

“The Hidden Bits”: Understanding Cervical Screening.

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This paper could also be called ‘Speaking about the Unspeakable’ because it deals with the topic of cervical screening from two perspectives: that of naming the ‘hidden bits’ with words that are difficult to speak out loud as well as words imposed on the hidden bits of women, and because it deals with research and information gathering which had unspeakable consequences.

It is based on three very different episodes of collecting information about cervical screening in New Zealand over the last thirty years. In 1992 I carried out some qualitative research on women’s knowledge of and attitudes to cervical screening for the Waikato Area Health Board. However, this research was bracketed by two major medical disasters to do with cervical screening. The first, in the 1980s, was what has come to be called ‘the unfortunate experiment at National Women’s Hospital’. It resulted in a governmental inquiry. The second disaster arose out of inadequate cytological laboratory practices in Gisborne which were revealed in the late 1990s. It also resulted in a governmental inquiry.

The Unfortunate Experiment at National Women’s Hospital

National Women’s Hospital (NWH) was built in 1964. There was some opposition to combining obstetrics, which deals with childbirth, and gynaecology, which deals with problems in women’s reproductive area. It was suggested by Dr Doris Gordon, then head of NWH, that putting the two together pathologised women’s reproductive role. This was not an idle suggestion. The history of the medical treatment of women has been one which defined anything to do with female reproduction as problematical, dirty, likely to cause mental upsets and demonstrated the need to control women who had a tendency to be peculiar or childish because of their hormones. However, the two specialisations were put together and the hospital also became a teaching hospital with links to the University of Auckland. This entailed a research function

The initial occurrence that led to this first inquiry was purely accidental. In the mid 1980s, a woman who worked at the Auckland School of Community Medicine read a piece of research a statistician colleague was working on for some doctors at National Women’s. She mentioned it to a friend, feminist freelance journalist Sandra Coney and gave her a copy. The paper was, like a lot of medical research designed for journal publication, a summary of the findings with little on the methodology. It appeared to be the outcome of an experiment on women who had had abnormal cervical smears that had not been treated. It

appeared that the figures suggested outcomes of the research that were very poor and included the deaths of some of the women involved. Coney spoke to the doctors who had written the paper and to some women who had had gynaecological problems referred to NWH and decided that some extremely unethical research had been carried on for years at NWH. Those few sentences disguise months of detective work, obfuscation from doctors at the hospital, incomprehension from patients and some lucky breaks in finding people willing to talk about what had been going on. Finally, the two women published a long article in Metro magazine in 1987 entitled "The Unfortunate Experiment". The article won several journalism awards and unleashed a scandal so large that a government inquiry was launched.

The inquiry was centred around Professor Herbert Green, a professor of medicine who taught and did research into cervical cancer from the time of his appointment to NWH in 1956. A year later the Pap smear was introduced to NZ and overseas studies showed that it could identify cell changes at an early stage, which allowed successful intervention. Studies also showed that if there was no intervention, while not all pre-cancerous cells developed into full-blown cancer, at least a third did. Therefore diagnosis was an important preventative measure.

The treatment for pre-cancerous cells in the 1950s was hysterectomy – total removal of the uterus and therefore of a woman's ability to have children. By the 1960s cone biopsy was used but this could also reduce chances of conception. Herb Green was a strong opponent of abortion and very concerned by anything that reduced a woman's fertility. Green told one of his patients that a woman would throw away her unique possession if she lessened her chances of conception and he said it was a woman's heritage to keep her uterus. This was not uncommon discourse for the time; women's magazines ran articles on how a man should be particularly nice to his wife if she had a hysterectomy even though she was no longer real woman. And a gynaecologist was on record saying, "I think of menopause as a deficiency disease like diabetes". The discourse of the time located female identity in the uterus.

Green developed a missionary zeal to save women's fertility. At first he suspected that CIS (carcinoma in situ – the precursor stage) did not always develop into cancer and eventually he persuaded himself that this was true. To test his belief he personally saw every woman who came to NWH for colposcopy (microscopic examination of a cervix which had shown some cell abnormality) for more than 20 years. He followed the progress of these women, recalling them often, taking cell samples but never treating them because he wanted to show the natural history of the disease and prove that cervical screening was a waste of time. At the inquiry stories were told of women who had been recalled for more than 20 years, many of whom had developed cancer and some of whom had died. One woman had had eleven smears taken, ten of which showed malignancy, she had had small bits of her cervix removed for analysis but had had no treatment and was told she was being recalled because, "she was a bit

of an odd bod” and Professor Green found her very interesting. This of course persuaded her she was being carefully monitored and no harm could come to her so for 23 years she returned to NWH until she developed full-blown cancer and the Professor was no longer interested in her. It was the figures from this research that came to the attention of Coney and led to her writing the Metro article, which provoked the inquiry.

