From Chaos to Coercion: Detention and the Control of Tuberculosis


This is a fascinating book. It uses tuberculosis to look at the balance between individual liberty and the public good: the tensions created between personal liberty and social responsibility, a strong theme in all work in public health. The context is New York in the 1990s, but as Coker states, “This book uses the lens of tuberculosis control, and in particular the detention of non-infectious individuals, to examine America’s response to its most vulnerable and marginalised citizens, and asks the question: ‘is detention of non-infectious, non-compliant individuals right from ethical, legal, and public health perspectives?’”

The book is divided into nine chapters. It takes the reader through TB in New York City in the early 1990s through an exploration of the history of the disease, the legal ramifications, the media, the actors, and the process of how the disease was investigated and controlled. It also describes the “seeds of the epidemic” that were present before 1990. The analysis describes the interaction between the legal system and the health system and its relation to international, national and local policies, and people. Permeating all of these are the broad human themes that Coker brings to the work: issues of how we organise ourselves in society and the ethical themes that underpin what we do and how we do it (chapter 7: Culture, morality and tuberculosis). Contained within the treatise too are many questions about the broader society in which TB is allowed to flourish, for instance how society mirrors the disease (the disease modifies in a peculiar manner the emotional and intellectual climates of the societies that it attacks—Rene and Jean Dubos, 1952) and how, by looking at the disease from a perspective that is broader than biomedicine, many issues are highlighted.

Examples are: the coercion of patients; legal themes; issues of health care, and finally an account of the perspectives of individuals (“actors”) and how they create health policy. Although the context for the story is New York, the messages it contains have a much wider relevance. This is because the broad themes addressed are issues about human beings, how they interrelate and what sort of society they create. The book highlights the potentially narrow perspectives that inform disease control strategies, and indicates the importance of other approaches. “A biomedically individualised approach that pays scant attention to the social causes of TB is often more acceptable to policy makers. It appears ‘tight’ and there are no ‘loose ends’” (page 210). But as Coker argues, there are so many other ways to approach tuberculosis control, and history, in all its guises, has many lessons for us. The book is about a complex variety of subjects, but Coker makes it very readable and understandable. He uses strong research skills as well as bibliographic information to support his ideas and concepts. If you are a person who is interested in the broad issues of health and society and how health policy is created, and certainly if you are someone who works in the control of infectious diseases, I highly recommend this book to you.

J D H Porter

Death Foretold: Prophecy and Prognosis in Medical Care


Many doctors these days are aware of powerful disincentives to the giving of specific prognoses. The mentioning of an estimated time, even if heavily qualified, is likely to be heard by both patients and doctors as “the doctor gave me two months to live.” The result? Patients and relatives feeling cheated if the prognosis turns out to be an overestimate, anxious or worse if an underestimate, and colleagues critical of the doctor for having had the arrogance to predict, no matter what the actual outcome. It is not surprising therefore that doctors wishing to avoid these results are reluctant to prognosticate at all and when forced tend to make their predictions so vague as to be meaningless. For Christakis, this response simply is not good enough. In a carefully written and very well referenced book he argues cogently that prognostication is a responsibility for doctors and that “shirking the difficult questions—as most doctors tend to do—advances neither medical knowledge nor the care seriously ill patients receive”. He does not see it as a failure of the system as the results of his survey of the attitudes and self reported practice of 1500 American physicians. While accepting that patients might be harmed if erroneous predictions of imminent death result in the withholding of interventions that would otherwise save a life, his study convinces him that most of the time the problem is the reverse. The concept of the self fulfilling prophesy is helpfully explored and with a powerful combination of evidence, argument, and understanding is developed into the notion of “the ritualisation of optimism”. Christakis shows that, whatever is communicated to patients, physicians caring for terminally ill patients routinely overestimate duration of survival by a factor of three or more; he suggests that it is reasonable to expect that, knowing of this bias, systematic allowance could be made in their prognostication for the group as a whole even if errors in individual cases unavoidably persist. It is hoped that, in changing their thinking, physicians might realise there is much that patients can hope for even when death is inevitable.

