

## Patient-centred ethics, the Cartwright Inquiry and feminism: Identifying the central fallacy in Linda Bryder, *A History of the 'Unfortunate Experiment at National Women's Hospital' (2009, 2010)*

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### Abstract

The Cartwright Report was published by the New Zealand government in 1988. It presented the findings and recommendations of a judicial inquiry into allegations that women with cervical carcinoma in situ had been untreated or under-treated in the course of medical research at national Women's Hospital. The allegations arose in an article called 'An Un fortunate experiment at National Women's Hospital' authored by Phillida Bunkle and Sandra Coney. The recommendations included through reform of medical and research ethics. These popular reforms are usually regarded as feminist achievements and significant ethical milestones.

A book by Professor Linda Bryder published internationally in 2009 and 2010 questions the reality of the 'experiment', the findings of the Cartwright inquiry and argues that the recommendations made little contribution to changes already underway within medicine.

This article draws on the records of the inquiry, particularly the case histories of the women involved to refute Linda Bryder's arguments.

### Summary

This article calls upon my personal recollections and documentary evidence to argue that Professor Linda Bryder's anti-feminist bias means that her book *A History of the 'Unfortunate Experiment at National Women's Hospital' (2009, 2010)*, is built upon a series of errors and so misrepresents the history of the Unfortunate Experiment.

Academic discussion of this book has presented the key issues as an intra-medical debate (Manning, 2009) between those who believe like Bryder that Green purveyed standard treatment and those who regarded Green as an incompetent doctor who had to be exposed. Concluding this debate in this way reinforces the idea that medical reform concerns the internal morality of the medical profession rather than external accountability of the medical system to patients (Paul, 2000). Such a perspective has minimised the feminist voice and obscured the extent to which the Inquiry and subsequent reforms grew from the analysis developed by the Women's Health Movement which was focused on systematically safeguarding physical safety premised upon respect for the ethical autonomy of patients.

Bryder suggests that Cartwright's recommendations came about from personal influence of Sandra Coney and myself upon the judge, sometimes implying a semi clandestine connection (Bryder 2009, 2010; 2010, June). In fact the only time I meet the judge was at a function one year after the Report was published, and do not recall ever speaking to her except within the formal legal constraints of the Inquiry room.

Patient experiences and case notes provided much of the evidence which premised the original *Metro* article written by Sandra Coney and I, and the three submissions to the Cartwright

Inquiry, from Fertility Action, written by Sandra Coney, Dr. Forbes Williams and myself. An analysis of case histories by the Inquiry's medical advisors was fundamental to the evidence upon which the Judge made her findings, reached her conclusions, and based her recommendations.

Our process and that of the Inquiry put the experiences of the women patients first. Sandra and I built our case upon a patient-centred vision of medical ethics which arose directly from our experience in developing the Women's Health Movement in New Zealand. The recommendations of the Inquiry embodied a patient-centred perspective; a singular achievement for feminism.

Bryder, by contrast, marginalizes the experience of women patients and fails to examine the evidence presented in their case histories. The reality described in these case notes contradicts the claims made by Associate Professor Green and his colleagues at the Auckland University Post Graduate School of Obstetrics and Gynaecology. In summary Green claimed that from the early 1960s and particularly in their 'special series' formally instituted in 1966, the hospital was providing conservative treatment of in situ carcinoma of the cervix (CIS) in the interests of saving women from more invasive treatment. Bryder's bias means that she invariably takes Green's part in this conflict.

## Introduction

The publication of Professor Linda Bryder's book *A History of the 'Unfortunate Experiment at National Women's Hospital'* (2009, 2010) both in New Zealand and internationally has prompted a reconsideration of both the events around the Unfortunate Experiment and the changes which followed from it, in which I was intimately involved.

## Background

In 1987, in an article entitled 'An Unfortunate Experiment at National Women's Hospital', Sandra Coney and I presented evidence that for many years some women presenting with (CIS) at National Women's Hospital (NWH) had not been treated or had been under-treated. We showed that Associate Professor Herbert Green and his colleagues at the Auckland University Post Graduate School of Obstetrics and Gynaecology had systematically followed this course so that Green could test his theory that CIS was a harmless condition. We reported that a significant number of these women had gone on to develop invasive cancer of the cervix and some had died (Bunkle & Coney, 1987). We provided evidence that in 1966 this regime had been formalised into a prospective research programme, which had never been formally ended. Even when, in the early 1970s, deaths occurred and the dangers had become apparent, the institution, including its Board, senior clinicians and particularly its head, Professor Bonham, did not act to save the remaining patients, and marginalised critics of the programme within the hospital.

Sandra and I had since 1970s been women's rights activists and had increasingly focused on women's health. We worked together on a variety of issues concerned with documenting and giving credence to women's experiences in the health system. We were alerted to the issue at NWH in 1986 when a retrospective study of the results of the research was drawn to our attention by a colleague. This study, by McIndoe, McLean, Jones and Mullins (McIndoe, McLean, Jones, & Mullins, 1984) reviewed the case notes of women diagnosed with CIS at the hospital between 1955-1976. Most were treated at the hospital 'CC' or Consultation Clinic under Green. Results were presented by arranging the cases into two contrasting groups performed retrospectively by McIndoe and his co-authors to assist analysis of the results. The largest

group of 817 women had returned to negative (normal) cytological cervical smears following biopsy diagnosis and differing degrees of treatment. If, as is usual, a return to normal smears is the measure of successful treatment these women had been successfully treated. Of this group, 1.5% developed invasive cancer. The contrasting, smaller group of 131 women, continued to have positive smears. Their outcome was starkly different. 22% of these women had developed invasive cancer by 1983.<sup>1</sup>

Our article was based around the experiences and case notes of one of Green's patients Clare Matheson (known at the time as patient Ruth) and extensive, mostly tape recorded interviews with doctors and other professionals associated with Auckland University and NWH (Bunkle & Coney, 1987).