At the inquiry experts were flown in from all over the world to testify that Green’s ideas were contrary to all evidence, that his presentations at international conferences were greeted with disbelief and that reputable journals refused to take his papers. This raised the question of why doctors in NZ had not questioned his experiments. It turned out that some had but the power of his position and his personality had over-ridden their objections. He was also responsible for educating student doctors and his rejection of the utility of screening programmes persuaded many GPs not to give smear tests to their patients. This was despite material published both by WHO and health departments of other countries, which showed significant reduction of deaths from cervical cancer when adequate screening programmes were introduced.

Several things came out of the inquiry: questions about informed consent were raised and problems to do with research ethics identified. There was also a clear indication that part of the Hippocratic oath – ‘I will treat other doctors as my brothers’ – was being interpreted as a familial binding akin to the Mafia and few brother doctors were prepared to publicly question Green’s ideas. This was all in the 1980s and caused reforms in obtaining patient consent, monitoring the ethics of research, patient advocates were appointed at NWH and there was a general raising of consciousness about women’s rights to information and kinder treatment. The government also had to take on board recommendations from the inquiry (headed by lawyer Silvia Cartwright, now Governor General of New Zealand) that there were benefits from screening programmes and a National Screening Register should be set up in NZ. This is where my study comes in.

In 1988 the government decided to set up a national cervical screening programme. Initially, a pilot programme was set up in Dunedin in the South Island and in 1990 the government decided to set up another trial programme in the North Island in the Waikato Area Health Board (WAHB) area and I was contracted to construct a telephone questionnaire on the topic.

To prepare myself for doing the questionnaire I read a lot of material on cervical smears: technological material on brush versus spatula; doctors’ recall systems, statistics on smears, cytology, histology, women’s experiences and so on. I learned many things but the most significant piece of information was that telephone surveys like the one I was being asked to construct had been carried out in Australia and the number of women who said they had had smears bore no relationship to the numbers of smears read by laboratories – women were massively over-reporting that they’d had a smear. It seemed important to find out

why – were they just saying yes to get rid of the interviewer, were they saying yes because they knew they ought to have had a smear, or did they not know what the interviewer was talking about? I persuaded the WAHB to let me do a series of focus groups to find out women’s understandings of the process and the words they used before constructing the questionnaire. They agreed and I set up focus groups old and young, rural and city women to discover if they knew what was inside their bodies, what could go wrong and what interactions they had had with doctors over this process. There was an editorial in the *Lancet*, which said

All the necessary scientific facts for saving most of the lost lives have been known for 20 years [i.e. since mid 1960s]... [But] many with invasive cancer in the older age groups have never been screened at all; some do not know about the test, some do not know where to go for it and *some do not have the vocabulary to ask for it.*

(1985. Editorial, “Cancer of the Cervix: Death By Incompetence”, *The Lancet*, August 17:363-4, emphasis added.)

Therefore I was interested in the words women used about this process.

The third piece of information came from “The Gisborne Inquiry”, April – Sep 1999.

The Gisborne inquiry was again triggered by one woman asking questions about why she and others, who had had regular smear tests over the years, been told that their cells were normal, then found themselves with cervical cancer. Where the NWH scandal came from a doctor suppressing the knowledge that some women had abnormal cervical cells, in the Gisborne case one particular laboratory which read the smears was getting them wrong in a huge percentage of cases. Again the fault was attributed to one doctor, Dr Bottrill, but the resulting inquiry raised many more questions about quality control and registration of laboratories, training of cytologists and pathologists and ultimately about the National Screening Register (established between 1990 and 1992). This was set up without building in the required safeguards which could have revealed the poor laboratory work affecting all the women of the East Coast area.

23,000 smears belonging to 12,000 women and read by Dr Bottrill were sent to Sydney for re-reading. 2000 women were advised of abnormalities they had not previously been told about. 616 cases of cancer were identified, 519 of which had not been picked up by Dr Bottrill. Once again there were the testimonies from women to the inquiry which were similar to the submissions to the NWH inquiry – “I knew there was something wrong but my doctor said it was OK because the lab tests were clear” (brother relying on brother again).

