



A patient's response to recent criticisms of the findings in the report of the Cervical Cancer Inquiry 1988

In light of the articles and letters published recently in the New Zealand Medical Journal relating to the Unfortunate Experiment, and Professor Linda Bryder's book *A History of the 'Unfortunate Experiment' at National Women's Hospital*, it seems timely and only just, that as one of the patients of National Women's throughout the years concerned, I should present my perspective. I was part of Professor Green's experimental group which becomes obvious when my clinical notes are read. I am the woman who was known as 'Ruth' during the course of the Inquiry. As a party to the Inquiry I received copies of all submissions and transcripts.

I agree with Professor Frank Frizelle that '...it is important...not to forget the real issues...' Patient consent to be part of 'research', 'trials', experiments' – call them what you will, was not obtained during the years in which Professor Green was carrying out his work at the hospital and his research was not confined to carcinoma in situ of the cervix. The progressions of carcinoma in situ of the vagina and of the vulva were also followed. Many women were harmed by these programmes and some died. Like Frizelle, I agree that the system was at fault, which is why there was an apology from the School of Medicine when the affair had drawn to an end, though not from the hospital. Professor Bonham who was Head of Obstetrics and Gynaecology, and Chairman of the Hospital Medical Committee at the hospital during that time, was found guilty of disgraceful conduct by the Medical Council who, in the aftermath, conducted their own inquiry.

There are opinions coming from some who know little about the affair, and have little knowledge or understanding of *The Cartwright Report* and recently produced scientific papers. For their sakes and for those who have not been fortunate enough to read the relevant literature on this topic, I will present my case history; I will also make some comments arising from the literature the Journal has presented to the public, in particular, the writings of Professor Linda Bryder, in the journal and also in her book. There are a number of errors in her book and in her recent editorial. She has corrected two of them in her book in regard to my personal history, but the major ones dealing with her interpretation of my medical history remain unchanged, and her belief that there was no experiment at National Women's is incorrect.

In order to clarify matters it is essential that I present a summary of my clinical notes with my own comments.

In brief:

- August 1964—Admitted for cone biopsy following an A3 smear.
- Green came to see me in the ward and said he was now not going to perform the biopsy. I was discharged after a colposcopy.
- March 1965—Colposcopy and punch biopsy. Path report = carcinoma in situ of the cervix.
- In a letter Green wrote to my GP on my discharge in 1979, he stated that I had had a cone biopsy in 1965. This is incorrect. I did not have a cone biopsy until 1971.

2.4.65 to 6.11.69

- Five smears = 'Cells suggestive of but not conclusive for malignancy.
- One smear = Cells strongly suggestive of malignancy.
- Four smears = Cells conclusive for malignancy.

23.3.70 Colposcopy clinic. Smear = Cells conclusive for malignancy.

24.3.70 Admitted. Wedge biopsies comprised of three sections.

1. Histology: Carcinoma in situ of the cervix.
2. Carcinoma in situ of the cervix.
3. Carcinoma of the cervix with microinvasion.

Discharged.

In 1970, a paper written by Green appeared in *The Australian and New Zealand Journal of Obstetrics and Gynaecology*.

Green wrote:

...The only way to settle finally the problem of what happens to in situ cancer is to follow indefinitely patients with diagnosed but untreated lesions...A group of 27 women (up to December 1967) are being followed without "treatment"...after an initial diagnosis of CIS has been established by biopsy.

21.5.70 to 7.1.71

One smear = Cells strongly suggestive of malignancy

Two smears = Cells conclusive for malignancy

14.2.71 Re-admitted

EUA Cone biopsy of the cervix

Histology: Carcinoma in situ with microinvasion of the cervix.

Discharged.

22.4.71–15.10.71

Two smears = Cells strongly suggestive of malignancy

23.11.71 Re-admitted

E.U.A. Wedge biopsy of the cervix

Histology Report: Carcinoma in situ of the cervix.

Discharged.