J Gilbert

In essence this is a book about some of the most important and pressing problems facing medicine and the relationship of biotics to these problems. By focusing upon issues such as organ donation, reproductive technologies, the internet, and genetics Pence ensures that this book is highly topical. It is a book that will be, for most readers, controversial. Pence seems to be on a mission to dispel commonly held misconceptions about a number of important issues. One issue that comes in for lengthy analysis, for example, is the claim that payment can “commodify” practices or persons in undesirable ways. There is an extended discussion of whether surrogacy may end up commodifying any resulting children, that is a substantial contribution to this on going debate. An area that benefits from similar treatment in the book is the claim that payment for organs and blood cannot be justified because of worries about the incentives that this would provide. On issues such as these Pence consistently challenges commonly held views. The topicality and provocative nature of this book alone are sufficient to recommend it. However, given the fact that Pence is trying to convince his reader that bioethics falls short of the mark in quite a general way it is notable that at times, the reader’s assent is gained more by rhetoric than argument. This is of course is not in and of itself a bad thing; if the arguments are adequate then a little rhetoric may aid the appreciation of the full power of an argument, but there are points where the rhetorical force of a particular point derives from a selective use of the facts and a stereotype of what is in fact a complicated phenomenon. Pence complains about “...the customary, patronizing tone of English-European writers—Oh look—what-those-silly-crass-warmongering-Americans-came-up-with-now...” (page 186). This comment plays little role in his analysis...
and is unlikely to improve the quality of any resulting discussion. Ironically, given Pence’s apparent dislike of stereotypes, he also offers a crude characterisation of Australian reactions to a headline in Australia’s Sunday Herald Sun about attempts to sell embryos on the internet. In this story, it helped that the site of evil was the United States, which the Australian media loved to criticise for its excesses of commercialism. … for traditional Australians, bewildering and scary place … the reduction ad absurdum was right there” (page 66). While it might be the case that there is something to this stereotype it can only ever be considered a crude characterisation of a fairly complicated phenomena and does not add much to the point Pence wants to make. This is a book for those interested in the big present and future issues. Furthermore those interested in ethics, bioethics and its consequences likewise should consult this book. This recommendation should be tempered, however, with the warning that by the end of this book what began as a fresh and invigorating challenge to bioethics and its position the problems of the day may become a bit irritating in its tone; a shame as this is otherwise a challenging book.

J McMillan

Brain Death: Philosophical Concepts and Problems

T Russell. Ashgate, 2000, £40.00, pp 183. ISBN 0 7546 1210 4

It is more than thirty years since the Harvard report of the Task Force on Diagnosis of Irreversible Coma. And twenty-five years since the UK Royal Colleges’ criteria for the diagnosis of brain death, Diagnosis of Brain Death, provoked passionate public debate. For many years now, however, the concept has been well accepted by the public and the practicalities of its use by the medical profession. According to a recent American book, however, some academic philosophers are concerned that the pragmatism of the doctors and the acceptance of the public has led too readily to acceptance of incoherent concepts and they would like to reignite controversy. The present book also argues that current concepts of brain death are conceptually inadequate and claims to present an entirely new concept of death with which it might be replaced. This is that death results from death of the organism as a whole, not of the whole organism. This concept was in fact fundamental to the original debate about brain death. What is new here, however, is the proposition that the only coherent interpretation of this is that there should be failure of control of bodily homeostasis. Russell admits there is no hope of discovering when death occurs—it will inevitably be a matter of selecting an arbitrary point when it is agreed that it has occurred. He reviews brain stem, reticular formation and neocortical death and the difference between brain death, the vegetative state, and the locked-in syndrome. While some reject brain-based criteria Russell is in favour of accepting that brain death (by his new definition) should mean death.

Discussing the necessary and sufficient conditions for life Russell argues for definitions that apply to all animals, rejecting the notion that humans are special.

