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 women look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination.

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 running PGD 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 the woman were a case, what lengths would be gone to 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 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 disease.

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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 ethical dialogue.

I have posted this response to Kenneth Boyd’s editorial on Mrs Pretty and Ms B as this article may provoke debate further in 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 discussions 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 patients I personally feel sympathetic 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 arguments 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.

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3 Doyal L. Doyal L. Why active euthanasia and physician assisted suicide should be legalised. BMJ 2001; 323: 1079-80.
Electronic correspondence should serve a function to increase people's interaction with each other off the cuff. Commentaries from people who may not be experts can be significant to the debate (such as Dr Lewis's letter) may be selected for publication in the JME. In many instances the very bedrock of moral-philosophical debate is ad hoc and ad hoc approaches are often difficult to put this book down! One discovers how different case studies lead to progressively deeper levels of understanding of the ethical issues, thus exposing "the human being at the margin". Along the way one is referred to books, chapters, and articles for further reading. As might be expected, Fulford's notion that an explicit analysis of values is helpful in defining diagnostic categories in medicine is a recurring theme. Dickenson's interest in informed consent (also in children), moral luck, and her feminist reconstruction of rationality, are drawn upon in several sections. Several of Dr Lewis's cases—cases that do not fit fully into clear diagnostic categories, where clinicians disagree about the precise diagnosis and may start functioning "like a grey area"—are used in this book down! One discovers how different case studies lead to progressively deeper levels of understanding of the ethical issues, thus exposing "the human being at the margin". Along the way one is referred to books, chapters, and articles for further reading. As might be expected, Fulford's notion that an explicit analysis of values is helpful in defining diagnostic categories in medicine is a recurring theme. Dickenson's interest in informed consent (also in children), moral luck, and her feminist reconstruction of rationality, are drawn upon in several sections. Several of Dr Lewis's cases—cases that do not fit fully into clear diagnostic categories, where clinicians disagree about the precise diagnosis and may start functioning "like a grey area"—are used.

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In Two Minds: A Casebook of Psychiatric Ethics


Although the title describes this as a "casebook", I feel as if I am caught in the maelstrom of evolution. The book 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 contemporary 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.


Editor's response

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 let the experiment run in a free way and look at the results. Then it will be clearer what rules are required.

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S Louw

Ethical Issues in Palliative Care—Reflections and Considerations


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.

The first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in medical ethics at the University of Oxford. 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. Webb 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 Draper, a consultant in palliative medicine and writer on medical ethics, reminds us that care is concerned 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 informed consent 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 lying. She reminds us that truth-telling and honesty are not always the same, and that an ethical dilemma is shared between honest and dishonest selective truthfulness. “There is a sense in which we are always selective with the truth”, she writes and reminds me of the saying: so helpful in palliative care that: “I am a truth-teller and a liar, a skilful user, respecting its potential to help and to harm”. The chapter on Advocacy by Patricia Webb defines advocacy as “the role of one with expertise who is invited to negotiate on behalf of another”, 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 patients to be involved in decision making. With good team care few patients need an advocate, except those few who prefer to be very passive, or who are unable to make decisions, such as those with severe learning difficulties.

The next chapter, How informed can consent be?, by Calliope Farsides, a senior lecturer in medical ethics, makes the point that it is often useful to consider consent not primarily as a legal concept but a moral one, and one that depends on the relationship between patient and carer being a relationship of trust, reciprocity, and beneficence, with mutual recognition of their duties and obligations. She goes on to look at the differences between...
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 practice our arguments and beliefs so that we can be comfortable and credible when moral ques-
tions about the end of life are discussed”.

The first chapter on “Teaching ethics in the practice setting by Rachel Burman, a consultant in palliative medicine, emphasises that medical ethics involves many disciplines, including medical, social 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 help with 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 another 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 and what she deems to be that raised. This would demonstrate this powerful teaching method and would also provide some relevant practi-
cal material for teams and trusts that are try-
ning to set up their own ethical committee.

