

The Cartwright Report Ten Years On A Critical Evaluation

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5 August 1998 marked the tenth anniversary of the release of *The Report of the Cervical Cancer Inquiry*.¹ The report followed months of investigation by Judge Dame Silvia Cartwright into the treatment of women with abnormal smears at National Women's Hospital in Auckland. The inquiry followed the publication in *Metro* magazine of an article by Phillida Bunkle and the author exposing unethical experimentation.²

The report made sweeping recommendations for new structures and processes to reform medical ethics and protect patients' rights. These aimed, firstly, to make informed consent central to relationships between health care professionals and patients, and, secondly, to enhance public scrutiny of medical practice. The judge argued that consumers must be fully involved in the delivery of health care, both as individuals and as representatives of consumers.

'The focus of attention must shift from the doctor to the patient,' said the report.

Recommendations of the Report

There were nine terms of reference for the inquiry and nine pages of findings and recommendations. The main recommendations were that:

- (1) The ethical committee at the hospital was to be disbanded and the Auckland Area Health Board was to establish one or more external ethics committees. These were to have half lay membership.
- (2) Treatment protocols for gynaecological disease were to be developed and maintained. These were to provide the basis for communicating information to health professionals and for communication with patients.
- (3) An independent patient advocate, responsible to the Director-General of Health, was to be appointed at National Women's Hospital.
- (4) The Human Rights Act was to be amended to include a statement of

patients' rights and Health Commissioner appointed.

- (5) A nationally planned population-based cervical screening programme was to be established. Implementation was to involve full consultation with consumer groups as well as health professionals.
- (6) One hundred and twenty-three women were to be recalled for further advice and treatment. These 'special duty' women were later expanded to 139. Another recommendation in the body of the report was for a review of cases of women with a diagnosis of dysplasia (abnormalities preceding carcinoma in situ) to see that their management had been adequate.³
- (7) The University of Auckland was to improve teaching of ethical principles and heighten awareness of ethical issues among staff and the public.
- (8) Medical training was to be improved in the areas of the proper detection and treatment of cervical cancer and precancerous conditions of the genital tract, organised screening, ethics and communication skills.

Implementation of the Report

Responsibility for the implementation of the report lay with a variety of agencies, principally the Ministry of Health, the University of Auckland and the Auckland Area Health Board.

Although the majority of the recommendations were directed at Auckland institutions, implementation was broadened so that many reforms occurred nationally. This was especially true of the reform of ethics committees and the inauguration of a nationwide system of patient advocacy.

Implementation of the Cartwright Report has been more complete than most other similar reports within the health system. This is because there was a high degree of public ownership of the process and findings. The inquiry had been held in public, it was

thoroughly covered by the media and the voices of women affected were prominent.

The findings validated work that was already under way by women's and patients' rights groups, and in the case of medical ethics and the cervical screening programme, by academics and public agencies, such as the Ministry of Women's Affairs and the Department of Health.

Despite this high level of support for the findings, a huge amount of work had to go into supporting the implementation and into continually reminding agencies of their responsibility. As the inquiry was launched under a Labour Government, there was a lack of enthusiasm from the incoming National Government. The effectiveness of consumer groups diminished while that of medical interest groups, some of which resisted aspects of the recommendations, was enhanced. Restructuring of the health system tended to sideline the ethical reforms of the Cartwright Report.⁴

The following discussion examines the implementation of the recommendations listed as from one to six above.

Ethics Committees

The status of ethics committees has been somewhat ambiguous since the dissolution of area health boards and the establishment of regional health authorities (RHAs). Servicing of ethics committees was taken over by RHAs, but the committees were supposed to be autonomous. The role of accreditation of committees is carried out by the Health Research Council Ethics Committee. However, it is not clear how well ethics committees are performing with regard to membership, functions, process and outcomes. An independent evaluation of the committees would reveal whether committees conform to the national standard and are providing significant protection to health care consumers and research participants.

In mid-1998 the Health Funding Authority (HFA) proposed reconfiguring the regional ethics committee, reducing their number. This raised concern about the independence of the committees if the HFA was able to dissolve some committees and change the composition of others. There was also concern about the loss of public accountability if proposals were being adjudicated by committees at a considerable distance from the area covered by the proposal.

There are other areas of concern. There appears to be confusion about when projects should be taken to ethics committees. I am aware of specific research projects which have not been subjected to ethical review because they have been termed an 'audit', even though they have subsequently been published in journals. Similarly, changes in treatment protocols and the introduction of new and innovative treatments are not always subjected to ethical review.