The allegations in the Unfortunate Experiment article were examined in a Judicial Inquiry chaired by Judge (later Dame) Silvia Cartwright. Sandra Coney and I, with the help of Dr. Forbes Williams and our Counsel Rodney Harrison, made three submissions of evidence to this Inquiry. The first (Bunkle, Coney, & Williams, 1987b) provided substantiation of our claims and an analysis of a large number of women's case histories. These showed that Clare's experience was shared by many other patients. The second submission (Bunkle, Coney, & Williams, 1987a) argued that the problems were systemic and advocated innovative changes to the regulation of medicine; and the third summarised these arguments, put forward draft legislation for change and provided evidence concerning 26 deaths which had resulted from the regime (Harrison, 1987).

Judge Cartwright's Report of the Inquiry, presented to government in July, and made public on August 8 1988, found that the allegations we had made were largely correct. She made a series of recommendations for comprehensive change in medical ethics which would place the patient and his/her interests at the centre of the medical system (Cartwright, 1988). These changes included the scrutiny of patients' complaints by a Health Commissioner external to the medical professions, a legislated Code of Patients' rights, the establishment of independent research ethics committees with half lay membership including a lay chair, and a population based national cervical screening programme free to users. These changes were a decisive move towards patient-centred medicine and are usually regarded as milestones in the recognition and protection of patients' rights and medical ethics.

## Revisionism

In 1990, journalist Jan Corbett (1990b) made a series of unfounded allegations of bias and misrepresentation in our article and subsequently by the Inquiry. Corbett alleged that we had misunderstood the nature of the 1984 retrospective study. She further asserted that we had based our claim that there had been an experiment on the mistaken belief that it was Green and his colleagues who had established two groups of patients. Furthermore, she argued that we had, as feminists, recruited Judge Cartwright to our point of view and the judge had colluded by ignoring, or failing to hear, contrary evidence.

The appropriate arena for these allegations would have been a judicial review of the inquiry by one of the parties to the proceedings. An unsuccessful attempt to bring a judicial review was made by Mrs. Smith, a neighbour of Green's, and Dr. Bruce Farris (Bryder, 2009, p.158) who, Bryder neglects to mention had been charged with professional misconduct over his contribution to events as a senior hospital board manager and member of the internal committee which had failed to stop the experiment. Bryder claims that the application for review was withdrawn and reiterates Corbett's view (Corbett, 1990a) that the outcome endorsed the view that we and

<sup>1</sup> A thirty year follow-up showed the risk of invasive cancer for under or untreated women was 31-50 %, but only 0.7% in women treated conventionally (McCredie, Sharples, & Paul, 2008).

the Inquiry had misunderstood the structure and significance of the 1984 McIndoe paper (Bryder, 2009, p.158). She claims that the Solicitor-General found that we were wrong (Bryder, 2009, p.160).

Bryder's account accepts as accurate secondary sources from newspaper and magazine accounts derived from highly partisan views (Smith, 1990; *Auckland Star* August 1 and 8, 1990) without checking their veracity against the primary documents (Bryder, 2009, p. 160). There are, as a result, multiple errors in her account.

She misunderstands the role of the Solicitor-General. New Zealand has an independent judiciary. The Solicitor-General is an officer of government, who acts on instruction from Cabinet. Applications for a judicial review are heard before a judge of the High Court.

In the High Court hearing, the Solicitor-General acted on behalf of the Attorney-General in arguing that the application from Smith be dismissed (Coney, 1993, p. 43). The Solicitor-General, as his document 'Application to Strike Out' makes clear (McGrath & Scholtens, 1990), was arguing for dismissal *against* Smith's application. The application was 'struck out' and 'dismissed' by a judge of the High Court, not by the Solicitor-General.

The views Bryder quotes as part of the judgement were in fact part of the presentation by the Solicitor-General while arguing *for* the strike out.

Bryder writes that the Solicitor-General 'while agreeing that Coney, Bunkle and Cartwright had misinterpreted the McIndoe paper, explained that he was disallowing it because of...' other reasons (Bryder, 2009, p. 158). Bryder continues, 'At least, Mrs. Smith observed, the Solicitor-General did acknowledge that the McIndoe paper, which was central to the Inquiry, did not describe a prospective division of patients into two differently treated groups, as the original Metro article had claimed' (2009, p. 158). This claim was made by Mrs. Smith *not* the Solicitor-General.

Bryder does not mention that Mrs. Smith acknowledged through her counsel that she had misunderstood Judge Cartwright's findings about the McIndoe study. Mrs. Smith, in fact consented to her application being struck out, 'agreeing the grounds on which she had sought the review had no substance' (Coney, 1993, p. 15). Bryder's assertion that the Inquiry findings turned on this paper is wrong, as is the assertion that Sandra and I had misinterpreted it in our original article. A check of primary documents would have shown how unreliable Bryder's sources were.

Yet to those resistant to the findings of the Inquiry, the High Court's dismissal of the application became further evidence of bias in the judiciary (Bryder, 2009, p. 160).

### **Professor Linda Bryder's revisionist history**

Corbett's challenges in 1990 slowed but did not stop the progress of reform of patients' rights. In 1994, New Zealand became the only jurisdiction with a legislated Code of Patients Rights and an independent external enforcement system in the Office of the Health and Disability Commissioner (as legislated in the Health and Disability Commissioner Act, 1994). A system of research ethics committees with half lay membership was established, which included supervision of clinical observational studies. A successful population based cervical screening programme based on cytological smears began (Skegg, 2009).

Bryder's argument sometimes relies on Corbett's evidence, rather than on primary sources. For example, Bryder makes a series of errors in recounting Clare Matheson's experiences (2009, pp 63-65). These errors could have been avoided if she had used Clare's own published accounts (Coney, 2009b, p.146; Matheson, 1989, 2010).

