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 book is about a complex variety of other ways to approach tuberculosis control, 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.

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 most patients and loved ones 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 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 so as a physician and with the backing of 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 prophecy 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 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-crasw-warmongering-Americans-came-up-with-now” (page 186). This comment plays little role in his analysis of...
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 reac-
tions to a headline in Australia’s Sunday
Herald Sun about attempts to sell embryos on
the black market. In this story, it helped that
older Australians for some years had been
feeling that they had fallen behind in the
computer revolution and that the internet—
thepcardinality of this evil. It also helped
that the site of evil was the United States, which the Australian media
loved to criticise for its excesses of commer-
cialism. ... for traditional Australians, bewil-
dered to think of their world ... the reductio 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 compli-
cated 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
bioethics and its philosophical underpinnings
should replace the accepted and well-tried
clinical concepts and problems

**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 recommendation for irreversible coma in
twenty-five years since the UK Royal Colleges’
criteria for the diagnosis of brain death, Dia-
agnosis 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
decision and the acceptance of the public has
led too readily to acceptance of incoherent
concepts and they would like to reignite con-
troversy. The present book also argues that
current concepts of brain death are conceptu-
ally 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 interpret-
tion 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
studies—especially those involving the
neocortical death and the locked-in syndrome.
While some reject brain-based criteria
Russell is cautious about accepting that brain death (by
his new definition) should mean death.

Exit from life from a religious viewpoint is when
the soul leaves the body. For some phi-
losophers it is when consciousness and
personhood are permanently lost. But biologi-
cal criteria are the most universally accepted
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 discusses a case study in which two disabled
children have been parents. 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
good and put their case with logic as well as
emotion and each chapter ends with a conclusion.
There is considerable discussion of “expressiv-
ity”, 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 particip-
ants 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 character-
istic (for example trisomy), that the disabled
contributors found unacceptable.

The final section of the book deals with practical matters. A lawyer voices concerns 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 con-
demn. Drawing on her 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 disorder as this
can be highly subjective and dependent on
individual experience.

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

There is agreement that pretest counselling,
particularly for screening for neural
tube defect or Down’s syndrome, is woefully
inadequate, and that when an abnormal
result is obtained there should be an offer of
the 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
democratically parents are in the position of
having to discuss their 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 this 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 tertiary 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 pre-
natal test and of 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. A rare and important condition or organ 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 patients 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 maximise the availability 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 procurements programmes 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 appendix gives a useful synthesis 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 preparation for organ perfusion) and “informed family consent” when interventions are required to facilitate organ harvesting, which are not indicated for the treatment of 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 patients and unnecessary for 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 function; and Transplantation.

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The report, while very much oriented to the American experience, is a useful resource for anyone working in this area. 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 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 criteria for eligibility for transplantation. It would appear, however, that a more productive approach 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 save fewer 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 transplant and there are other arithmetic errors. The report 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 potential 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 main 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 potential for the management of health services may, on the one hand, slow demand by imposing “stricter indications for medical treatments”, while on the other hand 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.

P Wainwright


Life Choices is the second edition of a collection of “some of the very best articles published in the Hastings Center Report over the last 28 years”. The collection has been updated to provide a challenging text for classrooms and to serve as a testimony to the achievements of the Hastings Center. The first edition was published in 1994 to mark the 25th anniversary of the Hastings Center’s foundation. The Hastings Center, based in New York state, is the oldest independent, non-partisan interdisciplinary research institute of its kind in the world and has become a highly influential organisation. The center’s mission is the study of the moral problems that arise out of the rapid advances in medicine and biology, and collaboration with policy makers, both in the private and public sphere, to aid the analysis of the ethical dimension of their work.

The collection is organised around themes which reflect the center’s research concerns. The introductory section is a consideration of the question “can ethics provide the answers?” 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 largest 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; terminating life support by withdrawing or withholding treatment; and suicide. The collection finishes with an essay by Daniel Callahan, Dan Brock, Cynthia Cohen, and Artir 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 it is 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 sensitive implementation. Our conviction, however, is that a fresh examination of those goals is now necessary”. The report identifies and defends four main goals that nurses 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. 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. Last chance therapies and managed care. The second edition also includes a new section on the cloning of human beings. This includes a useful summary of the National Bioethics Advisory Commission’s report on human cloning and responses to this by James Childress, a member of commission, and Susan Wolf on why the NABIC is wrong. In terms of the discussions of health policy this collection gathers together pieces by some of the leading figures in the field and indeed of mental health nursing. 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 accurately points to the many examples of inadequate conceptualisation of the so-called core concepts of nursing. He also makes lots of mileage out of what he refers to as nursing big ideas. I have to admit to being almost entirely in sympathy with the author’s self appointed task. I suggest that of the four chapters considering concepts that have gained nurse academics’ favour as being “central” to 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 structures of mental health service 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. The least compelling section of this interesting book is the final chapter. Two difficulties emerge here. Firstly, the focus on the individual practitioner, and his or her perception of the ethical, belies the significant influence of organisational structure and culture on accurate perception of the ethical. It also, by default, ignores the impact of professional socialisation. Secondly, while it may be accurate to suggest that “Ethics is a pervasive phenomenon of human life—every human action that can affect one or more of us has ethical content”, it is not very helpful. The usual difficulty remains: perceiving and forming judgements regarding those actions or situations where there is significant ethical content. I suggest that the failure to do the latter may either trivialise the moral domain of clinical practice or lead to a state of moral paralysis in the thoughtful practitioner. None the less this is a useful introductory text that offers effective conceptual analysis of a number of important concepts in nursing. Seedhouse also raises some significant questions regarding the function and purpose of nurses and nursing practice.