10.3.72–11.12.75

One smear = Atypical cells but no evidence of malignancy

Two smears = Cells suggestive of but not conclusive for malignancy

Two smears = Grade 3

In the *New Zealand Medical Journal* October 1974, Green had written:

...This series of 750 cases of in situ cancer, and the following of 96 of them with positive cytology for at least two years, represents the nearest approach yet to the classical method of deciding such an issue as the change or not from one state to another – the randomised controlled trial. It has not been randomised and it is not well controlled, but at least it has been prospective.

Bryder writes in her editorial that in a published oration to the 1990 General Scientific Meeting of the Royal Australasian College of Surgeons in Wellington, Sir Graham Liggins commented on the fact that the 1984 McIndoe article on which 'the cervical cancer inquiry was based, was misinterpreted by the authors of the Metro article and by the judge'. This misinterpretation according to Bryder consisted of regarding it as a prospective study rather than a retrospective study. Bryder's view does not equate with what Green published in the *New Zealand Medical Journal* October

1974.Green's study was prospective and McIndoe's article was a retrospective report of Green's study material.

27.1.76 E.U.A Ring biopsy of cervix. D&C.

Path report = Curettings: Sections show fragments of endocervical tissue and a few portions of carcinoma in situ of the cervix without stroma.

Biopsy cervix = Carcinoma of the cervix – Excision appears incomplete

The overall thrust of Bryder's argument is that Green was not performing an experiment. How then does she explain the conflicting management policies described by Green below?

In April 1968 Green's lecture notes to doctors state: 'Conventional treatment of CIS comprises cone biopsy excision' and that women with 'follow-up doubtful or positive smears require further biopsy excision or even hysterectomy'.

In 1969 Green describes a group of patients diagnosed and treated (sic) by punch biopsy that were given no further treatment and followed with persistent positive cytology.

Surely one group received conventional treatment and the other group were in an experiment of which I was part.

8.4.76–27.9.79 The five smears I had during that time were Grade 1.

This is taken by Linda Bryder as an indication that I had been well treated. It is also where Bryder's 'analysis' of my case breaks down completely as does her criticism of the expert Professor Per Kolstad's evidence.

Kolstad described my case as 'terrifying mismanagement'. Bryder makes the statement that '...under questioning at the Inquiry Kolstad admitted that his source of information on this (my clinical history) was primarily the *Metro* article.' In fact, cross examined by David Collins, counsel for Green, Kolstad made it very clear that his submission had been based on the *Metro* article but that before taking the stand he had read my file and stated that '...I have read it through and it seems to be well up to what was presented in the *Metro* article.' He reaffirmed adamantly what he had said earlier. For Bryder to state that his comment re 'terrifying management' related to one case only, namely mine, is extremely misleading. He studied other files such as those of Mrs T, 62W/10, Mrs L, 64W/214, Mrs R, 66W/74, Mrs C, 69W/63. In each case he used similar terms; 'mismanagement', 'severe mismanagement', 'horrified' by the 'mismanagement' and 'another example of terrifying mismanagement'. Under cross examination he was adamant that the women concerned had not had the appropriate treatment.

What Bryder overlooks is that in my case, the scar tissue caused by multiple biopsies had led to cervical stenosis. The defoliating cells from the endocervix are not available when the smear is taken. The condition also causes severe dysmenorrhoea. At the Inquiry, the dangers of this condition in regard to negative smears were described by Per Kolstad and also by Dr Colin Laverty, a gynaecological histopathologist and cytologist from Sydney who had been called by the Commission. Laverty said '...problems of increased age and previous conisation (often multiple)

must have affected the reliability of cytology in the group of patients which is the subject of this inquiry’.

Assisting Counsel Lowell Goddard pointed out during her final summing up, that this very danger had been spoken of in a paper by Kreiger and McCormack, which Green had used in 1966.

All this information was available to Bryder in the transcripts of the Inquiry and in my own book, both of which she has read. And there is little point quoting specialists who say that a patient need have only three negative smears before discharge as opposed to my five. Good specialists would not make such a decision when the patient was suffering from cervical stenosis and smears could be unreliable, especially when the last histological report of that patient indicated that some form of carcinoma was still present.