Life, Russell argues, implies the capacity to transform energy, to organise life processes either in a single cell or the whole organism and to adapt to changes in the internal and external environment. Homeostasis is a necessary but not sufficient condition for life and is the only manifestation that can be applied universally from amoeba to man. For the amoeba this capacity implies movement, avoiding harm, and ingesting food. For man it implies control of body temperature, fluid balance and blood pressure. There follows a convolutioned argument based on elaborate analogies to illustrate the problem of the difference between loss of control of a complex system centrally or by the accumulated failures of the peripheral components of the system, and when failure (that is, death) occurs.

Discussing operational changes in the diagnosis of brain death he admits there is no ready means of detecting failure of homeostasis, other than waiting for its delayed effects—low and falling body temperature and blood pressure and the passage of large amounts of urine. It is doubtful if many will be persuaded by his suggestion that these should replace the whole and well-timed criteria of brain stem death, “because to use both would cause intellectual confusion”.

Stylistically, the book has several weaknesses. There is, for example, the strange use of the word “monograph”—“my proposed monograph is a robust monograph”—seemingly to make it synonymous with thesis. And “any hypomonograph must be verifiable in principle” sent me frantically in search of a dictionary. My assumption that these were part of the usage and vocabulary of philosophers was dismissed by a professor of philosophy. The whole text reads like a degree thesis with frequent use of footnotes and quoting from sources. It would be interesting to see how the author declaims his current and future arguments.

Bennett

Prenatal Testing and Disability Rights

Edited by E Parent, A Asch, Georgetown University Press, 2000, £46.75 (hb), £17.25 (pb), pp 371. ISBN 0 87840 804 5

Here is a book that should be read by all those involved in the fields of prenatal diagnosis and genetic counselling. It is based on a two year project set up in the late 1990s by the Hastings Center in New York, in which prenatal testing and its likely future advances were discussed, from their contrasting viewpoints, by professionals providing such services and those committed to promoting disability rights. Changes between a group who see any form of prenatal testing for malformation as an unacceptable affront to those with disability and those who offer such testing in their daily routine will inevitably be difficult. And, reading between the lines it seems likely that the project nearly founded. One original intention was to develop guidelines concerning which anomalies might warrant prenatal diagnosis and abortion, and which were too mild for such action. The disability rights members could not agree to any such distinctions so this objective was abandoned. There was, however, firm agreement on other questions. In particular, there was agreement on the need for broader exposure to disability during training of medical students and genetic counsellors; on the need to demedicalise disability and focus less on the impairment, and more on the need for society to accept and accommodate those affected so that their disability was minimised.

The opening chapter is a useful overview of the disability rights critique of prenatal testing and the next two sections briefly review the literature. Those with experience of disability set out their views and those who see prenatal testing as by no means undermining the value of the disabled state theirs. The contributors write well and put their case with logic as well as emotion and each chapter is well ordered. There is considerable discussion of “expres sivity”, which in this context refers to the message that the offering of a prenatal test with the implied possibility of selective abortion, sends to society. Some argue that this is one that devalues the disabled community. The participants accepted a woman’s right to abortion. It is not this issue but the request for abortion of a particular fetus on grounds of one characteristic (for example trisomy), that the disabled contributors found unacceptable.

The final section of the book deals with practical matters. A lawyer voices concern that as more tests become available defensive medical practice will mean that more are offered until the medicolegal norm includes investigations that common sense would condemn. Drawing on her own extensive research experience Dorothy Wertz suggests criteria on the basis of which decisions could be made for offering or not offering a test. She argues that it is important that any such criteria are not based on the seriousness of the disablement but order as this can be highly subjective and dependent on individual experience.

The concluding chapters come from a fetal medicine obstetrician and a genetic counselling educator and her student, who describe the impact the discussions have had on them both personally and professionally.

There is agreement that pretest counselling, particularly for serum screening for neural tube defect or Down’s syndrome, is woefully inadequate, and that when an abnormal result is obtained there is no opportunity provided for the potential parents to obtain first hand information on both the joys and the sorrows of parenting such a child. With decisions having to be made rapidly and while parents are in the midst of coming to terms with their fetus being “different” this is hard to put into practice. Much will depend on the personal beliefs and attitudes of those who counsel them.

