

## The “unfortunate experiment” and the Cartwright Inquiry, twenty years on: why getting it right matters

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July 2008 marked the twentieth anniversary of the *Report of the Committee of Inquiry into allegations concerning the treatment of Cervical Cancer at National Women’s Hospital and into other related matters* (Committee of Inquiry, 1988), commonly known as the Cartwright Report. One of Judge Silvia Cartwright’s most important recommendations was the appointment of a Health and Disability Commissioner. Ron Paterson, the Commissioner from 2000 to 2010, pointed out in his 2008 Nordmeyer Lecture (Paterson, 2008) that:

...patient safety inquiries across the world consistently identify the same problems: health care below promulgated standards; lack of quality-monitoring processes; patients, family members and concerned staff being ignored and excluded; whistle-blowers being vilified; and persistent deficiencies in teamwork, systems and communication.

Why are the lessons of such inquiries so hard to learn? If the stakes are high enough, said Paterson, “the learning... will be hotly contested” (Paterson, 2008). Charges levied against some of his own inquiry findings have strongly resembled those recurrently raised against the Cervical Cancer Inquiry, where “the stakes were very high indeed” (Paterson, 2008).

The latest challenger is a historian. In August 2009, Auckland University Press published *A History of the ‘Unfortunate Experiment’ at National Women’s Hospital*, by Linda Bryder, a professor of history at the University of Auckland (Bryder, 2009). Bolstered by an extensive array of footnotes and references, she argues that, misled by her own ignorance of medical matters and by feminist determination to break medical power, Cartwright got it completely wrong, because the unfortunate experiment was nothing of the kind.

Few would have read the full report (Committee of Inquiry, 1988) when it came out. Reading it now is vital to understanding how Bryder has attempted to undermine its findings. To grasp precisely why it is she, rather than the judge, who got it wrong – and, more importantly, why the Inquiry was and continues to be so significant – it’s also essential to read *The Cartwright Papers: Essays on the Cervical Cancer Inquiry, 1987-88*, edited by Joanna Manning, who is associate professor of law at the University of Auckland, specialising in medical law policy and ethics (Manning, 2009).

Carcinoma in situ (CIS) has been described by Dr Charlotte Paul, one of three medical advisers to the Inquiry, as being at “the far end of the spectrum of abnormalities before cancer” (Barton, 2009). It is diagnosed by a tissue biopsy. By the mid-1960s, as his writings show, Professor Herbert Green had come to believe very strongly that CIS was rarely the precursor of invasive cancer. Exactly why he did so has never been fully explained; but in his essay, Ron Jones, Auckland professor of obstetrics and gynaecology, provides useful insights into Green’s

stance and the extent to which it was, to put it mildly, atypical (Jones, 2009). At some points, for example, Green seemed to view CIS as a separate, benign condition which might be present from birth – hence his short-lived project of examining vaginal smears taken from new-born baby girls without their parents' consent. After 200 smears he lost interest, but no one told the nurses, who went on to collect over 2000 more.

The Inquiry concluded that Green set out, with his superiors' approval, to prove his theory by observing women with persistent CIS (and in some cases, microinvasion and other symptoms strongly suggestive of malignancy) through repeated smears and biopsies over long periods of time, without informing them or obtaining their consent. If he was right, there would be no need to remove CIS (then done either by conization, taking a cone-shaped section of the cervix, or by hysterectomy – although by the 1960s at National Women's, hysterectomy was the exception rather than the rule). Nor would there be any point in setting up national cervical screening programmes. But if he was wrong, a significant percentage of the women would go on to develop invasive cancer, which in most cases could have been prevented by removing the CIS in the first place.

By 1970, it should have been clear that this was precisely what was happening. But Green simply reclassified some of the women who developed invasive cancer as having had it all along (in other words, it had originally been “missed”). Removing them from his data hid the true rate of progression and enabled him to go on producing statistics which supported his theory. In 1974, he reported (and Bryder uncritically repeats) that only 10 of 750 cases had apparently progressed to invasion, and 8 of these were doubtful. By then, colposcopist Bill McIndoe had identified 39 cases of invasion.