The Cartwright Report accepted the international experts' agreed definition of conventional

treatment for CIS or invasive cancer as the removal of the abnormal cells, followed up to ensure that eradication has been complete (Cartwright, 1988 pp. 106, 107). If cytological smears remain positive on follow up it shows that abnormal cells are still present. Further action will then be triggered to identify and remove those cells and ensure a return to negative, that is normal smears.

Bryder argues that the women were being appropriately followed because they had a great many treatments. Bryder uses the word 'treatment' ambiguously. The patients had many clinical procedures, but contrary to accepted international practice many of these procedures, which Bryder classes as 'treatments' were not intended to remove, but only to observe the development of abnormalities. This has recently been reconfirmed in an empirical study based on an independent blind examination of the original cytological specimens which found that 'women underwent numerous interventions that were aimed to observe rather than treat their condition' (McCredie et al., 2010, p.107). One of Green's 'special series' made explicit that his punch biopsies were intended to disturb lesions as little as possible.

In summary the propositions of Bryder's argument are:

1. Medical literature shows that debate about the nature and invasive potential of CIS was legitimate in the 1960s and has remained so.
2. Green's 'conservative treatment' was the similar to that of leading experts around the world, particularly Joe Jordan of Birmingham, Per Kolstad of Norway, and Malcolm Copleston of Sydney.
3. Green's conservative management regime was motivated by a legitimate intention to, and actually did, save women from unnecessarily invasive treatment, especially surgery.
4. Green's management was not about studying the disease but closely monitoring patients individually and treating them as appropriate. This was international best practice at the time; and shows that patients were neither under treated nor denied treatment.
5. Since he was providing best practice and did not divide patients into groups, distinguished by different treatment regimes, Green was not conducting an experiment.
6. Since there was no experiment the issue of non-consent to research does not arise. Green provided information to patients which was in line and possibly better than with normal medical treatment at the time, and the information provided in fact satisfied many patients.
7. Green's view of CIS as rarely if ever invasive was reasonable, as therefore was his and his colleague's resistance to a population cervical cytology screening programme.
8. Judge Cartwright accepted Bunkle and Coney's erroneous analysis, particularly she believed that Green had established two contrasting treatment groups, and wrongly based her assertion that there had been an unethical experiment on this error.
9. Judge Cartwright demonstrated bias in failing to acknowledge that many patients were very satisfied with their treatment by Green and felt sufficiently informed.
10. Judge Cartwright got it wrong because she was unduly influenced by Sandra Coney's personal feminist agenda.
11. The outcome was not a milestone in medical ethics, but based on erroneous conclusions occasioned by bias.
12. Feminists were powerful enough to sway the Judge and bias the Inquiry but they were not powerful enough to effect medical reform, which already had significant momentum.
13. The association between feminism and major ethical reform of medicine and human research is not therefore valid.

Each of these propositions has been subject to criticism in a thorough rebuttal (Manning, 2009) and publicly refuted by some of the senior doctors most centrally involved, particularly Professor, now Sir, David Skegg (2009), Dr. (now Dame) Linda Holloway, Dr. (now Professor)

Charlotte Paul (2009a, 2009b) and Dr (now Professor) Ronald Jones (Jones, 2009a, 2009b, 2009c).

Propositions 1-4 provide the foundation of Bryder's argument. If any one cannot be sustained in the face of available evidence then her thesis stands refuted. Together these propositions seek to argue that Green 'was part of an international community of medical researchers who were questioning the significance and status of a diagnosis of CIS' (Bryder, 2009, p.31). In a detailed critique of the errors in this claim, Paul (2009b) includes documentation of Green's 'scientific misconduct' (p.129) in a post facto reclassification of his research subjects.

### **The centrality of patient case notes**

Judge Cartwright did not base her judgements on a belief that Green had divided patients into clinically contrasted management groups. The Inquiry heard evidence from 84 patients and their relatives (Cartwright, 1988, p. 115). Most importantly the Inquiry went back to the original sources and carefully studied thousands of case notes. These were stored in a large walk-in safe at the inquiry and parties to the Inquiry, such as Sandra and I, had access to them on condition of anonymization of cases used in evidence. The Inquiry's team of medical advisors prepared a thorough Medical Review based on analysis of cases. The results are available in the Cartwright Report (pp. 228-238).

Judge Cartwright weighed Green's words against the evidence contained in patient accounts and medical case histories that showed what he was actually doing. She found that often a gulf existed between his claims and what actually was done for patients. By complete contrast, Bryder accepts Green's words at face value. Bryder did not have access to the case notes on which the Inquiry findings were based. Unlike the Judge, she neither interviewed patients, nor made extensive use of the publicly available case notes. Crucially, without the information contained in the case notes, Bryder has little evidence against which to assess the reality or otherwise of Green's practice.

The clinical notes showed a huge gap between what Green and his medical colleagues said they were doing and their actual practice, revealing not conservative management, but delays in definitive treatment of months, years, or altogether. Green, and Bryder, claimed that he was practicing 'conservative management' of CIS. At the time, this meant treatment by cone biopsy which conserved the uterus, followed up to ensure it had been effective in removing the entire lesion. Invasive cancer was treated at least by hysterectomy. In the notes, Sandra and I found that it was not uncommon for smear or even biopsy results classed as 'suggestive', 'strongly suggestive' or even 'conclusive' for malignancy not to be acted on. Some women were 'followed' for years as lesions grew more extensive and serious.

Indeed sometimes Green did not treat CIS at all, but only acted once the women had unequivocal invasive cervical or vaginal cancer. Even this was allowed to spread, sometimes for years, until it was grossly symptomatic and clearly visible on examination. At this stage, intervention was either terribly mutilating or impossible, giving the lie to Green's claim to be saving women from invasive interventions.

