Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer’s disease

I note with interest the controversy regarding a baby born free of an inherited predisposition to early onset Alzheimer’s disease through the use of preimplantation genetic diagnosis (PGD). As the medical geneticist for the PGD programme for single gene disorders in Melbourne, Australia, I have seen many couples who have considered PGD for a wide range of genetic conditions. My observation is that many people look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination of pregnancy.

An example of this is that in the last 11 years our unit has undertaken 13 prenatal diagnoses for Huntington’s disease from nine couples, whereas in the two years that we have been involved in it we have had six requests for PGD for Huntington’s disease and three couples have already had IVF cycles.

I have a number of concerns with the argument that the woman should not have a child utilising PGD because she is predisposed to Alzheimer’s disease. Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If so, then for this case, what lengths should go to prevent the woman becoming pregnant by natural means? If the commentators who make this argument agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder from having children by natural means, then assisting them to have children not predisposed to a genetic disorder is in my view entirely ethically acceptable.

The concern 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 Val171Ile 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 being born with a 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.

M B Delatycki
Preimplantation Genetic Diagnosis Team, Genetic Health Services Victoria, Royal Children’s Hospital, Flemington Road, Parkville, Victoria 3052, Australia; delatymc@cryptic.rch.unimelb.edu.au

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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 debate is that any peer review process would deal with it. These responses range from the scholarly and meticulously argued to distressing accounts of suffering. As both an avid reader of rapid response to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them should be when I wish to enter into dialogue with the author. I feel on sure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing up a response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to approach distressing accounts of suffering 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 alongside dubious arguments are posted from patients I personally feel squeamish about responding, finding myself caught between the roles of vituperative reviewer and empathic listener. As an editorial in the BMJ on the subject of electronic responses has noted: “We’ve begun to capture the opinions and experience of patients … and publish just about anything that isn’t libellous or doesn’t breach patient confidentiality”. Inevitably, such a broad range of responses will produce many that deserve to be challenged. Merely to ignore dubious argument implies that such opinions 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 web site 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.

W Lewis
Carreg Wen Surgery, Church Road, Blaenavon NP4 9AF, Wales, wlewis@drdelwells.freeserve.com

References

Dr. Lewis raises the important issue of what the rules of debate should be in electronic correspondence. As an 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 allow the export of information. The authors seem to be right in their argument that it will publish electronically any response to: Roddy E, Jones E, Yeager E, et al. On Hippocrates. BMJ 2002;325:496.

The core business of a journal such as 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 first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in biomedical ethics. She tells us that studying ethics encourages logical reasoning. The face of difficult decisions such as allocation of resources, access to services, best care, clinical research, and rights to life. She reminds us that clinical guidelines may not be much help in the face of an ethical dilemma with no clear right or wrong answer.

The chapter called Care versus cure by David Jeffrey, a consultant in palliative medicine, writer on medical ethics, reminds us that care is as much with the subjective feelings of the patient as with the physical disease, and aims to relieve suffering and improve quality of life. He emphasises that by sharing the reality of uncertainty (with patient, family, and colleagues) we can make more realistic decisions, and that information is a mechanism for sharing the power of doctors and patients.

Giving it straight—the limits of honesty and deception by Heather Draper, a lecturer in biomedical ethics, explores the difference between truth-telling and honesty, and the ethical issues facing doctors. She emphasises the importance of trust in the doctor-patient relationship: “There is a sense in which we are always selective with the truth”, she writes and reminds me of the saying so useful in palliative care: “truth is the only medical commandment...”. He emphasises the potential to help and to harm.

The chapter on Advocacy by Patricia Webb defines advocacy as “the role of one with relevant experience in an ethical dilemma with no clear right or wrong answer”, and is an interesting analysis of the power differences between patients and professionals. She makes the point that “patients have little power to influence the nature of care provision unless a determined effort is made to reduce their actual and perceived vulnerability”. She also emphasises, however, that skilful communication allows doctors to make decisions in the patient’s interest.

The next chapter, How informed can consent be?, by Calliope Farsides, a senior lecturer in palliative medicine, reminds us that informed consent is the basis for which the patient’s health can be taken control in bioethics, “providing lessons for medicine as a whole”. There is also a useful sample teaching seminar, showing how theory is put into practice.

This book is a collection of essays by a variety of specialists with a particular interest in palliative care. It contains seven chapters by six different authors.

This book will appeal to any reader who wishes to escape from the well-worn path of “four principles plus”. It is likely to be enriching to psychiatrists who feel that the DSM-IV and ICD-10 are constrained not so much by limitations of their science, but of their humanities. It provides thoughtful material for those interested in finding a way of resolving the tensions between physical medicine, psychiatry, and ethics. The book is a treasure trove of annotated bibliographies and very enjoyable to read.
tact and express consent and the problems of coercion and “sufficient information”.

In Euthanasia—slippery slope or mercy killing, Marny Prouse, a sociologist, director of nursing at a hospice, with a BA in law and now a risk and litigation manager, has written and edited a book on the euthanasia debate, and finally urges us “to research and practise our arguments and beliefs so that we can be comfortable and credible when moral ques-
tions about the end of life are discussed”. The final chapter on “Teaching ethics in the practice setting by Rachel Burman, a consultant in palliative medicine, emphasises that medical ethics involves many disciplines, including cultural sciences, law, theology and philosophy, as well as medicine. The teaching of medical ethics is ideally done, she says, in multidisciplinary groups with sensitive and detailed discussion of real life ethical dilemmas, with both philosophers and clini-
cians facilitating. In the USA ethical commit-
tees are commonplace in hospitals, where there is often a resident ethicist on the staff to handle clinical cases, developing policies, and education. In the UK ethical committees have been largely restricted to looking at research protocols, but the develop-
ment of clinical ethical committees to act as a forum and resource for managing difficult clinical dilemmas is accelerating.

