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 do not 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 the couple are healthy, what lengths should 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 our view entirely ethically acceptable.

The concern for the child of having a mother suffer from early onset Alzheimer’s disease is 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 having a specific genetic disease, but where they feel uncomfortable about terming 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 discourse is that any peer review process would deal with extremely intensely personal suffering, and that any written response to them would be distressing to 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 that submissions clearly showing distress also contain dubious argument 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 correspondence 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.

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References

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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.

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 biomedical ethics, explores the difference between care with a religious focus and caring for the patient who appears to have a religious delusion, and her feminist reconstruction of consent (also in children), “moral luck”, and her feminist reconstruction of consent not prima- turns “not on the facts about his experiences, but on a series of value judge- a field where clinicians disagree about the precise diagnosis and may start doubting their diagnosis. For example, the question of the differential diagnosis of a number of times, the authors of the DSM-IV claim that the system was “grounded in empirical evidence”. The reader is challenged to consider terms with the value related elements of the diagnosis of schizophrenia and related diagnoses. As with many other cases, the importance of a team approach is emphasised, bringing to bear, as it should, a variety of perspectives that may include elements of cultural formulation and the patient’s values.

Other chapters address teamwork and service organisation, and research ethics; a section on wider perspectives gives an international view; in an interesting chapter Ford- describes the basis for his belief that psychiatry can take the lead 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 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.

J Savulescu

In Two Minds: A Casebook of Psychiatric Ethics


Although the title describes this as a “case- book”, I feel as if I am caught in the maelstrom 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.

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J Savulescu

Oxford Centre for Applied Ethics, University of Oxford, Suite 7, Littlegate House, St Ebbes Street, Oxford OX1 1PT

Another chapter, Advocacy by Patricia Webb, describes the basis for his belief that psychiatry can take the lead 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 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.


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 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.

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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 contemporary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medical ethics 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 ethical issues raised by reproduction, birth, life and death, and dying. The issues considered include euthanasia and withdrawal of treatment, the persistent vegetarian state, abortion, cloning, and in vitro fertilisation.

By being 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 principles often thought dry and difficult. newcomers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Arthur 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 value of life as it is understood, and questions about the social significance of life in the context of severe illness. This is followed by a discussion of the death of a child, and how the child’s life is value judgments about the end of life are discussed. The third chapter, which introduces the ethical problems of euthanasia, and brain death are all dealt with.

The principle suggested by Watt also appears to be a realisation that even where 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 conjointed 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 where the parents wish it), in the same way as it is impermissible for the NZ doctor to use a patient as fodder for experimentation. In the conjointed 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 NZ doctor, by contrast, has the task of saving all of them, 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 justified. For example, consider whether it is required that a doctor refrain, on moral grounds, from treating either of the patients destined for certain imminent death is not moral reasoning gone awry.

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The “meat” of the book, however, is in 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 discuss the medical problems and then to introduce 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 discussed here: the ethical dimension, namely, the ethical 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 covers research ethics, justice, 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 are commonly brought up to set up their own ethical committees. In the UK ethical committees are commonplace in hospitals, where there is often a resident ethicist on the staff to help with ethical case, but in other situations few committees have been set up. Medical ethicists are called a more traditional approach to medical ethics. There is currently a dearth of contemporary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medical ethics and health care. This contribution is a short and useful introduction to such an approach.

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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
Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology


This encyclopedia 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 that emerge 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 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 encyclopedia that we read were well written and well edited 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 encyclopedia is that they are very well made, attractive, solidly bound books. This is reinforced by first use of the encyclopedia. A great deal of care has gone into making this reference work accessible and attractive to use. Two very minor additions that would make the experience even more pleasant 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 majorities 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 chapters are used supplementary to the material covering the rest of the world.

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 encyclopedia. This is primarily a collection for libraries.

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


This booklet (freely accessible online at http://bioethics.uu.se/biobanks-report.html) documents a seminar 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, 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 other countries 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 disadvantageous or even unethical 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 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 and chapter (either at the beginning or at the end) which could have served to tie together the rather heterogeneously written pieces on various ethical strategies. Bioethicists should be aware of the potential for over-analysing 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 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 underlying 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 must 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 are relevant for different purposes. In addition, the various 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)—although, unfortunately, without any hint of supporting arguments. Hansson’s idea of two principles of integrity (one about the individual’s right to control over the fact that a biobank may be used for different purposes (apart from basic research) and one about his 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 decisions to someone else.

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’s) 1995 embryo research panel, Green portrays both the ethical 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
that human life (and tacitly implied: full particular to the frequently encountered claim religiously motivated arguments and in par-
US, Green dedicates considerable attention to religious pressure groups in ER debates in the 61, page 155, page 169 and following pages).

Because of the significant impact of reli-
gious pressure 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 show-
ing 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 under-
stood 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 app-
proach” 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). Less detailed is an argument in chapter six attempting to establish that the concept of harm is, contrary to Parfit’s “non-identity argument”, meaningfully ap-
licable 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 rep-
resentative 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 ethics and the political sphere; it requires no previous familiarity with the topic and can thus also be rec-
ommended to the general reader.

H Schmidt

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 feminisation 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 Rokitansky Kister Hauser (MRKH) syndrome, Mulle-
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@dcm.cs.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 ESPM4, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).