The book spells out clearly the tension between offering parents the opportunity to avoid the birth of a child with disability and maintaining a positive attitude to those who have these disabilities. This message and the need to work towards a society where the disabled are welcomed as equals should be an ethos imparted at the training stage. The book provides an admirable resource for students, their teachers, and practitioners.

The book’s chief disadvantage is that it is based on American practice where money will buy investigations more readily than in the UK, but the ideas put forward can be applied to any local situation. The book also seems to indicate the existence of a serious hiatus in some US states between the funding of a prenatal test and an abortion arising from its result, a pitfall to guard against.

A C Berry
Non Heart Beating Organ Transplantation—Medical and Ethical Issues in Procurement


The problem of the supply of organs for transplantation is a major concern in many areas of health care practice and more generally in society. The availability of organs for transplantation remains the treatment of choice and in many situations this necessitates a cadaver donor. The possibility of harvesting organs from patients other than those who meet the criteria for brain death has received less publicity, but raises different ethical and legal questions, compared to the more usual situation of brain dead, ventilated patients. Given the general shortage of donor organs, however, this group of patients may represent a useful source.

This report was commissioned in 1997 by the US Department of Health and Human Services and concerns “the management of cadaver donors who died a cardiopulmonary death, called non-heart-beating-donors (NHBDs)”. In these patient death results from an “irreversible cessation of circulatory and respiratory function”, as opposed to cessation of functions of the brain. Questions had been raised about the medical management of such donors and whether the interventions practised could be said to be in the best interests of the patient or were in fact hastening death. The question considered by the report was: “Given a potential donor in an end-of-life situation, what are the alternative medical approaches that can be used to maintain the viability of organs from that donor without violating prevailing ethical norms regarding the rights and welfare of donors? The Institute will consider the alternative approaches, including the use of anticoagulants or vasodilators, from the scientific as well as the ethical point of view.” The bulk of the report concerns a review of the protocols for NHBDs obtained from 63 organ procurement organisations in the United States.

The report defines four categories of NHBDs and offers an extensive discussion of the problems of supply and demand for organ transplantation in the United States. An extensive review gives a useful synopsis of the report’s findings and the appendices include notes of a workshop on medical and ethical issues in maintaining the viability of organs for transplantation.

The general conclusion of the report is that the use of NHBDs is “an important, medically effective, and ethically acceptable approach to reducing the gap that exists . . . between the demand for, and the available supply of, organs for transplantation”. The authors conclude that the ethical questions posed by this approach “require attention, but . . . are . . . not significantly different from those that arise in cadaveric transplantation generally”. The authors summarise six principles or general approaches that apply to all cadaveric donors: 1. The societal value of enhancing organ donation; 2. Organ donors must be dead at organ removal; 3. Absolute prohibition of active euthanasia; 4. Complete openness about policies and protocols; 5. Commitment to informed consent, and 6. Respect for donor and family wishes.

Perhaps surprisingly, in view of the overall conclusion of the report, the authors are reluctant to set out clear criteria for the various procedures involved, but rely heavily on case-by-case decisions (for example, for the use of anticoagulants and vasodilators, and vascular cannulation for organ perfusion) and “informed family consent” when interventions are required to facilitate organ harvesting, which are not indicated for the patient’s medical condition. The legal framework is specific to the American situation, and the report talks of consent being obtained either from the competent patient or from “surrogate decision maker(s) for the incompetent patient”.

The ethical focus of the report is the way in which designation as a potential organ donor may lead to changes in the care of the patient in ways that clearly have no therapeutic value for that patient, but which have great potential value for the recipients of any harvested organs. The extent of these changes in care is illustrated by reference to a study of beating heart cadaver donors, which found that almost half the average hospital-stay cost was related to care that was considered futile for the donor patient. “The maximisation of improved organ procurement rates”. The discussion of these issues is organised under the headings of Policies and oversight; Medical interventions and ethics; Conflicts of interest; Determination of death; and Families. The general view seems to be that, with adequate safeguards, the interventions necessary to improve organ retrieval from NHBDs, although not offering any benefits to the donor patient, can be justified because of the greater social good derived from transplantation.