As Counsel Assisting the Inquiry, Lowell (now Judge) Goddard said in her summing up, that expert witnesses were unanimous in their condemnation of the reality they found recorded there (Goddard, 1987, p.24)(Goddard, 1987a: 24). They were shocked to discover the extent of Green's non-treatment and the length of delay in removing even the most serious lesions. According to those experts, Green failed to treat patients in a timely manner.

Bryder had access to the transcripts of the cross examination of international experts who consistently condemned Green's lack of treatment. Bryder, nevertheless, suggests that when

these experts gave evidence they were resiling from their former support for similar treatment. She explained the abhorrence these experts expressed about the treatment recorded in the case notes as a hypocritical attempt to absolve themselves from a record of similar management (2009, pp. 191-192).

Bryder's central premise is that Green's treatment was not experimental but rather, international best practice. Bryder denies the Judge's conclusion that by, 1966, there was a consensus on the treatment of CIS and that only Green was outside it. *'There was'* she Bryder argues *'no consensus about the invasive potential of carcinoma in situ, either in 1952 or in 1976'* (Bryder, 2009, p.28). (Bryder, 2009: 28).

Her argument depends heavily on her interpretation of the international expert witnesses to the Inquiry, especially Per Kolstad, Malcolm Coppleson, and Joe Jordan who were recognised world leaders in the field. The evidence about their work is, therefore, worth examining in some detail.

## Kolstad

Professor Per Kolstad, was an expert from Norway, who in 1973 had visited NWH and reviewed six cases and attempted to persuade Green to treat them.

In his evidence Kolstad reviewed the complete notes of two of these six cases (Kolstad, 1987, p.20). Of the first case, (Case one 64/ 48), he said that in 1973 he had 'advised Dr. Green and Dr. McIndoe that they should excise the complete lesion' ... 'Dr Green did not agree with me and he wanted only to follow the patients without any treatment'. She had CIS 'far down into the vagina' for which Kolstad had recommended radiation. (p. 20). Despite this advice she was 'followed' for another 10 years, 'the lesion was never treated and continued to shed malignant cells...' and 'this' said Kolstad 'is an example of mismanagement that should never have occurred' (p. 21). Professor Kolstad told the inquiry that if 'treatment had been given...in 1964, the patient would have been cured for extensive CIS lesion' (p. 22).

A second patient (Case 2, 66w/74) who had been examined by Kolstad in 1973 had died in July 1976, after what Kolstad described as 'severe mismanagement' (1987, p. 23). The notes showed that she had been followed for eight years without curative treatment with an abnormality on smear tests reported as 'suggestive' or 'conclusive' of malignancy.

Kolstad examined other cases put to him by the Inquiry. Responding to the case of a woman who died after 18 years of inaction (Case 3, 69w/63) Professor Kolstad said, 'I am horrified at the mismanagement of this patient' (p. 24).

Of Case 4 (60w/64) a woman with CIS of the vagina which 'was allowed to spread until it was impossible to achieve a permanent cure' he expresses a sense of amazement that she was followed for 17 years: 'The patient died ...another example of mismanagement' (p. 26). Had she been treated 'at the time' there was 'a chance of complete cure' (p. 26).

Commenting on our account and partial notes of Clare's case where there had been no definitive treatment through 15 years of smears mostly 'suggestive' or 'strongly suggestive of malignancy' and repeated incomplete biopsies showing CIS or more seriously microinvasive cancer, Kolstad said '*I am really horrified about the attitude of Dr. Green*' (p. 28) it is 'another example of terrifying mismanagement of CIS in a relatively young patient' (p. 29). He says of the decision by the medical disciplinary committee that it was her own fault for not asking for a smear after discharge from hospital 'I have never experienced such a committee decision in my life....The fact that 'Ruth' was blamed for not asking for a smear, is unbelievable' (p. 29).

In his evidence Kolstad was critical of the idea that Green's regime was saving women from invasive interventions. Kolstad was concerned for those women who suffered from the terrible

treatments made necessary by delayed intervention: 'it is not only a tragedy for those who have died from the disease, but also for those who have had to suffer from radical radiotherapy or radical surgery' (p. 32). Delayed treatment created the need for far more destructive interventions. In addition if pelvic lymph node metastases developed he said, 'it is absolutely unbelievable how much they suffer...' (p. 21). Most of this suffering could he believed have been avoided by early treatment.

It is hard to see how, when Bryder read this evidence about the case records, she could have continued to believe that Green was 'monitoring' or 'following' cases in order to treat them appropriately. Monitoring means taking action if there is no remission or if the condition continues or worsens. The case notes show conclusively that this was not occurring.

## Coppleson

Unfamiliarity with the case histories examined in detail at the Inquiry leads to some of Bryder's most serious errors. She, for example, claimed that when Professor Malcolm Coppleson from Sydney gave evidence critical of NWH (Coppleson, 1987) and later published his views (Gerber & Coppleson, 1989), he was protecting himself from criticism for similar treatment or had been influenced by what Bryder insinuates is bias by one of the Inquiry's medical advisors, Dr. Charlotte Paul (Bryder, 2009, pp. 192-193). Coppleson's purpose, Bryder argues, 'appeared to be to absolve overseas specialists from any responsibility' (p. 192). Having argued that Green's practice conformed to international views Bryder can only explain that the experts gave contrary evidence to the Inquiry to distance themselves when it became clear the inquiry was going against Green.

Coppleson's position had been the closest to that stated by Green. Like Green, in the 1960s he was concerned that young women were being given hysterectomies on the evidence only of minor abnormal smears (Coppleson, 1987; Coppleson, Reid, & Pixley, 1967, p.6). In evidence to the Inquiry Coppleson said that he valued Green's published work. He cited Green in support of his more conservative approach to treatment. He saw him as an 'ally' (1987, p.10) in 'getting the message across' (p.11) and in 'trying to stop the carnage' (p. 6). He said Green's study 'valuable to my efforts to obtain a more conservative approach' (p.10).

