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TITLE PAGE

“Lest we forget” as we move forward with cervical screening

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FIRST PAGE

"Lest we forget" as we move forward with cervical screening

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EDITORIAL

"Lest we forget" as we move forward with cervical screening

High income countries such as Australia and New Zealand are on the cusp of further substantial declines in the incidence and mortality of cervical cancer (1, 2). We have effective primary prevention available in the form of HPV vaccination for adolescents. The 9 valent HPV vaccination, new in 2018 in Australia's National HPV Vaccination Program (3) but part of New Zealand's program since 2017 (4), has the potential to prevent over 90% of cervical cancers (5) in young women who receive this new HPV vaccine as adolescents.

After decades of successful Pap smear programs leading to substantial reductions in both the incidence and mortality of squamous cervical cancer in both countries (6, 7), updated secondary prevention with HPV based screening is already underway in Australia (8) and coming soon to New Zealand (9). Taken together these two highly successful public health programs, HPV vaccination and HPV based cervical screening, are set to make cervical cancer a very rare disease within our lifetime.

As we look forward to realising this important goal, it is timely to remember the lessons of the past. New Zealand's "Unfortunate Experiment" was a shocking breach of the fundamental duty of care that all medical professionals owe to their patients. The authoritarian, and some would say patriarchal, way in which women were not even asked if they would consent to be involved in so-called research that asked much of them (in terms of hospital visits and surveillance procedures, some under general anaesthetic) and did not even offer them the standard medical care available at the time, is almost unbelievable. Tragically, this led to many of these women unnecessarily developing cervical cancer which should have been prevented and some of these women died of their cancers.

Although the events unfolded at National Women's Hospital in Auckland mainly in the late 1950s and the 1960s, it wasn't until Sandra Coney and Phillida Bunkle published the article "An Unfortunate Experiment" in the June 1987 edition of Metro Magazine that these events were brought into public attention (10).

In response to the allegations made in the Metro article, the NZ Minister of Health, Michael Bassett appointed Judge Silvia Cartwright to lead a judicial enquiry in 1988. The wide ranging enquiry largely confirmed the allegations made by Coney and Bunkle and made a series of important recommendations that touched on the management of carcinoma in situ at the National Women's Hospital, the importance of an organised National Cervical Screening Program in New Zealand as well as the ethical conduct and monitoring of research projects (11).

Importantly, in her judgement Cartwright recommended that histological and other supplementary material (such as cytological material and medical records) should be available for future properly planned and, importantly, ethically approved research.

This material has already been used in several important publications that describe the substantial risk of developing cervical cancer among women with cervical intraepithelial neoplasia 3 (CIN3) who did not receive treatment intended to completely excise the lesion (12-14). Further, these studies documented that, despite the fact that many women underwent surveillance, often with Pap smear or biopsy evidence of residual disease, they still were not treated.

It has been sobering to read of the more recent controversy regarding the Cartwright enquiry, in which a medical historian challenged the findings of the enquiry and the scientific evidence that supported them (15, 16). It is therefore essential that the clinical and pathological records and materials were made available for these studies and that they have been published in reputable journals following rigorous peer review.

In this issue of the Journal, Paul and colleagues present further important data emerging from the unfortunate experiment, documenting the outcomes for women who were not conventionally and therefore sub-optimally treated at the National Women's Hospital despite having been diagnosed with microinvasive (FIGO stage 1 A) carcinoma of the cervix. The authors acknowledge that this cannot be interpreted as the natural history of microinvasive cervical cancer, because this diagnosis requires complete excision of the lesion, in order to exclude more significant foci of invasion.

However, even at the time, the internationally recommended management of micro-invasive carcinoma was almost always curative. It is therefore extremely important to reflect on and publicise the findings of this analysis which sadly, and unsurprisingly, show that of eighty two women with microinvasive cervical cancer who were not offered treatment that met the standard of care at the time (including sixty women whose treatment was assessed as 'probably not curative'), fifteen went on to develop to cervical cancer over the next ten years and eight of these women died of their disease. Furthermore, long term follow-up to thirty years showed that of the women who had 'Probably non-curative, small excision', 40% developed invasive cervical cancer (FIGO stage 1B or higher).

With the recent changes to Australia's National Cervical Screening Program (8), and forthcoming changes to the New Zealand Cervical Screening Program (9), we are implementing the new paradigm of HPV based screening within much stronger evidence based frameworks than our previous programs had at their commencement. This is in the context of multifaceted and multidisciplinary evidence-based advice to government. Most importantly this advice has also included the voice of the consumers of these programs and this must continue as the programs evolve.

For many of us who work in support of cervical screening across Australia and New Zealand, changes to the technology and pathways underpinning our screening programs, while based on sound scientific evidence, are unprecedented in our working careers and have far-reaching implications.

This paper is a salutary reminder of what can happen when the interests of the public we serve are not put first. Whilst modern research ethics frameworks make an incident such as the “Unfortunate experiment” extremely unlikely in our current setting, we must continue to optimise the reach, quality and effectiveness of our cervical screening programs in the public interest, even when that sometimes means very challenging and confronting change for the supporting health services and workforce.

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