Such ideological manipulation is most likely when objective evaluation is incomplete. Manipulation is sometimes based on the invalid move from “Xness in life is a good reason to die” to “Xness in life makes life not worth living”. Extreme pain is a reason to die, but it does not necessarily make life not worth living. Other features of that life may provide stronger reasons to live. Severe disability is a good reason to die; but it does not necessarily make life not worth living.

Evaluation of the quality of life of a competent person’s life is not relative to that individual’s own judgments of the worth of that life. It is in this sense not subjective. It is in important ways objective. Battin displays loyalties to both camps, though her view is complex. I have not addressed Battin’s approach to valuing the lives of non-competent patients (“Fiction as forecast: euthanasia in Alzheimer’s disease”). That also seems to me problematic. My hope is that Battin will clarify her approach to valuing life in the future.

Conclusion
A book that fails to stimulate discussion is unlikely to be saying anything significant. This book says much that is significant, and there is much more to praise than to criticise. It is a fine example of scholarship, a rich resource of historical and contemporary examples, and US case law. For the second time in a decade and a half, contemporary bioethics owes a debt to Margaret Pabst Battin.

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Concepts and Measurement of Quality of Life in Health Care

In the introductory essay to this edited collection Lennart Nordenfelt suggests a number of questions, amongst which are the following: what is the purpose of measuring quality of life; is its aim to determine the extent to which resources should be allocated, for example, to health care in general, or to some patients rather than others; or is it instead to be used to measure the relative success of different medical interventions; given the relevant aim(s), which aspects of individuals’ lives bear upon their quality of life; and, finally, how should the values and tastes of individuals, as patients or voters, figure in the selection of those aspects? Such questions have considerable philosophical interest, and should be matters of urgent political concern. Each contribution to the collection contains views relevant to some or all of these questions. They are, without exception, thoughtful and serious discussions, though philosophically informed readers may find much of the territory they traverse familiar.

The volume is divided into three sections, the first of which addresses the concept of quality of life in general, and contains essays by E Ostenfeld, P Cattorini and R Mordacci, P Liss, T Moum and S Naess, as well as the editor himself. The second begins with a sociological essay, by M Bury, suggesting reasons why quality of life is now so widely discussed amongst students of health. It is followed by papers from A Fagot-Largeau, P Sandoe and K Kappel, and A Musschenga. These examine specific ethical problems arising for judgments about quality of life in the context of health care, and include one particularly illuminating account of how changes in an individual’s preferences might bear upon changes in her health status. The third section contains papers by R Fitzpatrick and G Albrecht, S Bjork and P Roos, A Aggernaes and M Kajandi, and focuses on problems of measurement. These are not, however, merely technical investigations, but include, amongst other things, a very helpful discussion of the moral problems involved in extending quality of life measurement to various decision-making contexts in health care.

One of the collection’s prominent themes concerns the extent to which standards of interpersonal comparison should depart from the objective dimension of individuals’ lives, concerning their biological functioning and basic capabilities, and encompass subjective aspects, such as the extent to which their lives are successful according to their own lights. Given the centrality of this problem, more reference to post-Rawlsian criticisms of so-called welfarist metrics, which focus on preference satisfaction, would have been welcome. For many contemporary political philosophers argue that whilst subjective standards are appealing for liberal reasons (since they lessen the need to rely on controversial judgments about what goods individuals should care about) they may be deficient for other reasons; for example, because of the existence of malformed or expensive tastes.

The absence of reference to such discussions is indicative of a more general feature of the collection, namely the extent to which it tends to treat judgments of health-related quality of life in a normative vacuum. Although references to utilitarianism are quite widespread, it would have been desirable to explore the way in which different conceptions of quality of life might be embedded in distinct moral and political theories concerning the just distribution of health care. That omission is striking given that, as noted, Nordenfelt himself suggests that one of the reasons to measure quality of life is concerned with resource allocation. Readers interested in those issues would do better to consult the very useful collection by Nussbaum and Sen.

References

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Primum non Nocere
Today: a Symposium on Paediatric Bioethics
Edited by G Roberto Burgio and John D Lantos, Amsterdam, Elsevier Science BV, 1994, 175 pages, US$142.75, 250 DFL

This book is an edited record of the International Symposium on Paediatric Bioethics held at Pavia in May 1994. Eleven (including paediatricians, an academic lawyer, an anthropologist and three bioethicists), of the main contributors were from Italy. Two contributors came from Chicago, and one each from France, Germany, the Netherlands and the United Kingdom. The proceedings make a stimulating and enjoyable if rather expensive read.
The archaic Hippocratic maxim "above all do no harm" was the title addressed by the participants: in the categoric form Gillon sought to "consign [it] to the history books" (page 37). This message followed von Engelhardt's admirably succinct historical review of bioethics, childhood and paediatrics, and an anthropological challenge from Galil as to the independence of bioethics as a new discipline.