The Inquiry questioned Coppleson closely on his exact position. Four times he testified that he would not have been involved in research like Green's because by the mid-1960s he was convinced about the potential of CIS to progress to invasion (Coppleson 1987, p. 15, p. 19, p. 20, p. 21). Progression, he says was 'No longer an issue in 1966' (p. 14). An accurate account of Coppleson's papers supports this assertion (Coppleson, 1977; Coppleson, K, & Dalrymple, 1981a, 1981b; Coppleson et al., 1967, pp. 152-173).

Coppleson said in evidence that the reason he had not criticised Green's protocol at the time was because he had assumed it would 'become obvious to the colposcopist if anything had started to go wrong....and therefore common sense would prevail and another form of treatment would be instituted' (Goddard, 1987, p.11). Coppleson was unaware, until shown the case notes at the Inquiry, that Green was not acting on the colposcopist's advice but just observing lesions developing.

Careful reading of Coppleson's published work in a temporal context shows that, like Kolstad, he did not change his fundamental position either at or after the Inquiry (Goddard, 1987; Paul, 2009a). Moreover, his practice had been very different to Green's. He always aimed 'to eliminate once and for all, the lesion by the most appropriate method' (Coppleson, 1987, p. 23). The only time he advocated significant delay in definitive treatment was in cases of CIS diagnosed in pregnancy, and then only until after delivery (Coppleson, 1977, pp. 177-178;



Coppleson et al., 1967, pp. 206-208).

Coppleson was at the forefront of developing 'conservative management' of CIS. By this he meant treatment without removing the uterus. Along with other means of examination and diagnosis, Coppleson was developing the 'new colposcopy' into a precise tool (1987: pp 2-4) which would allow the accurate grading, and most importantly, accurate prediction, of the likely course of a cervical lesion (pp 4-5). His argument was that while cytology or histopathology alone were not completely accurate, with the addition of colposcopy and close team work, diagnosis could be sufficiently precise to allow for treatment by measures which conserved the uterus, so long as follow-up was rigorous. 'Colposcopy can help the gynaecologist select, with accuracy and safety, those women who should be treated conservatively with local excision' (Coppleson et al., 1967, p. 196; see also Coppleson 1977, p. 178).

His views remained consistent throughout his career. When Coppleson advocated 'follow up' this was not a substitute for treatment, but *after* treatment to ensure it had been successful (Coppleson, 1987, p. 13; Paul, 2009b).

Bryder uses the subjectivity of histological diagnosis to suggest that grading was inherently so unreliable that Green's ignoring some lesions was a legitimate issue of clinical judgement. Bryder supports this assertion by quoting from Coppleson, particularly his 1981 chapter in *Gynaecologic Oncology* (Coppleson, 1981). But the consistent argument in all Coppleson's published work is that the addition of refined 'new colposcopy' to histology, combined with close systematic interdisciplinary co-operation, can increase accuracy sufficiently to overcome this problem.

Coppleson also gave evidence to the Inquiry that even in the 1960s he ensured that the patient was fully informed, and was clear that ultimately the choice in both treatment and research lay with the women themselves (Coppleson, 1987, p. 27).

## Jordan

Perhaps the most tragically untreated women were those whose lesions were allowed to spread into the vagina. Once vaginal invasion had occurred treatment options were limited and terrible. Since treatment of advanced cases was unlikely to be successful, treatment might well only add to the misery of the disease.

Dr. Jordan reviewed two such cases before the Inquiry (patients 60/69; 60/64) who had developed vaginal abnormalities. Jordan referred to the treatment 'dilemma' faced by the doctor once this situation had been allowed to develop (Jordan, 1987a).

It is clear that Jordan made his comments about the clinical 'dilemma' in the context of condemning the inaction which had allowed the dilemma to occur in the first place. Bryder, however, misrepresents this reference and uses it on four occasions to imply that other clinicians sympathised with Green's predicament (2009, pages 40, 51, 52, 55). She does not make clear that Jordan was making his remark in the context of condemning the development of that predicament in the first place as a result of inaction by Green.

In his evidence, Jordan describes how in the case of one of the two patients (patient 60/69) Green had overridden the pathologist and downgraded a histological diagnosis of invasion, justifying delays in curative treatment. In describing the 'dilemma' faced by Green in this case, Jordan explicitly condemns the eight years of delay in definitive treatment (Jordan, 1987a, p.2).

For the complex case of the second patient, (patient 60/64), where Green was faced by a similar 'dilemma' Jordan also criticised repeated delays in curative treatment as the cancer spread from the early 1960s until 1981, when she was finally confirmed as having 'generalised

cancersiation of the lower genital tract' (p. 4). As Jordan recognised repeated procedures had unfortunately not prevented this. But this did *not* obviate his view 'that some definitive treatment to the vaginal vault lesion should have been instituted in the early 1960s, and at the latest in October 1965, when the vaginal vault biopsy confirmed the presence of severe dysplasia' (Jordan, 1897a, p. 4).

### Similar research studies overseas?

In arguing that the treatment at NWH was not unique but represented international best practice (2009, p. 55), Bryder argues that international experts, including Professor Ralph Richart from New York (pp. 44-45) and specialist Joe Jordan from Birmingham University (p. 29) had undertaken or advocated similar studies.

After the Inquiry, Jordan did advocate a prospective study because he was concerned about effective use of screening resources, because more and more women were '*being referred to colposcopy clinics for assessment of even the most minor cytology abnormality*' (Jordan, 1988). This was over-loading the capacity of the screening system and possibly leading to over-treatment of young women with minor lesions. Jordan's views, published in a study entitled, 'Minor degrees of cervical neoplasia: time to establish a multicentre prospective study to resolve the question', was of low grade lesions *not* CIS, as its title makes clear.