P Kaye

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 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 well and clearly, especially transplantation. The general format of the chapters is to briefly dis-

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 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 en-
terprises 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 treat-
ment on one twin (even where 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 immoral. It is not enough 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 is followed by brief explorations of the controversial topics of abortion and embryo destruction. The final chapter looks at the question of moral disagreement and con-
scientious objection. It is a reminder, if any be 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 particu-
larly 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

Medical Ethics, 3rd edition

A Campbell, G Gillet, G Jones. Oxford
ISBN 0 19 558445 7

Medical Ethics, to quote the authors, is intended as a practical introduction to the ethical questions 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
major area is dealt with excellently and the second section (142 pages out of a total of 297). The “standard” topics of genetics, prenatal problems, birth, organ transplantation, AIDS, euthanasia, and brain death are all dealt with well and clearly, especially transplantation. The general format of the chapters is to briefly dis-
cuss the medical problems and then to intro-
duce the ethical dimension. This ensures that a reader not familiar with a certain topic is reminded of the problems before entering into the ethical discussion. The chapters on genetics and ending human lives are particularly good in this respect. Two topics not commonly found in introductory texts are included, one section, namely, psychiatry and the problems with aging and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section on research ethics, jus-
tice, law and “trying new things”. This rather broad area is dealt with excellently and the rather 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
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 topics that are addressed to some extent 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 genetics and related 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 for 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. The headings are 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 have increased this ease of use might have been to add page numbers to the list of headings and a contents page to the second volume. Nevertheless as a whole the collection was extremely easy to navigate.

The reviews on this 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 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, ethics, germ cell gene transfer”. The section by Georgia Wiesner, Susan Lewis, and Jennifer Scharf, “Ethics of subjects research, ethics and pedigree studies” was also excellent and well informed—both from a clinical point of view and also from a bioethics perspective. David Wasserman’s heading on “Behavioural genetics” is also a fascinating essay. The discussion of research into the XYY karyotype and the MAO mutation provide an excellent background to the section. Again, this section would make a valuable contribution for people wanting to do further work on his topic.

Overall, the editors have assembled an impressive cast, with many of the American names that you would expect to be involved in such a project. This does bring us to our first minor grumble: there are about a hundred contributors to this volume but only three are from the United Kingdom. This absence cannot be due to a lack of UK expertise and it is slightly disappointing that there is no contribution from writers based in the UK such as Ruth Chadwick, John Harris, or Soren Holm. This does raise the question of how attractive this volume is likely to be to the readers who are not in North America. In addition to the majority of authors, being from the USA much of the public policy and legal discussion in the volumes is US centred. It is hard to see how this could have been avoided, given the authors, however, it does mean that the researcher using this text will need to be careful to ensure that the used supporting evidence and background to biobank issues, that it would be relevant for a while to come.

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 workshop 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 in Sweden 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 research 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 individual researchers 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 different ethical and scientific strategies; business interests; ethical issues of biobank setting (Stefan Eriksson), and underwriting 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 apply. Furthermore, ethical considerations 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 “autonomous” 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 the use of the tissue and one about the right to influence the policy making process) is equally lacking in underlying reflection, since he falls to note that controlling what happens to me or parts of my body may well mean that I cannot delegate some of these 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” (xv). 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 advisory embryo research panel, Green portrays both the ethics 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
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 scientific legitimacy 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 six 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 shaping 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 complexity of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups with regard to the different forms of ER. In light of the fact that the author is chair of Dartmouth College’s department of religion and former president of the Society of Christian Ethics, one might expect that he would advocate a pluralist approach that reframes the debate with the restrictive conservative party in discourse. This, however, is not the case. Rather, he points out with frustration that a powerful conservative minority has effectively managed to obstruct and stall ER since the mid 90s. Emphasising the negative consequences resulting from ER being forced to take place almost exclusively in the private sector he argues fiercely and outspokenly in favour of a comprehensive federally funded exploration of the potential medical benefits at hand. Given the dramatic clash of interests of the involved parties, the author is centrally interested in the dramatic clash of interests of the involved parties, the author is centrally interested in setting the agenda in bioethical policy making, and advisory boards are more and more setting the agenda in bioethical policy making, the strength of Green’s book is that it presents a transparent and valuable case study of this practice. Questions regarding, for example, the criteria for selecting a competent and representative panel; how much power these institutions should be granted; what kind of standards and methodology for published reports is necessary; what degree of public participation is desirable, and how to deal with minority views, have obviously not been settled once and for all with Green’s book, but it is a stimulating and clear account which shows that these issues are just as important, difficult, and necessary as thorough academic debates on—for example, the relation of facts to values. The book will be of interest to anyone who is interested in the mechanics determining the interaction of bioethics and the political sphere; it requires no previous familiarity with the topic and can thus also be recommended to the general reader.

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**The Androgen Insensitivity Syndrome Support Group (AISSG)**

You are invited to the 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).