The concerns for the child of having a mother suffer from early onset Alzheimer's disease are that they will not have a mother to bring them up and the impact this will have. While members of the woman's family have developed disease in their 30s and 40s, this is by no means certain for the woman herself.

The only other report of people with this mutation also had early onset Alzheimer's disease, but the numbers affected are very few, perhaps too few from which to draw a definitive conclusion about the exact age of onset for those with this mutation. For example the average onset of the Val717Ile mutation is 57 years. This is a mutation involving the same amino acid (valine at position 717) and the substitution is for a chemically very similar amino acid (isoleucine compared to leucine). If the destiny of this particular woman is to develop Alzheimer's disease in her mid 40s or beyond then her child will be an adult by the time she is severely affected. Even if we assume that onset of symptoms will be when the child is about 10 years old, the family are aware of this risk and can take steps to be prepared and put in place plans for this. Are couples with other sociological risk factors that put a child at risk of emotional deprivation prevented from utilising reproductive technology in Australia at least, those who are from low income brackets or who use illicit drugs are not precluded from assisted reproductive technology, yet both these factors are associated with a number of poorer outcome measures for children. Finally, PGD is a major undertaking for families. It is a protracted, expensive, and very stressful process and ultimately there is no guarantee that a child will be born through using it. Many couples who consider utilising PGD do not go through with the process for these reasons and choose other reproductive options, including traditional prenatal diagnosis, and natural pregnancy with no intervention, or they decide against having children. Therefore families who undertake this process are generally highly motivated and, one intuitively feels that the resultant child is less likely to suffer social deprivation. This issue will only be resolved by long term follow up studies.

In conclusion, I believe that PGD is ideally suited to situations where families wish to avoid their child developing genetic disease, but where they feel uncomfortable about terminating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.

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References

Electronic submissions to the Journal of Medical Ethics
At the time of writing there appear to have been no electronic submissions to the Journal of Medical Ethics. It seems appropriate, therefore, to begin electronic correspondence with a consideration of some of the ethical implications of this new form of electronic dialogue.

I have posted this response to Kenneth Boyd's editorial on Mrs Pretty and Ms B as this article may provoke debate far beyond the medical and ethical establishment. This issue may be of tremendous concern to patients or their carers who are presently suffering in circumstances similar to those described.

The electronic response forum of the BMJ has been in operation for over four years. An editorial in the BMJ on physician assisted suicide has attracted 125 responses at the time of writing. An important feature of electronic dialogue is that any peer review process would deal with a degree of empathy. It is sometimes the case, however, that submissions clearly showing distress also contain dubious arguments that any peer review process would deal with severely. Where accounts of suffering along with dubious arguments are posted from people who are correct. Furthermore, it is astonishingly easy to post an electronic response, and the process contains no warning that opinions expressed may be severely challenged. We should consider what the rules of debate on this Journal of Medical Ethics website should be.

To prevent any misunderstanding, I wish to state that this response does not issue out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don’t ignore me.

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Editor’s response

Dr Lewis raises the important issue of what the rules of debate should be in electronic correspondence.

As editor, I feel as if I am caught in the maelstrom of evolution. The web has radically changed the nature of debate and the presentation of information and knowledge. It is not clear to me how and whether it should be controlled. My general approach has been to let the experiment run in a free way and look at the results. Then it will be clearer what rules are required.

Electronic correspondence, for me, is different from scholarly debate. It takes advantage of the web’s accessibility to give people the opportunity to express their own views and to see the range of views on a particular issue. At present, the JME operates on the principle that it will publish electronically any response which is not libellous or harmful in other ways. Electronic letters which contribute significantly to the debate (such as Dr Lewis’s letter) may be selected for publication in the paper version of the journal.

The core business of a journal such as the JME should be the publication of scholarly articles which contribute to knowledge. But as a medical ethics journal, it should also be engaging and relevant to professionals and non-professionals. We have introduced a current controversy section which reports an issue of current interest and we solicit off the cuff comment from people who may have an interesting view on that topic. Electronic correspondence should serve a similar function: to increase people’s interaction with the journal and with others.

Introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The centre-piece of the book is undoubtedly a series of well-chosen cases (thematically progressing from diagnosis to management and prognosis), each followed by an extensive analysis of the ethical issues, including contrasting arguments from different vantage points. There then follows a commentary by a practitioner with relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is rounded off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal cases.