The first part of the inquiry showed that laboratory standards were inadequate and steps were put in place for increased quality control. The second part dealt with the inadequacies of the National Cervical Screening Register. WHO and health departments of countries with their own national registers had published

widely on the appropriate way to set up a register. They said it should be centralised and that it should comprise of three sub-registers (cytology, population statistics and histology) which could be cross-tabulated. The process should also be opt-off – that is, women would actually have to ask not to be put on the register.

As it turned out 14 separate regional registers were set up – one for each area health board, they couldn't communicate with one another so if a woman moved from one place to another her records had to be put on paper and posted, histology could not be tied up with cytology so no one could monitor what happened to abnormal smears and it was opt-on so that every single time a woman had a smear she had to sign a release to allow it to be put on the register. Doctors advised very strongly against this configuration but it went ahead, duly proving its inutility and was finally and expensively centralised in 1997 – too late to pick up the misread cases of Dr Bottrill. The advice about setting up the system had come largely from computer companies, not fully aware of the medical requirements of an adequate screening programme. It had also been hampered to a degree by women's groups and Maori groups. They looked at the ethical problems revealed by the first inquiry and put in so many safeguards over women's privacy that the material collected for the register was not even available for statistical purposes. Maori groups went even further, saying that they were sick of being defined as the group with the worst health statistics (Maori women actually get cervical cancer at about 4 times the rate of Pakeha women) and therefore no information was to go out about Maori women.

The whole point of a screening programme is that it is medical and preventative and intended to reduce the number of deaths from cervical cancer. It needs monitoring and it needs to be based on efficient medical practices from surgery to cytology lab. With national statistics it would have been possible to see that fewer than average cases were being reported from the East Coast and further investigations made.

Analysis

This material raises several interesting issues: I will discuss two rather briefly.

DISCOURSE

The most interesting thread that ran through these three investigations was the language, much of it based on unequal power relations. As Fairclough said,

The ways in which we communicate are constrained by the structure and forces of those social institutions within which we live and function. Language is the primary medium of social control and power. Ideology is pervasively present in language.

(1989. N. Fairclough. *Language and Power*. London: Longman.)

Dr Peter Davis, at the NWH inquiry, made a submission that said the relationship of woman to doctor brings unacknowledged sexual politics into play. It enormously widens the gap in status that already exists between doctor and patient and extends the stereotype of passive woman and dominant male. Thus the physician may approach the woman with advice, commands and decisions rather than discussion – the relationship takes on the quality of a parent-child relationship. The woman is reluctant to ask questions because of her feeling of ignorance or a reluctance to cause trouble. She feels helpless in the encounter. The infantilisation of women is rooted in the power imbalance between doctor and patient. This was illustrated in Clare Matheson's evidence that when she told Professor Green that she was sick of coming to the hospital for repeated checks, he replied, "You will do what you're told".
(In Coney, Sandra 1988. *The Unfortunate Experiment*. Auckland: Penguin Books, p.243.)

In the NWH affair, there were the testimonies from both doctors and patients to the inquiry and the publicity sparked public debate in newspapers and magazines. The patients all spoke of their helplessness in the face of medical procedures and the medical testimony spoke of patronage. There were two interesting statements by doctors in letters to Metro magazine. One said women were acting like kids who were starting to grow up and were disappointed to find that their parents weren't perfect and another wrote that the inquiry "made poor old Herb into a symbol of medical oppression of the fair sex".

The pathologising of women's reproductive area sets an ideological base for understanding women's health and ill health. As well, the use, both in popular and medical literature about women's prime identity being in her reproductive organs contributes to this idea. Sexuality as well as reproduction comes into this construct and sexuality is equally pathologised in this discourse: because human papilloma virus (genital warts) is implicated in cervical cell change, and it is sexually transmitted, there was a suggestion originally that only promiscuous women needed smear tests. (Promiscuity in this context was initially defined as having more than one sexual partner. Later it was defined as having had four partners.)

The focus groups I conducted produced many interesting ideas from the participants about their bodies and their interactions with doctors. On the whole, while women knew they had a uterus/womb, most did not know about the cervix. Here are some of the statements women made during the focus groups about their understanding of their bodies and the smear process:

It's very sensitive isn't it? I mean it's our innermost parts and the most sensitive part. On the whole women are not baring it all, they're just not that way inclined, especially not our generation.

Had they asked a doctor for the smear? On the whole they waited to be offered one it because it seems rude to ask a strange man (or woman) to look at your genitals.