The report, while very much oriented to the American experience, is a useful resource for anyone working in the treatment of brain death. However, it raises, by inference, one or two troubling questions that do not receive any discussion. One concerns the problem of supply and demand. In 1996 the total number of cadaver donors in the USA was 5416. This number represented a 33% increase over a nine-year period. The transplantation waiting list on the last day of 1996 stood at 50 047 people, an increase of 14% on the previous year and of 212% over the previous nine years. These figures are discussed in more detail in the report, but the conclusion is that demand is growing faster than supply. The only discussion of possible reductions in demand concerns narrowing the eligibility for transplantation. It would appear, however, that more productive approaches might be to look for ways of reducing the number of organ failures, by preventive measures and by more effective early treatment of the conditions that lead to failure. At 1996 levels a 5% increase in cadaver donors will provide an additional 270 donors. A 5% reduction in demand would reduce the number of people on the list. Of course this analysis is too simplistic—for example, each donor cadaver may benefit more than one recipient, a proportion of those on the waiting list are for repeat transplantations and hence arithmetic “would still seem to favour attempts at prevention over attempts to raise the numbers of cadaver donors.”

A further perspective of preventive medicine concerns the paradox inherent in any general attempt to increase the numbers of cadaver donors. The report discusses possible conflicts of interest in the treatment of specific patients once they have been identified as potentially donors, but does not consider the wider conflict of interests faced by the patients waiting for transplants, their carers, and society at large. The availability of cadaver donors results from the death of a patient, a death that, other things being equal we would have preferred not to have occurred. As long as we rely so heavily on transplantation as the sole element of treatment we have a perverse incentive not to reduce rates of neurological or cardiopulmonary death. To put it less controversially, every advance in the prevention of such deaths represents a setback to the transplant programme.

Finally, in the context of supply and demand, the report touches briefly on the impact of managed care. The increasing management of health services may, on the one hand, slow demand by imposing “stricter indications for medical treatments”, while on the other it may diminish supply “by less often carrying the care of seriously injured or ill patients to the point of potential donation using life support and other critical care interventions”. Again, the ethical implications of these trends are not discussed.

The report talks of consent being obtained either from the competent patient or from “surrogate decision maker(s) for the incompetent patient”. It includes articles from James Rachels, Sidney Callahan, and Carl Elliott and these will be useful for students who are starting out on the study of ethics and want to examine the role that ethics can play in practical decision making. There are sections on rights and responsibilities; reproductive freedom; reproductive technologies; transplantation; and genetics. By far the most important section considers the ethical dilemmas raised by the termination of treatment. This section includes articles on setting standards for the limiting of care; terminating treatment for the terminally ill; treating neurological defects; active voluntary euthanasia, and physician assisted suicide. It brings together articles by Daniel Callahan, Dan Brock, Cynthia Cohen, and Artila Caplan, among others, giving the reader a good overview of the literature in this area.

The second edition includes a new section on the goals and allocation of medicine. This is an important addition, coming at a time when policy makers throughout the world are
faced with difficult choices over health care reform and how to set priorities for health care spending. The Hastings Center has conducted an international study on the goals of medicine and the executive summary of the resulting report is included in this section. The report starts from the premise that the ends of medicine not only the means used to reach these ends that are at stake: “too often it seems taken for granted that the goals of medicine are well understood and self-evident, needing only sensible implementation. Our conviction, however, is that a fresh examination of those goals is now necessary”.