Bryder elides the important difference between minor lesions and CIS. She used Jordan's 1988 proposal to suggest that internationally the controversy concerning the invasive potential of CIS continued up to and, even after the Inquiry (2009, p. 29, p. 31). The text of the proposal, however, shows that Jordan had accepted progression and supported population based screening. He was primarily concerned about the effective management of *minor lesions* in screening programmes.

Professor Ralph Richart, an expert witness from New York City had also undertaken prospective research; but once again it was into the development of low grade lesions *not* CIS (Bryder, 2009, pp. 44-45). In Richart's study, if CIS developed then it triggered curative treatment to remove it. Unlike Green's study, when invasion occurred the research was terminated as unsafe. Like Coppleson, Richart's patients were also fully informed about potential risks.

Bryder ignores the differences between minor lesions and CIS on the grounds that the reading of histology slides and cytology smears can be equivocal. This occurs because the stages are not discrete steps but part of a continuum of cellular changes from minor abnormalities to CIS to invasion. However, this is not unusual in medicine, and does not mean that clinically meaningful differentiation between levels of abnormality is not possible, especially if multiple investigative methods are used. From the patient's point of view these differences are critical. There is a huge difference in treatment and in its consequences. Treatment is far more difficult, damaging and traumatic in the later stages.

### The propositions in Bryder's argument

The argument in this paper shows that the first four steps of Bryder's analysis fail.

1. Medical literature and medical experts have agreed from the 1960s onwards that CIS has a potential to lead to invasion and should be treated by removal of the abnormality. The most recent re-analysis of Green's evidence shows that between one third and one half of CIS will lead to invasion if untreated (McCredie et al., 2008).
2. Green's management was not the same as that of Coppleson, Jordan or Kolstad, all of whom advocated the elimination of CIS with follow up *after* treatment to ensure removal had been successful.

3. Green's motivation may have been to save women from un-necessarily invasive treatment, but in the event his regime led ultimately to some women enduring a multiplicity of destructive and even mutilating procedures.
4. Objective analysis of Green's records and clinical material shows that he subjected women to many procedures designed to '*observe rather than treat*' their CIS (McCredie et al., 2010) and as I have shown sometimes even their invasive cancers.

## Women's experiences

National Archives privacy restrictions meant that Bryder had no access to cases and case notes. Nevertheless the appendix to the Cartwright Report contains the complete case notes of two patients who had been initially treated for CIS with small biopsies, and who had gone on to develop microinvasion which was not removed. They only had definitive treatment once invasion had developed, and then only after significant delays (Cartwright, 1988, Appendix 10, pp. 268-274; Appendix 11, pp. 275-286). The Judge commented that 'the outcome' for women like these 'has been very poor indeed' (Cartwright, 1988, p.114). These, and other case notes were also extensively discussed in the Report (pp.113-114; 89-90; 109-119).

These included those of Clare Matheson, who also bravely made them public in her book (Matheson, 1989). Bryder had access to the transcript of the cross examination of the experts about Matheson's case. Bryder's failure to make clear that years of delay in treatment meant that Clare's CIS had developed into *invasive* cancer, and ignoring the acute and ongoing suffering entailed by the highly invasive resulting treatments minimises the experiences of all the women patients.

Bryder claims that the Inquiry exaggerated women's ignorance of, and dissatisfaction with, their treatment (2009, pp. 58-59). She gives examples of patients who felt that Green was a good doctor who followed them assiduously. Many of these claims are, however, based on letters written by Green's patients at the request of his lawyer before the Inquiry began and before they knew what had happened to them.

Some women did feel sufficiently informed (Goddard, 1987, Annexure 2 patient 21; patient 70, p.28; patient 30, p.11) and some preferred not to know, but Green actively resisted giving information to patients who asked for it. Many patients made vigorous attempts to obtain information about their case. One suspicious patient took her pathologist brother to a consultation but was still frustrated. Of the 72 patients whose evidence is recorded, eleven used the words 'guinea pig' when describing their experience (Goddard, 1987, Annexure 2)

One of most moving pieces of public testimony was from a Maori man who was the only husband who went with his wife to give evidence to the Inquiry. His wife had 'asked to see her file... and was declined' (Goddard, 1987, Annexure 3, Summary, p. 5). She told the Inquiry 'I feel that a woman has a right to know what she wants to know from a doctor' (Cartwright, 1988, p.119). He had gone with her to the hospital to find out about her condition and was deeply distressed at being confused and patronized.

A minority of patients who gave evidence were supportive of Green but remained ignorant of their diagnosis. One man initially believed that Green had been particularly caring, until he realized he had been actively misinformed about the circumstances of his wife's death (Cartwright, 1988, pp.109-111).

Bryder quotes patient, Mrs. W, who was enthusiastically appreciative of Green's care in her public testimony. Bryder points out that 'She clearly enjoyed coming for check-ups' and had 'readily agreed' to provide tissue samples and be a demonstration subject (2009, p. 49). Bryder contrasts her satisfaction with Rodney Harrison's cross examination of Green about 'why

he did not adopt a more aggressive approach' to her treatment, and Harrison's suggestion that Green 'did not perform a vaginectomy in order to keep her for research purposes' (p.49). The implication was that the Inquiry ignored this woman's evidence, and that Harrison's questions demonstrated our bias.

The patient and Bryder were unaware of something the Judge, counsel and parties knew. This patient had not, as she believed, been cured. Her CIS had been observed while it spread throughout her vagina. Her testimony emphasised her misinformation and how seriously misplaced her trust in the hospital was. Her visits to the hospital were part of her follow-up as a research subject. Mrs. W and Bryder were equally unaware that her vagina had been photographed and discussed in medical journals (Coney, 1988, p.115). Mrs. W., in fact, provided poignant evidence that patients were not informed and were put at continuing risk as part of research.