Green described the condition in regard to the dysmenorrhoea in my notes when he wrote: ‘On examination the explanation is fairly obvious – the vaginal cervix has now almost disappeared and the external os is so narrowed as to be very difficult to pick up. A No 2 dilator could not be introduced ...she may need admission for a dilatation.’ I was obviously suffering from cervical stenosis still and this should have set alarm bells ringing.

This E.U.A. and Dilatation of Cervix took place on 5.4.77.

The Path Report following this procedure reads as follows: ‘Curettings: L.M.P. *Sections show Fragments of carcinoma devoid of underlying stroma, probably carcinoma in situ.*’

There was nothing equivocal about this report as Bryder states. Malignant cells were still present. That is obvious, and overall my file may indicate ‘follow-up’, but not the ‘careful follow-up’ that Bryder would have us believe. In the light of no definitive, conventional or adequate treatment, any thoughtful person would wonder just what was being followed up. Professor Iain Chalmers complains that no one has provided him with a definition of ‘conventional treatment’. As a practising gynaecologist in the sixties and seventies he should know what conventional treatment involved at that time. If he cannot remember then it has been defined in this response.

When Collins suggested to Kolstad that ‘...there was one equivocal pathological report of probably carcinoma in situ, correct?’ Kolstad’s reply was, ‘Yes. That is not equivocal, that is quite certain that there was something there that could be called carcinoma. They did not have underlying stroma therefore they couldn’t tell if this was an invasive cancer. That is the result of this report and that was on 5th of April 1977.’

Collins asked Kolstad if the pathologist could have reservations about the distinct possibility of it being carcinoma in situ when he uses the words ‘probably carcinoma in situ’, Kolstad’s reply was, ‘Yes, because he had carcinomatous tissue with no underlying stroma, but was a little suspicious that this could also be an invasive lesion and if I had that report, I would at once have done a conization.’

Finally in response to Collins’ insistence of the importance of the negative smears, Kolstad says, ‘I have tried to tell you over and over again now, that 5th April 1977 there was a positive histopathological report...’ It is clear that Koldstad did know

about the five negative smears and that he did not consider them evidence that the disease was cured.

8.9.77 Return to clinic.

Green wrote in my file that the cervix was still somewhat stenosed and commented that 'The histology report is somewhat surprising. Smear taken. See in one year.' Smear Grade 1.

27.9.79 Green wrote 'Findings as before i.e. atrophic cervix...I do not think any further follow-up is indicated.' Smear Grade 1.

This despite the persistent stenosis.

I was discharged from the hospital with no further treatment.

As Bryder says, '...the categorisation of smears was not a precise science.' The concept of false negative smears was not unknown in the sixties and seventies. All the more reason in my case, and the cases of other women, to not disregard a negative smear result after years of positive ones, and biopsies that repeatedly showed the present of, at best, carcinoma in situ, and especially so when stenosis had occurred.

1985. Smear test carried out by my GP returned a result of Grade 3. This time I decided to go to a private specialist. I had not moved between the public and private sectors of the health service prior to this as Bryder alleges in her book. (p 193)

Following a biopsy and examination at Brightside Hospital I was admitted to National Women's and on 28.10.85 I had a further examination under anaesthetic, biopsy of cervix and insertion of caesium after-loaders. The cancer was classified as Stage 1B, and the path report revealed the curettings showing invasive squamous carcinoma of the cervix, as did the biopsy of the cervix. On 17.12.85 I was subjected to a Wertheim's hysterectomy and pelvic lymphadenectomy. I have had no recurrence of the disease and see myself extremely lucky when I consider what happened to some other remarkable women that I came to know.