Several of these chapters contain helpful clinical case histories, but the next edition of the book should contain a further chapter, written by a clinical ethicist, with a collection of clinical cases and scenarios based on those discussed by ethical committees, together with a discussion of some of the key issues debated that they raised. This would demonstrate this powerful teaching method and would also provide some relevant practi-
cial material for teams and trusts that are trying to set up their own ethical committees.

P Kaye

Life and Death in Healthcare Ethics: A Short Introduction


This is a compact, nicely written book that provides a reassuring alternative to the utilitarian orthodoxy that dominates contem-
porary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medi-
cine 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 some of the basic principles raised by reproduction, birth, death, and dying. The issues considered include euthanasia and withdrawal of treat-
ment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

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

In the first chapter—for example, the Arthur case is introduced as a context for dis-
cussing putative distinctions between killing and letting die, and intending and foreseeing. Approaches to homicide suggested by compet-
ing ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of “per-
sonhood” are discussed. Watt considers the notion of life as good in itself and raises ques-
tions about the social significance of tube feeding. The Cunliffe case, in chapter 3, elicits a discussion of concepts such as that of a worthless life. The third chapter is devoted to the principle of double effect, and questions of au-
tonomy. In this chapter, Watt introduces a concept she calls “lethal bodily invasion”. Even if a Nazi doctor did not care whether his/her victims survived operation on him, the doctor’s intention to invade their bodies in a way he knew would do them no good, but only lethal harm, would be enough to identify his course of action as grossly immoral. This is plausible enough in the con-
text Watt suggests. In order to test her princi-
ple as outlined, however, Watt needs to exam-

ines other situations where the principle of double effect is impermissible. The principle of double effect is often raised in the context of self defence, defence of a third party, and war. Clearly, the book is an analysis of cases that would do well to read this. Later chap-
ters in this section deal with diverse cultures (ch 3) and the human body (ch 4). Of particu-
lar note here is the excellent treatment given to information, consent, confidentiality, and truthfulness. There is much to be gained here by the book’s intended audience. The chapter on the human body seems unusual in a book of this type, but is a well argued discussion of how the human body, both alive and dead, should be treated. This chapter also considers the ethics of postmortem examinations and biopsies both of which are in the public mind at present; this discussion is clear and full of “common sense” and would be of interest to most doctors. The discussion of retained organs and biopsies. The discussion of the ethical problems of mixed cultures is an unexpected inclusion and there is reliance on quotes from medical journals. Two topics not commonly found in introductory texts are included in this section, namely, psychiatry and the problems of patients with aging and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section covers research ethics, jus-
tice, law and “trying new things”. This rather broad area is dealt with excellently and the reader oddly named chapter on “Trying new and unusual things” is highly recommended reading for anyone wishing to introduce new treatments (medical or surgical).

Overall, the book is well organised and, while it is an introductory text, there are ample references to sustain the authors’ argu-
ments and for further reading. Case studies

Medical Ethics, 3rd edition


Medical Ethics, to quote the authors, is intended as a practical introduction to the ethical ques-
tions doctors and other health profession-
als meet. The book is divided into three main sections. Foundations, Clinical ethics and Medi-
cine and society; each section is further subdiv-
ided into topics dealt with in a single chapter. The first section deals very well with the more contemporary philosophy rather than that does not lay too much stress on the well estab-
lished “four principles” (chs 1 and 2). I have rarely read such a seamless introduction to the underlying principles of medical ethics and would also provide some relevant practi-
cial material for teams and trusts that are trying to set up their own ethical committees.
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 of the subject 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 genetic Enhanced 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 informative, and in the main looked 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. This impression 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.

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 the ideal introduction to the topic and one that would be useful as a required reading. Similarly positive things can be said about Robert Nelson's heading "Gene therapy, ethical issues" which 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 different purposes (apart from basic research, diagnosis, treatment, and securing quality of care) is noted by Hansson and Eriksson, no attempt is made to elaborate what different considerations arise in different countries. The value of the booklet is further decreased by lack of a substantial overview document that could serve to tie together the various "models" of informed consent, which does not serve to clarify any of the underlying normative issues, such as the question of what consequences may be taken to mean that I choose to delegate some decisions to someone else.

**PostScript**

Given that these two volumes cost £370 it's unlikely that any but the most enthusiastic and wealthy individual will be able to buy the encyclopaedia. This is primarily a collection of references to other sources that will be useful for those wanting to know more.

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


This booklet (freely accessible online at http://www.biobiotics.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 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 in Sweden and other parts of the West. For example, M G Hansson states, as a basic feature of the ethical background to biobank issues, that it would be disrespectful of researchers' integrity if their contracts were to be checked or reviewed by some external agency. As a result, the regulations and principles that have been developed for biobanks in the United States are opposite 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 elaborate what different considerations arise in different countries, and which could have served to tie together the various "models" of informed consent, which does not serve to clarify any of the underlying normative issues, such as the question of what consequences may be taken to mean that I choose to delegate some decisions to someone else.

**C Munthe**

**The Human Embryo Research Debates. Bioethics in the Vortex of Controversy**


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 committee on human embryo research the author also covers the various ethical issues that arose from the panel, Green portrays both the ethical problems and the increasingly 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
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 support groups, originating in the UK, providing information and support to adults and families 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 genital 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 conditions, for example, XY gonadal dysgenesis (Swyer’s syndrome), 5-alpha reductase deficiency, Leydig cell hypoplasia, Mayer-Rokitansky Kuster Hauser (MRKH) syndrome, Mullerian 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 Zealand (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 ESPMHR, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340 254; email: h.tenhave@efg.kun.nl).