Mrs. W was not alone. Goddard's summaries of the eleven interviews given in public were available to Bryder. They provide insight into why the Inquiry did not 'balance' the evidence in the way that Bryder claims it should. Of the eight patients, for example, who gave evidence on day 10, two, (Patients 70 and 71) (Bryder, 2009, p. 28), were very pleased with their treatment, including Mrs W. Goddard's summaries (1987, Annexure 3), however, make clear that all eight patients were misinformed, although some had made attempts to find out about their situation. The summaries show that the patient who complained that the hospital 'doctors talked about her as if she was a bit of furniture' (p.7) was not atypical.

Goddard's 'Summary of Patient Interviews' given in private (Goddard, 1987, Annexure 2) were also available to Bryder. There are summaries of 72 interviews. Ten of these 72 believed they had sufficient information, but checks against their case notes show that only a maximum of five were correct. The rest, even when they were satisfied, were unaware they had been treated unconventionally or put in danger.

The Summary of Patient Interviews records that when patient 75 heard about the Inquiry and sought information about her case she was admonished by a GP for pursuing a 'witch-hunt' (Goddard, 1987 Annexure 2,, patient 75, p.30). Her regular GP also refused to provide her with information about herself. Even after the inquiry began the hospital did not voluntarily inform their patients about their true condition.

Many submissions from groups associated with the Women's Health Movement argued for an urgent, independently-evaluated recall of all women potentially at continuing risk. The Judge recommended that it take place and began sending details of women at risk to the Minister as the information became available (Coney, 1990, pp. 204-206). It took, however, very persistent lobbying before this independent recall occurred. Bryder's claim that Coney exaggerated the outcome of this recall has been rebutted. The recall revealed that one patient had since died, one found to have invasive cancer and about a quarter needed further treatment (Coney, 2009, pp. 147-148).

Delays could be dangerous. For example, Patient 81 had presented in 1970 with a diagnosis of invasive cancer (Goddard, 1987 Annexure 3, p. 32.). The patient wanted surgery, but Green refused for three years. When she 'accidentally' saw another doctor she was treated with surgery and radiotherapy, which at that stage caused serious permanent bladder damage. Bryder says nothing about Green's delays in treating even *overt* invasion, about which there was no international doubt.

Ignorance left women unable to protect themselves. If they left the region they might not see a doctor until they became symptomatic. Some only found out about their diagnosis when they reported their symptoms to doctors overseas. One woman moved to Wellington where a consultant recommended treatment, which Green resisted, writing to tell the doctor not to treat

her, because of the importance of her case to his 'series'.

## Evidence of patient harm

Bryder accepts as accurate Green's statements that few of his patients developed invasion or died. Bryder is aware that Green achieved these results by reclassifying cases and removing most that developed invasion from his studies; but she appears to be so unaware of appropriate scientific practice that she defends this practice by claiming that other researchers undertook similar reclassifications (Bryder, 2009, p. 77, pp. 78-80). It is true that in medicine diagnoses are sometimes reviewed retrospectively. When this occurs doctors do not, however, go back and expunge the original records. Researchers most definitively do not remove retrospectively reclassified cases from research cohorts after the event (Paul, 2009a, p.129).

Bryder takes Green's words at face value, accepting, for example, the evidence in his 1964 paper that only one woman in his sample progressed to invasion (Paul, 2009a, p.124) or the claim in Green's 1974 paper that of ten cases of invasion only two represented real progression of pre-invasive lesions (Bryder, 2009, p. 47). But these figures were arrived at by what Paul calls 'scientific misconduct' which includes practices that in everyday language are called fraud. The Inquiry heard evidence that invasion cases were removed from these series by being retrospectively re-diagnosed as having invasive cancer at the outset; a conclusion that Bryder justifies and the implications of which she chooses to avoid.

Green not only removed cases from the study but tried to change the histology records themselves. Sandra and I were told by Michael Churchouse, Charge Technologist at NWH cytology laboratory, that their patient records were hidden under the floor boards to protect them from Green's attempts to alter them. The Judge was told by McLean about 'several occasions' on which Green 'crossed out' McLean's diagnosis 'on pathology reports and replaced it with his own' (Cartwright, 1988, p.109). McLean described to us finding Green in the laboratory going through the histology slides attempting to alter the recorded diagnosis. From then on McLean tried to protect the integrity of his specimens by classifying them under a different system. As Bryder noted, Green complained of this at the Inquiry, implying that McLean was unreasonable (Bryder, 2009, p.78). McLean was, at the time, the only fully-qualified specialist gynaecological pathologist in New Zealand. That his concerns about Green's unprofessional, unscientific practice were ignored demonstrates a serious failure in academic management at the hospital and university.

Our Closing Submission (Harrison, 1987, Appendix IV, pp.2-3) provided evidence that 26 deaths were associated with delayed and withheld treatment. Sandra showed how that figure had been compiled. By 1988, that figure had grown to 29 Coney, 1988). This claim has never been refuted.

The Report did not include a figure for deaths, although Appendix 12 lists 23 women who had died, including eight who died of cervical cancer and eight who died of vaginal cancer (Cartwright, 1988, Appendix 12, p. 287). More recently McCredie et al. (2010) have shown that eight of the 'core group' of women who began with CIS died, but this excludes those with vulval cancer, or who had delayed treatment for early invasion or those with recurrent or persistent disease after a cone biopsy and others with limited or delayed treatment.

Bryder argues, however, that claims that Green harmed women are exaggerated (2009, p.157). She quotes NWH gynaecologist, Dr. Tony Baird, saying there is no proof that recorded deaths were of patients in Green's studies. Case records, however, make clear those for whom treatment was delayed or withheld and who died. The fact that some of these cases might have come from other doctors in the hospital is hardly a defence.

