence. Green was not, on health grounds. Again, no individual accepting responsibility for anything was a key feature. Then it remained only for the lawyers to give their closing submissions on behalf of their clients.

A few additional points should be noted: Rangi Walker's statement (not part of the Inquiry) that Maori and Pacific Island women's complaints in the 70s that their babies were used in cervical cancer experiments were dismissed as folk stories; lack of interest from the media when women were giving evidence; Judge Cartwright's low-key but very impressive running of the Inquiry; and her comments in her closing remarks about the bravery of the women patients who came forward to speak to her.

The Judge's report was released on 5 August 1988 (Report of the Cervical Cancer Inquiry, 1988). When I finished reading it I wanted to celebrate: women were believed. It established without doubt that Green's 1966 experiment involved inadequate treatment for some women. The judge said, "I have come to believe that Dr. Green was in fact trying to prove a personal belief (p. 33) and that he "intended a study which involved no treatment or under-treatment of women with positive smears" (p. 35).

Patients who came to the hospital from any of the clinicians' private practices were *not* included in the experiment. "The other patients entering NWH, unconnected to a particular consultant's practice, were those passed to Dr. Green for inclusion in the 1966 Proposal" (p. 36). Those, in other words, without the protection of being a private patient of one of Green's colleagues. Those who could afford consultation got treatment, those who relied on the public health system were "eligible" for experimentation.

Judge Cartwright describes the proposal in operation as "scientifically unsound and dangerous to the patient" (p. 52) on evidence

available by 1969. "It was an attempt to prove a theory that lacked scientific validity and little attention was given to ethical considerations." Additionally, "Responsibility . . . extends to those who having approved the trial, knew or ought to have known of its mounting consequences and its design faults and allowed it to continue" (p. 69). The criticisms continue: "The medical profession failed in its basic duty to its patients" (p. 70). I remember well the day Attorney Collins began his cross-examination of Sandra Coney, promising to expose over 70 inaccuracies in the original *Metro* article. "The factual basis for the article and its emphasis have proved to be correct," writes the judge (p. 95). She also refers to Bonham's "convoluted answers to their questions" a characteristic also of his evidence. The report is consistently critical of the lack of action from the medical profession from 1966 onwards and this section ends with the statement, "I have no evidence before me that the 1966 trial has been formally terminated (p. 102).

The discussion of adequate management includes reference to the "sacredness of the genital area to Maori, and, to a lesser degree, to Pakeha women" (p. 115). It is great to see this issue along with the disruption to women's lives of repeated returns to the hospital (returns that would have been unnecessary if proper treatment had been given at the outset) and the embarrassment and humiliation of procedures, included as part of adequate management. Judge Cartwright establishes a special duty for herself and the medical profession towards women who have had a diagnosis of CIS of the genital tract at NWH, and spells this out in detail with over-riding concern for the patients.

Ethics and patients' rights take up a long chapter covering peer review, informed consent, research protocols, the poor performance of the NWH ethical committee, patients' rights, including the right to be treated with dignity, consent to inclusion in

trials, and the teaching of ethics. In all cases both the hospital and the university make a very poor showing. The conclusion of this chapter completely validates the claims feminist health workers have been making for years:

I prefer to advocate a system which will encourage better communication between patient and doctor, allow for structured negotiation and medication, and raise awareness of patients' medical, cultural and family needs. The focus of attention must shift from the doctor to the patient (p. 176).

There is more criticism of the lack of resolution of historical disputes between the staffs of the hospital and the university and of teaching standards. Using the same teaching notes with minor modification for 20 years is described as "intellectual impoverishment." The report finds strongly for a national cervical screening programme. It is so well written, thoroughly documented and lucid that I can see it having a value way beyond being a basis for improvements at NWH. Many of the principles of patient care and dignity, advocacy and responsibility are applicable to the whole health system, including our woeful mental health services.

Sandra Coney had barely drawn breath from the Inquiry before she was writing her book *The Unfortunate Experiment* (Coney, 1988). It was published at about the same time as Silvia Cartwright's report. In her introduction she gives two reasons for writing it:

First, so there would be a record of everything from a feminist perspective, highlighting the key issues for women. . . . The broad questions are more important than the individuals involved. . . . The second reason . . . was to place on record that this was a feminist effort (p. 9).

She discusses the danger that the "movement of women" stretching over 20 years, that forms the base on which the work of Fertility Action stands, will be made invisible. "Feminists get credited with the inconsequential and the odd, but not with the significant efforts they have made in areas such as domestic violence, employment and health" (p. 9).

