The missing manuscript

Frank A Frizelle

This edition of the NZMJ contains a number of letters about what became known as the ‘Unfortunate Experiment’. In many ways New Zealand has been fortunate as a result of these events in that they led to a complete revamp of our medical, legal, and ethical environment as outlined by Professor Ron Paterson’s editorial in the same edition.¹

Recent books²³ have not surprisingly generated a lot of conflicting views and heated debate as they have tried to shed new light on the events that occurred. It has been the re-exploration of events by Professor Bryder that led to her book being published, followed by two book reviews with contrasting views that the NZMJ published.⁴⁵

Then Professor Charlotte Paul contacted me wanting to write an editorial about the book review⁴ which was supportive of Professor Linda Bryder’s book. Given Professor Paul’s key role on the Cartwright Report and the career that she has since built at least in part on these issues, I suggested that she write either a:

- Letter to the editor which would be more appropriate if she wanted to disagree with a book review that we had published, or
- An article exploring issues around the Cartwright Report that had been raised by Professor Bryder’s book—but this must provide us with new insights into the issues and the article must not focus solely on criticism of the author, Bryder. (There are many other avenues, for example the Listener, for publicly disagreeing with a published book.)

The Journal received from Professor Paul a very wordy manuscript which didn’t fulfil the guidelines I had given her. We then spent some months reviewing her article and reflecting on whether it really did contribute anything to the debate. In the end I decided to publish it, but thought that perspectives should also be given by others and so I asked Professor Ron Jones and Professor Linda Bryder to separately write editorials, while pointing out that they would get to see each other’s editorials for comment pre-publication.

Linda Bryder produced an interesting and thoughtful editorial. Professor Jones refused the offer. Then Professor Paul withdrew her manuscript because she did not feel that it was reasonable to have Professor Bryder writing an editorial on this issue. Amongst much media publicity (including lead items on national media) within a few days of withdrawal of this manuscript Professors Jones and Paul published an article in the Australian and New Zealand Journal of Obstetrics and Gynaecology.⁶ They reported:

“…Our findings show that inclusion in this clinical study subjected women to many medical interventions designed to observe rather than treat their cervical intraepithelial neoplasia, and increased their risk of developing cancer of the cervix or vaginal vault. The greater numbers of subsequent biopsies that were performed on women in the core group (who received only a punch or wedge biopsy initially) attest to their assiduous follow-up…”
And “…Among women diagnosed with CIN3 in 1965–1974, the incidence of invasive cancer was ten times greater in the core group (who received only a punch or wedge biopsy initially) than in women treated initially with curative intent…”

Over the past few months the Journal received the letters on these issues (which are published in this edition) plus I asked for an editorial from Ron Paterson that outlines the medical-legal-ethical significance of the Cartwright Report.

We informed Professor Bryder that Professor Paul had withdrawn her manuscript and asked Professor Bryder to rewrite her editorial removing any reference to what Professor Paul had said in her withdrawn manuscript.

I have decided to publish these editorials and letters in the Journal despite my concern that the real issues are being increasingly lost over time since these events occurred. However the papers provide an interesting perspective and a somewhat insightful perspective.

Over this period I have received numerous emails from many self-interested parties offering advice on how to run the Journal and how I should deal with these issues. Choosing to publish these letters and editorials relates to the need for free discussion of the issues and not personal attacks on those who are the messengers.

With this current background it is important, amongst all this recent dialogue and the effect of various personalities, not to forget the real issues which are:

- Consent for studies at the time when these studies was undertaken were inadequate by today’s standards.
- People were harmed. This is described in the article by Professor Paul and colleagues in article in Lancet Oncology in 2008 where the authors state: “.. 1229 women whose treatment was reviewed by the judicial inquiry in 1987–88 were included. Of these, 48 records (4%) could not be located and 47 women (4%) did not meet the inclusion criteria. At histopathological review, a further 71 (6% of 1134) women were excluded because the review diagnosis was not CIN3. We identified outcomes in the remaining 1063 (86% of 1229) women diagnosed with CIN3 at the hospital in 1955–76. In 143 women managed only by punch or wedge biopsy, cumulative incidence of invasive cancer of the cervix or vaginal vault was 31.3% (95% CI 22.7–42.3) at 30 years, and 50.3% (37.3–64.9) in the subset of 92 such women who had persistent disease within 24 months. However, cancer risk at 30 years was only 0.7% (0.3–1.9) in 593 women whose initial treatment was deemed adequate or probably adequate, and whose treatment for recurrent disease was conventional.”
- A key unresolved issue to some would appear to be whether the two groups had received the same treatment or not. In the Journal it is argued by some that they did [receive the same treatment] as the division is dependent on treatment outcomes decided only at 2 years.

The context in which these events occurred is the issue for discussion, not whether they happened. The result, as Professor Paterson states, is that “ most importantly, there has been an attitudinal shift within the medical profession.”

The New Zealand medical system has gained much from what happened. Some individuals have been blamed for what happened, while it is in reality institutional systems that resulted in the problem, not a “rogue doctor”.

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Similar issues are worth exploring to avoid institutional blindness resulting in similar problems harming patients again.

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