When I first met with Graeme Overton and he told me that I had had positive smears during my years at National Women's, I was shocked and extremely upset that I had never been told this. Overton's comment was that Green was 'conservative' in his treatment. In a letter he wrote to the Medical Superintendent prior to my radiation and surgery for cancer, Overton's summary of my case ended with '...further biopsy in 1977 showing carcinoma in situ'. This shows Bryder as incorrect again.

There are other points Bryder makes that must be addressed.

Bryder notes that Archie Cochrane supported Green's research but she omits to observe that when the two of them made an application to the British Medical Research Council for funding to continue Green's work, it was declined as unethical. This was conceded by Green at the Inquiry. Bryder is misleading again.

As to the debate about how many of the women died as a result of this research programme, one would be one too many, but statistical and scientific research has shown that there were more than that. Those of us who were part of the experiments, and those who lost dear ones, are outraged that a lay person now tells us that all we went through was for our own good. There is no sensitivity shown to these people.

Women suffered from the research into the study of the natural history of carcinoma in situ of the cervix, and of the vulva and vagina, but there was also the trial known as the R-series. This was another of Green's trials and was approved by the Hospital Medical Committee in 1972. It was a randomised trial to gauge which was more effective, caesium treatment followed by surgery, or caesium treatment followed by radiotherapy. The patient was examined under anaesthetic in the theatre. If suitable for surgery the randomness was decided by the toss of a coin while the patient was still anaesthetised. Later the patient would be told that it had been decided that 'this' particular treatment was best for her. I know a woman who has been suffering since 1975/76 as her organs slowly deteriorate; a result of the radiotherapy she received when included in this trial after it had been ascertained that she was suitable for surgery. She has had over thirty years of misery.

The few matters I have raised relate largely to my own involvement in the National Women's experiments. Any thinking person must wonder how many other errors there are.

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References:

1. Bryder L. A History of the 'Unfortunate Experiment' at National Women's Hospital.
2. Frizelle F. The missing manuscript [editorial]. NZ Med J. 2010;123(1319).
<http://www.nzma.org.nz/journal/123-1319/4252/content.pdf>
3. Cartwright S. The Report of the Cervical Cancer Inquiry at National Women's Hospital. pp 232-233.
4. Cartwright S. The Report of the Cervical Cancer Inquiry at National Women's Hospital. pp 258-264.
5. McCredie MRE, Paul C, Sharples K J, et al. 'Natural history of cervical neoplasia and risk of invasive cancer in women diagnosed with cervical intraepithelial neoplasia 3: a retrospective cohort study. Lancet Oncol 2008,9 425-434.
6. McCredie MRE, Sharples KJ, Paul C, et al. "consequences in women of participating in a study of the natural history of cervical intraepithelial neoplasia 3. Aust & NZJ Obstet & Gynaecology. 2010. (epublication ahead of print).
7. Green G.H. 'Cervical Carcinoma in situ: An Atypical Viewpoint'. Australian and New Zealand Journal of Obstetrics and Gynaecology. 10 Feb. 1970. 41-8. p 47.
8. Green G.H. 'The Progression of Pre-invasive Lesions of the Cervix to Invasion' NZMJ. 80 OCT. 1974. 279-87. p 285.
9. Green G. H. 'Invasive Potentiality of Cervical Carcinoma in Situ'. International Journal of Obstetrics and Gynaecology. 7 August. 1969 157-71.
10. Kolstad P. Professor. Brief of Evidence.
11. Transcript of Inquiry p 5437.
12. Transcript of Inquiry. pp5444- 5455.
13. Transcript of Inquiry. pp5388-5394.
14. Matheson C. Fate Cries Enough. Hodder and Stoughton. p 186.
15. Brief of evidence for the Inquiry. p 17.
16. Matheson C. Fate Cries Enough Hodder and Stoughton 1989. p 186.

17. Transcript of Inquiry. p 5439.
18. Transcript of Inquiry. p 5440.
19. Transcript of Inquiry. p 5441.
20. Letter to Medical Superintendent. National Women's Hospital. 1985.
21. Cartwright Report. p 82.
22. Cartwright Report. pp 168-170.