A number of new ethics committees have been set up outside the network of regional ethics committees. An example of this was the clinical ethics committee which approved the withdrawal of life support for baby L at National Women's Hospital.⁵ It is not clear why regional ethics committees are not being used for such functions, to whom these institutional committees are accountable, and whether they conform to the national standard.

National oversight and coordination of ethics committees is another problem. After extensive consultation, a National Advisory Committee on Health and Disability Services Ethics was established within the Ministry of Health but this was never allowed to function autonomously. In 1997 the Ministry carried out a consultation on the functions and placement of a national group but this situation is still not resolved. While there was some support for a national ethics committee to be placed within the Health Research Council, many consumer groups feared that this tied ethics too closely to research and to the research community, and would undermine public participation. They favoured other options, one of which was placement alongside the Health and Disability Commissioner.

Treatment Protocols

Treatment protocols were designed to establish standard treatment for con-

ditions. Deviations from protocols would need to be justified, and, if necessary, referred to ethics committees. Information for patients would be based on protocols.

While a national protocol was established on the management of women's abnormal smears, in general there was opposition from clinicians to the concept as it was seen as inhibiting clinical freedom. Consequently, few protocols were developed.

The more recent movement towards developing guidelines bears some resemblance to the protocols Judge Cartwright envisaged. Consumers have welcomed this development as providing the potential for treatments to be more evidence-based and thus forestall the perpetuation of ineffectual or harmful treatment practices.

Sadly, the concept of 'best-practice' guidelines has been overtaken by the use of guidelines as a device for rationing, a trend which is not supported by consumer groups (nor many clinicians). Ironically, the Clinical Priority Assessment Criteria (booking system) is far more rigid than the concept of protocols which was so vehemently opposed by clinicians ten years ago.

Patient Advocacy and the Health Commissioner

Seven years of lobbying went into supporting the concept of a health commissioner as Judge Cartwright envisaged it. However, the office was established separately from the Human Rights Commission, which means that it is rather isolated and not in a position to benefit from the experience of the Human Rights Commission.

Currently it is not entirely clear how well the advocacy system and office of the Health Commissioner are functioning. There are only thirty-three full-time equivalent advocates, who often have to cover a wide area. In many parts of New Zealand the profile of the advocates in hospitals is not high and it is doubtful that the public knows that advocates can assist in difficulties with private providers, such as general practitioners and hospitals, and with therapists and alternative practitioners.

So far only one case has been taken by the Health Commissioner to the Complaints Review Tribunal and no consumers have taken cases in their own right, as the legislation allows. Al-

though consumers welcomed the Commissioner's report on Christchurch Hospital, there was concern that none of the cases discussed was referred to the Tribunal. This is the principal mechanism by which significant compensation can be paid. So far no patient has received monetary compensation through the action of the Health Commissioner's office. There seems to be a heavy reliance on an apology from the provider of services as an adequate resolution.

The Commissioner's office is gatekeeper to all disciplinary systems and there has been a reduction in cases referred to these. Indeed, it has been reported that doctors consider they have never had it so good. The Commissioner's office is currently involved in actions in the High Court against both the Nursing Council and the Medical Disciplinary Tribunal regarding process issues. There is a lack of information about the process by which the Commissioner's office finalises cases and whether consumers are satisfied with the outcomes. This is an area where Women's Health Action will be working in the near future.

Cervical Screening Programme

The National Cervical Screening Programme has been in place for eight years and has succeeded in reaching its targets for screening coverage. There is a high degree of public support for and understanding of cervical screening.

However, the programme has suffered under the health reforms. There has been a fragmentation of oversight and coordination with components of programmes contracted to different providers - for example, in some areas, health promotion separated from register functions. Recently the HFA decided to reduce the position of national coordinator to a half-time one and relocate it in Auckland, separating it from the national register in Wellington. Colposcopy waiting lists exceed the national protocol in most regions of New Zealand.⁶

The most serious omission is the failure to carry out a formal evaluation of the programme. The Ministry of Health commissioned a group to produce a plan for evaluation, and a draft plan was submitted in June 1997. However, the evaluation is still to occur. Without this we do not have detail about such quality indicators as whether women are being regularly

screened ('screening coverage', as defined, simply means enrolment on the register), the quality of smear taking and smear reading, and waiting times for colposcopy. In particular, the screening histories of women diagnosed with cervical cancer are not being reviewed to see whether these reveal failures of services.

