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 more 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 assessing 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 the same case, what lengths should be gone 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 consequences 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 of 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 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.

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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 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 discussion is that many couples look to PGD for “milder” diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.
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.

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 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.

Electronic correspondence should serve a similar function: to increase people’s interaction with the journal and with others.

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, 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. She tells us that studying ethics encourages logical reasoning thinking in 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 Fulford, 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 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 argues that truth-telling is an uncertain art. She tells us that studying ethics encourages logical reasoning thinking in 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 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 skilfully used, respecting its potential to help and to harm.

The chapter on Bioethics by Patricia Webb defines bioethics 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 skilfully used, respecting its potential to help and to harm.

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 Prowse, a sociologist, director of nursing at a hospice, with a BA in law and now a risk and litigation manager, has written and researched the end of life from 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 biological sciences, law, theology, and philosophy, as well as medicine. The teaching of medical ethics is ideally done, she says, in multidisciplinary groups with sensitiv-
eous 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 the broad practical issues in 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 medical 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 unusual things” is highly recommended
while it is an introductory text, there are

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Life and Death in Healthcare Ethics: A Short Introduction

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

Medical Ethics, 3rd edition

J Laing

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-
ded into topics dealt with in a single chapter.

The first section deals very well with the more contemporary philosophy rather than 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 this chapter would do well to read. 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 encompasses some of the ethical issues of postmortem examinations and biopsies both of which are in the public mind at present; this discussion is clear and full of “common sense” in its logic and reasoning.

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 discussion of the ethical possibilities. The chapters on genetics and ending human lives are particularly good in this respect. Two topics not commonly found in introductory texts are the ethical issues of the use of animals in medical research, namely, psychiatry and the problems with age and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section concerns 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’ arguments and for further reading. Case studies

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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.

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 issues, 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 modified 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 thought-provoking, and I think the main worked very well in the volume. Nevertheless as a whole the collection is likely to be of value to any reference work of this kind is that they are very well made, attractive, solidly bound books. The collection 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 have enhanced this ease of use would 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 first thing that strikes you about the two volumes of this encyclopaedia is that they are very well made, attractive, solidly bound books. The collection 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 have enhanced this ease of use would 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 Use of Human Biobanks, Ethical, Social, Economical, and Legal Aspects


This book (freely accessible online at http://www.bioethics.uu.se/biobanks-report.html) documents a conference 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 book provides a discussion of broad procedural and ethical issues 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 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 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 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 book 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 considerations and research on genuine ethical conflicts; empirical as well as normative studies of informed consent, and issues of civil as well as public law into a coherent picture of the biobank issue.

These chapters 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 undermining 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 many 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 argue for different 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 “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 right to control the use of one’s body and one about the right to influence the policy making process) is equally lacking in underlying reflection, since he fails to note that controlling what happens to me or parts of my body may very well mean that I choose to delegate some such decision 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” (ix). 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 embryonic research panel, Green portrays both the diversity of the panel and this 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 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 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 radically differing interests, for the different areas 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 avoid arguments by siding 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 isolating an ideal procedure suitable for governing negotiations between the conflicting parties. Here, Green draws strongly on the Rawlsian concept of *overlapping consensus* and urges discourse participants to be willing to abide by *public reason* and to set aside their individual special concerns out of respect for other individuals and the common good (page 61, page 153, page 169 and following pages).

Because of the significant impact of religious groups in ER debates in the US, Green dedicates considerable attention to religiously motivated arguments and in particular to the frequently encountered claim that human life (and tacitly implied: full 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 *Copernican 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). Least detailed is an argument in chapter six attempting to establish that the concept of harm is, contrary to Parfit’s “non-identity argument”, meaningfully applicable in the context of wrongful life cases (pages 126–128).

In the age of the “globalisation of ethics” (John Harris) in which ethics commissions 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.