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, when they 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 offering 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 converse were the case, 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 my view entirely ethically acceptable.

The chances 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 it 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 (leucine 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 termi- nating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.

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

Accepted for publication 14 August 2002

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 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 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 responses is that any peer review process would deal with responses range from the scholarly and meticulously argued to distressing personal accounts of suffering. As both an avid reader of rapid responses to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them should be when I wish to enter into dialogue with the author. I feel on sure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing the response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to approach distressing accounts of suffering with a degree of empathy. It is sometimes the case, however, that submissions clearly show- ing distress also contain dubious argument that any peer review process would deal with severely. Where accounts of suffering along- side dubious arguments are posted from patients I personally feel sympathy about responding, finding myself caught between the roles of vituperative reviewer and em- pathetic listener. As an editor in the BMJ on electronic responses, particularly on items that have attracted 125 responses at the time of writing. An important feature of 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.

To prevent any misunderstanding, I wish to state that this response does not issue out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don’t ignore me.

W Lewis
Carrig Wen Surgery, Church Road, Blaenavon NP4 9AF, Wales, wayne@delewis.freeserve.co.uk

References


www.jmedethics.com

J Med Ethics 2003; 29: 120–124

Copyright © 2003 British Medical Journal Publishing Group
S Louw

Ethical Issues in Palliative Care—Reflections and Considerations


This is a book 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 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. Dr 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 Jeffrey, a consultant in palliative medicine and writer on medical ethics, makes the point that it "may be expected, Fulford's notion that an explicit analysis of values is helpful in defining diagnostic categories, that medicine is a recurring theme. Dickenson's interest in informed consent (also in children), moral luck, and her feminist reconstruction of the Hippocratic Oath is much more than that. 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 "casebook and 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 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) 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.
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 contemporary bioethics. There is currently a dearth of biotechnological literature presenting what might be called a more traditional approach to medicine and healthcare. This contribution is 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 more common issues raised by reproduction, birth, death, and dying. The issues considered include euthanasia and withdrawal of treatment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

The book is divided into topics dealt with in a single chapter. The principle suggested by Watt also appears to be that of either or that even when 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 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 treatment 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 his experiments. 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 as wrongful as actions. The question 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 conscientious 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 particularly 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
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 medical students, trainees, and gauging the public debate on new technologies. Illustrative texts 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 encyclopaedia. 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://www.bioethics.uu.se/biobanks-report.html) documents a public hearing organised by a Swedish research project on the various social and ethical issues raised by the use of so-called biobanks—that is, large collections of human tissue samples. There is considerable interest among researchers, the biotech industry, and society at large in using biobanks for the continued investigation of genetic health factors that is now following the completed mapping of the human genome. Central issues are: the responsibility of biobanks or users of these to protect tissue donors in various ways; how these responsibilities should be balanced against business and research interests, as well as against the interests of people in a 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 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 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 ethical, social, and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER

United States ethicist Ronald M Green approaches the issue of embryo research (ER) in the very accessible form of a “philosophical memoir” (xvi). Reporting in detail from his experience of serving on several high level ethics advisory boards, focusing mostly on his membership of the National Institutes of Health’s (NIH) 1994 human embryo research panel, Green portrays both the success and the increasing more influential form of institutionalised ethics, as well as the social and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER

The Human Embryo Research Debates: Bioethics in the Vortex of Controversy


Ruth Chadwick, John Harris, or Søren Holm. Nevertheless as a whole the collection has been to add page numbers to the list of references to other sources that will be useful against. The headings generally have good majorities of authors, being from the USA are not in North America. In addition to the section on the traditional legal right of Swedish individuals to have some degree regarding the subject matter of ER.
itself and familiarises the reader with the technical issues and conceptual conundrums (potentially, 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 complex interplay 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 patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups with regard to the different forms of embryonic research, the development of contraceptive methods. Questions regarding, for example, 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 “plurilist 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 applicable in the context of wrongful life cases (pages 126–128).

In the age of the “globalisation of ethics” one might expect that he would acknowledge 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 conservaative 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 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 Coper- nican 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 “plurilist 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).

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 Baer.

Further information: Pat Johnston, Dunedin Conference Management Services, New Zealand (tel: +64 3 477 1377; fax:+64 3 477 2720; email: pat@dcms.co.nz).

European Integration: Philosophy and Ethics of Health Care

The XVIIth international congress of the European Society for Philosophy of Medicine and Healthcare will be held from August 21–23 2003 in Vilnius, Lithuania. Its theme is European Integration—Philosophy and Ethics of Health Care.

Further information: Professor Dr Henk ten Have, secretariat ESTPMM, Department of Eth- ics, Philosophy and History of Medicine, Univer- sity Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).

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 feminization syndrome or testicular feminisation syndrome)—and similar condi- tions, for example, XY gonadal dysgenesis (Sryer’s syndrome), 5-alpha reductase defi- ciency, leydig cell hypoplasia, Mayer Rokitsky- Kuster Hauser (MRKH) syndrome, Muller- rian dysgenesis/aplasia, and vaginal atresia.
Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer’s disease
M B Delatycki

J Med Ethics 2003 29: 120
doi: 10.1136/jme.29.2.120

Updated information and services can be found at:
http://jme.bmj.com/content/29/2/120.1

These include:

References
This article cites 7 articles, 1 of which you can access for free at:
http://jme.bmj.com/content/29/2/120.1#BIBL

Email alerting service
Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Notes

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/