## Sources of bias in Bryder's account

I have identified a number of sources of error in Bryder's use of the evidence available to her in case histories, medical publications and other sources of information. These include:

- Misusing the uncertainties of diagnosis, especially histological diagnosis, to justify clinical inaction;
- Ignoring the differences between minor abnormalities and CIS, and CIS and invasive cancer;
- Misrepresenting the subject of studies by Jordan and Richart;
- Misrepresenting the meaning and significance of Jordan's statement on clinical dilemmas;
- Overstating the satisfaction of patients;
- Justifying Green's scientific misconduct;
- Implying criticism of McLean for attempting to protect the integrity of his specimens.

There is a hole in the heart of Bryder's analysis, resulting from her neglect of the patients' perspectives. The proposition that lay at the heart of the Cartwright recommendations was that patient's reality formed the standard by which medical conduct should be judged. Neglecting to accept or at least acknowledge this key proposition meant that Bryder ignored or misinterpreted most of the available evidence and failed to appreciate the significance of the Cartwright Inquiry and its associated reforms. The patient-centred perspective is the elephant in Bryder's analytical room which she steadfastly neglected to discuss.

Sandra has offered a critique of Bryder's anti-feminism (Coney, 2009a). The general tone of academic criticism, however, positions the critics as moderators bringing balance by acknowledging but not endorsing feminist input (Paul, 2009b; Skegg, 2009, pp.96-97) and suggesting that the key division this debate has exposed was one between doctors. It is important for historical accuracy, however, both to establish that there was significant feminist input into the Inquiry.

## Patient-centred ethics and feminism

In addressing the first term of reference of the Inquiry about 'whether the CIS was adequately treated', the judge included not merely the management of the disease, but the treatment of the patient. The judge included 'acknowledgement of the dignity of the woman patient and her right to total privacy' (Cartwright, 1988, p.119) and 'knowledge and acceptance of her cultural needs' as well as the provision of accurate information, including 'about the consequences of treatment and the impact that her treatment or management may have on her personally, on her family, working life and her mental health' (p.119). This holistic concept of 'treatment' is what distinguishes the Cartwright legacy and makes the Report truly innovative. I argue that this was derived from feminism not as a result of personal influences but as a cogent development from a human rights perspective, as our submissions show.

For Sandra and me this perspective was intrinsic to our feminism. It arose directly from our analysis of our experiences in the Women's Health Movement. The validation of women's perspective was a central tenet of our feminism and as the Women's Health Movement grew a patient-centred perspective naturally developed from it. We gave priority to women's interests. As Sandra has written 'The major motivation for Phillida and myself in pursuing the investigation and then as parties to the Cartwright Inquiry was to make sure the women who still needed treatment got it' (Coney, 2009b, p.68). Our argument rested on an analysis of the personal and medical experiences of the women themselves.

This paper suggests that many of Bryder's errors of interpretation are the consequence of

moving women's experience to the periphery of her understanding. Sandra has pointed out that Bryder's indifference to the suffering of the subjects (Coney, 2009a, p.146) and apparent unconcern with their experience as patients. This indifference leads her to dismiss the development of patient-centred ethics as a significant step in the reform of medicine.

Bryder gives an accurate outline of the development of the New Zealand Women's Health Movement in the 1970s and early 1980s in New Zealand (2009, pp.109-124). But she identifies the Women's Health Movement as being characterised by a resistance to medical intervention (p.6). She argues that because Green was working to avoid hysterectomy he was more in line with feminist health principles than Coney, who Bryder believes (erroneously) was persistently advocating hysterectomy as a female cure-all (Coney, 1987; Coney & Potter, 1990). Bryder thus implies that Coney and I betrayed our feminism because we were so eager to condemn Green as a representative male doctor. That is, we were motivated less by concern for women's health and more by animosity against men, particularly as represented by male doctors.

While the Women's Health Movement did resist unnecessary intervention particularly in well-women care, it was equally concerned with the provision of safe and timely intervention in illness. The principles of the Women's Health Movement were summed up by Celia Lampe of the Ministry of Women's Affairs as 'Voice, Choice and Safe Prospect' (Lampe, personal communication with the author, 1987). Within the women's rights language of feminism at the time, women's empowerment expressed itself in health as a quest for patient-centred care. Protection of the patient's autonomy and human dignity was at the heart of our agenda. We sought to give the women's experiences credibility and place their interests as patients at the centre of the medical system. This was not brought about clandestinely but because of the applicability of our understanding of women's rights.

Judge Cartwright, 'made the experiences of the .... women who gave evidence the focus of the inquiry and she judged the profession's performance relative to their reality' (Bunkle, 1993, p.56). The medical hierarchy were initially bewildered by this challenge to their authority. One of my more vivid memories of the inquiry was Professor Bonham asking aghast 'Do I have to answer that question? And the Judge replying 'Unfortunately Professor Bonham you are here to be cross examined'. The Report's recommendations suggested that a 'shift to a patient focus.... must happen to the whole health service' (p.56). This paper argues that this vision of patient-centred care came directly from a feminist vision of empowerment.

In the final analysis, whether or not Sandra and I exercised undue influence over Judge Cartwright it an esoteric academic point. The key question before us is how best to secure improvements in the health of New Zealand women. It is especially disappointing that no commentators, not even those holding publicly-funded positions, have discussed how the vision of feminist, holistic patient-centred medicine can best be achieved within the narrowing confines of a national health system disintegrating and made mean by more than 20 years of neo-liberal managerialism. Whatever book is needed to provoke that debate, it isn't Bryder's exercise in gratuitous revisionism.

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left Parliament in 2002 and since then has taught Women's Studies in China and worked as a carer for people sick with ME. She currently lives in London where she has worked as CEO of two holistic cancer treatment centres and has completed her MsC in Integrated Health Care. She is currently a Research Fellow in Gender and Women's Studies at Victoria University of Wellington, New Zealand.

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