Bryder argues that, contrary to the Inquiry's findings, Green's views and approach were not out of step with expert opinion at the time. He was not conducting any kind of experiment, merely practising “conservative treatment” in order to avoid unnecessary surgery and preserve fertility – an aim which, she says, feminists should have supported.

Several essays in the *Papers* look back to the evidence and discuss the problems with Bryder's interpretation. I found “The Making of a Controversy” by Barbara Brookes, professor of history at Otago University (Brookes, 2009), particularly interesting, because she belongs to the same academic discipline as Bryder and has herself written medical history. She is therefore critiquing Bryder's work in terms of the requirements of that discipline.

Brookes notes Bryder's statement that the Cartwright Inquiry involved an “important story which should be told from the perspective of a medical historian” (Bryder, 2009, p.vi). She goes on to point out that “whatever the object of enquiry”, historians are “governed by the same conventions: to weigh and respect their sources, and quote them accurately; to seek all relevant sources to gain a multi-faceted view; and to interpret the past in a coherent and judicious way” (Brookes, 2009, p.102).

By contrast, says Brookes, “Bryder's history and, more disturbingly, her collection of evidence are thesis-driven. Her thesis is that Green and National Women's became scapegoats in a drama precipitated by an assertive feminist movement intent on destroying the power of the medical establishment. In order to make this argument, she works hard to vindicate Green... she gives priority to seeking any source that exculpates him, whether on CIS, informed consent, or patient treatment” (Brookes, 2009, p.104). Thus she “takes any source that suits her purpose at face value, even though a little checking (usually expected of historians) would have revealed its flawed nature” (Brookes, 2009, p.106). Moreover, her book “is framed in terms of possible criticisms of Green, rather than the issues explored by the Cartwright Inquiry” (Brookes, 2009, p.107). This point is particularly important, because it makes sense of the confusing way in which Bryder's book is constructed.

As a result, Brookes concludes that “What could have been a layered examination of generational changes within medicine that reflected the wider changes in society becomes... a caricature of hard-working, well-intentioned medical men brought down by power-hungry feminists” (Brookes, 2009, pp.116-7).

Reading Bryder’s book, I was struck by the extent to which she ignores much of the Cartwright Report itself, let alone the evidence behind it. Her decision not to interview any of the surviving participants, and to limit the issues covered in interviewing other important figures (Ron Jones, for example, was interviewed by Bryder’s researcher, but not about the experiment or the Inquiry), meant that she failed to clarify a number of complex issues, which are discussed by other contributors to *The Cartwright Papers*.

Charlotte Paul carefully and comprehensively details “the factual scientific matters that demonstrate the systematic errors in Bryder’s book” (such as confusing cytology and histology), and sets out “the problems with her style of argument”, which in Paul’s view fundamentally misrepresents the nature of medical knowledge and practice (Paul, 2009b, p. 119). Sandra Coney goes through other errors and problems related to Bryder’s argument that Judge Cartwright was herself led astray by sympathy for women with cancer and feminist determination to attack male medical power, and notes in particular Bryder’s dismissal of what even those women who did not progress to invasive cancer had undergone:

Review of the files by the Inquiry staff resulted in the need to recall over 130 women. A number of them had already been treated away from the hospital, but over fifty accepted a review by an independent colposcopist. Newly arrived in New Zealand, he later said he had never seen such mutilated genital organs. Repeated biopsies and other procedures had caused dreadful internal scarring for many women. (Coney, 2009a, p.69.)

In her second essay, Coney also stresses Bryder’s disregard for what the women concerned had to say about their own experience, noting, for example, that in the case of Clare Matheson, “Bryder preferred to rely on [journalist Jan] Corbett’s second-hand, pro-Green account, rather than using Matheson’s own story in her book *Fate Cries Enough*” (Matheson, 1989; Coney, 2009b, pp.146-7).