The book is extraordinarily innovative in many respects. Not only is the case history and analysis format interesting and methodologically robust, but the case material is so challenging and the ethical analyses so wide-ranging and detailed, it is difficult to do justice to this book down! One discovers how different analytical strategies lead to progressively deeper levels of understanding of the ethical issues, thus exposing “the heart of the matter” along the way. One is referred to books, chapters, and articles for further reading. Might as expected, Fulford’s notion that an explicit analysis of values is helpful in defining diagnostic categories and choosing treatment is an intriguing theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the philosophy of mind is a recurring theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the philosophy of mind is a recurring theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the philosophy of mind is a recurring theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the philosophy of mind is a recurring theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the philosophy of mind is a recurring theme.
Life and Death in Healthcare Ethics: A Short Introduction


This is a compact, nicely written book that provides a refreshing alternative to the utilitarian orthodoxy that dominates contemporary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medicine and health care. This contribution is a short and useful introduction to such an approach.

The book announces itself as being written with "both the general reader and students and professionals in medicine, nursing, law, philosophy and related areas in mind". Accordingly, it assumes no prior knowledge of ethics. It gives a neat introductory overview of several major issues raised by reproduction, death, and dying. The issues considered include euthanasia and withdrawal of treatment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

By the early chapters, with a real-life case, Watt captures the interest of the reader. The case is introduced and discussed passionately. It is then employed as a springboard for a general discussion of principles often thought dry and difficult. Newcomers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Arif case is introduced as a context for discussing putative distinctions between killing and letting die, and intending and foreseeing: approaches to homicide suggested by competing ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of "personhood" are discussed. Watt considers the notion of the end of life as good in itself and raises questions about the social significance of tube feeding. The Cox case, in chapter 3, elicits a discussion of concepts such as that of a worthless life. The oft-misunderstood principle of double effect, and questions of autonomy. In this chapter, Watt introduces a concept she calls "lethal bodily invasion". Even if a Nazi doctor did not care whether his victims survived, but believed in the broad doctrine of defensive action is well beyond its scope; however, it is profitable to analyse like cases where the principle of double effect is often summoned as a justification for deaths not intended, but not impermissible. A mentally disordered man, or child for that matter, runs amok with a shotgun in a school, is a marksman not justified in shooting to maim? If the aggressor dies, is this lethal bodily invasion impermissible? Would the marksman not be regarded as remiss if he failed to act to prevent the death of the schoolchildren?

The principle suggested by Watt also appears to numerosity in situations in which one knows that two patients will die and one is threatening the life of the other unless a doctor intervenes to save one. The doctor is required to do nothing and allow both to die. Such were the circumstances of the recent UK case of the conjoined twins, "Jodie" and "Mary". It is one thing to say that the doctor may decide not to intervene—for example, on the grounds that he wants to respect the parents' wishes: it is quite another to say that it is entirely impermissible to perform life-saving treatment on one twin (even when the parents wish it), in the same way as it is impermissible for the Nazi doctor to use a patient as fodder for experimentation. In the conjoined twins' case, there are relevant moral differences. The immediate aim, not merely the further end, of the doctor in performing the operation is to save the life of one of the children. The Nazi doctor, by contrast, has the saving of lives as, at best, his further end. It is worth remembering too that by Watt's own account, sometimes omissions to act to save a patient can be impermissible. It is important to consider whether the requirement that a doctor refrain, on moral grounds, from treating either of the patients destined for certain imminent death is not moral reasoning gone awry.

Chapter 3's conclusion is brief explorations of the controversial topics of abortion and embryo destruction. The final chapter looks at the question of moral disagreement and conscientious objection. It is a reminder, if any were needed, of the practical nature of moral theory.

It is the book's simplicity that leads me to believe that it will be read eagerly by students from a range of different disciplines. The layout and typographical style make the book particularly accessible. There is a comprehensive index and bibliography. If I have a criticism, it is that the book could have been longer. However, for those who want a basic text to introduce them to life and death issues in bioethics, this is a most welcome contribution.

J Laing
are used extensively throughout the text to illustrate the discussions. In my opinion, the authors have succeeded in producing a text that is a practical introduction to medical ethics. I would warmly recommend this book to all medical and nursing students and a copy should be in all medical libraries.

T Russell

Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology


This encyclopaedia is an important and comprehensive resource that is likely to be of value to a wide range of academic users for many years to come. It is particularly useful as a starting point for background research by bioethicists writing about topics in genetics and biotechnology. The collection takes a broad view, not ranging from core topics such as genetic enhancement and the ethics of genetics research, to a series of sections that take the form of national reports on the political, ethical, and regulatory contexts covering genetically engineered organisms. One potential problem for any reference work of this kind is getting out of date, given the changing nature of biotechnological research. The articles in the encyclopaedia that we read were well written and, in the main, likely to be relevant for a while to come.