Having reconstructed Hippocrates from the "do no harm" to a "try to be helpful" mode the participants concentrated on paediatric clinical ethics associated with advances in medical technology. Prenatal diagnosis and selective abortion was tackled by Boué, who, in the course of a competent paper, found the striking phrase "yield to mediatisation" for the activity of publicity-seeking researchers who contribute to the formation of an ill-informed but influential vox pop on ethical issues. Versluis discussed the recent report of the Dutch Paediatric Association on the main moral dilemmas concerning the prolongation of life and the hastening of death in perinatal practice. This statement, coming from the only nation in which active euthanasia is openly permitted, is particularly interesting.

Ethical issues arising from the increasing demands for donated organs and tissues needed for the recipients of transplantation therapy got full attention. Lantos argued that "involuntary altruism" is a morally acceptable justification for the harvesting (with appropriate safeguards) from minors of such material. The position in Europe in regard to bone marrow transplantation was well set out in papers from Burgio and Buzzi.

The well-worn topic of research on children was revisited in papers from Garattini (therapeutic trials) and Sereni (general remarks). Absolute objections to the use of children in any research were rejected while the obligation of researchers and research ethical committees to examine closely both the scientific merit and the risk-benefit of paediatric research proposals was commended.

Advances in genetic prediction and in gene therapy raise many ethical dilemmas which impact on children. These fields were looked at by Siegler and Notarangelo and colleagues, whose lucid papers will be of particular value to non-specialists seeking scientific information.

The final section is more general. There is a well ordered statement about the systematic teaching of bioethics to medical students from Cattorini.

Nordio gave an impressive insight into the thinking of a distinguished academic paediatrician about the special moral and clinical virtues required of a doctor for children. Some ethical principles for the organisation of paediatric services were enumerated by Guzzanti and the final paper by Corbellini described the tensions which arise from new medical knowledge and a bioethics based on "the philosophical background of traditional ethical theories".

The editors conclude that "bioethical problems should be experienced as an extraordinary opportunity for in-depth and clear discussion, starting from tangible problems, between social sciences and medical sciences to promote the development of a culture of reasonableness, responsibility, and solidarity".

The material contained in these proceedings provides some justification for this rather pretentious conclusion.

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Science and the Quiet Art. Medical Research and Patient Care


In London's National Gallery there is a painting by Titian entitled An Allegory of Prudence. It depicts three human heads. Facing the viewer is a bearded man in the prime of life: to his right the profile of an old man, half-hidden in shadow, and to his left the brightly lit profile of a youth, looking away, beyond the picture frame. Beneath each of them is an animal head: the old man is accompanied by a wolf, the central figure by a lion, and the youth by a hunting dog. Over them all is a Latin inscription: "Ex praetorio praevens praevidenter agit ni futurum(m) actione(m) deturpet." "From the past the man of today acts prudently so as not to imperil the future".

I was reminded many times of this mysterious painting, especially of the inscription, as I read David Weatherall's book. What he was asked to do by the commissioning editors was to write about himself and his work in a way that would be comprehensible to the non-specialist reader.

What he has produced is a book that is both less and more than this. Less because he has eschewed an intellectual autobiography, though he draws on the experiences of a lifetime spent in combining research and clinical practice, and more, because what he has done instead is to raise some fundamental questions about the contribution of science-based medicine to the care of sick people. As a practising doctor his central concern is for his patients, and the book can be read as a refutation of the idea that scientistic medicine is somehow at odds with humane patient care. Indeed, one of his main contents is that a practice that is not based on the best available science, limited though this may be in many instances, is an uncaring one.

The result is a substantial volume packed with ideas and insights, and many a warning about assuming that advances in basic medical science will lead rapidly to improved treatments. The paradox that medicine is an art that "has become harder to practise and knowledge of the ignorance that underlies it has increased" (page 52) is at the heart of his thinking, and his own clinical practice. Doctors have to live with uncertainty, and they - and their patients - have somehow come to terms with this uncomfortable fact.

In the opening chapters Weatherall examines the roots of medical knowledge and asks how much has been achieved. He claims no originality, but his breadth of view, his feel for the historical material, his stress on the big questions, on epidemiology and the impact of medical advances on populations across the world, make this part of the book well worth reading. The three chapters in Section IV, "The origins of our intractable diseases", bring the reader to the present and its challenges to medical science. They deal in turn with new ways of thinking about disease, including the crucially important mathematical and statistical advances of the last forty years or so the nature/nurture issue and the significance of aging, and the growth of genetic medicine. This is, of course, his own field of research. But while he is confident that the new techniques in molecular and cell biology will lead to a better understanding of the aetiology of disease and its pathologies he does not expect major advances in treatments in the near future, with the partial exception of some single-gene disorders. Basic research is one thing, the development and application of the knowledge gained quite another.