What these essays also show is that in her determination to exonerate Green and discredit those who called him and his superiors to account, Bryder uses techniques that run oddly parallel to the ploys Green himself used in his papers, his rebuttal of criticisms and his evidence at the Inquiry. These include selective (and much repeated) quotes from international experts, designed to align their views and practice with Green’s, when in fact they were diametrically opposed; misleading use of statistics, and obvious factual errors; and ignoring crucial but inconvenient material, including important statements by Green himself. Pathologist Jock McLean’s 1973 complaints about Green challenging his diagnoses, for example, are partially quoted only to be brushed aside. McIndoe’s increasing concerns, raised repeatedly from at least 1969, are similarly played down.

Like all the Inquiry’s critics, Bryder hones in on the 1984 paper written by McIndoe, McLean, Ron Jones and Peter Mullins (McIndoe et al., 1984). It was this paper (reproduced in full in the Cartwright Report as Appendix 7) which prompted Coney and her co-author Phillida Bunkle to begin researching the 1987 *Metro* article that led to the Inquiry (Coney & Bunkle, 1987). Nevertheless, as both Paul and Coney stress (but Bryder never acknowledges), the Inquiry’s conclusions about what took place were based not on the paper, nor on the article, but on the examination of the case histories recorded in over 1200 patient files, to which Bryder had no access. In his essay, Ron Jones (the only surviving 1984 author) explains that he helped write the paper partly because of one such case:

...one of Green’s patients with untreated carcinoma in situ of the vulva was referred to me (with preceding

clinical photographs). Since I did not work in Green's team, I had no contact with the women in his experiment. But here I could see with my own eyes exactly how a cancer precursor was allowed to progress to cancer. Despite radical surgery, the poor woman died – following years of observation and neglect. (Jones, 2009, p.78.)

The 1984 paper discussed 948 women followed for up to 28 years (to June 1983), or, chillingly, up until “development of invasion” (McIndoe et al., 1984, Table 2). All were initially diagnosed with CIS (in some cases, following a hysterectomy for other reasons), but not all were under Green's management.

In Group 1 were 817 women who stopped producing positive smears, indicating that disease was no longer present. By June 1983, only 12 (1.5%) of these women had developed invasive cancer, and of these 12 women, four died. In the much smaller Group 2 were 131 women who continued to produce positive smears, indicating the continuing presence of CIS. By June 1983, 29 (22%) of these women had developed invasive cancer, and eight died. Bryder claims that all these women were offered the same range of treatments. But Paul explains very clearly that the two groups had different profiles in three key respects: the timing of surgical excision, the proportion of biopsies which showed incomplete excision, and smear results.

Damningly, the original 1984 paper noted that the much higher rate of incomplete excision in the Group 2 women was “partly explained by the conservative management of Group 2 patients in whom complete excision was not considered a necessity” (McIndoe et al., p.256). The point is that in order to study the “natural history” of CIS, as Green set out to do (and repeatedly stated), its complete excision had of course to be avoided – hence the huge increase in risk for the women he studied.

As Paul points out, the differences between the two groups “should have been obvious to Green well within five years of beginning his study in 1965” (Paul, 2009b, p.131). Ironically, Green's study provided conclusive proof that his theory was completely wrong. Those left with persistent CIS were almost 25 times more likely to progress to invasive cancer than those without it.

Despite these appalling results, writes Jones, there was a “complete absence of visible response by the senior medical staff or the wider profession” to the 1984 paper (Jones, 2009, p.78). Without not only Coney and Bunkle's three years' work and publication of the *Metro* article, but also the follow-up (as Coney (2009a, p.67) explains) by journalists Paul Smith and Peter Kingston, there would have been no inquiry and no public knowledge of what had happened.