The first thing that strikes you about the two volumes of this encyclopaedia is that they are very well made, attractive, solidly bound books. The information is reinforced by first use of the encyclopaedia. A great deal of care has gone into making this reference work accessible and a pleasure to use. Two very minor additions that would be useful as a required reading. One is a summary of the points to be discussed and headings and a contents page to the second volume. Nevertheless as a whole the collection was extremely easy to navigate.

The editors have reviewed all start with a summary of the points to be discussed and then proceed to a general overview of the technology or history of the topic. For those topics on very contentious issue there is a discussion of the major arguments for and against. The headings generally have good references to other sources that will be useful for those wanting to know more.

These are very large volumes so we have based this review on a selection of its headings. Some of them are very good indeed. Dan Brock’s heading “Cloning, ethics” is also very well made. Although somewhat longwinded account of various “models” of informed consent, which does not serve to clarify any of the underlying normative issues, such as the question of what ultimate value such a model should be taken to serve or what is more precisely meant by the notion of an “automnous” consent. In spite of this, however, Eriksson makes several bold normative statements in the form of three principles (of which two seem to be mere logical consequences of the first one)—though, unfortunately, without any hint of supporting arguments. Hansson’s idea of two principles of integrity (one about the individual’s right to control his or her body) is somewhat lacking in underlying reflecation, since he fails to note that controlling what happens to me or parts of my body may be very well mean that I choose to delegate some such decisions to someone else.

C Munthe

The Use of Human Biobanks. Ethical, Social, Economical, and Legal Aspects


This booklet (freely accessible online at http://www.bioethics.uu.se/biobanks-report.html) documents a public hearing organised by a Swedish research project on the various social and ethical issues raised by the use of so-called biobanks—that is, large collections of human tissue samples. There is considerable interest among researchers, the biotech industry, and society at large in using biobanks for the continued investigation of genetic health factors that is now following the completed mapping of the human genome. Central issues are: the responsibility of biobanks or users of these to protect tissue donors in various ways; how these responsibilities should be balanced against business and research interests, as well as against the interests of people and society in general in case of conflict and, not least, what procedures of informed consent (including the hard question of the scope of the consent) should be deemed as appropriate in the biobank setting. Although formulating these issues against the background of the actual scientific, legal, and business situation in this area, the booklet provides few answers, but outlines various studies that are to be undertaken. Because the contributions focus almost exclusively on the Swedish context (an addition of “in Sweden” to the title would not have been misplaced), this makes the relevance of this publication to a broader international audience somewhat limited. In some cases, this focus becomes so overwhelming that Swedish research ethical practice and legislation is taken for granted, without any attention being paid to differences that exist between and other parts of the West. For example, Mats G Hansson states, as a basic feature of the ethical background to biobank issues, that it would be disrespectful of researchers’ integrity if their control over collected research materials, data, and results were limited by regulation; and he claims that this can be inferred from the traditional legal right of Swedish individuals to have such control. This presupposes, however, that this tradition (which is hardly a given from an international perspective, where universities and funding parties are often granted much more control) should be taken as universal—a presupposition that clearly begs relevant ethical questions. The value of the booklet is further impeded by the lack of a substantial overview chapter (either at the beginning or at the end) which could have served to tie together the rather heterogeneously written pieces on institutionalised ethics, as well as descriptive and normative studies of informed consent, and issues of civil as well as public law into a coherent picture of “the biobank issue.”

These chapters are of most interest from an ethical point of view deal with the basic conflict between individual integrity and social utility (Mats G Hansson); what model of informed consent is most appropriate in a biobank setting (Stefan Eriksson), and uncovering cultural conceptions of the body and its parts (Jacob Dahl Rendtorff). The treatment of these areas is rather shallow, however, in several respects. For example, although the fact that a biobank may be used for different purposes (apart from basic research, diagnosis, treatment, and securing quality of care) is noted by Hansson and Eriksson, no attempt is made to investigate to what extent different considerations arise in different contexts. Conclusions may be more or less applicable depending on what use of biobanks is being considered. Another example is Eriksson’s somewhat longwinded account of various “models” of informed consent, which does not serve to clarify any of the underlying normative issues, such as the question of what ultimate value such a model should be taken to serve or what is more precisely meant by the notion of an “automnous” consent. In spite of this, however, Eriksson makes several bold normative statements in the form of three principles (of which two seem to be mere logical consequences of the first one)—though, unfortunately, without any hint of supporting arguments. Hansson’s idea of two principles of integrity (one about the individual’s right to control his or her body) is somewhat lacking in underlying reflection, since he fails to note that controlling what happens to me or parts of my body may be very well mean that I choose to delegate some such decisions to someone else.