One woman said she had asked her doctor and when I asked her what she said she answered, "**Well, I said I'd been sleeping with a guy who is bit suss – could you have a look at me.**" Another woman said "**But is that a smear?**" and the first one replied, "**Oh well, while they're in there they look at everything.**"

Very few had the attitude of one woman who said,
I go once a year. I'm happy with the bits I've got and I don't want to wake up one day and find they're diseased – to me it's preventative medicine. I hate having it done but I'll go along.

If the doctor calls them up they go but don't like it

I hate it when the doctor says Whoops it's a bit cold. Sorry.

I hate having smears done. It's degrading and it hurts

Yeah I hate the way he says flop your legs open like a frog

You leave your pride at the door

Trivial matter loom large

I'll tell you one thing that always bothers me – what to do with my pants. Do you stuff them in your bag or fold them up. I don't know where to put them and afterwards you are all messy.

In matters of vocabulary they tended to refer to their genital area as "down there".

I know the word vagina but I wouldn't use it to a doctor because it's a doctor's word. I wouldn't want to say to a doctor "I've got a sore vagina" but I couldn't say 'sore fanny' either. We need to find a more casual way of talking about it.

The issues of unequal power were clear and the women felt they had few rights of ownership over their bodies:

My doctor would say you have thrush and I would say OK but he wouldn't say what caused it. She was asked why she hadn't questioned him further and she said **I felt the whole thing was not my business even though I knew it was, I mean, it's my body but these are professionals.**

Another one had been told she had thrush and she thought it was polite way of saying syphilis.

A older woman showed the complexity of the interaction with her doctor. He took her blood pressure which was a bit elevated before she had her smear. She said,

He said that might be because of what you're having done. I thought that was a sensitivity by the doctor. At one time doctors didn't think that you might be a bit stewed up yourself about having such things done. You know, I felt a lot better about it and even to the extent that he rang twice for the nurse and she didn't come and he actually went on with the examination even though she wasn't there and I felt that was a feeling of trust in me, you know, that he didn't have to worry that I was one of those people who might kick up a fuss. I sort of came away feeling thoroughly better that he treated me like that.

However, she went on to say that it was probably a one off and that if she had mentioned the little things that made her feel better he wouldn't have understood.

The evidence given at the Gisborne inquiry contained many similar statements from the women whose smears had been misread. The central theme of their testimony was that they did not feel it was their place to express their unease about continuing physical symptoms and that the doctor must know best.

The second issue arising from these studies is the question of research ethics. Ethical codes are codes for making moral decisions but they are time and culture specific. They are based on four core principles: autonomy, non-maleficence, beneficence and justice. However, there are several metaethical perspectives which underlie codes of ethics and each investigation or inquiry came from a perspective which could be seen as ethical. These approaches are:

1. Teleological ethics and professional purpose. This stance orients actions to ends which have been defined as good and believes in knowledge for knowledge's sake. While Professor Green broke the four core principles of non-maleficence and so on, he acted according to an ethic which believed in a justifiable end and a justifiable pursuit of knowledge.
2. Utilitarian ethics and cost benefit analysis. This approach is results-oriented and is based on the idea of the greatest good for the greatest number. This is more or less what the National Cervical Screening Register achieved although there is a footnote to this outcome.
3. Deontological ethics and categorical duties. This ethical code is based on the idea of categorical imperatives, of absolute right and wrong. It allows no room for change or exception. None of the three studies mentioned above followed this ethic unless a rather fixed idea about women by some of the actors counts in this category

4. Critical philosophy and advocacy research. This recognises self-interest and lack of objectivity in research but endeavours to speak FOR, not ABOUT, the participants with the intention of bringing about change for the better. I tried to do this. However, this can also have unintended consequences.

The NWH inquiry, which coincided with the rise of feminism in New Zealand, raised awareness of women, their right to have a voice in research which affects them and, more broadly, in the medical treatment they receive generally. The result of this consciousness raising was the establishment of patient advocates and the appointment of women to many statutory bodies and committees. Maori women, equally, gained representation and both groups insisted that informed consent and confidentiality be central to all research on women.

The interesting corollary of this was that when the national register was established, women's groups (and Maori even more so) insisted on so many safeguards that the register was virtually useless. This was commented on by the Scottish woman doctor who was brought in to oversee the inquiry. She has recently returned to New Zealand to present her final report and again commented on the barriers raised by women and Maori to the detriment of the medical purpose of the register.

This discussion of language notes the paradoxes: women who had no voice in some 1980s research; women given a voice in the focus groups but being unsure what to say; and, finally, women saying 'we know but we will not say'.