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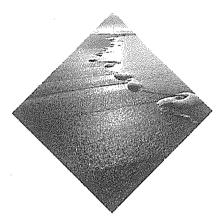
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John McMillan Bioethics Centre

Article

1998 Bioethics Summer Seminar

Number 1

We apologise to readers for the lateness of this issue of the Report. Publication was postponed in order for us to focus the Report on the events of the 1998 Bioethics Summer Seminar.

The Seminar was held from 13 to 15 February. As with the 1996 Seminar, the Health Research Council of New Zealand supported and was involved with the Seminar. It was held at Salmond Hall in the University of Otago, which proved to be an excellent venue, providing excellent facilities and superb fare at the dining table.

The feedback from Seminar participants has been very positive. When the planning committee first met to discuss the format for the seminar it was decided that it should maximise the opportunities for discussion of important current issues. The seminar was therefore designed to provide an environment in which participants could contribute to numerous workshop sessions rather than listen to a series of formal presentations.

The Seminar began on Friday 13 February with presentations by Bruce Scoggins (Director of the Health Research Council) and Irihapeti Ramsden (Ngai Tahu and Rangitane, Health Research Council Ethics Committee) on the use of body tissues. Bruce focussed upon some of the challenges presented by new genetic research. Irihapeti outlined for the audience the difficulties in defining what culture is and how genetic knowledge contributes to the understanding of ethnicity.

The afternoon session involved concurrent invited workshops. It is not possible here to describe all of the workshops. Six workshops focused upon current issues in the use of body tissues, including privacy and confidentiality, tissue banks, Maori and research, collection of samples in clinical situations and gene therapy.

On Friday evening (13 February) Professor Donald Evans gave his inaugural professorial lecture, titled Values in Medicine: What are we really doing to our patients? Holding this lecture during the Summer Seminar meant that people who had come to Dunedin for the Seminar were able to attend this important occasion. People that I spoke to after Donald's lecture were impressed with his performance. The University of Otago has produced a printed version of the lecture. We are pleased to be able to enclose a copy with this issue of the Otago Bioethics Report.

The seminar sessions on Saturday moved to a discussion of health and disability delivery issues. The first session of the day was led by Dr Janet Sceats (General Manager, Health and Disability Analysis Unit, Health Funding Authority, Midland Division). Dr Sceats outlined a draft system of the principles which should be applied at the different levels at which health funding decisions are made. Dr Sceats' important contribution to the day's discussion provided a warning of the

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temptation to oversimplify the complexity of health funding decisions. At the completion of her presentation, expert commentary was offered by Professors John Campbell, David Skegg and Murray Tilyard of the University of Otago.

The Saturday pre-lunch session offered a number of workshops and research papers. The research papers presented in this session are included in this special issue of the *Report*.

The afternoon sessions discussed issues relating to integrated care and good practice guidelines. The afternoon began with a plenary discussion by Catherine Te Miringa Holland (Tainui and Ngai Tahu, Business Health and Management Consultant), Mark Jeffery (Medical Oncologist) and Professor Murray Tilyard (Professor of General Practice). Catherine Holland's talk outlined how integrated care meant that health care for Tainui Maori could be delivered in a manner which was much more effective and appropriate than the previous more centrally controlled method of delivery. Mark Jeffery has been involved with the National Health Committee in the development of good practice guidelines. He observed that these involve the systematic review of clinical literature to determine optimal practice and, further, that they ought to be distinguished carefully from clinical protocols.

Professor Tilyard leads a very large group of general practitioners operating with budget holding practices. He argued that integrated care meant that health care funding could be targeted more effectively.

Following the plenary sessions, seminar participants moved into workshop groups to discuss the material presented in the plenary session. These groups reassembled at 4.15 pm and presented questions to the panel.

On Sunday the direction of the Seminar changed to a consideration of the 'Edges of Life'. Seven workshops were held covering the topics of Resource Allocation in the withholding and withdrawal of treatment, the posthumous use of gametes, the use of foetuses for treatment and research, management of the dying process, the foetus as patient, resource allocation (withholding and withdrawing treatment).

The 11am session was a hypothetical discussion led by Grant Gillett. The hypothetical format proved to be a good way to summarise issues discussed at the seminar.

The organising committee for the workshop (Donald Evans, Barbara Nicholas, Grant Gillett, Andrew Moore, Nicola Peart) are to be commended for bringing together such a collection of experts on important and current New Zealand issues in Bioethics.

Fay McDonald was the organiser for the Summer Seminar, without her capacity for handling the complexities of conferences, the Summer Seminar could not have run as efficiently as it did.



Research Ethics in Poor (and not so Poor) Countries

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This paper was presented at the 1998 Bioethics Summer Seminar

How commonly in a country such as New Zealand do health professionals now find themselves unable to offer services to the standard of the best known treatment or care in the world? Hold onto your answer. I return to this question below.

Turn now to a very different set of issues. As is well known, there are catastrophic problems of HIV and AIDS worldwide, but especially in Africa. Reputable current predictions are that 6 million pregnant women on that continent will have HIV infection by the year 2000 (Scarlatti; Lurie and Wolfe, 853). One part of this problem concerns transmission of the virus during pregnancy from mother to child. It is by no means the only part of the problem, nor even perhaps the most important, but it is a key focus of this paper. Right at the end, I turn very briefly to wider issues.

Research findings in the mid 1990s demonstrated decreases in transmission rates from pregnant HIV-positive women to their children of 50 per cent or more, with a course of zidovudine (hereafter, AZT) (Lurie and Wolfe, 853). But the treatment is complex, and far too expensive for poor countries to be able to introduce it as their new standard of care. Urgent research is consequently underway in search of something effective, but much cheaper.

At least two sorts of clinical trials seem relevant. AZT-equivalence trials look at whether there might be something just as effective as, but much cheaper than, the AZT regime now standard in rich countries. The earlier research suggested in particular that courses of AZT shorter than those so far of proven value might be equally effective (Lurie and Wolfe, 854). Placebosuperiority trials look at whether there might be something affordable by poor countries that is more effective than their currently available treatment. Here treatments such as intrapartum vaginal washing, vitamin A derivatives, HIV immune globulin, and very short-course AZT are compared to placebo, on the pessimistic assumption that placebo is approximately as effective as no treatment at all. Studies of both sorts have in fact been approved, and are currently underway (Lurie and Wolfe, 853; Angell, 848).

Are the AZT-equivalence trials ethically acceptable? Are the placebo-superiority trials ethically acceptable? Several writers in the *New England Journal of Medicine* (hereafter, NEJM) have vigorously responded 'yes' and 'no', respectively (Angell; Lurie and Wolfe), and the controversy has