Yet a few passages in the *Papers* left me with an uneasy feeling that medical professionals who firmly back the Inquiry's findings may still tend to blame the lay “outsiders”, Coney, Bunkle, and/or Cartwright, for some doctors' adverse reactions to it. David Skegg writes that “there were inevitably some downsides” following the inquiry, including “a degree of demoralisation among medical professionals, and among obstetricians and gynaecologists in particular. Good medical care requires strong trust between patients and their doctors. Many doctors felt that they had been unfairly tarred with the same brush as Green and his colleagues. There was insufficient acknowledgement that the situation in one unit at National Women's Hospital was exceptional” (Skegg, 2009b, p.9). Charlotte Paul goes further, specifically criticising Coney and Bunkle for ignoring Jock McLean's injunction to them “to avoid getting doctors' backs up and obstructing long-term changes...Coney's allegation that ‘it could easily have been another doctor, another hospital, another city’ implicated all doctors, and many felt that was manifestly unjust” (Paul, 2009a, p.93). In her second essay, she suggests that more doctors might have accepted the Inquiry's findings “if the criticism of the medical profession had not been so comprehensive” (Paul, 2009b, p.118).

But the point highlighted by Coney, Bunkle and the findings of the Inquiry was that the “unfortunate experiment” had been able to be set up, and continue for so long, only because of attitudes and views towards both medical expertise and women patients which were widespread throughout the medical profession. Those attitudes included the belief that although patients did not need to be fully informed, they should nevertheless have absolute trust in their doctors. It was this kind of trust that Green both relied on and insisted on in conducting his “unfortunate experiment”.

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It is precisely because CIS is indeed a cancer precursor that the screening programmes Green and others so influentially and persistently opposed are able to prevent many (though not all) cases of invasive cancer. Spurred by the Report, followed by a great deal of hard work by activists as well as supportive professionals, and despite many obstacles and failings, a national programme was eventually set up. Since 1986, as Skegg has pointed out (Skegg, 2009a), new cases per year fell from 235 to 157 in 2004-07, and deaths per year fell from 101 to 59 in 2004-06. It is estimated that, taking account of population increase, screening is now preventing at least 70 per cent of the cervical cancer cases that would otherwise be occurring in New Zealand.

Beyond cervical cancer itself, Cartwright’s greatest contribution to health care in New Zealand was, as Coney notes, “to make the women’s experience central and to shape her recommendations so that they would protect and empower patients in the future” (Coney, 2009a, p.70). It was this approach, together with the dedicated follow-up of women’s health activists and consumer groups, that resulted in the broader and in some ways even more significant legacy of the Report’s findings and recommendations: the profound shift in the status and rights of patients.

The comprehensive protective mechanisms and consequent changes of approach that now benefit patients and professionals alike are illuminated in the contributions to Part Three of *The Cartwright Papers* by Joanna Manning and Ron Paterson (2009), Jan Crosthwaite (2009), and ethicists Alastair V. Campbell, Voo Teck Chuzan and Jacqueline Chin (2009). They implicitly refute Bryder’s claim that the Inquiry and Report made little difference since such improvements would have happened anyway. Instead they show just how remarkable and world-leading those protections are, how well they work, what their international impact has been, and why the Inquiry and Report gave rise to them: “more than anything else, the success of the Code [of Patients’ Rights] lies in its *empowerment* [original italics] of patients and consumers. They are empowered by it to know that they have rights, to ask that they be respected, and to request information about their condition, proposed treatment and options” (Manning & Paterson, 2009, p.152).

Could such an “unfortunate experiment” happen again? The broad conclusion is that today’s safeguards make it unlikely, but not impossible: “systems alone, however well designed and efficient, cannot ensure ethical behaviour...the ethical conduct of research depends ultimately on [researchers’] integrity” (Campbell, Chuan & Chin, 2009, p.183). Would it be exposed if it did take place? Given how the media and institutional public relations teams now operate, writes Coney, the 1987 article that sparked the Inquiry probably could not be researched or published today. Both were the products of “a historic confluence of factors that no longer exist” (Coney, 2009a, p.62).

Finally, we should pay careful heed to Clare Matheson, the patient who, by being willing to have her case publicised, made possible the *Metro* article and therefore the Inquiry, when she says:

I do not think information derived from this data [obtained through the experiment] should be published or used in any way without clear acknowledgement of the price that was paid for it. The women and their families who paid – and are still paying – the price deserve that much respect. The abomination that took place at National Women’s Hospital should never be forgotten. (Matheson, 2009, p. 56.)

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