United States ethicist Ronald M Green approaches the issue of embryo research (ER) in the very accessible form of a “philosophical memoir” (xvi). Reporting in detail from his experience of serving on several high level ethics advisory boards, focusing mostly on his membership of the National Institutes of Health’s (NIH) 1994 panel on embryonic research, Green portrays both the scientific and the increasingy more influential form of institutionalised ethics, as well as the social and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER
itself and familiarises the reader with the technical issues and conceptual conundrums (potentiality, moral status, harming future persons) involved.

Green states in the title of *The Human Embryo Research Debates: Bioethics in the Vortex of Complexity* that he is concerned with a plurality of debates. Examining the discourse in the US, he first deals with the different areas in which ER is debated: of the book’s eight chapters, chapters one and four stress the relevance of ER for the fields of in vitro fertilisation (IVF) research, the study of birth defects, and the development of contraceptive methods. Chapter 6 deals with the relation of ER to reproductive cloning. Green formulates a comprehensive criticism of the National Bioethics Advisory Commission’s (NBAC) 1997 report on cloning, claiming that it contributed significantly to the neglect of ER in US public policy. Chapter seven covers NBAC’s 1999 report on stem cell research, stresses the importance of ER on the form of so-called “therapeutic cloning”, and again takes a critical stance towards NBAC’s shap- ing of the discourse.

As the above issues are of relevance to groups with radically differing interests, throughout the book Green also deals with a second level of ER debates. This concerns the complex interplay of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious groups with radically differing interests. In chapter six attempting to establish that the embryonic moral status is essentially a political question and “translates into the question of just how much protection it is reasonable and fair to give it at each point in its development” (page 39). Less detailed is an argument in chapter two attempting to establish that the embryonic moral status begins “at the moment of conception”. In chapter two he cites detailed current biological evidence, forcefully showing that even on the biological level this claim is difficult to uphold. Setting forth “a Coperni- can Revolution in our thinking about ethical issues related to the life sciences” (page 26, without mention of the Kantian origin of this metaphor) Green argues (a) that it is difficult to talk of one objective point of conception and that biological occurrences are best understood as processes rather than events. Hence, as nature does not provide us with clear cut boundary markers, he suggests analogously to the current practice of brain death that (b) the determination of threshold points involves deliberate choice and decision on our part in such a way that a reasonable compromise is achieved between the benefits and harms associated with the choice of a specific boundary marker, both for the wider public and health related research as well as for the entity under consideration. Arguing further against any kind of “single criterion approach” to determine the status of the embryo, Green champions a “pluralistic and pragmatic approach” characterised by the belief that “a variety of criteria interact and work together to lead to a mounting sense of concern and ultimately to judgments of protectability about entities” (“page 63 and pages following). Therefore, in Green’s view, the issue of the embryo’s moral status is essentially a political question and “translates into the question of just how much protection it is reasonable and fair to give it at each point in its development” (page 39).

The Androgen Insensitivity Syndrome Support Group (AISSG)

The Androgen Insensitivity Syndrome Support Group (AISSG) http://www.medhelp.org/ www/ais is a consortium of worldwide sup- port groups, originating in the UK, providing information and support to adults and fami- lies affected by some conditions affecting the development of the reproductive system. These are conditions that have been subject to considerable secrecy and paternalism in the past, and AISSG promotes full disclosure of diagnostic information with accompanying psychological support. It also encourages recent moves to evaluate the efficacy of geni- tal reconstruction surgery and supports the notion of autonomy and informed consent.

The conditions supported included AIS— androgen insensitivity syndrome (old name testicular feminization syndrome or testicular feminisation syndrome)—and similar condi- tions, for example, XY gonadal dysgenesis (Swyer’s syndrome), 5-alpha reductase defi- ciency, leydig cell hypoplasia, Mayer Rokita- nsky Kuster Hauser (MRKH) syndrome, Muller- rian dysgenesis/aplasia, and vaginal atresia.

9th Conference of the ABA: “Virtue and Vice in Bioethics”

You are invited to the 9th Conference of the ABA: “Virtue and Vice in Bioethics” on the 3–6 July 2003. The venue is Queenstown, New Zealand. Confirmed invited speakers: Art Frank, Carl Elliot, and Annette Baier. Further information: Pat Johnston, Dunedin Conference Management Services, New Zea- land (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcms.co.nz).

European Integration: Philosophy and Ethics of Health Care

The XVIIth international congress of the European Society for Philosophy of Medicine and Healthcare will be held from August 21–23 2003 in Vilnius, Lithuania. Its theme is European Integration—Philosophy and Ethics of Health Care.

Further information: Professor Dr Henk ten Have; secretariat ESPMHI, Department of Ethics, Philosophy and History of Medicine, Univer- sity Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@clf.kun.nl).