

published *On death and dying* - a book that **made** her famous and helped launch the hospice movement in the United States. Today, she thinks suicide may be a legitimate option. When asked which of the five stages of death (described and popularised by her) she finds herself in at the moment, she yelled, 'I'm pissed!'

Some gems from consent forms⁷

The following are from real consent forms received by the institutional review board at the University of California:

☐ 'You believe that you will understand what will happen to you if you agree to be a part of this study.'

☐ 'You are free to seek care from a

physician of my choice at any time.'

☐ 'When all patients have been enrolled, they will be shipped on dry ice...'

☐ 'Like interferon, conception should be prevented by men and women.'

☐ 'You should not participate in this study if you can think of a reason why you should not participate in this study.'

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REVIEWS

Intractable neurological disorders: Human genome research and society
Proceedings of the Third International Bioethics Seminar in Fukui, 19-21 November, 1993. Editors: **Norio Fujiki**, M.D. & **Darryl R. J. Macer**, Ph.D. Christchurch, New Zealand: Eubios Ethics Institute 1995

The disaster that Hesiod sees threatening a community that disregards justice... is not an eternity of damnation but the failure of nature to work - of crops to grow, of herds to bear, of women to produce normal children.

In the developing nations of the third world, infectious diseases continue to be a burden on the health care system and are the bane of the poor. The developed nations, freed of most of these diseases, are now grappling with chronic diseases at extremes of age.

As has been elegantly pointed out in the text of the proceedings of the seminar, the ability of modern medicine to prolong life in case of intractable neurological disorders in adults and to prenatally diagnose uncorrectable neurological diseases raises ethical, legal and social dilemmas which have never been required to be addressed in the past. Interventions at the end of life (ventilator care) or at the beginning of life or even pre-life (prenatal) represent major financial and administrative outlays.

The need for community based care is of utmost importance in these groups of patients. Continual medical therapy after the patient is sent home from hospital by 'home-visit medical program' is a revolutionary concept introduced in Japan. On the one hand it maintains continued medical supervision of the patient at home after discharge and on the other it pre-

empts situations whereby patients are denied re-admission due to non-availability of hospital beds during periods of symptom exacerbation at home. Deadlines indicating termination of periods of in-hospital care facility may become a reality worldwide following escalating expense of medical care.

It has been succinctly mentioned that patient care is no more the exclusive domain of the scientific-medical community but has to necessarily consider the right of self-determination of the patient and hold social, ethical and financial implications in perspective. Dignity of life, quality of life and sanctity of life are concepts which will seldom yield a solution in harmony when confronted with the request for euthanasia.

Human genome studies raise the **spectre** of 'eugenics' as **practised** by the Nazis in European war prisons and the Japanese in Manchuria during the Second World War. In the following decades those blots on scientific study have been virtually cleansed, however any new forays into genome research and genetic manipulations will have bio-ethical implications.

Genetic research is a widely accepted and encouraged subject. Prenatal genetic diagnosis, on the one hand, reliably predicts the probable occurrence of disease in the future and, on the other, offers the option of early implementation of primary prevention strategies such as dietary restriction and pharmacologic manipulation in primary hypercholesterolemia. Is our response the same to untreatable manifestations like Huntington's disease?

The debate for legalised abortions at will for social or eugenic reasons will never be conclusively resolved. Is the human

genome really sacred? Who will be the final arbitrator in allowing expression of one gene with so called superior qualities or obliterating the appearance of a gene with perceived inferiority or abnormality? Such questions have never needed to be answered in the bygone ages but will keep surfacing and nagging the human race in the future. The 'white man's burden' has surpassed all conceivable limits.

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Bioethics in High Schools in Australia, Japan & New Zealand. Darryl R. J. **Macer**, Yukiko Asada, Miho Tsuzuki, Shiro Akiyama, Nobuko Y. **Macer**. Christchurch, New Zealand: Eubios Ethics Institute 1996

Growing concern on ethics in research and medicine has prompted the investigation into the need for a formal curriculum in the field of bioethics.

The survey conducted by **Macer** and coworkers sought to identify the recognition, perception and inculcation of bioethical values in high schools in Australia, Japan and New Zealand. Although an impersonal form of survey (questionnaire) had been used without direct personal contact; it is perhaps a telling comment on the state and awareness of this concept that less than 50% replies (collectively) could be obtained, despite reminders. This is a stark statement on the prevalent situation as the subjects to whom these questionnaires were directed were teachers, who are instrumental in shaping **the** young minds and mould their thought