There is currently no advisory body for cervical screening, although the Health Funding Authority is consulting about how to re-establish a committee. Since 1990 there has been a progressive loss of consumer involvement in implementation of the programme.

Recall of 'Special Duty' Women and Dysplasia Review

The 'special duty' women were recalled and offered independent advice and treatment. By August 1989, 53 women had attended an independent clinic. Nine were found to have conditions needing treatment. In all about 25 women needed further treatment.

The dysplasia review has been a casualty of the dissolution of the Auckland Area Health Board, management changes and a lack of enthusiasm for the project. Despite constant requests from Women's Health Action for reports on progress of the review, partial information on the outcome only became available in late July 1998, and at the time of writing it is not clear what action National Women's Hospital will be taking on the findings.

The Cartwright Report in the Wider Context

While the specific reforms discussed above were, in general, implemented satisfactorily, perhaps the major effect of the report was the heightened awareness among the public of the need to be assertive in their interactions with health professionals. The right to ask questions and to expect adequate answers was emphasised.

Many doctors also accepted the need to inform patients more and include the concept of informed consent in their practice.

There has been no formal evaluation of the effects of this significant change in the culture surrounding people's use of health services. It is my suspicion that the effect was profound, there being a ripple effect through health services far beyond gynaecol-

ogy. New Zealand is a small country providing the advantage (and sometimes disadvantage) that change can occur relatively speedily and broadly. Virtually no one in the health professions would have been ignorant of the findings of the Cartwright Report. The report raised the profile of human rights in general, and contributed to other reforms, such as the Privacy Act 1993.

However, this raised ethical consciousness has had little impact on the health reforms process. Ethics have been compartmentalised as relevant only in clinical settings, rather than being relevant to structural change or government policy. There is a tendency to view the existence of the Health Commissioner as having completely taken care of ethics in the health sector.

No structure was put in place to examine the ethical aspects of the health 'reforms'. Yet health sector restructuring involves a large number of new ethical dilemmas, mainly around restricted access to services and withdrawal of services.

In mid-1998 the Canterbury Ethics Committee was asked by a Christchurch surgeon to review the 'booking system'. The committee itemised a number of ethical problems with the system and went on to state that it was 'very concerned' that there had been no formal ethical evaluation before it was introduced. It commented that it was 'extraordinary that every health and disability research project and innovative procedure in New Zealand, no matter how small, must be reviewed by an accredited ethics committee, but a system affecting many New Zealanders may be introduced without formal ethical review.'

Rationing and prioritisation of services are government policy, yet the ethical dimensions of these processes have not been formally scrutinised.

The move towards integrated care raises ethical issues in the extraction of private sector profits from public funds, 'cream-skimming' or rejection of high-cost patients, the use of financial and other incentives for providers, loss of patient autonomy, and the development of integrated electronic patient information systems. Integrated or managed care controls costs by restricting access to the providers, requiring preauthorisation of high-cost treat-

ments and referrals, reducing referrals and hospital stays, and refusing and withdrawing treatment.⁷

All these practices undermine informed consent. In managed care, patients' autonomy is compromised, as is the concept of partnership with providers. Managed care has been described as 'rationing at the bedside' but the rationing may occur in the health professional's head, or by way of his or her computer terminal, so that consumers may not even be told that certain choices are being withheld. Decisions about whether a person can get treatment may be made by a manager or other 'invisible diagnostician', whom the patient never meets.

These ethical issues have been raised by consumers but they are very seldom included in the discussions between health funding authorities and health professionals.

At the same time there has been a downgrading of consumer involvement in health care policy formulation. Judge Cartwright's recommendations were made when elected area health boards existed. Since that time there have been diminishing opportunities for consumers to participate in health planning. If this does occur, it is **at the time** and on the terms set by the particular health body.

Conclusion

The Cartwright Report led to major advances in patients' rights and health sector ethics. A number of new bodies were established to provide ethical review and protect the rights of consumers of health and disability services. There were greater opportunities for public involvement in health policy development and health services planning. Consumers were encouraged to be more articulate and questioning and health professionals were expected to share decision-making with their patients.

This enhanced ethical consciousness has not been taken into the health reforms process, so that many decisions which seriously affect the public are being made without considering the ethical aspects. The task for the next decade is to ensure that ethical review is required of all new policy before change is implemented.

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