The Unfortunate Experiment is easy to read, clearly written, and rattles along at a good pace. Quotes from the inquiry transcript, reports of conversations and anecdotes keep it alive. The detailed information, like the chronicling of Gladdy's visits to NWH over 25 years, and the specific information from hospital records of the treatment many women received is compelling. How can anyone believe that Green's treatment of women with abnormal smears was adequate after reading these case histories? Part of Green's defence of his actions was that what he did spared women unnecessary "mutilating surgery" such as hysterectomy. But the case notes show clearly, and Gladdy's story is a good example, that both the surgery and the mutilation took place anyway, over many years and many visits. Some of the women gave evidence at the Inquiry. "The few hours that we listened to these women were for me the most gruelling of all the hearing days," writes Coney (p. 109). Chapter Six, "The Women" is a horrendous and moving recital of what a few of the women in the trial went through.

A key aspect of the book is its discussion of power. Doctors deserve to hold the power because they have the patients' best interests at heart, the argument goes, "but the doctor decides what these best interests are." Doctors with these attitudes can be identified by the language they use, like "dear" and "How are we today?" where, "the doctor and patient are one and the one is the doctor." Those who ask questions are "worriers," "a difficult patient," "too introspective," or "neurotic" – all comments put on patients' files.

At the time of writing, Sandra Coney hoped for “far reaching suggestions for change which would ensure that we never again have to deal with matters such as those before the inquiry” (p. 254). Those hopes were realised in the findings of Judge Cartwright’s report and at a press conference when the report was released, the Minister of Health made a commitment to the report’s recommendations. But there is still the organised inertia of the whole medical industry to combat.

Committees to monitor, recommend, advise, and so on have been set up by the Auckland Area Health Board (formerly the Auckland Hospital Board), the university and the Health Department. Women in Auckland formed The Auckland Women’s Health Council and have succeeded in getting representatives onto several important committees. Phillida Bunkle, thanks to some heavy lobbying by influential women, was appointed to one committee in Wellington. Sandra Coney is being carefully kept off all of them. There is no evidence that the entrenched and powerful in medicine plan to do anything different, so it is going to take political pressure.

If any further proof is needed that NWH is not an isolated example of medical arrogance but a symptom of a whole system that denigrates women, then Phillida Bunkle (1988) provides it. *Second Opinion* is a collection of previously published writings following some of the major health battles feminists have fought in New Zealand since the early 70s and it clearly locates the Inquiry in its historical context. It covers ongoing issues in women’s health such as abortion, childbirth, the Dalkon Shield, and “lumpy breasts.”

The final piece in the book is the article “The Unfortunate Experiment,” without the editing changes made by *Metro*. The introduction to this contains a beautifully comprehensible description of carcinoma in situ and cervical cancer and the terms used to

talk about them. Rereading it, now so much more familiar with the details than I was when it was first published, I am again impressed by the thoroughness and dedication of Phillida Bunkle and Sandra Coney in taking on patriarchal medicine and making it squirm.

The three publications together, *The Cartwright Report*, *The Unfortunate Experiment*, and *Second Opinion* make a compelling case history of what medicine has done to women. The nonaccountability of doctors to their patients in New Zealand is made glaringly obvious and clear remedies are suggested. Real change will involve a redistribution of power and most of the medical boys will not give that up easily. And so the struggle continues, with medical powers-that-be on the defensive and determined to hold their territory and power but, because of the public impact of the inquiry, a large, well-informed, tenacious group of New Zealand women who are determined to carry the fight forward for women.

ENDNOTES

1. Accounts of the events of the Inquiry draw on articles I wrote for *Broadsheet* magazine as the Inquiry was in progress.

2. All unacknowledged quotations were taken directly from submissions or the daily transcripts of the Inquiry for use in my articles for *Broadsheet*. Because the unpublished transcripts were voluminous and the page numbering idiosyncratic, detailed references are not given.

REFERENCES

- Bird, Christine. (1987, September). Professionals against the people. *Broadsheet*, pp. 32–33.
- Bunkle, Phillida. (1988). *Second opinion: The politics of women’s health in New Zealand*. Auckland: Oxford University Press.
- Bunkle, P., & Coney, S. (1987, June). An unfortunate experiment at National Women’s Hospital. *Metro*, pp. 46–65.
- Coney, Sandra. (1988). *The unfortunate experiment*. Auckland, Penguin.