PostScript

LETTERS

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 offering 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 so, in this case, what lengths should be gone to to prevent the woman becoming pregnant by natural means? If the commentators 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 other only 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 their chosen 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
3 Towner D, Spriggs M. 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. BMJ 2002;287:241-55.

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 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 attracted 125 responses at the time of writing. An important feature 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 emerge 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
introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The centre-piece of the book is undoubtedly a series of well-chosen cases (thematically progressing from diagnosis to management and prognosis), each followed by an extensive analysis of the ethical issues, including contrasting arguments from different vantage points. There then follows a commentary by a practitioner with relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is rounded off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal cases.

The book is extraordinarily innovative in many respects. Not only is the case history and analysis format interesting and methodologically robust, but the case material is so challenging and the ethical analyses so wide ranging and diverse that it is difficult to put this book down! One discovers how different analytical strategies lead to progressively deeper levels of understanding of the ethical issues, thus exposing "the heart of the matter" along the way. 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 printed 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 comments 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.

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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 spoken widely 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 consult-
ant 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 sensitiv-
e 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 commit-
tees 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 this 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 perhaps debated that they raised. This would demonstrate this powerful teaching method and would also provide some relevant practi-
cal material for teams and trusts that are try-
ing to set up their own ethical committees.

P Kaye

Life and Death in Healthcare Ethics: A Short Introduction

ISBN 0 415 21574 9

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 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 recent issues raised by reproduction, death, and dying. The issues considered include euthanasia and withdrawal of treat-
ment, the persistent vegetative 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 prin-
ciples often thought dry and difficult. Newcom-
ers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Arbor 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 Fox case, in chapter 3, elicits a dis-
cussion of concepts such as that of a worthless life and the misconceived principle of double effect, and questions of au-
tonomy. In this chapter, Watt introduces a con-
cept she calls “lethal bodily invasion”. Even if a Nazi doctor did not care whether his victims survived or not, he is required to intervene to save them. 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-
ine other situations where the principle of double effect is applicable.

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 the latter. An important method of defensive action is well beyond its scope; however, it is profitable to analyse like cases where the principle of double effect is often summoned as a justification for deaths that are not intended but foreseen. If a mentally disordered man, or child for that matter, runs amok with a shotgun in a school, is a marks-
man not justified in shooting to maim? If the aggressor dies, is this lethal bodily invasion impermissible? According to Watt, a marks-
man not be regarded as remiss if he failed to act to prevent the death of the schoolchildren?

The principle suggested by Watt also ap-
pears to reconcile a situation that even two of the most obvious in the public mind at present; this is clear and full of “common sense” and if taken to heart would, hopefully, avoid further public outcries on the matter of retained organs and biopsies. The discussion of the ethical problems of mixed cultures is an unexpected inclusion and there is reliance on more contemporary philosophy rather than traditional arguments. The New Zealand back-
ground of the original edition shows through most obviously in this chapter but this does not detract from the arguments put forward.

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 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 dealt with—brain death and the double effect. The latter is in this section, namely, psychiatry and the problems with aging and dementia. Both are discussed sensibly 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’ argu-
ments and for further reading. Case studies

www.jmedethics.com
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 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 given countries and aligned organisations. 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. A word at the end 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 help would be 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 reviewers all started 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 pages on very contentious issues 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. Daniel Brock’s heading, “Cloning, ethics” is also a fascinating essay. The discussion of research into the XXY karyotype and the MAO mutation provide an excellent background to the section. Again, this section would have much to say for itself to people wanting to go further on his topic. Overall, the editors have assembled an impressive cast, with many of America’s 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 Sarah Chadwick, John Harris, or Soren Holm.

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 embryonic stem cell panel, Green portrays both the complexity and the increasing number of ethical issues raised by ER, and how this could have been avoided, given the discussions. 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 broad ethical approaches and on the detailed examination of ethical issues. 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 shapping 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 the different stakeholders: patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups. Here, Green stresses the importance of ER on the form of so called “therapeutic cloning”, and again takes a critical stance towards NBAC’s shapping of the discourse.

In the age of the “globalisation of ethics” and increasing technical issues and conceptual conundrums in bioethics, the concept of overlapping consensus is becoming less applicable. In bioethics, as in other fields of science, we are faced with a new form of complexity that requires a new approach to consensus building.

In chapter four, Green attempts 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 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 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 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 as such 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 “plurisitic 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 notion of autonomy and informed consent.

The Androgen Insensitivity Syndrome Support Group (AISSG)

The Androgen Insensitivity Syndrome Support Group (AISSG) http://www.medhelp.org/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.

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