The report identifies and defends four main goals that medicine should aim to achieve: the prevention of disease and injury and the maintenance of health; the relief of pain and suffering; the care and cure of those with a malady, and the avoidance of a premature death and the pursuit of a peaceful death. They argue that such a clarification of the goals of medicine is imperative as without such reflection, “the various reform efforts going on throughout the world may fail altogether or not achieve their full potential”. This report and the articles included in this section are a useful consideration of the often neglected area of public health ethics and include the important article by Daniels and Sabin. The importance of tools of analytical philosophy and the many examples of inadequate conceptualisation of the so-called core concepts of nursing. Seedhouse most successfully deals with the notion of advocacy; and the nurse as potential patient advocate. Seedhouse’s analysis is one of the most comprehensive I have come across.

In terms of his second challenge regarding leading the way in a more humane approach to health care ethics, the author also provides interesting insights into some of the tensions, inconsistencies, and incompatibilities in nursing, particularly in mental health nursing. Seedhouse raises some important questions for practitioners to consider. For example, he asks if it is possible to promote the mental health of patients within the current structure of mental health services delivery—and if so how? Is it possible to balance care and control? In their defence, some practitioners might argue that Seedhouse has a somewhat antiquated view of the mental health service and indeed of mental health nursing. However, as he accurately claims that in nursing, as elsewhere, “there is a need for a greater mystification. Described as nursing philosophy has not in many writers on this subject, there is nothing obviously partisan about Martin’s approach. The book is written in a somewhat dense manner, but this may simply reflect the complexity of the issue itself.

Unusually, Martin seeks to use evidence about fetal pain as one plank of her argument that even in early pregnancy terminations, account should be taken of evidence which suggests that fetuses can experience pain. Moreover, as part of the continuum of development, she argues that there are circumstances in which it is not intrinsically wrong to terminate a pregnancy. She concludes that after 24 weeks the fetus is possessed of certain characteristics which render it equivalent to the person to be born, thus justifying restrictions on abortion, save in rare and extreme cases. This is a thoughtful and interesting contribution to the debate.

L Frith

**Practical Nursing Philosophy: the Universal Ethical Code**

D Seedhouse, John Wiley & Sons, 2000, £16.99, pp 222. ISBN NO: 0 471 49012 1

This book is clearly written and well laid out. The short summary at the beginning of each chapter is a useful guide to the reader and also serves as a valuable summary of key issues for revision purposes. The author offers a number of case scenarios for the reader to work through and provides many practical examples of situational analysis and possible steps to ethical decision making. Seedhouse accurately claims that in nursing, as elsewhere, philosophical analysis is useful in helping to clarify ideas. Unfortunately, as he also accurately points out, to date much of this has been described as nursing philosophy has not in fact led to the clarification of ideas but rather to a greater mystification.

The author poses two significant challenges to nursing through the pages of his book: (i) use some of the tools of analytical philosophy to reconceptualise concepts central to nursing practice, and (ii) take a lead in developing a more humane approach to health care ethics. Chapters two to five deal with the first of these two challenges. They offer a significant and necessary challenge to nursing academics and practitioners alike. Seedhouse here points to the many examples of inadequate conceptualisation of the so-called core concepts of nursing. Seedhouse, in his own words, “central” to nursing, Seedhouse’s most successful challenge is a self-appointed task. I suggest that of the four chapters regarding concepts that have gained nurse academics’ favour as being “central” to nursing, Seedhouse most successfully deals with the notion of advocacy and indeed of mental health nursing. Seedhouse raises some important questions for practitioners to consider. For example, he asks if it is possible to promote the mental health of patients within the current structure of mental health services delivery—and if so how? Is it possible to balance care and control? In their defence, some practitioners might argue that Seedhouse has a somewhat antiquated view of mental health services and indeed of mental health nursing. However, as he accurately claims that in nursing, as elsewhere, “there is a need for a greater mystification. Described as nursing philosophy has not in many writers on this subject, there is nothing obviously partisan about Martin’s approach. The book is written in a somewhat dense manner, but this may simply reflect the complexity of the issue itself.

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For further information: tel: +32 2507 01 11; fax: +32 2512 01 18; email: post@caritas.be
B Jennett

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